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Vi(Abilities): Biology, Personhood, and Agency in the Neonatal Intensive Care Unit in the U.S. and Taiwan

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B.A., The University of Chicago, 1997
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An abstract of
A dissertation submitted to the Faculty
of the Graduate School of Emory University
in partial fulfillment of the requirements for
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ABSTRACT

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This dissertation is about beginnings and pre-beginnings. It is about what happens to small human bodies that are birthed before their organs have acquired the very basic capacities for life, before they are capable of corporeally existing in a world separated from the bodies of their mothers. It is about jumpstarting the premature lives of small human bodies that were perhaps never intended for life and sustaining these lives within neonatal intensive care units (NICUs)— buying time, dodging the limits of human biology, and waiting for physiological capacities for life to emerge. It is equally about how the many individuals who care for, are related to, and come to love them, cope with the heartbreak of knowing that technological interventions for sustaining premature lives necessarily include pain and the possibilities of a diminished quality of life. Most critically, it is about how individuals find their way in the midst of these uncertainties, indeterminacies, and hardships to transform a small premature human body, alive or dead, into a home for a soul; and in the process, transform and re-examine their own ideas of who they should be (or not be) and who they are (or are not).

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A mommy-phd is exhausting to say the least and laden with unforeseeable daily contingencies that seem to just suck up one's writing time. Choosing between one's passion and one's family is not really a choice, and despite great strides in our society, the motherhood-work balance is and perhaps will always be a quixotic pursuit. Both are a privilege but cannot be pursued simultaneously. It really does take a village and a lot of people who are willing to pitch in and lovingly help out with the pressing daily tasks of life when I have found myself in a bind. To my family and friends, my village---thank you all for your humor, fun spirit, positive energy, as well as all of your help with babysitting, home emergencies, play-dates, grammar checks, office use, pet-sitting, invites to dinner, and coffee pick-me-ups.

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This dissertation is about beginnings and pre-beginnings. It is about what happens to small human bodies that are birthed before their organs have acquired the very basic capacities for life, before they are capable of corporeally existing in a world separated from the bodies of their mothers. It is about jumpstarting the premature lives of small human bodies that were perhaps never intended for life and sustaining these lives within neonatal intensive care units (NICUs)— buying time, dodging the limits of human biology, and waiting for physiological capacities for life to emerge. It is equally about how individuals who care for, are related to, and come to love them cope with the heartbreak of knowing that technological interventions for sustaining premature lives necessarily include pain and the possibilities of a diminished quality of life. Most critically, it is about how individuals find their way in the midst of these uncertainties, indeterminacies, and hardships to transform a small premature human body, alive or dead, into a home for a soul; and in the process transform and re-examine their own ideas of who they should be (or not be) and who they are (or are not).

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Some lives begin with split-second decisions: “Does this kid look like a keeper or hopeless....Yes or No" (Frey 1995) (Ren, fieldnotes 1998) (Ren, fieldnotes 2004). A "Yes" begins a set of routinized procedures known as resuscitation. The "ABCDs": Airway, Breathing, Circulation, and Drugs. For the triage team operating under the ticking time bomb of death, it is both a practical pneumonic "how-to" for jump-starting the vital signs of life, as well as an ironic reminder of ex-utero life's most elementary prerequisite—the capacity for tiny sacs in the lungs to inflate with air—or breathing. "It's all about the breathing…a heartbeat alone does not mean much….even the ones you can't save have a heartbeat" (NICU resident). In her widely referenced *New York Times* article describing NICU practices at a Boston hospital, journalist Darcy Frey noted, "even a nonviable baby will sometimes have a heart rate" (Frey 1995).

"You do all you can to get a kid's lungs to open up…. You make your way down the alphabet, trying to get air into these little sacs, to get them to inflate" (NICU fellow). Sometimes all it takes is clearing the mucus and blood out of a newborn's throat (A-Airway). Other times, one has to physically force the lung sacs to open by repeatedly squeezing a black rubber bag attached to a masked newborn. Too little pressure and the lungs won't open, and too much can blow them apart (Frey 1995). This is B-breathing. The black bag is also often accompanied by the deliberately timed pushing of the index and middle fingers against a tiny chest, trying to make up any lag time between the "bag and masked" breathing and a "beating" heart that is needed to sustain the brain with oxygenated blood (C-circulation). And when the physical labor is not enough to induce breathing, a chemically induced adrenaline wake-up call is given—this is D-drugs **(**Kirpalani 2007).

The next thirty seconds to several minutes are fraught with composed intensity.

There will either be people running down the hall with break-neck speed, pushing sixty pounds of a transport incubator toward the NICU, sheltering one or two pounds of a baby; or there is silence followed by despair. Viability is determined—for now, for some, for those who *didn't* make it.

Thirteen million newborns each year across the world are birthed without having fully completed the fetal stage of human maturation (March of Dimes, 2009). They are commonly referred to as premature or pre-term infants[1]. Until recently, the causes of pre-term labor, which leads to the births of pre-term infants, were elusive and unknown. Now there is evidence that inflammation during pregnancy may lead to pre-term labor (Romero 2007).

Many of these infants born "too soon" will face conditions of prematurity or physiologic challenges with an environment outside the maternal uterus (extrauterine or ex-utero challenges) due to immature organ systems that are neither fully developed nor functional. This condition requires high-tech medical interventions in the form of NICUs (pronounced "NicYous"). NICUs offer the most advanced medical care for premature infants. They provide a place where medical and scientific expertise join forces with intensive care machines to save premature lives at the edges of viability.

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[1] Pre-term birth is defined as less than 37 weeks gestation. It is based on the scientific finding that full term human birth occurs somewhere between 38-42 weeks gestation (Engle, 2004). **1**. In this dissertation, I have chosen to use the term premature infant/newborn or preemie over the term pre-term infant/newborn because this study focuses specifically on newborns whose bodies and organs are immature and have yet to fully mature and become functional. The acute conditions they are treated for in the NICU are solely due to physiological inabilities to adapt to an extra-uterine environment (ex utero) as a result of immature and not yet functional organ systems. Thus, prematurity is the condition upon which they are admitted to the NICU. Newborns with prematurity or extreme prematurity are distinguished from two other groups of infants admitted to NICUs—-(1) full term newborns with acute illnesses such as pneumonia, sepsis, or correctable anomalies and (2) newborns with congenital anomalies that are not correctable at present that include chromosomal anomalies such ad Down Syndrome. Although there are overlaps in analyses of these various groups of NICU patients, this dissertation is solely focused on the experiences of NICU patients who are admitted for prematurity alone, and the medical caretakers and kin with whom their lives are intertwined. The conditions of prematurity and extreme prematurity underscore the immaturity of fetal organs and not necessarily on the gestational age of the NICU patients. Gestational age is one way to distinguish premature infants from one another. Pre-term has a specific definition of including all babies who are birthed before 37 weeks gestation. Most NICU patients who suffer from prematurity are indeed pre-term, but this is not always the case. For example, there are instances of a 36 week old pre-term infant who does not suffer from prematurity and will not require NICU treatment. At the same time, a 37.5 or 38 week old infant, who is categorically "full term" may indeed still suffer from prematurity and require neonatal intensive care treatment.

However, at the time treatment is initiated, a premature infant's prognosis is usually uncertain in a different way than either full-term babies with acute illnesses or babies born with congenital anomalies (March of Dimes, 2009). In the case of full-term infants with acute illnesses, treatments will likely either succeed or fail and the baby will either live or die. In the case of babies born with congenital anomalies, treatments cannot cure the underlying disease, even if they mitigate some of the symptoms. In this case, long-term prognosis is also predictable. They will live with the condition or die. There is no middle ground for either group of infants.

In contrast, premature infant patients face what neonatologists call radical prognostic uncertainty (Lantos and Meadow 2006). That is, at the time NICU treatments are initiated, the prognosis is radically indeterminable, especially for those suffering from extreme prematurity. "For any given baby, the potential outcomes range from early death to late death to survival with severe, moderate, or mild disabilities, to survival with no long-term medical or neuro-developmental problems" (Lantos and Meadow 2006). Furthermore, the disabilities associated with prematurity can be cognitive, pulmonary, intestinal, cardiac, or involve virtually any other combination of organ systems (Meadow 2006). Doctors cannot say what the outcome for any particular baby will be. The best they can do is to provide a range of possibilities that will cover a wide spectrum of situations. Even if doctors say a preemie has a 50% chance of survival, it is not very helpful because that is not the chance of survival for any *individual* premature infant. Rather, they are merely "quantifying the radical uncertainties" (Lantos and Meadow 2006:16). For these reasons, prematurity is both an acute crisis and a chronic condition (Lantos and Meadow 2006) (Sammons and Lewis 1985) (Harrison 1983) (Sears 2003)

(Gunter 2010). The acute crisis aspect of prematurity requires an emergency response driven by medical indications while the chronic condition aspect often requires value-judgment considerations.

Some premature babies will die. Many will receive care from NICUs. As specialized nurseries, NICUs are armed with an expert medical staff who are trained in the delicate care of premature infants. They also utilize various high-tech life-saving machines, as well as specialized medications, treatment protocols, and highly technical surgeries. NICUs now exist on almost every continent, in at least every large metropolitan city around the world. Their existence has saved countless lives, yet they also consume enormous amounts of practical, financial, and emotional resources, without any guarantees of success for individual premature patients. For this reason, the roles of NICUs in developing and newly industrialized countries are an area of debate (Eidelman 2002) (Costello 2000) (Singh 1997). NICUs have enabled the survival of premature infants who would not have survived several decades ago. But, they have also produced a population of human beings with a range of neurological, physiological, and/or behavioral handicaps (Saigal et al. 2000) (Saigal et al 2002), and with a range of experiences with these handicaps (Hack and Farnoff 1989) (Hack et al. 2005). President John F. Kennedy’s first-born son succumbed to prematurity in 1963. Today, there is no question Baby Boy Kennedy would have survived and most likely would have also thrived. In contrast, there is the case of Sidney Miller, born at 23 weeks. Although Mr. and Mrs. Miller did not wish to engage in heroic measures to keep their daughter alive, they also did not ask for Sidney to be terminated. Nevertheless, the hospital overrode their wishes to withdraw care and Sidney survived the NICU, but with significant disabilities. Her parents sued the hospital on grounds of a “wrongful birth” (Annas 2004). These are two ends of a spectrum that represent the consequences of NICU technology and care. Although the majority of premature infants do not fall into either extreme, these stories beg the question: What constitutes viability?

How the Problem and the Methods Emerged

(Participant-observations, Reflections, and Comparative Field-Sites)

One of the most powerful research tools that the field of anthropology is armed with is participant-observation (Douglas 1976) (Spradley 1980) (DeWalt, Dewalt, and Wayland 1998). This methodology enables anthropologists to embed themselves deeply in another culture to understand its inner social workings through a wide variety of ways and in a multitude of contexts (Meade 1928) (Malinowski 1929) (Evans-Prichard 1940) (Geertz 1984). In obtaining more nuanced and detailed information, participant-observation is often most powerful over an extended period of time. This allows researchers to discover discrepancies between what participants say versus what they actually do, and between what they think should happen in a system and what actually happens in that system. In short, participant-observation is particularly astute at capturing the nuances and details surrounding contradictions and conflicts in everyday life.

The foundation for this dissertation work began a little more than a decade ago when I became a member of a research team under the direction of Dr. William Meadow, a neonatologist and bio-ethicist whose work investigates neonatal epidemiology and ethics. Along with a handful of other students, my research task was to collect and track the day-to-day assessments of premature infants on ventilators. On each day, for every NICU patient who was on a ventilator, the Meadow lab obtained the daily intuitions of medical caretakers as they assessed how their premature patients were doing. These intuitions were then matched with follow-up outcomes obtained in part through telephone interviews I conducted after NICU discharge. The goal of this research was to understand whether and how daily prognostications of premature infants could determine future outcomes. After all, every NICU is deeply concerned with "doing no harm" while maximizing every premature infant's chance for survival outside the maternal uterus. Yet, as illustrated through studies in medical futility, the line between treatment and over-treatment in the NICU can be hard to determine (Cantor, Braddock, Derse, et al 2003) (Way, Back, and Curtis 2002) (Helft, Siegler, and Lantos 2000). Over 8000 responses and three years later, the results informally became known as "The Crystal Ball Study." It showed that neither algorithms nor medical caretakers' daily prognostications and intuitions were very good at predicting outcomes. Both strategies could only *sometimes* accurately predict outcomes of life and death while neurological disabilities were even thornier to predict (Meadow, Frain, Ren, Soneji et. al 2002) (Meadow, Hall, Frain, Ren et. al 2003). This study outlined a series of outcome trajectories for over 150 ventilated premature infants (Meadow, Frain, Ren, Soneji, Lantos et al 2000). More critically, it showed that a "crystal ball" did not (and perhaps can never) exist in the NICU. With the maturational development of premature bodies in a biological state that is still "to be determined" coupled with the NICU as an imperfect technological substitute for the maternal uterus, intensive care of premature infants is shrouded in radical prognostic uncertainties where outcomes for premature infants as an *individual* are and will remain difficult to predict (Meadow, Frain, and Ren et al. 2002) (Meadow, Hall, Frain, Ren et al 2003).

Gathering prognostic assessments from every nurse, resident, fellow, and attending not only gave me “insider” status, I also became familiar with the many facets of NICU life---its social organization, its premature patients and the physiological and medical challenges they faced, its medical staff and parents, and its daily triumphs and challenges at sustaining the emerging biological and social lives of premature infants. More importantly, my fellow research team members and I also became part of the everyday routine of the NICU. Medical caretakers would expect to see us and answer our questions twice a day. Once between 9-10 am after morning rounds, and once in the afternoon between 3-5 pm as they prepared for shift change. They looked for us and took time out of their busy schedules to give us their prognoses and intuitions concerning their patients. Along with their prognostications, medical caretakers (and parents through later follow-up interviews) would share their insights and stories about their NICU experiences.

In time, it became apparent that the very act of collecting Crystal Ball data on a daily basis inadvertently called upon NICU medical caretakers and parents to negotiate their experiences and meanings with premature infants, themselves, and each other. The power of medical intuitions came from the nuanced and often tacit knowledge (Polyani 1967) that medical caretakers acquired through interacting with premature infants, each other, and parents. Medical caretakers and parents often intuitively experienced and negotiated uncertainties, contradictions, and conflicts, yet these experiences were elusive and could only be illuminated through time and reflections. As a result, my interest in the NICU soon delved into what I saw was a central theme in the NICU— How did various individuals most intimately connected with premature infants come to understand and interact with premature infants and with each other in the NICU? How did those intimately connected to premature infants cope with the contradictions and conflicts inherent in attempting to transform biologically immature human beings into society's littlest "social" persons? How would another society outside of the United States deal with these same issues? With Dr. Meadow's generous mentorship, I was encouraged from the outset to pursue my own research interests concerning NICU experiences of personhood in tandem with Crystal Ball data collection. I became aware of questions and concerns surrounding personhood in the NICU that were no doubt informed by, but not directly related to the research agenda of the Meadow Lab. Dr. Meadow often encouraged us by saying, "People know you now, you are part of the NICU, when you are in there gathering data, walk around with a little notebook, talk to people, write stuff down, it will give you what you need when you do your work."

Thus, the Crystal Ball Study would provide an entrance into the world of the NICU not as an outsider, but as part of the routinized daily life of the NICU. After all, the Crystal Ball Study was derived out of the needs of the NICU staff and parents and it spoke to the most pressing daily issues encountered by every medical caretaker and parent---"How is the baby doing?" and "What will happen to him/her?" By being part of a research team, interactions and relationships with medical caretakers and parents organically emerged that called for negotiating understandings of premature infants as well as one another. These interactions shaped the particular problematic of personhood production that now animates this dissertation. Moreover, with the privilege of time, daily visits to the NICU also illuminated certain case studies that would emerge as "critical junctures" highlighting important aspects of personhood dilemmas in the NICU.

Over the course of three years and spending several hours each day in the NICU, I spoke to and interacted repeatedly with almost every NICU medical staff member that participated in the direct care of premature infants. These individuals included nurses, residents, fellows, and attendings (approximately 15-20 staff members in total). Furthermore, a little over one hundred NICU cases were tracked, as well as 60-70 parents were interviewed. These interactions resulted in the collection of intuitions and outcomes for the Crystal Ball data in tandem with participant-observation data that I collected for my own research project: (1) informal interviews and formal interviews, (2) direct observations of interactions between medical caretakers, premature infants, and parents, (3) participation in the life of the group and collective discussions, (4) analyses of personal notes and observations, and (5) documentation of the medical and social "life-histories" of premature infants. These "life histories" comprised of tracking how others' emerging understandings of premature infants' maturational and developmental capacities changed over time, and how medical caretakers and parents incorporated their understandings of these changes into both medical decisions and the emerging socially constructed personhoods of premature infants.

The implementation of the Crystal Ball protocol for the Meadow Lab would also provide a set of quantitative data obtained from medical chart information that included gestational age, birth weight, daily oxygen requirements, and diagnoses. In addition, quantitative data were also obtained through Denver Developmental Screening Tests (Frankenburg and Dobbs 1969) and Bayley Scales of Infant Development (1969, 1993) as a part of the Crystal Ball follow-up protocol. Although these data sets were part of the Crystal Ball Study, my experience in gathering quantitative data provided me with the opportunity to learn and understand a range of medical diagnoses and treatment protocols and procedures for NICU patients. It also provided a means to ground qualitative research from a common point of reference (gestational age, diagnoses, oxygen level, and weight).

It is widely recognized that the "control" aspect of any research project is difficult to maintain under participant observation methods because the investigator is interacting and reacting with others in events and situations that are not in his or her control (De Walt, De Walt, and Wayland 1998). In the NICU, because human gestation is a universal process of timed maturation and NICU treatment protocols are relatively standardized, I realized that qualitative data collected on the elusive experiences and concepts of personhood in the NICU could be grounded in common points of reference such as gestational age, diagnoses, oxygen level, and weight. As a result, I was able to pair (with permission granted) these quantitative variables obtained for each premature infant with qualitative data obtained through participant observation. This pairing would prove invaluable for cross-cultural comparisons of NICU experiences in Taiwan that I would eventually implement as the comparative aspect of this dissertation work. In short, when I investigated the cultural production of personhood in the Taipei NICU, I would now be able to compare the experiences of individuals (through case studies) across two locations within a specified maturational time frame anchored within the "controls" of gestational age, weight, diagnosis, and oxygen level.

The Meadow Lab was and still is a dynamic first introduction to the world of medical research and practice for many aspiring pre-medical students. Although I shared many of their interests, I was also more attentive to the social and cultural implications of medicine. Given my interests, I was invited to "tag along" to weekly closed-door ethics discussions that took place at the university's clinical-medical ethics center. What I quickly came to see was that medical-ethics dilemmas in the NICU were not only about trying to "do the right thing" for all individuals involved, but that determining a course of action for any specific set of NICU circumstances was intimately connected with larger social questions concerning the sanctity of life, the quality of life, and the social, cultural and legal norms concerning the moral status of embryos, fetuses, and infants. Participants that took part in medical ethics round table discussions came largely from the following four fields: medicine, religion, philosophy, and law. It was clear that a diverse set of moral stances were informed by each of these four fields, as well as by personal experiences. However, it was the interaction between medicine and law that often proved to be most powerful for determining courses of action in the NICU. Law, unlike philosophy and religion, carries the power of government enforcement. Although this would not necessarily be true in other cultural contexts, law is interactionally, categorically, and practically meaningful in the United States (Falk-Moore 1978). Whether through the power of enforcement[2] (Llwellyn 1996) (Haley 1991) and/or as a cultural model (D'Andrade 1992) (Shore 1998) (Amsterdam and Bruner 2000) for meaning-making, the American legal system could make individuals act in ways that

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[2] This is in contrast to the work of law in East Asian countries such as Japan, China, Taiwan, and Korea. In many east Asian countries, law has authority, but lack powers of enforcement (See Haley 1991)

were counter to his or her personal, religious, and philosophical beliefs. As such, laws and legal rationales could garner courses of action that were counter to deeply religious, philosophical, and personal beliefs.

Ethical dilemmas in the NICU were almost always buttressed by legal concepts and rules, particularly legal rationales and rules from various court rulings. Sometimes legal rules simply dictated courses of action that had to be followed. In these instances, parents and medical caretakers simply had to follow the letter of the law or risk serious legal repercussions and court battles. Sometimes individuals had to find ways around the law to carry out what they believed to be the morally correct course of action. Sometimes, the law acted as a guide for figuring out the appropriate decisions and courses of action. Most poignantly, individuals in the United States often turn to the law to partially resolve deep conflicts and contradictions between elusive experiences of individual actions and feelings; and how he (or others) perceive/s himself as fitting in or not fitting in with certain dominant cultural definitions for what he ought to be (or not be). Individuals engage in legal talk or political discourse over rights when their lives are "contested" and there is dissonance between actual experiences of personhood and cultural definitions of the person (Ginsberg 1989)[3] (Glendon 1991) (Amsterdam and Bruner 2000) (Friedman 1998). In the NICU, nowhere is this more emotionally wrenching than in medical-ethics cases involving parents who must make the Sophie's Choice between refusing medical treatment on the ground of deep religious beliefs and wanting to save the life of their newborn child with routine surgical procedures. How

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[3] Faye Ginsberg's work on the American abortion debate shows that contests about abortion are not always about issues of abortion pe se, but that dissonance between lived realities and dominant cultural definitions of motherhood often generate life crises in individuals, which they attempt to resolve through political and legal engagement (Ginsberg 1983).

could any parent possibly choose between the life of their child in this world and the damnation of their child's soul in the after-world? The legal system mandated overriding parental powers of decision-making, a guardian ad litem would be appointed, and the infant would receive surgery. By being forced to give up their right to make choices for their child, they were freed from having to make a Sophie's Choice decision. They could, with the help of the law as a social tool, save the life and soul of their child simultaneously. It was during these instances that I understood the more subtle ways in which law could act as a means of recouping a sense of control and power for parents. It also unveiled the intricate and dynamic interplay between law and the NICU.

To understand personhood issues in the U.S. NICU, I would have to understand the law and the American legal system. Eventually, I would be trained in law. Law school is itself a time filled with rituals and rites of passage (Mertz 1998). It is not only an education in the American legal system, but the language of the law is both ideology and praxis of many beliefs and tenets that are most fundamental to American culture (Mertz 1998). The unique opportunity of being simultaneously trained in anthropology and law once again allowed me to carry out another stage of participant-observation. As I commuted between graduate school and law school, spending half of the week in each program, I was both literally and intellectually away-from and a-part-of the indoctrination of American legal culture and values. Reading and learning to argue legal issues as a law student gave me a different perspective and orientation than either anthropological training or research in the NICU. When I read *Roe v. Wade* for the first time as a law student, I could gather its implications in a wider sense that extended beyond what I was taught in class.[4] The *Roe* Court, in providing the legal rational for its holding that abortion could not be proscribed before viability, defined viability in the context of being able to survive outside the mother's womb with "artificial aid" (see *Roe* 1973). This was a reference to the NICU, yet at the time of *Roe*, the NICU was itself just beginning to develop more sophisticated technological means for maintaining ex-utero life. Furthermore, lived experiences and realities of "personhood" that occurred in the NICU were not so black and white. In law school, I would learn that this reference to the NICU would be categorized as "dicta," a statement in U.S. legal terminology that carries authority and is directly relevant to the case, but it is not legally binding.

Studying law and anthropology simultaneously highlighted the relationship between law and society. The American Constitutional system is not merely a system of legal rationales and logic, but also a cultural system specific to the United States, and one that dynamically interacts with other parts of the social system (Glendon 1991) (Amsterdam and Bruner 2000) (Friedman 1998). In the NICU, both law and medicine would interact. It is what legal anthropologist Sally Falk-Moore categorized as a "semi-autonomous social field"---a field that can generate its own rules of conducts, beliefs, and values, but was also vulnerable to the perceived realities, beliefs, and values of the other social fields (Falk-Moore 1978). Law and medicine are two fields that co-interact and the NICU is one context in which these interactions take place.

Shortly after graduation from law school, I continued pursing NICU research

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[4] The first lesson a law student learns when reading legal cases is to hone in on the holding—the rule of any case that is actually enforceable. These are explicit sentences that use permutations on the phrase "the court holds." Holdings make up precedent, which are principles or rules that possess authority and can be operatively argued in future cases. The rest of the text of a legal case are considered dicta (the editorializing) that capture cultural beliefs and values. Dicta do not have any binding force. However, from an anthropological or sociological perspective, dicta in legal cases are a historical documentation of past and present cultural beliefs and values (Amsterdam and Bruner 2000)

interests. Upon attending a Society for Pediatric Research Conference, I met and was asked by Charity Tsai, a director of medical ethics education in Taiwan, "to help bring [an] American medical ethics [perspective]/expertise to the NICU in Taiwan." It was an opportune moment for both of us. I had intended to conduct fieldwork in Taiwan. Taiwan always held a personal interest for me because I was born there, Mandarin is my birth language, and Chinese is my ethnicity. However, having largely grown up in the U.S., I am experientially "Americanized" and English is my dominant language. Yet, I have always been well attuned to cultural differences both as a child of immigrants, and as an "American" outsider in Taiwan when my parents temporarily moved our family to Taipei in the early 1990's during the economic boom and registered my brother and I at Taipei American School. For Charity, I had the exact background she sought. She said, "You are both American and Chinese, you know law, worked in the NICU, and you speak Mandarin. You can help us set up a system for medical-ethics education, help us with our research interests. We can help you understand Taiwan and the NICU. We could learn from each other, help each other."

Returning to Taiwan for fieldwork, I was interested in the cross-cultural implications of personhood production in the NICU---How did individuals in another society, in a different cultural context, yet under the same universal NICU challenges, manage to live through and live with experiences of prematurity? I would re-engage with the NICU, as well as some of the cultural differences that I had experienced during my years in high school. In the Taipei NICU, I was also incorporated into the daily routines of medical caretakers. I was considered a NICU insider due to my U.S. NICU experience, but a cultural outsider. Participant-observation once again proved to be a powerful methodology. In Taipei, I re-cast the Crystal Ball Study (with permission from Dr. Meadow). However, this time, I used it as a methodological control, rather than as a protocol, for re-producing similar interactions between various actors in the NICU, as well as between various actors and myself. The intent was to strengthen a weakness of participant observation (Spradley 1983) (De Walt, De Walt, and Wayland 1998) and highlight cultural similarities and differences for emergent interactions within a set of controls.

I knew that cultural differences existed. I expected differences and recasting the Crystal Ball study was one way in which I could employ participant-observation to frame interactions and enable medical caretakers and parents in Taipei to react toward and/or against a set of questions and concerns that was found in the United States. At the same time, recasting the Crystal Ball study would also be one way in which similar themes across cultural and geographical divides could be captured more systematically. I was less interested in the actual prognostications or intuitions per se, than in the “process” (or lack thereof) of person making that generated the various responses. Thus, I repeated other aspects of participant-observation mentioned earlier---formal and informal interviews; direct observations of interactions between medical caretakers, premature infants, and parents; participation in the life of the group and collective discussions; analyses of personal notes and observations; and documentation of the medical and social “life-histories” of premature infants. These data were coupled once again with quantitative reference markers of birth-weight, gestational weight, oxygen level, and diagnoses.

During my one and half years in Taipei, I once again entered into a familiar routine of visiting the NICU daily, participating in the daily life of the NICU, speaking to the entire medical staff (15-20) through repeated interactions, asking questions, talking to parents (20-30), listening, and taking notes. I also collected vital chart information on every NICU admission (roughly 70) and tracked almost all cases of ventilated premature patients during their stay in the NICU (35-40). Once again, specific cases emerged as particularly insightful for illustrating cultural similarities and differences. More poignantly, because quantitative controls were in place, when the various Taipei case studies emerged they not only highlighted cultural variability, but they also validated shared universal themes concerning personhood dilemmas in the NICU.

An inquiry into personhood is about contradictions and conflicts between objective aspects of who we are (or are not) and who we should be (or not be); our inarticulable emotions and feeling; and our elusive experiences of selves and others that result out of interactions-in-the making. Furthermore, interactions change concepts of selves and others and these changes can only be discovered over time, upon reflections, and through stepping in and stepping out of one's field-site so that connections can be made within a larger matrix of social fields. It is only with participant-observation over an extended period of time that the dynamically nuanced relationships between elusive experiences of the person and cultural definitions of the person in culturally plural social spaces could be illuminated. I had come to know American cultural practices in the NICU, but returning from fieldwork in Taiwan revealed new insights into previously collected qualitative data.   A comparative perspective would highlight the interplay between medicine and law as culturally specific to the United States. In Taiwan, law was largely missing in the NICU, but replaced by specific rites of passage and an emerging Christian movement.

Vi (Abilities) Across Two Locations

This dissertation draws upon data collected from two different geographical locations—an urban intensive care unit for premature infants in Chicago, Illinois, U.S.A and one in Taipei, Taiwan, Republic of China.

In the chapters to come, I have chosen not to set out one scenario and then the other. Rather, I will move back and forth between the two scenarios. This is chosen to highlight the equivalence in technical and medical expertise and equal access to medical information and scientific research for parents and medical caretakers alike. Furthermore, because the Taiwan project directly evolved out of my participation in the U.S., they co-inform each other. In addition, this comparative data set anchors the emerging social interactions of person making with three universal constraints: life support technology and training; the shared underlying biological process of human maturation; and the physiological obstacles faced by premature newborns when the human gestational process has gone awry. As such, any commonalities that emerge under these universal constraints are just as significant as the particularities and differences.

Chicago, Illinois was where I was introduced to premature infants, the NICU, and the medical caretakers and parents whose lives are intimately connected to prematurity. As Chicago was also historically one of the sites where premature infants were introduced to the world at the turn of the 20th century during the Chicago World's Fair, this was fitting. In addition, it is in Chicago that funding came together to create the first specialized medical space—"the incubator station," for the care of premature infants

(Silverman 1970) not long after the Second World War. It would be in the Chicago NICU that I would come to know the medical conditions, the routines, the day-to-day ups and downs concerning the medical status of premature infants and the emotions of their parents and medical caretakers. It is also here that I would learn that experiences with prematurity in the NICU would carry ramifications outside the NICU, and be critically informed by various legal principals that are not always directly related to the NICU.

In the United States, the human developmental process lies at the heart of many fierce legal and political battles. Legislative bills that implicate the human developmental process and, in turn, the gestational human entity are becoming increasingly popular—from measures that govern scientific research on embryonic stem cell research, to property rights over frozen embryos, to the conduct of pregnant women, and perhaps with most controversy, to the personhood status of fetuses. In effect, ethical and philosophical questions asking, “At what stage does or should a human entity be considered persons?” and “What characteristics are or should be distinctive of human persons” are quickly becoming operationalized into legal statutes, rules, and procedures that will govern a range of human interactional activities interconnected with the human gestational process of fetal growth and development. However, they are done without a critical understanding of the nuanced social interactions “in-the-making” that are required to arrive at the very answers sought out.

In contrast, the development of neonatology and of NICUs has a relatively short history in Taiwan. It has only been in existence since the early 1990’s (Neonatal Staff, Personal Communication). To understand the place and role of the NICU in Taiwan, I will first provide some background on Taiwan.

Taiwan is known as Formosa or beautiful island. It is located in East Asia and situated on two important waterways, the Taiwan Strait, facing the southeastern coast of China, and the Luzon Strait, which connects the Pacific Ocean with the South China Sea north of the Philippines. The main Island of Taiwan is shaped like a sweet potato and is roughly the size of the Netherlands or Maryland and Delaware combined. The climate is marine tropical with a monsoon rainy season from January to March and hot, humid weather from June to October. Typhoons and earthquakes are common to the region.

The island of Taiwan has a long history of settlement by outsiders and international trade. Various indigenous ethnic groups were the first inhabitants of Taiwan and continue to live there (Brown 2004). This contributes to Taiwan’s pluralism. The island was ceded to the Empire of Japan by the Qing Empire in the Treaty of Shimonoseki after the First Sino-Japanese War in 1895 (Copper 2003) (Roy 2003). In 1945, Taiwan was freed from Japan as a result of World War II. Japan renounced all claims to sovereignty over its former colonial possessions, including Taiwan, but did not specify to whom Taiwan should be assigned. This fact and subsequent handling of Taiwan's sovereignty by the Allies of World War II led to the complex and unresolved issues of the legal and political status of Taiwan. Four years later the Republic of China lost mainland China in the Chinese Civil War to the Communist Party of China and resettled its government to Taiwan. The political status of Taiwan is disputed because it is claimed by the People's Republic of China, which was established in 1949 by the communists on mainland China and considers itself the successor state to Taiwan (Roy 2003).

After World War II, Taiwan underwent rapid economic growth that transformed the small island into a major economic industrial power. This growth was led by the people living in Taipei, its capital city. It was referred to as one of the “Four Asian Tigers” or “Four Asian Dragons” with South Korea, Singapore, and Hong Kong. Its economic rise was called the “Taiwan Miracle”, because of how rapidly the economy grew and how much the quality of life of its citizens improved. Taiwan had a per-capita gross national product (GNP) of $170 in 1962, placing its economy equivalent to those of Zaire and Congo. By 2008, its per-capita GNP, adjusted for purchasing power parity (PPP), had risen to $33,000, contributing to a Human Development Index equivalent to that of other developed countries (estimated as 25th in the world) (Taiwan Ministry of Budget, National Accountancy and Statistics, based on the 2007 figures). Today, Taiwan has a capitalist, manufacturing based, export-driven economy with decreasing government intervention. It is estimated that the annual growth in GDP has averaged more than five percent during the past three decades (US Central Intelligence Agency, World Fact Book, 2009).

This exceptional growth was due to the following contributing factors, (1) expansion of industrial employment, (2) increase in labor productivity, (3) US economic assistance, (4) privatization, (5) educated workforce, (6) a high rate of local savings and foreign investment, (7) solid infrastructure, and (8) excellent planning by the government. These characteristics are a point of pride for the nation of Taiwan and form a large part of its national identity—hard working, efficient, and intelligent (Copper 2003).

The future of the Taiwanese economy may not be as bright as it once was[5].

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[5] At the time of this research, Taiwan’s economy was undergoing a recession (2003-2004). Many feared that its economy would never recover. However, at present time, Taiwan is once again enjoying an economic boom due to its cultural similarities, locational proximity, and close trade relations with China.

However, their transformation from a developing country to an economically stable, democratic, international, and highly modern state is a true accomplishment. Taiwan is categorized as an advanced economy by the IMF, and as a high-income economy by the World Bank. Much of its historic growth was based upon the technology industry playing a key role in the global economy. Taiwanese companies manufacture a large portion of the world's consumer electronics, although most of them are now made in their factories in mainland China (Copper 2003). These economic accomplishments and its resurgent economic growth in recent years (Taipei Times 2010) is a source of pride with notes of bittersweetness for its people. Its international status in the world remains in the shadow of China. They are neither members of the World Health Organization (WHO) nor the United Nations (UN), and the majority of nation-states do not have official diplomatic posts in Taipei, including the United States. However, their close cultural, social, political, and historical relationships with China is also what has allowed their economy to continue to grow and thrive, and its people to consider China a second home. Many people, including the working and professional middle class own second apartments in China. Travel between the two countries is now free and open with daily flights (BBC News 2008).

There are two sides to Taipei. It is a city of thoroughfares and alley ways. It is at once an efficient modern city, with large paved roads, and a high degree order. At the same time, life happens in the streets of Taipei. “If you want to go anywhere, you take the big streets. It is a little boring and you don’t see much,” I was told by a friendly concierge at the New World Hotel. But, behind the big streets, out of nowhere are alleys. Life happens in the alleys of Taipei. This is where people shop, eat, sleep, and live everyday lives. This is where interactions happen.

Like the streets of Taipei that embody contradictions, the people of Taiwan are themselves conflicted by whether they would like independence from China or to belong to mainland China. The people of Taiwan have always taken great pride in seeing themselves as "miracle workers" in reference to being dubbed the miracle economy in 2001. Then it was hit by recession. My time in the Taipei NICU has to be understood in the context of this recession and the accompanying political rallies that took place between 2004-2005. Some called for Taiwan's independence in the face of this recession (The DPP party). Others felt that a call for independence was short sighted (The KMT party). Both sides took part in rallies. Both were impassioned, yet they also seemed playful.

When I look at pictures of these rallies that I attended (both sides), they always remind me more of pride parades than insurgent protests. These political rallies feel more like the experiences of tailgating during World Cup Soccer matches—impassioned, yet playful with the possibilities of a good bar brawl. People easily gather for pictures, adorned in the colors of their respective parties, singing their respective rally cries, and showing off their home-made picket signs. Arms linked together, fingers splayed in peace signs, heads tilted together with smiles, I am always struck by the disconnectedness between the messages of these signs and the people that carry them. The signs are always far angrier than the people, and the people are always far more cheerful than one would expect at political rallies. It always seemed to me that people desired the interactions and the solidarity with others more than the goals or intents of the political protest. It's unclear whether it's the people or the signs that are the caricatures.

It is my sense that these political rallies possess an air of passionate cheerfulness (Ren, fieldnotes and interviews 2004-2005) for many because they view both parties as actually sharing similar goals for Taiwan. In fact, there were quite a number of people who attended both rallies as a means of supporting different family and friends who have different political affiliations. Many also attended both rallies just out of sheer curiosity and “for the flavor” of political rallies. This is well known, and both parties strive to “one up” each other in recruiting attendees through radio advertisements and television spots. Both parties strive to continue and extend Taiwan’s “miracle economy,” and neither are extremist in their views of pro-independence or pro-China (Copper 2003) (Roy 2003). In addition, both parties believe in the prime importance of economic growth, universal healthcare, investing in advanced technology and scientific and medical know-how, and continuing Taiwan’s plight of gaining more significant international status. For those that happily participated in my photography efforts, political differences between individuals rarely cut into the core of who they are and who they wished to be. Although they were at a political rally, political identity seemed more fashion than flesh, more form than substance. It was more like supporting your favorite sports team than protesting wrongs and demanding rights.

In contrast, for medical caretakers, and especially doctors and nurses, the shadow of China’s progress intimately affect how they live their day-to-day lives, and meet the obligations of work and family. Politically, many fiercely support an independent Taiwan. For them, it is not the economic status of Taiwan that they are so concerned with, but its social capital. Medical professionals are amongst the best and the brightest individuals in Taiwan. There are very few spots in medical schools and nursing schools.

For the majority of medical caretakers I spoke to, they understand all too well that a life in medicine in Taiwan is about service and not economics. For them, Taiwan's medical system and its quality of health care delivery is a point of pride. Due to Taiwan's universal health care system, doctors are amongst the lowest paid professionals**.** Yet, they garner great respect, authority, and social capital. Healthcare is one of the level playing fields. As a nurse told me, "No matter how rich you are as a businessman, you still get sick and you still have to see a doctor, and you still have to come to the hospital and wait and take a number like everyone else."

Politically, the World Health Organization's continued rejection of Taiwan's request for full membership in its organization (due to China's insistence that Taiwan is already formally represented under China's membership) is a personal, social, and political blow to many highly educated individuals in Taiwan, and especially to those trained in the high-tech medical fields. This continued rejection by the WHO makes even their collective achievement as the 2nd best health care system (for quality of healthcare) bittersweet (World Health Rankings 2000). This accolade is commonly spoken of and commonly referenced, especially amongst medical professional. As my friend Hope, a doctor and a director of medical education of stated, "We are #2, only after Sweden and we serve so many more people. But, definitely #1 in Asia, even beating out Japan. This is why we work 12 hours a day, this is why Ming Jen gets dehydrated and has to go home and put IVs in her body while she is pregnant. We are dedicated. We always say yes when someone asks if we will see one more patient. We were the ones that helped with the SARS crisis, the nurses and doctors had no idea what was happening, but they came in and were ready to work. In fact, we helped isolate the SARS strain at Tai-da (Taiwan

University), but we do not get enough recognition, we cannot even get official WHO status!?"

In Taiwan, emerging experiences of personhood in the NICU touch upon issues of modernity and the place of social service, ethics, and morality in the context of modernity. An evolving sense of a modern communal "ethics" that include aspirations for a paradigm of universally shared morality is emerging; one that asks an individual to extend his or her obligations and responsibilities to others beyond one's family and kinship structures. This both challenges traditional concepts of kinship in Chinese society, but also creates new kinship relationships that stand outside of biologically or martially related individuals (Carsten 1995) (Strathern 1992). This is operationalized in newly instituted NICU rules that govern the conduct of medical caretakers in the NICU, guidelines concerning institutional board review for scientific studies, and attempts to re-design medical ethics curriculums for medical students. Individuals' emerging relationships with new "rules" challenge traditional notions of what it means to be a good person, what it means to be a good doctor, a good parent, and what it means to achieve success in a modern global economy.

With these thoughts in mind, it is my hope that findings from this comparative project will provide some practical and theoretical insights and guidance for individuals and societies in both Taiwan and in the United States. As personal, social and political debates over issues of personhood continue to emerge in various contexts in both locations, one way to enter any debate is to examine how societies other than our own grapple with the indeterminacies and contingencies of "Who am I?" (and "Who are you?"). These two questions are perhaps never more poignant than when a new human life is brought into the world. However, what happens when one's hopes for a healthy new baby are dashed and shattered?

Vi(Abilities)

(Life-and-Death and Agency)

This dissertation is about viabilities—namely, the many kinds of abilities (innate, learned, achieved, chosen, acted upon, withheld, and imagined) required of individuals, including premature infants themselves, to shepherd the biological and social survival of premature bodies born too early into an ex-utero world. Unsuccessful births that would have been considered late miscarriages fifty years ago are now modern medicine's smallest and youngest patients. Premature infants begin life physiologically liminal, but not necessarily categorically liminal. Our capacities to see and access fetuses inside the maternal uterus through advances in reproductive technologies have changed women's relationships with their pregnancies and have increasingly transformed the moral status of embryos and fetuses (Katz-Rothman 1986) (Rapp 2000) (Morgan and Michaels 1999)(Casper 1998) from fetal objects to fetal subjects (Morgan 2009 1998). However, the cultural production of fetal subjectivity (Morgan 2009) does not necessarily prepare us for the daily technical, medical, emotional, and moral challenges that medical caretakers and parents confront in the NICU when fetal organ maturation and its emerging biological reflexes of prenatal development occur outside of or wholly disconnected from women's bodies. Premature infants are fetuses born too soon, yet their early births and their technologically assisted NICU lives make them physiologically different than either in-utero fetuses or full term babies. Prematurity is understood by neonatologists as both an acute medical crisis because the fetal stage of human gestation has not been fully completed; and a chronic condition because surviving an immature birth means living through and living with radical prognostic uncertainties that full term infants do not face (Lantos and Meadow 2006). As such, experiences with prematurity are often not continuous with individuals' experiences with pregnancies, in-utero fetal subjects, full term birth experiences, or full term infants (*Chapter 1)*.

Premature infants exist on the edges of life and death or what is commonly referred to as viability. For them, viability is tied to the innate capacities of fetal organ systems to continue to emerge and mature outside the fetal-maternal system with the aid of NICU interventions, as well as to the innate capacities of fetal organ systems to withstand and overcome potentially traumatic NICU side effects. Viability also refers to technological innovations and how changing concepts of embryos, fetuses, and infants (Morgan 2009) are intertwined with NICU technological innovations that address physiological challenges when the process of human gestation no longer can take place within the in-utero maternal-fetal system (*Chapter 3)*. As such, it is about the inherent biological contradictions and conflicts between the in-utero maternal-fetal system and the NICU technological system (*Chapter 2*), and how it is only through social work that these two systems can be bridged.

For medical caretakers and parents in both Taiwan and the United States, the heart of viabilities is about how individuals come to know their premature infants and themselves as they manage, negotiate, and live through the uncertainties and indeterminacies surrounding the experiences of prematurity (*Chapters 4-7*). In the NICU, ways of "knowing" premature infants are different than experiences of knowing a full-term infant. In the NICU, medical caretakers and parents rely upon a wide array of what I call “epistemological idioms” in order to interact with and get to know premature infants. These can include learning to read monitors and chart information, telling stories, making signs to attach to incubators to both inform and encourage, as well as relying upon normative artifacts usually associated with babyhood such as clothing, bottles, and stuffed animals to signal the existence of a baby. Thus, epistemological idioms speak to the interactive work required to make premature infants both biologically and socially viable. For medical caretakers, viability speaks to medical knowledge and practice, and the capacity to diagnose, gauge, and intuit the effects (both positive and negative) of NICU technological care on the continued physiological development and maturation of premature bodies. For parents, viability is about maintaining hope, waiting and living through heartbreaking crises, and most of all finding ways of becoming parents (and parenting) in the face of extraordinary challenges.

For all individuals intimately connected to premature infants, viability speaks to the social work that is required to create, cultivate, and mediate relationships between themselves and premature infants, and with each other. It is about “morally imagined” (Beidelman 1993) choices and responsibilities that are enacted as a way of comporting oneself in the space of social interactions, especially when managing discrepancies between the worlds they are experiencing and the worlds they hope to achieve. However, doing so is not always an easy task. Individuals intimately connected with premature infants also live in social worlds that are influenced by values, beliefs, and practices associated with worlds outside the NICU, including family, religion, and law. Viability is therefore also about how individuals draw upon and interact with (or react against) these outside social forces in experiencing premature infants, themselves, and each other

(Chapters 8-9). No matter where in the world NICU technologies exist, NICU interventions create experiences of contradictions and conflict for all actors that must be managed. Vi(abilities) are ultimately a reminder of the diverse actions and "solutions-in-the-making" that individuals undertake as they interact with, choose for, and give biological and social lives to premature bodies that are "loved," but not yet known (*Chapter 10*).

Right/rite(s) to Life: Rites/rights of Passage

(Moral action and Constructions of personhood)

Concomitant with vi(abilities), another major theme of this dissertation is the cultural production of moral action--- How do individuals exercise their capacities for being a good person and doing the right thing. Morality relates both to society and to the individual within it, the person (Beidelman 1993). It is about choices of action that derive in part from judgments about what the world is and what the world should be, and the inevitable contradictions and conflicts that arise from discrepancies between the two. These choices of action are embedded in a cosmology and in our emotions, which both inform and impel our judgments (Beidelman 1993). For those intimately connected with premature infants, NICU care consists of choices of action that implicitly and explicitly honor a moral and often legal entitlement to life or a "right to life." However, doing so often treads a very thin line between sustaining life and inducing suffering; or even worse prolonging death. Parents and medical caretakers must often live with and live through the crushing disappointments that result when sustaining a premature life does not necessarily garner what is most yearned for---a breath, a cry, a blink, a grasp, a yawn, an interaction.

Personhood is socially made and requires interactional work. However, as this dissertation will show, sustaining a right to life does not necessarily mean a life is (or can be) automatically experienced as a social person (Morgan 1999). Anthropological work is rich in capturing the function of rituals and rites of passage (both formal and informal ones) associated with garnering the experiences associated with the production of social persons. Therefore, choices of action in the NICU are about finding the messy moral balance between being human and wanting to "do the right thing" in protecting the sanctity of any prematurely birthed human life ---i.e. a "*right* to life"; and needing to experience the interactive humanity of that life through the creation and production of rituals and rites of passage---i.e. "*rites*" to life.

The practice of "doing the right thing" requires interactive participation. Rituals and rites of passage, including post-natal ones that transform newborn babies into social persons (Conklin and Morgan 1996) (Morgan 1999), are particularly apt at conferring various rights of personhood to newly birthed bodies and their kin, including the roles, statuses, entitlements, responsibilities and other objective aspects of the person. Simultaneously, they are also apt at engaging individuals in the elusive experiences of the person or the subjective aspects of personhood (Jackson and Karp 1987) (Kratz 2006). At the beginning of ex-utero life, any ritual or rites of passage that include newborn human beings and their kin require infants to possess a minimum level of biological capacities for both survival and social interactions (Karp 1980).

Premature infants under NICU care can challenge the efficacy of rituals and rites of passage because a birth too soon is first and foremost out of joint with biological maturational time. As such, a birth out of joint with time is often incongruous with the "affective sequences" (Kratz 1994:37) found in many pre and post-natal rituals and rites of passage that are important for generating individualized experiences and meanings surrounding pregnancy, birth, and infant personhood. As a result, the elusive experiences of personhood for premature infants and those intimately connected to them are often missing. Premature infants begin life maturationally incomplete with biological capacities for ex-utero survival and social interactions still emerging. Yet, their very existence outside of the maternal uterus forces engagements with others in the social world and forces others to have to incorporate them into their existing social constructions of reality (Berger and Luckman 1991).

Therefore, prematurity experiences are about mediating between a "*right* to life" that is implicit in the use of NICU technological interventions; and a human need to socially experience oneself and others through rituals and *rites* of passage. In the NICU, experiences of "life" are not merely just about how to produce definitionally alive premature infants. Rather, it is about how premature infants can be experienced as socially living. Rituals and rites of passage provide sets of activities or "rules of conduct" (Durkheim 1912) that are enactments (including symbolic enactments) of a cultural belief or value. Rites of passage are a series of rituals designed to conduct an individual (or group) from one social state or status to another. The intent is to effect transformations in society's perceptions of the individual and in the individual's perceptions of herself or himself (van Gennep 1966) (Turner 1967). Thus, rituals and rites of passage can encompass a wide range of characteristics and serve an array of functions (Durkheim 1912) (Frazer 1922) (Erikson 1980) (Radcliff-Brown 1931) (Geertz

1984) (van Gennep 1966) (Turner 1967, 1969) that exercise cultural values and effect changes in people's experiences and perceptions of themselves and others. Anthropologist Robbie Davis-Floyd's work on "birth as an American rite of passage" provides a helpful summary of these various functions served by rituals and rites of passage in more detail (Davis-Floyd 2003:17). They are as follows: (1) To give humans a sense of control over natural processes that may be beyond their control (Malinowski 1954). (2) To "fence in" and manage the dangers perceived cross culturally (when individuals are between social categories), while at the same time allowing controlled access to their energizing and revitalizing powers (Douglas 1966). (3) To convey the belief system on which they are based, into the inmost being of the initiate (Turner 1967, 1969). (4) To renew and revitalize important cultural values for those conducting, as well as for those participating in or merely watching the rituals (Turner 1967, 1969) (Geertz 1984) (Abrahams 1973).

Because a premature infant's physiological maturation is still "to be determined," the prognostic and experiential uncertainties surrounding whether they will eventually become and/or act like full-term infants are a source of deep distress for medical caretakers and parents alike. Therefore, all of the aforementioned functions of rituals and rites of passages are relevant under NICU circumstances when individuals must face the de-novo complex situation of prematurity. This is especially true given that prematurity experiences for all individuals (including the premature infant) are ridden with uncertainties and indeterminacies for which prior experiences and existing cultural models (D'Andrade and Strauss 1992) (Shore 1998) for how to interact with premature infants and with each other are often inadequate, non-existent, or inarticulable. Whether they are already existent or a modified work in progress, rituals and rites of passage in the NICU can take many forms---from easily recognizable ones drawn from full-term birth experiences; to medical procedures and routines that substitute as de-facto rituals (Davis-Floyd 2003); to ones that are created organically through interactions-in-the-making (Chapters 6-7). Thus, rituals and rites of passage often provide a starting point for getting to “know” premature infants and interacting with them, and with each other in their context. At the same time, they enable those intimately connected with premature infants to construct both objective and subjective aspects of “babyhood” experiences for premature infants who may not yet possess the physiological capacities for doing so themselves. This gives premature infants a social life that is often more alive than what they are physiologically capable of. Often in the NICU, waiting for premature infants to “grow” into themselves and “out of” prematurity can be experienced as frustratingly stagnant. Rituals and rites of passage are one way to mark the progression of time, even when maturational progress is in stasis or seems to have back-tracked.

Thus, premature infants under NICU conditions are categorically ambiguous and rites of passage are one means by which others can socially construct them to embody who they wish premature infants to be or not be. Outlined by Arnold van Gennep (1966), rites of passage generally consist of three stages (1) separation of the individuals involved from their preceding social state, (2) A period of transition in which they are neither one thing nor another, and (3) a reintegration phase in which the individual emerges with a new identity and are now absorbed into their new social state. One important feature of all rites of passage is their transitional nature (Turner 1979). Victor Turner expanded rites of passage to include “liminality,” the stage of being betwixt and between, neither here nor there—no longer part of the old and not yet part of the new (Turner 1979). However, implicit in both van Gennep's outline and Turner's notion of liminality is the presumption that an individual's social state prior to beginning stage one is categorically well defined, as well as the presumption that one knows the social state that one hopes to achieve at stage three. It is stage two or the liminal state that is categorically ambiguous. That is, under most circumstances, part of the importance of having affective sequences to rituals and rites of passage presumes that individual statuses and roles are knowable at the beginning and ends of rites of passage. For premature infants under NICU conditions, none of the presumptions normally associated with rituals and rites of passage apply. Their inherent categorical ambiguity is deeply embedded in the fact that they embody the human gestational process still-in-action. As a result, they challenge the boundaries of our socially created categories of "fetus," "infants," and "baby." They are what Donna Haraway terms, "cyborgs"—or entities that are not definable or categorizable (Haraway 1991). In the NICU, categorical ambiguities surrounding premature infants often garner others to desire and experience them as "liminal" figures who are "fetus-infants" (Landzelius 2003). That is, perceiving and experiencing premature infants as betwixt and between a fetus and infant (i.e. "fetus-infant") is itself a categorical comfort and a way of knowing. This is even more so in today's social world where fetuses have become subjects in their own right, with their own identities (Morgan and Michaels 1999) (Morgan 2009). Although this approach is sometimes a successful means to manage the ambiguous identities of and experiences with premature infants, the chapters to come will show that premature infants and experiences with them can even challenge this kind of "categorical liminality" at work. Premature infants therefore challenge both the boundaries of fetal subjects, of infant subjects, and even of "fetus-infant" subjects. In turn, they not only challenge the identities of others who are intimately connected to both fetuses and infants, but they also render those who are close to them unknowable to themselves and each other. As a result, for those intimately connected with premature infants, the struggle to know and experience their premature infants is different than the experiences of those individuals intimately connected to fetuses and of those intimately connected to full-term infants. In the chapters to come, it will become evident that rituals and rites of passage associated with NICU premature infants are a double-edged compromise.

Rituals and rites of passage are also about the conferrence of *rights* and responsibilities (Beidelman 1993). As a result, they are often relied upon to designate objective aspects of personhood for premature infants. By doing so, premature infants become somewhat definable and rituals and rites of passage provide some means by which elusive experiences of knowing premature infants can begin. However, for the various reasons stated above, formal and informal rituals and rites of passage pertinent in the NICU are not always efficacious for transforming prematurity experiences into the elusive experiences of infant persons that are hoped for or wished for.

Many types of *rights* are at work in the NICU (e.g. right to life/death, right to privacy, right to "not be touched," right to one's body, right to medical treatment, right to independence) to help define roles, contexts, situations, and bodies where experiences are elusive and inarticulable. "Rights" signal and categorize what and who a person is, should be, or should become. Rights in these senses (and especially legal rights) exist independently of human action. They are experienced as 'objects' or entitlements existing outside of oneself, always ready to be plucked for a number of utilities (Glendon 1991). This notion of rights, particularly applicable to notions of individual rights found in American legal and political rationales and discourses, speak to a notion of human agency as force or control (Kratz 2000) (Karp 1988). In the NICU where premature bodies are not categorizable and experiences with premature bodies are elusive, rights are a source of categorical comfort and anchor the status of both premature bodies and those who are intimately connected with them. This enables the enactment of rituals and rites of passage by signaling and defining who individuals are and who they are to become.

In the case of premature infants under NICU care, a level of social maturity is expected when biological maturity lags behind. Therefore, rights or objective aspects of the person are drawn from both individual experiences and various cultural models of the person, including the law. Doing so is especially potent for bridging contradictions between social and biological maturity. This is especially true in the United States where legal rights, especially individual rights protected under the U.S. constitution (including abortion legislation), help define the status of fetuses and infants. Therefore, when rites of passage associated with normal births are drawn upon to jumpstart the social lives of premature infants and their kin, these rites of passage are not always efficacious and individuals therefore must rely upon various definable "rights" of persons to reinforce existing rituals and rites of passage that fail to produce affective experiences (Kratz 2000). Thus, what are intended to be **"*rites*" of passage** can and often do fail to produce the affective experiences individuals desire for themselves, their premature infants, and each other. What often does remain are a series of **"*rights*" of passages---**a series of objective characteristics of infant personhood that are projected on to premature bodies with these bodies incapable of exercising them; and heartbreakingly without the accompanying experiences so desired by those who care for and love them.

Vi(abilities) and all of the social work that is required to sustain and create biological and social lives for premature infants are intertwined with attempts to find and negotiate the moral balance between “Rights/rites to life” and “Rites/rights of Passage” that are creatively worked out in the day-to-day realities of premature infants (and for those who love them). This dissertation is both a documentation of this process and a celebration of the unconditional persistence of individuals to creatively overcome a complex situation of the heart that no one is ever quite prepared for.

The first chapter begins by documenting the varied experiences of prematurity from the perspective of three actors—premature infants, medical caretakers, and parents/kin. It begins by describing some of the joys, as well as the trials and tribulations of parenthood normally associated with full-term birth experiences. The intent is to both underscore the differences between normal birth experiences and prematurity experiences for infants and those connected to them, and to set-up a backdrop for discussing how the construction of premature infants as social persons often requires obscuring these differences.

CHAPTER 1: IT'S TOO SOON

The time is out of joint—O cursèd spite,
That ever I was born to set it right!
Hamlet (Act I, Scene V, 188-189)

On the night you were born, the moon smiled with such wonder that the stars peeked in to see you and the night wind whispered, "Life will never be the same."

Nancy Tillman, The Night You Were Born

(A favorite book of many families)

For those looking forward to bringing a new human life into the social world, expectations arise from the moment a woman suspects she is pregnant. "When will the baby arrive?" is perhaps the first question to be asked. For clinicians, a newborn's anticipated date of arrival, or due date, is always calculated from 40 weeks. Clinical medical tradition and practice has selected the pregnant woman and her experience of human gestation as the grounded reference point by which the human gestational process of fetal growth and maturation are calculated and measured[6] (Issacson 1991) (Hartouni

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[6] This is in contrast to embryologists who calculate and measure fetal growth and maturation from the first day of conception (Engle 2004). Clinicians (ob-gyns, neonatologists, and pediatricians) calculate and measure the age of embryos and fetuses during pregnancy from the reference point of a mother's last menstrual period. From the starting point of conception, full term occurs 38 weeks from the first day of conception. Until the advent of *in vitro* fertilization, calculating due dates largely relied solely upon a woman's memory of her first day of her last menstrual cycle. As conception roughly occurs 2 weeks after this date, a woman's pregnancy is calculated from the last day of her menstrual cycle and designated to end 40 weeks later. Thus, when a woman finds out she is pregnant, her ob-gyn will tell her that her fetus/baby

1997) (Rapp 2000) (Casper 1998). Most newborn babies do not arrive exactly on their due dates (Joseph and Kramer 1999). Nevertheless, expectations are set. It's part of what to expect when you are expecting. One expects a due date and then one expects some minor deviations from that due date. We have practices and discourses for managing minor deviations, so babies are socially known as a little "early" or "late" based on their due date. Just ask any mother and many will recall their child's due date, or at least remember whether their child was on time, late, or early.

Parents-to-be and their nexus of friends and family prepare themselves and each other for change, always with the due date in mind. Whether through baby showers, reading parenting books, scheduling vacations, redecorating homes, taking time off from work, or just meeting up for get-togethers, activities are coordinated with a sense of joyful anticipation tempered by the ambivalence of knowing the inevitable: "life will never be the same."

For most, the end of pregnancy brings about the romance and responsibilities of babies—babies that simultaneously inhabit the childhood world of goodnight moons and twinkling stars, as well as suckle for comfort, cry for milk and diaper changes, and always awake too soon, needing to be held, fed, and swaddled once again. Pregnancy also brings about membership into the club of parenthood, where the near absolute power and right to make decisions for another human being and to impose them is met with a perpetual undertow of self-doubt. This very combination of what author Ayelet

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is already 2 weeks gestational age or beyond. Unless a pregnant woman has undergone *in vitro* fertilization where the exact day of conception can be witnessed and therefore known, conception is unknowable and pregnant womens' ***experiences*** with how they conceptualize the age of their embryos and fetuses is based on 40 weeks. For women undergoing *in vitro* fertilization who did not have a last menstrual cycle, and even though the date of conception is known as it was clinically manipulated, a fictive first day of the last menstrual cycle is calculated for her upon leaving the IVF clinic and being transferred to an ob-gyn. Thus, an IVF pregnancy is also ***experienced*** from 40 weeks in order to be systematic with the majority of non-ivf pregnancies (Personal experience and communication 2006, 2007).

