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Phenomena of Neonatology

by

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Dedication

To my parents.

Abstract

Purpose and Problem: Neonatology, the study of the newborn, marks the moment when the infant enters the world and encounters the parent. As the branch of medicine concerned with caring for this new child, neonatology facilitates the process of receiving the child. It is after the delivery, the birth, that the newborn becomes a child, a relational being with a parent. With this moment, the newborn does not just enter the pre-existing world of the culture; the newborn is the originator of the social, the family.

Some infants are not simply received by their parents. Their birth is complicated by prematurity or medical problems prompting admission to a neonatal intensive care unit (NICU). The NICU is a techno-medical place equipped with technologies and personnel such that the parents may rarely find themselves situated in relation just with their child. How does such a parent experience his or her child? How do the techno-medical aspects mediate the relation? And consequently, what is the meaning of the ethical decisions that unfold? This study aims to gain insight into these experiences by considering the ethical encounter of the parent with the newborn child in the NICU.

Methodology and Methods: The project is situated within a qualitative methodology, phenomenology of practice. This is a context-sensitive form of interpretive inquiry blending philosophical, human science, and philological

methods. The aim is to identify and explore eidetic meaning aspects of the phenomenon of neonatology in text. Source experiential material was gathered by observation and interview of parents of children admitted to NICUs.

Significance of study: The parental experience of encountering the newborn child in the NICU is a particularly consequential and overlooked area of study. The research papers of this study aim to facilitate knowledge translation by striving to develop insightful understanding in the people involved in this phenomenon. In other words, through presenting thematic events, evocative anecdotes, and reflective texts, the professional or lay reader may become more attuned to the ethical experiences that parents may encounter as their children require care in a NICU.

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1. Introduction

Neonatology, the study (logos) of the newborn (neonate), marks the moment when the infant enters the world and encounters the parent. As a branch of medicine, the discipline deals especially with the ill or prematurely born child facilitating the process of receiving the child. Legally, it is only after the delivery, the birth, that the newborn becomes a child, a relational being with a parent.[1] The newborn infant does not just enter the pre-existing world of the culture, the newborn is also the creator and the originator of the social, the family. In a more philosophical sense too, neonatology as the study of the newborn child is concerned with origins and beginnings.

The poet Hesiod tells the geneses, the coming into being, of the ancient Greek gods (the *Theogony*). From the origin of Chaos, the gaping void, came the first parents: Gaia, the Earth, and Uranus, the Heaven. Their nightly unions bore offspring beginning a line of gods: the three Cyclopes, the three Hecatoncheires, and the twelve Titans. These first children, however, were not simply received by their parents:

> Loathed from the first by their very own father, who, when they
> were infants,
> Tucked them away in a hole in the earth and prevented their coming
> Up to the light; and Uranus rejoiced in his own evildoing.
> Earth, though gigantic, was painfully stuffed on the inside and
> groaned out
> Loud. She was quick to develop a scheme both cunning and wicked;
> Swiftly creating an element, gray-colored iron, of it she
> Fashioned a great big sickle, and said to her dearly loved children,
> Speaking out boldly, courageously, although afraid in her own heart,
> "My dear children, begotten, alas! Of a reprobate father,
> Listen to me and obey: let us punish your father's wrong doing;
> He was the first to conceive of disgraceful and criminal conduct."
> That's what she said. They were all of them frozen by fear, so that
> no one
> Uttered a word, until mighty, intelligent Cronus took courage,
> And he addressed in the following words his worshipful mother:
> "Mother, I would undertake to accomplish this deed, for I haven't

[1] Under section 223 of the Criminal Code of Canada, a fetus is considered a human being "when it has completely proceeded, in a living state, from the body of its mother whether or not it has completely breathed, it has an independent circulation or the navel string is severed." In comparison, from a phenomenological perspective, a fetus may be experienced quite differently than a newborn child (see: 5. Ethical responsibility and pediatric parental pedagogy).

> Any respect at all for our wretched, unspeakable father,
> Who was the first to conceive such disgraceful and criminal conduct."
> So he declared, and magnificent Earth was heartily gladdened.
> Taking her son by the hand, Earth hid him in ambush, and put a
> Serrated scythe in his hand, and disclosed to him wholly her dire plot.
> Ushering night in, Uranus visited Gaia, desiring
> Amorous intimacy; he extended himself all around and
> Over the earth, while his son from his ambush protruded his left hand;
> Taking the formidable broad serrated blade in his right, he
> Hastily cut off his own father's privates and cast them behind him.
>
> (Hesiod, 2005, pp. 58-59)

In spite of the grim scenario, the myth of Gaia and Uranus provides an uncanny metaphor for the human phenomenon of neonatology. It shows the primordiality of neonatology: the given-child must first be received by a parent or other significant care-taker. Indeed, neonatology describes the original encounter of the vulnerable newborn with his or her parent who hopefully takes the child in care—a profoundly ethical moment and perhaps also the moment that calls for fundamental ethical decisions.

Ethics of neonatology

The myth of Gaia and Uranus surely recounts a strange story. Gaia gives birth to babies with a single eye in their forehead, babies with a hundred hands, and babies of unusual power and strength. Furthermore, Uranus who himself was born from Gaia never had a father and could not possibly know what a father was to do with such unusual children. So the myth is not only beset with deep symbolisms about the origin of humankind, it also confronts us with questions about birth and the taking of responsibility for children. Although these questions are deeply ethical, it is puzzling what ethics is supposed to mean in this mythological context as well as for us modern mortals. What is the meaning of ethics?

From a language analysis point of view, the meaning of a concept lies in its usage. And the concept of ethics is used quite broadly and variously (Cahn & Markie, 1998). Distinctions are made between metaethics, which deals with the question where ethical principles come from and what they mean; normative ethics, which asks how we ought to conduct ourselves in practice; and applied ethics, which examines specific controversial issues (Fieser, 2000). The divisions, however, are not marked by clear boundaries with each area presupposing understandings of the others.

Etymologically, the term "ethics" originates from *ethos*, meaning "character." The arcane meaning of this word, and certainly the Greek's use of this word, was not merely limited to a subjective sense of a person's habit, temperament, or disposition. Rather, ethos transcends virtue conveying a

sense of receptivity. For example, the power of music to influence its hearer's emotions, behaviors, and even morals for the Greeks was an ethos (Weiss & Taruskin, 1994). More so, the ethos of music is neither wholly in the melody that moves the listener, nor is it solely in the listener who is stirred by song. Rather, ethos is found in the intertwining of the given and the response, in the moment of the encounter with what is other. We could say that ethos belongs to the self yet also originates in part from what is other.

And so as the numerous children were born from the unions of Gaia and Uranus, we can only imagine the ethical experience of Gaia—her pain, ache, and suffering—as each successive pregnancy carried the expectation and reminder of yet (an)other and all previously failed deliveries. When a child was born, Gaia could only hold it fleetingly before Uranus seized the newborn to return it back from whence it came. Undoubtedly, Gaia ached from the very depths where her children were forced to dwell. She could neither see nor touch her newly borns even though their presence was bodily. And so for Gaia, perhaps the depth of ethical responsivity was not merely figuratively found within, but also felt deep within her earthly being where each child was forced to dwell, within the earthen womb.

Uranus was (un)touched by his children, or at least only touched them in a very different rejecting manner. We could say he never bore the children in responsivity, before or after birth. So while Gaia is commonly considered responsible—feeling, caring, attentive—responding to the injustice inflicted on her vulnerable brood; Uranus is seen as unreasonable—cruel, heartless, and callous—deserving of his emasculation. In this sense, what is ethical seems to be born out of the responsivity of Gaia, and the lack of responsivity of Uranus, to their newborn children.

And so, the ethical demand experienced by Gaia is not to be understood in the return to character virtues as conceived in moral philosophy (Løgstrup, 1956/1997). And it goes deeper than a conceptual ethics, which from the beginning relies on principles, rules, commandments, or rights to justify action. It also transcends communicative ethics oriented towards common aims (Waldenfels, 2011). Instead, the ethical demand is found in an originary responsivity to (an)other (Levinas, 1961/1969). Gaia understands not in the mere sense of grasping the meaning of her children's confinement, but rather she understands by her motherly suffering through their pain. And in this sense, the phenomenology of neonatology expresses what Waldenfels (2010a) describes as a responsive ethics: an ethics that emerges from responding to (an)other.

Ethics and the decision of neonatology

From this mythical image of the phenomenology of neonatology we may recognize that ethics emerges from the encounter of the parent with the child. The meaning of this ethics is not to be found in a formal code of morality that dictates the appropriateness of ethical decisions. The ethical arises in the encounter of the mother or father with the newborn, and from this encounter fundamental decisions are called for. What does it mean to decide? What does it mean to make an ethical decision?

Night after night, Uranus coalesced with Gaia. As heaven pressed against earth, there was literally no place on the earthen surface for the children to dwell. To make room for the children required a severance of Uranus from Gaia: Kronos had to push him up out of the way (Campbell, 1949). And so from the perspective of Gaia, Uranus was above, the children were below, and she was stuck between. She could not remain in touch with either. Perhaps then it was not without sorrow that Gaia asked her children to castrate their father.

To be sure, the sorrow was not only the expression of the children's confinement. It was also the pressing responsivity of Uranus on Gaia. Their ethical responsibility to each other did not merely originate in a symmetrical pact, a marriage, or some other officiated union of fidelity. Gaia had encountered her partner.

The etymology of "decision" literally means "to cut off" from the Latin *de-caedere*. Cutting, simultaneously, de-selects (an)other option. The decision divides each time, existentially located between, what can and cannot be resolved; what is anticipated and unforeseen; and, what is tentative and decisive.

From the coherence of ethics and decision, it may be surmised that a truly ethical decision is more than a cognitive or deliberative affair. A decision cuts between responsivities. So perhaps as Gaia responded to looked down to her confined children, she could not help but look away from Uranus, the sky. The time for deliberation was over, and the decision could not be unmade.

And so the mythology of Gaia and Uranus speaks existentially to the phenomenon of neonatology, the meaning of the ethical decision. And reflection on this may help raise the issue of the ethical decision so that we may gain insight into dimensions of meaning of the ordinary and often extraordinary decisions that parents encounter in the caring for their children in the neonatal intensive care unit (NICU). We may begin to understand further that the phenomenal meaning of the ethical decision lies both in what we may consider as a decision and what is ethical in itself.

The legendary myth also depicts more than the ethical decision: it shows the newly born children as beings who have been granted life thanks to the technology of the first tool, the serrated sickle, or knife.

Ethics and neonatal technology

The children of Gaia and Uranus were vulnerable, in a way premature, unable to survive on their own. It was only with the provision of technique, the fashioning of the serrated sickle as technology, that the children were made to survive. Yet to understand the sickle as simply a tool may miss the profound meaning of this act. For with the giving of the tool, the children were (re)born to emerge from the earthen womb of Gaia as technical beings: forever constituted by and constituting technology (Stiegler 1994/1998).[1] Still, we may wonder how the provision of the sickle changed the children? How were they reborn? And, how did this technology subsequently affect the encounter between parents and their children?

To speak of a technology phenomenologically is to recognize that our being-in-the world may be shaped by technologies. Consider the stethoscope.

As I place the auricle buds in my ears, I find myself oriented to the head of the stethoscope, the diaphragm and the bell. I handle the head ever so carefully to avoid subjecting my ears to the amplified noises that this tool is capable of transmitting. In this sense, I find myself becoming strangely sensitive to the world as the diaphragm and the bell become my new ears. I am a medical listener. It feels strange to talk or listen to other's voices with the stethoscope on; not only because my voice is altered, but rather because it interrupts my focused listening stethoscope way-of-being. We could say that external voices remind me that I am wearing a device. As I lay the stethoscope against the child's chest, I find myself hearing for a world of beats, murmurs, and other heart sounds. When I locate the familiar heart beat, the world available to my other senses seems more distant then the steady rhythm of ta-dum, ta-dum, ta-dum. I am no longer listening to the child so much as I am listening to an organ. The stethoscope changes me and my world.

When a functioning stethoscope is routinely used, we may lose awareness of it as a piece of equipment to only hear the rhythm of the heart. This is not to say that we cannot look at the stethoscope, but rather that as embodying technical human beings, technologies may become unobtrusive in their

[1] While Stiegler gives the human as an inherently technical being, constituting and constituted by the artifacts of his choosing. In this dissertation I expand his prosthetic sense of the human to the realm of the ethical. The parent fashions their child with technics prior even to the child having developed sense of self: a wild cyborgean being.

presence (Heidegger, 1927/1962). Still, even though technologies may become transparent, they may have formative effects on our relation to the world.

The phenomenal meaning of the stethoscope consists in its capacity to bring about a medical relation between the wearer and the child. But how is it that in touching the child with the technology, the listener may now touch the child as a heart to be heard? Technologies are not just *in* our hands they also are *formative* of our hands. This means that as we create technologies, we are also (re)creating the sort of humans that we are, or will become (Stiegler, 1994/1998). The position of the sickle in the mythology of Gaia and Uranus illustrates that technology may further complicate the ethical encounter of parent and child, even though the technology was in this first instance applied to the parent by the child.

In the NICU, the child is not necessarily simply given to the parent. The relation is touched by technologies in various mediating ways (Ihde, 1990). It is not just that some of the devices are invasive, tubes physically penetrate bodily surfaces to deliver needed medicines or breathing support, and others are noninvasive, wires affixed superficially to measure heart rate, respiratory rate, oxygen saturation, and other vital parameters. Technologies may take the parent relationally closer (or further) from the child. As Albert Borgmann (1984) writes, devices may (de)world our relationship with things by disconnecting us from the full actuality of everyday life.

In the various ways that technologies may mediate our relation to the world, they massage our sensibilities—creating a pattern, an atmosphere, an environment of perception that works on us (McLuhan & Fiore, 1967). And by massaging our sensibilities, the neonatal technologies may change the pace and interaction between parent and hospitalized child.

In the case of the stethoscope, we may be reminded that even the simplest useful tool may have ethical implications as it becomes situated in the encounter with (an)other. While it may be entirely necessary for the healthcare professional that the stethoscope gives the child as a "heart to be heard", we should wonder about the ethical consequences of neonatal technologies that touch on the relation of parent with child. How do various technologies mediate the encounter of parent with child? And how does the application and use of technologies affect what we regard as an ethical decision for a child?

Existing Bioethical Literature

The ethical encounter between parent and child, with its capacity to be complicated by the technomedical environment of the NICU, has received

limited attention in the bioethical literature. References to this phenomenon occur in the published sources exploring medical-moral decision-making events.

In the NICU, death of the newborn is often the result of withholding or withdrawing of medical support, which constitutes a deliberative medical-moral decision (Arlettaz, Mieth, Bucher, Duc, & Fauchere, 2005; Barton & Hodgman, 2005; Berger & Hofer, 2009; Hagen & Hansen, 2004; Roy, Aladngady, Costeloe, & Larcher, 2004; Verhagen et al., 2010; Wilkinson et al., 2006). While end-of-life decisions are certainly grave choices, they are but one of the many decisions confronting healthcare professionals and families each day. Some decisions stand out, involving directions-in-care such as pursuing particular medical therapies or surgeries, while other decisions are part of day-to-day happenings, such as leaving the bedside, or raising a concern. These latter decisions may be so ordinary that they are often not even overtly acknowledged as decisions. They are seen-but-unnoticed. Still, regardless of the seriousness of decisions, parents have an interest in the various ethical aspects of the NICU.

Official guidelines recognize that parents are charged with relative autonomy (analogous to patient autonomy) that invests them with substitutive responsibility in making decisions for their children (Bell, 2007; Chance, 1994). The parent-child relation is the basis for the jurisprudential obligation and ethical responsibility that parents assume for their child. Parents, whose child is placed in the NICU, may experience this relation as new, sensitive, fragile, and emotionally overwhelming. Here, infant illness, medical technology, and multiple professional caregivers may affect this developing relation. It speaks for itself, that health professionals need to have a proper understanding of the relational experience of parental decision-making, especially in lieu of the considerable moral authority afforded to parents (Nuffield Council on Bioethics, 2006). Yet, in reviewing the medical ethical literature, the relational experience of parental decision-making receives little attention.

Much of the medical decision-making literature reflects rational choice theory. Authors seek to formulate and justify normative principles that govern optimal decision-making based on ethical theory (principlism, consequentialism, virtue ethics, ethics of care) (Ahluwalia, Lees, & Paris, 2008; Beauchamp & Childress, 2001; Blustein, 1988; Buchanan & Brock, 1989; Diekema, 2004; Donnelly, 1994; Hall, 2002; Ladd & Mercurio, 2003; McHaffie, Laing, Parker, & McMillan, 2001; Paris, Schreiber, & Moreland, 2007; Rhoden, 1986; Romesberg, 2003; Wilkinson, 2006). This literature clarifies the meaning of ethical concepts such as best-interest, tolerability, futile care, the rational parent, biographical life, medical intervention, quality of life, sanctity of life, personhood, dignity, and the nature of technology (Baumrucker et al., 2008; Bellieni & Buonocore, 2009; Chiswick, 1991;

Chiswick, 2008; Coggon, 2008; Cooper & Koch, 1996; Fost, 1986; Hester, 2007; Kopelman, 1997; Lagercrantz, 2007; Leuthner, 2001; Nelson et al., 1995; Ross, 2007). While this literature helps ground analysis of ethical dilemmas, it presupposes an understanding of the actual experience of professional and parental decision-making. The point is that much of decision-making is not based on rational choice. As an example, even when students and professionals are given hypothetical medical vignettes allowing consequential weighing of predicted survival, neurologic impairment, and potential years of life gained, decisions seem to be influenced by non-pragmatic reasoning (Janvier et al., 2008a; Janvier, Leblanc, & Barrington, 2008b; Janvier, Leblanc, & Barrington, 2008c). Prescriptive theories do not necessarily describe how decision-making unfolds at the bedside.

Research addressing real-life decisions has largely focused on the ethical practice of healthcare providers (Arad, Braunstein, & Netzer, 2008; Ballard, Li, Evans, Ballard, & Ubel, 2002; Barr, 2007; Cuttini et al., 2000; Cuttini et al., 2004; de Leeuw et al., 2000; Lavoie, Keidar, & Albersheim, 2007; Oei, Askie, Tobiansky, & Lui, 2000; Rebagliato et al., 2000; Sanders, Donohue, Oberdorf, Rosenkrantz, & Allen, 1995; Verhagen, Van Der Hoeven, van Meerveld, & Sauer, 2007; Weiss, Binns, Collins, & deRegnier, 2007). Consequently, the research does not attend to those with considerable moral authority—the parents.

Quantitative epidemiologic studies of parental decision-making have identified parental factors that correlate with the desire for medical intervention: medical prognosis, uncertainty about prognosis, physician preference, maternal age, race, and religion (Arad et al., 2008; da Costa, Ghazal, & Al Khusaiby, 2002; Doron, Veness-Meehan, Margolis, Holoman, & Stiles, 1998; Moseley et al., 2004). While these factors are significant determinants at the population level, they do not necessarily determine what happens at the individual level, where competing factors exist. This literature does not reveal how parents are relationally informed and directed by their own experience of parental responsibility. In other words, it does not show how parents are affected by the vulnerability, singularity, and alterity of their newborns.

Qualitative researchers have studied decision-making from the perspective of various methodologies. The findings of perception studies, open-ended interview, and survey studies are similar to quantitative epidemiological studies. Here, parental factors such as religion, faith, spirituality, hope, years of education, profession, prognosis, perception of the child's pain, and parents' own childhood environment may guide decision-making (Boss, Hutton, Sulpar, West, & Donohue, 2008; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Ritholz, Burns, & Truog, 2006; Vandvik & Forde, 2000). These studies also discuss parents' desire for good communication and involvement in decision-making (Boss et al., 2008; Brosig, Pierucci, Kupst, & Leuthner,

2007; Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; Wocial, 2000).

Ethnographic studies have provided insights regarding the sociocultural context of decision-making. It is clear that professionals and parents approach collective decision-making differently. Physicians tend to be concerned with "distancing aspects" such as giving honest information and warning parents of possible problems that may result in poor outcomes (Alderson, Hawthorne, & Killen, 2006, p. 1320). Parents, however, tend to emphasize "drawing together aspects" such as sharing knowledge, understanding, and planning to hopefully foster mutual trust in a decision-making space (Alderson et al., 2006, p. 1320). Communication between physicians and parents is important because the prognostication of outcomes may be ambivalent and uncertain (Abel-Boone, Dokecki, & Smith, 1989; Einarsdottir, 2009). How healthcare professionals express "medical certainty" may control or even erase the ethical nature of action or inaction (Orfali, 2004, p. 2020).

Parents may not understand what it means to be involved or to take part in a decision (Einarsdottir, 2009; Vermeulen, 2004). The meaning of involvement does not narrowly consist of parents explicitly voicing their opinion. Rather, involvement may be experienced as simply being present. Presence may relate to power. The experience of choice may leave parents feeling ambivalent about possessing authority. Yet parents may simultaneously desire and resent having to exercise control over choices affecting their child's life (Orfali, 2004; Orfali & Gordon, 2004). Parents may acutely experience the presence or absence of the support of healthcare professionals in the process of decision-making.

What professionals view as major decisions may not be important decisions for parents, and vice versa. To parents, day-to-day choices such as holding, breastfeeding, discharge planning may constitute major responsibilities, activities, and effects (Alderson et al., 2006).

Grounded theory studies concerned with parental decision-making have discussed issues such as ambivalence, information, communication, inclusion, and responsibility (Brinchmann, Forde, & Nortvedt, 2002; Carnevale et al., 2006; Carnevale et al., 2007). But these studies are aimed at theory development, using codification techniques that fail to provide a rich portrayal of the relational experience of decision-making.

Phenomenological studies have tended to focus more on parental values related to decision-making than on the phenomenon of decision-making itself. For example, Kirschbaum (1996) focused on such parental values as pain and suffering, quality of life, respect for person, best interest, family, faith, nature, and technology. Other phenomenological studies seem to have

moved into explorations of parental-physician role engagement, communication, emotional reactions, and the general contextual experience of the NICU (Payot, Gendron, Lefebvre, & Doucet, 2007; Pinch & Spielman, 1989; Pinch & Spielman, 1990; Pinch & Spielman, 1993; Pinch & Spielman, 1996; Wiegand, 2008). Unfortunately many of these studies focus primarily on parents' reflective rather than their prereflective experiences. In other words, they focus on what parents think about decision-making in the NICU rather than on the actual lived sensibilities of the experience of encountering their children and making a decision.

Based on a review of the literature, it appears that the parental experience of the ethical encounter with their child in the NICU, a relational ethics perspective of decision-making, is a relatively unexplored subject. This is in spite of the fact that parents may be confronted with difficult predicaments concerning the health, survival, and quality of life of their children, as well as being confronted with all of the day-to-day decisions that make up the life of parenting in the NICU. Also, in spite of the plethora of medical technologies utilized in neonatal intensive care, limited literature has addressed the ethical complexities of neonatal technologies from the perspective of the way these technologies may touch on the encounter of parents with their children.

The aim of this study then is to regard, understand, and grasp a deeper understanding of the ethical encounter between parent and newly born child in the NICU. In other words, the ambition is to rediscover what has been lost in reducing the study of ethics to principles, values, and so forth: to reawaken what we recognize as the ethicity of ethics. The treatment of this phenomenon will thus be *phenomenological*.

Phenomenology of Practice

The study is situated within a qualitative research methodology, phenomenology of practice (van Manen, 2007). *Phenomenology* as a research method is directed towards exploring a human experience (phenomenon) as it is lived through rather than how we conceptualize, theorize, or reflect on it. The aim is to "lay bare and exhibit the ground of a phenomenon yet while preserving it in its entirety" (Heidegger, 1927/1962, p. 23). And in this particular articulation of phenomenology, the designation *of practice* speaks to the concern with understanding lived experience not only in such a way that it speaks to our intellectual capacities (what it tells us), but also so that the understanding fosters practice insights, communicative thoughtfulness, and ethical sensitivities in professional practice (what it does with us). This approach to human science research references the work of Max van Manen (1990) which recognizes phenomenology as a method in itself, involving philosophical, human science, and philological methods engaged in achieving

and articulating through writing a "direct and primitive contact with the world" as experienced in everyday life (Merleau-Ponty, 1945/1962, p. vii).

Phenomenology as a method

Phenomenology signifies primarily a "concept of method" expressing the maxim: "to the things themselves" (Heidegger, 1927/1962, p. 24; Husserl, 1913/1982, p. 35). Abstrusely simple, these two frequently quoted phrases express the method of phenomenology.

To speak of phenomenology as a "concept of method" refers to the Latin *methodus,* method as a "way of going," rather than plainly point to method as a technique, procedure, or practice. Still, the phenomenological method is not a prescribed approach, series of steps, or collection of rules. Rather, each phenomenon requires a unique application of the method of phenomenology. As Heidegger writes,

> When a method is genuine and provides access to the objects, it is precisely then that the progress made by following it and the growing originality of the disclosure will cause the very method that was used to become necessarily obsolete. (Heidegger, 1975/1982, p. 328).

A fixed schematic of phenomenological method may not only prevent and stultify original thinking, it may also lead the researcher away from an approach which is sensitive to and appropriate for a particular phenomenon of interest. Instead, phenomenological method expresses a returning again and again, back to an experience as it is lived through. And just as we may say that experiences may be given in contingently different ways, we may say that there is no one phenomenological method. Instead, there is a common concern expressed for lived experience as a "concept of method" that is sensitive to this starting place.

The dictum "to the things themselves" expresses the concern to attend to what is immediately given in lived experience: the meaning of a recognizable phenomenon as lived through. It urges us to attend the "things" of our world (the phenomena) precisely as we experience them (their phenomenality). To use the word "thing" expresses a laying aside of an understanding of the world found after "naming:" conceptions, theories, models, and so forth. In other words, the phrase calls for a return to the world in the most basic sense of how we live through it—the thing-world of prereflective experience rather than the named-world commonly explored in other forms of inquiry. This return to the phenomenality of lived experience is distinctly what distinguishes phenomenological inquiry.

For the purpose of this study, the phenomenon is what is "given" in the parental ethical encounter with the child requiring care in a NICU. While we

may "name" such a moment as an ethical decision, the phenomenological concern is to attend to this moment as it is actually lived through (as it comes to be "named"). In other words, the focus is not on asking such questions as: How do parents make ethical decisions? What factors do they consider? How do parents view the process of making an ethical decision? Instead, the question attends to the meaning of the ethical decision as it is experienced and as we name it as experienced. And, in turn, the naming calls the experience into presence.

> The naming calls. Calling brings closer what it calls. However this bringing closer does not fetch what is called only in order to set it down in closest proximity to what is present, to find a place for it there. The call does indeed call. Thus it brings the presence of what was previously uncalled into a nearness. (Heidegger, 1971, p. 196)

We could say that the "return" to the things themselves, the philosophical method of the reduction, is the essence of phenomenological inquiry.

As we consider the method of phenomenology, we ought to also consider Heidegger's (1927/1962) famous formulation of phenomenology: "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (p. 58). The method of phenomenology may then be understood in the Heideggerian sense as the confluence of *phainomenon* (that which shows itself) and *logos* (making something manifest). Phenomenology is descriptive as the phenomenologist attends to how things appear. And it is hermeneutic because to make something manifest, to bring it to speech or text, is ultimately a linguistic and interpretive act. The language of lived experience, however, is also complex.

> Phenomenology is not as naïve as some people pretend. It does not presuppose that what appears is completely outside of language, but it does presuppose that what happens and appears to us is more than what can be said about it and what can be argued for or against it. The crucial point is not to assume that there is something given outside of language, but to concede that language precedes itself. (Waldenfels, 2007, p. 88)

Waldenfels points out that language is implicit in the constitution and the experience of lived meaning. It cannot be used to simply name aspects of prereflective experience. Instead, phenomenological research is phenomenological writing, the vocative, aiming to find text that is sensitive to express a particular phenomenon as it gives itself to experience. At the same time, phenomenology cannot just bring prereflective experience back to us as we experienced it, but phenomenology brings prereflective experience back reflectively.

As phenomenological researchers, we need to gather *others' experiences* in order to be able to reflect on them. Human science activities are engaged and utilized to collect and explore experiential material. The concern though is not with the subjective (personal) meanings inhering in others' stories. Instead, interest is directed towards intersubjective (recognizable) meaning. So we can say in phenomenology that we are interested in exploring examples of possible experiences such that we can articulate aspects of the experiences that may be recognized by a reader. Buytendijk (1970) referred to this recognition as the "phenomenological nod" (p. 596).

So, we may understand phenomenology as a textual form of inquiry aiming to produce written portrayals that explicate and explore a particular phenomenon. The concern is with the immediacy of a particular human experience prior to meditative or theoretical reflection. To reiterate, the focus is not on opinions, perceptions, or judgments about experiences; but instead on direct descriptions that explore what is "given" in a particular lived experience.

The method of phenomenology fundamentally relates to philosophical methods to explore prereflective experience (the *phainomenon*) and philological methods to express the phenomenon to the reader (the *logos*).

Philosophical methods (the *phainomenon*)

The basic method of phenomenology is the reduction. The notion of the reduction, however, is complex, articulated in a variety of ways in the philosophical literature. To those familiar with continental philosophy, this is neither surprising nor necessarily problematic because the philosophical tradition of phenomenology is quite eclectic, constantly questioning and rediscovering itself.

To begin to consider the reduction, we can articulate it as a taking up of an attitude of reflective attentiveness to the way in which we actually experience the world.

> I posit the stuff of knowledge when…I adopt a critical attitude towards it and ask 'what I am really seeing'. The task of a radical reflection…consists, paradoxically enough, in recovering the unreflective experience of the world…and displaying reflection as one possibility of my being. (Merleau-Ponty, 1945/1962, p. 280).

Without breaking contact from the concreteness of experience, the phenomenological attitude "slackens the intentional threads which attach us to the world and thus brings them to our notice" (Merleau-Ponty, 1945/1962, p. xv). As such, although the phenomenological attitude steps back from the natural attitude, the unreflective manner in which we find

ourselves in everyday life, almost unexpectedly it allows us to reach insights into our everyday living in the world.

The attitude of the reduction is thus grounded in lived experience, understood as the world as we actually live through it. The attitude to questioning lived experience is critical and rigorous yet open and tentative in that it continually asks, "Is that indeed the way a phenomenon appears (the phainomenon)?" As Eugene Fink writes, the reduction situates us in "wonder in the face of the world" (Merleau-Ponty, 1945/1962, p. xv). "Wonder" does not mean to speculate abstractly or probe curiously. Wonder instead recognizes that our questioning is directed to what lies at the threshold of lived experience. After all, reflecting on the manner in which we prereflectively live necessitates a re-encountering of moments of life that we have already lived. In other words, in the phenomenological attitude we find ourselves "in the face the world" as we live it.

Gestures of the reduction

Although the reduction may be understood in various ways, for a basic eclectic phenomenology of practice we can consider the reduction as the attitude that is achieved from the coming together of two opposing gestures: the *epoché* and the *reduction proper* (Taminiaux, 2004, p. 596).

The term epoché is related to the Greek skepticism. It means, laying aside, pushing away, or removing what obstructs gaining access to the way a phenomenon gives itself. A related term is *bracketing*: suspending judgments and beliefs about the world. In other words, the phenomenological attitude involves placing in abeyance assertions that arise from the natural attitude (beliefs, opinions, and theory). This gesture is crucial in the sense that it allows an opening to draw nearer to a phenomenon in a wondering attitude.

If the epoché can be considered as a negative gesture, the reduction proper is positive in character. The meaning of reduction proper is not to be found in the common references to lessening, lowering, or weakening. The reduction proper instead derives from the French *reducere* meaning "to bring or lead back." And what is brought back is "experience" itself prior to conception, theorization, or abstraction: how a phenomenon is given.

Moments of the reduction

Moments of the reduction may also be considered which are in themselves composed of the above gestures (van Manen, forthcoming). While in the process of phenomenological inquiry these moments of method are practiced more or less at once, we can articulate them separately to try to gain a more sophisticated understanding of the phenomenological reduction. Max van

Manen (forthcoming) has described these moments based on an eclectic reading of the phenomenological philosophical discourse as:

> • the heuristic reduction (wonder) – Bracket everyday and taken-for-granted understanding to awaken a true sense of wonder about a phenomenon of interest. Wonder differs from curiosity or marvel. It is the unwilled willingness to meet what is utterly strange in what is most familiar; wonder as the animated questioning of meaning.
>
> • the hermeneutic reduction (openness) – Bracket preformed assumptions, predicted hypotheses, and established interpretations to explicate a phenomenon; founded in a genuine openness to how phenomenon is lived through. It is to strive to approach a phenomenon free of inclinations and expectations.
>
> • the experiential reduction (concreteness) – Bracket all abstractions, constructions, and theorizations to return to the concreteness of an experience. It is a probing to express what is experienced prior to reflection, what presents itself directly and immediately, striving to be free of theoretical conceptions.
>
> • the methodological reduction (approach) – Bracket conventional techniques to develop an approach that seems to fit most appropriately with a particular phenomenon of interest.
>
> • the eidetic reduction (invariant) – Bracket incidental, variable, and subjective meaning to focus on unique invariant meaning structures of a particular phenomenon (eidos or essence). Invariant meaning refers to what makes an experience recognizable to more than one subject; what makes an experience what it is and without which it could not be what it is. This is the key-component of the "general" reduction. The eidetic meaning may be approached in a phenomenological text by holding in tension the universal with the singular, or considering variations of an experience.

It is also appropriate to consider what appears, yet remains absent, from the visibility of a phenomenon. As such we may add:

> • the responsive reduction (otherness) – Bracket what is visibly present to explore what appears, yet remains absent, from the visibility of a phenomenon. The responsive reduction opens to what is found between the text, the poetic, and the ambiguous. It is what is other, calling for an ethical response.

This responsive reduction is probably most clearly demonstrated in the work of Levinas (1961/1969, 1974/1981), Marion (1997/2002, 2001/2002,

2003/2007), Waldenfels (2006/2011, 2007), and the latter writings of Merleau-Ponty (1961/1993, 1964/1968).

Philological methods (the *logos*)

The philological methods of phenomenology are themselves not wholly separate from the method of the reduction as the writing of a phenomenological text is carried out in the attitude of the reduction. Still, it is appropriate to devote particular attention to the vocative research process (writing) of a phenomenological text.

This emulation of lived experience occurs linguistically through the vocative. While the reduction refers primarily to the phenomenological method of inquiry in order to reach the phenomenon, the vocative, from *vocare* "to call," relates to bringing the phenomenon to language (in a broad sense). Since phenomenology is concerned with prereflective experience, a phenomenological text cannot simply rely on semantic, discursive, or conceptual language to explain a phenomenon. A phenomenological text must also portray and evoke to resonate with the recognizable experience as lived through. To craft a phenomenological text tends to require (re)writing and (re)reading as the researcher seeks language and linguistic forms that are sensitive to the phenomenon itself.

While the appearance of a phenomenological text may vary, Max van Manen (1997) has pointed to moments of the vocative.

> • lived thoroughness – The phenomenon is placed in the lifeworld concretely so that the reader may unreflectively experientially recognize it. This may be achieved by including real world experiential material to place the phenomenon within the vividness of life.
>
> • evocation – The experience is brought from a theoretical existence to immediate presence such that it is sensuously near to the reader's experience. It evokes the reader to wonder, question, or understand the experience.
>
> • intensification – The writing gives words and phrases their full value so that the layers of phenomenological meaning become embedded within the text. This turn relates to the poetic quality of a phenomenological text that not only deepens meaning but also educes just the right image so that "felt understandings that lie beyond language come within reach." (van Manen, 1997, p. 356)

• tone – This means that the text not only explicates meaning but also touches the reader's understanding of meaning. As the reader is touched, he or she may become answerable to the appeal of the text.

• epiphany – The text may have a (trans)formative effect such that the reader grasps its meaning emerging from reading with new understandings of the world. This moment speaks to the formative value of phenomenology: what it does *with* us.

These aspects are considered in both the writing of a phenomenological text and the inclusion of anecdotal experiential material. The anecdotes themselves have a special place in phenomenological texts as possible examples of an experience that allow the reader to access the subjectivity of an experience. They also serve an eidetic function by placing in tension the universal with the singular, the invariant and variant, meaning aspects.

Human science methods

A central feature of this phenomenology of practice is a reliance on human science empirical methods to gather and explore a field of descriptive evidence, lived experience descriptions, from which underlying patterns and structures of meaning may be drawn. Although these methods may be utilized by other qualitative methodologies, they take on a distinct character in phenomenology.

Gathering experiential material

Empirical material for phenomenological studies consist of vivid textual accounts of an experience just as lived through. Ideally, they recall a particular instance of an experience in concrete personal terms. They may be gathered methods such as observation, writing, and interviewing. This gathering is a crucial activity so that the researcher can gain access to others' experiences (in this case, the parents of the NICU child). This collecting of experiential material should not be seen as an isolated research practice; rather, gathering is a process woven into the explorative questioning of a particular phenomenon of interest. In this way, phenomenology of practice is a nonlinear, iterative form of research that integrates philosophical, philological, and human science methods. Due to the ethical and time considerations of this study, material was primarily collected by interview.

As a phenomenological interview aims for experiential accounts, in some sense it may be considered as unstructured or open-ended. At the same time, the interview intent is guided by the phenomenological intent: exploring a particular phenomenon. Throughout the interview, the interviewer aims to have the interviewee lead them vividly through experiential moments. As such, the interviewer is attentive to the experience of being interviewed (place, person, time, and so forth)(Weber, 1986). For the purpose of this

study, all of the interviews were audio-recorded such that during the interview the interviewer could focus attention on the conversation rather than document comprehensive notes. After interview, the interviews were listened to repeatedly and transcribed.

At times an indirect approach, referring to something by referring to something else, was required to elucidate experiences that seem to surpass the realms of meaning and intentionality (Waldenfels, 2010b).[1] For example, access to the experience of responsibility may be gained from the description of the experience of encountering the child. As Waldenfels (2006/2011) writes: "Responsivity goes beyond every intentionality because responding to that which happens to us cannot be exhausted in the meaning, understanding, or truth of our response" (p. 28). This notion again relates to the responsive reduction constituting human science methods.

Interview considerations for the various parts (papers) of the study

All of the interviews were conducted with parents who had children admitted to one of the secondary or tertiary level neonatal units serviced by the Northern Alberta Neonatal Care Program. The papers of the dissertation emerged from interviews with two groupings of parents.

Carrying: Parental experience of hospital transfer – Parents whose child had to receive at least one interhospital transfer (between physically distinct hospitals) contributed experiential material for this study. Although some of the families experienced numerous interhospital transfers, all experienced multiple intrahospital transfers (within hospital yet between care teams, units, and so forth). Most families had never been in the NICU prior to the admission of their child. Some had never even been to a tertiary center, as their children were referred from remote or rural outlying areas.

The medium, the message, and the massage of the neonatal monitor screen; Technics of touch in neonatal intensive care; Ethical responsivity and pediatric parental pedagogy; and, The ethics of the decision in neonatal intensive care – Experiential material was gathered from parents who were judged by practitioners to be at increased likelihood of encountering direction-of-care decisions based on the clinical conditions of their children (e.g., extreme prematurity, complex congenital anomalies, significant neurologic compromise). An ethical decision was taken openly as a decision made for an other (i.e. a moment when a parent felt like he or she was making a decision for his or her child).

[1] Intentionality in the most basic sense means that *something* shows itself as *something.* Said differently, it means that something (actual, possible, or impossible) is linked to something else (a sense, a meaning) and is at the same time separated from it (Waldenfels, 2010b).

Although the reader could anticipate that parents interviewed for each study would be quite different, there was a great deal of overlap in acuity and other clinical material between the studies. And certainly the material from the *Carrying: Parental experience of hospital transfer* study contributed at least implicitly to the material that was later collected for the remainder of the papers. Overall, a wide breadth of examples of experiences were collected from both groups of parents. Admitting diagnoses varied greatly, including, yet not limited to, those related to prematurity, congenital anomalies, and transitional problems. Parents ranged in age, ethnicity, education, and socioeconomic background.

It should be clear, and made explicit, that this form of inquiry is an exploration of meaning to offer existential insights rather than apophantic ones. The insights from these studies are preliminary and exploratory as phenomenological studies are always tentatively open to further experience and study.

Reflecting on experiential material

Multiple methods have been explicated by Max van Manen (1990, forthcoming) to reflect on experiential material as a starting point for phenomenological writing which have all been utilized in the crafting of the research papers of this dissertation:

- Thematic reflection – This involves attending to the meanings that are embodied within a text both from a macro-thematic level (attending to the text as a whole) and a micro-thematic level (attending selectively to words, phrases, and passages of text). Thematic reflection aims to gain insights into the variant and invariant meaning aspects of a phenomenon.

- Guided existential reflection – This involves using fundamental lifeworld themes as heuristic guides for reflecting on human experiences: corporeality (lived body), temporality (lived time), spatiality (lived time), relationality (lived other), and materiality (lived things).

- Linguistic reflection – This involves being attentive to the language used to describe a phenomenon searching for meaning through etymological reflection (etymologic sources of words) and conceptual reflection (exploring differences in word meaning).

- Exegetical reflection – This involves the critical and sensitive reading of related texts. Phenomenological literature may be sought for comparison (literature that has addressed related topics) and insight-cultivation (literature which opens the reader to a different pathos, way of experiencing the world).

Appraising the Validity of the Research

The notion of validity in qualitative research broadly relates to "strength" from *validitas*. The more precise meaning of validity, however, may vary across differing methodologies as each approach may have its own agenda and limitations (Golafshani, 2003).

For example, evidence about cultural practices emerging from ethnographic studies may draw on a range of methods placing a priority on gaining an emic perspective such that the findings convey a sense of being there (Savage, 2006). While ethnography may provide rich textual descriptions of a culture or subculture, ethnography itself does not differentiate between description (cultural meaning) and that what makes the description possible (eidetic meaning). In comparison, grounded theory aims to generate systematically a substantive theory grounded in data (Glaser & Strauss, 1967). Evidence for the formulation of emerging theories may depend on the proper use of coding, the constant comparison, questions, theoretical sampling, and memos (Walker & Myrick, 2006). While grounded theory may abstract, examine, or explain social processes, it does not necessarily evoke understanding of the particularities of human experience. Among different approaches to phenomenological research, there are differences in how the notion of validity is articulated (Beck, Keddy, & Cohen, 1994).

Recognizing this diversity, it is problematic that some practitioners and researchers seem to assume that all forms of research, and in particular qualitative research, may be similarly appraised (Boulton, Fitzpatrick, & Swinburn, 1996; Cesario, Morin, & Santa-Donato, 2002). It is more appropriate that criteria aiming to generally assess qualitative research remain attentive to the differentiating features of the various methodologies that underlie the research (Mays & Pope, 2000; Secker, Wimbush, Watson, & Milburn, 1995; Tracy, 2010).

The reader of this dissertation may attend to the criteria for "strong" phenomenological writing as described by Max van Manen (1990) to evaluate the "strength" of this study. These appraisive criteria have been recognized by such journals as *Phenomenology & Practice* (http://www.phandpr.org/).

Principle of heuristic focus	*Heuristic attentiveness*: does the text induce a sense of wonder and questioning?
Principle of rich description	*Descriptive richness*: does the text contain concrete experiential (narrative) lifeworld material?
Principle of interpretive insight	*Interpretive depth*: does the text show reflective allusions and surprising insights?
Principle of distinctness	*Rigorous focus*: is the text constantly guided by a self-critical question of distinct meaning of the phenomenon that is being described?
Principle of addressiveness	*Strongly embedded meaning*: does the text "speak" to and address our sense of embodied, sensual, situated, temporal, or communal self?
Principle of practice-of-meaning	*Oriented epiphany:* does the study offer us the possibility of an ethical or inspirited grasp of life-meaning, human action, or professional practice?

Adapted from van Manen (1990), pp. 150-153.

Overview and Organization

This dissertation consists of six papers exploring meaningful aspects of what I name the phenomenon of neonatology. Not only does each paper offer different insights about this phenomenon, but each paper is also aimed at differing audiences. As such each paper varies in style, format, and length depending on the readership to which it has been crafted. All papers, however, are deeply situated within the tradition of phenomenology as a human science research method such that a reader may appraise each paper by considering the above principles of phenomenological validity.

(1) **Phenomenological method:** Phenomenological evidence as insightful understanding
In this article, I explore the meaning of phenomenological evidence in a phenomenological manner. This article provides an introduction to readers unfamiliar with phenomenology as to how a phenomenological study may contribute to professional practice.