Waldman refers to as a ceaseless “inner tsk tsk” coupled with the never-ending daily work of interactional decision-making through “little reflexes, instincts, and minute by minute adjustments” is what makes parenting an arduous endeavor. From naming, to figuring out bottle or breast, whether to sleep train or co-sleep, or when and if to vaccinate, these decisions are made as one interacts with the newborn infant and with each other. Yet, anyone who has ever shepherded and experienced a baby discovering his own emerging innate capacities—whether it is finding a breast, initiating a grasp, showing a smile, or producing a sneeze, cannot doubt that the act of parenting is itself the elixir guarding against exhaustion and turning sleepless nights into badges of honor. These descriptions illustrate some of the contradictory expectations, experiences, and ideals that surround the uneventfully eventful births of full-term infants and the start of parenthood.

Cultural and social norms surrounding full-term birth and full-term infants, like due dates, set expectations for pre-term births and premature infants. Not just born ‘a little’ early, but *too* early, premature infants and prematurity experiences fall outside the norms of expectations and deviations from expectations. It was only several decades ago that premature infants did not survive and would often be considered a late miscarriage (Anspach 1997) (Gustaitis and Young 1989) (Silverman 1994) (Humes 2006). Thus, as the experiences and ideals surrounding normal full-term infants are intertwined with those of premature infants, interactions with and about premature infants are also about thwarted expectations, dashed dreams, and dislocated bodies, selves, and others. More immediately, living through prematurity entails carrying on and moving on in the face of seemingly endless waiting—waiting for a premature body to grow, waiting for weight gain, lab results, developmental milestones, a little magic, waiting to do something and anything, waiting for responsibility, waiting to become a mom, a dad, a brother, a sister, a grandparent, a family; and sometimes, waiting for death.

For the many individuals intimately connected to the uncertain futures of premature newborns, the expectations and beliefs (in its broadest sense: physiologically, interactionally, relationally, practically, cognitively, and emotionally) surrounding full-term births will forever cast a long shadow, emerging out of coping, managing, and living through simultaneously “having a premature baby” and “prematurely having a baby” (Sammons and Lewis 1985). Often in contradiction and in tension, the prematurity experience has two sides. “To have a premature baby” is saying something about the emerging experience, state, and status of a premature newborn, both physiologically *and* socially. In contrast, “having a baby prematurely,” says something about the emerging experiences, states, and statuses of parents and family members. Medical caretakers are often caught between these two aspects of prematurity experiences. However, both aspects of prematurity experiences are contingent upon whether, how, when, and how much a premature newborn physiologically matures. These questions are unanswerable as new “to be determined” growth trajectories are themselves still emerging.

Yet, coping with a birth "out of joint" with time does not necessarily only include accepting and negotiating a myriad of unexpected realities; it also entails actively trying to "set *it* right." What that "it" entails can only be revealed as individuals are actively engaged in a multitude of interactions. Through interactions, individuals begin to piece together and fashion their desired futures (and sometimes fantasies) for and with their premature newborns. For the medical caretakers, interactions range from participating in formal and informal discussions on treatment plans and the coordination of medical caretaking work with team members and other relevant hospital staff; to educating, assisting, and preparing parents and family members for the care of their premature infants; and, of course, interacting with premature newborns in ways that are social, non-social, and “in between.” (e.g., talking to them, “playing” with them, putting in IV lines, drawing blood, reading and listening to heart monitors and ventilators, calculating medications, ordering and reading lab results). Likewise, it is also in the space of social interactions that parents come to decipher what ‘it’ means to "set it right." For them, ‘it’ entails interacting with various members of the medical and hospital staff (nurses, attendings, residents, specialists, and social workers); with their spouse or other family members; and also with their premature newborns in ways that are social, non-social, and "in between" (some examples include: talking, staring, reaching into the isolette, bringing in stuffed animals, using a breast-pump, and delivering breast-milk for storage). Together, it is through the infinite possibilities of interactions that individuals come to know, accept, and experience the prematurity crisis and the medical decisions pertaining to the care of premature newborns. In turn, they begin to grapple with the indeterminacies of “Who is the premature newborn?” and “Who am I?”—two fundamental questions underlying what it means to be a person. Thus, using a multi-perspective approach, this dissertation explores the experience of personhood in all of its modalities for three intimately connected groups of individuals living with and through the premature birth of a newborn: medical caretakers, parents, and premature newborns themselves.

In this chapter, I will orient the reader to many experiences of the NICU and of prematurity. In *Growing Matters*, I will introduce important background information and articulate the evolution of the "Crystal Ball" methodology. I have deliberately chosen to include a further discussion of methodology in a chapter about experiences of prematurity because one of the theoretical contributions this dissertation hopes to make is to draw out the interplay between universals and particulars. Given the universality of the human maturational process and the standardization of NICU equipments, the implementation of the same methodology in two different cultural contexts will invariably produce different experiences. These differences are part of the goals of this research. In *Vignettes,* the purpose is to give context to important background information and to highlight some common thematic obstacles found in both geographical locations. The intent is to present the details of various pieces of information in a manner that emphasizes the simultaneity of experiences between different actors at a particular shared point in time, while highlighting their differences. Specifically, detailed information will be provided regarding the human gestational process and how the maturational process has gone awry. In addition, details will be provided concerning the underlying physiological complications faced by premature newborns. Lastly, this section underscores the important presence of the universal biological constraint that is the human gestational process. It is always at work (or not working), and is a fact of NICU life that perpetually rubs upon and against social interactions-in-the-making.

Growing Matters
(Premature bodies and Crystal Ball interactions-in-the making)

A small naked human body lies in a spread eagle position in an elevated bed covered by saran wrap. Taped and pinned down by numerous wires, the small body glows from the red hue of heat lamps. There is no cry. Now dislocated from the maternal uterus, he has lost his capacity to move, suckle, grasp, blink, and hear. This is a premature newborn at the very edges of viability, born up to four months too soon, not much larger than the size of an iPhone and weighing a little less than eight sticks of butter. Although not all premature newborns are as young or as little, they almost always require life-saving interventions, and their arrival into the external world always induces the loss of physiological capacities they once had.

Saving premature lives requires high tech medical interventions in the form of neonatal intensive care units and their accompanying set of complex infrastructural and administrative structures, a variety of technological devices, treatment protocols, and specialized medical staff. NICUS are highly functional, efficiently designed spaces. With very little physical infrastructural variation, they are organized like functional labs. Sectionals of white countertops with many outlets, drawers, and shelves line the walls throughout large rectangular rooms. Various bags of blood, vials of medications, syringes, and miniature cords resembling thin phone lines lie on these counters. These various parts will connect the premature bodies to the collection of machinery required for life support—monitors that track heart rates, blood pressures, and body temperatures, ventilators, incubators, etc. Close to fifty miniature elevated beds are placed against units of counter-top space. Surrounding each bed is an arrangement of machines, gadgets, and monitors, which can easily be plugged into the counter-top units, as well as to each other. These machines spew out numbers while the monitors exhibit the graphed indications of life. Sprinkled throughout the intensive care unit are large deep white sinks for easy access hand washing. The room of the NICU is lit with florescent ceiling bulbs. The floor is a slick, waxed surface, with the lingering odors of a disinfectant—a sterile and bright environment is crucial for doing work on and for premature bodies. At night, the entire room is dark with numerous blinking lights. Sounds of machines whirring and bleeping create a high mechanical noise level.

Traffic in the NICU can be heavy and congested. Nurses and doctors stand over the miniature beds to pinch, prick, and tape the body down so that they can better insert and excavate various tubes and lines that connect the body to its life supply of medications and liquids. At other times, staff stand over countertops to record the blinking numbers and graphs into data charts. Respiratory therapists manipulate and record data from ventilator units, teams of surgeons can be found at various times either rounding or performing surgery, and various other branches of medicine can be found treading around the unit, trying to maneuver large pieces of equipment through small spaces. However, there are certain times during the day when medical work is not scheduled, when the NICU can be hauntingly quiet and the only sounds are those of machines purring. This is the physical space inhabited by premature newborns. It is their first ex-utero place of residence.

Immediate complications that require radical technological interventions into the human developmental process almost always include ventilation support for lungs not yet capable of breathing, temperature regulation through incubators or radiant warmers for immature bodies incapable of maintaining body temperature, and the constant monitoring of all blood chemicals and minerals for preventing systemic infections. In addition, there are more dramatic interventions for severe cases of prematurity. One example is the use of extracorporeal membrane oxygenation machines (ECMO) that mechanically circulate blood from outside of the body, substituting for the premature lungs and a heart that have yet to function. In between, there is an exhaustive list of critically routine and high-maintenance tasks that must be constantly coordinated, monitored, and maintained to insure the survival of premature newborns (e.g., blood tests, ventilator adjustments, maintaining IV lines, etc.). In short, premature newborns do not possess the three most basic physiological capacities for survival in a world outside the maternal uterus (ex utero): breathing, eating, and regulating the internal bodily environment against fluctuating stimuli of any kind in the ex utero world (i.e., homeostasis).

Although significant progress has been made in the field of neonatology, the prevalence of preterm births has not been reduced, due to a lack of knowledge about its cause. More critically, neonatal intensive care technologies and treatments have been at a relative stand still for the last thirty years. Every year, in NICUs around the world, hundreds and thousands of newborns are saved who, had they been born thirty or forty years ago, would not have survived. Although survival rates for newborns born with premature organs is around 90%, it is a mitigated success. Prematurity related morbidity, the existence of any form of disease that affects the health conditions of former NICU patients, has not significantly decreased and appears on the rise (Sammons and Lewis 1985) (Meadow 2000). Especially for those born with very premature organs, often weighing less than two pounds, and fitting into the palm of one's hand, neurological and physical disabilities are par for the course. Continued outpatient care and follow-up are required at a minimum, re-hospitalizations and surgeries are also likely, and more significantly, institutionalized care is sometimes necessary. For the majority of premature newborns who fall within a range of “normalized” prematurity (between 28-34 weeks gestational age), common complications that arise are often considered “family issues,” rather than medical ones. These include cerebral palsy, mental retardation and disorders of psychological development, behavior, and emotion.

As referenced in the introduction, it was through my participation in the Crystal Ball Study that I first gained insights into prematurity experiences. Furthermore, the re-implementation of the Crystal Ball questions as a methodological control would be critical for generating comparative insights between the U.S. NICU and the Taipei NICUs. Thus, a discussion of prematurity experiences would not be complete without more detailed descriptions of the Crystal Ball questions and its function as an interactive reagent for revealing various types of interactions-in-the-making that were produced between the various actors in the NICU. Each day, every medical caretaker (attending, fellows, residents, interns, nurses, respiratory therapists, etc.) was verbally asked one simple question with two parts: “How is your patient doing?” (1) “Do you think this patient will survive?” (2) If so, “What do you think the physiological and neurological outcome will be?” If not, “When do you think this patient will die?” With each question, medical caretakers were also asked to indicate their level of confidence (1-5 most confident). After discharge (or death), these prognostic assessments were measured against actual outcomes. Outcomes were obtained through records of developmental tests conducted by hospital staff, as well as through parental telephone interviews conducted by me. In the course of three years, a little over five thousand daily prognostications were gathered. The Crystal Ball Study was an apt metaphor that underscored the complex uncertainty that loomed over premature NICU patients. It was this metaphor embodied by the Crystal Ball protocol that proved to be the interactive reagent for revealing elusive experiences with prematurity. Whether a premature NICU patient lived or died (mortality outcome), and whether he or she will have physiological and neurological disabilities (morbidity outcome) in the future are two immediate uncertainties that medical caretakers and parents must face. Although these concerns are addressed statistically, they are rarely addressed experientially. Up to now, prognostications of mortality outcomes are accurate only for groups of premature patients, while prognostications of morbidity outcomes remain inaccurate. That is, whenever a survival rate is given in the NICU, it only applies to a specific *group* of premature patients (not the specific individual). For example, an 85% survival rate only applies to a specific group of NICU patients. It does not tell you who specifically out of that group will survive. For example, if there are 100 NICU patients who fit the criteria of “greater than 1500 grams and greater than 28 weeks gestation,” there is no way to accurately assess which specific individuals out of the 100 will be responders to NICU treatment and survive (i.e., the 85%) and which specific individuals will be non-responders and die (i.e., the 15%).

Furthermore, neonatal intensive care cannot rely on existing methods for determining mortality and morbidity outcomes for individual NICU patients. This is largely due to the fact that existing intensive care scoring systems that predict mortality and morbidity rely on a “point scores” method given for certain physiological declines (e.g., blood pressure, body temperature, heart rate, and lung capacity) with higher scores correlating with more disease. This prognostic scoring system is premised on a human body with fully matured organ capacities, from which mortality and morbidity are measured by degrees of physiological decline. Unlike patients in any other intensive care units (ICUs), premature patients' organ systems are still immature with the actual range of physiological capacities still *to be determined*. In other words, premature NICU patients do not have a prior history of physiological capacities to serve as a baseline for prognostications of mortality and morbidity outcomes. This places medical caretakers and parents in very difficult and often soul-wrenching cross-roads when medical decisions are not straightforward.

Because of this essential difference in physiology between NICU bodies and other ICU bodies, premature NICU patients essentially have to "show" or "not show" their physiological capacities *as* they actually emerge. For medical caretakers and parents to "read" the signs of growth and development, they have to tap into their "gut feelings" and intuitions. The chapters to come will argue that these intuitions are in part derived from interactional experiences both in the past and presently "in-the-making." As a result, there can be wrong interpretations of physiological cues and/or a lag time between the onset (or lack thereof) of capacities and the correct assessments of these onsets. A 'better' intuition would be one that could successfully read the physiological cues of a NICU patient earlier, rather than later.

Why does all of this matter? First, when medical caretakers cannot predict life or death with timeliness and accuracy, there is a great risk that NICU care could subject premature newborns to aggressive, invasive, and potentially painful therapies that would prolong death, rather than life. The possibility of futile care strikes at the heartstrings and informs the moral compasses of medical caretakers, parents, and societies alike. Second, even if medical caretakers could accurately assess survivability, it is critical for most families to understand what survivability really means. Lastly, medical caretakers draw upon intuitive prognostications of mortality and morbidity all the time. They underlie decisions regarding day-to-day treatment plans, as well as how high maintenance caretaking tasks are coordinated. For example, if a nurse senses that a premature patient is not doing well during a particular hour or day, she might choose to hold off on drawing blood to check on the patient's anemia status. Although withholding a specific medical procedure is never recorded in the charts, these decisions can impact the overall survivability and outcome of premature patients due to the vulnerability of their physiologies.

Although the "Crystal Ball" questions usually took medical caretakers less than thirty seconds to answer for each patient, it quickly became apparent that these questions tapped into a well of interactions "in-the making." As I made the daily rounds to each NICU patient's station, I would listen to their rationales for their prognostications and observe them 'working on' and monitoring their patients. Many medical caretakers would find me when they were not busy and often recount their day's events with me. They provided informal, unsolicited narratives regarding how they interacted with their premature patients, how they perceived their premature infants to be interacting back, how they interacted with others on their medical team and/or with parents, how parents interacted with their premature infants, and how they felt the parental visit was received by their premature patients. Other times, my questions would elicit "black humor" that replayed mistakes and tragedies of patient care, as well as non-NICU related stories, such as gossip about co-workers, love lives, kids, spouses, families, weekend plans, and vacations. What is interesting to note is that these informal narratives rarely changed medical caretakers' prognostications once they were made. Rather, these informal narratives were extensions of and part and parcel of prognostications themselves.

Although I rarely spoke to parents in the NICU out of respect for their privacy, I became well acquainted with them through telephone interviews[7] once their infants were discharged. I conducted developmental outcome assessments of discharged NICU patients by asking parents to recount "a typical day" in the life of their child. This question would elicit stories and narratives that were windows to assessing developmental outcomes. Rather than merely just knowing whether developmental milestones were reached, these stories gave a context to how parents integrated their child's development or lack thereof into their daily lives. In addition, it provided parents a welcomed venue to process their NICU experience. Many parents would express the same sentiment. "I'm still trying to figure out what happened, call back anytime, it was really nice just to be able to chat about how I felt." In short, the Crystal Ball project elicited data on the emerging personhood statuses and experiences of premature newborns, as well as of medical caretakers and parents. It is these "interactional" data that I gathered and would eventually use for this dissertation.

In Taiwan, it quickly became apparent that the Crystal Ball questions, "How is your patient doing?" and "Do you think your patient would survive to discharge or die?," did not resonate with medical caretakers. I was told that the questions were "too short" and that they did not know how to answer such short questions. I was also told that there are "so many things to say about each patient" and that they could not simply answer "yes" or "no" to survival. In short, I was politely told that the questions "did not really

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[7] The study did not want to over-burden parents with extra hospital visits.

make sense." However, despite their unwillingness to assess the survivability of their premature newborns, they nevertheless did have intuitions about their patient's survivability. After many formal and informal discussions regarding the concerns and questions that medical caretakers in Taipei felt were most important in the NICU, the Crystal Ball questions were reformulated. As it turned out, the reformulated questions captured the same theme (i.e. survivability), but now only *inferred* survivability. This nuanced difference in how medical staff across two geographical locations engaged with the same theme would help to explain other cultural differences in the chapters to come. In addition, it was unanimous that medical caretakers in Taipei would not offer predictions of neurological outcomes. Although they said they were unable to predict neurological outcomes, their actions and interactions suggested they did have some intuitions about them. Once again, I tapped into a well of "interactions-in the making." With help from medical caretakers themselves, the reformulation is presented below: (I would ask all of the questions in Mandarin, but when referring to the NICU patient, I would call NICU patients "NICU babies" or more accurately, "NeeC-u **B**aaybeee" in English with Mandarin phonetics, which was the common term used by medical staff in Taiwan).

> "Did your 'NICU baby' eat well today?"
>
> "Did he/she sleep well today?"
>
> "Did he/she produce any waste?"
>
> "What is his/her "xing ching" (heart condition)?" "Xing" is heart and "ching" is spirit or mood. Thus, "xing ching" can be translated as "What is the mood of your heart or what are your feelings?" This question is a

> double entendre that medical caretakers understood to mean how was the patient’s heart physiologically, as well as, “how do you think the premature patient was feeling today?”

The answers to these questions were tracked for every NICU patient that was admitted who required ventilation support, and then matched against actual life-and-death outcomes. In addition, medical chart information was gathered daily until ventilation support was no longer required. In the course of a year, over 100 patients were tracked in this manner. As these questions inevitably also tapped into interactions-in-the-making that underscored concepts of the person, it is not surprising that many NICU actors shared their stories, feelings, frustrations, hopes, and sorrows with me. These interactions, narratives, and stories that I became privy to are also critical components of the data set. These social data anchored by medical chart information and by daily tracking of intuitive prognostications will illuminate cultural differences and provide some grounded explanations for these differences. Although I spent a short length of time in Taiwan and did not formally track predictions of post-discharge neurological and developmental outcomes, medical caretakers would often speak to outcomes indirectly. They would talk about the types of parenting required and the level of responsibility they imagined for the parents and family members of their patients. As many medical caretakers were also parents themselves, Crystal Ball questions elicited many discussions and reflections of their own roles and experiences as parents. This almost always tracked with a sense of how well their patients were responding to NICU treatment.

Interviews with parents were conducted post-discharge, out of respect for their time of crisis. Parents would often recount their experiences with prematurity and of the NICU through an imagined sense of their child's emerging NICU experiences, as most NICU parents in Taiwan, in contrast to the U.S., did not actively participate in their child's hospital routines (e.g. feeding times, holding times, rounds, and bath times). Husbands or other family members usually made brief visits to the NICU during visitation hours. In addition, although I did not formally assess outcomes for premature patients in Taiwan, I was nevertheless able to gather a general sense of well-being and developmental achievements from parents, as well as their hopes and fears for their child in the context of developmental milestones (or a lack thereof). Due to a shorter length of time in Taiwan, the number of ethnographies gathered with NICU family members and medical caretakers are fewer, but with much richer detail. A case-study method was employed. In addition, because it was important to understand parenting, family, and kinship experiences outside of the NICU context, I spoke to anyone that I came across who was a parent or had anything to say about parenting.

Together, the U.S. and Taiwan versions of the Crystal Ball protocol provided a rich tapestry of comparative data on "interactions in-the-making" that underscored the emerging definitions and experiences of personhood for actors in the NICU. For those caught in the world of NICUs and prematurity, the Crystal Ball questions were the very questions that parents across both locations asked themselves every day: "How is my baby doing today?; Will he/she survive?; and What does the future look like for my baby?" However, answers to these questions will remain elusive until physiological capacities actually emerge. Yet, there is a lot of interactional work that takes place while individuals wait for premature bodies to grow and show its capacities. In many ways, it is only out of the interactions of individuals and their participation in social processes that *many* kinds of metaphorical crystal balls would emerge to provide a means of coping. Speaking about and imagining a future is inherently about taking and distributing responsibilities. Doing so can generate feelings of control and comfort, as well as of inordinate burdens.

The next section of this chapter will orient the reader more experientially. It begins to provide a context and sense of how answers to questions concerning the medical status of premature NICU patients are essentially about emerging definitions and experiences of personhood.

Vignettes
(Prematurity experiences from three situated perspectives)

The following is a series of vignettes. They attempt to show how a defined period of time can be experienced from three different situated positions or knowledges: **the premature newborn,** *the medical staff,* and ***the parents***. Donna Hawaray's concept of situated knowledges is a helpful framework for illuminating and organizing both the objective and subjective realities of human interactions (social, nonsocial, and in between). It is intended to simultaneously account for contingencies and meanings-in-the-making, "*and* a no nonsense commitment to faithful accounts of a 'real' world," one that can be partially shared, but never fully known (Haraway 1991:187). I have organized the vignettes experientially by designating each perspective with a particular font style. The **bold font signifies the premature newborn;** *the italicized font signifies* *the medical staff***,** and ***the italictized-bold font signifies the parents.*** This format highlights individual lived experiences while simultaneously emphasizing a grounded and positioned account of the NICU prematurity crisis.

These partial descriptions of experiences surrounding prematurity are drawn from narratives in the U.S. and in Taiwan. It is my intention that they appear somewhat disjointed and read like a flood of information. It will be unclear how these vignettes actually connect, and it is the task of the rest of this dissertation to show how individuals, in the space of social interactions, attempt to connect these various disjointed elements by working out competing goals, uncertain realities, and contradictory emotions suggested by these vignettes. The vignettes are also peppered with informational commentary. This is meant to provide another layer of critical background understanding (both experientially and informationally), which parents and other NICU outsiders only acquire through lived time, and in pieces.

(Crisis and Confusion)

DAY OF LIFE 1

“***Birth” Day***: *DOB*

“**Day of Life 1**” (and the other “days of life” to follow) signifies the emerging ‘experience’ of the premature newborn. With the very bare minimum capacities for life, it is an experience that remains unknown to others, and simultaneously can only be ‘communicated’ and known by others through interactions as these physiological capacities emerge. Thus, from the situated positions of premature newborns, because their capacities for interactions consist of unconscious reflexes at best, interactions with them are not *socially* reciprocal, only existentially reciprocal. That is, interactions that can be categorized as purely social are one sided—they can only come from caretakers and parents, and not the other way around. Only until physiological capacities emerge to an extent that the immature brain can process social interactions in its most rudimentary form can social interactions between premature newborns and others be considered socially reciprocal. Therefore, there is no accompanying text to the experiences associated with **'day of life.'** The premature newborn occupies a physical position (a physicality) in existential time and space, yet its status in social time and space is in-the-making, including his/her experienced degree of aliveness. This is a universal phenomenon of the prematurity experience, with which individuals must cope.

DAY OF LIFE 1: *"Birth" Day*

> ***"How sick is my baby?" (Parents, U.S. 1998 and Taiwan 2004)***

> ***"It's too soon. I'm only 26 weeks. I haven't even had a baby shower yet. I'm supposed to be due in July." "He's not ready, he still needs more time, we're not ready. This is a nightmare." "This can't be his birthday. He is supposed to have a summer birthday." "I can't stop crying. I keep dreaming that I will wake up still pregnant" (Mom, U.S.).***

"I just cry and cry and cry. This is a bad bad terrible dream. I did not think this can happen. My heart hurts so very very much. I do not want my baby to suffer, to have such bad luck already. She is so little, so small, her little body is not strong enough, she still needs my body…so very pitiable (ke lian)" (Mom, Taiwan).

"I just ran after the people running with the incubator. My wife told me to go. I didn't want to leave her, but she insisted that I go. Someone told me we were going to the Neec-U. I had no idea what that is. I just followed" (Dad, U.S.).

"I tried not to show worry. I do not say anything. I do not know what to say. I do not want my wife to worry. She needs to get better. My heart is 'in a rush'" (anxious/nervous) (Dad, Taiwan).

"My mother and my mother-in-law both told me not to carry heavy things. They say, …'just ask Jing Ming to carry things.' It's not like that anymore. They are old fashioned. We are more equal now, like the rest of the world. We both work. My husband cleans, picks up groceries, why can't I carry some things? This is a bad bad nightmare. It's my fault. I did not listen to them. I should have listened to them. I did not think this can happen. I don't know why I have/deserve such bad luck" (Mom, Taiwan).

“‘*Birth’day*” illustrates the experience of parents, and it is one of crisis and confusion. They were expecting a celebratory birthday, yet what they have is a day of birth gone awry. Parents are often overwhelmed by the admission of a newborn to the NICU. Faced with complex medical information, they must also negotiate their way through a complex system of care (Heimer and Staffen 1998). On admissions, parents are often given thick packets to orient them to unit rules and introduce them to numerous staff members. They are told who will care for their newborn, when they may visit, when and whether other family members may visit, which phones they may use, and where they may talk with other NICU parents. These packets often contain “baby gifts” such as fill-in-the blank calendars, memory books, and various other paraphernalia that encourage parental participation in the NICU process.

DAY OF LIFE 1: *DOB*

Patient I.D. 161100

DOB: 4-01-97

GA: 26wks

Weight: 750g

Sex: M

Apgar score: 0/4

Fi02: 0.1

RDS

8:30 a.m. urban NICU, U.S.A

Doctors and nurses are gathered for morning medical rounds. An American medical resident begins to present.

Resident: "Twenty-six-weeker, seven-hundred-fifty-grammer, male, born last night, mom came in—pre-term labor. No prior history. Apgars, zero, then four. RDS. Resuscitated with cpap. Already on steroids, surfactant, on full oxgyen, and prophylatic fluc. Likely complications include: BPD (Bronchopulmonary Dysplasia), PDA (Patent Ductus Arteriosis), NEC (Necrotizing Entercolitis), IVH (Intraventricular Hemmorhage), ROP (Retinopathy of prematurity), PVL (Periventricular Leukomalasia), anemia.

Attending: "Sounds good. This is the drill kids." (Turns to the patient's primary nurse) "Mary Jean, do you have anything to add?"

Mary Jean (nurse): "So far so good, I'll let you know…. just the usual….well, until things change….in the meantime, I will try and get some feeds."

Patient I.D. 79188045
DOB: 8-31-04
GA: 27wks
Weight: 900g
Sex: F

Apgar: 1/3

RDS

6:30 a.m. urban NICU, Taiwan

Doctors and nurses are gathered for medical rounds. A Taiwanese medical resident begins to present in English.

Resident: "This one, twenty-eight weeks gestation, nine hundred grams, female, and have respiratory distress. Mother came in last night, she had pre-term labor. There is no history. Apgar score at one minute is 1, then at five minutes is 3. Resuscitated with continuous airway pressure (CPAP). We give steroids, surfactant, oxygen level 100%. Also will give flucon. We need to watch for BPD, PDA, NEC, IVH, ROP, anemia.

Attending (in Mandarin): Ok. (Turns to the patient's primary nurse) How is your workload? Do you need more help? You have a lot of little ones right now. Do you have any insights to add?

Nurse: "Just the usual…Eating is always a problem…I will try and get some breastmilk…Just routine so far, unless things happen. We will watch carefully."

In contrast, "*DOB*" (*date of birth*) illustrates one aspect of medical caretakers' experiences—routines and order. What is a birthday gone awry for parents is a date of birth that will be used only as a basis for calculating the degree of prematurity in gestational weeks, which, when paired with birth-weight, allows premature newborns to be categorized as belonging in one group or another. This is a procedural constant that is found across NICUs all over the world. The NICU is an organization where the emergencies of new parents are transformed into routine organizational business. There is a routine for nearly every problem, whether it is medical or interpersonal (Heimer and Staff 1998).

Taken together, these vignettes, and others to come, foreshadow contradictory experiences and tensions. Routines for medical caretakers are unimaginable nightmares for parents. For the medical caretakers who experience hundreds of admissions to the NICU every year, parental milestones and rites of passage, such as a first bath or a first breastfeeding, are part and parcel of a routinized high-maintenance job. Simultaneously, the NICU is both a "first nursery" and a highly coordinated work place. All the while, there is a collective understanding that there are changes ahead.

Lastly, it is obvious that there is a lot of medical shorthand for a very complicated set of physiological issues that a premature newborn must overcome for survival. Parents are often informally peppered with this kind of information when they visit the NICU.

Below, a variety of relevant pieces of medical information that I have learned through attending many medical rounds are integrated with summaries taken from parental pamphlets and websites aimed at educating parents about complications of prematurity. Although the information below may seem overly detailed, it is important to understand the specifics of these medical conditions because it is often the first (and sometimes only) means by which parents and medical caretakers begin to "know" a premature newborn. Furthermore, these details become translated and transformed into idioms of expression for talking about prematurity experiences and premature newborns. Also, how individuals experience these medical descriptions and complications, and desire them to be, are often intentionally and bureaucratically transformed into elements of NICU-specific rites of passage, another component of this study.

The “26 weeker, 750 grammer” and “the female NICU patient of 28 weeks and 900 grams” are premature newborns. They are 26 weeks and 28 weeks old respectively, via gestational age. Gestational age (GA) is the age of an embryo or fetus while in utero. It is rarely calculated or recorded for full-term newborns, even if they are delivered slightly before 40 weeks or slightly after. However, it is one of the two most important recorded identifiers and biomarkers for premature newborns (the other is weight). When applied to a premature newborn, the gestational age is the length of his or in utero gestation time, up to the time of delivery. It is calculated based on the first day of a mother’s last menstrual cycle. For premature newborns, a date of birth is only relevant for determining the gestational age. In contrast to full-term infants whose age is calculated in days, weeks, and months once they are delivered into the ex utero world, a premature newborn’s age continues to be calculated and referred to in gestational weeks until (at least) the day of discharge.

Almost all premature newborns have respiratory distress syndrome (*RDS*); they do not have the capacity to breathe. As a result, they are usually born dead (or nearly dead) and must be resuscitated. *Apgar* scores are a simple and repeatable method by which the health of a newborn is determined. They are universally employed at birth. Five criteria are evaluated: **A**ppearance, **P**ulse, **G**rimace, **A**ctivity, **R**espiration) at one minute after birth and again at five minutes. A zero apgar at one minute means the newborn is momentarily dead and requires resuscitation. At five minutes, a second apgar score is then taken. Scores of 1-3 are generally regarded as critically low, 4-6 fairly low, and 7-10 generally normal. In other words, this is an immediate post-birth test of the "degree of aliveness" (or death).

Because fetal lungs do not fully mature until approximately 36 weeks, respiratory distress is a condition that occurs almost exclusively as a result of premature birth. Immature lungs do not produce an important substance called *surfactant*. Surfactant allows the inner surface of the lungs to expand properly when the infant makes the change from the mother's uterus to breathing air after birth. As a result, artificial surfactant and a ventilator are generally required. In addition, many premature newborns also receive a special kind of ventilation called continuous positive airway pressure (*CPAP)*. CPAP forces the air sacs in the lungs to stay open and allows for the delivery of higher levels of oxygen. The severity of RDS is inversely related to gestational age. That is, younger premature newborns have more severe respiratory distress. In addition, steroids are given to enhance the maturation of immature lungs. However, steroids also suppress the immune system and can lead to systemic infections. As a result, fluconazole (*flucon*), an antifungal drug, is used in the treatment and prevention of fungal infections.

Complications that accompany and/or result from respiratory distress can continue to affect the lungs, as well as almost all other organ systems. When artificial surfactant and steroid treatment fail to enhance the maturation of immature lungs and extended ventilator support is necessary for survival, lungs will begin to show evidence of deterioration due to the inability to withstand the constant pressure of ventilators. This condition is called Bronchopulmonary Dysplasia (BDP).

The immature heart can also cause breathing difficulties due to an open blood vessel that fails to close at birth. This condition is called Patent Ductus Arteriosis (PDA) and occurs because many premature newborn are still producing a fetal compound called prostaglandin E that circulates throughout the blood stream, keeping the ductus arteriosis vessel open. As the circulatory system of the in utero fetus is interconnected with the maternal circulatory system, this open blood vessel is a critical physiological structure that enables oxygen transport between the maternal and fetal systems.

Newborns before 34 weeks gestation are also at increased risk of bleeding in the brain due to immature blood vessels that may not tolerate the changes in circulation that take place during labor. This can lead to future complications such as cerebral palsy, mental retardation, and learning difficulties. This condition is called IntraVentricular Hemorrhage (IVH). When IVH persists, it can lead to Periventricular Leukomalasia (PVL), the permanent loss of vital areas of neural tissue, in particular motor fibers that control muscle movement.

Necrotizing EnterColitis (NEC) is a condition that occurs when a portion of the newborn’s intestine develops poor blood flow that can lead to infection in the bowel wall. This is also due to the fact that the digestive system is still too immature to receive breast-milk. In addition, because respiratory distress requires the use of steroids to enhance lung development, which at the same time suppresses the immune system, the introduction of breastmilk before the digestive system has fully matured can also initiate an immune response and lead to NEC.

Retinopathy Of Prematurity (ROP) is a potentially blinding eye disorder that affects those born between 24-26 weeks. ROP is an abnormal growth of the blood vessels in the eye. The cause is unknown, but it is suspected that ROP develops as a result of oxygen levels that are too high or too low.

Anemia is a medical condition caused by abnormally low concentrations of red blood cells, many premature newborns lack the number of red blood cells necessary to carry adequate oxygen to the body. It is diagnosed using laboratory tests, but at the same frequent blood samples also make it harder for red blood cells to replenish. Some premature newborns will require red blood cell transfusions, especially those under 1000g. Red blood cells are important because they carry a substance called hemoglobin, which carries oxygen. Premature newborns, especially those that have lower gestational ages, do not make enough new red blood cells. In addition, the red blood cells that they do make have a shorter life than adult red blood cells. Lastly, because frequent blood samples must be taken for laboratory testing, it is difficult for premature newborns to replenish red blood cells. Blood transfusions are common are for those weighing less than 1000 grams (2.2 pounds).

Lastly, when complications can no longer be named and used to explain why a particular premature newborn is doing poorly or has died, failure to thrive becomes the explanation and diagnosis. Failure to thrive lacks a precise definition, in part because it describes a condition rather than a specific disease. Premature newborns who fail to thrive do are unable to take in, retain, or utilize the calories needed to gain weight and grow as expected.

With this in mind, the next set of vignettes foreshadows how these types of medical complications are integrated into the daily interactions of medical caretakers and parents. Because this period of time in the NICU is largely about warding off complications and hoping for growth, parents and caretakers alike experience “waiting” in different ways.

(Waiting)

DAY OF LIFE: 2……….10………….20…………40……………….90……XX…

Doing, Doing, Doing: ***Hoping, Coping, Rollercoasting***

This second set of vignettes attempts to capture the general sense of the entire period of time a premature newborn spends in the NICU. For medical caretakers it entails “doing.” For parents, it entails “hoping, coping and rollercoasting.” The average number of bed days spent in the NICU is 75-90 days. Waiting is a general theme that runs throughout these vignettes. Despite the constant work that is done to maintain the survival status of premature newborns, NICU medicine generally employs a “wait and see” treatment plan. As medical caretakers must always balance the prevention of death with the encouragement of growth, parents are often told that “we will have to wait and see” before we decide what to do next. Medical conditions often change daily, and sometimes hourly. For parents, the “wait and see” approach begets more waiting. They are always waiting for a phone call to be returned, waiting for medical rounds to end so they can get more information, waiting to visit at the right time, waiting for weight gain, waiting for infections to subside, and most of all, waiting to take their babies home.

For medical caretakers, being constantly on-the-go and always having something to do is what happens during the ‘waiting’ time while premature patients attempt to “grow out” of prematurity and “into” various physiological capacities. Because it is often difficult to establish causality between how much work is done and how well NICU patients are doing, the experience of always doing something and never really knowing if it is going to work is a source of deep stress for many medical caretakers, especially nurses.

DAY OF LIFE: 2………10………….20…………40……………….90……XX…

Doing, Doing, Doing

"I tell my three year old, mommy cannot carry you, you have to do as much for yourself as you can. Mommy takes care of babies whose mommies can't take care of them. They cannot do anything for themselves. I have to do everything for them. And it's hard work. I have to feed them by putting in little tubes. Not easy. Mommy works every minute at work. Mommy is very tired. You are lucky you can do things for yourself, so try not to ask mommy to get things for you or carry you, if you know you can do it yourself" (Nurse, Taiwan).

"I have a lot do today, the NICU baby's mommy is coming in. She is almost done with "zuo yue" (a rite of passage that requires a period of rest and isolation after giving birth). I want to try and take out some tubes today, make the baby look nice for her mommy. I hope she is in a good mood. I need to get everything done now, so the baby can rest before her mommy comes to visit.

(Nurse, Taiwan)

"It's just the usual day of going going going. It's like this everyday, the shift flies by. Even when things are slow, there is always something that needs to get done. A phone call to return, a lab result to order. There is always a phone call I can make. You have work on the kid and then you have to work on the parents. A lot of parents need a little…sometimes a lot…of pushing to get them to come in, to see their kid, especially in the beginning. Then, when they used to stuff, they get pushy (laughing)….what about this, what about that, when can they come home. You do everything, but sometimes nothing happens, you just have to do everything and wait for the best" (Nurse, U.S.).

"I'm so exhausted. I just do procedure after procedure. The nurse today has a hard time with lines. I am not suppose to do lines, but I do them because we just help each other out. Some people are better some days, than others…..sometimes we think, is something bad like NEC going to happen or a brain bleed or something if we can't get a line in right away. So, that is why we help each other" (Fellow, Taiwan).

"The first three days, maybe even the first week are always crazy with a new one. You have nothing to go, you have no idea where they are, what their bodies are like, what they have been through. You just do everything you can to find out, but you don't want to stress out their little bodies. It's hard, everybody wants to get in here and do stuff right away, the CT people (Brain scans), the brain people (eye scans), the heart guys—the PDA people—the GI guys—the NEC people. Everybody has their thing their worried about" (Nurse, U.S.). There is a rush, people do their thing and then everybody waits for

awhile and it gets slow. I still have tons of things to do, but slow…not so many people coming and going" (Nurse, U.S.).

These medical caretaker vignettes begin to foreshadow a sense of rushing, yet, rushing towards a goal that is "yet to be determined." I refer to this as the "hurry up and wait" experience. Although highly routinized, medical caretakers' tasks of caring for their premature newborns require constant "doing." There is always another line that needs to be put in, another lab test carried out, a phone call to return, a temperature to record, an alarm to turn off. Medical caretakers, and in particular, nurses must record up to 10 biomarkers (e.g., blood pressure, oxygen, etc., heartbeat, etc.) every hour, 24 hours a day. There is not an idle hour in the NICU for them, yet, it is never quite clear when the doing should stop. Although the near future goal of NICU treatment is discharge, medical caretakers are aware of the uncertain outcomes that still loom ahead. Because there is very little understanding of fetal growth and development that can be successfully applied to NICU treatments, it is difficult for medical caretakers to frame and place boundaries on when to stop their caretaking tasks. For example, because conditions of premature patients can change dramatically, medical caretakers often have to initiate all sorts of testing (blood tests, brain scans, etc.) Yet, each time these tests are conducted, the already vulnerable premature body is rendered even more vulnerable. However, if tests are not conducted and complications arise, regret and guilt for "not doing enough" often arise.

Because there is often a "wait and see" approach to treatment plans, superstition and fate are important idioms for managing a "bad day" as well as a means to ask others for help in the NICU. Staff members have good days and bad days, good weeks and bad weeks, depending on how their patient's are doing. As my nurse friend Kammy said, "we all get our mojos at different times." Those with good mojos are often viewed as having more luck with medical procedures, such as putting in lines or getting a patient to successfully absorb nutrition. Those with bad mojos often employ the help of those who are having good mojos. This is also true for medical staff members in Taiwan. The common term, "tuo ni de fu" roughly translates into "riding on your good fortune" is often used and enacted by NICU nursing staff when they are requesting help from others.

Staff members rely upon various coping mechanisms to reduce the high-stress caretaking that is required for premature newborns (black humor, rescue fantasies, etc.). The constant interactions required to keep premature newborns alive create emotional attachments, albeit one-sided, between caretakers and NICU patients. As a result, they often unrealistically take responsibility for declines in a premature patient's condition while not being able to accept credit for improvements. This speaks to the unique nature of NICU medicine, where the treatment itself is a kind of "suspension in time" (Guillemin and Holstrom 1987), holding off infections, holding off brain bleeds, and holding off death until the premature body can grow "out of " its complications. NICU medicine has not acquired enough knowledge to fully and reliably jumpstart growth[8], it can only attempt to prevent complications while sustaining life.

In addition, medical caretakers have a clear understanding that part of "doing" their work also entails facilitating relationships between the NICU patient and his/her parents and family members. However, tensions can arise as parents start to actually

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[8] Steroids can be used while a fetus is still in utero or for certain cases in the NICU to attempt to speed up lung development. However, this is not always enough. The benefits of faster maturing lung cells must be balanced against a risk of infections and a range of possible significant side-effects (Halliday et al., 2009).

parent and move away from “spectator parenting.” These vignettes suggest that facilitating relationships between NICU patients and their parents are interactions laden with power issues. William Sammons and Jennifer Lewis at Boston Children’s hospital often remind themselves and their medical staff that when parents have learned to be “pushy,” it is a healthy sign (Sammon and Lewis 1985).

DAY OF LIFE: 2……….10………….20…………40……………….90……XX…

Waiting, Hoping, Coping, Rollercoasting

“***There is nothing I can do. When I go I just stare. I have nothing to say. They tell me it’s ok to talk to him. I’m always just waiting…waiting for them to call me and tell me its ok to do this or do that” (Mom, U.S.).***

“My husband does not want to tell me, he visits. I am at home, I have to rest so I can be strong when my baby is better. But I force him to tell me the truth, he says the baby might have a bleeding in brain. I do not want him to be retarded. It will be a burden to him. As mom, I take it, but sad for baby. I just try my best to pump, to give him milk. His stomach is ok, no infections. If he can eat, it will help his brain” (Mom, Taiwan).

“It is never good news. If good news, then always some bad news. If he can take breastmilk, then his blood is bad. They have to give him more blood” (Dad, Taiwan).

"It's exhausting. There is never any good news. It's always one good thing and a lot of bad things. If her lungs are better, then she has an infection somewhere else. If I go and see her one day, she might be stressed out the next day and not eat. We thought the lungs were better yesterday, but this morning her brain might be bleeding. I never knew what was going to happen in the morning. I can't count on anything. I guess I just have to focus on the good stuff and forget the bad stuff. There is too much bad stuff" (Mom and Dad, U.S.).

"When I go and visit my baby, it always felt weird. They had to tell me how to touch my her, where to touch, and how long I can touch her. When she got big enough and became a feeder and grower, they had to show me how to hold her—do the kangaroo holding thing. I already have a kid. I should know how to do this already, but they teach you, because you don't' know" (Mom, U.S.).

"There is nothing we can do for the baby. I just get the best breast pump I can. I called my friend in America and asked her to send me the best brand. It is called medela. It is the best. We do not have it here in Taiwan. This is what I do for my baby. I do not need to visit. The nurses take good care of her. My husband goes and checks after work. I went once. She was just sleeping. I just look and say thank you to the nurses. Everybody knows my job is to get better, to grow/nurture (yan) my own body so I can take care of my baby when she comes home" (Mom, Taiwan).

These parental vignettes begin to illuminate experiences of hoping and coping—two types of emotional waiting. In addition, there is a sense that even when parents participate, they are more spectators of parenting, than actual parents. One parent described his experience as “when I go the NICU, it’s kinda like the time I went to sea world. They teach you how to meet a killer whale. It’s like that. They have to teach you how to meet your kid. It’s a little weird because you are excited, feel a little bit like a kid yourself, but it’s *your* kid you’re being introduced to.”

Sociological studies have shown the extent to which social control in the NICU is institutionalized and designed to determine which parents are up to a minimum level of commitment and competence (Anspach 1997) (Heimer and Staffen 1998), and which are not. However, sociologists Carol Heimer and Lisa Staffen have shown that the labeling of parents as appropriate or inappropriate is inconsistent and often in flux. Although they do not explain why this is so, these vignettes suggest that because concepts of the self and of others are “in-the-making” at the same that premature patients’ medical status is also “in-the-making,” it is not surprising that labels of “appropriate” or “inappropriate” parenting are equally in flux and “in-the-making” during a patient’s NICU stay. The NICU period of a parent’s life is often a time where one is definitionally a parent, but circumstances render them unable to participate in the act of parenting. In addition, cultural beliefs about what constitutes an appropriate parent versus an inappropriate parent are quite different in the U.S. and in Taiwan.

For many, parental interactions often begin as emotional interactions that are interactively “imagined” (Beidelman 1993). “Imagination relates to the discrepancy between expectations and reality….[It] relates to the ways in which people picture a world different from that which they actually experience" (Beidelman 1993). Many moms "interact" with their premature newborns by pumping milk alone in a quiet room next to the NICU. Although these moms are not directly interacting with their premature newborns, the very act of breast-pumping creates an emotional interaction between the mother and her child---an "imagined" interaction of breast-feeding. Other examples include bringing dolls or toys into the NICU or recording one's voice or bringing music to be played for one's baby. As the medical status of premature newborns are never stable, moments of hope are intertwined with moments of despair. These experiences are widely referred and known as "rollercoasting" (Sammon and Lewis 1985), (Anspach 1997), (Affleck and Rowe 1991).

The next and last set of vignettes foreshadows the theme of uncertainty. It indicates the end of the NICU period and the beginning of life outside the NICU. For caretakers, discharge day marks the end of their responsibilities for their patients. For parents, it is homecoming.

(Uncertainty)

DAY OF LIFE: XX, 20, 30, 40, 50, …..XX

Discharge: ***Homecoming***

"Discharge" /"Homecoming" is the goal of parents and caretakers alike. These are vignettes about the future and how individuals relate the present to the future. For medical caretakers, experience has taught them that leaving the NICU does not mean leaving the complications of prematurity behind. Uncertainty looms.

For parents, homecoming means they are now held solely responsible for the growth of their child—physically, emotionally, intellectually, and socially. There is often a sense that family life is just beginning, despite the fact that their child is already many months old. For many parents, homecoming day is not their child's day of life 30, 40, or 50, etc., it is day of life 1. This sense of possibility is filled with both positive and negative aspects of uncertainty. Parents look forward to being together, having their baby sleep in his/her nursery, using their baby gear, wearing baby clothes—in essence, experiencing what normal parents experience. However, they are also filled with mixed feelings about leaving the safe cocoon of the NICU. They are losing their support system. They can no longer talk to their child's nurse everyday. They have gotten used to a certain routine. Their relationship with their baby has become grounded in familiar patterns of interactions, always mediated, and always with someone giving advice and guidance. Even though, at times the "helicoptering" of medical staff can be overly m/paternalistic, preparations for homecoming can also render parents to feel a little bit rejected and rushed away. In the NICU, there are countless routinized rituals of attachment for connecting parents to their babies, but very few rituals of detachment (if any) for parents to separate away from the NICU staff and the NICU way of life.

DAY OF LIFE XX, 20, 30, 40, 50, XX: *Discharge*

"*There is always a lot to do, we are discharging that baby in 34—Michael Jones. He's been a feeder and grower for awhile. I think he's going to be fine….I mean for the most part, he won't have to come in for surgeries or anything, and he doesn't have any bleeds. But, you never know if they are going to be normal, non-NICU normal. Some kids will* *have emotional stuff like hyperactivity, but that is not really a medical thing anymore. It is a school thing" (Nurse, U.S.).*

"I always try to run through a checklist of things that parents will need to know. Usually, it's just little tips to help them figure out what their baby wants. But, I'm never sure how much they are taking in. We've (the NICU patient and the nurse) been preparing for it all week. Trying to get him to sleep at night, and awake during the day. There is no day or night in here, so I try to cover up his bed, to tell him that he needs to learn to sleep at night so he helps his parents. It's nice when you have a little bit more time to prepare to send them home. We have enough beds right now, so it's not so sudden. The last couple of days, we just try to get the kid to rest, not do too much to him. Only the absolute necessary blood tests. Nothing major.

"This baby is going home. She has good weight, can hold her temperature, and can eat. I'm need to make sure I put on the clothes her mommy brought in. She has been home and is done recovering from pregnancy (zuo yue), she is ready for the baby, but she will have to learn about the baby. We have taken good care of [the baby] for her parents. But, her parents will have a lot to do. She has a shunt in her head and she is going to have to come in for more procedures. It is good that her mom got to rest, it is going to a busy and a hard work for them, but they live with her husband's mom and her mom is also in Taipei. They love their child. We as parents, never know what to expect. It is harder when they are NICU babies, there is even more not knowing what to expect. Normal parents, we worry about how they will do in school, can they get a job, will they

get married, but if you have a NICU baby, you might not even have time to worry about these normal parent things" (Resident, Taiwan).

NICU patients are usually discharged around their original due dates. Discharge planning is usually focused exclusively on the infant's medical condition and weight. They usually have to gain around 2500 grams or 5 pounds. However, NICUs are discharging patients earlier and earlier. Usually, as soon as they can maintain temperature stability, free of emergent medical conditions, such as apnea, and can be fed by some means other than gavage (tube feeding). However, discharge is rarely based on what the parents can tolerate or whether parents are ready.

In various studies conducted in the NICU, neonatologists and NICU medical staff have been faulted for worrying too much about the now and too little about the future (Heimer and Staffen 1998) (Anspach 1997) (Guellemin and Hollstrom 1986). Medical caretakers fully shoulder all responsibilities for premature newborns when they first enter the world. With any particular NICU patient, the daily non-stop work of "doing" only stops when discharge day arrives. For many medical caretakers, discharge day is one of those rare days where all of the work that goes into caretaking has a beginning and an end. Despite the countless routines in the NICU, the discharge day routine is one that does not require constant intuitive decision-making. It is a day where medical caretakers practically and emotionally transfer their responsibilities to parents. There is some sadness over goodbyes, but there is also relief over transferring the responsibilities of always anticipating and preparing for uncertainties and contingencies.

DAY OF LIFE XX: *Homecoming*

"I still remember when Allison came home. We were so excited and a little scared. You know, she has two birthdays. The day she was born of course, but we also always have a party on the day she came home. I sometimes forget her actual birthday and think her homecoming day is her birthday….. Once she became a feeder and grower, I would just go in and hold her and nurse her, and we got to know each other. But, it was a little weird to take her home and not have machines around to tell you if she is ok. I sort of got used to the machines and if my milk was too fast, the machine would make a noise and I would know to slow down" (Mom, U.S.).

"When my daughter come home, she already look like big. My husband always told me how little she was, so I expect a little little baby. But, she looks like normal baby size. The doctors and nurses did a good job, I'm grateful. I really really wanted to go and visit a lot, but I had to rest and recover from my pregnancy because I know she will come home and then I have to be the one that does everything. When you are a mom, sometimes you can't do what you really want, but what is good for your child. I wanted to visit, but I know that it is better for her if I rest and be prepared. Because, we have entire life, I have to be strong and prepared for anything, especially since she is NICU baby and was sick when she was born. I have to watch out for her because she already had a weak start in life and things will always be harder for her" (Mom, Taiwan).

"Coming home was not what I expected. Everybody treats it like a positive thing, but

it was really stressful. It sort of feels like they are kicking you out. You don't have a safety net anymore. When Timmy got home, he didn't sleep, he didn't eat, I couldn't get anything done. It seemed like he just wanted me to leave him alone. He didn't smile until 4 months. I wasn't even sure that we liked each other" (Mom, U.S.).

"When meimei came home, we didn't know how to do anything. We didn't know what she needed. I'm lucky I had my mother-in-law to help. We would take turns. She did not sleep. We could not put her down. Someone hold her all the time. It is a lot of work, but I think its ok because I didn't get to hold her when she was born, so now I make up for it. I rested and got strong for her" (Mom, Taiwan).

Going home for the premature newborn is a major change. His/her body has adapted to certain rhythms of life in the NICU. By discharge time, there are behavioral cues that have been established between the premature newborn and his/her primary caretakers. However, going home means the infant is dislocated once again. The infant's emerging capacities for social interactions can be a great source of comfort for parents, but there are many premature newborns that go home without having acquired these capacities (smiling, breastfeeding, self-calming, etc.). There is often a period of transition at home, before parents actually feel positive responses from their babies. That is, the idea that home *is* home also must be socially made in the space of interactions.

For parents, homecoming also marks the beginning of re-establishing relationships with friends and family. Because they have had a birth experience that is out of the ordinary from most people, many parents are afraid to approach friends and family members for fear of making them uncomfortable. On the other hand, friends and family often do not know how to help or what to say. Coming home is re-integrating with the social world you left behind. Medical uncertainties are no longer the primary types of uncertainties parents must face, yet they often remain a daily challenge.

Taken together, discharge and homecoming vignettes are about the myriad ways in which people interact to try and anticipate the future. Interactions between actors are often about transferring responsibilities, planning for responsibilities, and teaching responsibilities. Essentially, a sense of the future is specifically linked to planning for the future. Responsibilities necessarily entail planning for the future, but it is simultaneously also about making trade-offs for the now, with the knowledge that one never knows what tomorrow will bring. Parenthood is perhaps the most future oriented of all social roles (Heimer and Staffen 1998). In their study of parental labeling in the NICU, Heimer and Staffen found that in most cases a parent who only showed concern with their child in his or her present relationship, and showed no concern with the child's future, would be regarded as an inadequate parent. NICU parents are caught in a double-edged sword situation. Too much looking into the future can often lead to unrealistic expectations, yet, a focus on only the present can come across as being an inadequate parent. Parents often report that they do not have an adequate grasp of the relationship between the present and the future when it comes to anticipating who their baby is and what life will be like. Unlike medical caretakers who interact with many NICU infants, parents do not. Thus, they are not likely to possess the same level of intuitions about the needs of NICU infants. However, it is parents who must take the babies home.

In this chapter, I have attempted to illuminate an arc of prematurity experiences from the various situated positions of all relevant NICU participants through vignettes that foreshadow tensions, emotions, relationships, and power issues. This chapter has also provided background information to show how daily assessments of the medical statuses of premature patients are intertwined with and part and parcel of emerging assessments of the personhood experiences with NICU premature newborns, medical caretakers, and parents. It is through interactions-in-the making that these assessments occur, and can cast wide implications for the present and the future. Most immediately, these interactions dictate treatment plans that keep premature newborns alive. But, they also begin to help caretakers and parents experience each other, themselves, and their premature newborns.

This chapter has also attempted to highlight two critical constants that must be kept in mind throughout this dissertation. The descriptions and analyses of the social and cultural aspects of this dissertation are always acting against these critical points. They are often made into a normalized "constants" in the lives of individuals such that they become camouflaged and actively forgotten. First, the human gestational process is a universal across all cultures and geographies. The evolutionarily derived genetic unfolding of human maturational development is a universal in two respects: (a) Each human being is a genetically unique individual endowed with a particular growth trajectory that is derived from a unique genetic blueprint. (b) How that genetic blueprint unfolds is variable, but it is not limitless. That is, there is a very wide range of possibilities for how any human being will grow (and age), but it is not infinite. Our genetics dictate the starting and stopping points within a range of possibilities. Second, our knowledge of the human gestational process is incomplete. What we know is that genes provide starting and stopping points. We also know sequence and timing of the maturational process of human gestation in utero. However, there are many knowable unknowns and more than likely some unknowns that may never be known. Without adequate knowledge of the specific mechanisms of action that enable or prohibit growth and development of the human being, the NICU is a field of medicine that will only ever have partial success. It is in the context of this partial success that interactions-in-the-making must pick up the very important work of carrying on and moving on in social life.

In the course of having to make practical decisions for the premature newborn, questions of personhood arise for all individuals touched upon by the crisis of prematurity. The crisis of prematurity ultimately produces a dilemma of personhood whereby experiences and definitions of the person are in a state of constant indeterminacy, not only because of the very nature of indeterminacies surrounding social processes in general, but because the very biological givens of the human maturational process has itself become unknowable under the conditions of a life that is premature. There is a perpetual state of constantly being and feeling “in between” many unknowns with no sense of resolution in sight. The next chapter will begin to set the groundwork for why and what can account for individuals constantly experiencing being and feeling “in between” and always “rushing to nowhere” by placing prematurity in the context of biology.

Myer Fortes stated in his work on personhood: “The essential starting point of any person’s life history is the mere fact that he was born alive and survived to live” (Fortes 1987). The neonatal context is a situation where this essential starting point (i.e. life) is itself still physiologically emerging.

CHAPTER 2: DOUBLE JEOPARDY

“If we consider any person’s life history, the essential starting point is the mere fact that he was born alive and survived to live” (Meyer Fortes 1959:34).

What are the prerequisites for a human being to be born alive and to survive to live that life? First and foremost, all newborn human beings must possess organ systems that can function in an ex utero environment to enable breathing, digesting, and regulating its inner environment against fluctuations in the outside environment or weather (i.e., homeostasis). Secondly, to continue to sustain that life, they must garner meaningful interactions with others. Numerous studies throughout the last sixty years have shown that primate and human infants deprived of meaningful social interactions will fail to grow and can and will die (Bowlby 1958) (Spitz 1942) (Harlow 1958) (Ainsworth 1967) (Bowlby 1969) (Ainsworth and Eichberg 1991) (Scheper-Hughes 1992). The first requirement is universal for all human beings. The second requirement is local and variable. Together, I will refer to them as the “double prerequisites” for ex utero life.

However, as Clifford Geertz critically noted, drawing a line between these two aspects of what it means to be a human being is to falsify the human condition (Geertz 1973). This chapter is about universals and infinite variations in the context of the beginnings of human life. “What is the natural, universal, and constant in human beings and what is conventional, local and variable?” (Geertz 1973:36). The purpose of this chapter is not to draw a line between these two aspects of the human condition but to elucidate them in the context of prematurity and for the purpose of illuminating and analyzing the interplay between universals and particulars.

The ambiguities surrounding the viabilities of premature infants challenge and unsettle this double prerequisite for ex utero human life. Unlike the majority of human infants for whom the first prerequisite is given as a result of having survived their birth, the first prerequisite (i.e., possessing functional organ systems) is *not* a given for premature infants. Limits exist and there is only so much that can be done to shepherd in the maturation of organ systems (and of life) and keep death at bay. Yet, whether and how the second prerequisite (garnering meaningful interactions) is met remains infinitely variable. There are many possible resolutions. Thwarted into an environment for which their immature organs are ill prepared, premature infants' lives depend as much upon the innate mechanisms of biological maturation continuing to unfold as upon others working for their *potential* to achieve the double prerequisites for life. Therefore, they begin "life" in a situation of double jeopardy without guarantees for obtaining either. How, if, when, and whether they (and those who care for and love them) can overcome that double jeopardy is the central theme of this dissertation.