(2) **Ethics and the technological other:** The medium, message, and massage of the monitor screen
In this article, I explore the neonatal monitor as an exemplary medical technology in terms of its situatedness in the ethical relation between parent and child. This paper could be considered in the tradition of post-phenomenology as the focus is on the meditational role of a technology rather than on a single recognizable phenomenon (as tends to be the case in classical phenomenological studies).
Portions of this paper were presented at the *Centennial Conference 'McLuhan's Philosophy of Media'* held in Brussels, Belgium, October 2011 and the *Women & Children's Health Research Institute Research Day* held in Edmonton, Alberta, November 2011.
A version of this article is published in *Proceedings of 'McLuhan's Philosophy of Media' – Centennial Conference / Contact Forum, 26-28 October 2011*.

(3) **The ethical touch of the other and technology:** Technics of touch in neonatal intensive care
In this study, I explore how the phenomenon of the ethical moment which I name "encountering contact" is shaped eidetically through considering the kinds of contact afforded by various neonatal technologies: the isolette, the feeding tube, and the brain imaging equipment. The concern is not only with how the parent may be touched by the child but also in how various technologies touch on the contact of parent and child.
Portions of this paper were presented at the at the *20th Annual Western Perinatal Research Meeting* held in Banff, Alberta, February

2012 and the *31st International Human Science Research Conference* held in Montreal, Quebec, June 2012.
A version of this article is published in *Medical Humanities.*

(4) Ethics and responsivity: Ethical responsivity and pediatric parental pedagogy
In this article, I explore the parent's experience of ethical responsivity. The concern is with the lived meaning of ethics itself as it originates and wells up in the parent's experience of being touched by his or her child.
A version of this article is published in *Phenomenology & Practice.*

(5) Ethics and the medical other: Carrying: Parental experience of hospital transfer
In this study, I explore the significance of the medical other by considering the routine event of the hospital transfer. The significance of this medical other is explored through revealing this routine experience as a lived experience of carrying.
Portions of this paper were presented at the at the *19th Annual Western Perinatal Research Meeting* held in Banff, Alberta, February 2011 and the *30th International Human Science Research Conference* held in Oxford, England, August 2011.
A version of this article is published in *Qualitative Health Research.*

(6) Ethics and decision: Ethics of the parent's decision in neonatal intensive care
Here I consider what is problematic in our contemporary considerations of the ethical decision by showing the interplay of self, other, and others in the moment of what is the ethical decision.
Portions of this article were presented at the *University of Alberta Critical Care Research Day* held in Edmonton, Alberta, May 2012.
A version of this article is under review for publication in *Journal of Medical Ethics.*

Significance

The value of a phenomenology of neonatology emphasizes a return to an experience as lived. From a foundational perspective, phenomenological research itself gives the questioning of the meaning of a phenomenon its priority over and above gaining truths, drawing conclusions, or establishing theory. This questioning may contribute to new knowledge by opening a way of seeing, and a way of questioning, that which is readily passed over.

For this study, the aim then is to explore in a questioning manner the parental experience of encountering the newborn child in the NICU. This is a particularly consequential and overlooked area of study with little research having actually addressed this ethical event in a techno-medical context.

The moral imperative of this study is that ethics needs to be situated in the lives of our patients—their faces and their proper names. After all, do we respond to ethical dilemmas in practice by merely applying procedures, principles, or codes? Or do we find ourselves responding to a situation face-to-face, a decision as an event that grabs us from within? Introna (2002) writes, "Obligation needs a face and a proper name. We must experience it not merely know it" (p. 83). There is a necessity to understand how technologies may affect the experience of responsibility.

From the perspective then of the professional or lay reader, this study aims to facilitate knowledge translation by developing insightful understandings in the people involved in this phenomenon (parents, physicians, nurses, social workers, and other healthcare professionals). The professional reader may gain a perceptual sense of a parental being-in-the-world that is either distant from or overlooked by their own everyday experiencing of the world as a health professional. As such, ultimately this study aims to cultivate insightful and thoughtful medical care practices that attend not only to the cognitive but also to the affective dimensions of professional practice (van Manen, 1997, 1999).

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2. Phenomenological evidence as insightful understanding

A relatively recent cohort study by Allen et al. (2004) continues to reverberate through the neonatal medical community, evidenced by ongoing citation in medical, nursing, and social science journals. After controlling for medical vulnerability, the authors showed that maternal anxiety at hospital discharge was the strongest predictor for parental perception of child vulnerability. Children perceived as vulnerable were more likely to have developmental difficulties in early childhood. These variables were operationalized using validated measures such as the Spielberger State Anxiety Inventory, the Vulnerable Child Scale, and the Bayley Scales of Infant Development. It would seem that this study yields strong evidence for developing new policy.

The research findings could be used as evidence to justify and plan targeted interventions to reduce parental perceived vulnerability by taking parental anxiety as a modifiable risk factor in the hopes of improving developmental outcome in premature infants. As the authors postulate, a "brief, self-administered measure of anxiety" may be used to identify parents most likely to benefit (Allen et al., 2004, p. 272). This seems like an appropriate strategy. Yet we may also pause at this point to wonder: Could it be that maternal anxiety and maternal perception of child vulnerability is experientially the same phenomenon? In other words, could the study suffer from factorial tautology? What is it like to parent a premature child in the hospital? How do parents experience the transition home? In what ways may parents experience their children as vulnerable? Is maternal and paternal worry for their child a normal or a pathological phenomenon? There seems to be many questions that are unanswered and unanswerable in this study. We seem to lack important experiential understanding of factors that remain relatively abstract in this investigation.

Whereas empirical findings gained through inventories and surveys may serve helpfully as evidence in proposing certain kinds of improved practices, a qualitative type of evidence may be needed to better understand what it is that is judged in need of improvement. In other words, the relation between quantitative and qualitative inquiry may benefit from complementary investigations to better understand the types of evidence mobilized in proposing particular interventions for improved practice. The evidence of qualitative inquiry may serve to shore up, and fill in with meaning and insights, the evidence of quantitative findings. In contrast, it is possible also that qualitative evidence may point at the need for changes in established

routines and practices that are not perceived (yet) as problematic by empirical medical science.

In general, phenomenology may be conceptualized as a reflective study of prereflective experience (Adams & van Manen, 2008). However, the many proponents of phenomenological schools and traditions complicate the use and meaning of evidence. In fact, many famous phenomenological scholars never concern themselves with issues of evidence and rather consider their work a practice of scholarship that is in constant, dynamic review from their scholarly colleagues. Phenomenology, as a qualitative human science research methodology, is characterized by specific modes of inquiry that involve certain types of evidence. The question I would like to address is: how can insightful understanding serve as phenomenological evidence for improving healthcare practice?

Phenomenology evidence as understanding

To appreciate phenomenological evidence as insightful understanding, we may ask: What does it mean to grasp something? Is evidence merely a feeling of certainty in having reached a sense of truth? How does an experience give evidence? Husserl, the founding father of phenomenology, developed a phenomenological epistemology in his analyses of the structures of experience that involve certain kinds of evidence (Husserl, 1900/2001; Husserl, 1950/1999).

The question of the meaning of evidence posed for Husserl was not simply a matter of clarifying the sense in which we either possess it or do not. Rather, the notion of evidence concerns the very condition by which experience itself is possible. For Husserl (1900/2001), evidence (*evidenz*) occurs when a positing "intention" finds "fulfilment" in a corresponding, fully accommodated "percept" (p. 263). What does this mean? Let us turn to a concrete example of a mother witnessing evidence of cerebral palsy in her young son (a limp or mildly spastic leg).

The experience of the child's limp is given to the mother perspectively. This is not just to say that, as her son's mother, she sees her child limp; but also that a mother's knowledge of her child is given from particular perspectival vantage points. From visual perception, the child's limp may be better appreciated by seeing him walk from behind than in profile. Alternatively, the limp may be seen more clearly as he walks down the stairs yet may go unnoticed when he is wearing a particular pair of shoes. There is an insufficiency to perception in the sense of each view of the child is a partial picture that is subject to yet another experiential encounter.

To see the limp as evidential experience, to "grasp" the limp as a disability as such, is for the seeing of the limp (the intention) to fulfill the perspectival sense-making expectation of the parent (the percept). The fulfilling nature of evidence speaks to the grasping of evidence as "self-evident" as the parent's own expectations are fulfilled by the parent's own observations. In this sense, phenomenological evidence takes on the verbal form, evidencing, as an experiencing (or grasping) of something intuitively (Husserl, 1950/1999). This is not intuitive as instinctive but rather intuitive as spontaneously and necessarily evident.

Self-evidence loosely is not the same thing as certainty. The possibility of error is a condition of experiential evidence as our perceptual grasping of others and objects always remain inadequate (Husserl, 1950/1999). Perhaps the parent, in seeing the child struggle down the stairs, sees a toddler still learning to navigate stairs? Perhaps the parent sees the uneven gait as a mannerism? Perhaps the parent sees the leg as just sore? As such, the need for successive perceptual encounters need not lead to skepticism or annul experiential evidence but rather constitutes experiential evidence as tentative to new or stronger experiential evidence (Zahavi, 2003).

Husserl makes a distinction between different types of evidence: *apodictic* (indubitable), *adequate* (exhaustive), and *inadequate* (partial) (Husserl, 1950/1999). Evidence from mathematics (e.g., 3+2=5) is the paradigm example for indubitable evidence; adequate evidence can be more or less complete (e.g., watching a child walk); and inadequate evidence is in principle always perspectival (e.g., we can never see an object, such as a building, from all sides at once). In fact, we can never experience perceiving an object from exactly the same angle, in the same profile, the same context, and so forth. But it should be noted that even though perceptual evidence may never provide us with a view of the whole, Husserl points out that nevertheless we "see" (grasp) an "object" (thing, event, person, and so forth) as a phenomenon in consciousness. For example, the "seeing" of the house while only perceiving its external walls or internal features is the experience of intuitive grasping. This process should not be confused with concept formation (the abstract concept of house). Phenomenological method aims at the self-evidential grasping of a concrete phenomenon: I may grasp the lived meaning aspects of the house as a phenomenon given in consciousness even though the physical and mental dimensions of any particular house(s) can never be perceived in totality. In other words, the phenomenon of house, as we experience it, has no profiles. In the literature of phenomenology there exist elaborate discussions and attempts at dealing with numerous philosophical issues associated with Husserl's writings which remain beyond the scope of this paper.

Returning to the experience of a parent seeing their child limp, at some point the experience of the limp as cerebral palsy may be apodictic in the sense of

self-evident. To the parent, the child may have cerebral palsy (or not). As such, there may be self-evidentness to the phenomenological character of experience. This Husserlian exclusive apodictic evidence occurs when the intention finds "perfect synthesis of fulfilment" which gives to an intention the percept not merely meant but "in the strictest sense given, and given as it is meant, and made one with our meaning-reference" (Husserl, 1900/2001, p. 263). It should be noted as well, that in the case of the mother seeing her child limp, there is also the complicating factor of a medical diagnosis that can be experienced as final, fatal, or as suspicious in the pronouncement of the techno-medical diagnostic label, cerebral palsy.

While I have used sensory perception to discuss Husserlian evidence, this account may be loosely generalized to allow for the intuitive evidence we experience in reading a phenomenological text. Here, intention is in the reading of the text allowing the reader (as observer) to experience eidetic insights into the meaning aspects of objects, events, and other phenomena.

Phenomenological evidence as insight

The notion of phenomenological evidence as insightful understanding speaks not to some extraordinary extrasensory perception but rather a sensitive awareness reflecting a penetrating understanding of the character or hidden nature of a phenomenon. For phenomenology, this hidden nature relates to the notion of *eidetic* insight.

The notion of eidetic concerns the *eidos* (Greek: "form, shape") of a thing. In phenomenological human science inquiry, the researcher aims to get at the eidos of a certain phenomenon in the sense of the patterns of meaning or themes belonging to it. Turning from Husserl to his student Heidegger (1927/1962), phenomenology means "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (p. 58). Yet how is this to be achieved?

Phenomenological inquiry may be understood as reflecting on the lived dimensions of prereflective experience. As a research methodology, phenomenology thus becomes the study of a possible human experience, not just an individual person's experience. The notions of *doxa* (experience, opinion) and *aletheia* (state of revelation) may be helpful to clarify how phenomenology aims beyond the individual experience.

Returning to the example of the mother's experience of her child with a physical disability, a phenomenological researcher may gather a series of various mothers' experiences (*doxa*) to explore the experience of mothering a child with cerebral palsy. Foreseeably, anecdotes could include watching such a child play active games or navigate playground equipment. They could

be examples of a child gaining independence in walking aided or unaided. Alternatively, they could be experiences of a child losing independence, falling and sustaining an injury. The phenomenologist would aim to go beyond particular varying anecdotal experiences (*doxa*), striving to reveal lived meaning of the human phenomenon (*aletheia*).

Phenomenology may be seen as a pursuit of meaning offering the reward of "seeing-meaning" or "in-seeing" (van Manen, 2007). Perhaps watching a child with a disability falling may be an experience of not seeing just one fall but seeing fall after fall of the child who is stuck. Or perhaps seeing a fall is an experience of seeing injury and suffering unfold, with the anticipated need for more hospitalizations and medical treatments. Or perhaps falling is just part a child's walk or run and is not a real fall but just his or her way of being. If we begin to imagine what this experience could be like, we may gain insight into the lived meaning of it.

It should be clear though that this is not to say that phenomenological insights are positivistic; meaning is not a function of theory or an abstraction. The idea of phenomenological *eidos* does not refer to some immutable generalization or universal concept about human nature or human life. The notion of *eidos* is at most an *essence* in the weaker sense. Nor is phenomenological knowledge arrived at through psychological processes of induction. While phenomenology may aim to explore the structures of phenomena it does not presuppose that *eidetic* meanings may be used to re-build a phenomena. It is rather concerned how the meaning of possible human experiences may provide us with insightful understanding: "infuses us, permeates us, infects us, touches us, stirs us, exercises a formative affect" (van Manen, 2007, p. 11). Phenomenology aims to lift and reveal prereflective experience: "to bring back all the living relationships of experience, as the fisherman's net draws up from the depths of the ocean quivering fish and seaweed" (Merleau-Ponty, 1945/1962, p. xvii).

Phenomenological insight is existential as a revealing of *eidetic* meaning. It is not propositional in either the empirical sense (based on correspondence between an assertion and a state of affairs) or analytic sense (based on reason or tautology). Returning to our earlier discussion of understanding, phenomenological evidence may be apodictic (self-evidential), adequate (more or less complete or deep), or inadequate (essentially incomplete or always perspectival). The extent to which it is situated in one of these categories may relate to the phenomena of study, the strength of the text, and the experience of the reader. To clarify, a phenomenological text may only produce apodictic understanding to the extent that the textual portrayals resonate (fulfill) the kind of meanings that the reader seems to recognize not only within the text but perhaps also within his or her own experience. Phenomenological evidence may be thus seen as successful in the bringing

forth of a presence whose truth becomes manifest in the experiencing itself (Sokolowski, 2000).

Phenomenological evidence and phenomenology of practice

The practice of evidence-based medicine is not just the use of the best available clinical evidence. It is rather the integration of evidence with clinical expertise (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Clinical expertise speaks to:

> the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care. (Sackett, 1997, pp. 3, 4)

Evidence-based medical practice seems to demand of the clinician thoughtful attentiveness and ethical sensitivity. Experimental inquiry may provide evidence for diagnosis, prognosis, and other gnostic practice. But the more pathic forms of knowing that constitute a major dimension of clinical experience and professional practice may be less fully achieved by traditional medical science literature (van Manen, 1999). Phenomenological evidence as insightful understanding may contribute to these pathic areas of practice, while remaining attentive to tenants of sound research: free from unsupported presuppositions, assumptions, and taken-for-grantedness (van Manen, 1990).

The pragmatic concern of how to act in situations and relations, phenomenology of practice, may demand of the professional experiential insights and ethical considerations. By means of "pathic significations and images, accessible through phenomenological texts" phenomenology may "speak to us and make a demand on us" such that the "more noncognitive dimensions of our professional practice may be communicated, internalized and reflected on" (van Manen, 2007, p. 21). From the practitioner's point of view this kind of evidence is more ontological and requires a certain tactful understanding in medical encounters between medical practitioners and patients or patients' families. Foreseeably, phenomenology may cultivate good practice by sponsoring a thoughtfulness that constitutes a feelingly responsive thinking allowing integration of pathic and gnostic knowing. Herein lies the formative value of phenomenology: not what phenomenology *tells us,* but rather what it does *with us.*

Returning to the opening epidemiologic study, although the study identified a clinical area of concern that perceived parental vulnerability correlates with neurodevelopmental difficulties, the desirable and ethical integration of this evidence into the practice of the physician remains unclear. The phenomenology of perceived vulnerability and disability is not measureable or demonstrable in a similar manner as the scores or measures on an objective test. And perhaps we should not presume that all cases of parental anxiety are negative. A parent whose child has been hospitalized since birth may be understandably anxious at the prospect of going home. After all, first moments between parent and child have been shared in hospital and the medical nursery may have become a familiar and homelike place (van Manen, 2011). The child could still have medical issues so that leaving the hospital may involve taking home a child who is indeed medically fragile or vulnerable. Perhaps a clinician's attention to the anxiety of parents should remain attentive to the nuances of each individual case and how the parent is debriefed and helped to feel confident upon leaving the hospital with their child.

Concluding remarks

There are many kinds of evidence discussed in the discourse about evidence-based practice and just about all traditional medical science is oriented to contributing evidence for sound medical practices and interventions. Phenomenology as an example of qualitative research, and the types of evidence it produces, may complement empirical evidence for improved practices. As well, qualitative research in general may offer insights in the need for improved practices where empirical research is lacking, or where empirical research is less likely to be undertaken (Green & Britten, 1998; Grypdonck, 2006; Pope & Mays, 1995).

It is obvious that the issue of evidence and the field of evidence-based practice are complex and multifaceted. As well, qualitative research methodologies are quite diverse, situated in different ontologies and epistemologies (Guba & Lincoln, 2005). As such, we need to be attuned to the differing kinds of evidence provided by differing qualitative methodologies that depend on the discipline or the model of inquiry upon which it is based.

While in this paper I have discussed phenomenology, other forms of qualitative inquiry have their own agendas and limitations. For example, evidence about cultural practices emerging from ethnographic studies may draw on a range of methods placing a priority on gaining an emic perspective such that the findings convey a sense of being there (Savage, 2006). While ethnography may provide rich textual descriptions of a culture or subculture, ethnography itself does not differentiate between description (cultural meaning) and that what makes the description possible (eidetic meaning). In

comparison, grounded theory aims to generate systematically a substantive theory grounded in data (Glaser & Strauss, 1967). Evidence for the formulation of emerging theories may depend on the proper use of coding, the constant comparison, questions, theoretical sampling, and memos (Walker & Myrick, 2006). While grounded theory may abstract, examine, or explain social processes, it does not necessarily evoke understanding of the particularities of human experience.

Recognizing this diversity, it is problematic that some practitioners and researchers seem to assume that all forms of qualitative research may be similarly appraised (Boulton, Fitzpatrick, & Swinburn, 1996; Cesario, Morin, & Santa-Donato, 2002). It would seem more appropriate that criteria aiming to generally assess qualitative research remain attentive to the differentiating features of the various methodologies that underlie the research (Mays & Pope, 2000; Secker, Wimbush, Watson, & Milburn, 1995; Tracy, 2010). It is important to have a clear understanding of a particular methodology before appraising the evidence it provides.

Qualitative inquiries clearly have their own particular agendas, anatomies, and autonomies such that it may not be possible for them to be incorporated into the same framework as quantitative research (Morse, 2005, 2006). It should also follow that particular qualitative methodologies should not be synthesized and homogenized as a single qualitative model. Still we have to create and trust a crossing between epistemology and ontology, behaviors and qualities, outcomes and experience, as the clinician remains attentive to the nuances of individual cases.

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3. The medium, message, and massage of the monitor screen[1]

The innocent visitor who enters the neonatal intensive care unit (NICU) is likely to be struck by the scene of babies literally tied to medical technologies. Some of the devices are invasive: tubes physically penetrate bodily surfaces to deliver needed medicines or breathing support. Others are noninvasive: wires affixed superficially to measure heart rate, respiratory rate, oxygen saturation, and other vital parameters. By means of these adorning probes, information is transmitted to display on a monitor screen, usually positioned adjacent or above the child's isolette. The screen is designed for monitoring the child, and to alert the medical staff at times of need.

The neonatal monitor as a noninvasive medical technology would seem to be one of those things that we do not have to worry about. It does not pain or harm the body. Nor does it disturb bodily tissues or physiologic processes. On the contrary, it is meant to assist in healing and safeguarding the child. The impact of its use is confined and understood.

Yet, as a McLuhan medium, the monitor is perhaps more than a noninvasive device. The monitor as medium massages—creating a pattern, an atmosphere, an environment of perception that works upon us (McLuhan & Fiore, 1967). And by massaging our sensibilities, the medium messages: changing the pace and interaction between parent and monitored child (McLuhan, 1964).

The neonatal monitor experienced as baby and as monitor

As the parent enters the medical nursery, the baby may be sleeping but the screen-face of the monitor is always awake. The monitor displays a salutation without reciprocity or questioning. There is no courteous "hello," or interested "how are you?" Rather, the monitor displays a comment, a picture, a representation of how things are with the child. For a parent, looking to this screen may become a routine way of seeing his or her child on display.

Each day here I start the same way. I have a routine. I walk into the nursery,

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shelve my pumped breast milk in the fridge, wash my hands, and then make my way to Ava's spot. I see the monitor first. I check the screen just by watching for a few moments. If everything reads well, I hardly notice how it holds my attention as I lay my lunch and books on the shelf. Then I turn to look into her isolette, to catch a glimpse of her face, if she is lying just right. I try to find her nurse to check in, after that I seat myself in a chair to read a book while keeping my eye occasionally on the monitor. I usually half-read my book for an hour or so, before, I finally have a chance to disturb her.

How does a parent see his or her child when they encounter the monitor screen? And perhaps more pointedly, how is the child mediated by this technology? Objectively, what the screen shows is neither a video of the child's face nor a recording of the child's voice; rather, it is a real-time, continuous display of colored numerals and penciled graphics.

Emma is having a good day. She has had only a few dips in her saturation really just clustered around her nursing cares. Her temperature has been stable despite me holding her for over an hour. And her heart rate has been hovering nicely in the 160s. She seems in a nice balance, in a good place.

The monitor places the parent in an interpretive relation to the child. The electronic tracing of the monitor represents a transformation of information. To see the child on the monitor, the parent learns to read the meaning of graphic codifications: bradycardia (slow heart rate), tachycardia (fast heart rate), apnea (pause in breathing), desaturation (drop in oxygen content), and so forth. In this way, there is a hermeneutic aspect to the relational mediating role of the monitor as the parent engages in "referential seeing," interpreting each number in reference to the child (Ihde, 1990, p. 85). Thus referential seeing becomes a way of seeing more than what the naked eye can see.

I look at the monitor screen 'cause my eyes just happen to follow it. 'Cause, I want to see if he is breathing ok, if his heart is beating ok, if he is ok. And it is always fine. I always look at it just to know what is going on inside of him.

Penetrating beyond the visible, the monitor discloses and reveals hidden, inner aspects of the child. The parent may see the child on the neonatal monitor by means of numbers and waveforms as a measured being—a being that is either in a stable or unstable state. Regular numerals and patterns sooth parental worry, while atypical measurement indices raise parental concern. The neonatal monitor behaves somewhat like a barometer, thermometer, or other continuous measuring device. In measuring, for example, the temperature of a child, the monitor though does provide more than a measure of stability or change. The monitor presents the being of the child as a thing-like entity: being attentive to the child becomes being attentive to the monitored aspects of the child.

Whether the child is deep-in-sleep or wide-awake, the monitor is constantly and actively measuring things. The state of the premature or sick infant who is contained within the medical isolette, below the canopy of technological wires and equipment, is held artificially open, always available. Being in a constant state of audience becomes part of the parents' way of being-with the child as the monitor screen becomes the reassuring face of the child's presence. So much so that parents may not want to interrupt the presentation. They may be less inclined to check on the bodily being of their child, as that responsibility is surrendered to the technology. Instead, the parents take on the role of watching the watchful monitor screen—"seeing" the child without seeing their child.

One day I was sitting with her, and the monitor was dinging. It often dings and stops, dings and stops, so I gave it little thought. I thought it was within her normal pattern. After about five or ten minutes of it dinging, I finally got up and looked into the isolette. She was irate, thrashing around in there. She had soaked through her diaper. I could not help but wonder how long she had been like that, in there.

Available and unavailable, the web of monitoring wires frees the child from being touched and seen as a flesh and blood person. Touching the child may only interfere with the monitor trace, disturbing its regularity. Thus, the monitor may discourage parental action and active affection. Ambiguously, the monitor may be experienced not only as the being of the child, but also, as the monitor of the child.

The experience of the monitor as my-self as parent intertwined with monitor

I have tried to hold his hand by positioning my fingers just so between his fingers so he would grasp mine. He has always been shaking too much from the cooling blanket. He has always been withdrawn. But today was different. I called his name, and he opened his hand, then he held my finger. And it was like "Mom, you are here, you are here for me." I had very strong feelings. I think he had the same feelings, just like mine. Like you know when you hold something very strongly, the base of your nails turns white. Well, his fingers were white when he held my finger. He was holding my finger so very strongly. He wasn't holding my hand, he was holding my finger, because he wanted to do that. And then I told him, "You're going to be ok."

This mother describes moments of naked perception: an embodied parental being-with child as other in a world of bodily perception. Here, the mother encounters her child as an other who is so very much like her—of her, from her—yet visibly and invisibly other than her. In this place, the body is perspectival and perspective emerges out of the very stuff of the world

(Merleau-Ponty, 1964/1968). Still this moment, this way of being together as self and other, may be violently interrupted by the technology.

And just then I heard the monitor beeping. At first, I thought it was from another child's machine. Then, I realized that it was from my David's machine. It told that something was not normal. I looked away from David to the screen. I was scared. What have I done? Have I loosened a connection? Or dislodged something? I was worried. Maybe his blood pressure is going down? Maybe his breathing has stopped? I turned to the nurse who was there. She just watched the screen. At first she did not say anything, then she said, "Don't worry, it is ok to touch your baby."

If we probe further we may wonder, is the monitor truly ever just behind or beside the parent and child? Is it just the body of the child that is monitored? Or does the monitor somehow extend its reach beyond the child to the parent?

Sometimes after I leave the nursery and lay at home in my bed I still hear it. I still hear the room. I hear the alarms ringing in my head—the regular, irregular ringing. My house can feel so uncanny and quiet. There is a certain familiarity to that sound after a while. It is hard to leave that room.

The parent, who dwells in the nursery, is embodied in relation to the neonatal monitor. The rhythm of sounds may become part of the parent's being-in-the-world. The monitor is not just a bodily extension of the child; it is also a bodily extension of the parent. The monitor is woven into the (inter)subjectivity of parent as self and child as other—a way of being whereby technology vascularizes the flesh of a common world. As technology weaves into this substancing matrix, self and other are permeated, invigorated, imbued by its essence. In this way, the child and parent are transformed. We may wonder, whose and what body is this monitor?

A few days ago, the nursery was really quiet. A number of the nurses were on break, and the babies were all being so quiet. There was no ringing of monitors, just the airy sound of the breathing machines. It was eerie in its stillness. I just did not feel right. I could not get comfortable in there. I found myself talking out-loud to myself, just so I felt normal.

Unable to feel "right" without the technological presence, parents may feel uncomfortable and unfamiliar in a silent world—a world without machine—as their own bodies feel strange.

The experience of the monitor as my-child transformed into cyborg

I remember the feelings, holding my daughter in those first days. I was in shock.

My one pound baby girl. Just holding her with those monitors. It was a happy moment, but at the same time, I felt like that moment had been taken away from me. You never think about holding your baby full of tubes, covered in cords. Every time the monitor would beep it was like what is going on? It was very emotional. I could not look at her without looking at the monitors.

When babies are born it almost seems natural that they be left naked or swaddled to be maintained in their innocence. Dressing an infant even in clothes is almost unnatural as the baby may be made to appear prematurely like a little adult. Parents may expect to see their baby in their naïve, untouched nakedness. Yet when a child is monitored, the child may be experienced as transformed. Adorned with probes, intravenous lines, and other medical paraphernalia, the child is visibly and invisibly transformed. The parent is no longer holding the newborn child. Rather, the newly-born is reborn as cyborg.

What is a cyborg? A cyborg is more than a blending of human and technology. For example, the utilization of contact lenses or artificial limb to restore biological capabilities may seem no more cybernetic than a pair of glasses or cane, especially if the gained functionality is only restorative. Likewise, an infant fitted with a mechanical heart or insulin pump perhaps should not be considered as cyborg if these medical modifications only sustain physiologic function in the context of organ disease. So, how is it that a noninvasive monitor is capable of invoking cyborgification?

When you get used to it, you forget about it. I held her this morning before you came. It took three people to place her on me. The respiratory therapist held her tube, and her nurses took care of the wires and intravenous lines. I just held her then for a couple hours. As the monitor rang for a desaturation, and her breathing paused, I would rub her back. The trace returns to baseline and her breathing steadies. She comes up so well. Without even looking, I hear her come up. I can feel against my chest when she needs a suction. It is a wet, vibratory feeling, then the machine rings tube obstruction until we suction her out. I don't really look at the monitor more than I look at her face, her body, or any of the other medical instruments. But I constantly know how the monitor reads. I am always listening for the monitor, I am always listening for her.

The calling sounds of child and monitor; and the parent as present, responsive, responsible. Attentive and caring, the parent may sense the child both through the monitor and through his or her bodily being. As the child comes up from desaturation, bodily breathing normalizes and the trace on the screen steadies. Child and monitor respond. This embodied experiencing of my-child may be in both the parent's experiencing of raw bodily reverberations and the synthetic monitor sounds. And so, the experience of contact is perhaps neither wholly in the physical nor in the virtual; rather, it is in the intertwining of encroaching aspects of reality and a screen-mediated

cyber reality.

The cyborgian technology may be intricately woven into the embodied (inter)subjectivity of the sentient (hearing, touching, and looking) and the sensible (being heard, being touched, being seen). Here, the monitor weaves and is woven into the relationship of parent and child. It may be difficult to untangle and work out the connecting wires of the monitor. It may be difficult to just see my-child without its cyborgian shell.

I have been pumping throughout Taylor's entire NICU stay so I was really excited when the doctors said that I could try and breast-feed Taylor. I have a strong let down so before I even had a chance to put him against my nipple I was already leaking. I tried to get him latched, and every time he seemed to start sucking, the monitor would ring. I don't know if it was the position, the way I was holding his head, but I just could not do it. I kept looking up at the monitor like "Yeah, I get it…this is not working." But he did seem to be trying.

The parent may experience the mixed messaging of my-monitor-child. Monitor and child may be given to parental experience as entangled, knotted, crisscrossed. So much so, a mother may be unable to see the sole physical presence of her son successfully nursing from her very body as embodied perception may be in the blending of trace and child. In this way, the cyborg child emerges. Seeing just my-child, looking away from the monitor, may be experienced as almost impossible. What have we done?

Concluding comments

The neonatal monitor as a McLuhan medium has a complex thingy character, an ethical message. In massaging parental affective sensibilities, it reshapes the way that the child is experientially given to the parent. Seemingly, just like other things, the neonatal monitor may be understood to bear morality as it mediates parental perceptual experiencing from which (moral) decisions may be made (Verbeek, 2000/2005). Yet as the monitor is woven into human relationships, the monitor may carry more ethical significance than other seemingly ordinary things. The monitor penetrates the ethical moment, the ethicity of ethics, as it weaves into the relation of self and other, parent and child.

The technological intertwinement of self-technology-other or parent-monitor-child is not necessarily a regretful thing. Medically, the monitor is used as it has a necessary clinical role in monitoring the sick or premature child. Its utility is not in question. Yet, in exploring the way that it pervades the experiencing of self and other, the neonatal monitor can hardly be said to be neutral. The monitor may regulate behavior in often (un)recognized ways. So, while there is a medical need for monitoring technologies, the question

remains, how should these technologies be used if they truly are so (non)invasive?

Perhaps the answer begins with the word "reflectively." When neonatal monitoring is available the first question to be asked is, "should or ought it be used?" And, "does this particular child really need to be displayed on a screen?" And then, of the monitored child, "does this child still need to be monitored?" If yes, "are there at least some times when it may be safe to lay the monitor aside so being-with my-monitor child is solely being-with my-child?" These questions speak to a turning of the parent back to the child as child, rather than child as technologized cyborg child—an engagement with reality (Borgmann, 1999).

There are also questions to be asked of the technology itself. In the design of monitors and related paraphernalia, is there a way to make them more sensitive to the developing relation of parent and child? Designers should answer the plea for a morality of machines (Achterhuis, 1998). Medical equipment engineers ought to build an awareness of the ethical relations lived everyday through their novel technologies. As such, should the default functioning be a limited display, or perhaps a display that dims, fades away, when vitals are within normal limits? Beyond the display, attention to the development of wireless (or even electrode-less) monitors that may make it that much easier to just hold my-child, or move my-child connected yet disconnected away from the neonatal monitor screen is surely needed. Imaginably, the developing parent-child relation should serve as motivation for design innovation.

Ultimately a phenomenology of the parental experience of the neonatal monitor screen perhaps speaks most to the thoughtful, tactful, and often tacit dimensions of clinical practice in understanding the ethical relation of self-technology-other. The physician, nurse, or other health care provider that uses the monitor is not just technician, but rather a careful, caring professional. As technology becomes more pervasive and perhaps more transparent, it is crucial for practitioners to gain a renewed understanding of how parents experience being-with their children in the medical lifeworld. The neonatal monitor provides but one example for consideration in the manifolds of machinery in technologized medical health care.

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4. Technics of touch in neonatal intensive care[1]

The world of neonatal intensive care is a technological environment, inhabited by babies who are attended by nurses, physicians and other healthcare people. These professionals have dedicated themselves to look after the physical well-being of the newborns who have come into this neonatal intensive care unit (NICU) world with critical health needs. While an outside visitor would probably be bewildered by the scene of tiny babies in cubicles attached to wires, tubes and monitors, the healthcare professionals see an orderly world. They see babies with unique medical requirements. They understand the medical difficulties of these little embodied beings, and they respond to their needs in the best way they can.

But there is another kind of visitor in the NICU. And this is the parent. How does a father or mother encounter and experience his or her child in this high-technology place? This is an important question since the health and healing of the newborn is intricately interwoven with the parental being of the father and mother, but in ways that medicine perhaps does not yet fully understand. While the medical community realizes the critical importance of attachment between baby and parent for the present and future being of the child and the child's family, questions relating to the actual experience of this developing relation in a medical-technological environment such as the NICU remain largely ignored. So what happens when a father or mother meets or visits his or her child in the NICU? Do they see this child, just as any confused visitor might? Perhaps. But hopefully, the encounter between a parent and newborn is the beginning of something more consequential. Undoubtedly, the health of the child, the becoming of the parent as a mother and as a father, and the possibility of the birth of a new family depend on it.

Phenomenology as method

Phenomenology, as a human science research method, is directed at exploring the meaning of a recognizable lived experience, a phenomenon. The focus is not on opinions, perceptions or judgments about experiences; but instead on direct descriptions of lived experiences and achieving a "direct and primitive contact with the world" as experienced in everyday life (Merleau-Ponty, 1962, p. vii). Phenomenology is a textual form of enquiry that aims to express and explicate experience in rigorous and rich language. The textual process of writing is a key part of the research that involves

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finding language sensitive to the phenomenon, yet allowing the phenomenon to speak for itself as it were (van Manen, 1990). Like every other research approach, phenomenology employs certain methodological techniques (such as the epoché and the reduction) for investigating meaning structures that constitute the phenomenon to be explored. For an overview of this methodology see, for example, van Manen (1990). For other examples of the application of phenomenology in medicine, see Toombs (2001).

For this study, I focus on the phenomenon of "encountering contact" from the parental perspective of the NICU child. And by reflecting phenomenologically on a variety of examples, where the parent-child intentional relation is experientially mediated by medical technologies, I explore the eidetic (invariant) meaning aspects of this contact. More so, I examine how various technologies may have a bearing effect on shaping this relation. The technologies were chosen for their common use in the NICU and for the ways that they touch on the formative being and becoming of the relation between parent and child.

I should clarify that, for those unfamiliar with phenomenology, this form of enquiry does not aim to generate empirical generalizations nor does it aspire to develop theory (in the strong sense of the term). Rather, the purpose is to gain meaningful insights into possible human experiences. Not all parents will necessarily share these experiences in a similar manner. In particular, the "anecdotes" in this article serve as rhetorical devices to assist the reader to access the subjectivity of possible parents' experiences. The anecdotes may be considered as "fictional examples or paradigms" to let the reader understand something that cannot simply be easily explained in conceptual-discursive terms (van Manen, 1990). I also note that the anecdotes have been deliberately edited to contain no identifying information.

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Encountering touch

I remember the first time that I held my child's fingers, or rather that he grasped my index finger and held it. The nurse had put him in my arms. He seemed so fragile. I just stared at him. As his head turned, his eyes seemed to be looking for something to hold onto. And his arms were jittery fingers groping at the air until they found and grasped my finger. I was struck by his face. I looked at him, somewhat confusedly stunned. I felt taken aback. I was holding this baby in my arms who was my child. I cradled him so carefully, keeping everything tucked in and safe-the feeding tube and monitoring wires, just so. Although I held him in very close, it felt like he was really holding me, so firm was the grip of his little fingers. As he moved his arms, I moved my hand within his reach, allowing his fingers to close around mine. I did not even think about

these subtle gestures until they had already happened. As my child was holding me with his fingers and his gaze, I experienced a powerful and overwhelming sensation: this little baby was making me a father.

A father recounts his first time of holding his child, born of technology. Indeed, if it was not for the NICU, the child might not be alive. But, for the father this technological reality is simply a backdrop to his encounter with his child. In touching each other with their eyes and hands, in the crossing of gazes and caress, the father and child find each other, making contact. The word "contact" derives from *contingere*, meaning to touch or be touched closely, connectedness, in-touchness. To face another, says Lingis (1994), is to touch with the eyes, and the vulnerability of the other is felt in our eyes. It seems that in the contact of seeing and being seen, the touching of hands, the father encounters his own sense of fatherhood.

When the father speaks of being stirred by the *face* of his child, it is not just the physiognomy of his child's face that rouses him nor the fragility of the head, the color of the eyes or the child's delicately thin skin. When the father speaks of the grip of the child's fingers, he is not speaking of the amount of pressure exerted on his own finger. Rather, he is struck by the *face* of the child. The grip of the child's finger announces his presence as an other to the father. The father feels the child's grip physically, and feels this grip pathically, relationally and existentially as his own fatherhood. Buytendijk (1970) has suggested that touch may be expressive of a direct kind of intimacy as it establishes in a "feeling" way a close relation. In cradling his child, the father experiences both the child's touching and his own touch. It is a double aspect of responsivity and sensitivity as to touch allows for an experience of grasping understanding and opens the parent to a moment of being moved by the otherness of the child.

The father's story tells of a moment of rupture, interruption and provocation when he is struck by his child. In a moment like this, the meeting between parent and child is not just a meeting, but a true encounter: encountering the child's self in his or her singularity. How can the father be anything but bewildered and taken aback when faced with the *face* of his newly born child? Levinas (1961/1969) helps us understand the ethical command of the face. The face in its irruptive expression "calls me into question" (p. 83). As such, the experience of the other, the face, becomes the condition for the possibility of ethics. In the case of the father, it is his ability to experience his own response to the child's touch: his paternal sense of responsibility.

We may wonder though what happens when perception and touch become mediated by technology. In the NICU, the child is rarely experientially given to the parent free from technologies. Rather, the child is blended into the technical environment: contained in isolette or bassinette, connected by lines to machines, displayed on monitors. How then may a parent perceive his or

her child? How does a parent experience a child that seems wired into this medical-technological world?

In the next sections, I explore three different neonatal technologies that may affect the encounter of parent and child. The aim is to produce some insights as to how this ethical moment may be touched. In each of the following cases questions are raised: How is the child of technics given to experience? What can we learn about the parent's experience of subjectivity? How is technology seen or perhaps not seen?

The isolette and the restrained touch

In a few days it is going to be 3 weeks of him being here, stuck on a breathing machine. Still, even up to now, though I am here every day, I don't feel like a mother. I sit by his isolette, look through it, open it, reach inside it, every day just to be with him. But it does not seem to help. I don't know what to do. There is too much going on in there—tubes, wires, and needles, everything. Sometimes I just stand here and talk to him. I tell him that he is doing a good job, but I don't know if he can even hear my voice. At times, when I put my hand in there, he grasps it, holds onto it, and won't let go. He won't do that for my husband. He won't do that for my mom or my dad either. I am gathering that he knows it is me. But it is hard to say. There is just so much around. I mean there is a nurse on this side and another nurse on that side. And my husband behind me, talking to me. And I am just trying to be with him. I mean, I just wish they would all shut up, and let me just be his mother.

Sitting beside the isolette, doing all she can to have contact with her child, the mother finds herself unable to be a mother in the deeply felt sense of motherly belonging with child. Although the mother is bodily present, she still finds herself off to the side of the isolette reaching in-looking in at her child without facing the face of her child-unable to touch him with her look. It is true the mother can open the isolette. She can reach in to touch her child. But this is not necessarily the touch of contact.

It seems like the mother needs to overcome the technological barrier of the isolette and its medical accouterments. She is aiming to do just that by trying to look at her child again and again, day after day: speaking to him and touching him. But in spite of all this, her trying does not produce the contact she really seeks. She seems neither able to be *with* her child nor to *encounter* her child in this deeper sense. She is rather reduced to looking *at* her child, who, in her words, is stuck in the isolette on the breathing machine.

We may understand the isolette as a structural thing that houses a child: an external plastic womb. It is designed to be a contained and controlled place of incubation providing warmth, quiet and humidity until the child is ready for

the outside world. As a medical device, the isolette is a high-tech plastic box that facilitates medical care. It holds in its inner world the body of the child and a host of medical things.

There are technological artifices directly connected to the child: intravenous lines, breathing tube and monitoring wires. There are other devices placed for caring: syringes, suction catheter and stethoscope. In this way, the phenomenality of the isolette is not just to enclose the child but also to unite the child with the technological: clinical monitoring, artificial nutrition and various medical therapies. In a Heideggerian sense, the isolette not only gathers what it concretely contains; there are also "things" that are immaterially gathered as the technology seems to open the parent and others into a technical way of being with the child (Heidegger, 1971). The gathering is an existential assembling, a bringing together, of the child with the techno-medical environment itself. For the prematurely born newborn, the technological sustains the child in a clinical place affording the premature transition from womb-world to isolette-world.

The isolette invites the outsider to *look* in by virtue of its transparent fashioning. But when the mother reaches to touch her child, she encounters a barrier, the wall of the isolette. To enter the isolette, she must first unlatch the door. But even after opening the isolette, she still experiences an impediment. The isolette only permits the use of hands and forearms. No real holding. No true embrace. The isolette constrains and constricts, restrains and restricts. As well, the isolette only permits a particular kind of touching. It does not allow the touch of intimacy. The child cannot be held within her motherly arms. The child is held at an arm's length.

Although the isolette may invite the parent to look into the isolette or *handle* the child in a particular reaching fashion, there remains a containment to this container. With the doors closed, the isolette dampens the audible urgency of the child's cry. With the cover laid, the child's very bodily being is hidden. To the onlooker of the closed and covered child, he or she may seem shelved away, stored securely in its placement of the room. In this way, the isolette ambiguously prevents nearness as the incubator becomes a sovereign place so that handling the child may become disturbing the child.

As a technological enclave, the isolette is not only an isolating thing as its connectors and openings permit it to be connected to the technical paraphernalia of the NICU. For the parent, the isolette may come to represent the sights, smells and sounds of the NICU as being with the child may become a familiar experience of monitoring screens, antiseptic aromas and machinery sounds. There is a (multi)stability to this device. It may be removed and replaced, resettled into various relations, but once enclosing a child it becomes stable and constructive, constituting aspects of a larger system of relations (Ihde, 1990). This (multi) stability is not the same as

neutrality: "Within multistability there lie *trajectories*, not just any trajectory, but partially determined trajectories" (Ihde, 2002, p. 106). For the isolette, the trajectory is this system of relations which may include other objects (infusion pumps, ventilators, monitors) and other people (nurses, respiratory therapists, doctors).