Thus, the starting point of many analyses to follow must first begin with a more detailed discussion concerning the double prerequisites for being born alive and living that life. This includes general physiologic challenges that any newborn human being must overcome, as well as discussions of a "bio-social gap" or a gap between biological capacities and social interactional demands that is inherent between newborns and others. Parents and newborns each attempt to create relationships and attachments to the other, but the biological capacities of newborns lag behind the social-interactional needs and desires of kin and caretakers. The intent is to highlight biological, social, and experiential discrepancies between conditions of full-term birth and conditions of prematurity. Whether in the U.S. or in Taiwan, full-term newborns together with parents and kin must overcome the bio-social gap while premature infants and those associated with them must additionally wrestle with the burden of overcoming physiologic challenges presented to an immature body and its organs. Therefore, premature infants are faced with "a double jeopardy." Yet, how medical caretakers and parents choose to help premature infants and themselves overcome this double jeopardy to life is variable, personal, and locally lived.

Drawing on the work of Meyer Fortes, the second part of this chapter provides a theoretical overview of personhood to emphasize the full range of a person's experiences and idiosyncrasies. It speaks directly to how concepts of selves and others are critical for managing the uncertainties surrounding whether and how premature infants will overcome their situation of double jeopardy. Stereotypes and ideological definitions of the person (i.e., rules, roles, and representations), as well as the experiences of a person as an active agent (an individual) creatively interacting are both at play, sometimes in conjunction and sometimes in contradiction.

Personhood in its broadest, most inclusive sense, is the theoretical framework that underpins how human newborns and their kin interact with each other to form meaningful interactions, as well as social relationships and social attachments. It is critical for developing first relationships or "attachments" between parents and newborns in the context of normal birth and of prematurity. This is particularly critical as those whose lives are intertwined with premature infants must figure out ways of knowing and assessing the status of premature infants under NICU care—Are they getting better or worse? Are they in pain? Are diagnostics and treatments ushering in life or prolonging death? With incomplete knowledge of the human gestational process, both our capacities to read the status of premature infants under NICU conditions and their capacities to exhibit and show their status to us are very limited. This section sets the theoretical foundation for grounding this dissertation's main theme: How are concepts and experiences of the person enacted and negotiated in a variety of ways to help premature infants overcome the double jeopardy to life.

Beginnings of Human Life

(Gestation and Birth, and the Bio-Social Gap)

The maturation of a human entity from that of a zygote, to a blastocyst, to an embryo, to a fetus, and finally to a full-term infant connote certain significant stages of human gestation that embryologists and scientists have chosen to take notice (Morgan 2009). By using very broad strokes to describe this process, the intent is to underscore the universality of this biological process of human maturation while simultaneously revealing how ways of knowing and applying this biological process to the lived experiences of individuals can vary amongst different scientific fields, depending upon whether the subject is the pregnant woman or the maturing fetus. At the same time, the privileging of different experiences can shape how different scientific fields come to organize and know this human maturational process. Although this no doubt points to the culturally constructed nature of certain aspects of scientific knowledge (La Tour and Woolgar 1986) (Haraway 1991) (Martin 2001) (Rapp 2000) (Morgan 1998), continuity in the facts of human gestation across fields also equally point to the often under-analyzed ways in which these facts of biological processes impose themselves universally upon social worlds that cut across cultural spaces of geography, race, gender, age, and sexuality. Biological maturational processes are our shared commonality. Undoubtedly, how we engage with, organize, know, understand, and experience it are infinitely variable. Nevertheless, on the lowest common denominator level of analysis (Wimsett 2007**)**, facts of human gestation do not vary.

Gestation and Birth

In this section, I will describe in very broad strokes the maturation of a human entity from that of a zygote, to a blastocyst, to an embryo, to a fetus, and finally to a full-term infant. This will set the groundwork for a deeper analysis of variable experiences that is presented throughout the rest of this dissertation. The following are the observable facts of prenatal development that are commonly found in any biology textbook (Carlson 2008). It is important to have an overview and a clear grasp of these details because the experiences of prematurity for the NICU patient, medical caretakers, and kin are intimately tied to how differences between premature physiology and full-term physiology are experienced by various actors.

The material biological beginnings of any human life start when a sperm and an egg successfully fuse together to become a zygote. From this point on, it takes approximately 38 weeks for a full-term human newborn to emerge. That act is referred to as fertilization and normally occurs in the woman’s fallopian tubes. The period of development that begins with the zygote and ends with a full-term human infant is commonly referred to as gestation or prenatal development. As the zygote travels toward the uterus, it undergoes several mitotic divisions, cleaving first into two cells, then four, then eight, and so on and so forth. With further divisions, fluid enters the interior of the cells, forming a fluid-filled cavity called a blastocyst. One pole of the enlarging blastocyst (the inner cell mass) will develop into the embryo proper while the cells lining the cavity will contribute to the extra-embryonic tissue. By the end of the first week, the blastocyst will implant in the uterine wall.

The second through eighth week after fertilization is referred to as the embryonic phase. The embryo undergoes a great deal of complex morphological changes during this period to put into place the various structures and organ systems of the human body. In four weeks, the embryo changes from that of a two-layer disk, to a three-layer disk with a groove that is the beginning of the neural tube of the brain and spinal cord, and eventually to a more cylindrical shape as it folds unto itself (as the human body is cylindrical). By the end the eighth week, all of the organ systems begin to develop. In addition, during this phase the various supporting infrastructures known as extraembryonic tissue (which will become the umbilical cord), as well as the vascular relationship between the mother and the embryo (i.e., placenta), are established.

The fetal stage begins at the ninth week and lasts until the time of birth. Existing body structures continue to grow and mature and only a few new parts appear. However, during this stage, it is critical to note that the environment in which many organs develop (i.e. the in utero environment anchored in the vascular relationship between the mother and the embryo/fetus) is critically different than the ex utero environment in which these organs must ultimately function. For example, in utero, the fetal lungs are collapsed and play *no* role in fetal gas exchange. The fetus is surrounded in amniotic fluid and it is the placenta that provides gas exchange for the fetus. Yet, instantly upon delivery of the fetus, the “system” must be in place to have the newly birthed infant oxygenate himself or herself—this includes gas exchange as well as separate systemic and pulmonary circulations (Wigglesworth and Desai 1982). As for the fetal heart, the right ventricle does more than the left in the in utero environment. However, at birth, in the ex utero environment the left ventricle must take up the dominant role and be able to do continuous pressure and volume work for the span of a human’s being entire life. It must be able to handle human actions throughout the lifespan that can range from an infant crying to an athlete running a marathon. In addition, it is worthy to note that hemoglobins, the oxygen transport proteins found in red blood cells, are different in the fetus than in the newborn infant (fetal hemoglobin versus hemoglobin). This is another example of critical differences between the in utero and the ex utero environment. In the in utero environment, fetal hemoglobins have a higher affinity for oxygen than adult hemoglobins required for the ex utero environment. Furthermore, the site of hemoglobin production also makes a gradual switch from the liver to the bone marrow as the fetus nears the time of birth. The mechanism of this switch is currently thought to reside in an intrinsic development process within the red cell. The most important determinant of this switch is post-conceptual age and not the time of birth. Therefore, premature newborns who are born too early still possess fetal hemoglobins, as they have not reached the intrinsic point in their maturation process to generate ex utero hemoglobins. Lastly, and perhaps most importantly, studies suggest that sensory neurons of the fetus are more sensitive than those of adults or newborns. This is ideally suited to the low levels of stimulation in the uterus (De Camp 1997). This extra sensitivity has ramifications for social interactions in the NICU (see Chapter 5 and Chapter 6). These examples illustrate the critical point that temporal sequences of maturation are not environmentally negotiable, and when the full fetal maturational process is cut short, consequences abound. Maturation has “biotemporality” (Zerubavel 1981) or the set timing of events in living systems.

For your reference, there is an accompanying chart of prenatal development that is in the appendix. I have chosen to organize this chart through several orientations—weeks, size of the embryo/fetus, organ development, its “appearance” to those in the ex utero world or what we “see, hear, feel, and detect.” These orientations bleed into one another, yet, it is important to recognize how different individuals associated with a premature life can conceptualize and experience it differently at different times and in different situations. More critically, it will become clear that individuals actively and creatively interact with the irreducible realities of prenatal development placed in an ex utero world, both as a means of resolving and tackling the radical indeterminacies surrounding “What/who is this premature life?” and “Who am I or do I hope to be?” in relation to them.

The fetal stage ends with birth. In the context of the human maturational process, birth is an event that results in the physical dislocation of the human organism from the maternal in utero environment into the ex utero social world. This dislocation is what human maturation has been preparing the fetus’s organ systems for. Important physiological transformations occur during and up to several days after birth. These physiological changes are necessary if a fetus is going to make a successful transition into the ex-utero world. These transitions, like prenatal development, are another aspect of the irreducibility of the biological maturational processes.

The physiological status of the fetus changes most dramatically when the fetal lungs mature into ex-utero human lungs. The physiological transformation that happens to all full-term infants, right before delivery, is a process that does not occur for premature infants. They are as follows: As the full-term infant is born, the lungs begin to expand with air and rhythmic breathing begins. Resistance in the blood vessels, leading to the lungs, begins to decrease so that blood can begin to flow into the lungs for the first time. The umbilical blood flow stops. As a result, the blood pressure in the right side of the heart begins to decrease as the blood pressure in the left side of the heart begins to increase. This change in pressure between the two sides of the heart causes the foramen ovale (literally, a hole in the heart) to close. The “hole in the heart” was part of an open fetal-maternal circulatory system that enabled the fetus to be joined with its mother’s circulatory system while it was growing in utero. Where blood once bypassed the fetal lungs in utero, it now can be channeled to the lungs once the hole in the heart closes. Several days later, fetal hemoglobin will change into adult hemoglobin.

Together, the prenatal chart and the description of birth from a physiological perspective are intended to underscore the irreducibility of biological maturational processes in its lowest common denominator at the beginning of life. What is irreducible is the fact that all humans begin life with those biological processes in common. There is an immutable biotemporal sequence, much like the stages of development of a butterfly from that of an egg, to a caterpillar, and lastly to a pupa. The successful development of the embryo into a human infant requires both the development of organ structures and organ functions (morphology and functionality). Organ morphology and organ function do not necessarily develop in sync, but the development of each organ system follows a timed sequence grounded in each individual's genetic-evolutionary history. What we do know is that growth occurs in saltation and stasis or spurts (Lampl 1992). To paraphrase what Michelle Lampl, a human biologist and anthropologist often states, babies do not grow like a sponge, with all of the parts intact and functioning, just growing bigger and bigger. "There is no such thing as a sponge model of growth" (Lampl, personal communication). Although a fetus or baby may have the appearance of a small human being, one cannot presume that just because a baby looks like baby, it possesses the capacities or functions of a baby.

Second, and with equal importance, is the reminder that it is people who have created the stages of prenatal development by placing individual and cultural values onto particular aspects of the human developmental process (LaTour and Woolgar 1986) (Haraway 1991). That is, the mere description of these universal biological processes introduces a dialectical dimension where new understandings, research, technologies, and representations about these biological processes (both prenatally and postnatally) can produce more ambiguities, indeterminacies, and contradictions for individuals as they live and create their lives in the context of normal birth and prematurity (Morgan 1998). Therefore, it is critical to both directly engage with biological processes while simultaneously keeping in mind that it is people and interactions (not biology) that make newborn bodies into babies. In the context of prematurity, the stakes are high and it is a critical task of life and death to be able to do this. For medical caretakers and parents alike, the biology and sociality must be equally engaged, deliberately and creatively, if premature lives are both to be saved and to find a home. Not doing so could result in ineffective treatments, prolonged and unnecessary pain, and, even more disheartening, a prolonged death for a premature human life (La Tour and Woolgar 1986) (Haraway 1991). After all, the biological process of maturation is irreducible and will continue to impose itself on social contingencies (Fortes 1987).

Interactions for Life and the Bio-Social Gap

The biological processes introduced above impose a temporal structure to the "reality of everyday life" of parents and kin. It is a "facticity with which [they] must reckon and with which [they] must synchronize their own projects" (Berger and Luckman 1991). Simultaneously, any newborn human being must assert himself or herself as a "reality of everyday life"—a "here of my body and the now of my present" (Berger and Luckman 1991).

The post-natal period is a dangerous time for all newborns precisely because there is a lack of synchronicity or a "gap" between biology and sociality. Anyone who has taken care of a newborn will tell you that the post-natal period immediately after birth can be difficult. In her well-known memoir of new motherhood, author Anne La Motte writes, "I just had to wait until the end of the 3rd month…things would get easier…." As members of my informal mother's group used to say, "We need each other, definitely in the beginning, because all they can do is breathe, eat, sleep, and cry…and when you have to carry them around all of the time, it's like you're still pregnant."

Often socially experienced as the 4th trimester (Small 1998) by new parents and especially by mothers, this post-natal period can be understood as a lag in time between the biological capacities necessary for survival outside the maternal uterus that comes to fruition at birth and those capacities that can be construed as social, such as smiling, gurgling, and eye gazing, which others must "feel" toward newborns if social interactions are to continue. During this lag time, new parents often find themselves in what anthropologist Mel Konner poignantly refers to as a "one-sided love affair." He vividly described his inceptive experiences with his newborn daughter as follows:

"You whined, you gazed, you mooned around, you dreamed of orgies of tenderness, you saw in your mind's eye decades of future mutual love, dignified, courtly, publicly known. Meanwhile you suffered every known variety of emotional abuse, neglect, rejection, anguish, and humiliation. If you managed to somehow steel yourself for an hour, you were thrown a scrap—here an appropriately timed belch, there a split second of eye contact—and you tumbled back down into the well with glazed walls, stewing in your damned affection juices" (Konner 2003).

As anthropologist Mel Konner noted, overcoming this prenatal period is more complicated than the "click click" imprinting of baby chicks and ducklings that begin to follow their mother upon birth. Critical attachments between humans are essentially about establishing first successful interactions. This is hard work. As evidenced by the modern parenting bible, "The Happiest Baby on the Block," Dr. Harvey Karp advocates his five-step calming method for the management of fussiness and crying in newborns. He argues that newborn infants during the first three months of life enjoy five "S" soothing techniques that mimic the in utero environment: **S**waddling mimics the tight and cozy space of the in utero environment, **s**hooshing mimics the noises that are heard by the in utero fetus, **s**winging mimics the movement that the newborn felt in utero, **s**ide/stomach positioning mimics the position of the infant when it was in utero, and

sucking mimics what the infant did while it was in utero. It is arguable the extent to which Dr. Karp's method is scientifically supported. However, he does critically understand the experiences of parenting a newborn and taps into parents' collective uncertainties.

For human maturation to continue after birth, social and interactive work is crucial to the survival of newborns. The work of Rene Spitz (1965) has notably shown that responsive interactions between infants/children and their parents/caretakers are literally essential for survival. He found that children who lived in an environment of emotional sterility and isolation did not survive, despite being well taken care of and well fed. This finding was further anchored in Harry Harlow's famous studies of "Monkey Love," which found that affectionate ties were the key to normal development. When two groups of monkeys were separated from their mothers at birth, the group with the "substitute" wood block surrogate mothers matured normally, while those that were completely isolated without any means to exercise their need for affective ties matured abnormally (Harlow 1958). Dr. Karp, the messiah to new parents with colicky babies, taps into the uncertainties for babies and parents alike during the post-natal period.

Nowhere is this more poignant than Nancy Scheper-Hughes' work on benign maternal neglect in the barrios of Brazilian shantytowns. Here, mothers living in desperate conditions often cannot find the physical and emotional strength to interact with their full-term newborns. Many of these babies are benignly neglected and left to find a life in the world of the dead (Scheper-Hughes 1992). Thus, responsive and meaningful interaction is the second "substantive universal" (Geertz 1983) prerequisite for ex utero life. However, it is an obstacle that individuals can choose to overcome (or not) in countless ways, as evidenced by the infinite variations of human action and evidenced through the countless rituals and rites of passage found throughout time and across cultures surrounding pregnancy and birth.

The bio-social gap is an irreducible aspect of the biological maturational process that universally imposes itself on social relations (Fortes 1987) and must be managed for the survival of human newborns and the human species. Both we and our babies are biologically and physiologically equipped with the capacities to socialize and interact with each other to overcome this bio-social gap, but it is a deliberate choice. Even under circumstances of prematurity, both premature newborns and their caretakers and kin do, for the most part, successfully overcome this bio-social gap. That is, in most cases, we successfully attach and bond (Bowlby 1998) (Harlow 1999)—thereby ensuring the survival of human newborns and the reproductive success of the human species. But, how is this done? It is only through interactive work that manages social relations in the context of biological maturation.

This section underscores the notion that there are two prerequisites for ex utero life. This double prerequisite entails actions that garner both biological and social viability. This begs the question, what happens when birth occurs far sooner than the intended length of full maturation? What happens when a human newborn is birthed prematurely? How do these human newborns and their parents and caretakers manage to overcome the bio-social gap? The next chapter will begin to answer some of these questions. The answers are as infinite and variable as individuals make and create them. They are ultimately about how we come to understand ourselves and others in a variety of contexts—they are dilemmas of personhood or how we come to grapple with the indeterminacies of self and other (Karp 1988) in the context of the beginnings of ex utero social life.

Vi(Abilities): Personhood and Agency

The first critical relationships between human newborns and their parents or caretakers can only happen "in time," through social interactions. It is through the actively pursued and infinitely creative ways that individuals arrive at concepts of who they are and who they project newborns to be that normal birth and prematurity are lived through and experienced. Meyer Fortes recognized in his large body of work on personhood that the biological maturational process is something that imposes itself on social contingencies (Fortes 1987) and thereby creates indeterminacies of the self and other. Fortes, building on Mauss's concept of la personne morale, provides a dynamic approach to the study of personhood, where equal value is given to the culturally objectified and the subjectively apprehended aspects of social life.

Specifically, "From whichever way we approach our enquiry we see how important it is to keep in mind the two aspects of personhood. Looking at it from the objective side, the distinctive qualities, capacities and roles with which society endows a person enable the person to be known to be, and also to show himself to be the person he is supposed to be. Looked at from the subjective side, it is a question of how the individual, as actor, knows himself to be—or not to be—the person he is expected to be in a given situation and status. The individual is not a passive bearer of personhood; he must appropriate the qualities and capacities, and the norms governing its expression to himself" (Fortes 1987:251).

Analytically there is a critical distinction between the concept of the person and the individual. This distinction rests on the difference between how human beings come to know and show aspects of themselves; and to know and receive what others show and know about them. The concept of the person is comprised of socially-nominated or defined distinctive qualities, capacities, and roles (Jackson and Karp 1990). This is the objective aspect of personhood. Thus, the concept of the ***person*** is derived from Marcel Mauss's concept of la personne morale—the ideological definition of personhood in terms of rules, roles, and representations (Karp 1987). This can include a variety of instituted cultural models of personhood (Shore 1998), in particular medical and legal, that come into play throughout this dissertation. In contrast, the concept of the *individual* is invoked when persons exercise agency in complex ways that allow them to "experience themselves (and others) as deviating from, or not living up to, or uncomfortable with, who they and others feel they should be" (Karp 1987:81). This experience of gauging one's sense of self (and others) is idiosyncratic and unique, the antithesis of "a model" of any sort. Here, this distinction is helpful for understanding that dilemmas of person-making can encompass private internal experiences of conflict within an individual as well as conflicts between individuals. In addition, this nuanced distinction can analytically categorize and explain a constellation of experiences and feelings that can arise when individuals are confronted with dilemmas of person-making that are not fully conscious, but merely "emerging" (Williams 1977) or "on the edges of semantic availability" as "structures of feelings" (Williams 1977).

This understanding of personhood invokes the notion of complex agency (Karp 1996) (Kratz 2000). It speaks to the many kinds of human actions that are enacted as human beings, alone or in concert, adjust their lives to the conditions under which those lives are possible (Karp 1986b). Through interacting with others, individuals project meanings outward, showing themselves to others and enabling others to know them. In this process of adjustment and coping with a variety of outwardly projected meanings, faculties can be frustrated, hopes dashed (Karp 1987). As such, crisis points, of which prematurity is one example, become important points of entry for understanding personhood conflicts.

In the context of the beginning of ex utero social life, viability is a concept that demarcates the living from the dead; and specifically distinguishes between those bodies that possess the biological capacities for living outside the maternal uterus and those that do not (Rennie and Robertson 2005). The viability of any newborn human infant is dependent as much on the universal biological processes of maturation unfolding according to a temporal order as it is upon human beings' sociality with each other. Many abilities are called forth for a human fetus "to be born alive and to survive to live it." That is, the very viability of newborn human infants is as much grounded in a universal biological developmental process as it is dependent upon sociality. Thus, viability has at least two aspects—biological and social—and requires various abilities in many forms and involves multiple players. In this sense, viability is more appropriately understood as "vi(abilities)" to underscore the many kinds of abilities required to insure the survival of a premature newborn infant.

Although viability as survivability in the context of the beginning of ex-utero life is generally viewed as an involuntary state of existence (i.e., alive or dead), it does not necessarily signify individuals as being without capacity (Karp 1987). As Ivan Karp wrote in his analysis of ritual possession, “the idea of individual capacity need not only refer to naturally occurring abilities, but can be socially defined and created, as well as sought and lost” (Karp1987:83). This is exactly the scenario that finds premature newborns and those associated with them. Existing often on the edges of “viability,” appearing dead, but technologically alive, viability for premature newborns is socially defined, created, sought, gained, and lost day to day, week to week.

Thus, the abilities required to shepherd the survival of a newborn human being into the ex utero world include (but are not limited to) innate physiological capacities (e.g.breathing), the interplay between innate and learned capacities (e.g. breastfeeding and the moro reflex), as well as all forms of agency or human action. In addition, the data in this dissertation has found that abilities and human action can include “non-action” or incapacitation. This occurs often in hospital settings for premature newborns and parents alike. For newborn care, often “refraining from action” or “not doing something to them” is precisely the act that is intended in order to prevent overstimulating tiny premature bodies and allowing them to grow. In the case of parents, those who possess personal or religious beliefs against (or are conflicted by) medical care may go through the motions of refusing treatment for their child but secretly welcome medical paternalism and “forced” treatment. That is, individuals can choose to retract and endanger their socially defined status when caught in a difficult double bind. In many ways, inaction is often a purposeful way of acting against taking full responsibility for difficult choices. In this sense, viabilities are also about morality—relating to both society and the individual within it, the person. Individuals choose to give or take away personal and cultural significance to certain physiological reflexes or biological capacities as a means of negotiating their own morality and whether they have made good moral choices.

Therefore, in the context of agency or human action, I have chosen to incorporate a notion of vi(abilities) in order to be particularly attuned to biological capacities that are critical prerequisites for existential life but do not require human action. The maturation of functioning organ systems is innate. Part of the aim of this dissertation is to distinguish between various abilities that do and do not require human action. This provides an analytical construct for illuminating how various individuals, especially through interactions-in-the-making, find ways to translate and transform innate biological abilities into "agentive" abilities. As will become evident throughout the rest of this dissertation, this aspect of complex human action is important for overcoming one-sided interactions due to the fact that NICU preemies are semiotically incapable of communicating. That is, for actors associated with NICU preemies, coping means putting "reflexivity" into innate reflexes.

Second, imperiled by a birth that has occurred too soon, a premature life sustained through technological interventions carries certain consequences that are beyond the expected degrees of indeterminacies and social contingencies associated with a normal birth. For each preemie, NICU technological interventions are a de novo environment for their premature bodies. The expectations surrounding their growth and development *in* utero cannot be assumed to continue in the same manner or under the same time scale once they are *ex* utero. For example, an in utero fetus that can kick and suck its thumb at 27 weeks gestational age will not be able to perform these acts ex utero, if it is birthed prematurely. That is, once the biological temporal process of in utero human gestation becomes interrupted, how, when, and if a newborn with extreme prematurity will continue to grow and develop remains uncertain. Under normal circumstances, an innate biological milestone once gained, cannot be lost. However, in the NICU, this is no longer true. What is gained may always be lost, and what is not gained, may never be gained. As one NICU parent stated, "It is always ten steps forward, and five steps back. Things always change; you can go to bed thinking everything is fine, only to wake up finding that something bad has happened." The NICU presents each preemie with a de novo combination of biological obstacles to attempt to overcome, and while they are in the process of doing so, individuals associated with the preemie must manage and cope, with whatever means they have available, in whatever manner they can. Vi(abilities) is therefore also a reminder of the particular uniqueness of the prematurity context. This will serve as a point of reference and tension when in Chapter 8 the concept of viability takes on a legal definition in the United States and presents ramifications for a woman's right to choose in the context of *Roe v. Wade.*

This chapter has been about how individuals' experiences and concepts of selves and others are intertwined with the emerging biological capacities of newborns and, in turn, with the emerging identities of their newborns. Unlike full-term infants whose biological viability can be presumed and relied upon and is often in the background, in the NICU, for a period of time, a premature newborn only possesses its biology, which is front and center, but not completely knowable. Thus, a NICU preemie's viability must be both socially and biologically "made." In turn, we can also speak in terms of medical caretakers' and parents' viabilities, as their identities and experiences of who they are intersubjectively relate to those of their premature newborns. It is useful to understand personhood as epistemologies that grapple with the indeterminacies of the self and other (Fortes 1987) (Karp 1987). In the context of the NICU, these epistemologies are themselves indeterminate, in flux, and many times unavailable.

The next chapter begins with a historical perspective on the emerging status of premature infants as patients. This shift in identity is intertwined with technological advances both over one hundred years ago and more recently around the time of the Rights Revolution in the United States (late 1960's and early 1970's). Furthermore, the changing status of premature infants also shifted relationships between women, their pregnancies, and their fetuses and infants. This chapter also illuminates the dynamic interplay between NICU technological advances and the creation of unresolvable indeterminacies and uncertainties surrounding NICU care. Specifically, it argues that present NICU technological advances produce both similar and different kinds of indeterminacies and uncertainties than those at the turn of the 20th century. On the one hand, it underlines the universality of the human gestational process of maturation and shows how even modern day's technological advancements must address the same physiological challenges that technology attempted to address almost two hundred years ago. On the other hand, modern day's technological advances are different because they are not merely "aiding" the process of human gestation, but are intervening into it. This produces a more complicated set of circumstances for which individuals must find new ways to overcome the challenges of producing social persons.

CHAPTER 3: FROM EXHIBITION TO PATIENT

(Timeless Issues Surrounding Neonatal Care)

La plus ca change, la plus c’est la même chose

In 1888, Pierre Constant Budin, who would later become known as the forefather of modern day neonatology, enunciated three basic problems in the care of the prematurely born: (1) Their temperature and their chilling, (2) Their Feeding, (3) The diseases to which they are prone (Silverman 1979).

Today, in modern NICUs around the world, premature infants must meet the following set of developmental milestones before they are discharged (Cone 1985) (Spitzer 1996):

(1) The capacity to maintain a steady body temperature in an open crib for 24-48 hours
(2) The capacity to take all feeding by bottle or breast without supplemental tube feedings
(3) The capacity to gain weight steadily

Although the first incubators with premature infants were introduced to the public over a hundred years ago, a prematurely birthed infant’s physiological requirements for sustaining ex utero life has remained unchanged, and it will remain so for the duration of human existence.

With this in mind, this chapter briefly traces the development of the incubator in the late 1800's to the technologically sophisticated neonatal intensive care units of today. This emphasis is not on technological development but on the changing status of the premature infant in the context of technological change, and how concepts and experiences with and about the premature infant person are critical for understanding how incubators and NICU technologies were used. The themes of this chapter will emerge in varied ways as cultural differences between Taiwan and the U.S. present contrasting forms of interactions between individuals as they live through the prematurity experience. Whether we understand prematurely birthed infants as interdependent or independent of the mother; whether they are worth saving in the first place; and what does prematurity mean to different people at different times-, these themes vary according to how individual actors manage the "personhood dilemma" that arises with premature infants. The second point that this chapter underscores is the extent to which the emerging physiological capacities of preemies are as much a dynamic determinant of how we choose to interact with them as how we understand ourselves and others as individuals related to them. In this sense, biology must be engaged with directly to understand how we transform innate "reflexes" of physiological capacities (e.g., making red blood cells, breathing, digestion) into reflexive capacities attributed to experiences and concepts of who premature infants are and who we are in relation to them and to each other.

The arc of this chapter captures the emergence of the premature infant as a patient. As such, the premature patient, by gaining biological viability, gains the legal and medical rights to treatment while still lacking the social and interactional capacities to experience others and for others to experience him or her as a person. Here, biological viability does not garner social viability. Thus, the emergence of the premature infant as a patient is as much about scientific progress as it is about the shifting relationships we have with life at its beginning. Whatever name we give them, embryos (Morgan 1998), weaklings (Baker 2006), nurslings (Budin in Baker 2006), fetuses (Rapp 2000) (Casper 1998), cyborgs (Haraway 1991), fetus-infants (Landzelius 2003), patients, babies, children, or some combination of these names, the solidification of the premature infant as a patient gives him or her an independent status that individuals must take responsibility for. Thus, changing concepts of the premature infant are ultimately about changing social relations and the responsibilities that one takes on or lets go.

Brooding Hens and Child Hatcheries

(Technology and the Shifting Status of Mothers and Premature infants)

~1886-1942

Brooding Hens—Incubators as Extensions of Mothers

During the late 1800's, a leading French obstetrician named E.S. Tarnier observed an enclosed warming device for young chicks at the Paris Zoo (Dunham 1957) (Baker 2006). Inspired by what he saw, Tarnier borrowed this idea and applied it to prematurely born young humans, who often succumbed to hypothermia because their small bodies lacked the physiological capacity to maintain a stable body temperature. He referred to this rather simplistic warming enclosure, which required the manual replacement of hot water bottles every three hours, as a "conveuse" or brooding hen.

Although Dr. Tarnier cannot be given the honor of being the first to think of this solution, he was the first to persuade the French government and the French public at large that premature infants were worth saving. His timing was right. French politicians of the time were obsessed by the implications of their country's falling birth rate, which in 1870 was only half of that of rival Germany's (Meckel 1990). A growing French infant mortality campaign propelled the incubator as a substantial solution to the widespread anxiety over the prospect of depopulation. Infant mortality in this context became a political, rather than a humanitarian, concern, as it was a problem that robbed the nation of future workers and soldiers (Baker 2006).

However, despite the fact that maternity hospitals throughout Paris responded by expanding hospital care for premature infants in an adjoining but separate space employing incubators, the emerging status of premature infants as "worth saving" did not give them an independent status as a patient. Rather, the beginnings of the infant mortality campaign centered on the role of the mother. Although the incubator was used, it was viewed as having mixed results. Mortality remained high for premature infants. However, it was not the incubator that would become the focus of improvements but rather the constitutions of pregnant women and mothers (Baker 2006).

After all, the view of the incubator as a "brooding hen" underscored the notion that the mother's constitution and her motivations toward her infant were central to the survival of any premature infant. She was the source of high infant mortality rates, not the incubators. Thus, the premature infant was not viewed as having a separate constitution, but rather its constitution was tied to its mother. Even if a premature infant survived its prematurity, renowned obstetrician Adolph Pinard observed that it was likely to remain weak for the duration of its life (Pinard 1903, cited in Baker 2006). Implicit here is the notion that premature infants could not grow out of their mother's weak constitutions. Thus, another fifty years passed before premature infants finally shed their status as "debiles" or weaklings.

In the meantime, as the focus on mothers became the dominant solution for producing stronger babies, bonding and breastfeeding became institutionally encouraged. Dr. Pierre Constant Budin, who would take over his mentor E.S. Tarnier's clinic at the Paris Maternity Hospital, improved the conveuse incubator by placing plexiglass on the "brooding hen." He recognized that the incubator, albeit physiologically advantageous to premature infants, was also isolating. It is not a coincidence that the incubator is often referred to as an isolette. Thus, the intent of the plexiglass was to encourage and create a relationship between a mother and her premature infant without undermining a premature infant's physiological need for isolation. "The glass permits the mother to watch every movement of the poor, fragile little being, and thus by watching him, almost minute by minute, the mother becomes attached to her baby" (Belmin 1905, cited in Baker 2006). The incubator would be an extension of the mother, but not a substitute for her. It was an intersubjective bridge between a mother and her child. However, one where the intersubjectivity extended only one way—the mother could "watch" and bond with her child, but it would be months before her child would be able to interact back.

The premature infant's status would continue to be tied to that of its mother. As mothers successfully breastfed and bonded with their premature infants under Budin's care, these infants became known less and less as weaklings and were now becoming known "nurslings." Dr. Budin's textbook "Le Nourisson," or "The Nursling," became the groundbreaking authority on the care of premature infants, eventually bestowing on him the recognition as the forefather of modern day neonatology. For Budin, his focus always remained on the relationship between premature infants and their mothers. He continued to assist mothers even after discharge through supervisions of the infant in weekly consultations, emphasizing breastfeeding and bonding even more than incubator use.

Child Hatcheries—Technological Enthusiasm and Premature Infants as Exhibits

Around the same time, in Nice, France, an alternative approach for the care of premature infants would emerge with the development of a more sophisticated incubator. Alexander Lion, a physician and the son of an inventor, greatly improved the original Tarnier incubator with a thermostat and an independent forced air ventilation system. These improvements were intended to compensate for less than optimal nursing conditions, as well as for the care of younger premature infants whose bodies required fresher air and more precise temperature control. However, the improvements also shifted the center of focus. The mother was no longer the subject and solution to a premature infant's weak physiological status. Rather, the newly designed Lion incubator addressed the premature infant's own physiology and emerging developmental capacities over breastfeeding and bonding.

Due to the high cost of the improved features, Lion began charging admissions to the curious public onlooker. For 50 centimes each, anyone off the street could view what he called his "incubator charities" (Silverman 1993) (Baker 2006). In 1896, at the Berlin Exposition, a young associate of Dr. Lion and Dr. Budin, Dr. Martin Couney, would carry this idea and exhibit six Lion incubators housed with live German premature infants who were thought to have very little chance of survival. Not only did these six premature infants survive, but the incubator charity was now known as the “Kinderbrutenstalt,” or the “child hatchery.” It was no longer a charity that took in weaklings but a place where human babies “hatched” themselves into the world, much like baby chicks. The child hatchery was a sensational success, outperforming the ever-popular sky rides, ethnic villages, and freak shows of the time.

For the next forty years, until shortly before the Second World War, Martin Couney reproduced this sensation around the globe—Berlin, London, Buenos Aires, Johannesburg, Buffalo, Chicago, San Francisco, and finally settled his incubator hatchery semi-permanently on Coney Island and Atlantic City.

What Couney understood implicitly was that the key to saving the lives of premature infants required not only incubators but also an entire institutional system of support. Each time the exhibit traveled, a two-story building was constructed. The lower level housed the premature infants in incubators and the upper level housed a team of nurses and wet nurses required for their around-the-clock care. This was necessary as teams of nurses and wet nurses needed to be trained in the care of premature infants, as well as have a place to sleep, eat, and bathe. The staff could not be housed with the general public for fear of spreading infections to premature infants. Furthermore, methods of caretaking and note-taking had to be developed and transferred between shifts of nurses. Transport for bringing premature infants to incubator exhibits had to be coordinated. In addition, new techniques for overcoming prematurity-related issues had to be invented along the way. For example, as younger premature infants were now surviving hypothermia, Couney and his nurses faced the new problem of infant starvation. Many younger premature infants were too immature to suckle efficiently at a breast. For this issue, a nasal gavage feeding system was developed where small amounts of human milk were placed into the nasal passageway of premature infants.

The incubator technology had changed from an extension of the mother to becoming a substitute for the mother. A popular magazine at the time referred to the incubator as “an artificial foster mother” (Silverman 1993). Mothers were no longer critical for the survival of premature infants. An entire institution had come into existence to replace her. This shift in the relationship between mothers and premature infants and the introduction of non-kin medical care for premature infants had the effect of separating the mother’s identity from that of the infant’s, and in turn, from separating the mother’s constitution from that of her infant’s. The premature infant as a display also played a role in a growing cultural comfort towards dividing the mother-infant dyad. An institutional system set up for the care of premature infants not only connected premature infants to other non-kin, but the separation of the mother from the child paradoxically created a situation in the future where the mother or parent’s role in the NICU had to be socially “earned” (Heimer 1999), and a legal and social right for the premature infant to be treated with medical care became complicated waters for individuals, institutions, and society-at-large to navigate.

Straddling the world of scientific research and showmanship, Couney saw his life’s work as the successful propagandizing of premature infants—making premature infants known to the world, making them relevant as subjects of study and care by the world’s leading obstetricians and pediatricians, and most critically, giving them the status of patients so that they would eventually be cared for in hospitals rather than in hatcheries at carnivals or sideshows (Liebing 1939). The closing of his final and last semi-permanent child hatchery on Coney Island was organized upon the opening of the first hospital unit for the care of premature infants at Michael Reese hospital in Chicago (Silverman 1993) (Gartner 1995), headed by the famous pediatrician Julius Hess. With the opening of a hospital unit specifically designated for premature infants, they not only received a dedicated space, but with the assignment of Julius Hess, the care of premature infants shifted from obstetricians to pediatricians. This shift laid the groundwork for neonatology as a medical specialty (Gartner 1995).

These exhibitions of premature infants not only garnered medical interest but also gave the babies an individual status from that of their mother. As mothers gained access to far more powerful technologies capable of assisting their infants, they also lost a certain degree of control. The working out of these boundaries—among physicians, nurses, and parents—continues to be a major theme in modern neonatology today (Baker 2006). The changing status of the incubator, the mother, and the premature infant signal how interactions with innovative technologies can simultaneously create new emerging experiences, meanings, and values while permanently leaving behind residues (Williams 1977) of past experiences, meanings, and values. In other words, experiences, meanings, and values of the past are never completely replaced. They merely become fodder acting against and/or in consort with the present. The results can both be disarming and liberating. History points to how experiences, meanings, and values of the past are still active in the cultural process of the present (Williams 1977). This is especially true for incubators, mothers, medical caretakers, and premature infants in their shifting relationships with each other and with the wider public.

With the exhibition of premature infants, not only did medical interest in the infants grow as patients, but premature infants were now no longer viewed as damaged or weaklings. They became distinguished from diseased infants suffering from syphilis. “Don’t pass the babies by” was the cry of carnival barkers at various expositions and sideshows both around the world and in the United States. Indeed, they were not passed by. Today, their very presence in NICUs around the world have generated new experiences, meanings, and values, but residual ones of the past continue be felt and lived by various actors in the NICUs of today.

The critical organizational groundwork for the future developments of neonatology was laid during this time, as a result of the premature infants being exhibited. However, for the premature infant to fully become a patient in his or her own right, other innovations would have to be developed (ventilator support, micro-method blood sampling technologies, and the consequences of high oxygen therapy). These innovations would bring a new set of issues, both biologically and socially.

Premature infants in incubators as both weaklings encased in plexiglass to garner maternal affections and as carnival exhibits share some striking similarities to museum objects. They begin their social life on display and as display objects. As such, they are simultaneously the subject of institutionalizing forces as well as varied and often changing sets of practices, processes, and interactions (Kratz and Karp 2006). Unlike interactions with other humans or living animals, interactions with displays and museum objects are interactionally one-sided. In this sense, the emergence of premature infants into public awareness as sideshow displays, in their living stillness, foreshadows the contradictory relationships and tensions that arise as they gain the status of being patients in their own right. At the same time, the institutional support that is required to house them, whether in the late 1800s or in modern day 2011 remains an ever growing and complex system.

What then is it about premature infants that gives them the quality of museum objects? I argue that the underlying universality of the biological maturational process carries many of the same characteristics as museum objects—its existence and the facts of its existence are material, but our knowledge and the degree of knowability about them are derived in large part from our collective willingness to ascribe social significance to certain historical events and processes, or in this case biological materials and processes (La Tour and Woolgar 1986) (Morgan and Conklin 1996) (Morgan 1998). Thus, as technological capabilities to give biological life to increasingly more premature infants become more sophisticated, it becomes biology (i.e. biological process of gestational growth) that moves front and center—more on display—then the newborn as a social human.

Borrowing the idea of “conjunctions” from museum studies (Kratz and Karp 2006), the range of roles, definitions, and ways of interacting with premature infants or with each other in their context entails “conjunctions of disparate constituencies, interests, goals, and perspectives” (Kratz and Karp 2006:2). In particular, although each premature infant is both genetically and experientially an individual, the process of fetal growth and development and the physiological obstacles that each premature infant must overcome (e.g. breathing, digestion, maintaining a stable body temperature) are biological factors that remain the same throughout time and across geographies of space. When a premature infant whose still emerging physiologies render it incapable of interacting with those in the ex utero social world, the “bio-social gap” is widened (See previous chapter) and must necessarily be managed socially by others as they interact with premature infants in a variety of ways.

Whether they are onlookers paying one German mark each to view the “baby hatchery” or the parents, kin, and medical caretakers of the NICUs of today, a more pronounced bio-social gap that exists for all premature infants (see previous chapter) is socially encountered and experienced differently by different people and at different times and places. Thus, the universality of the bio-social gap intersecting with the varied ways that individuals experience and manage the irreducibility of the bio-social gap entail “conjunctions” (Kratz and Karp 2006) that exist across time and geographies. Those bio-social conjunctions produce contradictory experiences, meanings, values, tensions, collaborations, and conflicts of many kinds and on many levels (Kratz and Karp 2006). Although interactions with premature infants are bound by their biology and their still emerging (or the lack thereof) physiological capacities, “bio-social” conjunctions elucidate tensions, contradictions, and debates that arise both from within and outside of the neonatal context. These “frictions” (Tsing 2006) (Kratz and Karp 2006) speak to the ongoing complex of social processes and transformations that are generated by and based in how the irreducible biological process of maturational growth of fetuses and infants are socially managed through practices, processes, and interactions. They can also have ramifications far beyond the neonatal context, whether it is in the politics of abortion in the United States or the politics of modernity in Taiwan.

Today, all that is left of the presence of child hatcheries in the United States is a simple bronze tablet that reads, “ Dr. Couney was the first person in the United States to offer specialized care for premature infants.” This sober plaque crediting a scientific and medical milestone in the development of modern day neonatology is located on the boardwalk in Atlantic City, next to the entrance of a Holiday Inn. It is only this rather odd location that hints at the hazy boundaries between the beginnings of a groundbreaking scientific endeavor and a spectacle, between educating a wider public and showmanship, and between caring for and saving a tiny human life and exhibiting that life for all to see.

The next section of this chapter discusses how an era of innovation in neonatology that began toward the end of the American Civil Rights Movement (~1965) and continued until the early 1980s secured the premature infant as an independent patient and an individual (Lantos and Meadow 2006)—one that was no longer the sole province of obstetric care, but deserving of its own specialty.

The Emergence of the Premature Patient: An Era of Innovation

“Patrick Bouvier Kennedy, who lived 39 hours and twelve minutes, was the first to be buried in a new family plot at Holyhood cemetery in Brookline, Mass., marked by a single tombstone simply engraved ‘Kennedy’” (*Time* magazine 1963). He would have been the third child of President John F. Kennedy and First Lady Jacqueline Kennedy. He was born August 8, 1963. At 34 weeks gestation, weighing 4 pounds, 10 ounces, and 17 inches long, he appeared to be fine at first, but two days later he succumbed to respiratory distress syndrome, a common lung ailment found in babies with prematurity.

Press Secretary Pierre Salinger announced: "The struggle of the baby boy to keep breathing was too much for his heart" (*Time* magazine 1963).

The event struck the hearts of the American public. There was collective grief and despair. *Time* magazine described a weary President Kennedy spending the night before his son's death on a cot in the doctor's lounge at Boston Medical Center while his premature son spent his last days in a hyperbaric oxygen chamber.

In 1963 as in 1923, whether one was the premature son of a President who had to be snuck out a backdoor in an incubator to be transported for an hour to Boston Medical Center or a premature infant displayed at a World's Fair, they died from two causes: either because their lungs were too immature to receive oxygen or they were unable to get enough nutrition due to an immature intestinal tract. The death of Baby Boy Kennedy would spur innovations in neonatal care between 1965 and 1982 (Lantos and Meadow 2006): mechanical ventilation, surfactant, and total parenteral nutrition or intravenous feedings. These technological innovations shepherded in the survival of an entire population of human beings that would otherwise not have existed, and in doing so, brought about new moral and ethical dilemmas that parents, medical caretakers, and society-at-large would have to live with and live through.

Researchers understood by the early 1960s that respiratory distress in premature infants was caused by the lack of surfactant, a substance that allows lungs to inflate more easily with every breath, subsequently altering the course of technological development. Rather than fine-tuning the hyperbaric chamber to provide ever more supplemental oxygen, researchers shifted their focus to develop surfactant. Without surfactant, it was impossible for the lungs to use oxygen.

In conjunction with surfactant, innovators developed mechanical ventilation with enough distending pressure to support breathing by expanding the premature infant's surfactant-deprived lungs. The critical question became, how much pressure? (Deliveoria-Papadopoulos, Levinson, and Swyer 1965). The development of mechanical ventilation was accompanied by studies of its effects on blood gases and circulation, and outcomes of patients with differing degrees of disease severity. Only once infants were able to be kept alive for prolonged periods of time did much what is now known as intensive care develop: the use of intravascular catheters, blood or transcutaneous gas monitoring, arterial pressures, heart rate and temperature monitoring, water balance, metabolic status, and a myriad of other facets of care (Cooke, Friis-Hansen, and Lunding 1967) (Reid and Tunstall 1965) (Delivoria-Papadopolous, Levinson, Swyer 1965).

Total parenteral nutrition (TPN) would also dramatically change the survival rate of premature infants. Feeding exclusively through the vein, and therefore bypassing the mouth and intestines, was a grand achievement. Researchers at the University of Pennsylvania developed a precise combination of chemicals to infuse and the techniques to infuse them on dogs. In applying these techniques to humans, they were first tested on term infants who had undergone intestinal surgeries and could not eat by mouth. The first test subject was a newborn whose bowel had been surgically removed. After extreme consideration of medical, moral, and ethical aspects of the baby's problem, an ad hoc committee recommended the experimental procedure as a last resort. The baby, they reasoned, was dying of starvation (Dudrick 2003). A central venous catheter was placed and TPN feedings began. Although the baby was never able to eat by mouth, she survived 22 months exclusively on TPN, and then died.

Unlike mechanical ventilation, which had been used successfully in other clinical circumstances, TPN had never been successfully used in other populations. It was another dramatic example of the inter-relationship between research and patient care in the NICU.

However, what these two innovations have in common is the way in which the details of what worked (and what did not) progressed by trial and error, by experience. The successes of mechanical ventilation, surfactant, and TPN were based more on the clinical intuitions of doctor-researchers, than on the sequential process of hypothesis testing. The innovations would also inevitably engage with new moral and ethical dilemmas. As in the example of the baby who survived 22 months on TPN, how would one characterize this result? Was this merely a prolonged death or a life extended? Questions concerning what counts as success and what counts as progress or experimentation emerged and continue to this day (Lantos and Meadow 2006) (Doyle, Casalez 2001). In addition, the timing of these dilemmas happened to have taken place during and shortly after the U.S. Civil Rights Movements. As a result, this happenstance inadvertently brought the legal institution and legal reasoning into the NICU, particularly issues surrounding personhood and individual rights. Details concerning this aspect will be investigated further in Chapter 8.

How medical caretakers, parents, and society at large approached the various new moral and ethical dilemmas that exist in the NICU would depend on much more than just the guidance of principals of ethics and law, as espoused by philosophers, ethics scholars, and legal specialists and discussed endlessly in ethics committee meetings. Neonatology is a field that recognizes its own shortcomings, and every medical caretaker lives and struggles through elusive experiences of personhood as they interact with premature infants and with each other. No one is more aware of ethical dilemmas than the very clinician-researchers who, through trial and error, had to decide who would receive new/experimental treatment, when would they stop, and how would they characterize their results.

The nature of NICU interventions and the saving of premature lives, because it is based upon the emerging maturation of newborns born too early, is one that is forever shrouded in radical uncertainty. Yet, quite incredible progress has been made in spite of our incomplete knowledge of human gestation. Almost all premature infants older than 24 weeks gestation survive. However, as stated in earlier chapters, progress is a double-edged sword when notions of success and futility are often mere gestalt. Without new knowledge of human gestation, NICU care remains at a plateau and the consequences of this plateau are lived everyday by various individuals. Therefore, it is the task of this dissertation to show that it is the elusive experiences of personhood that individuals live with and live through that enable them to construct, reconstruct, justify, and make sense of their actions and decisions.

The word *patient* originally meant “one who suffers” (Webster’s Dictionary 1996). This English noun comes from the Latin word *patiens* meaning “I am suffering.” Implicitly, the experience of being a patient simultaneously recognizes oneself as the subject of suffering and is recognized by others as the subject of suffering. However, in the case of the premature infant, as this section has shown, being a patient takes on different valences—a death that could have been saved, a troubling life prolonged, and a subject of experimentation. At the same time, one can talk about the patience of doctors, nurses, and parents. They too suffer from having to make difficult choices and sometimes having to look the other way in the pursuit of progress. The death of Baby Boy Kennedy spurred the development of an entire field of medicine precisely because his death affected others.

Consequences and Liminalities

One critical consequence of this era of innovation is what I call techno-viability—viability now exists for premature infants that otherwise would have died and that not so long ago were defined as late miscarriages or even embryos (Morgan 1998). They are now kept alive not only through intensive care technological *assistance*, but the era of innovation in neonatology brought technological *interventions into* (as opposed to mediating) the human gestational process. The aforementioned innovations of positive airway pressure ventilators, surfactant, and total parentural nutrition (TPN) are examples. As the boundaries between technological assistance and technological interventions are often hazy, fluid, and non-linear, technoviability creates two kinds of liminalities that exist in the NICU. One is the classical anthropological concept of liminality as put forth through the work of Victor Turner (Turnerian Liminality). This liminality has to do only with the liminal social status of individuals as biological maturational processes render an individual “betwixt and between” social definitions of the person. The other, I argue, is a liminal status that is derived out of *interventions into* (and sometimes interference into) the biological developmental process, creating new biological realities that would otherwise not exist. These biologically based liminalities created out of technological advances, or “bio-techno-liminalities,” produce consequences that Turnerian liminality specifically did not account for.

At a high-tech intensive care nursery for developing fetuses born too early, NICU patients emerge into the social world as technologically mediated human bodies. As such, the NICU is particularly attuned to the dilemmas of person-making in a high-tech world. As the historical development of incubators and of modern day NICUs suggest, personhood dilemmas regarding how we understand and interact with premature newborns have to do with how we define and interact with newborn premature human bodies at the beginning of life, and subsequently how we transform them into members of society.

These technological assistance of and interventions into significant human experiences, especially in the beginning of life, inevitably raise a range of “personhood dilemmas.” Building on Meyer Forte’s work on personhood that encompasses both objective and subjective qualities of the person (the person versus the individual), personhood dilemmas are simultaneously about how we negotiate competing and contradictory definitions of premature infants, as well as how we elusively experience premature infants and each other in their context. That is, on the one hand, cultural models of babyhood, motherhood, parenthood, as well as specific medical and legal definitions and rules regarding the care of premature infants, provide us with objective definitions of personhood for both the premature infant and for other actors associated with them. However, due to the circumstances of premature infants under NICU care, these definitions are not always adequate for guiding how individuals should interact with and towards infants and each other. Thus, on the other hand, personhood dilemmas are simultaneously (and more critically so) about individual actors' elusive experiences with premature infants and with each other in their context.

Under the circumstances where premature infants are made technologically viable, medical caretakers and kin must interact with premature infants (and with each other), even when the premature infant cannot interact back. Various NICU actors not only face the consequences of sometimes having to decide difficult *Sophie's Choice* decisions between a life with grave disabilities or death, but even the mundane day-to-day treatment decisions and the routine work required to maintain a technologically viable life (changing IV lines, chart taking, rounds, and implementing feeds) require action and interaction. Similarly for parents and kin, although they bear the role of parents, they often do not experience themselves as such. Yet, they must continue with their life outside the NICU, while still maintaining a role in the NICU. As more formal definitions and cognitive stereotypes of babies, mothers, doctors, and nurses are often inadequate for providing guidance towards interactions (Fox 2005), it is the interactions themselves, the elusive experiences between individuals and premature infants and between each other in the context of premature infants that often inform how we come to know premature infants and ourselves. This kind of knowledge often cannot be articulated—interactions are lived, they are felt. They are what Raymond Williams calls "structures of feelings"—social experiences still "*in process,*" often not yet recognized as social but taken as private, idiosyncratic, and even isolating. They are often only recognizable at a later stage, when they have been formalized, classified, and in many cases built into institutions and formations (Williams1977:132).

Turnerian Liminality

Victor Turner provided anthropologists with the analytical concept of liminality for understanding the phenomenon and processes of mid-transition. The liminal status of individuals are about discrepancies and contradictions between social and biological maturity and the cultural recognition given to these processes (Fortes 1987) (Fortes 1959), whether they are adolescents emerging into adulthood (Turner 1967) or adults finding themselves in situations where their status and their experiences of self are discrepant (Fortes 1987). Either way, for the living, biological processes of maturation are implicitly understood as a process that is irreducible, marching towards death. As discussed in the previous chapter, human gestation is a genetically determined and evolutionarily derived process that selected for newborn human beings to be birthed between 37-40 weeks of gestation. For this very reason, early incubators were only successful for later stage gestational newborns (Baker 2006); only the slightly premature that needed some assistance with temperature stability, feeding, and protection from infections survived. However, as intensive care technologies advanced, developments such as steroids and surfactant were now capable of more than just technological mediation and assistance—"buying the preemies a little more time." Rather, new innovations enabled interventions into the human maturational process. Steroids and surfactant sped up lung cell development and maturation. Similarly, ventilators now keep immature alveoli cells from collapsing while providing oxygen. These interventions are a stark contrast to the early incubators with simple circulating air designs that largely, through isolation, provided fresh air while preventing hypothermia and infections. The premature infants of the 19th century would today be in an intermediate nursery, one that does not require interventions into newborn physiology and organ development, but would merely "assist" and "buy a little time" for premature infants. They would be known nowadays as the "feeders and growers."

For all premature infants under NICU care, Turnerian liminality consists of the classical anthropological problem of how to categorize and differentiate the undifferentiated biological process of human growth and development. In the context of this dissertation, the personhood dilemma associated with Turnerian liminality has to do with how individuals who are most intimately connected to NICU neonates come to experience and define the "cyborg" (human-machine) nature of neonatal bodies.

Because the premature neonate under NICU treatment is a body that is in transition and in a liminal state (Turner 1967), the NICU premature body exists at the boundaries between competing definitions and experiences of who is a premature infant. In turn, how various individuals intimately connected to premature infants define and experience themselves and each other in a neonatal context can also be deemed liminal. As NICU treatments often render neonatal bodies to be continuous with machines, wires, tubes, and taps, how medical caretakers and kin define and experience these bodies is often emotionally, interactively, medically, and practically contradictory and confusing. As one parent asked, "Where is my baby…the machines seem to have more life than my kid" (Ren, fieldnotes 1997).

Under these conditions, premature bodies are "cyborg fetuses" that resonate between the following conflicting characteristics: human and machine; life and death; natural and artificial; private and public. These characteristics are embodied simultaneously, in varying degrees, and in multiple combinations. As common expectations would dictate, individuals encountering these techno-liminal neonatal bodies with ambiguous identities must interact with and make sense of these bodies as well as who they are in relation to these bodies. Many scholars have documented parental and maternal experiences with cyborg neonatal bodies as well as with the NICU environment itself (Frohock 1986)(Affleck, Tennen, and Rowe 1991)(Pinelli, Saigal et al. 2008)(Landzelius 2003). Generally, it has been found that parents, especially mothers, express maternal uneasiness, as well as physical and emotional disenfranchisement, and ambivalence (Landzelius 2003). Here are some examples from my own fieldnotes (Ren, fieldnotes 1996-1998):

“I could not believe this was my baby. She was so tiny and bruised and I started crying because she was all hooked up and looked dead…It was hard to think that this was mine. She did not even look like a baby” (Telephone Interview).

“I had to come to terms with all the tubes and machines and remind myself that this is my baby. He looked like a creature from outer-space” (Telephone Interview).

“I thought this was impossible, this thing looks nothing like me, my husband, or anything I know. It was kinda a nightmare baby but it was real and you don’t get to wake up and make it go away” (Telephone Interview).

As illustrated, the dilemma of personhood that any individual who is interconnected with the NICU neonate encounters is, “Who is this strange creature?” “Who am I?” “Is this really my child?" (Ren, fieldnotes 1996). This dilemma arises out of inarticulate experiences "in progress" and as a clash between various cultural models of personhood and non-personhood. The former understands personhood to embody characteristics of *human, life*, *private*[1], and *natural* while characteristics of *machine*, *death*, *public*, and *artificial* are reserved for non-human entities, such as robots.

The problem of Turnerian liminality in the NICU is no different from issues of personhood that have been well documented in classical anthropology literature (Fortes 1987) (Turner 1987). NICU technology has given us a modern rites of passage whereby there is a liminal period of time where the NICU neonate is neither and both human-machine, life-and-death, private-public, and natural-artificial. As anthropologist Arnold Van Gennep summarized regarding the human life cycle, "the movement of man through his lifetime…is often punctuated by a number of critical moments of transition which all societies ritualize and publicly mark with suitable observances to impress the significance of the individual and group on living members of the community" (Van Gennep in Turner 1966:94).

Historically, when NICU technology could only insure the survival of late gestation premature births, NICU treatment merely just mediated or "gave a little extra help" to the human growth and development process. It bought some time to allow the natural biological process of growth and development to take place such that the premature neonate could get back on the track of the evolutionarily derived natural course of human growth and development. As such, the time spent in the NICU merely became an additional punctuated critical moment in the human growth and development process.

Today, the view that NICU treatment is merely just an extension of normal in-utero gestation is true only for a subpopulation of neonates (later gestational neonates). For neonates who are usually greater than 30 weeks gestation and weigh over 1500 grams, this "cyborg" condition is usually a passing phase and the dilemma of personhood will come to an end. That is, NICU therapy does not last forever and those with ideal courses of NICU treatment have simply become re-integrated into common experiences and cultural models of growth and development. An ideal course of NICU stay consists of having an assessed developmental outcome that follows the expected standard in-utero trajectory. These patients are eventually discharged from the NICU without any neurological disabilities. For parents and medical caretakers alike, they can often rely on existing definitions and experiences, both personal and institutional, as a means of experiencing their premature infants and themselves in a neonatal context.

Ethnographically, this phenomenon is captured by a "disappearance of corrected age." All NICU patients start out in life with two age calculations—actual ages and corrected ages. Actual age is how old the preemie is from the day of birth. Corrected age takes into account how premature they are and subtracts this number from the actual age. A preemie born two months early has a corrected age of ten months even though he/she is celebrating a first birthday. However, at some point in time, that difference no longer matters as the NICU graduate's neurological condition becomes no different than had he or she been full term. When this occurs, the premature neonates, and parents and kin, have become successfully re-integrated into social life, and family members will generally report "how far along the baby has come." For parents of this group of neonates, they have also become re-integrated into mainstream birth experiences. Their transformation into mothers and fathers is also complete. The following comments illustrate successful re-integrations:

“Michael has come such a long way. He is a funny baby and has so much personality now. When he was in the NICU, he was just this tiny thing lying there. I didn’t think he was ever going to be a baby. I can’t believe it. I’m really his mom now” (Telephone Interview).

“Jennifer has so much personality. She is a little person now and we can do things together” (Telephone interview).

“I can’t believe how much Diana now looks like my husband. She has come such a long way. We really could not tell her apart from all the others in the hospital. She was tiny and didn’t look like much, just a body with wires and tubes” (Telephone interview).

As these examples illustrate, the personhood dilemmas associated with Turnerian liminality always result in re-integration. For Turner, liminality allows for the reformulation of old elements into new patterns. Under these conditions, rituals and rites of passage are effective cultural mechanisms for managing liminal periods of time. Implicit here is the notion that underlying rites of passage is an unalterable biological order and biological trajectory of growth. Until the twenty-first century and the development of interventionist reproductive technologies and research (i.e. stem cells, steroids, in vitro fertilization) of which aspects of NICU technology are one example, this has been and is usually the case. Hence, liminality results from the inadequacy of social categories to capture the underlying biological process.

However, as NICU technology has improved to save younger and younger gestational entities, NICU technology no longer just mediates the human developmental process. Rather, in these cases, NICU technology intervenes *into* the fetal development process itself to introduce novel growth trajectories that otherwise would not have existed (Lampl, personal communication). Under these circumstances, a new type of personhood dilemma arises. The next section will discuss this in more detail.