The child may not be easily removed from the isolette without the help of nurses or other medical staff. The operation of the isolette and its connections are the expertise of these professionals. The parent may then find him or herself at the mercy of others to do the simplest of tasks for the child: changing diapers, feeding and so forth. Even touching the child may be felt as a supervised touch under the watchful eyes of others. Perhaps, we can see how the mother may experience herself as an outsider to the relationship of nurse and child. The experiential sensibility of maternity and paternity may become tenuous, fleeting and elusive as true contact remains out of reach.

The feeding tube and the cyborgean touch

Technologies, like the feeding tube, seem rather easily passed over, taken for granted, as they more subtly weave into the tactility of technical flesh constituting the medical lifeworld of a parent and child. Perhaps it is due to their plainness that we easily forget that they too touch a parent's encounter with his or her child.

The feeding tube is one of neonatal medicine's simplest of technologies. It is a flexible, silastic hollow tube usually inserted at the bedside by feeding it into the child's mouth or nostril until its end reaches its destination, the stomach. Secured in place by taping the exterior end to the angle of the mouth, the feeding tube becomes an extra body orifice, mechanically connecting stomach to world, offering a new way to touch the child. Bypassing the voluntary swallowing, the tube orifice is existentially different from the mouth orifice as food and medicines can be pushed slowly or quickly into the stomach by means of hand syringe or infusion pump. In neonatal care, this technology is used extensively as many infants may be unable to safely swallow due to prematurity, illness or some other issue.

Yesterday was a bad day for Amy. Her feeds had been put up quite a bit. More than I would have liked because she spits up a lot and you can see that she does not like eating. Her feeds are my pumped breast milk, all given through the tube, running in over two and a half hours. She gets nothing by mouth. And she has to eat every 3 h so that she really only gets half hour breaks between feeds. So yesterday, again, she was spitting up pretty much all day. I was just covered in it. And she was crying a lot, in pain. Every time the feeds would get started again, she would start fussing and get really cranky because she had got no

room in there left. The nurses and doctors, they were not listening to me. I totally understand my child needs the feeds. Really, all I want is for her to be able to just handle the volume and grow. But forcing it through causes her pain. And the nurses and doctors, they just keep going. Pushing the feeds down into her. I finally said, "I am tired of this. You guys need to slow this down. Just look at her!" They agreed and gave her a break.

As feeds are pushed in, both child and mother are in pain. The child seems unable to handle the volume, expelling what is forced in. Although this feed may be the milk *of* the mother, it does not appear to be experienced as *from* the mother.

It may be tempting to consider the feeding tube on a spectrum with bottle feeding as both devices afford provision of milk *by* another without the intertwining bodily contact and communication between mother and child epitomized in the gesture of nursing:

> Never have I been in such close contact with another being's skin, arms, and mouth than during those early weeks of continuous holding and feeding. I made milk, smelled like milk, was sticky with this stuff that was me, but not me, which produced in me the need to give it away (Simms, 2008, p. 11).

Still, the feeding tube does more than circumvent the bodily relation of infant mouth to mother's breast. It opens the child to a new technological intentionality whereby milk may be given, pushed into the child, in a technical way.

To provide food by a silastic utensil alters the usual experience of feeding: to touch the child with the intent of nourishing becomes a gesture of contact with the feeding tube. The child cannot seek, suck or turn away from the nipple to control whether or when to feed, how much to feed, and what pace to feed. The vocabulary of latching, pacing and burping is no longer descriptive of the experience. Instead, everything is programmed, controlled and set, as the feeding pump buttons read: start, stop, volume and rate. Feeding becomes scheduled with time on and time off. If feeding is tolerated without issue, the child's being is reduced to a stomach: a passive receiver of programmed nutrients and medicines. The routine of checking if the child is ready to feed can be relegated to ensuring that the feeding tube is appropriately positioned and secured. The child may not even need to be held as the tube affords an extended distance of feeding. In this way, the tube becomes a bodily orifice of a cyborgean-child.

For the professional and perhaps the parent, this care at a distance has the potential for disembodying and passing over a more originary ethical kind of caring touch that is encountered in a direct face-to-face encountering relation

of a care giver and child (van Manen, 2002). Still, an ethical care of responsivity and responsibility may transcend the mere provision of nutritive support.

There are things that I notice and know about Amy because I sit with her all day, every day. I know what she reacts to and how she reacts to things. I know she needs to sit up when you are running the feed, that you can't rock her. And that sometimes when she is upset that you need to just hold her. When I have to leave, I find that I just can't leave because the nurses and the doctors do not see her as I do. To leave is to leave her alone in pain. There is nobody who really knows her, nobody to hold her like a mother can hold her. It is just that I get so tired and I need to sleep. So on days like yesterday, I stay as late as I can. But even then it never feels like long enough.

The mother sees and feels the child's pain with her motherly body. When the child struggles with tolerating the feeds or the feeding tube, it may be difficult for the parent to watch his or her child struggle against the feeding tube insertion: thrashing, retching or literally grabbing to pull out the tube. Once inserted and secured, the child may throw or spit up the tube along with any undigested fed residual contained in the stomach.

The mother sees and worries. Yet, we cannot so easily accuse this technology of disrupting parental sensitivity and sensibility. Obviously, the child is supported by the technology of the tube for its critical medical needs. The mother is interlaced with a techno-scientific world of seeing her child, of knowing her baby. Her maternal body seeks for a genuine contact with her baby's body. It should be possible to accommodate and harmonize these different needs. The tube need not introduce a disembodied relation, but rather could mediate a new form of a technically embodied relation, a relation where responsibility of contact may remain. As the feeding tube is woven into the relationship of parent, professional and child, the professional may need to heed the mother's reminder to also "Just look at her!"

We may wonder further if there is more to this new feeding tube orifice, as it opens the child to a technical way of feeding, and opens and broadens the nurturing relation to a host of others-nurses, physicians and dieticians-who may see the child differently than the parent. The tube can turn into an issue for quarrel as the healthcare professional oversees supplies, directs feeding, and gives the orders to increase or decrease the volume. Thus, the parental expertise of knowing the child maternally needs to be balanced with the medical expertise of knowing the child's physiological needs.

The brain image and the technical touch

The children of the NICU form a diverse population. Looking at each child with a medical eye, the healthcare professional may get a sense of the

reasons for admission. Some children are quite small, being born too early; others behave abnormally or appear ill, from incidents incurred before, during or after transition from the inner-womb to outer-world. A few appear obviously malformed, marked by physical stigmata of syndromes and the remaining who appear well are admitted for observation or for convalescence at the end of their hospital stay. At times though, external signs are insufficient. A technical image may be required to better perceive and understand a particular part of a child.

Brain images can be produced by ultrasound, CT or MRI. All of these technologies have their own technical advantages and disadvantages, providing various degrees of and differences in resolution. In common, they produce images to be read by the technological eye of the expert. But what does a parent see who is shown an MRI of his or her child demonstrating brain damage?

I am not an expert, a doctor or someone with medical training. But, I can see what is shown to me, and what it means. I could see what they were showing me in the MRI of his brain. One side did not look like the other. The details of the one side were gone, and it was obvious to me that the damage was severe. It was like half the brain was obliterated into a mess of blurry white and grey. They said it showed a combination of blood and damaged brain tissue. It was horrible. Devastating. How can a child mature and develop when such a huge portion of the brain is damaged? What kind of future can he have? Now my son no longer looks the same. My son looks different after I saw that picture. It is as if the whole future, the planning, the expectations, everything has changed. He has now become that picture.

Looking at the MRI image, the father is afforded a uniquely technical view of his son. But he sees more than the technical image. It is not an outside view in the sense of another look at the head (and face) of his child from yet another perspective. It is not an apperception proper. There is rather a hermeneutic quality to this view, showing an image that, while being of the child, it is not the child *as* his child. While the father may be unable to name cerebrum, thalamus, cerebellum or other structural elements of the brain, his technologized eye does see *parts* of the *whole* of his child: parts that are damaged to the point of obliteration. In these damaged parts he sees a future or more accurately perhaps he sees a broken future. As well, his child no longer looks the same. While the medical specialist sees with a (dia)gnostic eye, the father sees with a pathic eye.

The gnostic eye is different from the pathic eye. The pathic eye sees the body meaningfully: innocent and vulnerable, disfigured and hurt. When a father or mother just see their child at the bedside, they do not see a body transparent and opened by the medical imaging equipment. Rather they see a closed body. They see their child in recognition of his or her familiar features. They

see the marks, scars and other bodily traces as memories of pain and hopeful anticipations. The pathic eye sees caringly, lovingly or worryingly (van Manen, 1999). The technological eye is a purely gnostic eye, visualizing and seeing the child's brain in constructive radiographic resolution. It is the eye that sees the world in terms of diagnostic images and pictures, to be analyzed, examined, probed and questioned.

In seeing the brain image, the father's ordinary pathic vision of his child is disrupted. It would seem that the MRI favours the diagnostic and prognostic eye at the expense of the parental pathic eye. The technical intervenes and insinuates itself in place of the pathic as if it is filling an existential void. The eye is drawn to the abnormal, the parts or structures of injury and damage. In a sense, the child's childness has become invisible. The parent may ask: What part has been injured? What function was it responsible for? And what will be the consequence? The MRI may lead us to ask what is wrong with the child rather than what is right, as the parent is drawn into the medical considerations of diagnosis and prognosis.

Yet, while the MRI shows only a picture of parts, this is perhaps not only what the father sees. After all, *everything* has changed. The future has been put into question, perhaps in some related way to the presence of the naked face putting the spontaneity of the parent into hesitation. What child has been given as this image? What child is this? The imag-ined child or the child of the real?

The brain image becomes the picture of anticipation. The full meaning of the picture may remain in question-the exact future of the child remains imprecise and tentative-but there is no doubt that the father's child is changed by the MRI. The child is now marked by an aberration: imaged as damaged and imperfect. The image has revealed a truth of the child: his brain is damaged. In this way, the MRI technology has brought an aspect of the invisible visible child into presence.

It should be clear that the way the MRI reveals the child to the parent is different than the non-technical way a parent comes to know his or her child. The MRI does not allow the arising of something from out of itself as the child would naturally be given to parental experience over the course of time (*physis*). Rather, the MRI brings the child forth in the Heideggerian sense of a technical *poiesis* (Heidegger, 1977). It is a bringing-forth not of the child in his or her ownmost being, but rather an interrupting and challenging bringing-forth. It is a technological poiesis whereby the MRI challenges the natural *physis* of the child. In this sense, the child is perhaps revealed by the MRI to be the child of lost dreams, lost hopes and lost anticipations. How does the parent now gaze upon the child? And if the child can gaze back, how may their gazes meet and be sensed?

Without the MRI, a parent sees his or her child as he or she develops over time. The child's strengths and challenges may only be revealed and discovered gradually. In the absence of this technology, it is only in being with a child, in spending time with him or her that a parent may come to know that his or her child has injuries. This is perhaps even more so true for a child in the NICU who gives less of himself or herself to the world.

Consider the infant born early, not quite prepared to interact with others in the same manner as the full-term child. A premature child may provide only elusive cues and subtle responses to the caring onlooker. The preterm child may lack motor maturity, fluidity of movement, unable to suck and swallow. While the term child may calm to recognizable voices, the preterm child may be characterized by the stilled calmness of immaturity in sleep-wake and attention-interaction states, seemingly never quite able to become fully awake and open to those around.

Also, the care giver's response may be inappropriate or overlook what the immature baby may be sensitive to. The premature child may only sooth to the steady pressure of well-placed hands mimicking the containing uterus rather than the well-meaning sensitive stroking of the child's brow or hand. This relational difference may also be true of the sick or damaged child whose interaction is restricted for cause of illness, brain injury or even a consequence of the medical technologies needed to sustain the child: sedation, paralysis and so forth. In this context, as risks are naturally higher for adverse outcomes, the parent may look for technological information to *supplement* the common knowledge that comes with experience.

The MRI supplement is more than an addition of information. The supplement is the image and representation of nature that is neither in nor out of nature (Derrida, 1967/1976). Once seen, it is necessarily seen. The significance of the MRI supplement carries the meaning of the Latin *supplementum*, as something added to supply for a *deficiency*. This is radical in the sense that our view of the child without the MRI image is lacking and thus deficient. Without the MRI image our understanding of the child's being is not whole. In other words, prior to the MRI image, the child has been given to the parent as marked by a non-presence, an undetermined condition. This undetermined condition is the unknown of expectation, opportunity and future. Will the child excel in football or mathematics? Will she marry one day? Will he take after his father or his mother? Will she get a good education? The eidetic nature of the MRI is the provision of a supplement that supplies this deficiency. It transforms the expected of the child in the sense of it showing not just how the child is at this moment in time, but also giving the child in advance of the child: a sense of anticipation of the future to come. In this sense, the MRI gives the non-expected of the child to fill an un-expected expectation.

The role of the supplement is ambiguous. It provides an additional view of the child, but the question is how and to what extent this extra image of the child is helpful in contributing to the parent-child relation:

> It is the strange essence of the supplement not to have essentiality: it may always not have taken place. Moreover, literally, it has never taken place: it is never present, here and now. If it were, it would not be what it is, a supplement. Less than nothing and yet, to judge by its effects, much more than nothing. The supplement is neither a presence nor an absence. No ontology can think its operation (Derrida, 1967/1976, p. 314).

As presence (un) necessary supplement, there is an absolute *affectivity* and *alterity* to the MRI image as it *affects* and *alters* the father's relational experience to his child. In seeing the image of the child, the representation, who or what is it that the father sees? For in the moment of seeing the image, the father may not see the child he had known in the initial or imagined contact. Indeed, everything has changed, as the imaged child is now the anticipated imaged child. It is both the child present before him, but also the child he will come to know: to touch and be touched by. Perhaps in this way, the MRI may be contaminating of the originary perception of the child as a welcome *other*. The MRI gives the child technically.

Further reflections

It would seem that NICU technologies may have a bearing on a parent's experience of his or her child and that NICU technologies (as most technologies) are not merely usefully instrumental in their consequences: they carry *ethical* significance.

A distinction may be made between the ethical significance and the *moral* relevance of technologies. The moral relevance speaks to the way that technical devices open up (*effect*) new possibilities for human actions in the sociopolitical order of things. In medicine, we may consider the use of certain technologies as creating the possibilities for moral dilemmas. For example, the availability of the isolette and associated equipment
effects the opportunity to provide medical care to infants born extremely premature at the threshold of viability. And as a moral dilemma, the parent and professional must then weigh the implications of these technical innovations as the risk of morbidity (such as severe disability) may call into question the appropriateness of technological intervention.

This moral relevance of NICU technology is ultimately founded on what is ethically significant: the lived (technical) experience of the other. The way that these technologies may subtly shape the experience of the other may have ethical consequences as sensibility itself may be touched. In other

words, the techno-medical materiality may incur ethical morbidity by virtue of its significance in the being and becoming of the parent and the child. Thus, ethics as formative for morality speaks to the fact that these technologies *affect* our actions: rendering ethical relevance as morally relevant. In other words, how we experience the other (the affect) may meaningfully influence the way we act on the other (the effect). This technical sensibility, the substance of this paper, is complex.

While we may be unable to ask a child directly how his or her sensibilities are touched by NICU technologies, we may wonder about the existential consequences of these technologies for the newly born child. After all, newborns come into the world with a need for touch: a symbiotic sensibility between parent and child that is usually met in the skin-to-skin holding and nurturing of the child. It would even seem that the very young child does not yet distinguish between its own skin and the skin of the care giver. The mother's breast and skin is part of the symbiotic self-other. The psychology and anthropology of touch and bonding signifies the importance of the subtleties and complexities of contact. But the experience of holding, touching, gazing and mutual sensing may be hindered or helped by the NICU technology. The newborn in the isolette may lack the opportunity for this primordial contact that is critical in the shaping of the deeply human. The feeding tube may be medically necessary and yet obstruct the sensibilities of pleasure, desire and rhythm of the nurturing being of child and the mother. And the brain image may show the parent a child marked in such a way that prior, present and future sensibility is called into question by what has been revealed in the picture. Merleau-Ponty speaks about the interplay of touch and perception as humanizing crossovers.

> A human body is present when, between the see-er and the visible, between touching and touched, between one eye and the other, between hand and hand a kind of crossover occurs, when the spark of the sensing/sensible is lit, when the fire starts to burn that will not cease until some accident befalls the body, undoing what no accident would have sufficed to do (Merleau-Ponty, 1961/1993, p. 125).

I have tried to raise issues of the modalities and meanings of the crossing of touch and gazes in the technics of contact in the NICU. Stiegler has suggested that technics, the technologies that keep us warm and fed and comfortable, are the ancient humanizing forces in the history of humanity and the development of human communities (1994/1998). In the NICU, the ontology of technics is the medical expression of these old and modern anthropological technologies. We need to be cognizant how these technologies may put in question the humanizing meaning of contact between parent and child.

Of course, it should be clear that the highly technologized environment of the

NICU is not inherently problematic, as these technologies all have their important healing and lifesaving clinical uses. The incubator is critically important to provide an environment for supporting the child, just as the feeding tube may be necessary to provide nutrition for the child. As well, advances in medical imaging have allowed new understanding of illness and aid in delivering medical therapies. So, I do not mean to question the utility of neonatal medical technologies but to show the possibility for technologies to have more than their intended effects.

These explorations, therefore, aim to speak prudently to the formative value of phenomenology: not what phenomenology *tells* us, but rather what it does *with* us. As a reflective practitioner gains insight into the ways these technologies may leave traces on the parent-child relation, hopefully, this same practitioner will become more thoughtful and tactful in his or her dealings with those pathic dimensions of clinical practice (van Manen, 1999, 2007). After all, in the context of the NICU these technologies have the potential to open a way of being in which the professional may contribute to the sensitive, developing relation of a parent and child.

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5. Ethical responsivity and pediatric parental pedagogy[1]

Introduction

When we speak of ethics in medicine, we tend to think of the moral correctness of certain actions and decisions. We may question if starting or stopping a particular intervention is right or wrong. And at times, we may even wonder whether providing any medical treatment is appropriate. In neonatal care, the focal concern of bio-ethical deliberations for the medical staff is usually the newborn child. And it is the parent who carries substitutive responsibility in medical moral decision-making. This responsibility is in part a *jurisprudential* matter, written into the professional moral code of the medical practitioner and the administrative institution within which health professionals operate.

From a parental point of view, ethical responsibility for the child is not necessarily due to a formal code of ethics. Parental responsibility arises in the encounter of the mother or father with the newborn. What does it mean for a parent to experience ethical responsibility for his or her child? And how is this responsibility phenomenologically associated with responsivity to the newborn? In other words, what is the existential source from which ethical parental pedagogical responsivity originates? This would seem to be a primary concern that lies at the heart of neonatal practice.

To develop an understanding of parental responsivity to the newborn in the context of neonatal-perinatal care, we need to be attentive to the empirical variety of experiential encounters that may occur in this medical setting. Consider an account of a father's responsivity to the initial encounter with his newborn:

The moment he was born they rushed him off to the corner of the room. He was ashen. I watched as they put the breathing tube in, pushed on his chest to try to get his heart going, and finally had to resort to putting an intravenous line into his abdomen. I never heard him cry yet I felt sick in watching. When I was able to get in there, to stand beside his bedside, to look at him, I just wanted them to stop. If there had been a spirit of life in that body, surely it was gone now. He looked bruised and mottled. And his skin felt cold. Although they wanted to transfer him to another hospital for more treatment, I could not help but hope that his body would just die. I could not stand to look at his face. He was so

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damaged.

We may feel that we understand the pain and hurt expressed by the father in response to the encounter with his newborn child. But our understanding has to probe deeper. It has to gain a measure of the experiential substrate where ethical responses acquire their meaning. In the words of the father, we sense that beyond the pain stir emotions and responsivities that are preverbal, almost impossible to put into language. We see how the father already expresses an ethical response in his hope that his son's "body would just die." But is it correct to say this? For us to say, "his son's body" already presumes a possible mis-interpretation of the father's felt responsivity. Did the father already experience the newborn as his son? Or is even this assumption possible in such a moment of chaotic mental distress?

The child before birth: Abstruse responsivity

Before the child is born, and perhaps even before the discovery of being pregnant, there already have been born certain expectations: the bodily changes of pregnancy, the coming of the child, and the becoming of the parent. Yet to say that a parent "expects" may occlude an ambiguity that inheres in the relation of expectant parent with unborn child.

To be pregnant is to bear a growing child within—a relation of constant touch and bodily responsiveness that marks an existential entangling of mother and child. In this sense pregnancy is a way of being. Still, although the child is continually present in the woman's expanding body, the child may not be constantly felt as (an)other to the mother. Instead, it is with sudden jabs and shifting pressures that a woman may be reminded that a being is inside. As for the father (or partner), the child may be seen outwardly through the changes in body size and shape of the becoming mother. A well-placed sensitive hand may feel for the unborn child. The hand experiences a double touching: waiting to be touched by the child from within and touching the child in response. It is as if the child exists in an in-appropriable "other" world, a womb world. And in these phenomenally different situations for mother or father, we may wonder about the experiential equivalents of the subtle signs by which the child is given in expectation.

Although I am now 5 months into my pregnancy, the realization that we are having a child is still surreal. We found out that it is a girl and have already chosen a name. And although I use that name to name her when she is kicking, waking me up in the middle of the night, I still wonder if that name is going to fit.

There is an otherness to the child that remains difficult to name and is experienced beyond expectation. Etymologically, the word expect derives

from the confluence of *ex-* as "thoroughly" and *spectare,* "to look." To expect is to regard someone (or something) as likely to fulfill an established view or match with a known image. The act of naming brings the child into being, but the named child may not be the child to be seen. Prior to delivery, the child is not "seen" in the conventional sense.

When we saw the first ultrasound image we needed help to tell what we were looking at. On the screen, the ultrasound technician pointed out the arms and legs. She was able to get a good profile of the head so we could make out the nose, chin, and mouth. The heart was easy to see as well because of its motion. Those were the parts I remember seeing. The technician could not tell the gender on the scan so it was unclear if it was a boy or girl. Still, we felt relieved to know that everything looked okay and that we could anticipate a healthy child.

The child will hopefully be okay as the scan is reassuring. Still there are aspects of anticipating that remain unexpected. It is not just that the ultrasound lacks a degree of resolution. Rather, the medical technology is unable to fully show the child in its being. Something escapes presentation in the anticipation.

It was from the fetal echocardiogram, the heart ultrasound, that they figured out the problem with the heart. We met with the doctor after the scan and talked about what it meant and what could be done. It seemed like something fixable. Still, the doctor said it was early enough on in the pregnancy that we could chose to terminate. It was my choice whether I wanted to have a child who required heart surgeries and potentially so much other medical care. I remember going home that evening, and laying in bed with my hands on my belly. I tried to feel her. She was in there but felt distant. I really wanted to have a child, but I was not sure about this.

When advanced technology is introduced into the relation of parent with the unborn child, things start to change. It is as if the visibility afforded by ultrasound, the abnormal heart, has dissipated something "other" that the mother can only feel for. So as the mother lies in bed feeling for her child, technology has already touched her pregnant being. The child who remains "in there" becomes "distant." We may wonder if the fetal imaging technology does justice to the (in)visibility of the child?

The newborn child: Encountering (an)other responsivity

With time, the child is born. For the baby requiring medical care, it is not simply the child and the parent who are admitted to the neonatal intensive care unit. An abundance of medical technologies are also introduced: some highly sophisticated and others seemingly ordinary. The parent may see the

child buried beneath, behind, or within this equipment. Consider a mother's experience.

For some reason I was still expecting to see my child swaddled in a blanket or lying tucked into the so-called fetal position. I was expecting her to lie there peacefully even if she was small or sick. But when they brought me to her, it was hard to see her. I had to look in at her from the incubator portholes. There were wires and tubes obstructing the view of her skin and hands. I was looking for something human in there. I was looking for her face.

The parent enters an unexpected place where materiality obstructs the parent's first touching encounter with the child. And in the absent visibility of the child's face, the parent is touched by the tangle of technology.

Other times the face is apparent,

The first time I saw and held my child I felt taken aback. It was so much more than I expected. Here was this little child who appeared almost like a little stranger. And yet, he was also instantly recognizable. I just stared at him. I looked at his fingers, his hands, his hair, his eyes, all of his little features, all for the first time. I was overwhelmed by the so many things I wanted to see. Still, the more I looked, the more I found my gaze constantly returning to his face. It was not that he was looking at me, but I could tell that he felt me. Looking at his expression, he seemed to settle into my arms. He was my son. I was holding him in my gaze and he was holding me, and I did not want to let him go.

The experience of the newborn child may be like an aporia—familiar yet strange, recognizable yet new—more than the meeting of sense and sensibility. Language falls short to describe the encounter with the newborn's face, the appeal, the expression. And from this encounter, the responsivity of the parent is called into question as the father finds himself "taken aback" yet also held by an otherness beyond expectation. Emmanuel Levinas writes of the fecundity of the father-child relation:

> I do not have my child; I am my child. Paternity is a relation with a stranger who while being Other…*is* me, a relation of the I with a self which yet is not me. (Levinas 1961/1969, p. 277)

It is as if paternity introduces a sense of otherness already within the parent. This otherness is not just strangeness but rather an evoking appeal belonging to the enigma of the child's being, an otherness that cannot be reduced to "me," the self of the parent. In the words of Levinas (1961/1969), the self of the "I is not swept away, since the son is not me; and yet I *am* my son" (p. 277). And as the child is not "me," yet is of the parent, the child is also the future, the infinite, the transcendent: "the fecundity of the I is its very transcendence" (p. 277).

It would perhaps be a mistake to limit paternity or maternity to genetic factuality. A mother responds to the crying call of her newly adopted child.

I could not look at her as if she was just someone else's child. Although she was not from my womb, although she was not of me, I saw her and she saw me. She looked right at me. I could not placate myself that this was someone else's child and therefore that I could shed my duty to pick her up, to respond to her crying. I felt her. In hearing her cry, I was already responding. Perhaps, I did not have to pick her up. But, I did have to hear her cry. I could not leave her bedside even if I could not touch her.

Here, responsibility arises not from the (in)ability to sooth the child; but rather from the child's demand on the mother. It is the experience of encountering the crying face of her newborn.

What the mother responds to is not just the countenance of the child. The child's look and cry become a raw experience of proximity. She sees the child with a "listening eye" (Levinas, 1974/1981, p. 38). And it is as if the sound of the child's cry "overflows so that form can no longer contain its content" (Levinas, 1949/1989, p. 147). A single sensory faculty seems insufficient to perceive the fullness of the call. It would be incorrect to take ethical responsivity superficially in the physiognomy of the child's physical features or in the shrill timbre of the child's actual vocalizations. As Jean-Luc Marion (2000) says, "To receive the face implies not so much to see it as to undergo the impact or feel the shock of its arrival" (p. 226). This is the ethical moment as evoked by the parental encounter with what appears, yet remains absent, from the visibility of the newborn-child face.

In skin-to-skin togetherness: Sensual responsivity

In the beginning, the techno-medical environment and the condition of the child may be overwhelming.

It is really nice being able to finally hold her against my skin. To lay my hands on her back and feel her breath rather than look at her through the incubator. Still, it is terrifying. I am constantly waiting, holding my breath, for an alarm to ring, or something to go wrong. It is hard knowing what to do, and whether I am doing the right things. I have been expecting her, expecting being a mother, but I just don't feel prepared for any of this. I don't know how to hold my child even though I know I need to hold her.

The ethical demand may flood sensibility, exceeding parental capacity, leaving responsivity tentative. It is not simply the techno-medical sophistication; it is "my" (in)ability to hold "my child." But with time and

support, self and other may gradually seem to fuse.

Kangaroo care, holding him skin-to-skin, is our time. It's so settling to feel his warm skin against mine. I get him nestled in, on my chest, and just lay my hands over him. His breathing steadies. He holds a breath, I hold a breath. I find myself sighing without even meaning to just as he exhales. It's like my body senses his and harmonizes with his. I do not normally even give it any thought. We just are together sensing each other's hearts beat. Sometimes I will read a book with my free hand. Other times, a friend will be there and we talk quietly. I don't really need to concentrate on him; I am feeling him as he is feeling me. To have him close—it just feels so good, so calm. Sometimes we just need to lie there together, and let the day pass by.

Despite the environment of the newborn medical nursery, the mother is able to just be with her son in almost (in)voluntary automaticity. It is as if all of the wires and tubes, the pumps and monitors, the nurses and doctors, fade into the background. The mother touches her child just as she is touched by him in a perceptual crossing of bodily presences. They lie attached in touch. They breathe in touch. They are touched by each other's touch. And from this attached being of touching and being touched emerges the pedagogical being of mother with child. It is a sensitive being whereby the boundaries of self and other are blurred. The interplay between touching and being touched reflects an elusive exchange of sense and sensibility. We may recognize this reflexive sensitivity of the touch in our own hands:

> When I touch my right hand with my left, my right hand, as an object, has the strange property of being able to feel too.... it is not a matter of two sensations felt together as one perceives two objects placed side by side, but of an ambiguous set-up in which both hands can alternate the roles of "touching" and being "touched." (Merleau-Ponty, 1945/1962, p. 93)

While there is an experiential difference between the mother reaching to touch her child and that same motherly hand being touched by her child, the hand is ambiguously capable of both gestures. It is as if there is an indistinct identity within difference as parent and child are neither completely coincident nor disjunct. Instead, we have a boundary of touch alit with affectivity. The mother need not constantly look at her child, nor reflect on his well-being. Rather, she is in contact with him: engaged in activity through the passing of the day.

Both parent and child may be seen as born with this primordial sensibility. And the parent retains this infantile responsivity to a world of others even after having developed an individuated sense of self. This is a human capacity that we may easily pass over as being with others is basic to our very being as human beings (Heidegger, 1946/1998). So much so that in everyday

activities, for the most part, we may spend time with others, work with others, talk with others, and so forth without pausing to have any reflective beliefs about them or their beliefs of us. In newborn medical care, we may witness this being together when we observe activities as gestures—breast feeding, diaper changing, kangaroo care—performed so routinely that a parent does not struggle and does not pause. But just because these activities may be performed without explicit effort and reflection does not mean that a parent is not deeply affected in a touching attachment with his or her child. Still, we may wonder, what does it mean to be with (an)other in ethical responsivity?

He is a different child since the surgery. He does not have to spend all of his energy working so hard to breath. His life is more than growing, more than waiting, more than being sick. Now when I hold him and if he becomes unsettled, I do not just find myself trying to settle him. I find myself wondering, "What do you want? And what do you need?"

Ontologically, for the mother to be in touch in ethical responsivity is not to grasp the totality of the otherness of her child. It is not to understand his every want and unmet need. Touch instead speaks to the touch of touch: to be with (an)other in a feeling way (Buytendijk, 1970). And the capacity for touch allows the mother to be touched by the otherness of her child. Her way of being with him is an affective contact whereby otherness is felt rather than appropriated. To put it in another way, the otherness of the child touches yet transcends the mother's touch. This touch provides the origin of the pedagogical moral response: "what ought I to do for you?"

Although the technological may fade into the background, it is still situated in the relation of parent and child. So much so, the parental and child being may become intimately interwoven with the techno-medical devices. We do not need to look to extraordinary technologies as examples. Even routine and everyday technical tools touch the relation of parent and child.

When you get used to it, you forget about the technology. I held her this morning. It took three people to place her on me. The respiratory therapist held her tube, and her nurses took care of the wires and intravenous lines. I just held her then for a couple hours. As the monitor rang for a desaturation, and her breathing paused, I rubbed her back. The trace returned to baseline and her breathing steadied. She comes up so well. Without even looking, I hear her come up. I can feel against my chest when she needs a suction. It is a wet, vibratory feeling, then the machine rings "tube obstruction" until we suction her out. I don't really look at the monitor more than I look at her face, her body, or any of the other medical instruments. But I constantly know how the monitor reads. I am always listening for the monitor. I am always listening for her.

The opaque presence of the technology dissipates to reveal a technical

touching attachment of parent and child. The Merleau-Pontean "flesh" is the generative of what makes possible the intertwining of the sensate and the sensible: "an anonymity innate to myself" (Merleau-Ponty, 1964/1968, p. 133). While not being (solely) material, the flesh arises coincident and constitutive of intercorporeity. In the newborn intensive care unit, the technological may become the "flesh" experientially offering parent and child an (in)tangible connection. The parent's experiencing of her child is not only biologic but also technical in the mechanical reverberations of the respiratory circuit and the synthetic sounds of the monitor screen. We may wonder what the parent responds to? The biologic? The technical? Or a blending of both? Surely the way that these technologies may subtly shape the experience of self and other may have ethical consequences as sensibility itself is touched.

Some space between us: (Re)encountering transcendent responsivity

From being in touch with the child, the parent is responsive. Yet while their bodies are together in contact, we may wonder if (an)other meaning pervades this primordial affectivity?

Consider the mother nursing her child. In response to the mother's initiating touch, the child mouths the air searching for the breast. And when the areola is found, and a latching is achieved, child and mother are literally connected in physical contact. Still, even if this phenomenon is representative of an instinctive "rooting" reflexive touch, it is not just the mouth closing on the breast that founds attachment. Jean-Luc Nancy reminds us of what is transcendent to touch: "mouth slightly open, detaching itself from the breast, in a first smile, a first funny face, the future of which is thinking" (Derrida, 2000/2005, p. 21).

Perhaps ethical responsivity needs a mouth that opens to smile, or, less romantically, a mouth that opens to cry, to disturb the natural nesting of nursing. For Heidegger (1927/1962), it is only in special situations that the primordial mode of being with others may become interrupted, leading to instances of pause, reflection, and deliberation. And during these disturbances, a parent may see his or her child as occurrent, objectively present, looking back at the parent with his or her face in stark relief. This is the face of otherness.

Yesterday was the first day that she opened her eyes and I actually got to see it for myself. Before then, her eyes had been still fused from prematurity. It happened when we were bugging her. We were taking off all of the monitoring stickers and changing her diaper. We were going through the motions like so many times before. Even though it has only been a few weeks, my hands have

gotten so used to the routine. I found my fingers moving to slide the diaper beneath just as her nurse lifted up her legs from the other side of the isolette. And then it happened, she was looking at me. Her look became a statement, "Here I am." And at the same time I felt it as a question, "Does this need to be done now?" I was taken aback. To see her, and to see her respond to my touch, I felt it well up the inside of me.

These are occasions when a parent, in being touched by the look of her child, is attached in a contacting recognition. The parent is drawn to withdraw yet also to draw nearer: to know the child and to see the child as in-appropriable "mine." This is the pedagogical ethical space between self and other that itself needs space. For the family in the neonatal intensive care unit, we ought to wonder how a parent finds such a space when just being with the child can be technically so difficult.

The changed child: Other than responsivity

As time advances in the medical nursery, the child changes. But change is not always good.

I came back to see him the night he had his brain bleed and he looked different. He seemed to just stare vacantly forward. In many ways he looked better than the day before. He was less puffy from excess fluid. His heart rate and blood pressure were reading better on the monitor. Certainly, he was on fewer medications. His color was even better than before, although they said it was from the blood transfusion. But he was different. He did not respond like my Jacob. He just lay there when I touched him. Something was very wrong with him. I questioned, "Can he hear me?" I asked, "Does he know who I am—that I am here?" I really did not hear the nurse's attempt to appease me. Jacob did not look like my child.

For the parent, identity surpasses appearance, as Jacob looks better but does not look like "my child" of expectation. He has become unfamiliar, strange, and alien. And in this moment it is as if the strands of attachment are stretched to breaking. The child no longer reaches back responsively. The touch is not the same.

Sometimes, the strength of the appeal may propel the parent nearly away.

I could tell something was wrong after he was born. It was like the nurses and doctors did not want me to see him. They were gathered around, talking about him, and as I walked towards them, it felt like they were holding him back from me. When I saw his face, I understood: he was malformed. I stepped back. I did not want to hold him. Even in seeing him, I felt uncomfortable and uneasy, as if I needed to shake something off my skin. I could not help but look at him but I

also just wanted them to take him away. To put him somewhere where I did not have to see his face. Looking at that face, I just felt like he should not be there. I felt like someone else's child had been placed here in place of my child.

Responsibility may be experienced as pain, too much for a parent to bear. In this account, the father's reaction is visceral, as he has already been touched by what he does not want to touch. It is a child from him yet also so different from him: a face that he can neither look at nor look away from. Perhaps for some parents, in an environment of technology and illness, what is other may be too other. And so we may worry about the child who remains untouched and has no one to touch.

Attachment: My responsivity

Distance may afford an understanding of the potential closeness of parent and child.

Sometimes I need to go home. I need a break from the hospital, and everything there. But it is also hard being at home. When I am home alone, I feel uncomfortable. The house becomes too quiet. The lights are too bright. And there is too much space around me. It's kind of like walking into an empty house. No matter how much noise you make, the house stays empty. It is as if my ears are straining to hear him. As I think about my son back in the hospital, I start to leak. I smell of milk. Then, I know where I should be.

The parent is with(out) her child as the leakage of milk provides an existential reminder of the absent presence of her son. And the home loses its phenomenal meaning of familiarity. After all, how can the parent feel at home when her child must dwell in another place? As we consider this prereflective intimacy, we may reflect on the phrase: "The soul is the other in me" (Levinas, 1974/1981, p. 191).

For Levinas, the "soul" is not some spiritual entity. Instead, the soul is the ethical event (the responsivity) of the "other" evoking concern and, therefore, formative of "me." The parental recognition is a moral event as the mother, in thinking of her son, recognizes where she *ought* to be. This does not mean that the mother needs to return to the hospital to respond to the ethical call. Rather, it means that the parental response has already happened prior to and regardless of her (in)action—she is existentially open to her newborn, with the capacity for such wonders as attachment, love, and pain.

This openness to the newborn other is given in asymmetry: "I approach the infinite insofar as I forget myself for [the other] who looks at me" (Levinas, 1996, p. 76). Before contemplation and deliberation, there is an experiencing of the needful necessity of the child. The parent is touched by the ethical

demand of the child, prior to asking for something in return, feeling this otherness, the child's need, from within. And the mother, as giver of milk, is the child's bodily need. Such is the origin of attachment as *estachier*, to support in need.

Yet what is problematic for the hospitalized family is that the child may need more than his or her parent can provide. After all, in newborn intensive care, the child needs some degree of medical care. Often, even the child's nutrition is provided via intravenous or silastic feeding tube. And the hospital staff regularly does the routine care of changing diapers and mixing feeds. This medical "mothering" of need may render fecundity ambiguous.

It feels like there are so few things I can do for Tysen. I come in everyday and sit beside his isolette waiting for something I can do. I watch the nurses do their assessments. I listen to the discussions on rounds. And I busy myself rearranging the cards on his shelf. Every so often I can help a nurse with his diaper changes or participate in some other care. It feels good to get in there, but even then, I still find without them, without the nurses, I can't take care of my own child. It's like although I gave birth to him, he is still not mine. And if he is not mine, who is his mother?

We need to consider how attachment develops when opportunities for a parent to touch and be touched by his or her child are presented in a medical manner, mediated by a medical other. And how can we tactfully support those parents who must proceed to repeatedly leave their newborn children day-after-day in a hospital nursery when they already feel distant. Perhaps many of these children are not only born premature, but also are prematurely separated from their parents for days, weeks, or months. There may well be latent existential complications to such divisions for the parent and for the child.

Concluding comments

The parental experience of ethical responsivity, and the formation of touching attachment, is saturated with complex meanings. Hopefully, as we gain insight into this phenomenon, we can better understand the necessity of nurturing moments of togetherness between parent and child, especially when medical care is required. Neonatal medical care—or the birth of a premature, ill, or malformed child—has the capacity of complicating the touching contact of parent and child.

Only a few aspects concerning ethical responsivity have been introduced, and they deserve further thoughtful reflection. Additional experiences should be explored. Particularly, gaining insight into such situations whereby parents are untouched and unattached to their children is crucial for health

professionals who find themselves caring for such families. Perhaps even more troubling are those moments when parents find themselves opposed or even repelled by their children as may happen when a child is born visibly malformed. Alternatively, we could consider the unplanned or unwanted healthy child. Certainly the child born to the parent who is troubled by depression, anxiety, or some other mental affliction also deserves attentive reflection.

The profundity of parental ethical responsivity speaks to the significant position parents play in making decisions for their children. Still, if we understand that the experience of ethical responsivity shifts, changes, and develops in the becoming of the parent-child relation, we may wonder about the relevance of this metamorphosis. Is the decision a parent makes for an unborn child ethically different from a decision made for a newly born child? How is it that some situations may ease or complicate a decision? Does the phenomenality, the givenness of the child, matter in considering the morality of a decision? These questions surely deserve consideration. As the lived meaning of the ethics of parent and child finds its birth in a technical place, such as a newborn medical nursery, we may have to consider the existential consequences of a technical life. After all, it is from this techno-medical place that the parent and the child must grow.

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6. Carrying: Parental experience of hospital transfer[1]

Newborn infants who are born prematurely or who become ill after birth are admitted to a neonatal intensive care unit (NICU) for ongoing care. Care occurs across a spectrum of need depending on severity of illness from least intensive (Level I), to intermediate (Level II), to most intensive (Level III) neonatal units. Some procedures in neonatal health care are so routine and innocuous that they are scarcely granted much thought. The transfer of infants between hospital environments is one such common and daily practice. Limited numbers of beds and other rationed resources may necessitate transfer for appropriate allocation of care. Hospitals specialize in particular services such that a transfer may be necessary for consultation or surgery. Sometimes, transfer may allow infants to be closer to their families' homes, facilitating contact between parents and their children. As such, transfer may be part of a transitional change "on the way home" to a regional hospital, or it may be that the infant with ongoing long-term needs has "outgrown" the nursery. A transfer may involve a major move between geographically distanced hospitals, or a minor move, just down the hallway to a new unit. Distant or neighboring units may differ dramatically in acuity and care culture such that distance alone is only one feature in the manifold of experiences. In the end, it is common for premature or sick babies to spend weeks to months in various hospital units, with multiple transfers marking their journey along the way, before they are finally able to go home.

In the literature of pediatric care, the qualitative parental experience of having a child placed within the nursery has been explored from maternal and paternal perspectives, employing a plethora of qualitative methodologies including narrative, ethnography, grounded theory, phenomenology, qualitative description, and metasynthesis. The few publications that mention or address the specific experience of transfer have recognized that many parents find the transfer as a whole stressful, even when it is a sign of improvement in their child's health (Kolotylo, Parker, & Chapman, 1991; Kuhnly & Freston, 1993; Meyer, Mahan, & Schreiner, 1982; Page & Lunyk-Child, 1995). Even when transfer occurs between close spaces, to a next-door room, changes in personal space, the tone in the room, and the transfer itself may carry significant meaning to parents (Hall & Brinchmann, 2009). In general, insights from this literature tend to be curtailed by the summative nature of the studies, reducing the potential depth, richness, meaningfulness,

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and complexities of the portrayals of the parental experiences. It would seem that the exploration of the meaning structures of transitional subjective experiences themselves, such as hospital transfer, are well addressed by phenomenological studies as the particular and universal are held in tension (Briscoe & Woodgate, 2010; van Manen, 1990). Yet, specific phenomenological studies of the parental experiences of infant transfer in a system of highly regionalized and geographically distanced neonatal care do not appear in the literature.

Methodology

The aim of this study was to explore the phenomenon of hospital transfer from the perspectival experience of parents caring for their hospitalized child. In particular, the focus was on parents of premature or sick infants requiring hospitalization from the time of birth in a NICU. To maintain an open attitude to the subjective experiences of parents, the phenomenon of hospital transfer was taken broadly as a felt change in place either within or between hospitals. To explore this topic, a context-sensitive form of interpretive inquiry, a phenomenology of practice, was employed (van Manen, 1990, 2007).

As a human science research methodology, phenomenology of practice represents a blending of hermeneutic phenomenology with qualitative empirical methods. In hermeneutic phenomenology, the author aims to describe and interpret the lived world as experienced in everyday situations and relations. The concern is with the immediacy of human experience prior to meditative or theoretical reflection. The purpose of phenomenological inquiry is not to develop theory (in the strong sense of the term). Rather, the aim is to produce qualitative portrayals by means of a dynamic blending of interrelated heuristic activities involving explorative questioning of a particular phenomenon or event—in this case the parental experience of their infant's transfer.

A central feature of this phenomenology of practice is a reliance on qualitative empirical methods to gather a field of descriptive evidence, lived experience descriptions, from which underlying patterns and structures of meaning may be drawn. This gathering should not be seen as an isolated research practice; rather, gathering should be seen as woven into the explorative questioning of a particular phenomenon of interest. In this way, phenomenology of practice is a nonlinear form of research, as "data collection" (gathering) and "analyses" (reflective questioning) are performed concurrently. Phenomenological methodology is well suited to serve practitioners who, in their day-to-day practice, may be unaware of or insensitive to the depths and subtleties of other people's experiences as lived.