Techno-Bio-Liminalities

NICU outcomes can vary from the “ultimate success story” of perfect miracle babies; to a life of severe disabilities; to anywhere in between these extremes. As mortality rates continue to decline such that 70%-80% of all NICU neonates survive to go home with their families, morbidity rates (degree of neurological and physical disabilities) continue to increase (Spitzer 1996). A three-year study at the University of Chicago Hospitals has found the following (Meadow et al. 2002):

(1) If an infant has what can be considered a relatively “benign” NICU course (ventilated, but never thought likely to die or survive with significant morbidity), there is roughly a 90% chance that the infant will be neurologically normal at a year.

(2) If the infant is sick enough to prompt a prediction of “survive with moderate to severe morbidity” (but never sick enough that anyone predicts death), the glass is partly

full (70% of these infants are developmentally normal at one year) and partly empty (30% are not).

(3) If, however, the infant is sick enough to engender a prediction of death, the likelihood of neurologic normality at a year, should the infant survive, is less than 5% (Meadow et al. 2002, 2003).

Because NICU technology does not uniformly produce developmentally and neurologically normal infants, it is important to distinguish between the standard trajectory of in utero development and alternative ex-utero NICU created trajectories. For all premature neonates falling into categories 2 and 3, NICU technology intervening into the biological process of fetal growth and development produces a set of new physiological and biological realities that would otherwise not have existed within the evolutionarily derived natural course of fetal growth and development. In discussions with human developmental biologist and anthropologist Michelle Lampl, she posits that it is possible we are changing growth and development trajectories in ways we don’t even know yet. All we can be sure of is that the evolutionarily derived fetal growth and development process has been intervened into and, for some population of premature infants, their growth and development are following alternative trajectories that would otherwise not have existed (Lampl, personal communication). The many cases of very premature identical twins under NICU care illustrate this point (Meadow 2000). Identical twins possess exactly the same DNA, while in utero shared the same in utero environment, and when they arrive into the ex utero world requiring NICU interventions, they also share the same degree of prematurity. However, far too many cases of identical twins under NICU care have produced very different outcomes, with one twin significantly more disabled than another, and even in appearance, no longer looking identical.

Because the artificial environment of the NICU is not a perfect match to the in utero environment, it is necessary to distinguish between the standard trajectory of in utero development and alternative ex-utero NICU-created trajectories.

From a physiological perspective, this difference results in two types of viabilities. Legally defined viability is the capacity for a fetus to survive outside the placenta. The first type is evolutionary viability: the evolutionarily determined point at which an in utero fetus can survive outside the placenta, or as my very pregnant friend who was a week overdue said, “The kid will pop out when his little body is ready.” The second type is technologically assisted viability, or what I call techno-viability. This distinction occurs because NICU intervention into the standard developmental process has produced what medical caretakers understand as “new” kinds of human beings with alternative NICU-created growth trajectories. A popular website that informs and educates NICU parents stated: “It is unfair to think of the preemie as either a fetus or a mini full-term baby. Preemies are…a NEW kind of human being…unique, and deserve special treatment” (www.spencerhope.org/understanding_your_preemie.htm).

Unlike Turnerian liminality, epidemiological and clinical data suggest that we are altering the intended maturation of premature infants by subjecting them to an ex utero environment (i.e., the NICU) for which their immature organs are ill prepared. Many neonatologists would agree that alternative trajectories of maturation and growth are at work (Stahlman 2006) (Hack et al. 2003). As a neonatology fellow said, "Even if they are normal, you always have to wonder if they could have been more. You just don't know what their potential was. Sometimes the difference is so small between where they were supposed to be and what happens after the NICU, but sometimes it is very, very large." Although developmental specialists do not yet know the mechanisms that result in different growth and maturational outcomes for premature infants, clinical outcome data suggest that there are at least two other alternative growth and maturational trajectories in addition to the standard NICU growth and maturational trajectory (Hack et. al. 2003) (Spitzer 1996) (Meadow and Lantos 2006). They are:

(1) Some patients had assessed developmental outcomes that appeared to match in utero rates, but suddenly declined and death was only delayed.

(2) The last alternative trajectory is what many neonatologists refer to as the "grey area" cases—patients whose assessed developments were marked by radical prognostic uncertainty. These NICU patients possessed unpredictable outcomes that ranged from death; to survival with severe neurological disabilities; to survival with moderate disabilities.

Radical prognostic uncertainty, as discussed earlier, is defined as the long-term indeterminate nature of neonatal outcomes for premature newborns. Doctors cannot say what the outcome of any particular baby will be. Instead, the range of possibilities covers the spectrum of outcomes, from the very best to the very worst. For this reason, prematurity is both an acute crisis and a chronic condition—encompassing two different kinds of liminalities. These two kinds of liminalities are often hard to distinguish. Yet, their consequences are experienced differently for different people at different times. For parents and medical caretakers alike, their own concepts of selves and others, both by definition and relation, are also impacted as much by the Turnerian liminal status as by the bio-techno-liminal status of premature infants, producing differing degrees of responsibilities toward premature infants and carrying different implications for what constitutes a good and moral medical caretaker or parent.

Underlying the cyborg nature of gestationally younger NICU bodies are emergent biological realities that introduce “new elements” into the evolutionarily informed natural course of fetal growth. Hence, techno-bio-liminality is a historically specific twenty-first century dilemma of personhood that arises out of technologies intervening into the developmental process and producing a set of biological realities to which scientific researchers are still working to delineate the specifics. Some examples include blindness caused by the high rate of oxygenation introduced by ventilators, the reportedly higher pain tolerance threshholds of NICU graduates, or scases of cerebral palsy that would otherwise not exist. In the meantime, because person-making interactions and processes have to continue, the personhood dilemma under techno-bio-liminal circumstances becomes more complex than what we saw in Turnerian liminality.

As such, a liminal state under bio-techno-liminal circumstances is rendered not merely because social categories or cultural models are inadequate in capturing the heterogeneity of the fetal growth and development process, but rather, because the underlying biological order of fetal maturation and growth has been altered by NICU technology (i.e. Radical Prognostic uncertainty). However, because we do not always know or understand the consequences of these alterations, how medical caretakers and parents experience and define premature infants, as well as themselves, is often an ongoing struggle that can be contradictory, confusing, and also inarticulable.

Since we have ever improving technology, there will always be a time when scientific data lag behind how individuals experience and make sense of newly emergent biological and social realities. Ultimately, it is this gap that individuals and institutions must live through and learn to provide “partial and temporary solutions” (Shore 1998). In comparison to Turnerian liminality, I suggest that techno-bio-liminality possesses many of the characteristics of Victor Turner’s concept of a transitional period. However, I also suggest that technobioliminality possesses some unique features that were unforeseen at the time of Victor Turner’s writings.

One such difference is that Turnerian liminality did not take account of liminal states emerging out of technologically created new biological realities that beg for cultural interpretations that are in the process of emerging, unarticulated as “structures of feelings” (Williams 1977). As Turner stated in the *Forest of Symbols,* “Rites of passage are found in all societies…where change is bound with biological and meteorological rhythms and recurrences, rather than with technological innovations” (Turner 1967:93). Experientially, Turnerian liminality eventually ends in re-integration whereby precious social categories, which were under challenge during the liminal period, are eventually reconciled with liminal experiences. However, in the case of technobioliminality it is not clear whether liminal experiences of newly emergent biological and social realities *can* be re-integrated into existing social categories. Yet, they must, because the ex utero corporeal existence of techno-bio-liminal premature infants demand it. It is the work of the rest of this dissertation to address this issue in more detail through analyses of experiences of NICU patients and their families in the United States and in Taiwan.

In the chapters to come, this dissertation presents ethnographic studies of how individuals attempt to manage bio-technoliminalities in two NICUS—Taiwan and the United States. The history of the NICU in Taiwan begins from the problem of bio-techno-liminality, as NICU technology emerged in Taiwan only in the late 1980s and early 1990s, when NICU technology is largely understood to have reached a plateau (Meadow and Lantos 2006). As such, it was globalized as both a technological advance and an institutional advance that carried with it certain presumptions about ethical standards of treatment for premature infants, as well as ideas and prejudices regarding what constitutes "appropriate" roles and interactions for parents and medical caretakers in the context of premature infants (Heimer and Staffen 1998). The next section, an interlude of sorts, gives some background on the social organization of the NICU. This will be followed by a description of some obvious and critical differences between the Taipei NICU and the Chicago NICU. The intent of the rest of this dissertation is to provide some thoughts on why these differences exist, in spite of the two NICUS possessing the exact same technologies and the same biological obstacles that premature infants face.

CHAPTER 4: AN INTERLUDE

The modern social organization of the NICU is largely dictated by the technological innovations that were developed in the NICU. Both mechanical ventilation and TPN (as discussed previously) are technological innovations that required more intensive monitoring by doctors and nurses than any treatment that had been previously given to infants. At the same time, the experiences within the two NICUs are quite different.

Social Organization of the NICU

In the case of mechanical ventilation, the researchers who pioneered the technology specifically wrote, “This method is completely dependent on continuous well-trained, experienced nursing and medical supervision, with 24-hour facilities for biochemical determinations. Infants undergoing mechanical ventilation must never be left alone. Maintenance of adequate airflow into the lungs is crucial, and the breakdown of less than 5 minutes will reduce an infant in relatively good condition to a moribund state. For hope of success, a suitable organization for intensive care incorporating the above principles is essential” (DeLavoria-Papadopolous 1965:479). Here, I will begin by briefly describing the outlines of the rather standardized social organization of NICUs that is found both in the United States and Taiwan, as well as around the world.

The suitable organization would eventually become regionalized networks for perinatal care that introduced new levels of cooperation between obstetrics and pediatricians. Second, regionalization required complex inter-relationships between community hospitals and centralized referral centers. Finally, because NICU care is extremely expensive, the highest level of NICU care would be concentrated in major metropolitan cities that would provide access to surrounding areas.

The care of premature infants and other critically ill newborns also requires the orchestration of a large number of individuals that include a wide array of medical caretakers and parents. On the medical caretaking side, there are attending physicians, fellows, and residents, along with consulting physicians, fellows, residents, nurses, therapists, and technicians. This is roughly the order of the official status hierarchy in place. Attendings give orders to residents who then provide orders to nursing staff. However, in practice, official status hierarchies are often disregarded. Social authority often trumps institutional authority. Although residents must sign off on orders carried out by nurses, they freely admit that nurses train them. As one resident stated, "Nurses are the bosses around here." Seniority is often dictated by experience in the NICU, rather than by the level of education.

On the kin side, visitors to the NICU can include mothers, fathers, grandmothers, siblings, and other kin and close family friends. As will become more evident, parents in the U.S. visit the most, while in Taiwan, mothers visit far less, while fathers and grandmothers can visit briefly. However, as a premature infant nears discharge, most mothers will visit more frequently, but still for brief moments of time. One other difference between Taiwan and the United States is the length of visiting hours. In the U.S. parents are allowed and encouraged to visit anytime, and at least daily. In Taiwan, visiting hours are limited to two hours a day, at the end of the day, and by appointment only. All of these individuals participate in a formal and informal dance of coordination and information exchange.

NICUs have a fairly rigid division of labor. Coordinating the division of labor is as much of a task as the medical caretaking of patients. There are several important organization routines that help coordinate the efforts of a vast array of health professionals. On daily morning rounds, the head nurse (and any other nurses who would like to participate), residents, fellows, and attending physicians on duty would go around the bed spaces of each patient and discuss the patient. This report serves as an update for others to be informed of the patient's progress and enables the attending to both keep track of a patient's progress and the resident's training. Daily progress reports are recorded in the patient's medical chart by the doctors, along with any changes in the patient's medical status and course of treatment (Staffen and Heimer 1998).

As residents finish their rotations in the NICU, they will write lengthier off-service notes to brief the incoming residents on the patient's hospital course. Nurses also keep detailed written records that include recording observations of the patient's status every hour. These include oxygen settings, any laboratory results, temperature, etc. When one nurse's shift comes to an end, he or she will usually give a verbal summary to the incoming nurse. In addition to these formal organizational routines, nurses and physicians communicate throughout the day. There is always much informal communication between and among nurses and physicians, especially when a patient's condition changes or if new diagnostic test results have been returned. Much of the work is done through these informal communications. By the time rounds come along, most relevant individuals are usually up-to-date on the developments that pertain to their patients. Formal routines are generally for the purposes of group cohesion and training. It is rare (almost never) that ethical dilemmas or difficult life-and-death decisions are discussed during formal meetings. Rather, it is during informal conversations that medical staff wrestle with difficult treatment decisions and or ethical dilemmas.

FIRST ENCOUNTERS

Chicago, Illinois, USA

Walking into the NICU for the first time in 1996, I was awestruck by its appearance. Resembling a space-age laboratory, the surrealistic sight of tiny infants surrounded by large machines could have been a scene out of any science fiction novel. Completely unlike hospital nurseries I had visited once or twice, it was a nursery in a bizarro world, in an alternate universe. The sights of numerous wires, machines, and gadgets provoked me to rethink those qualities I had conventionally associated with newborn infants. I noticed the sound of whirring machines instead of the cry of infants, the rows of miniature elevated beds covered by saran wrap instead of a crib surround by colorful blankets and pillows, a myriad of wires and tape that brace the infant in an almost immobile position instead of the embrace of a parent sitting in a rocking chair. Intellectually I knew that I was seeing a tiny human baby. However, both those little bodies and the context in which the tiny bodies were placed made me think, "Are they really alive? Are they human?" "Why do they look like little aliens?" "Why does this place look like a laboratory" "Why do they look like little specimens?" I was fascinated—the technology in the room was awe-inspiring. But, I also felt ashamed—both for staring a little too much and not feeling overwhelmingly sad when I knew their tiny lives were on the edge of death.

I also felt guilty. After all, whether around the room or taped on the elevated beds and incubators, everywhere I turned, I saw indications of "BABY." There were name tags, poster signs stating "I eat at Mom's," cute printouts of baby's first footprint, rocking chairs, stuffed animals, booties and hats, and at the doorway entrance there was a picture-collage of smiling babies with the title: NICU graduates. All of this baby paraphernalia felt grounding, almost talismanic—they were reminders that these little bodies are babies and that they do become normal, happy toddlers. However, they also made me a little indignant and judgmental: Why would anyone want her baby looking dead and hooked up to so many tubes and machines? Why not just try again for another baby? Or if you couldn't have another baby, why not adopt a normal baby?

I would learn that my initial reactions and contradictory feelings are not unique. Some days I would adoringly stare at their tiny fingers and toes, forgetting momentarily that I was in the NICU. Other days I would stare in disbelief; they looked like dead babies. Every parent I spoke to and many medical caretakers recalling their first time working in the NICU shared my reactions. However, unlike me, they also had to live through these experiences and the consequences of these experiences. In the NICU, images of cute babies do not exist—an extremely low birth weight baby, who is 600g and 26 weeks old, and still has his eyes sealed, looks more like a fetus than a gurgling 7-pound bundle of joy.

Over time, I became used to these sights and sounds. What was once awe-inspiring became normalized. On any typical day, the NICU was filled with the sounds of machines and the chatter of people, with the comings and goings of parents, and the daily work routines of doctors and nurses. It had the rhythm, sounds, and traffic of any workplace.

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Taipei, Taiwan: The NICU Revisited

Ah Zhang introduced me to the Taipei unit for the first time. It had been several years since I had been in a NICU. The ventilators, the premature bodies, the layout of the room, even the routines appeared the same.

However, what was startling was the quiet—it was really, really quiet, uncannily quiet, except for the sounds of machines. Nurses and doctors went about their routine work, quietly and silently. No one noticed me or cared. No one spoke to each other, unless they were on rounds and were presenting. There were no signs, no posters, no pictures, no bulletin board, and most striking, no parents.

Ah Zhang is in her fifties; she has been a nurse since her mid twenties, straight out of nursing school. She has always worked in pediatrics, but for almost the last decade, she has been in the NICU. She is affectionately known as Ah Zhang—"Ah" is a diminutive, used for young children or very old people, that is affectionate, familiar, and plays against relational hierarchies. Zhang means general. These two words normally would never go together. As expected, she is loved and feared. She holds down the fort. But, this is how she is known, it is one part of who she is, and it is who she has become. She is functionally, emotionally, socially, organizationally in charge of the NICU. She is part mother hen, part general, and part mentor, sheltering her cadre of nurses from bad days and laughing with them on good days. I have no idea what her real name is, and I'm not sure anyone else does either. She is both an individual and an institution. She is always cheerful, keeping everyone's spirits high, but also enforces the rules.

When I remarked how quiet the room was, Ah Zhan looked bewildered and remarked, “Is it loud in the NICU in the U.S., you mean it is the machines that are loud?”

I told her that the machines are loud, but that the people are often louder because they “forget” they are in the NICU, and to hear each other, they have to talk over the machines.

She replied, “What’s there to talk about to each other? Don’t they know what they have to do; don’t they have to pay attention to do their work? You mean they talk to the babies?” Her perspective gave me a lot to think about. All I could tell her was what I observed and learned from interviews: “Sometimes they talk to the babies, they talk to parents about the babies a lot, parents also like to ask a lot of questions, but they also just sometimes like to talk to each other when things get slow.”

She was surprised and proud, “I know, things can get slow in the NICU, but we read the studies and they say the noise is not good for the babies. So, we just don’t talk. It’s hard to not talk to each other, but we do it for the babies. But, I think it’s interesting why some nurses in your NICU would want to try and talk to babies—I think talking to the NICU babies would be much harder than not talking to them. What would you say to them? Why would you want to talk to them? They just need to rest and to grow. These NICU babies just need quiet. Plus, don’t you think a person who talks to a NICU baby may look a little crazy? It’s unnatural to talk to someone that does not talk back. Why do the nurses at your NICU keep talking, didn’t they read the studies?”

Ah Zhan was exactly right; every study that had come out in the last ten years or so has recommended a quiet and dimmer NICU. Noise can cause overstimulation of premature infants. NICUs in the U.S. are very much aware of this and they have policies set up to decrease noise levels. However, at least in the Chicago NICU, this is hard to enforce and hard to self-regulate. After all, parents are encouraged to come in at all hours of the day, and communication is encouraged between staff members and between nurses and parents. Morale is also important. And, it is not a coincidence that when it is quiet in the Chicago NICU, something has gone very wrong, and a heartbreaking death is on the horizon for a little being. As my Chicago nurse friend Nancy used to warn me, “It’s quiet in there.” Those were the days I would dread; those were the days where I collected “number of days until death data.”

Only I was uncomfortable with the silence. Silence for me was associated with the morbid. For the staff in the Taipei NICU, silence was just the opposite. Silence meant everything was running smoothly, there was no need to talk or communicate. I would learn later that when there was a lot of “noise” or commotion, which was quite rare, that’s when things have gone very, very wrong in the Taipei NICU.

Ah Zhan and I continued our tour. She introduced me to several nurses, told everyone I would be hanging around for awhile, and then asked me what I thought of her NICU. I told her I was impressed. Indeed I was. They had achieved an equivalent level of care to any first rate teaching hospital NICU in just over ten years. They knew the studies, they knew the procedures, and when I inquired about mortality and morbidity rates, Ah Zhan told me that almost all of their babies go home. It’s rare for a baby to die. I would learn later on through data analysis, that this was true. The Taipei NICU housed mostly infants over 1500 grams and over 27 weeks gestation. This was a population of kids that generally survived NICU care. This would also confirm for me that the two NICUs were equivalent in medical care standards.

Before I left our meeting, I finally asked Ah Zhan whether they had any pictures or posters, or a wall of pictures that I perhaps didn't see or was somewhere down the hall. Her reply was, "What do you mean? No, we don't have posters, why do you need them?" "Who would look at them?" I said that some parents in the U.S. bring toys in to their babies when they visit and they like looking at pictures of babies that have graduated from the NICU. She nodded, "Oh yes, some parents will bring some little toys in here too. The nurses will put them in the drawers and just take them out if they know a parent is going to visit." But, we do not have pictures of these NICU babies grown up, who would want to be reminded or let strangers know their child was a NICU baby. That's a little weird."

Also, "Parents feel so bad when they have a NICU baby and they don't know anything about what is going to happen, wouldn't it be too cruel for them to see happy normal babies who used to be in the NICU?" "We can't guarantee that for them—why would you give them false hope?" "Won't they just panic more and feel more bad about their situation?"

Drawing on my interviews with parents in the U.S., I answered her, "Some parents do, but most of the parents in the U.S, find it comforting, it gives them hope. Parents in the U.S. are encouraged to visit the NICU as often as possible and to get to know their NICU babies. So, the posters and pictures are nice for them to see.

She seemed to understand and said, "I guess, if they didn't have anything to look at, they would be bored. It's not like they can do anything. So, that makes sense." She then went on to describe parental visits: "Parents here only visit during visiting hours, which is only two hours in the evening. The moms do not come, they have to "Zuo Yue" (a post natal ritual) and stay home, but their husband or a family member will come in and check in with the nurse, to make a good relationship with the nurse, and then leave quickly. They respect our work and do not want to add to our workload. Also, we like visiting hours, because it would be too stressful if they just dropped by. We always make sure the NICU babies are not stressed out before visiting hours, this way, they can seem their best for their fathers and grandmothers. And, we always, always do extra work when we know the mothers are visiting for the first time. We work extra hard to plan all of a baby's procedure earlier in the week so that they are rested and not beat-up looking when their mom visits. Their husbands will tell us and we will make sure that their baby is the best it can be on that day. You would never want to scare a mom and show her an ugly, taped-up baby. Plus, a mom who looks unhappy and worried will scare the baby, give it bad 'chi.' This is why we have limited visiting hours."

Déjà vu:

Walking into the NICU for the first time in Taipei, my experience was one of déjà vu. The French psychic Emile Borac coined the word "déjà vu" and he regarded it to mean something that is familiar, accompanied by a sense of eeriness, strangeness, and weirdness. Although I had never been to a NICU in Taipei, this description most appropriately summed up my initial reactions.

I was familiar with everything I saw, yet the similarities felt eerily foreign and the difference felt strangely familiar. The physical equipment and layout of the room was almost identical—the ventilators next to the elevated heated beds strewn throughout the room and anchored by units of module shelving; the incubators housing premature infants whose paper think skin still lacked any pigmentation that connoted a difference in race of the patients between the Taipei NICU and the Chicago NICU; the general organization and physical layout of the room where a rectangular space without windows was divided into designated bed-spaces, the medical charts recorded the same information, and even the daily log book that registered incoming patients was the same brand. Almost every day for over three years, I visited a NICU in the city of Chicago for various research projects, so I knew the more subtle aspects of a NICU, it's rhythm and timing—that babies were fed every 3-4 hours, that vital signs were taken every hour, that rounds occurred early in the morning and then later in the afternoon.

In Taipei, these medical routines were almost identical—feedings, vital signs, rounds—yet, there did not seem to be protocols or routines for social interactions, whether with premature infants or with parents. Furthermore, things I had barely noticed while in Chicago suddenly seemed so obvious when I visited Taipei. The most striking: no one wears watches, whether in Taipei or Chicago, even though they seem to need to record medical charts on the hour, every hour. Instead, there was a central clock in both units. These similarities provoked a sense of the uncanny—the familiar things were so familiar that I could have been in Chicago, which felt eerily unsettling. As I was welcomed into the formal morning rounds, even the diagnoses and presentation of premature patients during rounds conformed to the organization and structure of many rounds I had tagged along on back in the U.S. The Taiwanese doctors and nurses were even required to present all of their patient histories and updates in English. It was only when I heard the deliberateness of their pronunciation for various premature conditions, the grammatical errors in their presentations, and whispers of Chinglish between residents did the NICU feel familiar again. After all, I was halfway around the world in Taipei, Taiwan, a high-tech modern city, off the coast of China, where everyone spoke Mandarin and/or Taiwanese and where cultural differences abounded everywhere I turned.

A comparative study inevitably provides an entry point towards understanding cultural similarities and differences. In the case of studying two NICUs across two different geographies, my two "first" encounters across two geographies provided many conjunctions by which frictions and the experience of frictions generated varied articulations across two different sites (Kratz and Karp 2006). The conjunctions are centered on the premature body's physiological requirements for ex utero life and the ways in which NICU technology intervenes in order to "help grow the body." All premature infants have the need to develop the same capacities for existential life—breathing, digestion, and temperature control. Yet, cultural variations—social, familial, and legal—interact with the NICU premature infants and those related to them in varied ways. It speaks to the uneven effects produced by global flows. At the same time, aspects of the outside are always brought into the NICU, our expectations from what we know inform how we relate to new circumstances. No one in Taipei would expect to see mothers in the NICU or very many social interactions. However, I came from a different situated experience. I would also learn that there is a right of passage called zuo yue where mothers are secluded from the outside world, and this accounted for the beginnings of why there was so little parental presence or social interaction with premature infants or with each other about them.

With these thoughts in mind, I am reminded of Georg Simmel's concept of the "stranger"—a person who comes today, but stays tomorrow, but is neither here nor there. The stranger's membership within a group involves being outside it, and confronting it. It is a specific form of interaction (Simmel 1985:144). In this case, the NICU-infant complex is the stranger. As such, by the fact that it does not belong and has not belonged to Chinese societies of the past, it will import qualities into, which do not and cannot stem from the group itself (Simmel 1985). How the NICU premature infant will interact and intervene into existing Chinese cosmologies, norms, and practices concerning the person and the family is the topic of the next chapter.

To summarize, the specific differences and similarities between the two sites present the following questions: (1) Why was the Taiwanese NICU *so* quiet, where were the interactions? (2) Why did everything appear so much less bureaucratic? There were routines, but mainly routines for medical care, not for social interactions. (3) Why weren't there any pictures, posters, or parents? Without a system for encouraging parental visits, would parents and their premature infants be able to bond? After all, didn't bonding require physical presence?

The next chapter will begin to answer these questions with a discussion of personhood in Taiwan.

CHAPTER 5: MAKING PERSONS, DOING MONTHS

(Chinese Concepts of the Person and Zuo Yue)

"There is a me inside of you; and There is a you inside of me—this is the Chinese way, this is what it means to be a Chinese mother" (Mother in Taipei).

This chapter presents Chinese constructs of the person as relational and will show how this relational construct of self and others under NICU circumstances manages the dilemmas of biotechnoliminality and personhood for both premature infants and those intimately connected with them. Specifically, personhood is enacted and experienced relationally through the common Chinese rites of passage known as "zuo yue zi" (doing the month(s)) or commonly referred to as zuo yue. Zuo yue is a post-partum rites of passage where new mothers undertake a series of avoidance rituals and are confined in the home for 30 days (and up to 100 days). This set of post-partum practices can be traced to the Qing Dynasty (Wu 1979) and is still enacted today in varying degrees by a majority of post-partum women in Taiwan, China, Hong Kong, and various other diasporic Chinese societies around the world.

Specifically, this chapter argues that the interaction between NICU conditions and zuo yue positively integrates the still emerging NICU premature infants into kinship structures while at the same time creating new relationships and concepts of selves and others for both premature infants and their kin. This assertion draws upon the notion of kinship as created through shared experiences of person making for premature infants and, in turn, for those related to them (Carsten 1995, 2004). Zuo yue under NICU conditions produces not only differential effects for premature infants, family members, and medical caretakers, but often shifts power relations within kinship structures outside of the NICU for parents and medical caretakers. As will become evident, the consequences of new and altered relationships often extend outside of the NICU in such a way that a relational personhood is becoming imbued with aspects of ontological concepts and categories of the person (See Chapter 8). This produces a sense of self and others that enables individuals to form strong and primary relationships with others outside of one's web of kin-based social relations, generating the emergence of concepts and experiences of persons that are more autonomous and possessing more "individual" rights (and responsibilities) and are at times even wholly separated from one's webs of kinship. These new ways of forging relationships can signal a possible cultural shift in Chinese concepts of the person and family (Yang 1994).

This chapter presents Chinese cosmologies of the person that most relates to the NICU. Parts I and II discuss the concept of family and guanxi (the art of social relations) and Zuo Yue Zi, respectively, and integrates how NICU scenarios dynamically interact with these aspects.

I: Chinese Cosmologies and Concepts of the Person

In Qing dynasty China (1644-1911), "Male and female, Confucian subjects always appeared as part of something else, defined not essence but by context, marked by interdependency and reciprocal obligation rather than by autonomy and contradiction" (Barlow, 1989:10). Persons were not shaped or defined by abstract categories, but were always caught up in paired and complementary relationships that used kinship as the imaginary referent for a series of discourses that completely obscured socio-economic associations of extra-kin nature (Barlow 1989:11).

Rather than creating discrete and unified ontological categories of persons each having the same equality of rights, the Chinese subscribe more to a relational construction of persons. That is to say, the autonomy and rights of persons and the sense of personal identity are based on differences in moral and social status, as well as on the moral claims and judgments of others. Chinese personhood and personal identity are not given in the abstract as something intrinsic to and fixed in human nature, but are constantly being created, altered, and dismantled in particular social relationships. Furthermore, the boundaries of personhood are permeable and can easily be enlarged to encompass a scope beyond that of the biological individual. As a result, Chinese culture presents a frequent lack of clear-cut boundaries between self and other (Yang 1994:192).

Anthropologist Fei Xiaotong made a similar point when he categorized modern Western social structure as an "organizational mode of association" (Tuanti geju) and the Chinese system as a "differential mode of association" (Chaxu geju) (Fei 1992). In the Chinese system, morality can only be defined through and by personal relationships. "In the pattern of Chinese organization, social relationships spread out gradually, from individual to individual, resulting in an accumulation of personal connections. The metaphor that Fei draws upon is one of the images of "ripples" formed from a stone thrown into the lake, each circle spreading out from the center, becoming more distant and at the same time more insignificant (Fei 1992:65). Therefore, the self is at the center of a dynamic process of relationships, reaching out to be in touch with other selves and to communicate through an ever-expanding network of human relatedness (Tu 1981:114). A newborn infant is always born *into* a family consisting of a set of social relationships that existed before its birth and will exist after its birth (Wolf 1978). The focus therefore is never on any particular individual, or the birth of any newborn, but on the nature of relations *between* individuals (King 1985: 63). Therefore, a Chinese social morality makes sense only in terms of these personal connections (Fei 1992:70).

In Western organizational modes of association, personal relationships depend on a common structure. People attach themselves to a preexisting structure and then, through that structure, form personal relationships. In the U.S, many types of groups are formed based upon common experiences or interests. These can be and often are the basis for forming strong personal relationships (e.g. preemie parent support groups, neonatal nurses groups, grief groups). Membership requires each individual undergoing the particular experience to initiate contact and to choose to join a group. Friends and family advise or share information but rarely directly mediate these relationships. One only needs to have a common experience with another to join a group or to become personal friends with another (e.g., new mother groups, alcoholics anonymous, reading groups).

Fei’s description of patterns of Chinese organization cannot be separated from the importance of family in Chinese cosmologies. Although social relationships form a network composed of each individual’s personal connections, each individual’s primary social relations, or his or her most “inner circle” is first and foremost the family. These are the primary relationships, and even very strong secondary social relations outside the family are often derived in some way from the family. The family is an entity that one cannot create. It is both form and flesh and someplace that others make a space for you. It is a home (jia), not a house (fan zi). Through the family and ancestor worship, the core of Chinese religion (A. Wolf 1974), people are part of an immortal vehicle. Their place in that vehicle assures their link with the past and the future, offering them personal and cultural meanings transcending death. Their tenure in the family places upon them privileges and obligations, the chief of which is to improve the family's fortune and status while not bringing shame upon it. Related to this obligation is another, requiring them to treat their own person and body as if they are inviolable as the family (A. Wolf 1974:133-134).

As Arthur Kleinman's work in Taiwan has substantiated, the family is frequently thought of in Taiwan as a circle whose perfect roundness symbolizes the ideal of harmonious integration of all individual members. He states, "Children learn that within that circle are the most significant meanings and transactions in their lives, and that how others come to regard and value them determines and is determined by how they regard their families. Achievement is not only for them, but also for the family. Shame falls on them and on their families together, while misfortune and sickness affect both" (Kleinman 1981:134).

The chief model for the individual's interactions in society is the father-son dyad (Wolf 1978). This relation is the template for many other kinds of relationships—teachers, supervisors, those older, and in general, those who are socially superior as well as those younger and socially inferior. For Kleinman, it is a cultural metaphor that holds significance for almost all other relationships, in addition to practitioner-patient relationships. Kleinman attributes this relationship to constraining the individual, among other things, from revealing his personal emotions openly. "Even more strikingly, it invests intimate relationships with more affective significance than one's own thoughts, fantasies, desires, and emotions. Family and other close interpersonal relations become a person's paramount interest; coping with them becomes a sign of adult competence, and problems with them are more important to him than other personal problems" (Kleinman 1981:136).

The worst problems are family problems. Emotions are expected to be appropriate to situations and family settings, and they should be managed in reaction to external events. Implicit in this relationship is the requirement that individuals continually and reflexively monitor how others feel and act. This information is then used to interpret and modulate one's behavior so that one may respond appropriately to others. Within the family, it is the younger person, with less status, who generally monitors his or her feelings and actions in order to modulate or respond to elders (i.e., mothers, mother-in-laws, father, father-in-laws, teachers, supervisors, doctors, etc.). Therefore, "filial piety" is more than just the honoring or caretaking of one's parents or parents-in-law, it is also the modulation of one's behaviors and feelings in their presence. When personally upset, one is to endure "disturbed feelings, and not to value them over those of parents and siblings" (Kleinman 1981).

Although Kleinman emphasizes the hierarchical nature of the father-son relationship, the family is also an extremely flexible institution that has adapted well to changing cultural, historical, and material circumstances (Wolf 1978a) (Wolf 1978) (Martin 2001). This flexibility is in part due to the relational aspect of Chinese personhood where practices and actual interactions-in-the-making dictate informal and ever-emerging rules of interactions, which often trump more formal and ideal rules of engagement. For example, as much as younger children are supposed to modulate their feelings in the presence of parents and older siblings, it is often the case with many families that the youngest or weakest child is the “bao bai” (the treasure or the one to be treasured). The youngest cannot help his or her birth order and is often intersubjectively experienced and perceived as inordinately burdened with having to always accommodate parents and older siblings. As a result, parents and older siblings dote upon the youngest. A relational personhood, one that emphasizes “a you inside of me and a me inside of you,” creates a deep intersubjectivity between individuals such that any institution or institutional rules of engagement, of which the family is one example, are ultimately experienced as flexible and always contingent. This is especially true for institutional rules and legal rules.

Individuals in Chinese society always assume that any rule, whether formal or informal, can be altered, as long as one interacts face-to-face with another and creates personal connections. The only “rules” that cannot be altered are the dynamically emerging rules created through interactions in-the-making, in the now. That is, the only rules of interactions that cannot be changed are rules that are forever in the becoming, in the moment-to-moment dynamics between individuals as they engage in an intersubjective dance of feeling and action. For this very reason, many people I interviewed would often comment, “People make me so tired.” However, nowhere is intersubjectivity and the subversion of rules more evident than in Taipei traffic, where no one stops at stop signs. Rather, one always cautiously and very slowly proceeds, relying upon and feeling the intention of other drivers, rather than just trusting the work of stop signs. When I asked a taxi driver why no one stops, he remarked, “People drive cars, people have to pay attention to other people and what they are doing in the cars; you can’t just follow signs on your own and drive as if you are the only one on the road”

(Taxi driver 2004). As will become evident in Chapters 6 and 7, this is a critical point of contrast to concepts of the person found in the American NICU. In the U.S., the work of interactions is to construct a concept of "individual persons" for premature infants. Personality traits and actions that signal the capacity to act independently of other people are projected upon premature infants.

Guanxi—the Art of Social Relations

Guanxixue or guanxie involves the exchange of gifts, favors, and banquets. It includes the cultivation of personal relationships and networks of mutual dependence, as well as the manufacturing of obligation and indebtedness. This informs the primacy and binding power of personal relationships and their importance in meeting the needs and desires of everyday life (Yang 1994:6). It is largely understood by Asian scholars as an underlying cultural assumption shared by Chinese people and Chinese diasporic societies around the world (Yang 1994) (Farquar 2002) (Tsing 1999) (Ong 1999) (Haskell 1999).

Anthropologist Mayfair Yang's work concerning guanxixue in socialist China in the 1980's and 1990's shows how this corpus of assumptions and practices about guanxixue has been woven into a "vociferous self-conscious discourse with both popular and official forms. It is a discourse that treats these personal gift-exchange practices as something new, a social phenomenon gaining strength in recent years."

There is a constellation of terms associated with guanxi. *Laoshi* is one such term. It means a "good moral person," a person who follows the responsibilities given to him and sincerely behaves according to his status and role. In the context of guanxixue, its meaning is subverted into "easily manipulated, naive, and a mindless tool of whatever power is above them." People who are good at guanxi are not morally bad, but just simply smarter than others. Guanxi relates to a sense of self consciousness—the concept to the individual that is a point of resistance to the concept of the person (Yang 1994).

Another term that is equally associated with guanxi is the notion of "renquing" or "feelings for other people"—in other words, humanity. Renquing is a discourse of human feelings. It has a venerable history; it is found in ancient Confucian discourse where it refers to the natural human feelings and emotions found in father-son relationships, family and kin relationships, and friendships. "These feelings and sentiments were to be the source from which issued "ritual" (li), the proper conduct of social relationships, and social events and affairs that made possible and preserved the whole social order. Embodied in the giving of gifts is the giving of renquing" (Yang 1994). With each favor or gift transfer, one is also transferring one's deepest and most sincere feelings—these feelings are viewed as actually embodied by the gift, the favor, or the act of connecting people together in the formation of new relationships.

Ideological, jural, and behavioral distinctions exist for the concept of the person found in the concept of guanxi. Behaviorally, a person engages in guanxi when they either give or receive a gift, or give or receive a "banquet," (a nice meal) or give or receive a favor or favorable connections to another. Unless it is in context, it is impossible to tell who is the granter of guanxi and who is the grantee. It is also difficult to tell which action is associated with which intention. That is, a giver of a gift could be reciprocating a previous gift in hopes of garnering a favor, rather than initiating a relationship. Over time, it is likely that the first initiator of guanxi becomes obscured and a relationship of mutual interdependence becomes established. Ideologically, persons engaging in guanxi can be thought of as either “fake, self-centered, selfish, and/or a liar.” On the other hand, depending on whom you talk to and in what context, guanxi can also take on the concept of renquing (human affect) or humanity. Because guanxi is a relational concept, the person who is seen as selfish is often described as so in the context that he is manipulating another’s renquing with a gift. Here, the concept of the selfish person and the person filled with humanity co-define each other. Jurally, gift giving has to be escalated to maintain guanxi. To stop guanxi, someone has to commit an offense, usually the reciprocity of the “same gift” or “a small gift.” In addition, if someone owes you guanxi, you are not required to ask for reciprocity. Rather, you can “store” up favors and accumulate power in a relationship (Giddens 1991).

Guanxi implies that one of the fundamental aspects of a relational personhood is the capability to engage and interact with others. However, at the same time, every person is connected to another through family and kinship ties and through guanxi or webs of social relations. In this sense, Chinese concepts of the person and experiences of self and others are fundamentally social, yet this does not necessarily imply that interactions must be dyadic—that is, the interaction taking place is *not* necessarily about the two people who are present. Rather, two people can interact about a third person and that third person is experienced as equally present as the two who are physically present. One is just as much present in spirit as one is in flesh. After all, a Chinese person (both as a person and an individual) can only be known in context. Thus, whether one’s physical presence is present or absent does not matter, as long as one exists in context. Guanxi and relational personhood can draw in many different people and ever widening numbers of people, giving them social viability without their actual presence. In the

NICU, this means mothers can bond with their infants without actually being present. They can bond through stories about their babies as others convey them, just as much as they can bond by physically touching them or visiting them.

In Taiwan, as in other Chinese societies, it is not shared experiences that bring people together but the sharing of social relationships in context that bring people together. As Mei Hui, a Taiwanese mom told me, "I was so lucky that my uncle's good friend's niece also had a premature baby; he would ask his friend to ask her niece (Tina) for some advice. My uncle would come to visit my parents, my husband, and me, and tell me things his friend's niece had experienced and learned along the way—her feelings, her family's feelings, what they have had to do for the baby, which doctors to see for premature babies, which hospitals are the best, which home nurses we should ask for—just so many things." "Only after a year did we happen to meet at my uncle's party, we of course had heard so much about each, we 'had' to be friends and we were immediately very good friends…. We share so much in common. Luckily, I like her very much," Mei Hui laughs.

For Mei Hui, the guanxi relationships were so strong by the time she actually met Tina that they were already "bonded" and "had" to be friends. The implication is that even if Mei Hui did not like Tina (or vice versa), they would have accepted each other and incorporated each other into their own webs of personal social relations out of a sense of duty. Once incorporated, Mei Hui would need to reciprocate to Tina in the future and Tina would have to continue to provide advice and support, as long as Mei Hui desired it. Although non-kin, they were connected through kinship guanxi relations. They could not choose otherwise, as their webs of personal social relations had pre-connected them. They were in many ways “fated” through others to be in each other’s lives.

In contrast to how Mei Hui and Tina came to support each other is an alternative model of support that the Premature Baby Foundation of Taiwan is attempting to implement. Established in 1992, its goals and purpose are to set up and implement an institutional system for the hospital and post-discharge care of premature infants. They call their goals “actions.” What is particularly interesting about this organization is that providing parent support groups is merely one of many actions that the foundation undertakes. When I spoke to Julie Hu, who is the liaison for the foundation, she told me that they have been very successful with all of their actions except the parent support group. However, they are actively trying to promote it by finding ways to connect parents of preemies with one another.

Julie states, “I hope that one day, parents will not be so timid and just come and join. Some parents come but they still think it is sort of unnatural. They don’t trust it—this get to know other people just because you both had premature babies. In the United States, you don’t have this problem, right?, people just join groups.” “I think it is because people are afraid of obligations to another person they do not have a personal connection with. Chinese-Taiwanese people usually meet people through our families or childhood friends. But, it is not always the case that people will have someone in their circle of relationships who has a premature baby. We tell them, there is no obligation when you join, we don’t want anything from you. People never really quite believe us, especially those parents who are less urban.” “So, we now have turned the parent support groups more into information meetings, where we give them information, and we have other doctors and nurses there. This way, they feel they are getting, instead of having to give." "We want to support parents emotionally and socially, but some of them get enough support from their families already and don't need that kind of support. But, we are seeing more and more mothers joining; I think they are changing their minds. Plus, I think other parts of our program are doing well, especially the in-home nursing visits and the coordination of follow-up visits in hospitals. Parents and grandparents are very dedicated to these kids…so our nurses will suggest for them to come."

What Julie and the premature baby foundation are attempting to do is to create interactions and personal relationships between individuals through "shared" experiences that are neither kin-based nor guanxi based. Although the Premature Baby Foundation has not found its footing with parents of preemies, an emphasis on shared unique experiences implies the notion of personhood as something more than relational—that is, as concepts of selves and others that are more ontological, where different individuals are "equal" in their experiences and their shared experiences can stand alone and be defined outside of the kinship and guanxi relations. What Julie and the Premature Baby Foundation ask parents to do by joining is to act on behalf of their own experiences, without obligations to each other.

In fact, many mothers who were initially hesitant to join these groups did report in a recent study that "they felt supported by other parents" and "they helped them experience a sense of unity; they listened to one another and shared the same struggles, fears, and anxieties; and they felt that other parents could not "fully" understand what they were going through" (Lee 2009).

Those sentiments were also familiar to Mimi, a research assistant to several NICU attendings, who gave birth to a premature baby girl. For Mimi, joining a premature parent group not only helped her relate, but it gave her a new concept of herself. It was not necessarily something that she sought out, but it "just happened." She stated, "I would never have really relied on people outside of my family or close relations, but this is a very different situation…I know the research, I know the doctors and nurses, I have done many studies about premature babies…but, this is different…unless you have watched your own child in the NICU, you cannot understand…. Juju (her NICU graduate) has changed everything for me…even though she was premature, she has changed our family, she has given me more power, I am not so agreeable with my mother-in-law now. She was always a good mother-in-law, I don't have any complaints, it's not about her, it's about me. I have changed. I don't think about other people as much anymore. I am more independent in how I feel, and how I act, I'm not so concerned with other's people's feelings and actions" (Ren, fieldnotes 2003).

Although a relational personhood will undoubtedly continue to dominate in Taiwan, these more "non"-relational, more individuated concepts of selves and others do exist and are emerging in Taiwan. As will be evident in Chapter 8, these concepts of the person are more than just relational, they are also individual and ontological, with a sense of equal rights to access, feel, and act upon one's emotions. This shift will influence the choices and lifestyles of medical caretakers that extend beyond the NICU and the hospital walls.

Making Persons in the NICU
(Case Studies)

These examples better elucidate how relational concepts and experiences of the person are played out under NICU circumstances.

A Hole in My Heart

Baby Girl Lee was born at 27 weeks, weighing a little more than 1000 grams. Her diagnosis: Patent Ductus Ateriosus (PDA). The ductus arteriosus allows blood to bypass the baby's lungs by connecting the pulmonary arteries (which supply blood to the lungs) with the aorta (which supplies blood to the body). Soon after the infant is born and the lungs fill with air, this blood vessel is no longer needed. It will usually close within a couple of days. If the ductus arteriosus does not close, there will be abnormal blood circulation between the heart and lungs. The PDA is specific to the in utero fetal-maternal system.

Referred to by many parents as “a hole in the heart,” some premature infants will need surgery to close this blood vessel. Some just need a little more time with the aid of medicines. For Baby Girl Lee, the treatment plan was to take a wait-and-see approach, with most doctors and nurses prognosticating that the blood vessel would close on its own. During this time, she was on a ventilator.

Walking into the NICU, I pass by Shu Jen. She tells me, “Ping is in a bad mood. She is upset. Her baby, the one with PDA, pulled out her breathing tube today.”

“Isn’t that good?” I say.

She replies, “Yes, I don’t think it’s bad for the baby, but I don’t know if it’s good. Anyway, it happened to me sometime ago, and I felt bad. I know how she feels. She is a really good nurse, but when a NICU baby pulls out her own tube, it makes other people think you did not pay attention. But, even more, you feel so bad for the people and you feel it's your fault. They must have been struggling so much, they must have been not comfortable at all…to pull out their own tube."

I walk into the NICU and over to Ping. I tell her that I heard.

She says, "We nurses like to try several times, in small steps, to see if a baby can extubate. It always makes us feel so bad when a baby self-extubates—she is so little, she must be so uncomfortable if she has to work so hard to pull her tube out, we must not have been paying enough attention."

I tell her that in the U.S. the doctors and nurses like to see this. Nurses will often get excited when a baby has "self extubated"—literally pulled out his breathing tube. The staff of the NICU likes to see this. They say the baby knows when he's ready, that if he has the strength to free himself from the noxious tube down his throat, then he's probably strong enough to get by without it (Humes 2004:79)(Ren, fieldnotes 1998).

Ping only seems to half believe me. She says, "Really? I guess that's another way to think about it. But, it's just that when I tell her parents, I know their heart will hurt for their baby (xing ton). No one can think it's comfortable to have a tube down your throat. I should have tried to take it out again. My heart aches a little too. I'm usually really good at anticipating what people want, what babies want."

For Ping and Shu Jen and most of the nurses in the NICU, what constitutes good medical care is not only being able to take care of one's patients, but also to anticipate their needs. Premature infants are thought of generally as small, weak, and needing more help. Self-extubation not only potentially signifies that one was not "paying attention," but it undermines the relationship between the medical caretaker and her premature infant. It is a signal to Ping that she is not "reading" her patient in the right way. More so, it undermines her sense of self as someone who easily can anticipate another's need. When her patient self-extubated, although it signaled a maturational success, Ping experienced it as a social failure.

Clever Girl: A social-relational concept of success and failure in the NICU

Lao Wu was struck by polio as a child. He walks with a limp and his back is crooked. He also suffers from scoliosis. He tells me that he helps make websites for people who are in the import and export business. "I am so lucky that I am born in a time where the Internet exists. Otherwise, I would be poor and I would not have a decent/good job. I'm not very wealthy, but I am comfortable. People don't like to be around handicapped people in Taiwan, I think it is just too awkward for everyone. Everyone is concerned by the feelings of everyone else. I live outside of Taipei and come from a big family, so I'm never lonely. They have to accept me however I am," he chuckles. "So…being a web designer is perfect and I like the work."

"The only thing that my family really wanted me to have is a wife, but it's hard to find a wife for me. I don't feel handicapped, but I am. And usually handicapped people have to marry each other. I didn't want that and my family does not want that either. They say, 'Lao Wu, you are so smart with the Internet and make good salary, why do you have to take a handicap wife just because your legs don't work?' I wanted my chance to meet someone that would not care about my handicap…to see that I have other things to offer them. My money is as good as the money from someone with a good back and good legs. Plus, I'm a good person. Marriage is always tricky… You always do a calculation—What's my asset? What's her asset? Can our assets combine?"

"So, I sign up for a dating service that introduces me to girls from other countries. It is not seedy like people think. Sometimes it is, but I paid top dollar for a legitimate service. I meet my wife online. I looked at pictures and I just liked her smile. I remembered her. So, when the service had a "first meet" event, I looked for her. She is from Thailand. Her family is poor. All of the girls are poor. I know they are looking for money to support themselves and their family, but that does not make them shallow. Just because you need money, doesn't mean you can't love the person that helps. I am giving her exactly what she needs because I liked her from the beginning. I wanted to help. Marriage is too hard for it to be only money-based. You still have to live with the person and sleep with the person. So, this is how I met Suzie."

There is a growing trend in Asian countries for men who cannot find wives to turn to companies that introduce them to "foreign brides" (Wai Hai Xin Niang). These women are usually from a poor southeastern Asian village and gain citizenship (and by extension employment) through an arranged marriage. It is widely understood by men who participate in these interactions that they are obligated to send money back to their wife's family. Marriages are often conducted en masse and they are widely covered by television. These marriages have come under public scrutiny in recent years during the time of this fieldwork (China Post 2005).

Although I never met Suzie nor have I spoken to her, I ask Lao Wu about his wife. "How is your wife doing, is she doing Zuo yue?"

He recounted, "Yes, yes of course. She is doing really well and working really hard to rest and zuo yue. She really wants to come and see the baby, but my mother and sister insist that she zuo yue. They tell her that it will make her strong so she can have another baby and be ready when our baobao comes home. So, I come to NICU. I come every other day and get an update from the nurse. I can see she is growing every day. We are going to take her home soon. With my wife doing zuo yue and the baby not at home yet, it's a little like she is still pregnant, but I can see her and experience her in way that I couldn't if

"I married and got a foreign bride because I do not have much to offer a good girl from a Taiwanese family. I am a handicapped person. I had polio as a child. It is difficult to be a handicapped person growing up in this society. We are seen as having bad luck. But, I think I also have good luck. I make a steady income doing export and import. But, I want a family too. People date online all the time. It is the modern times, why not use the Internet to date. I go online, it is a dating service—they just get girls from other countries. In Taiwan, I would have not have a chance with so many women. This is not a big deal in other countries. I like my wife. We did not get to know each other the traditional way, but we become friends first and then I liked her (Wo shi huan ta le)…then we had a baby."

"Like" or (Xi huan) is a concept that is relationally based. *Xi* is luck, huan is "to welcome." Together these two terms mean, "to actively work to welcome in luck." *Xi huan* is used for serious relationships between husband and wife and between parents and children. It is a deep "relational love" whereby one has to consistently work to "like" another through relating and interaction. It is roughly equivalent to the Western concept of "love." However, the word love (ai) in Mandarin is a fleeting and intense emotion. It is not something that must be worked on to maintain. It is instinctual rather than relational. It carries connotations of “a crush” or “an infatuation.” Love in Mandarin does not require work; it “just comes upon you, like a cold.”

For Lao Wu, meeting Suzie and having a connection with her was fate. It was meant to be.

Their child, a baby girl, was born at 28 weeks, weighing over 1500 grams. Like many NICU patients, her course of treatment has been a “routine” rollercoaster ride, some ups and some downs, but she will be discharged in the next week or two.

During a typical check-in afternoon, I’m told that Lao Wu and Suzie’s bao bao (or baby) is going home. It was a happy occasion. The nurses have grown fond of the bao bao. They can’t seem to remember her name nor does it really seem to matter. She is simply known as that “clever girl.”

When I inquire why she was called a clever girl, Amy her nurse walks over to the isolette and points, “Look, doesn’t she just look clever (jing)? Yes, I think she looks quite smart (Xong ming).” I continued, “But, I think many of these babies are smart.”

Amy said, “Maybe… but this one is clever (jing)—I don’t know about smart, maybe she is smart too. Her mother is very *jing*. This little clever girl is going to give her mother citizenship. She doesn’t really even need Lao Wu anymore, if she doesn’t want to stay with him. Because her baby is premature, you know, she will get a lot of help from the premature baby foundation. They can probably even help her find a job, if she wanted one. It’s like she has special services now. And, it’s all free. How lucky is that. She comes from a poor village in Thailand, and she is now here in Taipei with first-rate services and care. Plus, Lao Wu is a very good upstanding man, too bad he is just handicapped. Suzie has good luck, she comes from nothing, but she was able to find herself a good husband, and now they have this “one” who will bind them. She [the baby] will do good; she might have some gross motor issues, some scars from NICU treatment, some set backs, but overall, she will be fine. She will not burden her parents too much. She might actually give them some opportunities, they will have to come to Taipei for check-ups, and they will be able to meet some other parents and get some special services. It will make them more cosmopolitan. Right now, they live outside of Taipei.”

Amy then says, “Watch this, she always knows when it’s time to eat. See, you think she is asleep.” Amy puts some breastmilk in a bottle and Clever Girl opens her eyes. “Watch this.” Amy then takes away the breastmilk and dabbles a little bit of sugar solution on the baby’s lips. She likes this sugar solution thing more than the milk. When Amy switches back to the breastmilk, Clever Girl doesn’t want it anymore. Amy laughs. “See, clever. I told you.” Amy then gives Clever Girl a little bit more of the clear sugar solution before coaxing her back to breastmilk.

The infant’s identity and personhood are placed in the context of who her parents are. This then informs how medical caretakers come to know and assess what constitutes a NICU success story. It is in the context of who the parents are that determines “success” or “failure,” not outcomes based on developmental and neurological assessments alone.

Several days later, I run into Lao Wu just before Clever Girl is moved to the intermediate nursery where her mother will be visiting her. He reflects on his NICU experience:

"Suzie is very excited, but she is so worried that baobao will have some handicaps. "I don't care that the baby may have some problems, we all have some problems. She is doing good. My wife is resting at home. I come and visit and they tell me, maybe she will have some scars from NICU procedures. I do not care. I have a family now. The nurses are nice. They take good care of her. I can tell. They do not seem that concerned for her. They know that I know how to manage handicaps. And, I know I can manage handicaps that might come up. This is my family now, I actually have a family now; I can take care of her. She is like her mother, very strong, and she has a nice face. She has also made my wife and me stronger together."

Cue-Based Care

Because persons are known and experienced in the context of others, largely without an ontological and independent notion of self, several studies in Taiwan have bemoaned Taiwan's NICU nurses' lack of implementation of "cue-based care." Cue-based care is largely what is done in the United States and many Western countries with NICUs—it teaches nurses to look for individual "signs" or "cues" of physiological response from premature infants. For example, when a patient's heart rate goes up during a procedure, one would notice this and then immediately swaddle the infant afterwards to provide comfort. This also leads to a level of attentiveness towards premature patients that enables nurses to better organize a patient's day. Many studies have shown that cue-based care leads to better outcomes as it provides attentive and more precise medical care for premature infants. Another example is feeding "on demand" rather than feeding according to a schedule. This orientation toward premature and infant care draws upon concepts of the person as an “individual,” one that is capable of determining his or her own needs.

Initial studies in Taiwan have found that nurses do not generally perform cue-based care. In a study that used qualitative research methods to grasp the richness and diversity of nurses’ beliefs and experiences in taking care of premature infants, the authors found the following:

“The results generated three themes: (1) timely and skillful management of the preterm infants; (2) compassionate and holistic care for the infants and their highly stressed families; and (3) the relationship between good nursing care and meeting the needs of preterm infants, families, physicians, units, and the environment” (Liaw, Chen, Yin 2004). They reason, “It is apparent that the approach to care delivery in NICU practice is still clinical-based, and that there are some obstacles to the delivery of cue-based care. The reasons for this include lack of knowledge, incomplete collaboration with team members, and insufficient support from the administrative systems” (Liaw, Chen, Yin 2004).

Although their conclusions are valid and indeed nurses often feel “a lack of knowledge, incomplete collaboration, and insufficient support,” it is not clear that improving those aspects will generate cue-based care here. After all, American nurses in American NICUs also have similar complaints, as do residents.

Observations and interviews with nurses do not point to a lack of attentiveness towards their premature patients. Rather, they were already employing this type of care, yet they didn’t recognize it as such. For the nurses in Taiwan, this type of care was not done “for the babies” but in preparation for a mom’s visit when she finished her zuo yue.

For example as one nurse states, “You pay attention to the NICU babies, and you prepare and work very hard all month so you can know the baby and find right time for the mom to visit—because you do not want to present her with a baby that looks beat up. So we try to have the baby off the ventilator before she is done with her zuo yue. To do this, you have to watch the baby very carefully…make sure you do not stress the system and just let them grow.”

In addition, during my conversations with nurses, they often revealed that they see part of their job as maintaining good relationships between various groups of people. They emphasize following a schedule for the babies, rather than always employing “on demand, cue-based” care, not because they did not want to but because they had other people to consider—the specialist who is coming in and taking his lunch hour to consult, making sure that their work is done so that the fellow resident does not get trouble, or just making sure that their patients follow certain schedules when necessary because they do not want their patients to be seen as “difficult.”

In a society where concepts of the person are relational, it is perhaps more important that the premature infant is part of a larger web of relationships. It is part of how personhood is constructed for them. The self-extubation example showed the “attentiveness” of nurses to the individual needs of patients. In fact, all NICU nurses in the Taiwan NICU were extremely attentive to the individual needs of preemies. But, ultimately, they live in a social world where personhood is social. Where one must anticipate the needs of others and be considerate of others’ actions. My observations showed that nurses do deviate and follow cue-based care for a large part of their care. They simply just do not distinguish “cue-based” from “clinical-based.” For them, attentiveness is not something that has to be taught. It is simply practiced. Perhaps, it's not so much a lack of attentiveness or that their nurses believe more in clinically based care that makes cue-based care seem non-existent in Taiwan's NICU. Rather, it is because they believe in thoughtful relational care that premature infants cannot always be treated as completely "individualized."

In the U.S. cue-based care is contextualized in a discourse of a premature infant's "likes and dislikes" (See Chapter 6 and 7), implying a concept of self that is individually experienced. That is, positive and negative physiological responses of the premature body towards various treatment protocols and procedures are assigned cultural significance as "individual and idiosyncratic likes and dislikes." No doubt there are genetically based individual variations as to how each body physiologically responds to treatment, but in the U.S. NICU, these genetic variations are ascribed social significance and "individualized" experience.

The reading of positive and negative physiological responses to treatments in Taiwan is not socially ascribed in the same way. Rather, good, attentive, and detailed nursing is provided for all premature infants, and differences in how a body physiologically responds to treatment is understood as purely differences based in biology. Therefore, the presentation of a "cue-based" protocol as "understanding each baby's needs as an individual," imbued with the discourse of likes and dislikes" does not motivate Chinese nurses to be more attentive than they already are. However, as consistent with relational concepts of selves and others, Chinese nurses view the premature infant in relation and in the context of the mother and its family and kin relations. Thus, for the sake of mediating the future first-time meeting between a mom and her baby, whereby one wants to present the most healthy and “healthy looking” baby possible for the mother, the nurses are extremely attentive to the positive and negative physiological responses of their premature patients. One only has to observe the meditative and concentrated caretaking actions of the Chinese nurses to see that attentiveness if not at issue.

II. Zuo Yue (Doing the month)

For one month following a birth, the new mother must follow “zuo yue” prescriptions and proscriptions. She must remain in bed, keep warm at all times, avoid any cold air or wind, not bathe or wash her hair, not brush her teeth. She is to do little or no physical activity and maintain a strict diet. The diet consists of foods to strengthen the body by restoring good blood. The new mother can eat chicken, soups, eggs, pickled foods, foods cooked with spice, and drink wine.

In addition, the avoidance of all physical activity extends to taking care of the newborn baby. The mother-in-law or other female designee will tend to the newborn so the mother can rest and restore her weakened body. Family members, and especially the mother –in-law or one’s own mother, will take full responsibility for the care of the newborn for one month, while the new mother rests.

Historically, these rules were likely established to help preserve the health of the mother, create a social barrier for a fragile newborn that may or may not survive, and strengthen the interdependence of the family unit.

The enactment of zuo yue brings together three aspects of Chinese cultural norms and practices. First, it draws upon Traditional Chinese Medicine and its ideas for restoring the health and wellness of post-partum women and, in turn, promulgating the health of their newborns and future children. Second, zuo yue underscores the shifting relations of power between various members of a family and those responsibilities toward the family (Ahern 1978)(Gates and Ahern 1981) (Ahern 1981). Third, it draws upon folk notions concerning the role of women and concepts of fetuses and newborns (Moskowitz 2001). By first setting these aspects of zuo yue under *non*-NICU conditions, it will provide a point of reference for how zuo yue interacts with NICU conditions.

Traditional Chinese Medicine: The premise of zuo yue avoidance rituals is based on the belief that the post-partum woman is weak due to an imbalance between Yin and Yang that was created during pregnancy and childbirth. "Deficient energy and blood, as well as blood stasis are typical among new mothers. Avoidance rituals are an effective means to block 'invasions of pathogenic energy.' This is the main reason for avoiding wind, cold food, and any contact with cold/cool water. This is all the more true if a woman miscarries or gives birth unsuccessfully" (Shanghai First Maternity Hospital 2010). However, because of modern electricity and hot running water, institutions of Traditional Chinese Medicine no longer prescribe to an avoidance from bathing, teeth brushing, and hair washing. In a healthy person, the Yang, (positive, active energy) and the Yin (negative, inactive energy) are balanced—they flow freely. It is thought that due to the loss of blood during childbirth, a great deal of Yang is lost, and therefore Yin remains. A body with more Yin is experienced as fatigue. In addition, a set of "zuo yue" foods and herbs are also prescribed to further restore Yang energy.

Traditional Chinese Medicine understands zuo yue as a time when the elements of the body must be mediated and placed in good relation once again. The intent of achieving a balanced body during zuo yue is to insure that the post-partum woman has a balanced constitution so that she can provide the most balanced and healthy breast-milk (Yang, personal communication) to insure the health of her child. In addition, a healthy body is thought to insure a good pregnancy and a healthy "next baby." Health is not a stagnant concept in Chinese medicine. Rather, even a woman who has had good health and a healthy baby is required to undergo zuo yue because the childbirth itself changes the relationship of energies within her body and they must be corrected. Each childbirth requires work to "regain" health. At the same time, a miscarriage or a loss or even a premature birth can be explained by the bad previous "zuo yue" or a previous body imbalance. For post-partum women and new mothers who have experienced a bad birth outcome, zuo yue is a means of empowerment as they can rebuild their bodies towards another chance at a successful birth.

Shifting Relations of Power: Traditionally, it was the mother-in-law who took responsibilities for enforcing zuo yue avoidance rituals and caring for her daughter-in-law and a newborn grandchild. This was logical considering the basic function of the Chinese family was to provide training for future adult members (M. Wolf 1987). As Marjorie Wolf's work on child training and the Chinese family found: "No matter how antagonistic the young wife may feel toward her mother-in-law or how confident in her own abilities, at the birth of her first child she finds herself in need of the older woman as she will at no other time (M. Wolf 1987:232). Chinese families, and in particular, mothers-in-law recognize the practicalities of needing to care for a newborn infant. However, interviews conducted with mothers-in-law also found that they used this time as a way to re-connect or establish new patterns of social relations with their daughters-in-law. They were very aware that this is an important time when how a mother-in-law related to her daughter-in-law can change and alter the future course of relations between them and the dynamics of the family. This can be done either positively or negatively. Below is an example of a positive interaction.

Li Popo told me, “I try my best to just support my daughter-in-law Mimi, I mother her as if I am her mother and I mother my grandchild at the same time. I think this helps her see how much we share together and how much we have in common. However, it is also hard, because I don’t want her to think I am too “lo suo” (or intrusive). I don’t want her to resent me and think I am taking over…. So I have to be very careful, and not over-help sometimes.”

When I spoke with Mimi, she confirmed Li Popo’s intentions, but also reiterated how much she needed help. “I really needed to zuo yue, I couldn’t do anything, my mother-in-law would bring the baby in for me to breastfeed and then she would let me sleep. I think it helps for a new mom to get to know her baby gradually. Otherwise, if she is too tired, she may get angry and scare her baby or cause the baby distress. This is not good for the baby. The baby needs to grow. I’m lucky to have a good mother-in-law. I think the mother and the baby can have a better relationship if the mother does not have to be with the baby 24 hours a day.”

In contrast, tensions between mothers-in-law and daughters-in-law, as well as between mothers and daughters, can also grow during zuo yue. Although this was not the case for any of the NICU families I interviewed who seemed to pull together more (not less) during a crisis, this was certainly not always the case under normal birth conditions. Often, tensions centered on disagreements between a mother-in-law and her daughter-in-law’s disparate views of what constituted appropriate and adequate zuo yue practices. My friend Betty said, “My mother-in-law is so old fashioned, she is driving me crazy. She watches me like a hawk: ‘Don’t walk so fast,’ ‘Don’t eat that cold ice cream, your body needs more soup,’ ‘Do you think it’s a good idea to go outside, you should rest.’ I tell her that I just had a baby and I feel great. I’m a very active person and this feels like home confinement. I want to go outside with my baby, take walks in the stroller, meet friends. But, she is worried about my next baby. It’s not that I don’t want to zuo yue, but I don’t think you have to do it exactly so old-fashioned. I think it is true mothers need to rest, but I think every mother is different. I’m not saying I want to do everything or that I don’t like the help, but just that my idea of rest is not sitting at home. My body is resting, but my brain is going crazy.

“I can take all the stuff about me, but it really annoys me when she tells me what is good for the baby and what is not. I tell her that people in America are up and around after having a baby. They do not sit at home. Isn’t that right? People even exercise. Plus, I tell them the baby is fine. He is almost a month. He should be able to go outside and have some fresh air. I always sneak out with the baby when she is doing errands. People in Taipei like to do stuff, walk around, see stuff. I’m not sick, I just had a baby. People do things after having a baby all the time. I see movie stars from America who carry their babies in those pouches walking around or even jogging.”

Chuckling, Betty ends our conversation by telling me, “I got a kangaroo pouch from Japan (i.e., baby sling) and wa wa (baby) and I sneak out for ice cream and a waffle. Thank heavens, thank earth, next week my month will be over—I’m close to crazy.”

As evidenced, the relationship between a new baby and its mother is mediated by a third person. As the mother-in-law mothers her daughter-in-law and her new grandchild simultaneously, she is not only practically helping with childcare but also mediating a growing and lasting bond between mother and child. Implicit in the concept of zuo yue is that too much contact with anyone or anything can be draining, including one's child. Thus, what is required for a strong bond between a mother and her infant is not necessarily a long length of physical contact or presence, but the constant relational presence between them held by a third person. Here, the mother-infant relationship is not merely dyadic, but triadic and often times even multi -"adic" as mothers-in-law will informally bring in other relatives (including her daughter-in-law's mother) to help her take care of her daughter and grandchild.

Folk Beliefs Surrounding Fetuses and Newborns:

In the room where the pregnant woman is located, "the spirit of the embryo" is roaming around. This is what a Tang Ki (Shaman) told me when I visited a temple in Taipei. To avoid damaging this spiritual copy of the child, a pregnant women is warned to be especially careful in her actions so she does not subject her unborn child to various kinds of harms—ill health, malformations, etc. Specifically forbidden for pregnant women are dangerous objects such as needles, nails, knives, and fire (Ahern 1978) (Moskowitz 2001). Women may wear a preventive talisman in the form of a red thread attached by a safety pin at the level of a navel. This was thought to prevent bad luck for the growing embryo (Moskowitz 2001).

Similarly, the rituals surrounding delivery are meant to push away the bad spirits and ghosts, the bad effects that could dirty the soul of the newborn baby. It is common for women in labor to light a red candle to exorcize the wandering souls that potentially fight for the body of the newborn child so that it might be reincarnated there (Kartchner and Callister 2003) (Hsu, Tseng, and Kuo 2002).

These superstitions persist into the zuo yue period, when a newborn infant is still fragile. Fetuses and infants are thought to have souls. Unlike adult souls, fetal and newborn infant souls are thought of as particularly susceptible to fright syndrome, during which a soul can flee if its body is startled (Ahern 1978) (Harrel 1986) (Topley 1978). As such, people who are bad tempered or angry are kept away. This is congruent with Mimi’s statement about not wanting to be a tired or angry mother for fear of scaring her newborn.

What these folk beliefs have in common is recognition of the dynamic and changing relationships between a pregnant woman, her body, and her fetus. None is ever conceptualized or known apart from another. Even from the very beginning, emerging fetuses and newborns infants are known only in context and in relation to others around them Abortion challenges this scheme, and thus there are fetus-ghost appeasement rituals to provide for and reconnect the aborted fetus to its mother (Moskowitz 2001).

As evident from the above discussion, zuo yue is a rites of passage that mediates. Zuo is the character for “sit” and that same character can also mean “to make” or “to do.” Zuo without any modifiers means “to sit,” but placed in front of a noun or adjective as a signifier, such as “work,” it becomes “to do work” (zuo shi). Particularly on topic, when zuo is placed in front of the word “person” to form “zuo ren” or “to make persons,” the meaning of zuo is further illuminated. Zuo Ren means to be a good moral person. Thus, ‘to-make’-a-person (or zuo ren) requires an individual to conduct herself and act towards others in ways that are socially and morally appropriate.

To sit or “zuo” is literally and figuratively grounding. When one is invited into another’s home, the guest is immediately implored to “zuo zuo” (sit sit). The guest is asked to rest and to ground herself. This centers both parties for the emerging interactions. Implicitly, zuo recognizes that a guest has traveled to the host and that the guest has been in motion and “in flux” getting to her destination. Thus, for the guest to be present in-the-present, she must sit/ground herself and “let go” of how she got here. Zuo therefore looks to the future, while taking stock of “the now.”

Yue (the second character of Zuo Yue) is the character for “moon” or “month” or “time.” However, despite the easy reference to the waxing and waning of the moon and its implications for repetitive cycles of change, the Chinese idea of the cycle has little to do with “the regeneration of time by the ritual repetition of paradigm” (Ricoeur 1985). Rather, the Chinese model of temporality is entirely based on natural periodicity, and as M. Granet has argued, the prototypical Chinese representation of “yue” was shaped out of the periodization established by dynasties and reigns. With each new reign or dynasty, a new calendar was promulgated, which was intended to create relational experiences between the new dynasty and its people (Granet 1934 in DeBernardi 2004).

It is in this context that Zuo Yue or “sitting/doing the month” must be understood as a transformative time that recognizes the in-flux consequences of pregnancy both on the mother’s and the newborn infant’s body, as well as on social relations and concepts of selves and others for various members of a family or kin group. As Granet’s analysis implies from above, Zuo Yue is particularly attuned to the abolition of the old world order and the creation of a new one. Thus, zuo yue is particularly attuned to a “new order”—whether it is the dietary and ritual avoidance work required towards bringing about a new state of health for the post-partum woman and her pregnancies in the future or the new relationships and power structures that emerge as a result of a new birth. Zuo yue is a transformative time when the possibilities of a new order are either ripe for integration or capable of supplanting old orders. Thus, under the new conditions, zuo yue enables fresh concepts of selves and others to emerge by letting go of the past, anticipating the future, and mediating emerging relations in the now. However, this time continues to require that one act with moral and social appropriateness toward others, even in the altered world order. In essence, a new world order requires new moral and social sentiments and codes of behavior.

Implications of Zuo Yue Under NICU Conditions: The emergence of the "individual" in the relational

In Western medical literature addressing premature experiences in Taiwan, zuo yue is often thought of as a cultural "obstacle" (S. Lee 2009) (Hung and Chung 2001) (Shih 1996) that needs to be overcome. Although this set of literature recognizes that Taiwanese mothers reported less stress both during and after NICU discharge, and that they did not have any issues bonding with their premature infants, the literature is nevertheless concerned with the impacts to both mothers and preemies when mothers do not sufficiently come into the NICU to take part in skin-to-skin contact with their preemies (Chang 2009) (Yin et al 2000) (Hsieh et al 2000). The routine of holding one's half naked preemie next to one's naked skin is known as *kangaroo care*, so named for the similarity to how kangaroos carry their young—enveloped, enclosed, protected, and dyadic. Kangaroo care was developed specifically for premature infants in areas of the world where incubators were unavailable or unreliable. To promote social bonding and affection between mothers and premature infants, kangaroo care was eventually brought into the most advanced NICUs. Although widely promoted as beneficial for the mother and the preemie alike, there are important caveats to this general perception (Luddington-Hoe et al 2006) (Bergman et al 2010). Premature infants have to reach a certain level of physiological maturity and stability before kangaroo care can be initiated. Although recent work has shown that kangaroo care can be used on ventilated and extremely premature infants, the leaders in kangaroo care were careful to state the following in their abstract:

The patients "were considered stable on the ventilator at low settings (intermittent mandatory ventilation < 35 breaths per minute and $FiO_2 < 50\%$), had stable vital signs, and were not on vasopressors. A protocol for implementation of KC with ventilated infants that uses a standing transfer, with two staff members assisting to minimize the possibility of extubation, is presented. Also discussed is the positioning of the ventilator tubing during KC. This protocol was implemented without any accidental extubation throughout an experimental research study" (Luddington-Hoe 2003).

As evidenced above, how much kangaroo care any preemie can benefit from depends on the physiological stability of the child. Furthermore, although widely advocated and its benefits undeniable for stable and older preemies, the authors do point to the dangers of "accidental extubation." They also write very specifically about how kangaroo care must be carried out. It requires two staff members and careful attention to the positioning of the ventilator tubing. This practice can often be experienced as "more stressful" than the picture of a loving embrace. As one parent stated, "I didn't like kangaroo care when Jenna was really, really little. I know it’s good for them. That’s what they tell me, but it seems stressful for everyone. You are not alone with your baby, holding and cuddling her. There are two or three people. Someone holding a tube here, someone watching a monitor there. Someone watching you holding your baby…to make sure the baby is still stable. And the whole time, you are thinking to yourself, ‘Please don’t let me damage her.’”

Kangaroo care requires a constant assessment of benefits and risks, and it is questionable as to how much “benefit” is obtained for extremely young and extremely premature infants. As a nurse told me, it is a case-by-case basis. “You assess how much the parents need it, what kind of day the kid is having, what time it should be done, there is a lot of little things that go into it. But, it’s great once they are stable. No doubt.” Thus, kangaroo care even for parents who greatly desire it may be highly regulated, with restrictions that can vary day-to-day, hour-by-hour.

Mothers who undergo zuo yue have notoriously low rates of kangaroo care compliance (Chang 2009). Only roughly 10% of mothers of premature infants participate in Kangaroo care. Zuo Yue is cited as the primary reason. However, a second reason given by mothers is that hospitals only permit limited open visiting hours (around 30 minutes to an hour, twice a day) and that permission must be granted for additional visitation. As will be clear with the ethnographic evidence presented below, the cultural logic and practice of zuo yue is both deeply ingrained and consequentially very effective for overcoming personhood dilemmas and biotechnoliminality issues that often result in a lack of bonding between mothers and premature infants.

Preparing for a mother's visit:

Nurse: "Everyday, especially in the beginning, before we have met the mothers, we focus and concentrate very hard to take care of their NICU babies. We know that if a baby does not seem healthy or if it seems scary to the mother, it is not good for anyone and can make the mother even more worried and lead to bad health for her. This is not good for the NICU baby either. It has to go home and we want it to go home to a strong and happy mommy. So, a first visit is very important and you have to prepare very well. But really, every visit is important, it doesn't matter if it is the daddy, the grandmothers or the mom…in the beginning it is always the daddies, who come straight from work. But, whoever comes, they are going to report back to the mother, so you always want to do your best to prepare. Many family and parents will usually call first during the day and ask if it is a good time to visit, even though we have open visiting hours for 2 hours at night. They also want to make sure they do not distract us, they also do not want to stress their babies, even if they miss them. So, I think visiting hours takes pressure away from everyone—us and the parents."

Working Hard to Rest: Interviews during the zuo yue period

Shu Shu (a NICU mother): "I missed my baby very much, but my missing him is just about me. I need to think about him and the best way to think about him is make myself stronger, so that when he is big enough and strong enough to breastfeed, I can have the healthiest and most nutritious breast-milk for him so that he can grow and become strong. I work hard every day to rest and get stronger. My heart often panics and says, 'Hurry up body, hurry up month. I need to get out of here and see my baby. However, my husband

and my mother, and my mother-in-law go and visit him and they tell me stories about him and his nurse. They go almost everyday, so I get stories everyday and then we talk about him and think about his future with us. What we want to do with him, what we think he will look like, who he will look like, whose bad personality he will have (laughing)."

Lao Wu (the father from earlier in the chapter): "Every other day I go to the NICU, I talk to baobao's nurse and get an update. Suzie really likes to hear them. She always calls me on my way home from the hospital because she wants to hear news. She always asks, 'Is she getting bigger, who does she look like today?' Today, she looks like me (he chuckles). That's what I'm going to tell Suzie. I used to make it up because the baobao was so tiny and really didn't look like anything. But, more and more now, she looks like a baby. She is coming home and Suzie's zuo yue is almost over. She is going to come to the hospital next week and learn all about taking bao bao home. Bao bao is getting transferred to the upstairs nursery. I actually already know quite a lot. Because every time I go, the nurses tell me something about how to take care of baobao. "

Then, I ask "Do you talk *to* bao bao when you are there?" Lao Wu answers, "Oh yes, yes of course, we talk *about* her the whole time. The entire time I am visiting, her nurse and I talk about baobao." I try to clarify, "I mean, talk *to* baobao and say stuff like, 'Daddy is here.'" He answers, "No…hmmm…I guess I can, but people might think it's a little weird. I don't see other people talking to the babies. I don't think these babies are ready for you to talk to them. They are not going to respond, so there is no need to talk to them."

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Sociologist Carol Heimer's nuanced and thoughtful study of the impact of institutions on personal responsibility in two American NICUs noted, "Not all parents have a clear understanding of the connections between present conditions and future outcomes. Better-educated and more middle class parents were more likely to have basic information about developmental sequences. But regardless of class or educational background, parents who spent more time in the NICU were more likely to pick up information about developmental processes, about how to assess their child's progress and about how they could intervene to help their child overcome deficiencies" (Heimer 1999). In the U.S., for those parents who are aware that early interventions might help a child compensate for medical insults or congenital anomalies, parents with a strong orientation to the future work hard to arrange for physical therapy or to place their child in a comprehensive zero-to-three program. This is their way of working hard to overcome NICU prematurity conditions (Heimer 1999).

Two points are pertinent and illuminating. First, attention to the future is a core part of responsibility. This includes working out potential discrepancies between one's expectations for the future in general and expectations for one's child's future (Staffen and Heimer 2001). Second, access to and basic information about the biology and physiological facts of development spur parents to become more aware of the future. Implicit in this finding is a concept of the premature infant as an individual, with an independent biology from that of its mother. Thus, for American parents to "connect present conditions to future outcomes" (Heimer and Staffen 1998:46) they must understand their premature infants as having a separate biology from themselves. To help their premature infants means to help them as individuals. Choosing and enrolling them in various post-discharge programs is a way of focusing on their individual development. The key emphasis is on how to get them 'to get themselves' back on track.

In Taiwan, there is a contrasting formulation for understanding how a mother relates to her infant. The concept of zuo yue connects the health and wellbeing of mothers to their premature infants precisely because it is premised on the relational inseparability between the mother and her premature infant. She must strengthen herself so that she can strengthen him. By focusing on her own future, she is also simultaneously focusing on his future. At the same time, because other actors are also focused on the health of the mother equally, if not more so, the mother is able to take the attention placed upon her and transfer it to her premature child, even if she is not present.

Zuo Yue allows for the easy transference of affections and emotions (and bonding) between multiple individuals because it is a relational practice. In Taiwan, responsibility extends to responsibility for another's social relationships, not just to the care of the continued biological maturation and growth of the person. Thus, although mothers and fathers are not learning about the developmental milestones during their child's NICU stay, they are reinforcing and establishing social relationships between their child and their grandmothers, fathers, family friends, etc. They are building and learning about the networks that will be the child's social viability. Whether consciously or unconsciously, they are developing a network of shared responsibility for the child so that the mother does not become the de facto sole caretaker, which is often the case in the U.S. As others take charge and get to the premature infant for the mother, they are also becoming the first people to learn practical skills for the care of premature infants. Thus, when the premature infant goes home, the father, the grandmother, and anyone else who was a frequent visitor will know just as much, if not more, than the mother. Although fathers in Taiwan do not traditionally have a strong presence in a child's life, many mothers reported that their husbands were their greatest support and that they remain involved fathers (Ren, fieldnotes 2004). Similarly, mothers often reported that they became more bonded with their mothers and mothers-in-law, as well as the elder women to each other. I'm told they strengthen ties "because a family has had to regroup and find strength" to help *our* "ke lien bao bao" (our pitiful and treasured baby) together. New relationships form under the duress of prematurity, and the boundaries of kinship circles widen. Maternal and paternal grandmothers are now bonded to each other.

From another perspective, "individual" elements of persons have been added to relational experiences of the person. To have harnessed a new relationship between one's own mother and one's mother-in-law requires that each see the premature infant as an individual, with the support of the premature infant experienced as an end goal in and of itself. Without this "otherizing" or "individualizing" of the premature infant, it would be untenable to think of the burdens that a premature infant may place upon existing relationships and webs of relationships. To see the premature infant simultaneously as both inside and outside of kin relationships and webs of social relations enables new relationships to be created and new power structures to emerge. As one mother reported, "I just hope that this new baby is not too spoiled. He already has too many people wanting to bao bai (treasure) him." Here, the transformative capacity or power (Giddens 1991) lies not with elders or ancestors, or those higher on the social hierarchy, but with a premature infant whose full physiological capacities for interactions have not yet completely emerged. (Social viability trumps the biological viability)

How then, did the premature infant through zuo yue come to stand inside and outside of kinship relations? I argue that it is through the emotional affective construct of ke lien (pity or pitiable). Premature infant are often described as “ke lien.” The concept of ke lien is generally applied to orphans, paupers, handicapped individuals, or anyone who exists on the outer edges of society and social relations. A common saying is “bu yao ke lien zi shi”—(Don’t pity oneself). The notion promulgated here is that when one pities oneself, one becomes egocentric and no longer relational and inter-subjective, and therefore no longer intimately connected to the others, taking oneself out of one’s social relations and joining the ranks of those who are pitiable. It is a common admonition when children and teenagers express signs of mental distress.

As Kleinman’s work in Taiwan has noted, physical sickness, not emotional distress, is a legitimate excuse for personal transactions that are outside the norm (Kleinman 1981). In the case of the premature infant, his physical “sickness” is undeniable. Yet, he is unable to interactionally show any emotional distress to his family. At best, a premature infant can show “distress” through monitors and physiological cues, but visitation is limited so parents and kin never quite learn mechanical cues that signify physiological distress. In this context, a premature infant’s very prematurity provides the means by which any emotional distress attributed to him becomes legitimate. He becomes a “special case,” an exception to the normative rules regarding kinship relations and intersubjectivity.

Under normal circumstances, “the family inhibits the expression of dysphoric and strong affects where people examine and express only superficial and shared ideas and feelings" (Kleinman 1981:138), but in the case of the premature infant, it is not the premature infant that is expressing his pitiable state, but his family members who are projecting what they feel about him onto him. Although one may argue that this could lower the status of the premature infant to that of orphans, the handicapped, and "others" outside kinship relations, it does not for the reason that his prematurity (a physical ailment) legitimizes and exceptionalizes his ke lien state within kinship relations. Most importantly, although he can't interact back, his personhood has been firmly incorporated into existing relations and interactions exercised. I argue that is due to the zuo yue period where mothers and their newborns are interconnected (You inside of me, me inside of you) through Chinese medicine principles, mediated relations, and superstitions that this is possible. By relaying information about their premature babies to them, and having mothers interact back to the stores, the mother interacts with her husband and kin for herself and on behalf of her preemie.

In Taiwan, zuo yue provides a means to integrate the NICU preemies into kinship structures while at the same time creating new relationships and concepts of selves and others for both premature infants and their kin. These relationships are made through interpersonal terms, by establishing connections between persons (Strathern 1992) (Carsten 2004) and through processes of interaction that establish a narrative presence for premature infants. In the context of the NICU, there is no question that parents and premature infants are biologically connected to each other, yet the period of zuo yue and the interactions that occur during this period show that biological kinship alone is not necessarily enough to establish relationships between premature infants and parents.

Work must be done. Relationships are created through human engagement in the day-to-day, about the day-to-day (Carsten 2004).

Zuo yue practices also fill in the “bio-social” gap that is created by “being born too soon.” It does this by extending a traditional cultural process beyond its normal social-cultural boundaries to include different participants in different settings. It also shifts the burden of physical and emotional bonding away from the mother to a wider range of individuals (e.g., fathers, grandmothers, medical caretakers, friends, etc.), thus insulating the mother from the stressful realities and experiences of the NICU.

In addition, through creating a narrative presence for premature infants, the contradiction between the double prerequisites for life (i.e., biological function and interaction) that is specific to the prematurity context is managed. Extremely premature infants’ bodies and organ systems can mature without over-stimulation while attachments and bonds are formed through interactions *about* the baby. As the timing of zuo yue (one month) is often compatible with the timing required for premature infants to reach a level of physiological stability, mothers are prepared to meet their babies and are already bonded upon a first meeting (Ren, fieldnotes 2004).

These findings in Taiwan are grounded in a relational concept of the person. They have shown how concepts of the person interweave with various biological and social elements to create new relationships. Under NICU circumstances, a situation has arisen where science has produced a novel set of experiences for people in Taiwan. Where premature human organisms would not have survived twenty years ago, they now do. This requires an explanation for why this new reality should be, who premature infants and their kin are and should be, and how individuals come to interact with each other under these new circumstances. The various case studies presented in this chapter have illuminated the work of narrative mechanisms for mediating NICU realities with lived experiences. This enables people to fit new identities, relationships, and interactions into their lives. However, it is important to note that medical caretakers are largely left out of the zuo yue narratives, even though they are responsible for taking care of premature infants during this time. Chapter 8 will analyze and elaborate upon this point further.

Before then, the next chapter will introduce NICU interactions in the U.S. as a point of contrast with these findings. In the U.S., explicit post-natal rites of passage do not exist for integrating a newborn into the social world. Rather, the almost year long process of pregnancy through "birth" is perhaps the most significant, yet not explicitly recognized rites of passage in the United States (Davis-Floyd 2003). As such, a premature birth cannot be easily incorporated into this existing rites of passage. By definition, a premature birth is an irreconcilable contradiction that renders "birth as an American rites of passage" a failed rites of passage. As such, this next chapter will describe the ordered and routinized, yet quietly desperate attempts by medical caretakers and parents to gain order and attempt to "unmake" what is experienced as a failed birth or rites of passage.

For the most part, unlike the NICU scenario in Taiwan where narrative mechanisms seem to have mediated the ambiguities and uncertainties surrounding techno-mechanical premature bodies, the next two chapters will show how prematurity experiences happen differently in the U.S.[9] What will become evident in the U.S. NICU is that instead of narratively constructing stories *about* premature infants to each other, concepts of

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[9] Lynn Morgan's work on cross-cultural understandings of abortion have shown that different cultures experience the same issues differently (Morgan 2009).

"individual rights" with discursive and emotive references to the law, are constructed *for* them and endowed *upon* them as a means of attempting to create agency for premature infants. In these next sections, I begin by showing that in the U.S. NICU, social interactions between premature infants and others are "one-sided." This is in contrast to the Taiwan NICU where social interactions with premature infants do not directly involve premature infants (i.e. they occur in narratives *about* premature infants between others).

CHAPTER 6: GETTING TO KNOW YOU--ONE SIDED INTERACTIONS AND EPISTEMOLOGICAL IDIOMS

“We have no sense for empty time.” (William James, Psychology)

“These little guys are like snowflakes. They are delicate. You try not to do too much, if you don’t have to. They don’t do well with too much of anything. They just need time…time to grow. You really have to figure out a way to stay on top of it. To keep attention. It’s easy to forget they are there…there…You never know if you are hurting them.”

This is how Janelle, a NICU nurse described her caretaking interactions with her preemie patients. It reminded me of the well known William James characterization of consciousness, “A snowflake crystal caught in a warm hand is no longer a crystal, but a drop.” There is one warm hand, one individual, existing in the context of a snowfall, turning the passing of time into an experience. There is also a tenor of solitude, of an experience that is personal, unshared, selective, yet purposive. These characterizations speak to NICU parents and medical caretakers across geographies. Interacting with NICU preemies, especially at the beginning, is like interacting with only yourself, your own consciousness. It is a one-sided interaction, but one with vital consequences that must be overcome and managed: “Premature infants and their parents do not bond” (Sammons and Lewis 1985), but they *must* if preemies are to survive and live beyond their births.

For parents, interacting with their child is often first experienced as time “standing still.” “You just stand there and look. They look like little aliens in a pod. You can’t touch them in the beginning. You can’t do anything. Five minutes feels like an hour. I don’t want my wife to visit. It’s too stressful…..to just stand there and look. (NICU Father, U.S.). “We can’t touch them, we can’t talk too loudly, it’s almost that we are better off staying away, but then they want us there, to get to know the baby…But, what is there to know right now, other than, don’t do this, or don’t do that” (NICU Mother, U.S.).

One-sided interactions are further complicated by the non-human qualities that premature bodies exude. Preemies under NICU care do not look like miniature versions of full-term babies. NICU parents often describe the first time they meet their child as “shocking,” “hard to look at,” and “not sure what they are” (Ren, fieldnotes 1997). “Preemies under NICU care have been described as appearing to exist in a “state of suspended animation” (Anspach 1997), distorting reality, and appearing nonhuman (Whittier 1999). Parental memoirs and studies of parental experiences in the NICU have documented a variety of ways that preemies are known: “little aliens,” “froglike,” and “a bunch of grapes” (Tannen and Rowe 1993) (Frohock 1995) (Whittier 1999) are just a few common examples.

These various names referring to premature infants not only describe the physical attributes of premature infants under NICU care, but they speak to a state of non-recognition (Anspach 1997) that parents often face when they first meet their premature newborns. NICUs are daunting places, they are laboratory like, sterile, and mechanical. No parent can ever be truly prepared for the sight of their child in the NICU. Premature infants under the tentacles of life saving machines often appear as if they are from another world. Their paper-thin skin, downy fur-like covering, and unformed ears often induce parents to remark that they look like little aliens. Some preemies are immobilized. With arms and legs splayed wide open and turned-out hips laid perfectly flat against warming beds, premature infants have also been described as looking like specimens of frogs that are displayed and pinned, For most premature infants, immature lungs are the medical condition that must be managed. “Lungs are life in the NICU” (Bartoo 2008). When describing this condition to parents, doctors will often refer to alveoli in functional lungs as tiny “pouches” that accommodate oxygen exchange. They will often tell parents that their child does not yet have alveoli that look like “bunches of grapes.” For parents, “bunches of grapes” do not specifically refer to the anatomical structure of alveoli, rather this term has been coopted to refer to the small physical size of their preemies. For parents, they associate bunches of grapes with a “handful of grapes”—something that can fit into the palm of one’s hand. As one father stated, “Joe is so small that he can fit into my palm, like a bunch of grapes.”

Metaphors provide imaginative power as a means for parents to overcome the unfamiliar and cover it with the familiar (Beidelman 1993). T.O. Beidelman in his work on moral imagination defines and summarizes the work of metaphors as follows: Metaphors derive from the Greek *meta* (beyond) and *pherein* (carry) to mean “to transfer.” “It is akin to symbol, to throw together,…to analogy, [and] to gather up” (Beidelman 1993:5). The use of metaphors is to “productively imagine” (James 1948) and link whole domains with one another in order to form over-arching systems (Beidelman 1993) (Whittier 1999). For parents, referring to their child as “a bunch of grapes," "a little alien," or "froglike" not only provides them with a vocabulary for articulating what they see and how they feel, but empowers them "to confront the incongruity and ambiguity that surrounds premature infant bodies (Beidelman 1993).

For medical caretakers, who are more accustomed to preemies, the daily medical necessities for maintaining the biological viabilities of preemies require not only intensely focused labor, but also a zen-like emotional stamina. One-sided interactions can be trying and discouraging. Although preemies are clinically and legally defined as "viable" under NICU care, their biological viability remains in flux and ridden with many unknowns. Will their bodies be able to maintain homeostasis and keep a stable body temperature? Will their lung structures eventually mature and enable them to breathe? Will the structures of their fetal heart close-off as it should to become a normal infant/adult circulatory system? And, will the oxygen carrying capacity of their fetal red blood cells appropriately transition to ex-utero red blood cells? These are just some of the physiological uncertainties that surround the beginning of ex-utero life for premature infants. However, these biological uncertainties have to be managed. Do we go up in oxygen? Do we run more tests? Do we schedule surgery or take a wait and see approach? Medical decisions in the NICU carry foreseeable and unforeseeable consequences, yet they have to be made. Treatment plans have to be drawn-up, and procedures and daily care-taking tasks have to be carried out. Making these types of decisions and choices require an understanding of premature body systems and the effects of NICU technology on it. At each step of NICU treatment, medical caretakers must learn to "read" various emerging physiological developments (either positively and negatively) in order to make the next set of treatment decisions. As discussed in previous chapters, doing so is rarely ever straight-forward and requires an “intuitive” sense of each individual preemie patient’s progress. It is only by knowing any particular premature patient over a length of time can one become more effective at “reading” and knowing what the monitors, the blood tests, and the oxygen levels indicate. Is a slight increase in a preemie’s red blood cell count just an insignificant variation or a sign of an infection to come? Getting to know premature infants is therefore the key to both their biological and social survival. But, how is this done?

As one NICU nurse stated, “I have to give them little personalities, or else I go a little bit crazy” (NICU nurse) (Ren, fieldnotes 1998). “It’s hard to be the one that is always doing something to them” (NICU resident) (Ren, fieldnotes 1997). “I have to think of it as gardening…gardening delicate plants and flowers. You just try to do everything carefully, just concentrate on the doing, and just don’t expect to see the growing everyday. I just tell myself that nature will take its course” (NICU nurse) (Ren, fieldnotes 1997). This NICU nurse is hardly alone in her need to construct personalities for premature infants. It is only with time that reciprocity on the part of premature infants is no longer the outlier, but the norm. Yet, while medical caretakers and parents wait for preemies to develop and grow out of prematurity, there is not much they can do. They will continue to act on and be acted upon by the passing of time. How they come to experience the passing of time when they can do very little to help premature infants grow is one aspect of coming to terms with one-sided interactions.

This chapter is about one-side interactions that result out of technoviability or the technological interventions into the human gestational process that are required for sustaining and giving biological life to preemies. Preemies are “not done yet” (Ren, fieldnotes 2004). They still need more time to grow. Ideally, continued fetal maturation of organ systems should continue to take place in the uterus. When premature infants arrive “too soon” into the ex utero world, not only are the very basic biological prerequisites for ex utero life still emerging, but they are not guaranteed to continue.

In particular, this chapter is about how individuals in the U.S. NICU use various means to think about, get to know, and decide how to medically and socially interact with preemies. These “means” can vary from reading monitors, to interpreting charts, to drawing upon one’s intuitions, to interacting with others about the preemie, to handling the preemie in a certain way, to moving or standing in a certain way, to just “doing” or “feeling” one’s way through the flow of NICU social life. I refer to these “means of thinking about, knowing, or deciding” as epistemological idioms. In some instances, these epistemological idioms are obvious and known. In other instances, they are “social experiences *in solution*“ or “structures of feelings” that are still experiences “in process,” and often felt as “private, idiosyncratic, and even isolating” (Williams 1977: 132-133).

As a means of maintaining biological viability and constructing social viability, giving personality traits to premature infants through various means are a helpful way to think through and mark biological markers of progress. Specifically, this chapter centers on one kind of easily identifiable epistemological idioms—paper signs placed around selected incubators by the nursing staff and/or by parents (See attachments to come). These signs not only illuminate other epistemological idioms, but they are in themselves epistemological idioms that are both given and still “in solution.” They motivate medical caretakers and parents, although not always in the intended ways, both internally as “self help” or self-knowing and externally as a kind of “advertising” or showing. Nurses are generally responsible for choosing, making, and placing signs around the bed spaces of certain premature infants. The act of placing signs around bed spaces not only helps mediate interactions between premature infants and other medical caretakers (e.g., residents, night nurses, parents, and respiratory therapists), as well as between preemies and parents for the sake of encouraging bonding, but doing so also benefits the nurses themselves. As nurses have indicated, making signs are a way of staying motivated, connected, and “tuned in” to one’s patients. Signs translate biological markers of progress to social attributes. At the same time, they also endow premature bodies with personhood characteristics, giving them social viability, when biological markers of progress are unclear and/or when maturational progress appears to have plateaued.

As Genevieve told me, “I used to work in the peds ICU and even though lots of kids are really sick, you know they rely on you and you give your heart and soul to them because you become bonded to them. It is heart breaking sometimes, but it is also in some ways easier, more gratifying work. I know that can sound weird, but the NICU is harder because it’s easy to be disconnected from these little ones. Especially, the really little ones, and especially during a long day. You have to give them little personalities, you have to try and get to know them and make a life for them. That is how they are going to get the best care. That’s how we have to stay on top of it. One little oversight and they are dead. You miscalculate a decimal point on meds and disaster—it’s happened and it happens, more than you think. You prick too hard and they bleed out. We have to watch out for them, especially with the new monthly residents. Signs help. It gives them personalities, it makes people pay attention.”

In general, signs are one way of managing the radical indeterminacies surrounding the biological and social status of preemies, these various paper signs are a launching pad for creating and reproducing relationships and attachments *to* preemies, but not necessarily *with* them. Creating attachments “to” preemies underscores the one-sided nature of interactions and signal attempts to bridge a bio-social gap until they can “interact back.” In turn, actors associated with NICU preemies are also creating and reproducing their own concepts and experiences of selves and each other in the context of NICU preemies. Thus, signs are an entry point for revealing both objective and subjective aspects of personhood for preemies and for those intimately intertwined with them.

This is important because I argue that the very existence of preemies under NICU care challenges existing expectations surrounding how personhood should be experienced and understood both privately, as well as in interactions with others and by others. That is, regardless of whether one experiences and/or considers preemies as in utero fetuses or miniature babies, and regardless of how one feels about the personhood status of fetuses or babies, incipient individual experiences with preemies under NICU care do not fit into any experiences we have lived, know; or expect to live or know. A preemie’s physiological maturation under NICU interventions results in de novo developmental trajectories that may be homologous to developmental maturation under full-term circumstances, but many times, they are also likely to fall outside of developmental norms grounded in our evolutionary past (see earlier chapter to come on viability). That is, by creating de novo environmental factors that affect preemie growth and development, the NICU is inadvertently introducing new elements to biological and social life, as well as a new population of human beings that otherwise would not have existed. In turn, these new elements create ambiguities surrounding who premature infants are and how we should interact with them and act for them. As famed pediatrician and researcher T. Berry Brazelton said, “Preemies are not behind, they are running a different race altogether.” But, what that race is—is a black box. In the meantime, we are compelled to interact—even alone, experiencing, thinking about, knowing, deciding, and attempting to do our best and be our best for the sake of trying to set things right. All of this requires social and reflexive work.

With these thoughts in mind, the organization of this chapter begins with a brief description of one-sided interactions with *Interactional Vignettes*. Then, in the section, *Signs—Please Tell Me Something*, I will describe several paper signs and provide brief analyses of their generalized public messages. This points to signs as indicators of cultural models of personhood (Shore 1998), as well as cues for meaning-making and organizing competing values and ideas about the preemie and those related to the preemie. That is, the messages on these paper signs often convey the objective aspects of personhood, such as some common ideas for how parents, medical caretakers, and society at large should think about and interact with preemies. As one will notice, many of the signs take on a language of “individual rights” and confer various types of rights upon premature bodies in order to endow them with agency. In turn, through the attempted creations of an agent-oriented presence, signs convey normative ideas about who individuals should be (or not be) in their relationships with preemies and the types of interactions that *should* be taking place. Lastly, and more critically, in “Getting to Know You,” each sign will also be situated in a particular narrative, giving the signs a specific context. The aim here is to illuminate some of the elusive experiences of personhood. In particular, how do individuals in the space of interactions wrestle with contradictions and ambiguities between what they see and how they feel; and with what they *should* see and how they *should f*eel.

Interactional Vignettes

This section presents vignettes of “interactions” that are one-sided. The intent is to capture the appearance and feel of these one-sided interactions and how the one-sidedness shifts over time. Although I refer to specific individuals, I also want to convey common patterns of interactions between three sets of actors: medical caretakers, parents, and preemies. Over the course any preemie patient’s NICU stay, these patterns of interactions are often organized out of and constrained by the interactions between two factors that speak to the universality of the biological process of human gestation: First, the maturational timing and sequence of in utero development; and Second, by the degree to which NICU treatments impede a preemie’s functional development of biological organ systems. Individual actions toward and with preemies, as well as with each other, are in many ways non-deliberately routinized by the temporality of biological processes. Thus, many of these patterns of interactions hold true across geographical locations. At the same time, a third factor, the expectations of interactions based on notions of personhood will also simultaneously shape interactions. This is of course variable and contextually dependent. Here, variations are infinite across and within various geographical locations. Therefore, these patterns of interactions are also a window into understanding how universalities in general interact with variable particularities. The NICU is but one example. As scientific endeavors and research into human biology continue to make break-throughs, this interplay between universals and particulars will become ever more important. Stem cell and genetics research are two other examples that come to mind.

Here, I once again employ different fonts to show different perspectives. **The preemie's perspective is represented by a bold font**; *The medical caretaker perspective is in italics;* ***The parental perspective is in bold italics***. These examples come from different points in time. They highlight the how modes of interactions change and evolve over time as each set of participants learns from others and as the preemie himself/herself changes and gains capacities. What begins as dyads of interactions, eventually transforms into more complex and subtle ranges of interactions.

Interactional Vignettes 1: The Beginning Days
(Approximate Days of Life 1…3….7…..14….)

Staying Alive

Until a preemie's system has acquired physiological stabilities, including body temperature, heart rate, and respiratory rate, any kind of stimuli can induce significant enough physiological stresses to cause death. These stimuli range from looking into an incubator, to standing too close to the incubator, to general sounds, the brightness of lights, the temperature of the room, and of course, all medical procedures. Thus, in the beginning of many preemies' NICU courses of treatment, there are very little interactions with them, other than the absolutely necessary medical procedures.

Preemie

Bed 36, Baby Girl Jones is 26 weeks, 750 grams. She has trouble maintaining a normal body temperature. She lies in an incubator. Her eyes are shut. At times,

she has periodic jerky movements and muscle tremors. Other times, she appears unresponsive and motionless. When this happens, she is "shutting down." This is a biological response to overstimulation, a biological defense against the intrusiveness of the physical environment. In addition, deprived of her last trimester in utero, Baby Girl Jones has not developed the early responses and coping mechanisms to an ex utero sensory environment. One moment she can breath rapidly, the next her breathing can stop completely. One moment her skin color looks normal, the next it turns mottled and blue. These physiological changes, unlike that of a full-term newborn, are NOT stimulus specific. Many different stimuli can cause death inducing physiological changes.

_____**Preemie-***Nurse*

Mary moves very deliberately and slowly. She doesn't talk. She looks at the monitors, watching to see if there are any dips in the graph. She writes in her chart for the next 10-15 minutes, every two minutes or so, she looks up at the graph. The dips are only minor. This goes on for the next half hour.

With everything looking fairly stable, Mary has decided to turn baby girl Jones' body, in order to make her more comfortable. She covers the isolette with a blanket, and then with both hands, reaches into the isolette. One cannot see what her hands are doing, they are covered by a blanket that drapes over the isolette. This helps the preemie tune out other stimuli while she is about to be turned. Mary's actions are controlled and deliberate. She is supporting the preemie's head and extremities, and turns the preemie in one smooth motion or "en bloc." This reduces physiological changes in the preemie and reduces disconjugate motions. All of this takes less than 2 minutes. When she is *done, Mary steps back, looks back at the monitor and watches it for the next couple of minutes until the dip of the graph has returned to baseline.*

Preemie-*Nurse-****Parents***

> *Mary: When she talks,* she *makes constant eye contact with the monitor, not with the parents and not with the preemie. Her voice is really low, you can barely hear her. She is looking at the monitor as she explains the following to Jill and Dave (the parents). "She knows you are here. She has been through a rough time. She needs to rest. They are really fragile. She is doing pretty good. See. I've been talking to you and you see this line, it hasn't dipped (i.e., Graph). If it dips and doesn't go back up, then we need to stop talking. We have been running a lot of tests. We need to let her sleep…get her beauty sleep. Ok…see this dip…see how still she is now…it means she needs rest. It's her little body saying she needs quiet time. Sounds make them shutdown. Here, I'm going to put a little blanket over the incubator. She turns to the parents, "This way, we can talk a little bit more. Let's step over here." Mary is now standing two arms lengths away from the incubator, still between the parents and the incubator. She is explaining baby girl Jones' conditions. As she talks to the parents, every couple of minutes or so, her gaze moves away from the parents and checks the monitors.*

Parents: Jill and Dave are standing two arm's length away from their daughter's bed. They have not given her a name yet. Between Jill and Dave stands Mary, the NICU nurse, who is one arm's length away from the preemie and inches away from the monitors. Jill and Dave are listening. They seem frozen. Over the course of 15 minutes, they have not really moved. Other than that. They have not said anything.

They don't want their baby to shutdown. *Mary looks at the monitor, then says, "see how there aren't any dips here," She's doing good. Here, you can come closer, come take a look.* ***Jill and Dave, move closer. They stand there, peer into the incubator. Jill has tears in her eyes now. They look for the next 5 minutes or so. Silent. Dave is holding Jill's hand.*** *Mary concentrates on the monitor. Mary sees a dip in the monitors. She says, quietly, "I think we should give her a little rest now"—you see this, this dip, she is telling us she needs to have some quiet time.* ***Jill and Dave move back. They nod a little. They are now staring at the monitor.*** *Mary puts a blanket over the incubator. Mary says, "This was a good visit. They are fragile. They are little. It's important for you to come…to be here…to get used to things… to learn the signals." She looks at the monitor.* ***Jill and Dave are also now looking at the monitor.***

In these beginning days, there are several patterns of interactions that are significant. First, a preemie's "interactions" with his world are NOT social. His/her physiological changes, unlike that of a full-term newborn, are NOT stimulus specific. Many different stimuli can cause death inducing physiological changes. In the beginning, it is hard to differentiate and determine the specific causes of physiologic change**s.** How its body reacts to the stimuli in the ex utero world is purely about energy conservation, for the sake of maintaining life. The non-specificity of stimuli prevents preemies from interacting with their environment in a patterned and organized way. Preemies are biologically disorganized. This is significant because specificity of stimuli provides a way to "communicate" even if that communication consists of merely observing a simple stimulus-reflexes pattern, like a jellyfish's response to light. Without a way to "read" preemies in any predictable way, interactions with preemies are not only one-sided, but it becomes difficult to create any sense of knowing them, even in the most basic of ways.

Second, we see both the nurse and the parents watching the monitors. Mary, the nurse, often reassures herself that Baby Girl Jones is doing well, because the monitors are not showing any dips. Her interactions with the monitor, as well as her interactions with parents that include teaching them how to read the monitor, are ways for her and the parents to imaginatively “interact” with the preemie and with each other. She watches the monitors for potential progressive signs of her preemie patient decompensating or forced into physiological instability. Usually in full-term newborns or adults, physiological instability happens in progressive stages. There are generally warning signs before a heartbeat suddenly stops or a person turns blue. This is not the case for many preemies at the beginning stages of NICU treatment. In fact, consistent with the lack of capacity to respond to specific stimuli, monitors rarely show a progressive response. Rather, when overstimulation occurs, every alarm is triggered at once. In fact, small dips in the monitors do not mean anything at this point. One must generally read these small dips in conjunction with reading the heart rate. For older and more stable NICU infants, the heart-rate on a monitor will usually bounce between 120 and 150 beats per minute (bpm). For a sick preemie or one during the early stages of NICU treatment, the heartbeat is usually 140 bpm and the number stays that way, until the entire body is under distress—at which point, it would be obvious even without a monitor (i.e. The preemie turns blue and/or every alarm is sounding). As a result, there is really nothing very significant to read on the monitors except for the small graphical dips, which are just the very small variations that do not actually effect the heartbeat. However, medical caretakers and parents continue to read and interact with monitors in ways that indicate more physiological communicativeness than is actually possible.

Third, parents are often overwhelmed by the way preemies look and by the daunting presence of NICU equipment. Many visits are required before they are comfortable enough to initiate unmediated interactions with their child. Mary is part medical staff, facilitator, hostess, and parent to the parents and the preemies. She teaches Jill and Dave what to look for on the monitor and invites them to move closer to the incubator. At the same time, she also tells them when to step back and when the interaction is over. She is a gate-keeper/facilitator of interactions between parents and their child. It is very common for U.S. parents to feel conflicted about having a third person mediate interactions between their babies and themselves. On the one hand, they are comforted. On the other hand, they can also feel inadequate and powerless.

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Interactional Vignettes II: The Rollercoasting Days

(Approximate Days of life….8……70….)

Five Steps Forward, Ten Steps Back.

This is a period of time when the preemie begins to acquire some of the essential capacities for physiological stability. However, growth is a double-edged sword. It is both a necessity for survival, but it is also a time when the acquisition of new biological capacities can be overly taxing to a preemie’s physiology and cause significant setbacks. It is a time when preemies can seem to advance one day and then get worse the next. Many parents often dread the morning phone call. They know all too well that bad news can happen at any time. “If there is one good thing, then there is always something bad or worrisome that follows. There is never one day where everything is just fine. Everyday is a rollercoaster (Mother, U.S. NICU)”

Preemie

Baby Girl Jones longer decompensates—-Her heart rate can now bounces between 120-150 beats per minute. She has now acquired the innate capacity for variability. When she turns blue or when her heart rate stops, there is usually some delay before a physiological systems crash. There are less episodes of apnea (stops in breathing) and changes in color. They also start to exhibit more spontaneous twitching and startling. This is the moro reflex. It is an infantile startle reflex that is an indicator of the central nervous system becoming more integrated. It is a reflex that responds to unexpected loud noises and comprises four acts: startle, arms spreading, arms unspreading, and crying. It begins to emerge around 28 weeks gestation and is not in its complete form until around 34 weeks. It is normally present in newborn infants until around 4 or 5 months post-natal age. Its absence and its presence beyond 4 or 5 months is an indicator of abnormality. The emergence of the moro reflex is one example of an innate physiological capacity that can be perceived and known by others as a sign of maturational progress.

*Medical Caretaker-Medical Caretaker-**Preemie***

Preemie: There is an alarm.

Betty (a nurse from the other side of the room): "Mary, do you want me check on bed 36."

Mary: "Yes, thanks…she's probably just fine."

Betty walks over to bed 36, looks at the monitor, she sees that the heart rate has dropped, then looks at the incubator and then walks away.

Parents: **Preemie:** *Medical Caretaker*

Preemie: Baby Girl Jones lies in the incubator. There are irregular and frequent motor movements. The respiratory rate is also irregular, but no alarms sound. There is variability in her heart rate. There is rapid eye movement. She is in light sleep.

Jill just arrived. She says, "Hi Mary,"

Mary: "Hey, She's doing well."

Jill: She walks over to her baby's incubator. She looks in and whispers, "Hi, momma's here. I'm going to feed you, ok?" She looks at the heart rate. It jumps around, but no alarms sound. She looks into the incubator. She checks to see if her baby is turning blue. The baby seems fine. "OK, I'll see you in a little bit." Jill leaves. She walks out of the NICU, down a hall to a quiet dark room. She sits in there for the two hours. She is pumping breastmilk, trying to get her milk to letdown without the physical suckle of a small nursing mouth, trying to imagine what her baby will look like in the future so that she can trick her body into letting down milk.

(A couple of hours later……)

Jill comes back into the NICU. "Hi Mary, here it is."

Mary: "Good job. That's some good liquid gold today." "Are you going to hang out a little bit?"

Jill: "Just a little. I've already been here." Jill stands next to the incubator. She does not touch her baby. She just looks. Periodically checking the monitors. She is there for the next 15. There is not really a place to sit, although there is an empty rocking chair nearby. Like most moms, she will never sit in the rocking chair. She touches the incubator, softly mumbles to it. Then touches her hand to her mouth in a kiss, then gently places her kissed hand on the incubator. She walks away. Jill will call Mary when she gets home. She will call again before she goes to bed. When she wakes up in the morning, the first thing she will do is call Mary. She will do this everyday, for the next forty days, until her baby is home.

(A couple more hours later….)

Mary: She goes and gets breast-milk out of a refrigerator, prepares it, and then stands to the side of the incubator. She is staring off into space as she bottle feeds her preemie patient. She does not hold her. She does not talk. She just stands there quietly, appearing relatively disengaged for the next half hour. She has a soft cover fiction book at her work station, it is opened to a page. Periodically, she looks down and seems to read a couple of sentences. Next, she glances across at the monitors, rests her eyes on the screen for a minute or two, and then circles her gaze back down to the preemie for several seconds. This sequence of movements goes on for the next twenty minutes or so.

Most of the time, she just stands there, looking away from the incubator. This is how she feeds Baby Girl Jones, who is now Lizzie. This is how Lizzie likes to feed.

During these roller-coasting days, it is through trial and error that medical caretakers and parents begin to establish patterns of interactions with premature infants. The physiological capacites of premature infants are beginning to emerge, yet they are not obvious. As the example of Mary feeding her premature patient suggests, Mary has figured out that bottle-feeding can be too overstimulating for Lizzie. As a result, Mary compensates her own behaviors to accommodate that of Lizzie's. She never makes direct eye contact with Lizzie, does not speak to her or others, and stands several inches away from the incubator. All the while, Mary glances between the monitors and her book, both of which appear to give her a focal point for different reasons. The monitor provides her a way of assessing Lizzie's stress level. The book provides her a means of exercising "restraint from doing" so that Lizzie will not be overstimulated. At the same time, Jill and Dave are now also becoming more familiar with their child. They are starting to take on some of the care-taking roles, including reading their baby's physiological signs and providing breastmilk. In both cases, Mary, Jill, and Dave have adapted and shifted their own expectations of interactive behaviors in order to interact with baby Lizzie.

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Interactional Vignettes III: The Almost Home Days
(Approximate Days of life 7……20…….50…….100…..)
Practicing

Jill walks into the NICU, she washes her hands, grabs a gown, and makes her way to the intermediate nursery. It's dark and quiet in there. There are several rocking

chairs and several parents in rocking chairs. She grabs a rocking chair and pulls it close to her daughter's incubator. She lifts the cover off the incubator and says, "Momma is here sweetpie. Do you want some cuddle time?" She is careful, but no longer self-consciously careful. She checks the monitors and slowly reaches into the incubator, looking at her daughter. She picks up her daughter in one smooth motion, something that takes practice. She is wearing a spaghetti strap camisole. This is a well thought out and planned choice. This way, she can simply pull the straps down underneath her hospital gown to expose her skin. She has learned that some clothes can be cumbersome. The goal is to place her daughter's half naked body against her own skin as smoothly, as quickly, and as delicately as she can. This is her routine. Mother and daughter sit in a rocking chair. Jill is quiet, she periodically watches the monitors and then at her daughter. Her baby seems fine. Her body is relaxed. This is good. The room is quiet. Several other parents are doing the same thing. No one talks to each. Each is aware by now of the dangers of overstimulation. Each is lovingly holding their child, quietly, silently.

Preemie: Her heart rate is steady. Her body is relaxed. Her eyes open a little and then closes again. She is in a kangaroo hold with her mother. She has gained weight and her vital signs are now stable. Periodically, she seems to be nuzzling into the crook of her mother's neck. On good days, she can latch on to a breast and suckle for several seconds.

(20 minutes later…..)

Jill: Today was good day. Her daughter was able to latch on for close to a minute. She doesn't want to over exert her daughter. She whispers, "You did such a

good job today, what hard work, you must be tired. Momma will be back later ok? Night Night." She places her daughter back into the incubator with one gentle swoop. She covers the incubator. Reaching into her purse, Jill writes a note to Mary.

The note reads: "Another good latch, almost a minute! Mary, can you hold off on bath time until Dave gets there. He is running late? Also, there was a little fussiness today. Perhaps hold off on bloodwork tomorrow? Thank you, xo Jill.

(10 minutes later….)

Mary is back: She sees the note. Reads it and smiles. She tells me, "They are going home soon." She and Jill talk a couple of times a day on the phone. She always gives Jill an update and then schedules her kangaroo care sessions. This way, she can make sure that not too many tests are done on the days that Jill or Dave is here. She wants Jill to continue her successes with her daughter.

Jill is becoming more assertive. She is becoming more confident and starting to take charge of her child. She is no longer overwhelmed by the sight of NICU technology and has become a lay expert on NICU procedures. Mary welcomes this "take charge" attitude and sees it as a sign that Jill and Dave are ready to go home. However, some of her colleagues would view Jill's note concerning holding off on blood work as overly meddlesome. As the preemie matures, relationships and power dynamics will continue to shift between parents and caretakers. Everyone fundamentally agrees that a parent who takes charge in the NICU is a parent that is ready to parent. However, it is not always easy for medical caretakers to let go and give up control over the care of their NICU patients when they were the ones who mothered them through the hard times or fought with residents over the unnecessary blood tests. They were the ones who vigilantly looked over the dosage calculations of residents, making sure that they are exactly right. They are the ones who taught parents how to hold a baby, offered a shoulder to cry on, and found words of encouragement to nurture the parents. As Mary the nurse often says, “discharge is always sweet—mostly sweet …with just a little bit of sadness.”

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As one will notice, most interactions are only minimally discursive. They are mostly acts of doing. In many cases, the doing is itself not particularly interactive; and in the beginning days of NICU care, the “doing” is often a deliberate act of restraint. Therfore, it is important to pay attention to the actions of the various individuals—how do they handle the baby, how far do they stand from the baby, with whom or what are they making eye contact? It is only over a period of time that one begins to understand what the various non-verbal actions mean. What often appears as a flow of routinized generic activity, such as a nurse turning over a baby, is actually a deliberately engaged act of preventing physiological disorganization. There are nuances to how a preemie is handled. Although many of these actions, such as swaddling or turning a preemie, or bottle-feeding, are homologous to actions one might undertake with a newborn full-term infant, there is a level of deliberateness that persists in each action that is consciously repeated that would not exist during interactions with full-term infants. Although the very first interactions between any new parent towards his/her full-term baby may be particularly deliberate, this deliberacy of action is lost relatively rapidly over a short period time as parents become more familiar with their child. In the NICU, parents must learn a set of “preemie” rules that are quite different than how they expected to act as new parents. Parents of preemies must learn to read and understand one’s baby that are not consistent with general rules of interactions with full-term babies. Most critically, the well-established knowledge that responsive social patterns are crucial for normal development and for survival (Spitz 1965) do not apply until premature infants are stable and mature enough to manage the many kinds of stimuli associated with social interactions. A deprivation of social interactions during the early stages of NICU treatment will not lead to a failure-to-thrive as seen in orphanage infants, but just the opposite. For example, parents are informed early on that a premature infant who just lies there is not under-stimulated but over-stimulated. They are also informed that restraint from interactions should be the default. These “preemie rules” are often counter-intuitive to what mothers, fathers, grandmothers, and kin know or are taught about babies. What good mother avoids eye contact when breastfeeding a child? What good parent refrains from holding his/her child? What good parent does not speak to his/her child?