As a physician working in multiple neonatal intensive care units, I am continually confronted with the task of patient transfer. However, I tend to be removed from the pain, joy, grief, and relief experienced by parents. Therefore, in an effort to gain a more intimate understanding of the experience of transfer, parents were recruited for interview from four local hospital nurseries in a western province of Canada spanning the scope of acuity seen in neonatal intensive care (Levels I, II, and III). These interviews facilitated exploration of a particular, intimate field of descriptive evidence, as the entire research study was carried out alongside my ongoing conventional clinical practice in neonatal intensive care.

In total, I conducted in-depth interviews with 12 parents, 8 mothers and 4 fathers, who had their child transferred in and between hospital environments. I want to be clear that I am not using terms such as sample or sampling procedure . The goal of phenomenological research is neither to sample nor generalize to a population. Rather, the aim is simply to reveal, open, and explore a possible human experience. As Merleau-Ponty (1945/1962) said, the objective of phenomenological description is "to bring back all the living relationships of experience, as the fisherman's net draws up from the depths of the ocean quivering fish and seaweed" (p. xvii). Respectfully, therefore, I provide only general background information to help to contextualize the findings of the study. I hope that by refraining from giving detailed demographic or ethnographic data (means, ranges, and so forth), I will avoid confusing the reader of the nature of phenomenological inquiry. As described elsewhere, sampling criteria (size, cross section, demographical information) are examples of empirical research criteria and should not be confused with phenomenological research method (Norlyk & Harder, 2010).

To be eligible for this study, a parent's child had to receive at least one interhospital transfer (between physically distinct hospitals). Although some of the families experienced numerous interhospital transfers, all experienced multiple intrahospital transfers (within hospital yet between care teams, units, and so forth). Some of the babies were admitted primarily for observation and monitoring, others for high levels of support including mechanical ventilation, cardiovascular medications, intravenous nutrition, and neonatal surgeries. Admitting diagnoses varied greatly, including yet not limited to those related to prematurity, congenital anomalies, and transitional problems. Parents ranged in age, ethnicity, education, and socioeconomic background. Most families had never been in the NICU prior to the admission of their child. Some had never even been to a tertiary center, as their children were referred from remote or rural outlying areas. Interviews took place after transfer, and were conducted for the purpose of exploring and gathering experiential material, stories, and anecdotes that speak to the phenomenon of transfer. Parents were interviewed one to three times for 30 to 90 minutes at a location of their choice. All interviews were

audio-recorded, transcribed, and reviewed to ensure clarity of transcription. Parents described multiple hospital transfers that provided a wide breadth and a vast range of subtle varieties of experiences.

In keeping with this phenomenology of practice, reflective methods (including thematic, guided existential, linguistic, and exegetical reflection) were used to identify and reflect on variant and invariant meaning aspects of the transfer experience (van Manen, 1990, 2007). The eidos and eidetic themes refer to the unique, or the more invariant patterns of meaning of the experience of transfer. Phenomenological evidence is always tentative and always subject to yet another phenomenological exploration. Wholistic and line-by-line readings of transcripts were employed for thematic exploration of lived experience descriptions. Through guided existential reflection, fundamental lifeworld themes were used as heuristic guides for reflecting on the parental transfer experiences: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). Linguistic reflection involved attentiveness to conceptual and etymological aspects of the etymology of transfer, and exegetical reflection involved the study of related and sometimes seemingly unrelated literary and phenomenological texts in search for new insights and perspectives.

Anecdotes were drawn from the interviews to assist the reader of the research to access the subjectivity of the experience of transfer. Anecdotes were constructed from the interview material by deleting extraneous, redundant, and identifying material to strengthen transcript stories into the direction of the phenomenon and its themes. Names of interviewed parents were replaced with pseudonyms. The anecdotes were crafted to attend to the subjective rather than objective aspects of experience. As such, no effort was made to verify whether a parent's account of an event was in keeping with the way things actually happened. In this way, although the anecdotes do not make claims to ethnographic or empirical validity, they aim to evoke iconic validity to arrive at plausible descriptions of possible human experiences. Follow-up interviews were held with parents when possible to revisit their experiences and explore certain meanings and significances of their experiential descriptions.

The process of writing of this text was also a key part of the research that involved finding language sensitive to the phenomenon—yet allowing the phenomenon to speak for itself, as it were. This textual process required continual writing and rewriting. Drafts of the text and presentations of narratives were reviewed with diverse groups of health care members (physicians, nurses, respiratory therapists, dieticians, social workers, and parents of children who had been cared for in the NICU) to ensure the phenomenological descriptions and anecdotes resonate with lived life, triggering instants of recognition and evoking immanent (subjectively felt) phenomenological evidence.

Situating within the phenomenological tradition

The focus on lived experience is an application of the phenomenological concept of perception. Merleau-Ponty has shown that perception is not merely an event or state in the mind, sensory organs, or brain, but a function of a person's entire bodily relation to his or her environment (1945/1962). Prior even to having a perspective that we can call our own, we are already interlaced with the world—a world of sense and sensibility, touch and tangibility, seeing and being seen. It is through an understanding of this embodied being-in-the-world that ordinary and everyday perception takes place at a primary, corporeal, and prereflective level. For example, researchers such as Simms and van den Berg have shown how the child's developing corporeal being is closely entwined with the corporeality of the world (Simms, 2008; van den Berg, 1961/1983). The child's perception of the world in its fullest, most complex, and most subtle sense is the fact of its preconscious or prereflective act of existence. But this is also true of adults who are cognitively able to reflect and think about the way that we normally experience our world prereflectively.

A starting point of this study is that the neonatal setting provides a unique challenge to researchers who are interested in seeking out the implications and promises of the phenomenological literature on perception and embodiment. We need to attend to the question of how the infant's preconscious perceptual systems (hearing, sensing, smelling, and feeling) are subtly but complexly integrated into the physical environment in which the child is placed. Yet, at the same time, we need to gain a more differentiated understanding of how, at this prereflective level, the parents perceive their infant's situatedness and subjectiveness to the care and handling of medical personnel. For the purpose of this study, the neonatal unit is considered the center where the infant's perception of his or her world and the parents' perceptions of their relations to the child's embodied existence—as well as to the parents' own responsiveness and situatedness in this shared world—may be studied.

Ethical issues

Permission to conduct this study was obtained from the university health ethics review board and appropriate health authorities. Strategies to diminish the possibility of participant identification included careful selection of anecdotal examples and alteration of specific information that might increase the likelihood of identification. To avoid conflict of interest between my roles as researcher and clinician, I neither enrolled nor interviewed families at a time when I was involved in their care. Other strategies were utilized to avoid coercion, such as limiting recruitment

strategies to poster presentation and word of mouth. Furthermore, participating families had to initiate contact with the researcher. No incentives were offered for participation.

Findings

The inquiry into the phenomenon of transfer yielded thematic events around which the research text has been constructed and composed: carrying across, carrying between, carrying contact, carrying caringly, and carrying home. Each of these thematic events of the eidetic or unique meaning of transfer is presented from the perspectives of the parental experience of self, the parental experience of their child as other, and the parental experience of health care people as other other. In reading this phenomenological text, the reader may ask questions such as: What is a parental experience of their infant's transfer like? What modalities of carrying the child speak to the singular meaning (eidos) of transfer? How may the transfer of an infant be experienced by the parents in terms of various modalities of carrying? Are the themes of transfer properly captured by the following eventful descriptions: (a) how transfer is a carrying across from here to there and with or without parental presence; (b) how transfer is a carrying between changing places; (c) how transfer is a carrying contact of parent–child intouchness that is enabled or compromised in this experience; (d) how transfer is a carrying with care; and (e) how transfer is experienced as a search for place as home?

Transfer as a carrying across

The experience of transfer is already alluded to in the etymology of the term transfer . Hospital transfer is a carrying across of the child from one place to another. The very word transfer means to bear, bring, carry (ferre); from one place to another, across (trans). A shared eidos of crossing emerges from reflection on the various stories of carrying by way of bassinette, ambulance, or airplane between places such as holding arms, incubator, or hospital unit. As researcher I could not help but be reminded of the ancient image of the mythical ferryman, Charon, who carried the traveler across treacherous waters to the safety of the shore opposite or carried the soul across to Hades.

A mother recalled trying to find her way across, to, and from the intensive care nursery in the first days:

I remember walking down endless corridors and stopping at a chair, just sitting down crying, you know. Because I am just so overwhelmed with emotions, fear, terror, all that stuff about my child. Where did they take her? I can't remember, because I go up so many flights of stairs, and I turn so many corners. I gave birth to this child but I cannot find my way to her.

For the parent, who has to make his or her own way during the transfer, the crossing is not just a traversing of space to be reunited with their child. It is a crossing to an unknown different shore. The parent may be drawn into a searching path starting from a place of loss, the lost anticipations of the expected "normal" birth. And, it is also the crossing of the emotional space and existential abyss separating the parent from his or her child. Thus, the routine procedure of transfer of the infant can pull the parent into a complex state, mood, and set of events that are deeply emotional and, at heart, surprisingly difficult to probe, understand, and describe:

I know he had to be moved, and that it was for the best. But still, it is terrifying that someone thinks it is a good idea to take your brand new baby and put him on an airplane without you, to take him to another city, and put him in a hospital, all by himself. We just had him and I so needed to be near him. I so needed to know he was all right.

He was calm when I left, and was not crying when we got there. And the people who transported him had gone. So whether or not he was crying and in distress during this first day of his life, I will never know.

Even when the parent is unable to accompany the child during transfer, but is offered the option to go, it may provide a sense of comfort:

It made me feel more relaxed, that the option was there, that I could ride with her. Just so I knew that, I don't know how to explain it, that I could still have that option. It is a weird feeling when someone says that you can't go with her. After all, this is my child! And I have to be there for her.

Perhaps the transfer becomes less suspect when knowing, "I could ride with her." The crossing becomes a bridge that I too can take, a drive that I too can make. It becomes accessibly less alienating.

Yet, a child transferred across and away can leave a parent feeling left behind. A mother recalled the experience of cesarean section as she awaited her child's birth, catching only glimpses before he was taken away—she was left outside trying to look in:

I was trying to look at the overhead light, because I could see a reflection in the glass, a reflection of him. So when they were taking him out, I could not obviously, yet still, I caught a glimmer of him. That was the only glimpse I got. Then, I was left alone, waiting and wondering. As I was recovering from the C-section, all I could keep thinking was I need to find some way to get to the NICU to be there, to see him.

As the newly born is taken across, the parent may be left without her or his

new child. The first happenings—eyes opening, harsh cry, tenuous movements—are missed forever because of distance. Moments cannot be recreated. So, being transferred across may not merely refer to physical space; rather, it may be felt as an experiential, relational gap as the parent (the self) is separated from their child (the other). In this way, even when the reasons for transfer are medically sound and the measured distance small, the child is still away, and the parent feels the absence.

Sometimes, in the case of a transfer close in time to delivery, the family is further divided. When Josh and Heather's son Taylor was born extremely prematurely, Josh went back and forth, camera in hand, as Heather recovered from the cesarean section. Returning and returning, over and over again, there was a weighted responsibility of being across and having to travel back across as Josh tried to bridge the distance. The first time Josh returned to Heather, Taylor was doing well: "'Beautiful,' I said that he was absolutely beautiful. I was so relieved just letting it out." Subsequently, Taylor stopped breathing and things became difficult:

I couldn't tell her. I couldn't take that to her. I was weak in the knees to tell her. I was trying to stay strong because Heather could not race back to see Taylor like I could. I was trying to wait for good stuff to happen, trying to stay strong, but things were taking forever. They had a hard time getting a breathing tube down. I think they tried three times. Then they could not get an umbilical line in, and worked on that for forever. Looking at him, there was nothing there. He was just lying there, lifeless, his limbs spread out. They continued to work on him. Then a nurse came and said, "She is asking for you." I kept trying to delay going back, just for a few more minutes, just so I could say everything was fine.

Another father, John, recalled a sense of relief, as his wife was medically stable to come across to the nursery—relief as the family had finally made it across together:

I think the biggest thing was just having my wife there. Finally, she was not in another part of the hospital. Finally, I did not have to run back and forth between them. Finally, I could have my wife there and I could have Sebastian there, and everyone was just there together. Being separated, having him in the NICU and my wife in postpartum care, that was probably the hardest part.

Carrying across, splitting the family between places, leads to more than physical distance. Families can be thrust into a way of being of separateness. Being separated perhaps can be all the more intense for parents of twins, triplets, and other multiples if the babies too are spread between nurseries. Certainly the family away from home, with limited social supports, now separated, may be all the more alone.

Transfer as a carrying between

Children come from a primordial place of close contact, a place of interiority—the containing pressure of the uterine wall, the regular rhythm of heartbeat, and the conducted sound of the mother's voice. Even after a baby is born into the exterior world, he or she may remain calm to the impressions of the first (uterine) place. Within the embrace of mother, the child is brought back to remembrance of the interiority of inside life. We see babies calm when they are bundled in containment, as they lie skin-to-skin against their mother's chest, reacquainting to her warm touch, distinctive aroma, and recognizable sounds. In this way, we are witness to the primacy and primordiality of place. A place world that prior even to having a perspective we may experience as our own. Perception is bodily, the body is perspectival, and perspective emerges out of the very stuff of the world: "My body sees only because it takes part in the visible where it opens forth" (Merleau-Ponty, 1964/1968, pp. 153, 154).

Hospital transfer is always a change between places. If parents sense that their child has a shared place in the world with them, then it follows that a transfer into a hospital nursery may be a kind of existential severing for both parent and child—a dramatic change from a sphere of interiority to exteriority, from the cradled simplicity of parent holding child, to something altogether different. The child is carried between.

To the uninitiated, arriving into the highly technological medical environment of the NICU is a surreal journey that few are prepared for. As a baby is brought into the nursery, he or she is hooked up to a variety of machines. The baby is laid in a medical bassinette that resembles a space-aged automated greenhouse. Colored wires, silastic tubes, and adhesive tapes dress the baby to allow continuous monitoring and provision of medical support. Extra equipment, such as a mechanical ventilator or an infusion pump, is brought to the bedside. Multiple screens display information to measure and monitor the baby's condition and medical interventions. Periodically, broached alarms trigger warning lights and sounds. Nearby tables are covered with paraphernalia. Various health care professionals visit the bed, assessing both child and equipment, taking notes and chatting in medical lingo. Seeing their child after the transfer in the NICU may be profoundly unsettling and disconnecting for parents:

Then, when I saw her again, she looked like a little stranger. And yet, she is my child. I was traumatized, as a father, to see my child hooked up to all of those things. She was lying there sort of with her arms and legs spread. There were probably six to eight pumps running, IV tubes going into her tiny limbs and body, and just all kinds of different machines with lit-up screens. She was lying there supine, on her back, as if crucified. I could not help but feel so very close to her, and achingly distant.

I was totally disconnected. I could not pick him up, could not hold him. There was so much running everywhere. It was hard to just see him, to see what he looked like, features and stuff like that. The tubes running down his nose and mouth, lines running everywhere. He was swollen with the stuff. I was just trying to make him out. And he was so tucked in that little incubator. Like a little fragile cyborg who I did not dare touch for fear of disturbing any of the artifices attached to his body.

As the child is carried between, the NICU may be experienced as a radically different place. A child critically ill, touched by hurt and sickness, may evoke pain and distress in the parent. Moreover, relationally it is not just a child who is carried between; rather, it is this parent's singular "my child." Embodied in place and relation, the child may be affected in subtle ways as a transfer between may be both a change in place and a felt relational change in the child.

There is a certain indistinctive medical quality to the nursery hotel as each patient's spot is designed with the intention of uniformity and sameness, of housing the prototypical NICU infant. An empty unit marks individual spots only by number or letter, each vacancy undifferentiated, serving as a mirror image to another—a place of deidentifying commonness and conformity. We could even ask when a child is grounded in this place, how is the child unformed? Where the child was previously open to the world, still carried by the family, the child now is contained and cut off from the parents in a medical incubator, a "concealed box." The infant may be experienced as less approachable and more fragile to touch, a different baby in the isolette just from being there, even when the isolette and paraphernalia are only used for monitoring.

A parent may be sensitive to these felt changes in their child. Jean was born after what would be considered a routine pregnancy and delivery to most physicians. In fact, many would describe the birth as unremarkable. However, on closer look at Jean, her left hand appeared malformed. The neonatal team was called to the delivery room to assess, and after "10 or 15 minutes" with her parents, she was taken to the nursery "just to be safe." Although it was perhaps prudent, the family's first time together was cut short, "feeling like only mere minutes." Her father recalled,

I went with Jean to the NICU, it was kind of a whirlwind . . . I almost felt in the way. She was in her little bassinette, incubator that they have, and I was kind of just standing there, out of place. And did not know what was going on. Like I should not be there.

In the NICU, Jean was placed in a standard isolette with monitor. No invasive procedures were performed or bloodwork drawn. She was simply brought into the unit for observation. Still, as the child was carried into the nursery,

the father was left out of place, unable to pass between. Casey (1993) pointed out that the experience of being out of place is corporeal. Just so, the transfer is a bodily change from what is expected and recognizable in place to somewhere altogether out of place. The experience of interiority, the typical and familiar, has been taken away through transfer. As a mother remarked, "I felt robbed of my experience that I should have had."

A transfer between places is always an experience of a different place: sometimes subtle, other times obvious. The new place may carry the possibility of invasive procedures, surgeries, or other interventions. Alternatively, the new place may carry the promise of an improvement of health with discharge home on the horizon. Still, even when a transfer "should be a good thing," it may still be wrought with worrisome meaning for the parent and child. In this way, changing between places may be hard for the parent, and also for the child. The "new place" may be reflected in the parent's perspectival experience of self, and child as other. Moreover, the relation of parent and child is different in this new place, as technology may disturb a parent's experiencing of their child. For example, the neonatal monitor may mediate the mother's experience of her child—bother, discomfort, stress—as she watches the dips in measured oxygen saturation on the monitor screen:

I felt kind of uncomfortable to do kangaroo care. There was no privacy. The few rocking chairs that they had were hard, and how long can you sit in that! It was like a big gym full of babies, too loud to have that quiet time you need with your own baby. Yeah, you can pull a curtain, but even then you are still sharing the space with others. I felt that the atmosphere was hard on my daughter as well. She was very noise sensitive, she would desat and desat in response to the place. Normally, she would never have required that much oxygen, but the place was irritating her. We never experienced a sense of personal place. We just shared some space.

Transfer may mark a change in bodily perception of self and other. With transfer, the parent's bodily anchorage in the world may change because the world itself, and therefore the parent-as-self changes. And, the parent's experience of the infant transfer may be a change in the felt spatial being of the child as other. The encounter with the other, the experience of the face to face, as Levinas (1961/1969) presented it, is seen as an encounter with what lies outside of self and within the realm of the spatial. Thus, place may be seen as a complex but unitary structure, encompassing the self and the other, both spatially located and embodied (Malpas, 1999). Carried between places, the parent-as-self and the child-as-other are changed.

Transfer as a carrying contact

Carrying the child, by whatever ambulant means, involves moments of

presence, connectedness, and contact. Yet, these moments may also signify absence, disconnectedness, and loss or longing for contact. Contact in carrying is not only a matter of physical touch; contact has to do with factors of spatial and relational proximity between people and the sense of community and intimacy that may be at stake in hospital transfer.

There is a special weave of the parent–child bond as perception is entwined, interwoven in what Merleau-Ponty called the flesh of a common world (1964/1968). The connecting flesh is more than the bodily tissue of a corporeal body; rather, the flesh is the substancing matrix, the milieu, conditioning sense and sensibility, perceiver and perceived, self and other. A father and mother recalled moments of connectedness, the father first, at the beginning, and the mother second, at the end of hospitalization:

Having him hold my finger was the best feeling ever. Obviously he had not been in my tummy, I hadn't felt him kick and stuff like that. So, when he clenched my finger—I can't even explain the feeling. Just like everything almost came right off, the weight on your shoulders. I knew then that he was a fighter, an amazing little boy. He had a wicked grip, very strong. It felt like the biggest hand in the world just grabbed my hand and shook it. Like someone just came in, and grasped my hand with all their weight and shook it . . . and yet, it was only my finger.

For the whole nine months, I was Jack's only constant. My husband came as much as he could, but I was the only one who was there every day, and Jack was the only person I saw every day, so that creates a really neat bond. Everything else changes, where you sleep, the hospital food available that day, the friends that you make, your schedule, everything changes. Every time you make plans they change, so you can't rely on anything. The only constant that we had was each other.

In the context of neonatal care, the parent may be the only constant caregiver for a child; doctors change, nurses change, social workers change, and so forth. We could wonder about those children whose social situation is such that no parent or other constant is present in their life: Who is truly there in touch for such a child? Who is singularly present in contact worrying for that particular child? Yet, perhaps this question is for another study.

As a child is transferred by ambulance or plane to a different hospital, a parent may somehow feel a loss of contact, not just from his or her child, but also from a sense of dependability:

As I was leaving town I could see the ambulance in the rear view mirror, with the lights on going to the airport, and I just thought—I have to get there. The things that were going through my mind were the sounds that my daughter was making. The mask on her face. It just tore me apart. I could not share these

sensations with anyone . . . that is all I could think about was that sound. It was a sound of suffering like no one could do anything for her. It was her crying on that warming table with that mask, just this sad cry that was just like a "help me" little cry, just made me feel so completely useless as a parent.

Separated, decoupled, and unwoven, a parent may feel unglued; a bond just untangling that should have been tightly knit. Wanting to be with the child, and wanting to be there for the child, the parent may continue to hear the summoning cry. The parent may experience a deeply felt need that cannot be met. In the words of Levinas, responsibility is primordial:

> The I is not simply conscious of this necessity to respond, as if it were a matter of an obligation or a duty about which a decision could be made; rather the I is, by its very position, responsibility through and through. (Levinas, 1996, p. 17)

When the responsibility cannot be exercised, the sense of felt contact with the child may turn ambiguous:

I think the first night he was born, the nurses were like, "There is your baby." And it was just almost surreal, like, "Yeah, we have a baby." But the ambiguity started to sink in more as he was moved from place to place. I remember just speaking on the phone and being like, "My son is in the hospital," and as soon as I said that I was like, "I used 'my son' in a sentence. I must have a child." And yet, it seemed that I was not convinced of my own fatherhood.