I have shown that in a U.S. NICU context, what may look like a nurse not paying attention (i.e. Mary feeding a preemie while reading a book) is often a deliberate act of disengagement. As illustrated in the case of Lizzie, it is quite common for NICU preemies who cannot seem to gain weight, but are otherwise on the road to recovery, to feed much better when they are not distracted by extra interactional stimuli such as talking, holding, or even just someone looking at them. Interactions, although critical for both biological and social survival, can nevertheless be equally dangerous if performed at the wrong times.

One-sided interactions in the NICU occur in fits and starts, lack spontaneity, and can extend over a period of time without clear signals as to when they are about to begin and/or when they are about to end. These characteristics challenge normative "situational proprieties" of interactive conduct that include common courtesies of turn-taking, greetings and goodbyes, and culturally learned practical knowledge about spatial arrangements, lengths of conversation, eye contact, and other rules of conduct (Goffman 1990). These findings illustrate that premature infants who are incapable of social interactions, yet possess corporeal presences that others desire to make into and experience as persons, can inevitably alter the interactive conduct of medical caretakers and parents. It speaks to the power of corporeal premature bodies to instigate and inspire the imaginative forces of medical caretakers and parents to create meaningful interactions in their presence. Implicitly, one-sided interactions also suggest the deeply troubled interactive relationships that U.S. medical caretakers and parents have with ambiguous and non-agentive premature bodies.

This major theme is elaborated upon in detail in the section to follow. Specifically, it argues that one of the consequences of desiring an "individual-action- oriented-presence" for interacting with premature bodies (as opposed to a "relational-narrative-presence" in the Taiwan NICU) is that interactions with premature infants are often experienced by medical caretakers and parents as unbearably awkward, incomplete, and/or disappointing. Yet, these experiences are the norm. How then do individuals under U.S. NICU conditions manage?

Signs—"Please Tell Me Something"

Taking care of and interacting with NICU preemies is often solitary, and at times it can also be a lonely, strange, and scary experience. "What you put out, you don't get back" (Ren, fieldnotes 1997). Humans will interact, even alone. It is how we cope. However, what happens when the physiological realities of premature bodies cannot meet the interactive expectations of others? This chapter introduces the use of paper signs as epistemological idioms that help medical caretakers and parents define who premature infants are as persons and as individuals, as well as who they are as persons and as individuals in relation to premature infants. In using paper signs to designate and define certain desirable personhood characteristics and experiences, individuals in the NICU are participating-in and creating informal rituals and rites of passage for premature infants and themselves. Unlike the cultural situation in Taiwan where the post-natal rites of passage zuo yue exists society-wide, post-natal rites of passage do not exist society-wide for newborn infants, parents, and kin in the United States. As anthropologist Robbie Davis-Floyd has noted, "Although pregnancy and childbirth are life-changing events, in our [U.S.] technologically oriented society there appears no society-wide spiritual or humanistic rites of passage to initiate newborn mother and child into American life" (Davis-Floyd 1992:1). Rather, post-natal rituals and rites of passage in the United States are informal and personal. They consist largely of a series of commonly shared expectations and actions that prepare for a baby's arrival (e.g. attending prenatal classes, going on a "babymoon" vacation, decorating a room, having a baby shower, and others) and a series of shared personal "interactive experiences" that occur post-natally (e.g.

staying up all night, breastfeeding, losing baby weight, and other actions and experiences associated with baby care-taking).

For NICU medical caretakers and parents alike, the NICU situation renders them incapable of sharing in these common personal experiences of babyhood. Thus, they find themselves in a complex social situation without adequate cultural resources to rely upon. This section argues that the creation and practice of using paper signs as a means of creating an individual-action-oriented presence for premature infants is one way in which NICU individuals manage the crisis of prematurity, bridge the experiential differences between premature births and full-term births, and initiate premature bodies (and each other) into the social world.

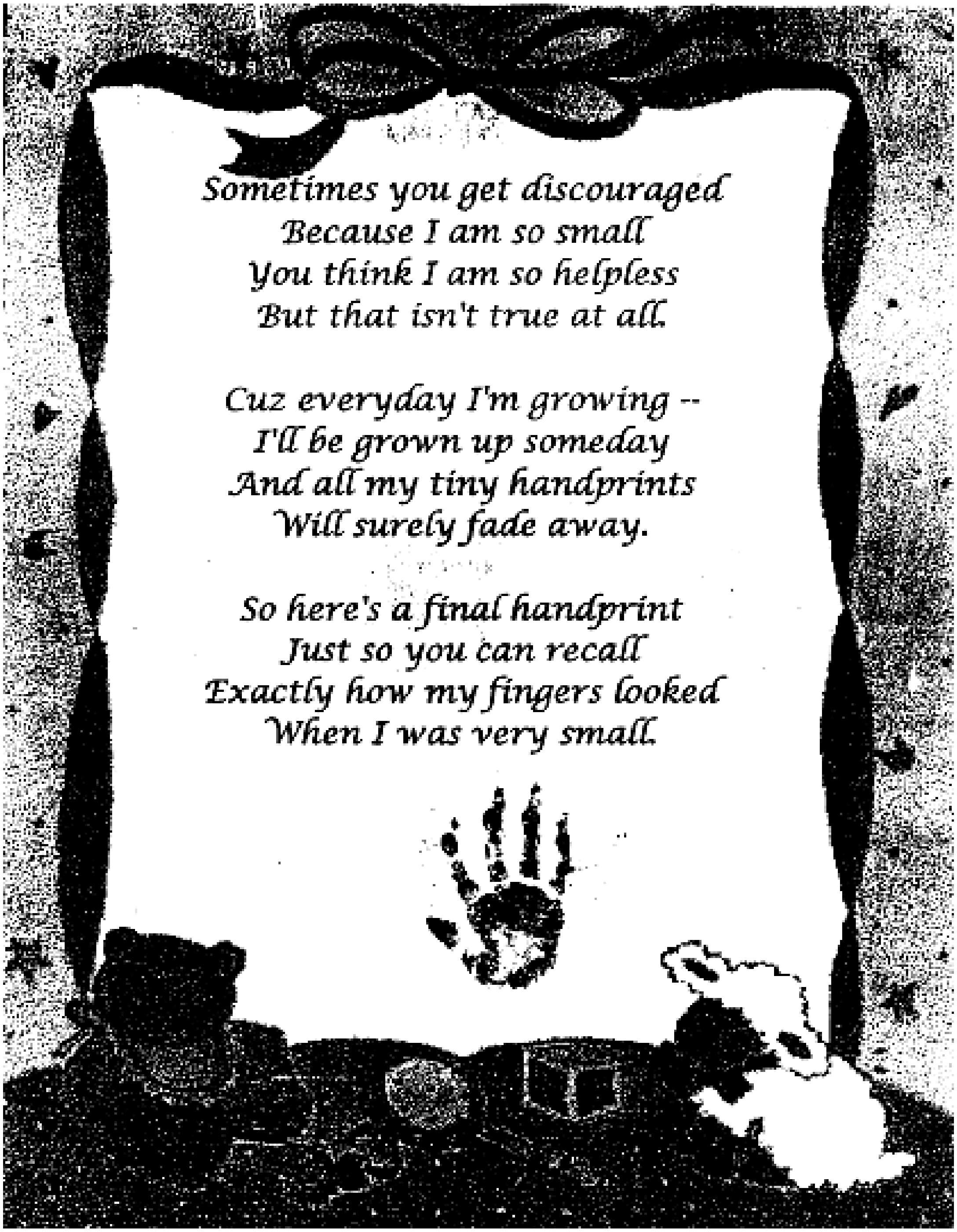
In general, paper signs speak to and translate between various sets of norms. In particular, interactions-in-the making often buttress up against three general sets of norms. (1) biological norms, or norms surrounding a preemie's expected growth trajectory that is based on our present knowledge of the human growth and development process. (2) social-cultural norms surrounding babyhood (3) clinical norms, or norms concerning clinical practices, diagnoses, treatments, and other aspects of clinical care.

At the time of this research, no official policies existed for signs. Whether they were placed on an incubator was purely at the discretion of a preemie's primary nurse. Therefore, not all premature infants systematically received signs. Through informal observations and daily visits to the NICU, I found that premature infants who were "easy cases" did not generally receive any signs. These premature infants are usually older gestation infants who are only required ventilator use for a day or two. At the same time, premature infants who were very young with extreme prematurity also did not receive signs while their conditions were still unstable. In general, premature infants who were expected to survive, but occupied a middle-ground between these two groups received signs. This is the majority of NICU patients and although not every one would receive the same number of signs or for the same duration of time, the majority of NICU patients did receive at least one sign during their stay in the NICU. Signs are usually placed during the period of time characterized by “waiting” or “rollercoasting.” These are periods of time where concepts of selves and others are employed as ways of overcoming one-sided interactions.

Signs are generally placed by nurses around the bed-spaces of certain preemies that medical caretakers intuit will survive to be discharged from the hospital “with none to moderate neurological deficits.” In all of my time in the U.S. NICU, I have never met a parent who was upset because her child did or did not have a sign. When I asked parents about whether they noticed signs, many would look around at the room and then say, “Oh yeah.” When I asked them what they thought of signs, many would simply say, “They’re nice.”

In general, parents only read signs that were attached to their own child’s bed space. There is not a lot of spoken awareness of other people’s premature infants. Uncertainty abounds in the NICU. I suspect that for many parents, there is not a lot of reserve energy for noticing other parents or their particular set of circumstances. There are no guarantees in the NICU. Parents know all too well that some preemies will die, some will have neurological issues, some may have developmental issues, others may be perfectly fine. The reality is that no one is guaranteed a healthy, trouble free NICU experience or child. Thus, it is often daunting enough to just keep up with one’s own child’s medical conditions.

I am More Than What You See
(Sign 1)



Sometimes you get discouraged
Because I am so small
You think I am so helpless
But that isn't true at all.

Cuz everyday I'm growing --
I'll be grown up someday
And all my tiny handprints
Will surely fade away.

So here's a final handprint
Just so you can recall
Exactly how my fingers looked
When I was very small.

This sign gives the neonatal body an infant voice. Using the first person pronoun

“I” and addressing the reader as “You” metaphorically constructs a close and intimate relationship between the infant voice and the reader. The neonate, his parents, and his caretakers are now a team. They are promoting his/her growth out of prematurity ‘together.’ They are a team, they are a family.

The intended reader here is the parent of the particular preemie whose bed space is adorned with this poem. However, it is just as likely that other medical caretakers and parents, not associated with the specific preemie, will also glance at the poem, but not likely read it. Given the physical spacing of the NICU, the various medical conditions of the preemies, and, in turn the norms of behavior influenced by these factors, it is generally uncommon and socially unacceptable to stand over another preemie’s bed-space and take one’s time to read signs found on other preemie’s incubators. However, a quick glance is appropriate, and as will become evident in the signs to follow, different signs are meant for different individuals, and are intended to communicate and mediate between different valences of privacy (or ‘publicness’). With this particular sign, the message is much longer than other signs and to fully read it, one must stand close to the incubator. Unless one is connected to the specific preemie whose bed-space bears this sign, at best, what one could see are the colors, the baby animal motifs, and the handprint that is the size of two thumbprints. Signs like this one are therefore socially private, but somewhat publicly available. Glancing at signs such as these on another preemie’s bed-space is similar to eavesdropping on another person’s conversation at a coffee shop. One notices and takes note, but does not let on that one is doing so. Thus, this sign mediates and inhabits a space that is both private and public. Premature infants all reside in one large room. Anyone that enters the room has visual and experiential access to any premature infant. They often appear publicly displayed. Visiting one's preemie is an intimate moment, yet the public display quality they possess are often daunting to parents. Signs can create a sense of privacy, taking away the display quality of premature infants by providing a focal point for parents. Thus, signs that do not convey medical information (like this one) are intended largely for overwhelmed parents.

In the first stanza, the infant voice appears to relate and understand the anxieties and fears of his or her parents. The voice explicitly recognizes that you will "sometimes…get discouraged" by the smallness and helplessness of the neonatal body. This statement shifts the role of the preemie from that of a helpless body to someone with insider knowledge. The infant voice gains authority and credibility as a first-hand 'expert' of his/her own medical condition and becomes a voice of confidence and assurance. Acknowledging this, he/she also indirectly recognizes the extraordinary nature of his/her situation.

The infant voice continues, "You think I am helpless, but that is not true at all." By emphatically denying its smallness and helplessness, a degree of control and the capacity for communication are metaphorically endowed upon a body that is biologically capable of neither. This shifts the role of the preemie from someone who is completely helpless to someone with the authority to refute the common perception of "smallness and helplessness"—a euphemistic glossing over of the fact that the preemie body is often completely dependent and intertwined with the wires, tubes, and monitors that are the tentacles of mechanical life. The implicit message is that the neonate is in control and can bring about his/her own growth. More importantly, it provides the assuring message that growth is occurring all of the time.

For parents, the compassionate voice of their infant child encouraging them to step outside of their own feelings, perceptions, and assessments of a particular situation, is one compelling way of addressing and acknowledging their grief and bereavement (Kubler-Ross 1969) (Lindemann 1944), while attempting to generate some sense of "moving on" or "emotional adaptation (Goldberg 1979) (Henig 1992). Riddled with guilt and feelings of inadequacy as well, the experience of being premature parents is often described as living in a state of "chronic sorrow" (Olshansky 1962) (Harrison 1983) (Lee, Penner and Cox 1991) (Hurst 2001). Many times, parents cannot and may not trust that their child will survive the NICU. In fact, 90% of all preemies survive to be discharged from the NICU. However, prognostic uncertainty as to how NICU care will impact each individual is hard to determine. How then does one continue and move on amidst chronic sorrow?

The sign is therefore both a motivator and motivational, it is a life-coach of sorts whereby the coach and the message are one in the same, making the interactions a two-way interaction. That is, the implicit "work" of this sign is to conceptually intertwine itself with the preemie, incorporating metaphorical capacities and a sense of control with a preemie body that is incapable of sociality. The sign gives and sustains a social life for the preemie, in the same manner that intensive care machines give and sustain biological life. The sign attempts to transform the preemie body into a social individual, capable of participating in interactions. It attempts to place reflexivity in a body whose biological reflexes are still emerging. Whether this is successful varies by context. Signs like this can remain merely as objects that convey a message without much social force. Enabling reflexivity to exist socially when the existence of biological reflexes are still under question is not always successful.

Despite the fact that neonates often progress so slowly that “they seem not to progress at all,” (Guillemin and Holstrom 1986:113) the second stanza of the poem paints an image of a growing body. As the infant voice affirmatively states, “…everyday I’m growing.” Although perceptible evidence of growth may not be evident, this statement not only promises growth on a daily basis, but also implicitly promises growth without any setbacks (i.e., linear growth) until adulthood. As the infant voice states, “I’ll be grown up someday and all my tiny handprints will surely fade away” (my emphasis). This notion of linear progress hides the fact that a neonate’s condition can change within the course of a night or even a few hours. Furthermore, a notion of linear progress overlooks those neonates who do not get better despite the finest medical care (Layne 2003).

The second stanza can also be perceived as an attempt to erect a façade of ordinariness for a neonatal body that appears unusual and is undergoing extraordinary medical treatment. The implication here is that the present bizarre appearance and the uncommon circumstances of the body are not permanent and that the changes, although invisible, are happening and will allow a neonate to graduate from the NICU. The changes will naturally bring about the fading away of the handprints, along with the fading away of all characteristics out of the ordinary. In essence, the message here is that the infant “will grow up” someday to be just like every other person. However, parents and medical caretakers are often aware that, in spite of the poem’s reassurances, there are no guarantees that any particular preemie will grow out of his/her present condition to become like any other infant. The tone of the infant voice underplays the reality that some infants may become oxygen dependent for the rest of their lives and/or experience developmental and neurological delays.

Unlike full-term infants who can assert their own presence through blinking, moving their arms and legs, sucking, crying, and gazing, many preemies begin their time in the NICU without the capacity for movement. Despite this fact, the third stanza of the poem creates a presence for the neonatal body. The phrase, “here’s a final handprint” portrays an infant who is actively giving the handprint to his/her parents. The ability to give another one’s hand signifies having some independence of body. Furthermore, because touch is the primary form of interaction between new parents and babies during the early stages of infant-hood, the fact that preemies have not developed the capacity to receive is challenge towards bonding and attachment between parents and their preemies. By giving a handprint to parents, it is as if the neonate is metaphorically giving the parent/caretaker a hand to hold. The use of the phrase, “Here is a final handprint,” not only commands parents to accept the handprint, but the command itself asserts the infant’s presence as if the infant is saying, “Hold my hand.”

As the poem closes, the infant voice assures parents that, with hind-sight, the present ‘growing pains’ will become cherished moments. To anticipate the future when parents will want to remember “exactly how [the neonate’s] fingers looked when [he/she] was very small,” the infant voice offers the parent a physical piece of memorabilia (i.e., the handprint, the size of two thumbprints). This physical handprint underneath the poem conveys a visual sense of the natural body, as opposed to an artificial body. It serves to amplify the humanness of the infant, while de-emphasizing a body attached to artificial life-support equipment. Although machines and artificiality surround the infant, the handprint serves as a visual reminder that somewhere amongst the wires, tubes, and machines is small human person with a small human hand.

In many ways, constructing a voice for the silent and immobilized neonatal body is powerful way to reassure parents that the premature body is a willing participant of NICU treatment. The parent or caretaker no longer appears to be forcing NICU therapy upon a body without a voice, but the infant is now a willing participant. Here, a consenting voice is constructed for a body without any ability to exhibit any type of consent as to his/her own medical treatment.

Because parents and caretakers are often forced to make difficult treatment decisions involving painful and invasive medical techniques, a sense of the infant's consent alleviates parents' and caretakers' compulsion to justify these decisions. For example, when progress is so slow that it appears invisible, neonatal treatments may appear futile and it may become difficult to continually subject a body to invasive procedures when that body cannot express or indicate pain. Thus, during times when a neonate's condition is met with uncertainty, constructing a voice for a neonate to champion his/her own growth serves as a way to remind caretakers and parents that their efforts are not futile. Furthermore, it implicitly validates having chosen to continue treatment.

Decisions in neonatology are often "plagued by prognostic perplexity," (Henig and Fletcher 1983:117) parents and caretakers must often confront "a roller coaster" clinical course, with various ups and downs and many "comebacks and crashes," all without any guarantee that one will ever get off this ride" (Guillemin and Holmstrom 1986: 145). This poem provides a positive fixed attitude that everything will be fine, that all the uncertainty will fade away, and that the neonatal body will be grown someday. This fixed attitude, even an unrealistic one sometimes, “seems to help in coping with an otherwise unbearable insecurity” (Harrison 1983:5).

Most importantly, this sign is an invitation to parents to physically move closer to the bed space. It provides a focal point and compels “reading.” It is one of the few focal points surrounding an incubator that stands out amongst the metal, machines, and wire. It is a brightly colored piece of paper, surrounded by Easter colors of blue, yellow, and pink, and featuring common nursery motifs. One almost immediately recognizes a handprint, a familiar memento that speaks to American parents and the cultural expectations surrounding babyhood. As nurses have reported time and time again, “parents just love the little handprint, it’s like those handprints my kids bring back from art class. It makes them feel good and gives them something to do when they come in and their kid is just lying there.”

This is me…….”Please Don’t Interact with Me”
(Sign 2)

My Developmental Plan

My strengths are: “I am too cute for my own good, I have a lot of hair, I cooperate with all my nurses, I have an adorable twelve year old brother.”

My time out signal are : “Desat, HR (Heart Rate) decreases, finger splaying.”

These things stress me out: “Being on my back, suctioning, heel sticks, baths, having a crusty, yucky mouth.”

How you can help me: “I like to be on my stomach. I like to be tucked in and swaddled. Only touch me when I really need it…or I’ll show you.”

The second sign creates an identity for the neonate by portraying the neonate as a self-aware and introspective being. It is almost always constructed by and placed by nurses. It is intended for both medical caretakers and parents. The categories, “my strengths,” “my time out signals,” “these things stress me out,” and “how you can help me” create a personality profile for each individual neonate. The infant voice knows what she likes, what causes her stress, and what are her strengths.

We also see the cultural efforts of the NICU to construct an impression of the neonatal body as a "private body.” In the section entitled, “How you can help me,” the voice states, “Only touch me if you really need to…or I’ll show you.” The phrase “I’ll show you” is a very serious warning, but its presentation is playful. Too much touching and a premature infant can become over-stimulated, with potential threats to his life. Yet, the premature infant is otherwise doing well. Thus, the nurse is caught in a bind. She wants to encourage parents to visit. At the same time, she wants to vigilantly protect her preemie patient’s continued progress, which she knows is dependent upon restraining interactions from parents and preventing unnecessary tests and procedures other medical staff members may carry out. Nevertheless, if she is successful at restraining interactions, she wants to insure that there is a bond between her patient and his/her parents. Her rather elegant solution is a serious warning wrapped in a playful delivery.

Here, privacy is not only assumed for the neonate, but the implication is that the neonate is aware of the times when his/her body is being intruded upon. Furthermore, the neonate can even metaphorically protect herself/himself against the person who has intruded upon his/her body unnecessarily. This quote exemplifies a voice that treasures the right to be left alone. However, the reality of the situation is that necessary medical procedures are performed completely at the discretion of caretakers. They are performed at the most convenient times for the caretakers. It is generally at the discretion of individual medical staff members as to whether or not they will consider the length of time between medical procedures.

However, upon closer examination, the personality profile is really a medical course of treatment established for each preemie. The descriptions listed under each category include types of medically beneficial procedures, which the neonatal body should receive (e.g., suctioning, heel sticks, putting the neonate on his/her stomach, keeping the neonate tucked and swaddled) and medically alarming signals which caretakers should never over-look. These signs of physiological distress include when the body is desaturated, when the heart beat decreases, and when the infant’s fingers are splayed. In fact, these signs are warnings against interactions with this particular preemie. A lack of interaction is necessary for biological viability (the potential to possess a human body that is capable of existing and surviving in the ex-utero world). However, it impedes social viability (the potential to be accepted as a social person). Yet, the more one refrains from interacting with the preemie, the more biologically viable she is and thus, the more she needs social relationships to secure her social viability. The NICU situation is an ironic paradox and this sign addresses the situation as such. This sign simultaneously recognizes that this preemie’s condition will likely improve and result in a good outcome, but also warns that a good outcome is dependent upon refraining from any sort of physical contact and/or interactions with the preemie.

Here is yet another example of the contradictory relationship between the double prerequisites for life. NICU medical staff understand all too well that meeting both prerequisites for life are critical for survival. The often unspoken fear is that discouraging parental interaction at any point, even when it is not biologically appropriate, could lead to a failure to thrive, abandonment, or even benign neglect once the infant is discharged. What should be occurring in utero is now front and center in the external social world. This situation is a birth out of joint with time. The order for acquiring the double prerequisites for life are out of order. The acquisition of functional organs should have been acquired first, before any newborn is expected to work toward attachments with others. A newborn should not have to grow functional lungs at the same time that he is required to assert his presence in the lives of his parents.

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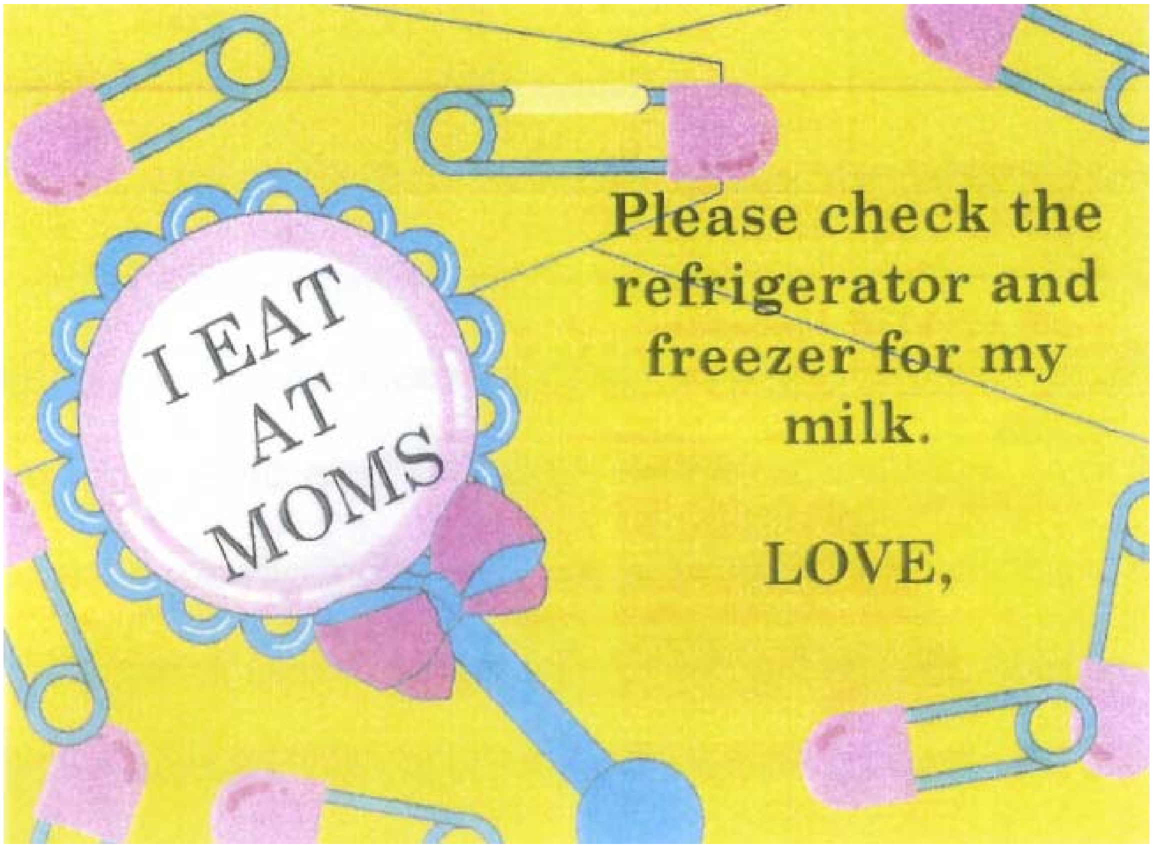
Achievements: “I Eat At Moms”
(Sign 3)



Please check the refrigerator and freezer for my milk.

LOVE,

This sign is the only one out of the three that are systematically given to all premature infants who are capable of taking breast milk, but who are not yet strong enough to latch-on to a nipple for breastfeeding. This sign constructs the neonate to be an agent of his own actions. The neonatal body “eats at mom’s.” The voice here is active and in the present tense, implying that the infant actually “eats.” “Eating” signals a naturally growing body and implies having a body with the ability to digest and process foods. Furthermore, the ability to choose what one wants to eat is an integral part of what it means to be an agent of one’s actions. Here, the infant voice is asserting her right to choose where and what he/she eats.

The mother/child relationship is the central focus of this sign. The words, “I Eat at Moms,” are spotlighted by the surrounding white area against a yellow back-drop while the words, “check the refrigerator and freezer for my milk,” appear as an after-thought. The effect of emphasizing the mother-child relationship is to convey a sense of the natural body while drawing one’s attention away from the medical reality of feeding a neonate. The infant voice also appears to prefer mother’s milk over other types of feeds, such as a special solution of lipids.

Many preemies are born without the capacity to obtain nutrition on their own. For those preemies who cannot yet tolerate breast milk, a nutrient solution is directly placed into a vein through an intravenous line. For those who have graduated to breast milk, but still cannot suckle and/or tolerate large amounts of breast milk, a mother is sometimes allowed to pour small amounts of breast milk (as little as a teaspoon full) into a feeding tube that is inserted through the nose or mouth and directly into the stomach to deliver and remove undigested foods and fluids from the body.

Because mothers are displaced from their role as primary caretakers while their baby is in the NICU, the ritual of pouring a small amount of breast milk into a feeding tube is one way to reinforce a sense of connection between the mother and the neonate. This sign acts to remind a mother that she is still a mom or has become a mom, as well as that her role as a biological mother, with the capacity to produce breastmilik, is intrinsically and irreplaceably needed for the survival of her child. The capacity to produce breastmilk is therefore particularly loaded.

Furthermore, the placement of this sign on any neonate's bedside is a significant milestone. It is an achievement—a graduation. This sign turns what is an innate biological aptitude into a social achievement, even before the preemie actually has required the capacity to suckle at the breast. Other significant innate biological aptitudes, which although do not receive signs, are often similarly transformative. These include "graduating from heat" (i.e. the premature infant is now able to sleep under a blanket), graduating to "open doors on the isolette"(i.e., the premature infant can now maintain homeostasis), and graduating from preemie nipples to full-term ones (i.e., they are strong enough to suckle a normal amount of liquid without choking or getting too tired) (Layne 2003: 635).

In essence, all three messages found on the three signs are selective exclusions, exaggerations and creations of certain crucial dimensions of human personhood. Neonatal bodies possess the dichotomous personhood characteristics of life/death, human/machine, natural/artificial, private/public, independent/dependent and ordinary/extraordinary. The three signs exaggerate and emphasize the characterstics on the left side of these dichotomies while excluding the characteristics on the right side. Similarly, by ignoring elements of death, machine, artificial, dependent, public, and extraordinary, which also characterize neonatal bodies, the three signs can now effectively create attributes that NICU individuals have always wished neonatal bodies to possess, but which they lack or only ambiguously possess (e.g. life, human, natural, private, independent, and ordinary). At the same time, they negate those personhood characteristics that NICU individuals hope premature infants will outgrow (death, machine, artificial, public, dependent, and extra-ordinary).

Another way to socially construct personhood for a being who cannot assert himself/herself is to project agency for a neonatal body that cannot interact with his/her environment in any kind of a meaningful way. During a neonate's hospitalization, nurses will often consciously try to create 'good' memories for the neonate so that his/her parents can record these interactions and experiences in baby books or journals. Creating 'good' memories involve giving parents a sense that their preemie is indeed a little person with the capacity to interact and become an agent of his own actions. One way to do this is to create a set of 'experiences' for the neonate. These various NICU experiences are based on "a number of markers of linear progression" founded upon the biological process of human gestation. In the NICU, the innate developmental maturation that should have occurred in utero are now viewed as achievements. From the perspective of medical caretakers and parents, they *are* achievements. Whether it is through giving consent, deciding and implementing treatment plans, pumping breastmilk, performing kangaroo care, showing up for visitation hours, or even just patiently waiting and showing interactive restraint, each group of actors worked in their own way and in conjunction with each other to create an ex utero environment that kept death at bay for premature infants. From the perspective of premature infants, these "achievements" are merely pre-beginnings. They are merely the innate maturational process completed or at least partially completed well-enough to enable life in the non-NICU ex utero world to begin.

Since preemies cannot react and cannot actually show preferences, all three signs serve as social instruments by which preemies communicate to others. Even though neonatal bodies are characterized by what may be perceived as conflicting attributes, only elements of life, human, natural, independent, private, and ordinary, which are attributes consistent with American notions of personhood, are communicated. The elements of death, machine, artificial, dependent, public, and extraordinary, which also characterize neonatal bodies, are explicitly ignored by the signs, yet their absence points to the darker sides of preemie personhood. Thus, by communicating one set of attributes while excluding another, the signs manage the darker undercurrents of preemie and parental personhood in the NICU.

The signs in the NICU are one mechanism by which the bio-social gap that exists between parents, medical caretakers and premature infants can be bridged. At the most basic level, the inability to connect and bond in normative ways is heartbreaking for parents. The knowledge that physical loving contact can be harmful is counter-intuitive to human nature. What loving parent does not want to experience the magic of a miniature hand wrapped around one's index finger, feel the softness of baby skin, or lovingly gaze and hum to a nursing newborn? Loving one's child in the NICU means having interactional restraint—Don't touch, Don't get too close, Don't talk too loudly, etc. For the preemies, stimulating interactions appear to be constant and everywhere—medical procedures, bright lights, human voices, diagnostic blood tests, intravenous tubes, feedings, diaper changes, parental visits. As many will eventually benefit from parental contact, parental contact can also be a double-edged sword. Therefore, signs do much of the contradictory work that is required to insure the survival of premature infants both in the near term and the long term.

In particular, it is critical to note all three signs rely on various kinds of "rights" to define and reduce the ambiguity surrounding premature infants. It is in their utilization of a rights-centered discourse that signs provide individuals in the NICU the capacity to create interactions, personalities, and achievements that otherwise would not exist. In doing so, the various individual rights discourses found in all three signs enable NICU individuals to create an agent-oriented, yet individualized presence for premature infants, with whom they can now transform a one-sided interaction into a truly interactive one. In turn, the capacity of signs to create an interactive presence for premature infants further enables both premature infants and their family and kin to take part in some aspects of commonly shared experiences of babyhood that can be considered the informal rituals and rites of passage found in American society, which are intended to initiate and accept newborn mother/child into the social world (Davis-Floyd 1992).

However, the work of signs in the NICU is first and foremost *not* about initiating mother/child into the social world. Rather, it is about utilizing the power of rituals and rites of passage to define and create concepts and experiences of personhood that are desired (i.e. life, human, natural, private, independent, and ordinary), while simultaneously obscuring the ambiguity of NICU premature bodies and negating the characteristics and experiences of personhood that are undesirable and less than hoped for. In a difficult complex situation where individuals often find themselves constrained by circumstances they have no control over, pessimism and the will to troop on can reign. Signs as epistemological idioms that anchor informal rituals and rights of passages enable NICU individuals to imaginatively act, transform, and overcome the anguish of “waiting” for premature bodies to grow *out of* death, their dependence on machines, their artificial existences, their publicly accessible bodies, and their extraordinarily precarious existences.

The next chapter places the three signs in specific case-study contexts. By doing so, the aim is to investigate whether paper signs are successful at producing the intended transformations that are desired. What will become evident is that as premature infants' bodies grow and emerge out of prematurity, they may challenge and/or reinforce the characteristics and experiences of personhood that were constructed for them. What happens when signs endow premature bodies with various kinds of "rights" for which they may or may not be able to exercise or fulfill?

CHAPTER 7: FINDING AGENCY, FINDING ABILITIES

Uncontextualized, the various paper signs described in the previous chapter manage the darker undercurrents of social persons in the United States for parents, medical caretakers, and society-at-large. They speak to what many individuals intuitively recognize, but cannot express. Nobody wants a child that is more dead than alive, more machine than human, more artificial than natural, and more dependent than independent. Nobody wants to subject a child to extraordinary medical care that may prove to be futile. Nobody wants to prolong pain and death. No one wants a child that is only a body, without the potential for a self, publicly displayed, trampled upon without any rights. No one wants to be the person that would subject a helpless preemie to all of this. These signs attempt to address and appease profound fears through instruction and motivation. It is no surprise that individual experiences often contradict what these signs say. If they did not, medical caretakers and kin would not need them. Parents and medical caretakers do in fact live with many, if not all of these fears. What these signs say is often not what they feel or how they feel. Yet, just trying to live the imagined partial realities of these signs provides some relief.

Drawing from Meyer Forte's work on personhood in Oedipus and Job (1959), we can see analytically that these paper signs serve a dual purpose. They illuminate ideas about personhood in the neonatal context that are "expository of social conflict, at the same time that they are also mechanisms for muting conflicts that cannot be resolved in any final sense" (Karp on Fortes 1987:717). In particular, one specific function of these signs is to be particularly attuned to social conflicts that arise due to a mismatch between different aspects of biological time as they become intertwined with the ex-utero social world.

Managing The Mismatch Between Biological and Social Vi(abilities) (Right/Rite(s) To Life: Rites/Right(s) of Passage)

Biology dictates a certain order to things and place, and where there is a disturbance in these events, so there is also a disruption in the proper sequential processes to social life. At the heart of the fetal growth and development process is a universal biotemporal form, a timed sequence to the physiological and functional maturation of organ systems (Jeanty and Lampl 2003). This biotemporal order is distinguished from concepts of time in social life by its regularity, irreversibility (Berger and Luckman 1991), and the predictable sequential relations among the stages of development, such as the fairly predictable temporal location (Zerubavel 1981) of conception, implantation, lung maturation, puberty, or menopause in the life cycle (Zerubavel 1981). However, as biological processes are emerging cellularly and physiologically, there is perceived irregularity and 'reversibility.' Under normal circumstances, these "still to be determined biological capacities" during the emerging human gestational process occur in-utero. Existing in-utero creates a barrier (albeit incomplete as we have ultrasound technology) to the ex-utero social world and the social experiences of time. As a result, when fetal maturation occurs in utero, it does not challenge how we experience the genetically based biotemporal order of the human gestational process, even when we endow them with personhood before they are born ex-utero. In other words, a fetus who is umbilically attached and living in the placenta is not fully in the social world in the same way that an ex-utero unattached newborn infant is. For starters, in-utero fetuses do not breathe. They also do not occupy a physical space independent of their mother's body. No doubt much insightful work has shown that in utero fetal life can be fully incorporated into an ex-utero social world (Rapp 1999) (Morgan 1998). However, the point I want to highlight is that there are drastic differences between the placental environment and the ex-utero world. An in utero fetus can only have a living social presence in the ex-utero world umbilically attached to its mother's system. It does not have a corporeal existence independent of its mother.

Nevertheless social time still possesses both objective and subjective aspects. There is a personal time of subjective consciousness—"the undifferentiated flow of "duration which I feel passing within me," as well as a "collective rhythmic form to social life" where temporal rhythms are grounded in objective social life, giving them a morphology of segmenting categories. It is this very layering of social time on top of a still emerging biotemporal order that produces different tenors of one-sided interactions found in the NICU between parents and premature infants. Interactions that feel restrained to parents are over-stimulating for preemies. In fact, the emerging biotemporal order with all of its still radical indeterminacies are explicitly on display as individuals continue to live in both a subjective and objective world of social time.

There are three analytical time frameworks used to evaluate the progress of fetuses and infants (Isaacson 1996). These three concepts of "age" for NICU preemies are often contradictory. There is a sense of the NICU preemie's age as it relates to his mother's last menstrual cycle—gestational time, there is a sense of age based on the physical appearance of the NICU preemie—morphological time, and there is a sense of age based on the functional ability of the NICU preemie, which includes the many capacities that are prerequisites for existential and social life—functional time (Isaacson 1996). While discrepancies between these various temporal frameworks for measuring the development of the fetus or baby can exist anywhere along a woman's pregnancy, as long as the fetus remains in-utero, many of these discrepancies do not produce deeply contradictory consequences. In utero, these various temporal processes, although not always exactly in sync, their lack of synchronicity does not carry the same implications. After all, fetuses are evolutionarily intended to stay inside the uterus until they are morphologically and functionally ready. This usually happens within a designated window of gestational time. However, with NICU interventions, contradictions between the various "ages" of preemies have biological and social consequences.

That is, without the intervention of NICU technologies, discrepancies between these temporal frameworks are practically moot upon birth. That is, either a fetus is born alive and survives to live that life or it does not. When a newborn does not survive, no matter how short that life may be, discrepancies between these analytical frameworks become adequate explanations for why an infant did not survive. For example, when a full-term gestational infant does not survive, it is plausible to explain his death by underscoring his body's functional and morphological immaturity. This is often true for newborn full-term babies with congenital defects. Spending 40 weeks in-utero provides a degree of morphological and functional determinacy that does not ontologically challenge biological and social concepts of the person and the individual.

Therefore, paper signs as part and parcel of informal rituals and rites of passage implicitly bridge two biotemporal norms. *First* is the biotemporal order of human gestation from conceptus, to embryo, to fetus, to infant, to adolescence, to adulthood. This is a universal human growth and development trajectory with individual variation.

Because NICU interventions occur during the late fetal growth stage, a time when the physical form of the human infant has been completed, but the internal organ functions required for an ex utero existential life are still emerging, there is now a *second* biotemporal order—a NICU biotemporal order. For each individual preemie, the difference between where they were "meant" to be biologically and where they might actually end up as a result of NICU interventions is indeterminate and laden with unpredictable biological and social contingencies. This is why prematurity is described by Drs William Meadow and John Lantos as both "an acute crisis and a chronic condition" laden with radical uncertainties that are unique to the NICU (Lantos and Meadow 2006).

Since the preemie cannot always be touched, interactions with preemies are largely visual and imaginative. It is the look of their body or "body idiom" (Geertz 1973) that communicates most loudly. The body is visible and accessible in the NICU in ways that it is not in utero (except by technological means). Thus, physical changes that are going on is imperceptible since it is the organs that are still maturing. Thus, parents will have to learn that what is happening is not necessarily visible as they might wish.

The mismatch between these biological norms of human maturation are at once the immediate cause of social conflicts and expository of wider biologically based conflicts. Because the NICU preemie's many biological capacities are still emerging, its own personhood status is under question while its experiences as an individual are fully produced and reproduced by others. Here, biological developmental processes are front and center—who is this NICU preemie? Simultaneously, these biologically based social conflicts are also expository of social conflicts that extend beyond the personhood status of preemies, including “What constitutes motherhood, fatherhood, and parenthood?” “What does it mean to do no harm in medicine?” and “What constitutes a dignified life or death?” These two aspects of biologically based social conflicts are inextricably intertwined.

The neonatal situation is an instance of biological processes forcing themselves on social relations that must be managed (Fortes 1987). However, these biological processes have to be managed. How various individuals in the NICU choose to understand who they are in relation and interaction with others is intimately intertwined with the emerging biological capacities (or lack thereof) of premature infants. When anthropologist and mother to a premature infant Linda Layne joyfully exclaimed in her diary, “Jasper graduated from heat today,” she not only felt the pride of a mother for the first time as many of her non-NICU mom-counterparts have, but she also recognized that it is a kind of pride not normally experienced by first time parents who revel in a first suckle at the breast or a first smile. The pride of having one’s child being able to maintain a regular body temperature (Layne 2003) seems both a little absurd and truly a moment of celebration at the same time. In turn, experiences with contradictory ideas of the infant person also generate contradictory concepts of selves and others in medical caretakers and kin. Medical caretakers, and in particular nurses, are often conflicted about playing the role of parents and teachers to both preemies and their parents. In addition, traditional medical hierarchies where doctors possess the authoritative power to prescribe medications and treatment plans often pose a structural challenge to the daily functions of NICU medical caretaking. By necessity, many nurses also find themselves taking on the role of attending doctors without official authoritative power, training inexperienced interns and residents at the same time they must also carry out treatment plans “signed off” by these junior doctors who look to them for guidance. Furthermore, nurses also take on the roles of social workers and even legal advocates when difficult medical decision-making is at stake. At the same time, parents are often angered and saddened by being unable to parent, relegated to the roles of a bystander, an observer, and even when they do get to participate, their role is often one of assisting in medical caretaking tasks, rather than parenting.

The patterns of various one-sided interactions described in Chapter 6 and further analyzed in this chapter implicitly point to these contradictory ideas regarding who one is supposed to be and how one experiences these various roles. All individuals in the NICU are perpetually moving between various roles, dictated by the emerging or lack of emerging biological capacities of preemies. Whether it’s medical caretakers, parents, kin, or others associated with the NICU, many report a deep emotional fatigue and “never feeling settled.” As a medical fellow once said, “There is a routine for everything, there is a protocol for everything, but you never really feel like you know what you are doing is right.”

Liminalities abound, but often without the relief of re-integration that comes from a completed change in state. In other words, the informal rituals and rites of passage anchored by a rights discourse found in the three signs do not always produce the affective experiences that are hoped for. In other words, when rituals and rites of passage occur before premature infants possess the requisite capacities for interaction, they often fail. That is, the goal of rituals and rites of passage is to not only initiate individuals into new roles and confer new statuses, but it is more importantly to generate the desired affective experiences of personhood (Kratz 1994). In the NICU, the use of a rights discourse to create rituals and rites of passage can achieve the former goal, but not the latter. As a result, although premature infants are initiated into the social world of babyhood with various "rights," including a most critical "right to life," the affective experiences of life itself are often not achieved. Thus, preserving a premature infant's biological life (or "right to life") does not necessarily generate social viability ("rites" to life). In turn, rites of passage that are intended to create meaningful affective experiences of personhood often times turn out to be merely a series of "rights" of passage.

Anthropologist Robbie Davis Floyd interviewed new mothers of full-term infants and found that reintegration occurred when "they no longer felt trembly or potential," but "mundane" and "mainstream," when they finally feel as though they have successfully "crossed a barrier" and swum up on the other side (Davis Floyd 43, 1992). For NICU medical caretakers, parents and kin, these feelings are sought after, but continue to be indefinitely elusive until premature infants grow out of prematurity. Because the work of keeping preemies alive is intimately intertwined with the biological capacities of preemies, it is only with the achievement of a level of biological stability, that moments of reintegration and temporary resolution emerge. However, they are rarely, if ever, permanent. As a mom of a 3 year-old former NICU graduate said, "Johnny scores very high in some areas and low in others, everyone tells me he's normal because he averages normal, but when you take the individual parts, he isn't. We still have to live with the individual parts of his development that are not yet normal. But everyone tells you he's fine. Yes, he's fine, but he is not fine" (Ren, fieldnotes 2000).

Given the interplay between biological developmental processes on concepts of selves and others, as well as on social relations between individuals, it is evident that the tenor of various one-sided interactions changes in relation to a biotemporal order. In other words, the degree of “one-sidedness” changes in relation to the emerging capacities of preemies. It is in this context that signs must be understood.

In the beginning days of any preemie’s life in the NICU, one-sided interactions involve interacting with a preemie body whose biological capacity for life is not yet fully determined. It is also a preemie body whose biological capacities have regressed. Whereas in utero, a preemie body of 28 weeks can kick, suckle, turn around, hear sounds, possess various sleep cycles, and most critically, have the capacity to variably exercise these capacities through sensorily interacting with its in utero environment; this same body, once delivered to the outside world before 40 weeks, will lose these capacities and their re-emergence is not guaranteed. Furthermore, in many cases, there is a “developmental” price to be paid for their re-emergence, sometimes it is only in the short run, sometimes it is forever. Although almost all preemies are eventually discharged from the NICU, medical caretakers and parents are now all too aware that NICU preemies are significantly much more susceptible to a range of issues that although are not (yet) directly linked to NICU care, they are a result of an alternative growth trajectory that otherwise would not have presented itself (Saigal et al, 2002, 2003) (Hack et al, 2005) (Doyle et al., 2001). Many cases of identical preemie twins speak to the existence of two biological developmental trajectories all too well. A conceptus split into two embryos with the same genetic material, developing into two fetuses under identical in utero conditions, and then delivered prematurely at the same time, these double preemie lives often show the realities of NICU interventions producing alternative growth trajectories all too well. Although identical twin preemies often start out with similar medical conditions and with similar treatment plans, it is not uncommon that the outcome of one twin is normal and the other is compromised. Sometimes the discrepancy is small, one may be more prone to pneumonia than the other. Other times, the discrepancies are significant, one may have cerebral palsy and is wheelchair bound for life while the other is completely normal. For singleton NICU preemies, medical caretakers and kin may never know exactly where the biological developmental potential "could have been," but when outcomes are not ideal, the undercurrent of living with an alternative developmental trajectory is lived every day.

Thus, one-sided interactions during the "beginning days" of the NICU are steeped in these kinds of unspoken and darker undercurrents of alternative growth trajectories of biological personhood, which are inextricably intertwined with future possibilities for social personhood. Especially for preemies that are the most biologically vulnerable and require ventilation, this period is often characterized by a NICU induced corpse-like "stillness." This is achieved through giving Pavulon, a neuromuscular blocker that relaxes or paralyzes the skeletal muscles, in order to improve oxgenation and reduce dangerous blood pressure effects. As a result, any potential "communicative" sign is now pharmacologically neutered. For those preemies who do not require ventilation and/or pavulon, their physiological interactions with the ex utero sensory environment is one marked by deep sleep, non-stimulus specific tremors and jerkiness, and the occasional moments of open eye-lids. However these physiological cues are not what parents and kin would expect. They do not generally mean alertness. Rather, just the opposite. Jerkiness, tremors, are signs of "shutting down" while open eye lids signal deep REM sleep and a kind of preemie hibernation, rather than interaction.

Here, interactions during this period of time are biologically and socially one-sided for preemies and those who care for and about them. A preemie's nervous system may be able register environmental stimuli (e.g., lights, noise, medical procedures, etc.), but it is difficult to tell. For medical caretakers and parents always looking for signals and cues, and any clue as to how well the preemie is doing, they are often discouraged by a body that just "seems to lie there" (Ren, fieldnotes 1998), not signaling anything. For preemies, "not dying" is the most obvious show of a signal regarding the its medical status. However, "not dying" is a difficult signal to measure and show to others, and one that is hard for others to know. There is often a disconnect between what preemies can physiologically "show" to others and how other actors can "know" the preemies. It is only in the last five to ten years that medical caretakers and researchers are beginning to understand that a "lack of signals" or cues can signal "overstimulation" rather than a lack of response to stimuli. It is through working out and learning a different set of biological and physiological epistemologies in the space of interactions-in-the making that a "lack" of perceived biological responses from a preemie's body's becomes something more.

Under these circumstances, interactions with preemies and with each other in the context of preemies are about interacting with mechanical designations of vital signs. One has to "read" into the stillness or learn a new way of interpreting physiological cues. It is not so much that NICU preemies are non-interactive, but that they are socially non-interactive. Their physiological cues are often misread or mistranslated socially. It was not until a little over a decade ago that researchers began to understand that preemies could experience pain. Prior to new findings regarding the development of the preemie nervous system, preemies would undergo significant and painful surgery without anesthesia because it was thought that they could not sensorily register stimuli or “interact” with the ex utero world. One-sided interactions in the NICU during the beginning days are characterized by an inherent problem of interacting with other human beings who do not have possess the functional capacities to existing in a social world where all interactions, even the reading of biological cues are laden with the social.

During the “roller-coasting days,” one-sided interactions take on a different tenor. This is a period of time where medical caretakers are beginning to learn the idiosyncratic physiological signals or the lack thereof of their preemie patients. Interaction is socially one-sided, but physiologically the preemie body is now beginning to “show” positive signs of distress or lack of distress. For example, their bodies can noticeably turn blue or stiffen under duress. One does not have to rely solely on monitors to read the preemie.

Lastly, during the “almost home” days, both the biological and social one-sidedness of interactions are beginning to fade. Nevertheless, because the NICU preemie is still very much a preemie and does not yet have the capacities of a full-term infant, the biological cues and signals that parents are just becoming acquainted and comfortable with will soon change again as preemie’s begin to acquire the physiological and more social behaviors of full-term infants. For example, a mother who is used to a certain kind of feeding routine in the NICU may find that very little she has learned in the NICU to help her preemie feed better will apply once she gets home. As many parents have reported, “Home is a completely different ball game. You have to relearn everything” (NICU father). With a change in environment from an intensive care unit to a home environment where medical contingencies are replaced with the more quotidian contingencies of everyday life, the preemie will once again become difficult to “read” as he or she must adjust to a new set of stimuli, a new set of people, and a panoply of circumstances to which there is rarely a routinized plan in place for managing them. Parents often become discouraged as they feel they must start “over from the beginning again” and are disheartened that their time and experience in the NICU does not actually buy them as much knowledge, stability, and/or management skills as they had hoped. What is supposed to be a period of re-integration often feels like an extended liminality where individual and family life are betwixt and between once again—but, no one is quite sure betwixt and between what and when and if this liminality will ever be resolved.

Sign 1, the “Growth Poem” implicitly speaks to these various universal biological and physiological contingencies of a NICU preemie’s maturation and how they may be interpreted in light of the contingencies of social life outside the NICU. However, despite the fact that they speak to circumstances that are relevant during the beginning days, they are not routinely placed around the bedside of every preemie, and more surprisingly are never placed on incubators during the beginning days of a NICU preemie’s life. Rather, the common time they are used are either during the “rollercoasting days” or “the almost home days.” In the discussions to follow, the reason behind this will become evident. Sign 2, “The Personality Profile Sign” is generally placed toward the end of the “beginning days” period and anytime thereafter. Although they are also not placed on the incubators of every preemie systematically, the timing of their placement usually occurs throughout the “rollercoasting days” and their removal usually occurs when the preemie is moved into the intermediate nursery or the “grower and feeder room.” In general, these signs are used when medical caretakers, and in particular primary nurses, felt that a particular preemie was doing “better” than what their physiological markers of progress indicated (e.g., blood count, oxygen levels, etc.). Sign 3 “I Eat At Moms,” is the only sign that was routinely placed on the incubators of all preemies who receive breastmilk. In each case, the sign and the timing of when the signs are placed or removed are significant. T.O. Beidelman’s work on Kaguru thought processes has shown how individuals will focus on different temporal frames in order to gather a sense of control and order.

These various paper signs are utilized in this context as a means of managing time. The preemie body, although without the capacity for communication and interaction, does possess an unintentional “body idiom” (Goffman 1990)—the impressions inadvertently given off by the NICU preemie body. There is no “time out” in any social encounter, even a one-sided one, from a body idiom of a newborn person that is more dead than alive, more artificial than natural, more mechanical than human. The very corporeality of the preemie body, although not a full social person yet, does have a biological individuality whose knowability is just emerging, but its body can only communicate stillness and death. This is a stream of impressions that points to a mismatch between biological temporal processes. Gestationally, the preemie is a certain number of weeks and continues to age. Morphologically, the preemie body looks complete, but functionally, the body is still emerging. Signs therefore discern a preemie-specific temporal frame by providing a meaningful bridge that connects the three temporal frameworks. For example, the growth poem assures parents that although they may not see continued morphological growth such as weight gain, the preemie is nevertheless functionally growing. In this way, signs explain away discrepancies between different biological temporal frameworks, enabling individuals to perceive certain outcomes as more likely than others, while current conditions prevail with varying degrees (Beidelman 1993).

Informed by the timing of biological growth and development, the non-situational analyses of the above paper signs point to the “more public and artificial versions” (Beidelman 1993) of what it means to be a baby, a parent. In part, they are what psychological anthropologist Bradd Shore defines as “instituted models” or conventional, patterned public forms put forth by social institutions that provides us with cultural resources to help give “partial and temporary resolutions to what may be ultimately irresolvable predicaments” (Shore 1998:305). In this view, cultural systems do not invent values so much as they organize “the perception of value-laden situations with standardized and culturally acceptable formulations” (Shore 1998:304). By presenting these paper signs first on their own, without a specific context, what I have attempted to point out are contradictions between these normative concepts of who or what a baby should be; who we should be in relation to them; and how we should act towards them and how they should act towards us—and the many ways in which NICU interventions challenge these idealized concepts of the person. The individuals associated with preemies live between two worlds—the world of the NICU and the social world outside the NICU. These paper signs bring together their two worlds. As such, they are both culturally acceptable formulations of babies, parents, and medical caretakers, and because the NICU is a situation that exists outside the expected norms of pregnancy and birth, they are also idealized formulations, which are not the norm under a NICU context.

However, it is also important to understand the interplay between paper signs and various NICU individuals in specific contexts. For example, when a parent comes into the NICU to visit and stands over the incubator, just watching, her one-sided interaction is largely “within,” invisible to the outside observer. However, when she does this same act in the context of a sign, another actor can begin to speculate how she must feel, and thereby instigating new interactions or altering existing ones. Simultaneously, the parent herself, prompted by whatever message is on a paper sign acquires the sense that there are expectations for how she should feel. As a result, she may begin to stand over the incubator with “more purpose,” and at the same time feel more resentment or anxiety about her interactions with her preemie child.

In this instance, although the various signs that anchor informal rituals and rites of passage may have successfully initiated a parent into the world of motherhood and may have provided her with a well defined sense of her role and status as a mother, it remains unable to transform a premature infant into a full-term baby. Thus, the use of signs as epistemological anchors for rituals and rites of passage is only a partial success. Affective experiences of babyhood/parenthood also depend upon the emerging capacities of premature infants to genuinely interact “back” toward his/her parents (and not just imaginatively so). This is because although rites of passage can define and tell us who a person or individual is, it cannot generate the experiences that surround an “individual-oriented-presence” that American medical caretakers and parents hope for and expect from their premature infants. After all, despite the progress of science, we are still not very successful at manipulating and “speeding up” the biological clock of human maturation to meet the social and interactive demands of an ex-utero world. The next section provides two cases studies that show what happens when the development of preemies actually happens. That is, how do their actual development and continued maturational growth (or non-growth) challenge or reinforce their development as marked by signs intended to construct rites of passage?

Signs in Context

With these thoughts in mind, this section/chapter attempts to illustrate how paper signs, in spite of their organizational features as cultural models, are also critical launching pads for social interactions-in-the-making, producing and reproducing an awareness of ourselves and others in intended and unintended ways. As T.O. Beidelman insightfully stated, “to interact with others we must imagine what their own needs and views may be, often working through a process of combining projection and introspection” (Beidelman 1993:2) or “imagination” (Beidelman 1993). Specifically, when placed in a particular context, paper signs will not only show different situational definitions of the person, but through instigating imagination it “delves into the murky, ambiguous interstices between these different situational definitions of the person, of social roles, values, and beliefs” (Beidelman 1993:9). They turn what is a one-sided interaction, an interaction that is largely with oneself and internal, into an externally oriented interaction, even if the social form of the interaction remains the same.

Placing signs within specific narratives will illuminate how a mosaic of experiences are produced and reproduced as individuals interact with each other in and out of the neonatal context. Paraphrasing Simmel, we are made up of mixed feelings, “as composites of many drives and of opposite sensations” (Simmel 1971: 77), which is “entirely self consistent” (Simmel 1971: 77). What Simmel means here is that countervailing tendencies are “a given” of the human condition and that they are part and parcel of who each actor is as both a person and an individual. Therefore, signs are at once general and particular, and as launching pads for social interactions-in-the-making, they assist with “building up” a mosaic of experiences for various individuals in the NICU. I argue that paper signs produce and reproduce social viability for preemies, kin, and medical caretakers, when the biological prerequisites for existential life (or biological viability) are still emerging.

The specific ethnographies below will provide a context to show how the messages conveyed by these paper signs are “keyed” (Goffman 1990) into various cultural norms of medicine, babyhood, parenthood, and the normative expectations for how full social persons should be, both biologically and socially. By organizing and framing various kinds of experiences with and about preemies, these signs have drawn on the familiar in order to speak to the strangeness of the NICU preemie, bridging the world inside the NICU with a social world outside the NICU to which actors and preemies must re-integrate when they leave the NICU.

Simultaneously, and more critically they are also launching pads for social interactions. As will be illustrated through specific ethnographic contexts below, signs compel three important elements of interactions. Drawing from Anthony Giddens theoretical construct on the production and reproduction of social life, they are (1) meaningfulness (2) moral order and (3) relations of power. First, signs provide a form of meaningful communication that translates between different sets of mutual knowledge (Giddens 1979:106-107). As evident from the various analyses presented above, signs attempt to translate various NICU conditions about the NICU preemie into a general language about babies. And vice versa, they bring aspects of babyhood to the NICU preemie and aspects of parenthood to the parents. In addition, they are it is also a way to communicate practical knowledge regarding the care of NICU preemies, personalizing many routinized tasks.

Second, the constitution of interaction as a moral order can be understood as the actualization of rights and the enactment of obligations (Giddens 1979). In the NICU, rights and obligations come in various guises. Due to prognostic uncertainty, there is always an undercurrent of anxiety over whether individuals and society at large have the right to impose treatment on preemie bodies. On a more practical level, because the preemie cannot consent to his or her own treatment, studies of NICU decision-making have pointed to discrepancies between access to information between parents and medical caretakers (Anspach 1997), as well as how the NICU can organizationally motivate various individuals to take responsibility for the care of infants (Heimer and Staffen 1998). Thus, signs are implicitly part of the larger organizational structure to parse out rights, obligations, and responsibilities in certain ways. Whether this is successful is context dependent. As Giddens stated, the “realization is contingent upon the successful actualization of obligations through the medium of responses of other participants” (Giddens 1984:108).

Third, paper signs resituate relations of power by giving imaginative resources that actors can mobilize in order to acquire a sense of control. For example, giving a personality to a preemie through papers signs (see sign 2) enables individual actors to feel as though they can intervene in a series of events as to alter their outcomes. Here, signs instigate interactions-in-the making filled with transformative capacity (Giddens 1984).

With these thoughts in mind, two specific narratives will be presented below to contextualize the paper signs. They are “Lizzie Lollipop” and “Miracle Michael Jordan Jackson or MMJ.” Each is a foil for the other and represents two contrasting neonatal outcomes. Lizzie Lollipop is a preemie that everyone expected to do well from day one, and in fact, did do well. She never had any difficult medical crises and was not a “difficult” or “grey area” case. She is the poster-child of NICU medicine. Someone who otherwise would not have lived almost fifty years ago, does in fact survive and becomes in every way re-integrated into the social world. She is a preemie that medical caretakers never remember once they leave the NICU. Statistically, Lizzie makes up at least 80%-90% of NICU cases. Only her parents remember her time in the NICU, yet in follow-up interviews, they do not have much to say about it except, “Oh yeah, it seems like so long ago. We forget she was a preemie. But, now that I’m thinking about it, it was a really hard time. We have just forgotten. It’s like it was another life. She wasn’t even her. She wasn’t really ours. It was a strange time (Lizzie’s mom).” For Lizzie and her parents, her stay in the NICU, although a difficult period of time while it was happening, is more like a pre-history rather than a part of a her life history. For Lizzie, the biological processes of growth and development have “caught up.” The biological processes of maturation that were front and center during the NICU days are now “underground” once more in the continuous flow of social life, as they should be—“intuitively recognized” and imposing itself on social life, but not explicitly determinative of social life (Karp 1988).

Like Lizzie, MMJ also survived. However, his survival is indelibly marked by the NICU. MMJ is a preemie that many believed “should not” have survived, but in fact did. He is a “kid with lots of death dives (Ren, fieldnotes 1998)” –a “grey area” case (Lantos and Meadow 2006) that underscores the fine line between success and futility. He is simultaneously a preemie and a case scenario that no one ever forgets. He is that 10% of neonatal cases which are the most troubling, generating ethical dilemmas that have personal, collective, social, moral, and legal implications. Here are their stories. I will first present their stories, then I will analyze their stories in the context of paper signs placed on their incubators.

"LIZZIE LOLLIPOP"

Lizzie the lollipop kid, born at 28 weeks, and weighing a little over 2 pounds, is in the corner, next to "the kid on ecmo" (on a heart-lung machine). There is a lot of action on this side of the room, The kid on ecmo is fighting for his life, and there are people coming and going and checking up on him. He doesn't have a name yet. His parents are waiting, he is known as the "fighter," but he seems to be doing well and everyone is hopeful. Lizzie, his neighbor, is doing well too. In fact, very well. Mary put ups two signs on top of her isolette today—A growth poem (Sign 1) and a list of Lizzie's likes and dislikes (Sign 2). Today is day 10.

Mary tells me, "She is just fine, I just don't want anyone messing around with her too much. She really needs to just be left alone and then she can make her move to the feeder and grower room. People get a little wigged out by the ECMO kid, who we can't do anything about, and then they check on Lizzie a little too much."

"So, you think everything is fine, right?"

Mary smiles at me and says, "Hand me one your lollipops, the little ones, those dum dums" "Watch this………" She takes the lollipop and gently nuzzles it against

Lizzie’s lips, as if it was a nipple. She prompts Lizzie a little bit more. “Just wait…give it some time…she has to get a sense that its there. She might also be asleep….” We wait 5 or 6 minutes, chatting in a low voice. Intermittently, Mary brushes the lollipop against Lizzie’s lips.

Full-term babies love the taste of sugar water and will almost immediately turn their heads and begin to suckle and search for more. Lizzie’s responses are less organized. Mary continues, “You sort of have to feel her…..But, just wait…” Another minute goes by and I see Lizzie’s mouth begins to pucker. It looks like slow motion, it doesn’t look like a reflex, like its supposed to be. She is “re-learning” how to suckle, something she was capable of doing in utero, but has not been able to do again until recently. It’s a little strange to see it. What is a reflex looks like work. She is awake now, and seems to now fully grasp that this is a treat, not another painful procedure. Mary seems ecstatic…”Look, her little tongue wants to lick it. This is a good one. She will be just fine. I think she is giving that ECMO fighter some good luck.”

The two papers signs that are taped on top of Lizzie’s incubator are signs reassuring people that “she is doing just fine.” As Mary told, me, “I just don’t want too much prodding and poking. She needs to be left alone.” Preemies cannot be touched too much (Sammons and Lewis 1985)

It also reassures her parents. Her parents cannot seem to grasp that their daughter is coming home that she will be fine. It’s hard for them to trust it. Her parents had a hard time even approaching the incubator. The growth poem is intended to help her parents feel comfortable visiting. To give them a sense that they are supposed to be there, that their child knows. As Mary is telling me this, she grabs a couple more lollipops and hides them in her pocket. I'll see how the mom is and maybe I'll show her the lollipop. But, I also don't want them to get too hopeful. You really never know what will happen. There are always one or two kids that just suddenly go south for no reason. It's probably better just to keep this a little secret between us." I need to read the parents. Then, I'll decide. In the meantime, I think the sign will help. When they come and visit, it will just remind them that Lizzie is fine.

I always carry around a bag of candy when I collect data in the NICU. It was the only way to initially get doctors to take a minute out to chat, but now it has become part of the protocol and people expect it. The nurses always request hard candy, and the residents always chocolate. The nurses want a low calorie treat, more frequently as a distraction from routine boredom. The doctors who are on call and in a residency period, filled with tests, lack of sleep, and all of the accompanying pressures of getting a fellowship, are in survival mode. They need calories. Everything for the residents is new and stressful, they are just learning the routine and it is hard work. They need chocolate. Mary tells me that Lizzie is a lollipop person. She needs something to do. She needs motivation. Mary takes a dum dum lollipop and wiggles it around Lizze's mouth and Lizzie immediately begins to suck the lollipop. Mary then says, "I keep telling everyone that she is ready to move, to be a feeder and grower, but the docs are playing it safe because her numbers are still flat. They are waiting for her red blood cell count to go up a little bit more and her white blood cell count to come down a little bit more."

Mary then tells me that it's because the kid on ecmo is making everyone nervous, it makes Llizzie seem less stable. At the same time, "This has been a lucky part of the room. Even the ecmo kid seems to be doing better than everyone's expectations. So, I'm ok with not moving Llizzie for now. I'll fight that fight later." "I'll just entertain her for now." Mary continues, "Any kid who likes a lollipop is going to be just fine. She needs to be with other kids like her." Lizzie is a lollipop kid and not a chocolate person. She is not struggling to survive. She is just trying to get through the routine. Today is day 10. So, for the next 15 days, Mary and I do the lollipop test. Lizzie looks forward to it. She always sticks her little tongue out and then sucks. On day 20, Lizzie was moved into the intermediate nursery, just 30 feet away, on the others side of a partitioned wall with a connecting door to the NICU. The Ecmo kid is now off Ecmo and after a couple of months, also goes home.

"MIRACLE"

That bed 48 has a name now. Did you see it? Janelle the NICU nurse informs me. "You like that name?" There is no hint of sarcasm or judgment. I shrug and say "What do you think today?" "I think he's going to live. I don't think he's going to live well." She stops momentarily, and looks me in the eye. "I'm very confident." I know instantly how to code her responses. L5, S5, which means, "live, highest confidence, severe neurological impairment, highest confidence." I make my way to the residents, the fellows, and finally the attending. Everyone agrees. I have been tracking intuitions of this "24 weeker, 650 grammer, bed 48" for 9 days now. In the first couple of days, there was not a single medical caretaker who thought this premature newborn would survive. Today is day 50.

Bed 48 is now Miracle Michael Jordan Jackson, baby boy, born April 15, 1997. He weighed 650grams, and was born at 24 gestational weeks, four months before his due date. A split second decision was made to resuscitate him—Did he look “like he could make it” or “hopeless” (Frey 1995)?” He was born to a sixteen-year old teenager. Addicted to cocaine and heroine, she did not know she was pregnant. His APGAR score, was 0, and then 2 out of 10—a clinical scoring system to determine the degree of “aliveness” before and after resuscitation. It is also an idiom for “dead, resuscitated, and barely alive” (Ren, fieldnotes 1994). As with almost every premature delivery, he was rushed, docked, and connected to a space. In this case, bed 48. No one seems to remember the teenage mom’s name. I’m told, “You only focus and remember things that are absolutely necessary.” I only saw her visit once. Her visit was around 5 minutes long. She was sitting in a wheelchair, someone was saying, “that is your baby, you get that.” Rose, the grandmother, is bed 48’s designated primary caretaker, functionally and legally. She knew immediately what she would name him. Rose is a hard working forty-something year old single mother and now grandmother who lives in one of the housing projects on the south side of Chicago. She told me it was exactly what comes to mind every time she thinks about him: “He IS a “Miracle/miracle…you know what I mean.” Every one told her he would die and urged her to sign a DNR (A do not resuscitate order). She thinks he is a miracle for even getting himself born. “That baby knew his momma’s body was damaged and he just needed to get out. And out he got.” She calls him Miracle Mike, Mikey, or MMJ (mini Michael Jordan). He is also named after Michael Jordan, the superstar basketball player for the Chicago Bulls, who, in 1997 was on his way to claiming another world champion trophy. Rose tells me, “He also needs an everyday name….the only every day name that goes with Miracle is Michael Jordan….that Michael Jordan can do anything, and Mikey already did the one thing MJ can't do…come back from the dead."

The nurses tell me that Rose rarely visits. Rose tells me that she never really needed to visit, "I don't know how to work and read all of those fancy machines. Mikey is in a nice place. They take care of him 24 hours a day. There are lots of fancy doctors and nurses. I'd like to be in a place like that if I'm ever in the hospital." Here, it is worth noting that class differences are often at play in NICU interactions. Several studies of found that parents who belong to lower socio-economic groups generally request continuation of treatment even when they are advised against it (Meadow and Lantos 2006).

I have never met Rose, I have only spoken to her on the telephone. In fact, I never got to speak to Rose while Miracle Mikey was in the NICU. I was only able to track Rose down after Mike was discharged, as part of a follow-up study. During our first conversation, I asked Rose how Mikey was doing. She tells me that he is "A growing boy. Still going strong." We chat about the past for awhile and it was only after I begin my follow-up questionnaire called, "Your Baby's Day," that she informs me that he doesn't live with her. He is in a home for disabled babies and kids. As I'm closing my conversation, I ask Rose my last question, "Do you know some of Mikey's favorite things?" This is always my last question. I decide to ask anyway, just to be thorough. She tells me to call Mary, "Mikey's everyday momma" over at Lake House. As I'm thanking her for her time and for sharing her thoughts, Rose tells me. "You know, he got out of this neighborhood. My daughter, his momma, felt so guilty about him. She is in rehab and running with a good group now."

I have become familiar with telephoning the nursing staff at Lake House. There are always a couple of NICU graduates who reside there and I have called to track their post-discharge outcomes. I talk to Mary, she is cheery, as always. Today I ask her about Miracle Michael Jordan Jackson. She says, "Oh yeah, Miracle Mikey. He is growing. He's starting to take solids, a little bit of baby food. No issues. He is a good eater, sort of amazing, considering, kids like him often still need to be tube fed." I go through my questionnaire. Miracle Mikey is now a little over 18 months actual age, 12 months corrected age. He lays on his back and they are working with him to help him lift his head. This is the major milestone of the moment. He can track eye gaze, he can smile, he can make sounds, he can hear in one ear, he can see. He can also kick his legs and move his arms. He has the developmental age of a 4-5 month old. He may never learn to talk though. My last question is always, "Tell me some of your baby's favorite things to do during the day." The answers from this question will not make the Pediatric papers that will be published. But, I have found that it provides a good closure to conversations and helps the primary caretaker remember other insights and reassess their responses. For the next hour, Mary chats about all of her kids. Miracle Mikey is in many ways a miracle compared to some of his other housemates. "He likes people and gets excited about food, he actually eats and seems to like it."

Miracle Mikey lived in the NICU for 150 days. I know this because we gathered an assessment for him everyday. With the exception of the first 4 or 5 days when everyone thought Mikey would eventually die, the next 10-20 days of assessments made by medical caretakers were mixed. Some still thought (or hoped) Mikey would die, while others said "L5, S5." That is code for "live, highest confidence, severe neurological impairments, high confidence." The difference in assessments is not so much a difference over disagreements over Mikey’s prognosis. It was mainly a difference over whether people thought Rose would sign a DNR. The medical caretakers were split. Eventually, over time, people came to realize that Rose would never sign a DNR and all of the intuitions became unanimously L5, S5. Once in awhile, someone will “go out on a limb” and answer “die.” They are usually “newbies,” not necessarily new to neonatal care, just new to this unit. These newbies are for the most part right. They just haven’t been around for the “Mikey ordeals” (Ren, fieldnotes 1998). Most premature newborns like Mikey die within the first three days of life, when persistent high-tech medical treatments no longer provide any benefits (Meadow et al 1992). Most parents sign DNRs for preemies like Mikey. Medical caretakers can sometimes become frustrated and angry with parents who refuse to sign DNR orders. Their continued efforts no longer “feels right” because the connection between continued treatment and a positive therapeutic outcome appears “futile” (Schneiderman 1990) (Helft, Siegler, and Lantos 2000). “No one wants to make their little lives more painful” (Ren, fieldnotes 1994).

The NICU team, especially Janelle, Mikey’s primary nurse, and always his champion, does not think of him as a miracle. There were times of frustration with his daily care and sadness for his quality of life. For Janelle, she was the one that poked him with heel sticks, put in and took out IVs and tubes, and the one that talked him through and swaddled him afterwards, trying to ease his discomfort. Janelle was not shy to let people know that perhaps death may be better than life with severe disabilities. She would often, and only half jokingly whisper to me, “I’m old, I could just trip over the electric cords.” But, Janelle is also the one that places signs around bed 48, informing other medical caretakers of Mikey’s “habits” and things to watch out for. As she says, "I'm just leaving notes for his sitters," telling other medical caretakers how to read his monitors and his body language when she is not in the unit.

The next day after talking to rose, I'm back in the NICU. Janelle has a new primary. "This is good one," she tells me, with a hint of a smile and deep relief. The new bed 48 is only 9 weeks premature. Her name is Hannah and she will be off the ventilator in a few hours and will be moved to the intermediate nursery. It is the "vacation room," a section within the NICU, partitioned off by a wall and a door where preemies go to feed and grow, before they go home. It is only 10 feet away, and within the NICU, but it is a world away.

I tell Janelle about my conversation regarding Miracle Mikey. She says, "who?" I say, "bed 48, remember?" She takes an anxious, but involved breath, "How is he? That is one kid I will never forget. He took a lot out of me." I tell her that he eats, he likes people, and that his mom is in rehab, turning her life around. She fittingly says. "I didn't expect him to eat. And I guess, he saved his mom." "I'm still not sure about the name though."

The NICU narratives of MMJ and Lizzie illustrate both the commonality and the stark differences of experiences in the NICU and their long-term ramifications. For 90% of the NICU preemies, like Lizzie, their time in the NICU is a prehistory, a time remembered only by the parents. Any developmental issues later in life may or may not be traced back to being born prematurely. For Lizzie, the biotemporal gap that was expansive at the beginning of her life in the NICU has closed and the mismatch of social interaction and biological development is no longer evident. It is a distant memory. In the case of the other 10% of preemies that survive their time in the NICU to discharge, like MMJ, their life is forever informed by their experiences in the NICU and by their premature birth. They have lasting disabilities. The biotemporal gap, loses its temporal nature and their growth and development takes a different trajectory. Part of the complexity of social interactions in the NICU is that it is difficult to impossible to differentiate these two groups while in the NICU. The medical caretakers are unable to predict with accuracy the projected outcomes of their patients. The signs that are placed in US NICUs are but one mechanism to mitigate the uncertainty of the situation and give a voice to the voiceless. Moreover, the signs project a future where the preemie is a "normal" baby. For most NICU preemies the signs do predict a future they will realize, but for other's it is just a wish and a hope. Like the original Michael Jordan, MMJ will need to dig deeply and find a level strength that is beyond the capacity of most normal people to succeed, but in MMJ's case it will be to have a functional life.

Lizzie Lollipop and MMJ are two case studies that illuminate how the development of premature infants are marked by signs to construct rites of passage. In the NICU, individuals struggle with unmarked or "empty time," a period of physiological maturation that occurs independently of human agency. There is a lot of "waiting around" for premature infants to grow and mature. In the meantime, medical caretakers and parents must pass the time and are forced to make sense of and interact with premature bodies. For premature infants, their survival not only depends upon biological viability, but also social viability. That is, even though they cannot attach to their parents, it is imperative that their parents attach and bond to them. Signs are a creative social tool for both shepherding in biological and social viabilities, as well as a means of managing the discrepancies between different aspects of biological and social time.

In addition, signs draw their interactive power from a uniquely American cultural orientation towards a notion of “individual rights.” This is especially powerful for endowing signs with the capacity to perform the functional work of informal post-natal rituals and rites of passage. Although post-natal rites of passagedo not exist society-wide in the United States, signs are able to construct rites of passage for parents and their premature infants by drawing on notions of “individual rights.” Legal scholar Mary Ann Glendon states, “Rights in American culture is set apart from the notion of rights in other liberal democracies by its starkness and simplicity, it’s prodigality in bestowing the rights label, its legalistic character, its exaggerated absoluteness, its hyperindividualism, and its insularity” (Glendon 1991). Glendon’s work argues that individuals engage in “rights talk” when they either desire privacy, personality, autonomy, self-sufficiency, and independence or when they feel these aspects of their lives are threatened. In the NICU, these very characteristics are desired for premature infants and are threatened by the ambiguous status of premature infants that also bring in the darker sides of personhood with which individuals are not comfortable (e.g. death, artificial, machine, dependent, public, and extraordinary).

The work of Faye Ginsberg on American women’s engagement with the political and legal processes concerning the abortion issue argues even more poignantly that individuals engage with legal notions of rights when they experience discontinuities in judgment between their lived experiences and the dominant cultural values and beliefs that define them. Ginsberg writes, “abortion activism creates both an interpretation and arena of action that activists use to reframe in social terms of what they had experienced initially as problematic shifts specific to their individual lives” (Ginsberg 1989:156).

Signs in the NICU, which draw upon an individual rights discourse, function similarly on behalf of parents. By constructing informal rituals and rites of passage, signs allow parents to reframe in social terms what they experience as problematic.

However, in both the Taiwan NICU and the U.S. NICU, medical caretakers are largely left out of rituals and rites of passage that are used to help parents live through and interact with ambiguous premature bodies. The next two chapters speak to how medical caretakers attempt to resolve their own prematurity experiences. Whereas parents can look to medical caretakers to help them in a variety of ways, including being a shoulder of experience and support, what do medical caretakers themselves do? Who do they turn to? What are their ways of coping or reconciling their prematurity experiences with their lived experiences? In both places, medical caretakers must look outside of the NICU for answers. In Taiwan, many look to religion and politics. In the United States, they utilize and turn to ”rights talk” (Glendon 1991) as a means of finding a balance between moral rights (i.e. doing the right thing) and upholding a “right to life” that is part and parcel of their everyday work in the NICU.

CHAPTER 8: DOUBLE PASSAGES: ZUO YUE AS RIGHT(S)/RITES OF PASSAGE

This chapter revisits the rites of passage known as zuo yue (sitting months) and asks, what are the consequences for medical caretakers? As discussed in chapter 5, zuo yue is a right of passage that frames the practices of mothers, kin, and medical caretakers alike. It not only shifts the focus of recovery and attention from the premature infant to the mother, but by doing so, it produces differing consequences for different individuals. In chapter 5, I discussed the consequences of zuo yue for family and kin relationships, arguing that the premature infant becomes "othered" and incorporated simultaneously into kin relations, standing both inside and outside of family relations. As a result, existing kin relations are altered while new ones emerge (such as those between the postnatal mother's mother and her mother-in-law).

In addition, I have also argued that because zuo yue practices largely take place outside the NICU, it also further contributes to a different ambiance in the Taipei NICU. The most prominent difference being a lack of infant-specific epistemological and cultural idioms for talking about and interacting with premature infants and with each other about premature infants. Rather, because Chinese ideas of the person are relational and the mother is at the center of zuo yue practices, premature infants become a part and parcel of interactions *about* them—interacting and talking about them is equivalent to interacting and talking to them.

However, medical caretakers, like premature infants are both inside and outside of kin relations. Family members are greatly indebted to medical caretakers (especially the nurses) for the care they provide, but also recognize that it is their job. Few open visitation hours are provided by the NICU. Interviews revealed that limited visitation hours further illuminate relational aspects of personhood. The NICU personnel found that extending open visiting hours does not actually increase parental visitation (Personal communication and Ren, fieldnotes 2004). Most parents will call before they visit, even with open visitation hours. This is especially true when an event or an occasion is considered serious, as is the case of the NICU. Parents expect nurses to meet them at the door and nurses expect to meet parents at the door. Telling or expecting someone to just “show-up” during a certain time would be inconsiderate and be viewed as morally improper. This is just a part of what it means to “zuo ren” (make persons or to be a good person).

In many ways, visiting hours are antithetical to relational concepts of the person. Extending them for longer hours would be socially construed as “not convenient.” It would suggest to parents that they “Should not” call nurses (Ren, fieldnotes 2004). Thus, providing some window of visitation hours is viewed as meeting the generalized norms of NICU clinical practices that doctors and nurses read about in scientific journals or were trained under in Western countries. Interactions in the NICU are considered serious. They are first and foremost about the premature infant. Family members know very little personal information about nurses and doctors who take care of their premature infants. Any personal information that is conveyed between medical caretakers and kin are almost never about medical caretakers. That is, medical caretakers come to obtain direct and indirect information about parents and kin members through interactions relaying the overall health and activity status of premature infants, but rarely is it the other way around. Casual rapport that often develop between parents and NICU caretakers in the U.S. are a rarely found in Taipei. In the NICU, general practices of social engagement that occur in everyday life do not happen. Everyday Taipei life is casual and informal. People love interactions and are always interested in the personal lives of others. However, the NICU visitations are not considered part of everyday life. Unlike the U.S., where parents and caretakers attempt to incorporate aspects of everyday life in the NICU, in Taiwan, aspects of the NICU are brought outside of the NICU to be integrated into the everyday practices and engagements of life.

With these thoughts in mind, I first argue that zuo yue practices produce "total institutional" qualities (Goffman 1990) for medical caretakers (especially nurses) in the Taipei NICU. This is largely an oral history. Written accounts of the emergence of the NICU in Taiwan remain unavailable. Second, I show how medical caretakers, are themselves transformed by zuo yue practices as they stand both inside and outside of zuo yue practices. That is, medical caretakers are critical actors in the caretaking and conveyance of information about premature infants, yet they do not have a relational stake in the emerging relationships between premature infants and their families. This set of conditions opens medical caretakers to create and alter ideas of "Who am I?" and "Who are the premature infants?" Lastly, I argue that these emerging ideas and experiences of selves and others take on a more "ontological" and "individual" aspect of personhood where medical caretakers begin to see themselves and premature infants as having legitimate social (and perhaps eventually legal) rights and responsibilities that extend outside of kinship structures. These newly emerging social rights and responsibilities that medical caretakers endow themselves are imbued with a discourse of "*individual rights*" that is perceived to be universal and ontological. Medical caretakers view themselves as becoming "more modern" as they take on more individual and autonomous notions of the person. After all, the individual rights discourse is prominent in the everyday political discourse of Taiwan. This fieldwork was conducted at a time when large rallies took place calling for Taiwan to break all informal ties with China, declare formal independence from China, and demand international recognition of its independent status from the global community. It is through ethnographic data that I present these arguments.

What time is it?—Total Institutions and New Concepts of Self and Others.

In the middle of a conversation with Ah Zhang, the head nurse, I'm having a déjà vu moment as I look in the direction of the central clock, which is also the only clock in the NICU. She too glances over and says in Mandarin, "it is 15:30." Military time doesn't really register with me. Ah Zhang notices my infinitesimal pause as I attempt to do a fast conversion in my head. She says, "it's 3:30 *la*." "La" in Mandarin is a friendly, non-judgmental, non-derogatory form of "duhhh." It corrects and signifies another's momentary lack of comprehension of the obvious and is often used between good friends, both as a reaffirmation of intimacy and for preserving face. It usually follows a statement of the obvious. For example, if someone is looking for a missing item and it is right in front of them, a friend will say "it is here… *la*" (zai je li la).

We both laugh. I tell her I'm going to head out in the next hour because I want to avoid the notorious Taipei traffic. Military time is used to record vitals every hour in medical charts. Other than this use of clock time, the NICU seems to exist in its own isolated world, governed by the bio-temporal needs premature bodies. Ah Zhan tells me, "We don't need to know what time, we just do whatever they need until the next shift comes. You just pay attention to everything, record everything, so you can catch the bad things before they happen." "We just need to keep infections away so they (the premature patients) can grow. It is very hard to do this. We use so many antibiotics and things and they still get sick. All you can do is watch carefully. This is why we have a no talking policy in the NICU." "This makes sure the nurses pay attention and do not get distracted. It is easy to get distracted and want to talk to another person in here." "Plus, they say that studies in Japan and U.S. show that it is better for the babies, helps them grow. This is probably because nurses pay more attention." "You know, Japan has the best survival rates—not America. They are just so careful, so disciplined. I think it is their culture. Everything they do and make is precise and delicate—food, clothing, electronics… No wonder they are so good with premature babies." We try to imitate them here. Try to be more precise, concentrate and watch more. Always being more delicate. Trying to make sure they don't get disturbed too much. Not always run tests." All of this can be draining, sometimes it's very hard to force yourself to come in—to know that you have to pay attention and concentrate like this. It's solitary. It gives you a lot of time to think.

We carry on with our conversation for the next hour or so, something we do on an almost daily basis. Ah Zhang gives me the update on each "NICU baby." Here and there, peppered throughout, she reflects on her own NICU experiences through the years, gossips about this nurse or that doctor, rants amiably about family issues, healthcare in Taiwan, and social hierarchies in general and in the NICU, and inquires about my life in the U.S. and my experiences with the NICU.

Her updates are as much about the medical conditions of each NICU patient as they are statements and commentaries about their families, particularly the mothers. I'm surprised at how much she knows about the mothers since I rarely see family members; and when I do, it is usually the dad or a grandmother who stops by for a quick visit, chats with a nurse, and leaves. It's a rare occasion for any NICU visitor to stay for more than ten or fifteen minutes. I suspect that Ah Zhan goes out of her way to interact with the parents and kin members of almost all premature infants. She takes pride in knowing information about each premature infant's parents and kin. It is how she gets to know the premature infants themselves.

I look up again at the clock, trying to get a sense of how long I've been in the NICU. It is probably three or fours, but it often feels like an entire day. Ah Zhang, always noticing when I look at the clock, chuckles and says, "It's hard to know what time it is in here…*bah*…..OK…You should leave before the traffic…..I have to go and prepare notes for the night staff."

"Bah," like "la" is not a formal word, but an emotive expression. It is a rhetorical idiom that signifies a moment of reflection on the part of the speaker and carries the tenor of "don't you think?," but without having to say it. It can be easily inserted between words, groups of words, and anywhere in a sentence or phrase. However, one would never start a sentence or phrase with "bah" or "la." It is a moment of insight that is part and parcel of the interaction, and results out of the interaction itself.

I thank her for her time and tell her I will see her tomorrow. "Yes, you will see me tomorrow, everyday…, everyday is the same, just not weekends. I'm not here on the weekends." "I am out on the weekends," she laughs. "You know, I look forward to you coming to visit, you bring a little something different, you bring outside energy. You make my day shorter. You are not part of this, you find everything interesting. It makes me happy to be around you."

This is usually how we end our daily check-ins, around 4:30pm or 5:00pm, an hour or two before the evening nursing staff shows up. I know this, because I always wear a watch and I have to take it off right before I enter the NICU. I usually always show up during the "afternoon lull." Over many weeks, I have come to know the afternoon lull as roughly between 3-5. I never meet with NICU staff at any specified clock time. As they tell me, "we are always here." Our meetings are always before a feed, after a feed, before a procedure, after a procedure, before rounds, after rounds. They are always "event" based and it is up to the NICU outsider to figure out how events in the NICU correspond to clock time.

I'm always slightly disoriented when I step outside on the streets. The rhythm and buzz of people coming and going, working, shopping, eating, and living life are always a stark contrast to the silence of the NICU. For me, Taipei is particularly loud. Sensory overload is everywhere. At every turn, creative placement of multi-media is begging for a person's attention—loud radio announcements blasting out of in ground speakers on sidewalks, television screens set on maximum volume on public buses advertise various products, and merchandise hawkers in alleyways with cheerleading megaphones proselytize the benefits of super absorbent dishtowels and home goods. These are part of Taipei city life. It is a city immersed in interactive consumerism. People thrive on interacting with all kinds of objects, services, goods, foods, clothing—anything and everything. Especially, anything and everything that is new or different. Lin Lin says, “Today’s hot item is tomorrow’s old news.

Empty quiet spaces are hard to come by in Taipei. Every inch of usable space begs for interaction. Stores, restaurants, spas, coffee shops, vendors abound. It is rare to be quiet and alone in Taipei. This is even true for the majority of hospital patients. In the alleyways adjacent to the hospital where this research took place, it is quite ordinary (but extraordinary for me) to see in-room hospital patients in gowns and slippers, pushing their IV carts while searching for an empty stool to sit on and have a bowl of noodles. The first time I encountered this site, I was taken aback. Aren’t hospital patients suppose to be isolated in hospital rooms?

When I inquired about this practice, my friend Dr. Tsai simply laughed and said, “ I know, coming from America, this must be an odd site. What can I say? This is just what happens in Taiwan. We like to be out in the world. It’s hard for patients to be in a hospital for days and weeks. They get bored, tired, and lonely. Family can’t visit all the time. They need to “take new breaths or get some air (chuan chi),” be outside. So, we just let them—if they can do it. Sometimes nurses will even help take patients for some buns or a snack. We get bored here easily. This is why many of us can’t live in places where “birds don’t lay eggs”—a common saying that communicates a fear of isolation.

The NICU is a place of isolation. It must be. To survive, premature infants must be isolated from the outside world. As mortality and causes of death have fallen in the NICU due to the introduction of pulmonary surfactant, infections as a cause of death are on the rise for the youngest population of NICU premature infants (Doyle, Gulton, Chuang et al 1999). It is not very surprising that recent studies have found toys brought into American NICUs for the purpose of “teddy bear diplomacy” (Landzelius 2003) and bonding have also been found to be potential reservoirs of infections (Hanrahan and Lofgren 2004) (Davies, Mehr, Garland, et al 2000).

It is in this context that the isolating nature of the NICU environment on nurses must be understood. They are not undergoing zuo yue, yet they are isolated from daily life, much like mothers undergoing zuo yue. In many ways, nurses are even more isolated from others than even lay mothers who undergo zuo yue practices. Lay mothers are freely encouraged to bond with their babies, family, and kin members. They are not isolated, but protected from the environmental stresses and the responsibilities of every day life. This includes taking care of their children. In contrast, nurses and medical caretakers are largely sheltered from even interacting with each other. They possess all of the responsibilities of caretaking, which often require them to turn inwards. As a NICU nurse said, “You spend so much time in quiet, you can’t help but think.” Yet, when they leave the NICU after work, they too, like me are bombarded with the city life of Taipei. However, unlike me, they live here. It is what they know, it is what they are used to, and for most, it is what they have chosen. Life inside and outside the NICU are in contradiction.

Working in the NICU, although often personally rewarding, is also isolating. In a world that is highly interactive, where a sense of self and others are always relational, anthropologist Arthur Kleinman has argued that individuals in Taiwan do not possess an individuated self and are out of touch with their own individuated emotions precisely because of a relational concept of persons. He argues that individuals in Taiwan are taught to be more in touch with others’ feelings than one’s own.

The isolating nature of NICUs primes individuals toward introspection. Erving Goffman in his study of asylums defines the total institution as everyday places that possess an encompassing or total character (e.g. prisons, mental hospitals, homes for the handicapped), and are symbolized by barriers to social intercourse with the outside. Unlike the basic social arrangements in modern society where individuals tend to sleep, play, and work in different places, with different co-participants, under different authorities, and without an overall-rational plan, members who reside in totalizing spaces do not have separate spheres of existence (Goffman 1959:6). "They all have very much in common" (Goffman 1959:2). Goffman further notes that these rooms, suites of rooms, buildings, or plants also encompass physical barriers that prevent easy departures (locked doors, high walls, barbed wires, water, moors, etc.). Thus, total institutions are "a social hybrid, part residential community, part formal organization"— forcing houses for changing persons, each is a natural experiment on what can be done to the (self)" (Goffman 1959:6).

As evident from Ah Zhan's narrative, the NICU shares many of the similar characteristics. However, in this case, it is the medical caretakers, who experience the totalizing institutional effects of the NICU, not the premature infants.

This is due to a critical difference between the NICU and other total institutions described by Goffman. Specifically, one must look at the intent of the isolation. In the NICU, the barrier to social intercourse with the outside is not derived to keep its members (i.e., premature infants) away from society, but exactly the opposite. The barriers to social intercourse are not barriers against departure by the members, but social barriers against admittance by the outside world. Infections are a major cause of death in NICUs, and thus to protect premature infants, social and physical barriers are constructed to protect those on the inside from the dangers of the outside.

In the Taipei NICU, zuo yue practices hinder visitation by others outside the NICU. There are two implications that can be drawn. First, although this does not appear to impact bonding between premature infants and their mothers and kin, it does prevent the formation of deep and personal relationships between medical caretakers and the kin of premature infants, as well as between medical caretakers and their premature infants in ways that are more family-like (This is a point of contrast with American NICUs). This is especially noteworthy given the importance of family and kin in Chinese society. Second, NICU medical caretakers exist within the confines of Taipei Hospital and their moments of introspection in the NICU must also be understood in the context of the social and cultural life of Taipei Hospital.

As will become evident with a discussion of Taipei Hospital and the ethnographies to follow, these contexts create contradictions and tensions for medical caretakers. Living in a society outside the NICU where family and social relations dominate and where ideas of selves and others are always relational, NICU medical caretakers spend a majority of their working lives in a space devoid of relational interactions, and yet they are the critically important persons that are responsible for the viability of their premature infants—both biological and social. For medical caretakers in the Taipei NICU, this can only be felt as a deep sacrifice (interviews confirm this). That is, to keep death at bay while creating and giving social viability through the creation and maintenance of social relations for others (i.e., Preemies and their families) without becoming incorporated into another's family and without the benefit of the social relations one has created, medical caretakers in many ways must construct alternative experiences and constructs of selves and others. These experiences and constructs of selves and others have in common a sense of "individual rights" that contradict relational personhood found in kinship relations and the family, as well as in guanxi relations.

The emergence of an "individual" and "rights" oriented personhood comes out of the juxtaposition of zuo yue practices emphasizing the strong social and familial relations between family members against the totalizing institutional characteristics of the NICU created out of the need to isolate premature infants and their immature immune systems from the outside world. From this perspective, medical caretakers become liminal and are themselves informally going through the "zuo yue" rites of passage as they mediate the zuo yue relations between premature infants and their kin. For medical caretakers, they emerge out of the zuo yue rites of passage with the experience that premature infants exist as "individuals" first —that is they exist outside of their own family relations and must be integrated. While NICU mothers are undergoing zuo yue and strengthening their bodies, doctors and nurses are working to strengthen their babies. Each day, medical caretakers come into the isolating environment of the NICU to "work very hard for little babies that do not have families that can take care of them." This is what Ping often reminds her four-year-old son when he is not cooperating during pre-school mornings. She leaves her own son to the care of her kin while she takes care of someone else's. She reasons, "This matters because they matter too. Each one of us matters, even without family there. We can't always put our own family first. I work at my job and sacrifice not seeing my own family to take care of another who is not in my family. I want to show my son that it is not only family that take care of family."

How then, and in what sense does all of this matter? How would the interplay of these factors foreground individuality rather than relational personhood? The next section will address these questions. I argue that there is a third factor that orients the interplay between these two factors. Medical caretakers, isolated in the NICU, move between the NICU, the hospital and the world outside the hospital walls. For some (not all), the Presbyterian mission of Taipei Hospital and the readily available ideas of Presbyterianism emphasizing “individuals in community” will prove to be enlightening.

All Individuals Matter

The history of Taipei NICU must be understood in the context of the history of Taipei Hospital. Taipei NICU was developed around the late 1980’s and the early 1990’s (Personal Communication). It came about not only through Taiwan’s modernity initiatives in science, biotechnology, and medicine, but also as a project that was shepherded by Taipei Hospital. Taipei NICU is the largest NICU in Taipei, with 26 bed spaces. Almost all of the neonatal care research includes or are solely done in the Taipei NICU. They collaborate with researchers both within and outside of Taiwan.

Taipei Hospital was established in 1912 as a private Christian Charity Hospital. It was associated with Reverend Dr. George Leslie Mackay, the first modern missionary in northern Taiwan. The hospital is deeply rooted in the Presbyterian cuse and is under the spiritual guidance of the Presbyterian Church in Taiwan (PCT) (Personal communication 2004). The PCT has been in Taiwan for over 100 years. It is the largest Christian group in Taiwan (Lin 1974) and is well known for strongly supporting local communities and Taiwan independence.

Interviews with individuals of PCT understand their religion as placing great importance on education and life long learning, as well as exhibiting their faith in action. Presbyterian tenets also call for the validation of people as individuals (Wu 1979)(Yang 2008). However, unlike other Christian faiths, they also place great importance on “confessions of faith”—the expression of faith as a community (and not as an individual). The idea here is that individuals are encouraged to understand scripture, but it is the group’s expression and understanding of their faith that is ultimately of prime importance (Oxford English Dictionary, Presbyterianism 2007). This emphasis on group “faith,” which draws on relational aspects of personhood has particular relevance and poignancy for individuals who undergo conversion. This will become evident in the ethnography that follows. As my friend Hope, who is a doctor, an elder at her church, and a political supporter of Taiwan independence said, “Everyone is important, everyone matters.” “We need to look for connections with all people through charity and hospitality. This is what my church teaches.”

One way to put these beliefs into action is through advocating for Taiwan independence (Lin 1999). Presbyterianism espouses “individual” legitimacy of each person, and what better way to exemplify that than to espouse the legitimacy of an entire nation. How this plays out in the NICU will be discussed in the story of a nurse’s conversion to Presbyterianism and her rationale for it. Presbyterian tenets emphasize both “individual” and relational aspects of selves and others. Therefore Presbyterianism is experienced as both a contrast and a support of Chinese notions of the family.

The five attending physicians on staff at Taipei NICU were the original founders of the NICU. Dr. Ming Chen Shu is viewed as the mother of the NICU. She was not only a founder attending physician, but also one of the first female attendings. She is known as an aggressive advocate for the life premature infants. When I spoke to her she recounted the progress that has been in how parents have come to experience of premature infants. She stated, “In the beginning, no one wanted their premature babies to be in the NICU. We had to work very hard to convince parents that their babies were not dead, that they could live and that their life, although it might be imperfect, was worth the effort.” “Many could not really accept the unknown. They would want to take their babies home. The technology seemed scary to them. They think maybe their baby can survive at home, even without the technology. However, we would tell them, if you take your babies home, your babies will die at home.” “Of course, once they realize this, they do not take them home. No one wants to bring death to their house. It is bad luck.” “We tell them, we are here to help you, we are here to support you, we will take your child and care for it. You do not have to worry.” “This would comfort them, it would take responsibility away from them.” “Some babies would die. Some babies would live. Either way, parents seemed to accept the fate of their babies.” “But, all of us neonatologists, we had to do a lot of soul searching. Should these babies be saved? We had to find our faith in our feelings toward what it means to have a life. I was not religious when I began my career 30 years ago.” “I am today.”

In the NICU, NICU preemies are experienced as both “individuals” and as part of their kin. However NICU caretakers are not a part of the kinship relations or guanxi relations of their patient’s families. For medical caretakers who do not have families of their own or who cannot always participate in family relationships, how do they legitimize and validate their efforts and work? For almost all NICU medical caretakers, their nurturance and caretaking of preemie are marks of "renquing" (humanity), called forth and justified on the general ethical principle that all life is worth caring for and saving (including premature lives). This way, they are not simply the servant's of other's social relations. By, experiencing themselves as fundamental to creating and saving the social viability of premature infants (and not just their biological viability), they are able to maintain and continue to participate in a social world that calls for a relational personhood, but one that is now infused with elements of "individual rights."

Two ethnographies that follow will illuminate the above in more detail. In these two ethnographies, particular attention must be paid to how individuals are oriented to external causes and practical remedies. This is a fundamental attribute of a Chinese style (Wolf 1978). Personal ideas, values, and feelings are conveyed *indirectly* through descriptions of situations. Personal comments are added as one observes the listener's response (Kleinman 1981).

See me for me, pity me, "ke lien" me

This ethnography illuminates experiences of Ming, Tin, a NICU fellow, and her emerging "right" to have "individual" feelings and emotions that does not have to be endured and "swallowed up" for the sake of one's parents.

My very good friend Ming Ting pulls me aside and says, "I am having family trouble." Ming Ting is a neonatology fellow. This means, other than the attending, she oversees all of the premature patients. For the most part, she and Ah Zhan (the head nurse) run the NICU. Ming Ting writes out orders for various treatment protocols, trains residents, and performs various surgical procedures. Ah Zhan is her right hand. Their relationship is one of deep affection and true collaboration. Ah Zhan interacts with Ming Ting much like an aunt or cousin. Normally, medical caretakers do not really interact with each other in the units, but Ming Ting and Ah Zhan have to coordinate their care plans and these work interactions bleed into personal interactions. Ming Tin is pregnant with her first child. She is 28 weeks and will not be taking maternity until two weeks before her due date. She never stops working. But, when it comes to family trouble, she will get people to cover for her, especially Ah Zhan, and sneak out into the hallway to try and fix whatever has happened. Arthur Kleinman in his study of psychosocial stress in Taiwan noted that family trouble was the worst kind of trouble one could have. The family is an entity that existed before one was born and will exist after one is dead. Through the family and ancestor, the core of Chinese religion (Wolf 1974), people are part of an immortal vehicle. Their place in this immortal vehicle assures their link with past and future, offering them personal and cultural meaning transcending death." (Kleinman 1981: 133-134).

For Ming Ting, when her family "has troubles" while she is at work in the NICU, in her own words, "It is so stressful because how do you prioritize the preemie's need for medical care—it can be life and death for them (biological viability)—and my family's loss of face when they are in a crisis (a relationship one) which can never be recovered (i.e. Social viability)." "I try to tell my mother that these are little babies who really need me, and her reply is "You give everything to them, but what about us, we give everything to you, are those babies going to give you anything back. " "But I then try to tell her, mama… I'm a doctor…but my mother says…sighs, and says, I don't know what to do with you."

We sit in the hallways and she tells me, “You are my friend, we have so much in common, we have a special friendship, I think we must have been related in a former life.” I wholeheartedly agree and nod. She continues, “I want you to write this in your notes, this will help you understand Chinese society….I’m so mad at them…I need someone to write something down…in a kind of official way…so that my feelings mean something…so I don’t forget and just let them have their way. You need to remind me when I go back to my old ways and let me/make me feel bad.”

Ming Ting begins: “Maybe I’m pregnant, maybe I have depression, maybe I do not have sleep, I have no idea what is happening to me, but I am angry at them. It’s like something happened. I think about having this baby, I think about the kind of parent I want to be, and I think about my work, and the parents of these NICU babies, and I think about these NICU babies—how they give so much trouble to their parents from the very beginning—their parents have xing tong (heartache) maybe their whole lives. I think to myself, I hope my baby is not a NICU baby. I know how hard all of this is on their little bodies and you are never sure what is going to happen to them in the future. I think to myself, I will appreciate a healthy baby and not burden my healthy baby.”

“When I have this baby, I’m going to hire an ayi through a zuo yue zi company, not use my mother in law or my mother. I will be too exhausted with all of the managing. This way, my parents and my parents-in-law can come and help, but I do not practically need them all the time. If I hire someone, then I do not owe them anything. I do not really have to have relationships with them, this way, it will be easier for me. I just tell my parents and my in laws that the ayi does the housework, but they can come and help with the baby. I’m going to zuo yue zi for myself. I think to myself, these premature babies are going to give their parents so many burdens, they already have, and most of the parents I talk to are so thankful that their baby is alive and not a vegetable that they do everything for them. I think, that is how parents are suppose to be. These parents know that their kids probably won't be able to shao shun (show filial piety) because they are NICU babies and may not be normal, but they are still so happy to have their baby. This is the kind of parent I want to be. Isn't helping your parents and being a good daughter something you should choose to do, not something you have to do?"

"I get mad at my parents when I work here in the NICU everyday,—my parent's constantly tell me how much effort they have put into raising me and how I have not repayed them enough. But I look at NICU babies, how much trouble are they giving their parents? Their parents worry about them and they cause their parents so much xin tong (heartache) right from the beginning, but their parents—you know I see them in clinic all the time—their parents don't complain, they are happy with whatever their child can do. They are grateful their child is not dead. They don't have expectations." These NICU parents see their babies for what they are and they do not have demands. When I get depression, I think maybe they are luckier than me, they have no burdens. I know that sounds strange, and I'm not trying to ke lian zi ji (I'm not pitying myself). I'm just saying, I see how other parents can be different, they are from Taiwan too—they are Chinese and Taiwanese—-just like us. But, they can accept their child for their child—they don't worry, what is this person going to think if my daughter doesn't visit me, what is that person going to think if she doesn't show she cares for me, or what will people think if my daughter just works all the time, but does not make the money or get the prestige. Maybe these NICU babies are luckier…because their parents "ke lien" them from the beginning. Maybe if you give xin tong (heartache) from the beginning, then your parents can’t burden you. Can’t my parents “ke lien” me sometimes too?

“All my parents complain about is that I don’t spend enough time to help them out with their life in the south. But, I don’t make very much and Taipei is very expensive. My mom says that she needs more money, that my father and her either want me to take care of them or buy them some help to clean their house. But, they have enough money, they have just lost face because their friend’s daughter lives close by and takes care of them. They constantly tell me say to ‘We raised you, you are smart, and now all you do is think of yourself, you work for yourself, your career, but what about us….do you want your baby in your stomach to do the same to you.’”

Ming Ting’s narrative centers around the discourse of ke lien (or pity) and her self emancipation from the social relations associated with zuo yue practices. However, she still chooses to zuo yue, but with hired help, with money that she has made herself. The fact that she absolutely finds zuo yue indispensable speaks to the continued dominance of zuo yue as a relational cultural practice and a relational cultural logic that is not completely replaceable. Min Jen’s insistence of zuo yue enables her to construct relationships with her newborn, and still gives her parents and her in laws a means of relating, albeit now more on her terms.

In chapter 5, the discussion of ke lien centered on the notion of pity. To “pity oneself” is to essentially draw a circle around oneself and isolate oneself from one’s close relations, not taking into account of other’s feelings. Only those individuals who generally exist at the boundaries of society and do not have strong claims to social relations (e.g., orphans, the handicapped, beggars) are ke lien (or can be pitied). One pities them precisely because they have no one else to rely upon and therefore find themselves needing the pity of others. Thus, for MingTing, she is negotiating her experiences and senses of herself (and her family) through a discourse of ke lien. She is both a medical caretaker and a mother-to-be. As such, she is in a liminal position and ripe with transformative possibilities for recomposing her sense of self and others (Davis-Floyd 2003). I argue that under these circumstances, she is particularly apt to incorporate elements of the individual and of rights into her understandings of self and others.

For Ming Ting, she experiences NICU babies as “lucky” and loved unconditionally by their parents and kin, without reciprocal obligations. She desires this for herself and asks, “Don’t I have a right too?” Her duty as a daughter and her duty as a doctor are in conflict. Caught in a double bind where she cannot be both a good doctor and a good daughter, she chooses to reframe her relationship with her parents as overly burdensome, rather than reframe her relationship with her career or her experience of preemies’ relationships with their families. For her, it is not that she doesn’t want to help her parents or spend time with them, but that she cannot. She wishes her parents would empathize with her personal “Gordian knot” of reciprocal obligations and responsibilities. The circumstances of her patients are too dire and their lives depend on her. By choosing her patients’ needs over the needs of her parents, Ming Ting places the lives of un-related children over the lives of her parents. As a doctor, she *must* always choose saving a biological life (the preemies) over a social life (her parents). Biological viability trumps social viability. Anything less, she would not only be a bad doctor, but a bad person. At the same time, she is also a mother-to-be who desires to create and maintain relationships between herself, her newborn, and her kin (i.e., she still wants to zuo yue). Her desire is for her parents to empathize with her “feelings”—i.e., her internal struggle between competing ideas of who she is. Her parent’s desire is to be more inter-subjectively connected to their daughter. They too wish their experiences (i.e, embarrassment with friends, feelings of neglect, etc.) to be “known.” For Ming Ting and her parents, they each experience what it means to be a good parent differently. For Ming Ting, being good parents include unconditionally honoring the individual emotions and feelings of a child (i.e.,to experience children as individual persons). A parent-child relationship should not feel burdensome or obligatory to a child. For Ming Ting’s parents, good parenting means having taught your child that they must honor their relationships with their family and kin first. These are the proper priorities. When Ming Ting consistently allow the demands of work to overtake the requests of her parents, they view her actions as “selfish.” When they ask for money from Ming Ting, they are symbolically asking for her to share her daily experiences with them. Money is the physical manifestation of her work, the fruits of her labor, and symbolically of her. If they can’t have her tangible presence, they will settle for a tangible piece of her through the receipt of money. They reason, if she can’t share herself with them (which is what they want), then she can share the fruits of her labor. They view her as always choosing herself over them, and choosing other people’s kin over her own. Each party wants to have their sense of self and others validated. Both feel let down. Both are hurt. Both still care. Both are still intersubjectively tied to the other.

We are all family under *God (i.e., Christian god)*

This ethnography is about a nurse's yearning for connection and for relationships. She is isolated not only in the NICU, but she also does not have adequate social webs of relationships within which she belongs. Her family is outside of Taipei and she does not have kids or a husband. Taking care of someone else's child with such careful effort everyday, she realizes that despite her hard work, she does not have a reciprocal connection with her preemie patient's families. This brings into question her own worthiness as a person. The following is her story.

Shu Jen is 30 years old, she just passed her five year mark in neonatal nursing. She too, like Ming Ting and all the medical caretakers in the NICU, find themselves both inside and outside of the zuo yue experiences of NICU mothers. This is her story. Her narrative illuminates how she comes to terms with how her work and her family shape her sense of self and others. Ultimately, her work with NICU babies enables her to transcend her family's social background and become "equals with other's who come from good families" (Shu Jen 2003).

"My mother and father are from the country, we are not high status people, we are good people and we have friends, but we do not have the "guanxi" webs of social relationships that someone from Taipei would have. I was always a good student and I came to Taipei for school because I did well on the national tests and was accepted at Taipei's number one nursing school. I like the NICU because it requires thoughtfulness, you have to pay attention, every action matters, how you turn a baby over, how heavy to touch them, how to schedule procedures—it all matters. You do more than even doctors many times. It is intense in a very concentrated way, it is a challenge, you have to quiet yourself down to work. All of this make me 'turn in,' to myself and think."

I think this is also why some people leave. It is too quiet—too difficult for them—-they cannot stand the pressure that it causes to their world outside of work. Many nurses start out single, then get married, then become mommies. Once all of this happens, you cannot just “go away” in the NICU for 6-8 hours. Many nurses, when they get off of the hard NICU work, they have to go home to a bunch of “everyday troubles”—-you know, all of the stuff that you have to do to manage your family and relatives, especially if you have kids. When you are in the NICU working on your shift—-you cannot take calls from family, you cannot solve problems at home with family members—-all of the outside world goes away, whatever it is going on outside in the NICU has to go away, there is no space for it here because these babies require your full attention.

Also, practically, how do you go in and out of the NICU, everytime you come in you have to wash your hands, gown up, take off all of your jewelry, change clothes, there is so much infection in Taipei…Many of us don’t even eat or drink for the hours we are on—-just in case something happens, if you leave, you have to make sure everything is taken care—it’s too much trouble.”

“I converted to Christianity one and half, almost two years ago. This hospital is a Christian hospital—-did you know that?, I think it is the only one in Taipei, it is also THE BEST pediatric hospital in hospital and one of the top residency and nursing residency programs in Taiwan. It has some of best clinical doctors…even Tai Dai (Taiwan university), the most well known to Western people, can’t compete without us, and can’t do research without our population. We have so many more patients and we do so much more clinical work. The public knows that, that is why they come here. So, they don’t think ‘Christian,’ they just think ‘best’ hospital. We are famous for treating difficult cases. It is not until you start nursing working that you realize there is something more. You are exposed here to other kinds of thought—-not by people telling you or anything, but your work, helping helpless children, spending so much of your effort helping poor families, and you travel to other countries for clinic training and you see all the different people that you can help, it makes you think…..about who you are…"

"Well, let me tell you story of how I come to be a Christian and you will understand how I come to have different thoughts. I can't explain it. I tell you the story."

"A good friend who is a nurse here invites me to go with her to a meeting with her Christian group. She says that I might like it and that I could meet some friends since I do not have family in Taipei. I think it is weird, my family, we always bai bai and go to temples (worship of gods), why do I want to go to a Christian Temple (i,e, a church). I don't even know what it is. But my friend tells me, it is a good way to make connections with different kinds of people. Since, my family is not in Taipei, I do not have a husband or kids, and I do not have good guanxi circles here anyway, I think 'it can't hurt.'"

"When I went to the Christian Temple, I saw EVERYONE—-I mean doctors, who come from very good families, very high status, very good guanxi relations, they have converted to Christianity. I also see just very average people, even cleaning people and hospital orderlies. They invite me to go. I'm skeptical—-why do they invite me? We have no connections, we come from such different backgrounds…. But I realize everyone there is equal, we are all one family, we are all the children of "one father"—I didn't know that a god could be a father. In the Chinese religion that I know growing up, god is a god. Your ancestors and your father are your fathers. Here, I realize, I do not have to give up my ancestors or my actual father, that we are all human and that this Christian father is all of our fathers and he is there always for us, even if we don’t know about him. He is like nature, the air we breathe, the life.”

Connection and the desire to participate in relationships with others is the theme of her story. Her story underpins the “inner circle” nature of families and webs of social relations. She is in many ways a social orphan in Taipei. Her family is far away and her parents are “not high status people” and cannot give her connections in Taipei. When I asked her about friends, she says, “Of course I have friends, lots of friends from nursing school, but most now have families of their own and of course they have to take care of them first. Families always come first, before friends.” Shu Jen desires to be a part of a family, to have a place within webs of social relations, but she also recognizes that families and webs of social relations are exclusive. Not anyone can be a part of them. They have to have something deeply in common, something that deeply relates each individual to another. For her, a common hobby or a common experience between people is not enough to create a “family.” A family for her requires people coming from the same body, a family is based in biological kinship.

She views Presbyterianism as providing biological kinship. She tells me, “God gave his flesh to people and we take it, we share his body and his blood. He has given birth to all of us. He is the ultimate father and all humans are one family.” Her conversion to Presbyterianism allows her to make sense of her work in the NICU. Each NICU baby is also a child of god and therefore, she is their family, and she takes care of them. This way of constructing a sense of self and other enables Shu Jen to live through her fears of “working for nothing” and “getting nothing back.” She does not want to be viewed as an individual, but rather desires to viewed as interconnected with others. Religion for Shu

Jen is not so much about finding a greater power than oneself, but about finding a legitimate family.

NICU conditions can create isolation and ungirdle concepts of selves and others that are generally dominant in Chinese society. In this chapter, we stepped outside the confines of the NICU to illuminate outside forces that can shape experiences of selves and others inside the NICU. Specifically, three contexts shaped medical caretakers' concepts of selves and others—the zuo yue period, the political forces in Taiwan, and the social cultural context of Presbyterianism. These contexts are interwoven with relational concepts of the person and of the family to create new and alternative understandings of selves and others (e.g. new concepts of parenthood), as well as create new relationships (e.g. church membership) (Chen 2005).

In the next chapter, we turn back to the U.S. context to address how medical caretakers manage dilemmas of personhood that arise in the NICU. What do they do? Where do they turn? Specifically, this chapter argues that medical caretakers look to and engage with notions of individual rights grounded in American legal traditions. For some, taking part in hospital bio-ethics committees and discussions enables them to create a "narrative distance" from their daily work in the NICU and from the personhood dilemmas they experience in the presence of premature infants. For others, the act of making signs in the NICU or talking about their personal lives outside of the NICU during work hours enables the creation of a "narrative distance" from the ambiguities and uncertainties that surround taking care of premature infants.

CHAPTER 9: "RIGHTS TALK": RIGHTS OF PASSAGE-RITE TO LIFE

"*I wanted the world to be in uniform and at a sort of moral attention forever*"

F. Scott Fitzgerald 1925, The Great Gatsby

"The unborn have never been recognized in the law as persons in the whole sense"

(Roe v.Wade 1972)

For medical caretakers in the NICU, the articulation of moral and ethical dilemmas surrounding the hi-tech care of premature bodies take time to emerge. These dilemmas are often felt before they are articulated. In their book, Neonatal Bio-Ethics: The Moral Challenges of Innovation, Drs. William Meadow and John Lantos write, "In the beginning, people did not really understand how to articulate or analyze the real and important ethical and moral issues they sensed. Instead, these conundrums were vaguely perceived by a few intuitive and far seeing souls" (Lantos and Meadow 2006:41). One of these intuitive souls referenced by them is Dr. Mildred Stahlman at Vanderbilt University. Dr. Stahlman was among the first group of neonatologists to frame medical caretakers' elusive and contradictory experiences with saving the lives of premature infants. She stated, "One must conclude that we have probably preserved some of those infants' lives only to have them survive with cerebral palsy, mental retardation or both. For this we must assume responsibility, as we must for those bright and attractive children who were on a respirator for hyaline membrane disease (i.e. lung disease)" (Lantos and Meadow 2006:38). Dr. Stahlman understood neonatology as creating choices and responsibilities in situations where heretofore there had been only fate (Lantos and Meadow 2006).

As this dissertation has argued, concepts and experiences of the person are intimately intertwined with how individuals make choices and take responsibilities for premature infants. As discussed in earlier chapters (Chapters 6-7), NICU medical caretakers wrestle with various sorts of NICU interactions that produce contradictions and conflicts between “doing the right thing” and upholding a “right to life” (which is part and parcel of NICU care). This chapter asks, how do medical caretakers in the American NICU attempt to resolve contradictions and conflicts that arise as a result of the NICU care they provide. Specifically, this chapter argues that medical caretakers engage in “rights talk” or a language of rights that is a particularly American (Glendon 1991). Implicit in this argument is the recognition of the intimate connection between the institutions of law and medicine that is also specific to American society (Starr 1982) (Heimer and Staffen 1998) (Tribe 1992). Although it is beyond the scope of this dissertation to discuss the theoretical grounding and details of the institutional-institutional interactions between law and medicine (see Heimer and Staffen 1998), this chapter nevertheless begins in Part I by describing the case of Baby Doe. Baby Doe was a legal case that occurred in the 1980’s and solidified (for good and bad) the feedback between the law and the NICU (Pless 1983) (Meisel 1989)(Paris 2001)(Rhoden 1985) (Lantos, Robins, and Meadow 1999). Although the many forces of law (tort, civil, criminal, fiscal, regulatory, and constitutional) influence the practice of NICU medicine in various ways (Heimer and Staffen 1998), the case of Baby Doe specifically addresses issues of moral authority in the NICU. As it speaks directly to the moral tensions between a “right to life” and “doing the right thing,” it continues to loom over the NICU. For good or bad, the resulting Baby Doe Rules, although eventually struck down by the U.S. Supreme Court, remain a source of moral guidance and have given shape to issues surrounding rights to life in the NICU.

Because legal cases, such as Baby Doe, are a combination of enforceable rules, moral guidance, and narratives that reveal actual events and the cultural practices of everyday life surrounding difficult moral issues, medical caretakers engage with and draw upon the law as cultural models for understanding and making sense of their experiences. In many ways, the personhood dilemmas encountered in the NICU are technological extensions of society-wide cultural debates over the moral status, roles, and responsibilities of embryos, infants, and women. As such, the complex day-to-day interactional issues informed by “rights talk” in the NICU can also inform other debates surrounding the moral status of embryos, infants, and pregnant women are intertwined. In particular, abortion jurisprudence and emerging “right to life” issues that center on genetics and stem cell are compelled by similar personhood dilemmas found in the NICU. For this reason, it is important to step outside the NICU and understand how rights, responsibilities, and roles are assigned in American jurisprudence that concern the moral status of human beings with ambiguous identities. Abortion jurisprudence, including the famous cases of *Roe v. Wade* and *Planned Parenthood v. Casey*, is one place to begin. Thus, what will become evident in Part II is the disarming parallel between personhood issues that exist in U.S. abortion jurisprudence and the personhood dilemmas that exist in the NICU. Grasping this parallel better elucidates the complexities surrounding personhood dilemmas in the NICU, as well as provides a glimpse of what is to come in the future.

Lastly, part III takes us back into the NICU and argues that medical caretakers engage and utilize “rights talk” as a means of partially resolving and coping with personhood dilemmas in the NICU. Specifically, for reasons that will become evident, I draw upon legal scholar Mary Ann Glendon’s characterization of the “American” discourse and practice of individual rights to argue that “rights talk” (Glendon 1991) is well situated to obscure the ambiguities surrounding premature bodies. As a result, rights talk provides a level of temporary and partial relief from one-sided interactions that can become emotionally draining.

PART I: The Looming Shadows of Baby Doe in the NICU

Janelle, Miracle Mikey’s very knowledgeable and experienced primary nurse, and his most stalwart protector and advocate, struggled with what she viewed as cruel and futile NICU care (Chapter 7). For Janelle and others in her situation, neonatal nursing can “take a toll on one’s soul.” In one of our conversations she stated, “Everyday, we poke and prod them. They are so little and I’m not sure Mikey will ever have a good quality of life. What am I doing? What are we doing? There is already so much suffering in the world, why are we creating more? Sometimes bodies are not meant for this world. I am not sure that bed 38 is meant for this world. I am becoming an old lady and I’ve been doing this for a long time. Sometimes, I wish I could do something….say something to someone, really talk to his grandma and tell her [that] it’s only a cord that keeps him here. But, it’s not my place to make these decisions or do anything about it. I *can’t* do anything. My hands are tied. Nowadays I might bring legal trouble, create more trouble for myself. Especially these days….after that Baby Doe scare. We (doctors and nurses) have no more say.” People always think that its doctors and nurses who force all of these machines on to these little guys, but most of the time, it’s the other way around. It’s the parents who can’t give up.

The Facts and Ramifications of Baby Doe

The following details of the Baby Doe case are drawn from Drs. Lanto’s and Meadow’s summation of facts found in their book (2006). Baby Doe was a full-term infant born in Indiana and weighed 2722 grams at birth and his length was measured at 50.8 centimeters. “At birth, the presence of Down’s syndrome was readily apparent from the flat nasal bridge, broad epicanthal folds, upward slanting eyes, and rounded calvarium. A catheter could not be inserted into the stomach” (Pless 1983). Baby Doe had an esophogeal atresia, with a tracheostopheageal fistula that made it impossible for him to eat. Anything that he swallowed would end up not in his stomach, but in his lungs. This was a condition for which surgical repair was routine and routinely successful. Without surgical repair, Baby Doe would either die of starvation or pneumonia. However, the baby was also born with Down’s Syndrome with a complicating factor that he had an enlarged heart, which together with decreased pulses led to a diagnosis of aortic coarctation (i.e. a heart problem).

The parents felt that a minimally acceptable quality of life was never present for a child suffering from such a condition. And further, they strongly felt it was not in the best interest of their two other children and the family entity as a whole for the infant to be treated. The rationale for withholding surgery was that even with surgery, due to the child's severe and irreversible mental retardation, the possibility of a minimally adequate quality of life was non-existent. The infant's pediatrician, although agreeing with the ob-gyn's prognosis, nevertheless recommended that the infant be transferred to another hospital where he could receive surgery.

The trial court concluded in one sentence that the parents having been fully informed of two possible medical opinions have the right to choose a medically recommended course of treatment for their child under the present circumstances. However, the court did appoint a local child welfare authority as a child's guardian ad litem to determine whether to appeal the case. The guardian ad litem did not appeal and Baby Doe passed away on his sixth day of life.

The Baby Doe case came ten years after *Roe* legalized abortion in the U.S., as well as ten years after the Rehabilitation Act of 1973 which enshrined the right of disabled Americans to be treated fairly, and without prejudice. These were also the early years of the Reagan Administration, who promised to change the course of abortion jurisprudence and protect what they saw as the sanctity of life. Through the Baby Doe Case, President Reagan sought to establish a "right to life" that would set a precedent for changing the course of the abortion debate and re-set the outcomes of *Roe* and *Casey*. Specifically President Reagan wrote the following in an article entitled "Abortion and the Conscience of a Nation":

> What more dramatic confirmation could we have of the real issue than the Baby Doe Case of Bloomington Indiana? The death of a tiny infant tore at the hearts of

> all Americans because the child was undeniably a live human being—one lying helpless before the eye of the doctors and the eyes of the nation. The issue for the courts was not whether Baby Doe was a human being. The real issue was whether to protect the life of a human being who had Down's syndrome, who would probably be mentally handicapped, but who needed a routine surgical procedure to unblock his esophagus and allow him to eat. A doctor testified to the presiding judge that, even with his physical problem corrected, Baby Doe would have a "non-existent" possibility for a "minimally adequate quality of life"---in other words, that retardation was the equivalent of a crime deserving of the death penalty. The judge let Baby Doe starve and die, and the Indiana Supreme Court sanctioned the decision (Reagan 2001).

What resulted was a set of rules that came to be known as the Baby Doe Rules. These rules specified and defined a very narrow criterion for withdrawing care from newborn infants. It was a clear espousal of a near absolute "right to life." As such, it gave shape to and made explicit the moral tensions between a "right to life" through medical treatment and a right to die (Pless 1983) (Hentoff 1985) (Annas 2004) (Koppelman 1988). The Baby Doe Rules also put into place enforcement mechanisms for reporting any suspected withdrawal of care. The enforcement mechanism behind the Baby Doe Rules was the threat of withdrawal of federal Medicaid and Medicare funding to hospitals, essentially shutting down any hospital that did not comply. Eventually, the Supreme Court struck down the Baby Doe Rules as unconstitutional. Yet, they continue to loom over NICU practices as a cultural model for informing value judgments about and interactions with NICU infants.

Both the Reagan administration and the supporters of the "pro-choice movement saw the establishment of Baby Doe Rules as a rearguard action for creating a legal precedent that was intended to undermine the right to abortion protected under *Roe and Casey*. Although there is a law on the books with criteria for decision-making regarding the withdrawal of care, there have been very few legal cases that actually invoke the law (Meadow and Lantos 2006). It is difficult to tell why this is so. One possibility is that these cases are still common, but that state protection agencies are not enforcing their own laws. What is more widely perceived by neonatologists to be the case is that "doctors and hospitals have incorporated the moral standards of the Baby Doe regulations in relatively straightforward cases such as those involving babies with Down Syndrome or myelomeningocele (brain swelling) but not in more difficult cases of say, premature babies with chronic lung disease and brain damage" (Lantos and Meadow 2006:67). In the case of full-term infants, the fetal stage of maturation has been fully completed. And, although cases like Baby Doe are indeed tragic, there is medical certainty over the diagnoses and prognoses of their conditions. Thus, legal guidelines that favor one moral stance over another are relatively straightforward and easy to set up and follow. However, in the case of NICU premature infants, because they are still undergoing fetal maturation, there is deep medical *un*certainty. When medical *un*certainty leads to moral uncertainty, this chapter argues that legal rules and concepts reach into the NICU in a different way.

To this day, the power of the Baby Doe case is not in its legal force, but its narrative force. It is first and foremost a story about the fundamental clash between the moral stance that each baby is an "independent moral agent with rights that needed to be recognized and protected" (Lantos and Meadow 2006:79), and the moral stance that each baby is "a *potential* moral agent whose survival depended primarily on his or her parents' choices" (Ibid.). The Baby Doe controversy made explicit three competing loci of moral authority that are part and parcel of interactions that take place in the NICU. That is, whose values should be exercised upon premature bodies, and whose values can best allocate rights? Should doctors and nurses exercise their own values, reflect societal values, or ascertain the parents' values? Each of these loci of moral authority is inextricably linked with various actors' interactions and experiences with individual preemies. As this dissertation has shown, how these three competing loci of moral authority are worked out is a product of interactions-in-the-making. Furthermore, it is not a coincidence that these three loci are intertwined with the three positions that are under debate in *Roe* and *Casey* (See Section II below).

PART II: Rights Talk in the Law

In the United States, as evidenced by the Baby Doe case, legal cases are narratives about moral actions and choices that take place in the cultural practices of everyday life. They are the documentation of personal interactions and personal conflicts. This chapter argues that in the United States, when ambiguities strike, individuals and society turn to the law. To begin, I discuss the role of law in American society beyond that of merely regulating behaviors.

Role of Law in American Society

In 1835, the famed French political thinker, historian, and perhaps the first unofficial anthropologist of American culture, Alexis de Toqueville published Democracy in America. Based upon his travels though a new America and its burgeoning democratic society, he observed and noted many differences between America and Europe. One such distinction was that Americans are highly concerned with “individual” well-being. They place great reliance on law and the ways in which laws infuse into everyday life to legitimize, maintain, or right wrongs in the pursuit of individual life, liberty, and happiness. He noted that there is no political or social question in America that does not turn into a judicial one (Friedman 1998). His observations of American society, institutions, and cultural practices remain true to this day. As Constitutional scholar Lawrence Friedman wrote in his monograph on American Law, “All sorts of social and economic issues up in [Constitutional] law. And, in court, these questions get *answers;* moreover both sides usually respect what the courts decide” (Friedman 1998:314). The courts are forever intimately concerned with intimately personal and emotional issues such as obscenity, abortion, sexual deviancy, personal morality, and drug laws.

In America, unlike other countries, law and the legal processes possess not only aspects of social authority, but also serve as cultural authority (Starr 1982) (Friedman 1998) (Amsterdam and Bruner 2000). Authority is defined by sociologist Paul Starr as “the possession of some status, quality, or claim that compels trust or obedience.” It also “signifies a potential to use force or persuasion, though paradoxically authority ends when either of these is openly employed” (Starr 1982). Starr understands social authority in the Weberian sense as the regulation of action while cultural authority refers to “the probability that particular definitions of reality and judgments of meaning and values will prevail as valid and true” (Starr 1982). It entails the constructions of reality through definitions of fact and value and, in the United States, it resides in law (as well as objects, references (dictionaries, maps, etc.), and scholarly and scientific works). Cultural authority may be used without being exercised—-it is often consulted, but its most relevant work is attempting to resolve ambiguities.

The American Constitution is “living law” (Friedman 1998) or living “cultural authority” (Starr 1982) for two significant reasons. First, it is enforced. There is social authority behind the cultural authority of law. Second, Constitutional law is “one of society’s means of maintaining continuity and value judgments across time and space and changing conditions. It does not encompass all value judgments but is centrally concerned with those that are seen as affecting the stability of the community—including the criteria for determining which ones these are” (Amsterdam and Bruner 2000).

How does law do this? Law scholar Anthony Amsterdam and social science scholar Jerome Bruner provide the following description on how the law works to penetrate the spheres of human activity: “The corpus juris prescribes general rules about what is permissible and impermissible in delineated spaces of human activity and to establish institutions and procedures for constantly instantiating those rules with reference to specific cases (Amsterdam and Bruner 2000:140)” Legal cases are the bridge between the “small” and “individual” particularities of everyday cultural practices and the “grand”

and "timeless principles" of legal doctrines, analyses, and rationales that courts have invented, developed, and spread (Friedman 1998) (Amsterdam and Bruner 2000).

With these thoughts in mind, I now draw upon a discourse analysis of *Roe* and *Casey* to illuminate the parallel themes and issues in law and the NICU. The debates and tensions in abortion jurisprudence mirror what is occurring in the NICU. In particular, these are the tensions over the moral statuses of ambiguous subjects who are physiologically still emerging. Specifically, these tensions exist between the *independent* moral status of fetuses and premature infants and the *potential* moral status of them. In the former, rights to life are absolute. In the latter, rights are contingent on social relationships and lived experiences, such as the consideration by Baby Doe's parents that saving his life would jeopardize the well-being of their existing children and their family as a unit.

The Roe Framework

Roe v. Wade, 410 U.S. 113 (1973) was a landmark controversial decision by the United States Supreme Court on the issue of abortion. The Court decided that a right to privacy under the due process clause in the Fourteenth Amendment to the United States Constitution extends to a woman's decision to have an abortion, but that right must be balanced against the state's two legitimate interests for regulating abortions. The first is the protection of prenatal life. The second is the protection of the mother's health. The *Roe* Court states that interests in the potential life of the fetus become stronger over the course of a pregnancy, and thus it tied the state regulation of abortion to the mother's current trimester of pregnancy.

The Court later rejected *Roe's* trimester framework in *Planned Parenthood of Southeastern Pennsylvania v. Casey* (505 U.S. 833 1992). *Casey* reaffirmed *Roe's* central holding that a person has a right to abortion up until a certain point in one's pregnancy, but overturned the pregnancy framework in favor of a viability standard that was defined in *Roe*. The *Roe* decision defined "viable" as being "potentially able to live outside the mother's womb, albeit with artificial aid," adding that viability "is usually placed at about seven months (28 weeks) but may occur earlier, even at 24 weeks with the successful aid of technological assistance" (*Roe* at 151).

The *Roe* framework was constructed by Justice Blackmun who drew upon his experience as a lawyer for the American Medical Association (Garrow 1994). He modeled the tripartite framework in *Roe* after the clinical and society-wide tripartite trimester model of pregnancy. In upholding a woman's right to choose abortion, the *Roe* Court declined to formally confer personhood status upon the fetus. The Supreme Court declared that so long as the fetus was unborn, it was excluded from the word 'person' as used in the Fourteenth Amendment (*Roe* at 151). As such, its personhood status is both moot and irrelevant for purposes of deciding whether a state could constitutionally proscribe abortion. The Court reasoned that anti-abortion statutes, like the one challenged in Texas, "could not really be about protecting the prenatal life of the fetus because the pregnant woman undergoing abortion cannot herself be prosecuted for self abortion or for cooperating in an abortion performed upon her by another" (*Roe* at 151).

This momentary appearance of clarity on the status of fetus as a non-person quickly became obscured when the Supreme Court also declared that the right to choose abortion "was not unqualified and must be considered against important state interests and regulations" (*Roe* at 151). Not surprisingly, the Court found that this right could be limited by the state's interest in safeguarding the health of pregnant women undergoing abortion. However, the Court also found that the state also has "*another* important and legitimate interest in protecting the potentiality of human life" (*Roe* at 151). Recognizing that these two interests are inherently interconnected and will at some point become incommensurable, the Court attempted to make each interest analytically "separate and distinct" from the other. Each interest "grows in substantiality as the woman approaches term and, at a point during pregnancy, each becomes compelling" (*Roe* at 151). For the period of time before either of the two legitimate state interests becomes compelling, the pregnant woman's privacy interest in abortion is the most dominant. Thus, approximately from conception until the end of the first trimester, the state cannot regulate the practice of abortion.

At the end of the first semester, the state interest in maternal health becomes compelling due to the epidemiological fact that mortality in abortion may be less than mortality in normal childbirth. As a result, the state "may regulate the abortion procedures to the extent that the regulation reasonably relates to the preservation and protection of maternal health." Some examples of these constitutionally valid regulations include qualification and licensure requirements for the person performing the abortion and for the facility in which the procedure is to take place.

The state's other interest in the "potentiality of human life" becomes compelling at the point of viability. The Court explained that because a fetus at the point of viability "presumably has the capability of meaningful life outside the mother's womb" (*Roe* at 151), state regulations that are protective of fetal life after viability have both logical and biological justifications. Hence, a state's interest in protecting post-viability fetal life may constitutionally "go so far as to proscribe abortion during that period, except when it is necessary to preserve the life or health of the mother" (*Roe* at 151). This elaborate holding refrains from giving absolute protection to any relevant interests. Rather, the Court perceives three relevant interests: that of the pregnant woman, a state interest in her health, and a state interest in potential life. These interests are mapped onto the trimester medical model and each ripens and becomes compelling during a particular period of time in the pregnancy.

The rationales behind the *Roe* and *Casey* decisions reveal thematic parallels to the NICU. The NICU is the technological ex-utero extension of the cultural debate over the moral status of still emerging human entities—embryos, fetuses, and premature infants. As such, the *Roe* and *Casey* decisions are much more than just about providing guidelines for the practice of abortion, they are ultimately about the allocation of rights and responsibilities (Tribe 1992). In the abortion debate, as in the NICU, social life constantly grinds up against the universal process of human gestation and thus rights and responsibilities cannot be easily allocated without directly dealing with the very allocation of rights is intertwined with interactions and relationships between medical caretakers, women/parents, and fetuses/premature infants. In other words, I argue that the Supreme Court in *Roe* implicitly understood that any position on abortion must necessarily take into account the shifting relationships and interactions between various relevant actors. To draw out the relationships between various actors in the abortion debate, the Court must necessarily construct varying identities for the fetus. That is, they must first define the fetus, before they can rule on abortion.

Who is the Fetus?

Embedded within this tripartite framework are the Court's checkered presentations of the fetus's personhood status. Throughout the opinion the fetus is referred to by different names as the Court balances and delineates how much weight is to attach to each of the relevant interests. Using discourse analysis, I will show that the personhood status of the fetus varies according to the Court's evaluation of a fetus in a particular context. Words signal emotional commitment rather than just mere information (Lurhmann 1978). In this particular case, what I mean by emotional commitment is the degree to which one conceptualizes the fetus on the spectrum between non-person and person. Here, the Supreme Court's choice of different words to represent the fetus signals varying degrees to which *Roe*'s analytical framework will recognize the range of emotional commitments to the fetus as a person. I argue, these words which signal a range of emotional commitments is therefore akin to constructing narratives of "affective experiences" (Kratz 2006) for various actors in the abortion debate. What the socio-linguistic analysis of *Roe* and *Casey* will reveal below is that a sincere effort to balance the moral tensions found in the abortion debate is not just about constructing rules and guidelines that allow or disallow certain sets of medical practice. Rather, the spirit of abortion legislation is about imbuing rights with "rites" so that a "right to life" or a "right to an abortion" is about providing a safe harbor for which many competing experiences of personhood dilemmas in abortion can be honored simultaneously and protected under the law. Thus, to do so, the relationships between actors and their experiences have to be alluded to. However, they are window-dressed under a legal discussion of "rights," when in effect the dicta surrounding the *Roe* and *Casey* decisions suggest that the various shifting rights concomitant with a woman's pregnancy are imbued with constructed affective experiences that individuals undergo during rites of passage. Hence an emerging human entity's potential right to life is really an emerging "rite" to life.

Below, I present three shifting identities that are attached to fetuses under *Roe* and *Casey*.

The fetus as medical object

It is not insignificant that the Court employs the word "fetus" when it is engaged in explanatory dicta. These moments include the presentation of the general issues of the case, arguments on either side, or relevant legal and historical background on the status of the fetus. Notice the use of the word fetus in the context of the Court presenting the State of Texas's argument. It stated, "The appellee and certain amici argue that the *fetus* is a 'person' within the language and meaning of the 14th Amendment." In a similar instance of providing the state of the law, the following was concluded, "No case can be cited that holds that a *fetus* is a person within the meaning of the 14th Amendment" (*Roe* at 151).

In these contexts, the term "fetus" serves several purposes in constructing the over-all tone of the opinion. Used by doctors and scientists to specifically denote in-utero human entities undergoing the gestational process, the word "fetus" was developed as a neutral technical term that was intended to be free of any social, cultural, religious, or normative judgments on the status of the fetus (Issaccson 1991). As such, the term "fetus" connotes an objective medical stance toward the gestational entity at issue and appears to ground the *Roe* balancing scheme in the facts of human development, rather than admit it as a pure balancing of normative interests. Also, because the *Roe* opinion does not give absolute protection to any interest, it is important for the Court to choose a word to represent the growing gestational human entity that would be recognizable and used by either side of the abortion debate. As a technical-medical term, "fetus" serves this purpose. It can carry multiple interpretative meanings. Some individuals will understand the fetus as a baby or child, others will see it as a mass of maturing cells, still others will perceive it as something in between.

However, when the Court does execute a holding on a particular interest, it replaces the technical medical word "fetus" with more partial descriptors. Termed as "her pregnancy" and "unborn," the personhood status of the fetus is underplayed when the Court is focused on the interests directly related to the pregnant woman. In contrast, personhood status is highlighted when the Court is abridging a pregnant woman's interests in the third trimester and recognizing a state's interest in the growing fetus. Here, the descriptors "potential life" and "fetal life" are used.

The fetus: AKA "unborn" and "her pregnancy"

In the former context of underplaying personhood status, the Court relies on the terms "her pregnancy" and "unborn" in place of the word "fetus." The following are two illustrations. First, in establishing the right to choose abortion, the Court held, "this right of privacy…is broad enough to encompass a woman's decision whether or not to terminate *her pregnancy" (Roe* at 153*).* As the object of a pregnant woman's potential choice for medical termination, the fetus becomes transformed into "her pregnancy." Because this statement is the Court's most forceful recognition of a pregnant woman's determination of her own best interest, the reference to the fetus that she is carrying must de-emphasize the possible construal of its personhood status. Otherwise, the Court would be viewed as privileging the rights of one group of persons over another or worse yet, as protecting the interests of one individual by taking the life of another without due process of the law. Hence, the words "her pregnancy" are used (*Roe* 161-163). As such, it connotes a "thing" owned by the pregnant woman with which she can do as she pleases, akin to a personal property right.

Second, the fetus is also referred to as the "unborn." This term is employed in those parts of the opinion when the Court is directly refuting Texas's argument that a fetus is a person within the meaning of the Constitution. It held, "The word 'person' as used in the Fourteenth Amendment does not include the *unborn*." This statement not only excludes fetuses from the status of persons, but also equates "fetus" as being interchangeable and synonymous with "unborn." In a later part of the opinion, the Court rebuts suggestions that fetuses possess the status of persons due to the recognition of their interests for purposes of inheritance, recovery for prenatal injury, and wrongful life suits. The Court argued that these situations were very narrowly defined and thus could not logically be construed as "according legal rights to the *unborn*." In its final invalidation of the personhood status of the fetus, the Court concluded, "In short, the *unborn* have never been recognized in the law as persons in the whole sense" (*Roe* 161-163).

Implying the fetus to be more than a "thing" owned by the pregnant woman, the word "unborn" in these statements recognize the existence of a developing separate entity. However, unlike the word "fetus," which specifically denotes a *human* gestational entity, "unborn" is a generic term. In effect, "unborn" can encompass any gestational entity existing in the animal kingdom, from an insect to a house-pet, to a human being. Connoting non-exclusivity, “unborn” also de-emphasizes humanness and, in turn, is conceptually distanced from the notion of a person.

With the word “unborn” in replacement for the word “fetus,” the Court in the aforementioned instances presents a conception of the fetus as a non-person and non-human, but separate entity. This presentation is critical because the Court is demarcating a fine line between a pregnant woman’s determination of how best to implement her abortion choice and the extent of a state’s power to intrude upon the practice of abortion in the interest of the pregnant woman’s health. To permit states to limit a pregnant woman’s ability to exercise her right to abortion through licensing restrictions, the Court must first diminish the extent of her “ownership” in “her pregnancy.” Hence, as a separate entity, the word “unborn” carries out this reduction of ownership. However, the Court must also not go so far as to implicate the fetus to be a person. Recognition of personhood status would give the fetus an absolute Constitutional right to life under the Fourteenth Amendment. This conclusion cannot be logically squared away with criminal abortion statutes, like the one in Texas, which allow for the termination of the fetus when the pregnant woman’s life is in jeopardy, but not under any other circumstances. Concomitantly, the Court also does not want to contradict its prior decision that held the privacy right to include abortion.

The Fetus: AKA “potential life” and “fetal life”

Here, I will argue that despite the Court explicitly holding that the fetus is not a person, the fetus is nevertheless presented as having achieved varying degrees of personhood status when the Court is upholding a State's interests in the "potential life" and "fetal life."

Through Texas's arguments made on behalf of the fetus, the connotation of the word "life" can be shown. Texas argues that states have a general obligation to protect human life and that because human life begins at conception, this general obligation for protecting human life must necessarily extend to the protection of *prenatal life*. This line of reasoning is based on the theory that the beginning of life designates the beginning of personhood. Thus, Texas's presentation of the fetus as "prenatal life" and "beginning of life" assumes that a "life" signifies a human life and, in turn, a person.

As a consequence of Texas imbuing the word "life" with personhood status, it can be argued that when the Supreme Court uses the word "life" in referring to the fetus (e.g., fetal life, prenatal life, potential life, as opposed to unborn, her pregnancy, or fetus), it is favoring Texas's conception of the fetus as a person.

In several instances, the Court employs the word "potential life" when referring to the fetus. Textually, these moments occur when the Court is holding that "so long as at least *potential* life is involved, the State may assert interests beyond the protection of the pregnant woman alone" (*Roe* 157).

Constitutional scholar Jed Rubenfeld has argued that as a matter of constitutional coherency and logic, to be a "*potential life*" for which the state can actually possess an interest, the Court is covertly treating this supposed *potentiality* as an *actuality* (Rubenfeld 1991). After all, a compelling interest cannot be premised on "potential" human life, but only on actual human life. He further reasons, if there was indeed a compelling state interest in the potential human life, then this compelling governmental interest would exist from the moment of conception and thus abortion may be barred completely. Because neither the Supreme Court nor the most conservative criminal abortion statutes bar abortion completely, it logically follows that the protection of *potentiality* of human life is really about the protection of the fetus as a person.

For Rubenfeld, because "potential life" is equivalent to "actual life," he would view the Supreme Court's use of the words "potential life" and "fetal life" as equivalent attempts to covertly treat the fetus as persons. However, through discourse analysis I argue that when the Court employs the word "life" in referring to the fetus, it differentiates between "potential life" and "fetal life." In the next section, I will show why this differentiation matters.

With the following paragraph, I will illustrate how the Supreme Court confers different degrees of personhood status upon the fetus by transitioning between two linguistic references for the fetus.

> With respect to the state's legitimate and important state interest in *potential life*, the 'compelling' point is at **viability**. This is so because the fetus then presumably has the capability of meaningful life outside the mother's womb. State regulation protective of *fetal life* after viability thus has both logical and biological justifications. If the state is interested in protecting *fetal life* after viability, it may go so far as to proscribe abortion during that period, except when it is necessary to preserve the life or health of the mother (*Roe* at 159).

In this paragraph, we see the Court transition between the terms "potential life" and "fetal life." Notice the Court's coupling of "a state interest" with "potential life" in the first sentence, as opposed to, the coupling of “state protection” with “fetal life” in the third and fourth sentences. I argue that this linguistic switch signals an equivalent conceptual switch in the Court’s understanding of the fetus’s personhood status. Thus, as the ‘compelling point,’ viability demarcates not only a linguistic boundary between the pre-viability in utero fetus and the post-viability in utero fetus, but it also signals a different degree of personhood that is achieved by the fetus. Linguistically, potential life is used to refer to the in utero fetus before viability whereas “fetal life” is used to refer to the in utero fetus after viability.

Tracking this linguistic transition, the conception of the personhood status of the fetus, before and after viability, also differs. As a pre-viability fetus, a State interest in “potential life” is a “less rigid” personhood claim than a State interest in protecting “prenatal life” or “fetal life”. As a “potential life,” the fetus achieves quasi-personhood status. As such, it does not possess enough personhood status for a state to proscribe abortion and “unduly burden” a pregnant woman’s choice to abort. However, the fetus does possess enough personhood status such that the “woman’s privacy is no longer sole and any right of privacy she possesses must be measured accordingly.” As a practical matter, a state may attempt to persuade a pregnant woman to decline an abortion on behalf of the “potential life” so long as it is not considered a “substantial obstacle in the pat of a woman seeking an abortion of a nonviable fetus.”

In contrast, the post-viability in utero fetus appears to achieve full personhood status. As the Court stated, the protection of “fetal life after viability” can justify a state “to go so far as to proscribe abortion.” The State’s ability to directly interfere and constrain a pregnant woman’s right to choose abortion implies that the fetus as a “fetal life” has achieved enough personhood status for a state to constrain the actions of another individual on its behalf. The fetus is no longer a pregnancy owned by the woman. As a “fetal life,” the fetus’s status can be analogized to the status of an infant life, child life, teenage life or adult life. As a specific kind of life, embodied by a particular kind of human person, the fetal life is essentially a fetal person. Hence, the fetal life cannot be forced to compromise its own interests to life in order to further the interests of another individual.

Drawing on recent legal scholarship that recognizes the role of the Supreme Court as an arbiter of values, rather than just setting limits on the practice of rights, legal scholar Terry Maroney argues that common sense rationality has always ruled legal decision-making, especially in Constitutional law cases. However, what she recognizes as a newly emerging phenomenon is the way in which the U.S. Federal court systems are shifting their notion of common sense to include emotions or what she argues is an “emotional common sense” rationale. She defines emotional common sense as “What one thinks she simply knows about emotions, based on personal experience, socialization, and other forms of ‘casual empiricism’” (Maroney 2009: 856). However, coupled with the legal notion of rationales, which is an operative definitional term with legal and logical authority, the federal courts of the United States, and judges in particular, are now in the arena of anthropology and sociology, rather than law. However, they do so without the methods or the training to appreciate pluralistic cultural contexts. Furthermore, the use of emotional common sense as a rationale brings into question, “What is the appropriate role and function of law in a democracy?” and “What is the appropriate relationship for law and social science?” Through constructing shifting identities for fetus that are defined relationally to others, Meyer Fortes notion of the “individual” which captures the elusive experiences of persons is now merging it with an American legal concept of the “individual” bound in atomistic individual rights. The hybrid is an elusive concept of the person that applies to fetuses, babies, women, and those in their lives, masked behind a more simplified concept of an individual person bound up with “individual rights” and with all of the authority and institutional power of an individual rights discourse.

Abortion jurisprudence and other cultural debates that wrestle with ambiguous subjects demonstrate a need for a relational notion of persons in legal jurisprudence. However, the move toward an “emotional common rationale” in Constitutional legal cases, now explicitly in play through recent partial birth abortion cases (see *Stenberg v. Carhart*), is not the only means to incorporate a relational notion of persons into the law. A historical example exists. During the American colonial period, the self was understood as bound to others. This is the Law of Coveture. It binds together the lives of the husband and the wife. The woman loses her legal status as a person and becomes embodied by the legal status of her husband. Dependent on the body of her husband to protect and provide for her, the woman can now carry out the required duties of her role – to maintain a household without the burden of polity. The husband, through his obligation to provide for his wife, children, and servants is now conceived of as an independent with certain privileged rights to govern and rule over his household, as he finds necessary. However, the husband’s independence is only relative. In his own way, the husband is also bound and a dependent. He is bound to his community and dependent on it to provide him with a position within the social structure. In exchange for his rights to govern and rule over his own household, he must carry out his civic duties and participate in the public sphere. In some ways, the independent individual is never fully separated from the public sphere (Novak 1996) or each other. Relationships are recognized as constantly in flux and shifting and it is protection of a wide range of shifting relationships that is protected through the Law of Coveture.

What I hope this extensive analysis of *Roe* and *Casey* has shown is that when rights define who a person is and should be in the context of shifting relationships, rights become imbued with certain privileged affective experiences that are rationalized under an “emotional common sense” with operational power. Through constructing emotionally rationalized identities for the growing fetus (i.e. as medical object, a woman’s pregnancy, potential life, and fetal life), rights take on the function of “rites”. By doing so, it leaves out other legitimately experienced concepts of selves and others, and values certain emotional orientations over others. When relational concepts and affective experiences of the person and individual are hybridized with traditional legal rights and incorporated into a Constitutional system, the effect is that we are no longer legislating medical practice (which is an appropriate arena for the law), but are moving into a realm of legislating emotions and experience---an arena that must and should include the work of the social sciences so that pluralistic concepts and experiences of the person can continue to flourish.

PART III: Rights Talk in the NICU

In this last section, I will draw upon references from previous chapters in conjunction with a discussion on abortion legislation to argue that “rights talk” in the

NICU provides ways of working out various competing ideas of personhood and personhood experiences that are experiential struggles with the ambiguous moral status of premature infants. This section argues that medical caretakers engage in rights talk in various ways to help obscure ambiguities.

Characteristics of Rights Talk

Drawing from the work of legal scholar Mary Ann Glendon, this section argues that the characteristics of rights talk are particularly well suited for actors in the NICU to construct concepts of selves for premature infants. Although Glendon argues that the characterization of American rights talk or a language of rights impoverishes American society by creating ego-centric individuals who lack a sense of duty and obligation to others (Glendon 1991), this section argues that the very characteristics of rights talk that are impoverishing are exactly the traits relied upon in the NICU to obsure or manage ambiguities. The following is summary of Glendon's characterization of American "rights talk."

(1) It encourages our too human tendency to place the self at the center of our moral universe

(2) It is simple and stark

(3) It is absolute

(4) It creates insularity around persons such that one becomes an island unto oneself.

(5) It is characterized by self-expression

(6) It characterized by entitlements

(7) It seeks to create persons that are completely free without responsibilities (or burdens)

(8) It possesses things, feelings, values, and beliefs totally.

(9) It demands, without being asked to act justly.

(10) It is characterized by an insistent “I want.”

(11) Rights talk embodies selective exaggerations and omissions

By making certain dimensions of human personhood normative, engaging in rights rhetoric may act to encourage medical caretakers to temporarily obscure aspects and experiences of personhood that challenge them. It is an emotional break from the contradictions embodied by premature infants under NICU care. Thus, through various voluntary, non-routinized activities, medical caretakers can begin to work through individual personhood experiences with premature infants (and with each other) by engaging with them from another perspective, from another emotional orientation, from a slightly farther distance. The process of making signs, participating in ethics consults and rounds, attending NICU conferences, and socializing in the NICU are all ways that medical caretakers attempt to transform the actual presence of premature infants into a narrative presence. By doing so, it changes the orientations of their interactions with them. The following are several examples of medical caretakers engaging in the practice of rights talk. What they are all searching for and engaging in are activities that provide “a little distance.”

A Little Distance

Dr. Carter has not slept in two days. He is an attending in the NICU and despite his hectic work and research schedule; he always shows up for important school events that his kids are a part of. He will dash out in the middle of the day to attend a school play, an assembly, or to coach soccer. He also leads a team of student researchers. To say that he is a busy is an understatement. He is known for his good nature, his humor, his intelligence, and most of all for his deep compassion towards NICU staff and families. Dr. Carter also always makes time to attend ethics meetings. They are not mandatory; he has much on his plate, yet he rarely misses one.

Although sometimes the ethics meetings are concerned with his patients, many are not. He always just says, “They are fun.” In meetings he is a thoughtful and lively participant and almost always reminds the lawyers in the room who tend to over-emphasize individual rights that the right of families as an “individual unit” must also be considered in any ethical decisions. He describes himself as a consequentialist—-someone who gets to the heart of the matter and tries every avenue available to achieve those ends. He is a self proclaimed “big picture guy.” But, he has a memory for details. He also has a passion for law, respects the power of legal rules, but is never bound by them. He is clearly the favored attending among nursing and resident staff. People always like to be on his service. They often remark, “Dr. Carter’s months are always easy. He is always lucky and kids always seem to do better” (Nurse 1997). “I am always surprised that the hard cases seem to vanish when he is on service for the month. People are just more at ease” (Resident 1997). “He always seems to see the forest through the trees. He never freaks out. You can always go to him with an issue and you leave feeling like it’s all going to be ok” (Primary nurse 1997). “When we get freaked, he just tells us to go for a walk or take a lunch. I think it really helps, he helps you maintain a distance so you can read what's happening" (Fellow 1997).

He is also a favored expert witness of many lawyers. In fact, Dr. Carter is known as someone who "knows the ins and outs of law like a lawyer." "You don't have to prep him much. He always knows what he's doing" (Lawyer 1997). In addition to medical journals, he is also well published in legal journals and collaborates with well-known legal scholars.

When Dr. Carter attends ethics meetings, he often draws on ethics issues in the NICU as a way to inform ethical dilemmas in other hospital units. He is one of the rare individuals who seem to never burn out. This is quite extraordinary given that NICU medicine is known as a high stress field (Braithwaite 2008). Many residents report that the NICU is one of their hardest rotations. Why then is Dr. Carter not overly burdened by personhood dilemmas, even though he is deeply aware of them and engages with them on a daily basis? When you ask him what working in a NICU is like, he often states that it's rather routine; it's a "pretty happy going place."

Dr. Carter rarely talks about himself. However, working with him over the years and seeing how he interacts with others in the NICU and during ethics consults, one quickly realizes that he engages in rights talk when situations in the NICU become filled with tension. Whereas "rights talk" can be viewed as overly absolute and potentially divisive, under NICU circumstances it can "help everyone see the forest through the trees" (ethics and NICU fellow). One resident paraphrased what he remembers Dr. Carter saying during rounds one morning, "Medical paternalism is not all bad. Yes, parents have rights, but it can be too much burden. Rights can be a pain. The burden of making decisions cannot rest only on families alone. We, doctors and nurses, need to step up and take some responsibilities for decisions too. This is how we support families. So people, medical paternalism is not dead yet." For Dr. Carter, "rights talk" is more practice than talk. Although he does not always use the word "rights," he places himself in interactive and intellectual arenas where rights talk is prominent. In every ethics discussion, legal implications and specific cases are almost always discussed. I suspect, for Dr. Carter, engaging with rights talk enables a certain comfortable distance so that he can "see the big picture." His view of the Baby Doe case is that it provided the field of neonatology with a "collective sigh"—a breather of sorts that enables individuals to acquire a little bit of distance.

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I walk into the NICU and I see Mary, Lizzie Lollipop's nurse standing at the nurse's station. She is making "the personality profile sign." She has a blank piece of paper and a sharpie and she is writing each line out. She chuckles to herself and I ask her what is so funny. She says, read this. She has written, "Don't touch me, or I'll show you." She says to me, "That's good right? They'll know it's me and I'm serious about people staying away from Lizzie. They can only mess her up." "That kid is a trooper; she would totally fight them if she could. She gets it." Come with me, "I'll show you a trick." (This is when she shows me the lollipop trick, Chapter 7). She takes one of my lollipops, and grabs some tape along with her sign. We get to Lizzie's bed, and she sticks the sign on Lizzie's bed. She doesn't say anything to Lizzie; she just double and triple tapes the sign so “this way it will DEFINITELY not fall off.” “This way, people can’t say I didn’t see it.” “Doesn’t it just scream, get out of my hair?” I nod. It does.

It is obvious that making a sign for Lizzie provided Mary with some distance. The sign that she made is filled with “rights talk” (See chapter 7). On another occasion, before Lizzie was admitted to the NICU, Mary recounted how she used to be a PEDS ICU nurse. She compared the PEDS ICU with the NICU and said, “Peds has great kids and great people. The cases are harder, because many don’t survive. But, in some ways, it’s easier to work there. You get to know the kids, the families—-it’s heartbreaking, but also you have so many special bonds and special relationships that will inspire you for a lifetime.” “In here, I have to make up little personalities for them. It helps. Otherwise, it seems a little empty. If you don’t do it —-make personalities, you can’t *see* them. Then you can’t relate to them or their parents.

For Mary, part of constructing personalities for premature infants is through the making of signs. Explicitly and implicitly, the creation of personalities is almost always in the language of “wants.” Unlike Taiwanese/Chinese parents who often talk about how a baby will look, medical caretakers in the NICU almost always talk about personality. If he is “a fighter” then that implies he has a right to medical treatment and perhaps a DNR order should not be considered just yet. Personality traits are often about one’s right to be independent, to exercise entitlements, and to assert one’s wishes. These are the details of “rights talk” that Glendon criticizes as being too hyper-individualistic and egocentric. Yet, these very traits enable medical caretakers to better define the ambiguities surrounding premature infants and interactions with them.

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Janelle is having bad day. Miracle Mikey crashed last night---for the second time this week. However, his grandmother still refuses to sign a DNR. The nurses and residents are all in a bad mood. “Stay away,” says Miriam, who is my co-research assistant. She continues, “Seriously, if we don’t get any intuitions, it’s fine today. It’s just a really bad day. I was there for rounds.” I ask, “Did you get the intuitions for today?” “Of course everyone gave me their intuitions, they always give them, I think they like to do it---but the energy in there is really bad.” “I’m not sure they will give you a second reading in the afternoon though. They just may be too occupied. But, I’m just saying, it’s not a huge deal if we miss one day.”

I walk to the NICU and I am prepared for the worst. I walk in and Miriam is right, the energy is bad. It actually seems quieter and darker than usual. There is a surgery happening and of course, it’s on Miracle Mikey. I walk out of the NICU. I think about just ditching for the day. Instead, I come back several hours later. I find Janelle and ask her for her intuitions. She says, “You know what I want to say, what I hope, this is just too much.” “But, my intuition is that he will survive this too.” “So, you know what to write down.” I write down L5, S5 (Live with highest confidence, severe neurological impairment with highest confidence). I thank her and was prepared to move on to others to gather their intuitions. However, to my surprise, she starts to recount a story about a family picnic, her siblings, and how no one ever got her. She tells the story about how her sister will just “never let her be.” If she wanted to play piano, then her sister wanted the same. If she wanted to try dance class, then her sister “wanted that too.” “Can’t she just be her own person and not take what is mine?” She stops partially through the story, and then moves on to tell me how she has off this weekend. She is not sure what she will do. She had promised to babysit for her niece’s toddler, but she is now re-thinking her plans. She now wants to do something fun. “After my week, I deserve it.” Her story rambles and I can’t quite grasp all of the parts. She seems to be just talking and sharing. Fifteen to twenty minutes later, she finally settles on telling me the story about Miracle Mikey and his “teenage drug-addict mom.” She says, “He does not deserve all of this. You gotta give that kid some credit. He is a fighter. Maybe, he doesn’t want a DNR.”

Out of context, Janelle’s ramblings would not appear significant. However, in the context of her day and her relationship with Miracle Mikey, it becomes clear that Janelle is overwhelmed with the ambiguities surrounding Mikey’s situation. She brings in aspects of her life that at first appearance seem unrelated to what is happening in the NICU. Yet, upon further analysis, it appears that stories about “what is mine,” “what is yours,” and Mikey’s individual personality as a “fighter,” is yet another example of “rights talk” that enables a relief of distance to be created. In Janelle’s case, it recalibrates her day, her projected relationship with Mikey, her emerging concepts of self for both herself and for Mikey, and most critically, it provides her with a little distance so she can regroup. She ends our conversation by saying; “There is always so much to do. I better get going and get some notes done. I don’t want anyone not being careful tonight. Mike cannot take another crash.”

Rights talk helps to better define who premature bodies are (or are not) and who we are (or are not) in relation to them. In general, medical caretakers partake in activities that are related to issues in the NICU, but also enable them to create some “distance” from their professional lives. In parallel with the findings in Taiwan where zuo yue rituals enable parents and kin to create a narrative presence for premature infants that very rarely results in direct interactions with premature infants, medical caretakers in the United States attempt to transform the actual presence of premature infants into a more distanced "narrative presence" that enables them to re-orient their relationships with premature infants and create new interactive experiences.

In her work on the abortion debate in a small American community, Faye Ginsberg found that life reviews are compelling during critical shifts throughout the life course, particularly when there is dissonance between such moments and cultural definitions for them (Ginsberg 1989: 137). Ginsberg interviewed with women on both sides of the abortion debate and found that "life crises" transitions from one culturally defined stage to another at which there is regularly experienced individual stress reveal contention over cultural definitions. Her work has shown that a sense of life crisis may be even more likely in situations of rapid change when the social rules for an assumed life trajectory are called into question.

Abortion activism, Ginsberg argues, creates both an interpretation and arena of action that activists use to reframe in social terms of what they had experienced initially as problematic shifts specific to their individual lives (Ginsberg 1989: 138). For Ginsberg, women engaged with abortion activism and drew upon notions of individual rights as a way of managing their own life crises created out of discontinuities between their own lived experiences and the dominant cultural definitions of their experiences. For NICU medical caretakers, the crisis situation is the prematurity experience. It is a life crisis in a double sense. First, it is a life crisis because the very situations they need to manage and reconcile are contradictions that arise between upholding a "*right to life*" that is part and parcel of their everyday NICU work and their own conflicted experiences with "doing the right thing." Second, it is a life crisis in the sense that prematurity experiences in the NICU can create discrepancies in the lives of medical caretakers themselves. I suspect that Janelle's personal stories while she was under the stress of Mikey's second crash are representative of how her work life influences her to take stock of her personal life.

No parent or medical caretaker ever wants to take full responsibility for withdrawing care. One is never sure whether one is ever doing the right thing. "Nothing ever feels totally right." Whether treatment is continued and a life is sustained or if withdrawal of care is chosen, no action in the NICU ever feels completely right or wrong. Doubt is the norm and looms large over many aspects of NICU care. There is no magic in the words or phrases found in the U.S. Constitution (or any Constitution) or in rights talk, but it is the extent to which rights talk and/or the law bridges the "small" of people's everyday lives with the "grandness" of principles that makes rights talk and the law a living social instrument for managing biological and cultural ambiguities that surround the most controversial cultural debates in American society.

CHAPTER 10: SOULS, HOMES, AND THE EXPERIENCES OF LIFE

This dissertation has been centrally concerned with the making of social persons. In particular, what happens when the start of ex-utero human life begins in contradiction and conflict under the high-tech interventions of NICU medicine? Plato's famous cave allegory talks about the notion of "paradigma" with regard to how individuals are chained by their own particular ways of seeing and experiencing the things around them. Individual paradigms are in part about one's expectations, and nowhere are these more deeply felt than the expectations surrounding the birth of a new human being. When confronted with situations that challenge our ideas and experiences of who we are and who we wish to be, we often first resort to what we already know or have experienced, and then only when we must, do we begin to change and alter our expectations, and our experiences of ourselves and others. This dissertation has been about all of the different kinds of "abilities" that are required of individuals to manage and carry on when the beginnings of ex-utero lives have gone awry.

Across oceans, in Taiwan and the United States, all individuals who experience a birth too soon must face the same bio-social dilemmas of personhood. In other words, viability—How do we keep premature infants alive until their organ systems become mature enough to survive in an ex utero world? And, how do we insure that they may continue to live that life? In the meantime, how do we live through parenting a newborn child who we cannot touch, cuddle, or comfort while managing the often self-shattering discrepancies between our own expectations and hopes, and all of the uncertain realities surrounding prematurity overwhich we have very little control? Each in their own way, three groups of actors (premature infants, parents, and medical caretakers) across two different culturally plural societies, experience and live through parallel dilemmas of personhood that result from NICU interventions. However, they do so in different ways.

Premature infants come into the ex-utero world with in-utero organ functions. Yet, NICU interventions are imperfect but extremely successful at keeping death at bay while extending the potential for continuing lives that otherwise would not have existed. This places them in a complex and contradictory situation—social life has begun, while biological life is still "in-the-making." Preemies begin their social lives as fleshly human avatars. Biology is front-and-center and on full exhibit, with bodies that are without capacities for agency and interactions. Yet, they corporeally exist. As blank slates, who we make them to out to be, and how we interact with them—before they can make themselves—are mirrors for our own elusive expectations and experiences of personhood. While waiting for premature infants to grow, individuals create profiles and personalities for premature infants, hoping they will take on lives of their own. However, biology and technology constrain the limits of what we can do for them. Sooner or later, our initial experiences with them will change and be challenged as their bodies mature and gain capacities for interactions (or stop doing so). The ambiguities surrounding premature bodies and the contradictions between biological and social viabilities will have to be socially managed and partially resolved. To do so, individuals will draw upon objective and subjective aspects of personhood as they interact with premature infants and with each other.

In Taiwan, NICU parents will turn to family and kinship structures. Mothers will undergo post-natal avoidance rituals of zuo yue while their premature infants are in the NICU. As mothers are confined at home, fathers and kin will visit the NICU, interact with nurses, and carry back information about their premature infants. At home, family members will talk about the baby, drawing upon relational concepts of the person to create a narrative presence for their baby that does not burden or require his/her actual presence. Experienced as valid and real, these “narrative” interactions incorporate premature infants into families and webs of social relationships. The extra social and emotional work that family members undertake to manage and initiate premature infants and each other into post-natal life often create and generate new relationships between kin as well as create identities for premature infants that otherwise may not have taken place under normal birth circumstances. Many premature infants possess special status in their families and become the “beloved treasures” of family and kin members even before they are discharged.

The Taipei NICU is quiet, isolated, and filled with very few interactions. Medical caretakers often experience this isolation by turning inwards and re-evaluating relational concepts of selves and others that are predominant in Chinese/Taiwanese societies. Without many opportunities for interactions, many become drawn to individual and atomized concepts and experiences of the person. The variable and elusive experiences of personhood that NICU actors in Taipei live with and live through inevitably create new relationships, alter existing ones, and recompose selves and others.

In the United States, premature infants also challenge normative experiences of babyhood. Parents and medical caretakers must also manage and overcome personhood dilemmas created under NICU conditions. However, their experiences and interactions with premature infants and with each other are creatively managed and partially resolved in different ways than those individuals in Taiwan.

In the U.S., parents do not have society-wide post-natal rites of passage to help define roles and statuses, and shape post-natal experiences. As parents, they turn to medical caretakers to help guide them through the rocky ambiguities surrounding prematurity. Medical caretakers understand all too well that relationships between parents and their premature infants must be created and encouraged for the sake of the preemies and their survival. Therefore, creating bonds and attachments between parents and premature infants are just as important as medical caretaking decisions and tasks that keep preemies alive.

One way in which this is done is through the making of paper signs by nurses. Paper signs help construct voices and personalities---in effect agency, for premature infants by drawing on “rights talk” to simultaneously help define and obscure ambiguities surrounding premature bodies with which individuals find discomforting and troubling. Therefore, through a language of rights, signs mediate and create interactions between parents and premature infants by providing emotional padding to soften the contradictions and ambiguities embodied by premature bodies under NICU treatment. Inevitably, these interactions anchored by a kind of “rights talk” become de facto informal rituals and rites of passage. Rights, utilized as rites, attempt to mark progress and to shape elusive experiences of selves and others. However, they are not always ritually successful at garnering the experiences that individuals hope for and the identity transformations that are sought after. Nevertheless, they are partial and temporary solutions-in-the-making.

As individuals who have repeated experience with premature infants and NICU technology, medical caretakers in the U.S. shoulder the majority of responsibility for the biological and social viabilities of premature infants. They are not only experts at NICU care, but they are almost always also experts at the social care of preemies and their families. However, what about themselves? They mediate challenging prematurity experiences for others, but where do they turn when their experiences of personhood are challenged? Day-to-day, how do they manage the ambiguities surrounding neonatal bodies, and the moral tensions introduced by NICU care? They turn to the law. In American society, the role and function of law is not merely to socially control human conduct. Rather, it is in the law that many of American society's most deeply controversial social issues are wrestled with, debated, and resolved (both for the long term and temporarily). The dilemmas of personhood found in the NICU mirror debates over the moral status of embryos and fetuses found in American law, and in particular debates centered on abortion jurisprudence. In the law, personhood debates are framed in a language of individual rights. Rights define entitlements and responsibilities. As such, in contexts where the moral status of ambiguous human subjects are debated, rights help define these ambiguous subjects, who we are in relation to them, and in recent years, even what experiences we "should" have with them and with each other in regard to them (*Carhart v. Stenberg*). For these reasons, when a legal language of rights enters into everyday practices and become "rights talk" (Glendon 1991), rights talk take on both the power to define and the function of rites simultaneously. For medical caretakers who are the experts at managing all aspects of prematurity experiences for others, engaging in rights talk practices through a variety of activities can partially alleviate the contradictory personhood dilemmas they encounter and experience. Legal cases provide a rich tapestry of narratives concerning ambiguous subjects that medical caretakers in the U.S. can draw upon and utilize to help each other and themselves partially resolve issues of personhood in the NICU.

Prematurity experiences challenge biological, social, and cultural presumptions of life. Small tiny bodies are brought into the social world without capacities for interactions. Parents who love them and medical caretakers who take care of them must manage and live through this time of uncertainty and radical indeterminacy. In the meantime, while we wait for them to grow out of prematurity, we search for ways to incorporate them into our lives, to give them social presence where there are only biological functionalities. In the U.S. we work in all manners to endow them with personalities and capacities that are unique and individual—We work to give them souls. In Taiwan, we work in all manners to give them a place in our web of social relations—We work to find them homes.

However, resolutions concerning the moral status of ambiguous human entities are never fully resolved. Dilemmas of personhood appear and reappear. Globalization has widened our access to other ways of experiencing things and doing things, but it also runs the risk of creating new dilemmas of personhood as cultural systems of medicine and law are transmitted and hybridized around the world. As I was leaving the field in Taiwan, NICU medical caretakers were just beginning to engage with American law and ethics as a means of providing more and efficient and uniform care to preemies and their parents. Like American individuals, individuals in Taiwan are equally seduced by the capacity of a language of rights to define and shape ambiguous situations and persons. Although relational concepts of the person are experientially better solutions for managing personhood dilemmas, they take much more social interactive work. After all, relational concepts of the person are part and parcel of social interactions-in-the making. In contrast, a language of individual rights and “rights talk” are just the opposite. They are clear, absolute, and hyper-individualistic. These characteristics of rights, among others similar traits, do not require social interactions pe se to activate their use. For individuals in Taiwan, rights talk can be a relief to the burdens of always having to consider others’ experiences. In the NICU, rights talk is becoming incorporated into codes of ethics and notions of patients’ and physicians’ “rights.” These run counter to relational aspects of the person that have always been practiced in Taiwanese/Chinese society and in the Taiwan NICU. How these two aspects will clash and/or hybridize remains to be seen.

As demonstrated in the U.S. scenario, a language of rights and “rights talk” are not a panacea for resolving issues concerning the moral status of ambiguous human entities. The shifts that have been and are happening in abortion cases (as well as other constitutional cases concerning individual rights) show the impoverishment of a language of rights to incorporate the elusive experiences of every day interactions (Glendon 1991) (Maroney 2010). U.S. Courts have found that legislating “rights” in cases concerning irresolvable personhood dilemmas require engagement with the elusive experiences of individuals. That is, despite the power of rights to define, they run out of steam when the contingencies of human life overtake and spill outside the boundaries delineated by them. Nowhere do we see this more clearly than in the NICU. Rights talk offers temporary solutions for obscuring ambiguities concerning the moral status of ambiguous subjects, but they do not remain so for long.

Premature infants eventually grow and mature in ways that are unpredictable; and as they do, they can challenge the picture we have painted of them and for them through rights talk. In American life, this is also true. In 1973, it seemed that a balance between a woman's right to have an abortion and a fetus's right to life was worked out in what appeared to be a clear and concise guideline. However, soon enough, the elusive experiences of human life took over and women never expected that choosing abortion and experiencing that choice would be in contradiction. Life is contradictory and experiences with life are elusive. To place all of our faith in rights without concomitant faith in our own elusive experiences is a disservice to our human capacity to manage contradictions and conflict.

No one understands this disservice better than Norma McCorvey. She sought refuge in "rights" in her confused twenties that resulted in three unwanted pregnancies by becoming Jane Roe. However, the much sought after clarity to her life that the *Roe* victory brought her soon unexpectedly vanished. In her autobiographies (1994) (1998), she describes her experience of randomly encountering a fetal development chart in a doctor's office waiting room that she had seen many times before. However, this time would produce a contradictory experience. She saw a "baby" rather than a "fetus" for the first time. For Norma McCorvey, this unexpected experience would change her. She would completely turn her back on the pro-choice movement and become a supporter of fetal rights. This dissertation is as much a warning against the legislation of elusive experiences of human life, as it is a celebration of the diversity and humanity of uncertainties and indeterminacies in any human life.

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APPENDIX 1: CHART OF HUMAN MATURATIONAL MILESTONES BY WEEK

Time in Weeks	Size	Organ Development	"Appearance"	Capacities
1-2		None: Unfertilized egg.	Single cell	None
3		None: Formation of embryonic membranes, 2 cells thick	Multiple cells	None
4		None: Formation of embryonic membranes, 2 cells thick	Ball of cells	Embryo implants
5		Gastrulation: The precursor of organ development begins: laying down the blueprint for organ development begins. E.g. Vasculature begins to develop in embryonic disk, Primitive heart tubing, neural groove, notochord	Looks like a tadpole with a tail and arm stumps	Gastrulation/Cell differentiation
6	0.4 cm (1/8 inch)	Precursor organ development continues. E.g. Heart bulge, first traits of lung appear, spleen appears, neural tube closes, differentiation of the spinal cord	Hole for a future mouth appears, Ears begin to form as otic pits, arm buds and a tail are visible. The branchial arches or grooves which will form structures of the face and neck form	Gastrulation continues A beating heart bulge
7	0.8 cm (1/4 inch)	Precursor organ development continues. E.g. Brain divides into 5 vesicles, rudimentary blood moves through primitive vessels, connecting to the yolk sac and chorionic membranes. Precursor kidneys	Leg buds form and hands form as flat paddles on the arms.	
8	1.3 cm (1/2 inch)	Precursor organ development continues Lungs begin to form	Hands and feet have digits (no longer webbed)	
9	1.8 cm (3/4 inch)	Precursor organ developments nears end—all essential organs have at least begun	Nipples and hair follicles begin to form. Fetal heart tone can be heard using a Doppler. Location of the elbows and toes are visible. Spontaneous limb movements can be detected by ultrasound	Spontaneous limb movements
10-12	3 – 8 cm (1.2-3.2 inch)	Red blood cells are produced in the liver	Facial features begin to develop. Starts to look like a fetus. E.g. closed eyelids (will not re-open until 29 weeks), face	Fetus can make a fist

			is well formed, limbs are long and thin	
13-16	15 cm (6 inch)	Pancreas and liver can now produce fluid secretions.	Fetal skin is transparent Lanugo (fetal hair) develops on the head. External genitalia visible	Sucking motions are made with the mouth. Active movements
19	20 cm (8 inch)	Organs continue to develop	Mom can feel movements "quickening" Heartbeat can be heard with a stethoscope, nails appear on fingers and toes.	More active
23	28 cm (11.2 inch); 0.93 kg (2 lb 0.6 oz)	Alveoli or air sacs begin forming in the lungs.	All eye components are developed. Eyebrows and eyelashes are well formed. Fingerprints and footprints continue forming	Hand and Startle reflex
27	38 cm (15 inch); 1.2 kg (2 lb 11 oz)	Brain develops rapidly, Nervous system begins to develop (allows for some control of body movements)	Looks like a baby, but with transparent skin, lanugo hair, and not much body fat.	-Some control of body movements begin to develop due to nervous system developing, eyelids can now open and close, beginnings of hearing begin (but will continue postnatally until 18 months ex utero), gas exchange is now possible due to the beginning functionalities of a respiratory system.
31	38-43 cm (15-17 inch); 2.0 kg (3 lb)	Lungs are still maturing, not yet mature for ex utero life, but rhythmic breathing movements begin. . **Surfactant** production begins (a lipid-protein complex made by the lungs so that alveoli lung cells do not collapse upon inhalation). Very critical Organs can now store iron, calcium and phosphorous Thalamic brain connections, which mediate sensory input, form.	Looks like a baby…Eyes are now fully open. Body fat begins to increase rapidly. The physical appearance of a baby is present, but lungs are still immature	Can do some of the actions of babies. Rhythmic breathing movements occur, but lungs are still not mature.
35	40-48 cm (16-19 inch); 2.5- 3 kg (5 lb 12 oz-6 lb 12 oz)	Surfactant production almost complete. A baby born this time has a high chance of normal survival, ut may require medical interventions.	Looks like a baby. The lanugo "fetal" hair begins to disappear. Skin is no longer as translucent as body fat continues to build	Can perform some actions of babies (e.g. thumb sucking, moving arms and legs, sleeping, turn around). Lungs are becoming more stable.

36 to 39	48-53 cm (19-21 inch); > 3 kg (>6 lb 12 oz)	Full term, lungs have the capacity to function ex utero	Head hair is now course and thickest, small breast buds are present, lanugo “fetal” hair is now gone.	Breathe, eat, excrete, cry, sleep. However, the more social capacities have not yet developed (eye gaze, smiling, clapping, etc.)

* Information taken from Moore L. Keith. (2008). Before We Are Born: Essentials of Embryology and Birth Defects. Philadelphia, PA: Saunders/Elsevier.