Another father described the connection to his son, Ken. The child was transferred to the nursery while his mother remained an inpatient in the adjoining maternity hospital. With Ken in the NICU and the mother in postpartum, the father shuttled back and forth, straining to be "here" and "there," yet neither "there" nor "here." The routine transfer for observation in the NICU left father in limbo:

I didn't feel the connection to Ken right away because it was like, I hardly got to know him. I don't know if it is a standard dad thing or what, but it was like, yeah that is my son. But, I don't really know him, and he has a team of people that are surrounding him and keeping an eye on him. But, I know my wife. I wanted to make sure everything was okay with her, and she needed to know what was going on with Ken. We were not thinking about ourselves at all.

Beneath our distinctiveness as individuated selves or persons, our experience of this vulnerable other may arrogate the experience of self. Consider the newborn baby, responsive to others even prior to gaining awareness of the self as an autonomous being. When we stroke a baby's cheek, he or she roots reflexively; in comparison, when we place an object in his or her mouth, the baby sucks eagerly. Of course, these primitive reflexes

are not empty movements. Rather, the movements are intentional, directed in expectant relation to another, the mother. In this way, the mother and child are paired. The infant's body transcends the matter it is made of by having an intentionality that ties it to the body of the mother—complementing the mother who fits her perceptions into the visible folds of the infant's body (Simms, 2008, p. 15). A reading of Levinas (1961/1969) may illuminate the fitting complexity and disparate asymmetry of the parent's experience of child: "I do not have my child; I am my child. Paternity is a relation with a stranger who while being Other . . . is me, a relation of the I with a self which yet is not me" (p. 277).

We see parents yearning for contact with their children. Parents reach for opportunities to touch and sooth their child through the portholes of infant incubators. Intravenous lines and monitoring wires are untangled and carefully handled so a baby may be taken out of an isolette to lie skin to skin against the mother's chest. Here, the mother holds the baby ever so delicately in comfort, despite the cumbersome medical technology—tubes, wires, breathing tube all cautiously secured in place. Although we see a pattern, each baby is a singularity, an individual child of a particular parent, resisting generalizing objectification. The experience of a hospital transfer is in this way not simply a "someone" being transferred but rather, for the parent, it is "my child" being transferred.

Rose's parents were waiting for her to be transferred from a small-town hospital to a tertiary care hospital. Her medical condition was critical. The hospital staff acknowledged that they were working beyond their experience with equipment ill fitted for the requirement at hand. Her parents recalled their daughter's condition on presentation:

She looked awful. Never been so scared in my entire life. She was letting out constant cries that were sort of muzzled by the oversized oxygen mask that they had over her that was covering her mouth, nose, eyes, going up to her eyebrows . . . covering her whole face . . . cutting into her eyebrows. . . . I thought she was going to die . . . and no one mentioned anything.

I just talked to her, told her that we loved her. I really thought we were going to lose her. I was afraid she was going to have a heart attack. I was so afraid that her heart was just going to give out. The waiting was torturous.

Clenched in gripping anxiety, Mom accompanied Rose in the airplane:

I remember sitting in the plane and watching her through the glass, and praying that we were going to make it. I could see attendants looking at each other, talking to each other. Of course, I couldn't hear anything, and they were kind of making faces at each other and I was like—is it good or is it bad?— I could see that they were talking about what was going on with her and I could

see both their facial demeanors. I was probably overanalyzing every little facial expression that they were making. I just felt totally alone on the plane. I realized that she might be passing away any moment, utterly alone. I could not touch her and I could not talk to her.

Carrying out of reach, beyond touch, there may be a chasm between parent and child—decoupling distance. Despite this distance, the parent may reach for their child in caring worry, identifying connection. Parent and child are intertwined as self and other. Feeling isolated, clutched in anxiety, the other other, the transport team, may become an absent presence of carrying.

Transfer as a carrying caringly

In the carrying transfer of an infant, there is a holding and protective bearing that is already detected in the etymology of the term carrying . Certainly, carrying a child involves a modality of bearing that comprises a guarding and caring for. Beginning perhaps in pregnancy, the child is carried and contained caringly within the womb of the mother. Here, "life begins well, it begins enclosed, protected" (Bachelard, 1958/1994, p. 7). Yet birth reveals the child to an open world—a social world. Parents may be struck by their child as other, feeling the weight of responsibility as they hold him or her in their arms—first looks, mouthed yawns, and grasping touches. The child comes to be in the parent's social world. But, being in a social world also means that a child can be taken away by some third party, the other other:

It's just one of those things, that when you are a mom and sending your baby over, it's not that you don't trust people to take care of her. I mean, it is the health care system, they should be okay, but you just want to be there. It's not like I could help her or that she could hear me through the isolette or anything. I don't know, it's just an irrepressible need to be there, to know she is being cared for and about.

The transfer of a baby requires a specialized team of people, including nurses, physicians, respiratory therapists, emergency medical service workers, and other health care professionals. One father described the experience of his daughter being electively carried by ambulance between hospitals for a consultation as the parents were left to follow behind the ambulance by car. The father recalled an unnamed woman who seemed responsible for taking his child to the receiving hospital:

And so the ambulance people came and they swapped out their beds for the crib that they put him in. And one of the nurses, I think she was a nurse, I don't actually know, she may have been a resident or something, I don't know, she was in scrubs but everyone there is in scrubs, I met her for about twenty seconds from the NICU. Anyway, she took him, then he was gone.

The woman doing the transfer was experienced as a third, the other other. The third may be nameless in anonymity, generating hesitation and apprehension in the parent. However, the third person does not have to be felt as impersonal. A mother described her encounter with a nurse, David, after the birth of her extremely premature child, Julie. The baby required emergency transfer by helicopter after birth. The mother only saw her child briefly as the transport nurse scooped her away:

The nurse, David, was really understanding of the circumstances, compassionate and stuff. He explained and went through everything. He assured me that Julie was in really good hands and I did feel comfortable with her going ahead. For the first week, I could not even look at David without crying. If he had not done what he did, Julie might not be here. David will always have a special place in our family.

Nurse David was doing more than moving a child; he was carrying her in his "good hands." Despite the critical condition of the baby, there was trust and confidence as the mother gave in to accepting the transfer. Yet letting go may be difficult. Another mother described her felt need for togetherness, presence, and protection:

It would have been really hard for me not to stay with him during the transfer, because I would have thought, well, what if he is scared? He has never been in an ambulance, never been outside, never been to this place. What if we get stuck in traffic and are held up for an hour? And there is always the thought that if you are not present, the nurses will assume that you are not involved, and they will not treat him as well. They may say that the care is the same no matter what, but I think that being there does affect the care. I always felt like I needed to be there as much as I could be, to ensure that he was getting the best care, to make sure the nurses knew that I loved him, and was watching over him.

Carrying in care is more than providing medical care. Care also comes from a caring worry, experienced as an affliction, an ethical demand of parental responsibility (van Manen, 2002). Jian's mother described an experience of "being called" back to the hospital as her son was electively transferred between units:

The transfer was pushed back so they had to take Jian right around the same time that I had to leave for dinner. From home, I called the nurse to ask, "How is Jian doing?" I needed to know, but all she could tell me was, "He is doing good . . . he is sleeping . . . he is saturating fine." But that was not enough. I just wanted to know, how is he sleeping? What side is he laying on? Does he have a blanket? These are all the little mother things that a nurse could not tell me. I wanted to be sure in my mind that he was okay. So, my husband drove me back to the hospital. When I walked into the room, there was Jian sleeping. But I wanted to

touch him. I wanted to feel him close. That night, I held Jian, sleeping in the chair, all through the night.

Coming back to the hospital, Jian's mother took him back. She held him in her arms in responsive responsibility. Only a "being there" in presence, what could not have been achieved by a distanced phone call, alleviated her motherly worries.

Transfer as a carrying home

Transfer always involves a motion in relation to place, and the spatial experience of place may profoundly impact the mood—(dis)comfort, (in)security, and so forth— and sense of well-being or ill-being that the parent experiences in relation to her or his child. When parents and child dwell in a place, something changes. Now, the space of the place may become familiar and homelike. A mother described the nursery as her daughter's first home:

I call this place home, as silly as that may seem. But it is what you make of it. We can pull the curtain whenever we want, we can read, we can sit, and we can do whatever we need. This is the first home my child knows. Yeah, this little room is our home.

Almost surprisingly, with time, despite the intrusive technological complexity and superficial anonymity of hospital space, the medical nursery may acquire the atmosphere of dwelling, being at home: familiarity, connection, and sometimes stillness. Yet, the NICU may become more than a home place; it may become the family's home. An out-of-town mom recalled coming back to the nursery after a trip to her house home for the weekend:

We are going on two and a half months here. This has become kinda like home. I went home for a few days, and it was all right . . . but then, when I came back I said, "Ahhh, I'm home again," because this is kinda like where real home is right now for me.

So, almost strangely, the parent can feel in place, at home, in a space that is altogether different from his or her regular house home, as they are afflicted with an almost an uncanny anxiety of not feeling at home in their true house home (Casey, 1993). We may wonder: How can parents ever feel at home in such a medical, technological place? Is this problematic? Is that what is or is not desired?

Embodied in place with his or her child, the parent may become accustomed to the communal rules and routines of the nursery. For example, the parent may feel at home while going through such familiar bodily practices of washing hands at the communal sink, keeping things tidy under the counter,

and drawing up a chair to sit and care for their child. In this way, a parent may develop a familiar spatial and secure relational way of being in the NICU shared malleable space:

I started breastfeeding and just had this really maternal connection with Tim, and wanted to stay here. So, I had my own room, a boarding room, and I really liked that, having the same place to go back to. I could listen to my radio, and I had my sewing machine there and I could work in the evenings, that kind of thing. There were other moms there so we would have supper together. It became our place. It filled a need that I had. It let me stay with Tim, and it gave us a sense of community.

The ability to be at home is perhaps essential to our nature as free beings, being in a place both of and for the self. Home permits an experience of passivity—a settling background to our day-to-day life, providing support and structure (Jacobson, 2009). The home may offer inner space for our inner life, "the house shelters daydreaming, the house protects the dreamer, the house allows one to dream in peace" (Bachelard, 1958/1994, p. 6). As much as they can, families may actively make the nursery their own. For example, just by drawing barriers around them, a mother and daughter can create the shell of a nesting place. Curtains may become walls, with the sliver of light shining through adjacent panels serving as windows. One mother compared two nursery spaces:

The space there was just not homey compared to here. Here you have a little drawer to put stuff in, and you have a little shelf to put stuff on, and you can kind of make it home for whatever amount of time that you are here. There, they do not have that. There, the space is just an open wall, lined with all the babies.

Building by decorating and dressing a space is a sort of body outside our own, a second skin that opens room for bodily dwelling in place (Casey, 1997). Parents may settle in, and spread out their own bodily being into place. In other words, personalizing space by placing pictures, clutch toys, and other personal artifacts may be a felt productive activity through which parents may make a place for themselves in the nursery, a means of which their own dwelling is articulated. When as health care professionals we pull the curtain or open the door to walk into these spaces, we may feel the tension of intruding into a space no longer our own. We cross these inviolable self-enclosures that now may be felt as altogether private. We find ourselves peering between curtains like an ornithologist peering through bushes at an inhabited nest. A physician recalled in passing:

I remember one night on call being asked to assess a baby. The curtains were closed so I knew the family was present. I peeked through the curtains to check if the mom was pumping, or if some other activity was going on that I should

not interrupt. The mom was sitting in a chair beside her baby with one hand cradling the bassinette. She was watching her child sleep, deep in thought. I would have knocked on the curtains, if they had been doors, if I could have. Instead, I meekly said, "excuse me."

Transfer may illuminate the meaning and significance of place by exposing the creation of an abrupt displacement as the home nursery is left. Although the transfer may be a move to a place that feels in the end more or less positive than the earlier place, the transfer may still feel like a disruption. And so, the parents now find themselves out of place. If the new place is experienced as alien, then everything is measured against the familiarity of home. Little things become big things. A mother described her sense of moving from a "little corner that felt like home" to a new, different, open-area nursery, and then moving back "home" again:

This is how I compare it: You are coming from like, a five-star, and going to a two-star. That is how I felt going over there. I understand that it is busy because it is surgical and all that kind of stuff, so it is obviously going to be different. But, it just did not seem as welcoming as it did here. It is almost like Las Vegas over there, lights and dings, and everybody is running all over, and I had a hard time just because this is the only place I have known. The way they do things over there is just so different from the way they do things over here.

As parents settle in place in the nursery, relationships develop. Parents can be seen watching out for each other and each other's children. The nursery may become "my child's neighborhood." Yet, with transfer, relations with staff and other parents may be broken or lost, again to be out of place:

You get to know your neighbors. You need that companionship with the other mothers, to hear their stories, their experiences, to make it a little more comforting to you. So I was nervous in a way to know that, oh gosh, I have got to meet all new moms now.

The goal of care in the NICU is generally that eventually all children will be discharged to their house home. The journey home, though, may be marked by complications, some expected and others unforeseen. Sometimes transfer marks a change in the expectation of going home. As Sean's breathing difficulties persisted despite his evolving maturity, elective transfer was organized to a surgical NICU for a specialist airway examination:

There, they were all preemies, and most just need to grow and learn to eat and then go home kind of thing. Whereas here, it is mainly surgical babies. Lots of them are heart babies; they need to have one to three surgeries. So you need to go through a big stressful surgery date and then wait for them to get better, and then wait again, and it is more uncertain in a way. There, everyone is scared when they have a preemie because it is more unexpected, but once you

get over that, in general, lots of the babies just need time, time to eat and get stronger, those kinds of things. Here, it is more like the issues that they have are them, like you have a heart condition that follows you around for life. It is a different feeling. Coming here, I had to face that Sean was not going to just grow out of his problems and go home.

On this path of being carried home, transfer can leave a family in disarray and abandoned. As the future become more uncertain, Sean was transferred to a general pediatric floor bed to make room in the surgical NICU. To complicate matters, Sean became increasingly breathless, struggling with his breathing. A resident came to assess Sean, asking his mom, "Why are you here?"

I said, "We came from the premature hospital and I would really like to go back there." And she said, "Normally we discharge from here," and that really made me stressed out, because I still thought we were going back to the premature hospital. I wanted to go back there. I had friends there that I had spent the whole spring with. Friends I was counting on seeing again, those kinds of things. And I felt like the doctors and nurses there were more in tune with my child's situation, like they knew who we were. When we came here, people did not know him, and I was worried about his care. Like, I know his medications got switched around. I know he was on caffeine at that time, and the dose was either halved or doubled or something like that. Just this feeling like I needed to know everything so that someone did not make a mistake. We felt abandoned, like the doctors who knew us had just forgotten about us.

Coming back to familiar ground, with home on the horizon, may promise the return to a place of dwelling and belonging:

I was so relieved and happy when we got back here. He had all his stuff in the bottom of his crib. He still had his spot in the room. It was a different spot, but it was the same room, with his same specialists that were following him before he left. I was so relieved just because I felt like this is where he has been taken care of. Here he is actually known.

It was nice. It was like a weight off my shoulders. I did not have to worry about her like, is she going to be okay? Or, is she going to be taken care of? It was nice to come back. I felt more relaxed, I did not feel as tense, that I knew she was safer. Not that I was worried that she was not safe, but that I just did not have to worry, I guess.

In coming to a place of home, there may be a sense of passivity in place—relaxation, release, and relief. With a foundation of home, the future may again be revealed as free. The future may seem open and the journey out of the neonatal intensive care within reach.

Concluding comments

The routine transfer of infants between hospital environments may be far from routine and innocuous from the family's perspectival experience. In this study, I explored the phenomenon of transfer to reveal a lived experience of carrying. The thematic events of carrying across, carrying between, carrying contact, carrying caringly, and carrying home speak to the eidetic meaning of transfer, and draw our attention to a relational ethics of care. In transfer, the carrier bears the responsibility to not only reach the destination, but also care for the carried while carrying. As such, for the parent, to have their child carried by another is to have their child cared for and cared about by another, even if only for a brief time.

In giving practical consideration to the phenomenon of transfer, perhaps the focus should be less on the physical distance between places, and rather on acknowledging that the experience of transfer relates to this felt carrying between lived places. As a lived experience, it is the perspectival, subjective experience of place that is considered. Place change, then, may also include the experience of changes in relations, routines, and so forth. Distance may be but a contextual feature of the transfer experience. From this perspective, a transfer just down the hallway may be a profoundly meaningful experience for parents. Even the experience of a new team of professionals taking over care of a child in the same physical space may dramatically alter a parent's experience of a place. Places may have embedded meanings—my child's first place, a place of loss, a painful place—such that leaving or coming to a place may have more to do with the existential experience of that place than its physicality. Transfer as a carrying experience between felt places speaks to the sensitivities and understandings required of the health care team that is responsible for both major and seemingly minor hospital transfers.

At a system level, we see the need for family-centered initiatives that support both child and parent, separate and together. When possible, a parent accompanying his or her child during transfer seems a natural way of being, rather than a parent traveling separate to find a way across to his or her child. Similarly, infrastructure development for hospital nurseries to provide not just a space for the child, but also a place for the family seems intuitive. Although mother–baby units and close-proximity boarding rooms are structural goals, the need for personal place is more fundamental. Prioritizing family–child space in the form of initiatives that truly bring parent and child together, such as kangaroo care where the child is laid skin-to-skin against the parent's chest, may help return the family to a pedagogically responsive way of being. The image of the child and parent together in touch starkly contrasts with the child as monitored, distanced away in an incubator. Neonatal intensive care admission and hospital transfer is a journey with which few families are familiar; thus, the offering of guided and virtual tours in the anticipation of admission and transfer may be

appropriate for many families. Correspondingly, family-friendly informational materials to help make transparent and understandable the "routine" happenings of the neonatal intensive care may be valuable. Through sensitive practice we may help parents and their newly born to grow together as a family, to make a place for themselves in the nursery, and to cope with the changes inherent in their neonatal intensive care story.

At an individual family and professional level, an understanding of hospital transfer as an ethical responsibility of carrying speaks not so much to a change in specific procedure or hospital policy, but rather to a sensitivity of care. Members of the health care team need to relate to families not only as knowledgeable, skilled technicians, but also as thoughtful, tactful professionals. We must consider the complexities that make up the manifold of the experience of transfer in our being with families in both our routine and uncommon day-to-day practices as caring professionals. In this manner, before, during, and after transfer we continue to be responsible in a collaborative and supportive relationship with the families whose children have been entrusted to our care.

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7. Ethics of the decision in neonatal intensive care[1]

Introduction

In North American contexts, the prevailing standard for newborn medical decision-making is the "best interest of the child" whereby parents are invested with responsibility as surrogate decision-makers (Bell, 2007; Chance, 1994; Nuffield Council on Bioethics, 2006). The ethical decision tends to be understood as a rational, deliberative affair such that prevailing bioethical discourses approach it as a dilemma to be analyzed or a problem to be solved (Ahluwalia, Lees, & Paris, 2008; Ladd & Mercurio, 2003; Leuthner, 2001). Consequently, a number of different conceptual models have been developed that try to mediate between abstract ethical theory and actual healthcare practice by providing a structured framework for evaluating moral issues (Beauchamp & Childress, 2001). Although the realization of best interest from the parental perspective may be the goal of decision-making, the actual parental lived experience of the ethical decision has received limited attention. The thoughtful question to ask is: what is the meaning of the ethical decision as it lies in tension between a theoretical understanding of rational decision-making guided by moral principles and the actual practical decisions as they may unfold at the bedside?

The aim of this study was to explore the phenomenon of the ethical decision as experienced by parents in the setting of the newborn intensive care unit (NICU).

Materials and methods

A qualitative methodology, phenomenology of practice, was employed (van Manen, 1990). This is a context-sensitive form of interpretive inquiry representing a blending of phenomenology with qualitative empirical methods. The intent is to explore the meaning of a recognizable experience, not to develop theory (in the strong sense of the term).

The focus was on the lived experience of parents who were judged by practitioners to be at increased likelihood of encountering direction-of-care decisions based on the clinical conditions of their children (e.g., extreme prematurity, complex congenital anomalies, significant neurologic compromise). An ethical decision was taken openly as a felt decision made

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for another (i.e. a moment when a parent felt like he or she was making or was being asked to make a decision for his or her child). This phenomenological understanding of the decision situates ethics in the lived experience of the face-to-face encounter, or the intersubjective relation, with another (Levinas, 1961/1969; Waldenfels, 2006/2011).

Experiences of 14 parents who had a child admitted to the NICU were elicited by audio-recorded interview. This number is in keeping with other studies of this methodology abiding by the need to balance breadth and depth of experiential material (van Manen, 2012). Admitting diagnoses varied greatly, including, yet not limited to, those related to prematurity, congenital anomalies, and transitional problems. Parents ranged in age, ethnicity, education, and socioeconomic background.

The qualitative material was treated as "data" for "analysis" by reflective methods (including thematic, guided existential, linguistic, and exegetical reflection) to identify and explore variant and invariant meaning aspects of the phenomenon of study (van Manen, 1990). Anecdotes were drawn from the interviews to assist the reader of the research to access the intersubjectivity of the parents' experiences by deleting extraneous, redundant, and identifying material to strengthen transcript stories into the direction of the phenomenon and its themes.

The textual process of writing and rewriting was also a key part of the research involving finding language sensitive to the phenomenon. Drafts of the research text were reviewed with a diverse groups of healthcare members as well as parents of children whom had previously been admitted to the NICU to ensure that the text resonated with experience as lived, evoking the so-called phenomenological nod.

This study was approved by the Health Research Ethics Board at the University of Alberta, Edmonton, Canada.

Results

The inquiry into the phenomenon of the ethical decision yielded five thematic events around which the following research text has been composed:

The ethical experience as the decision that was never a decision

An observer may witness the possibility of a decision unfolding in the NICU. Sometimes it is the outcome of an investigation that announces the need for a coming decision such as a head ultrasound showing severe brain injury in an ill infant. Other times, it is the constellation of intensive therapies being utilized in the deteriorating condition of a child that signals a decisional juncture. In these moments, healthcare professionals may call on parents to

discuss options—the possibility of a decision. Foreseeably, the discussion alternatives may include initiating, limiting, or withdrawing medical therapies. Yet for a parent, choice is not always seen:
The doctors kept on asking us about withdrawing care. We felt pressured to decide, almost hounded, to take Sam off life-support. It was as if they thought that we did not get it, that he could be severely disabled, that his chances were so poor. Yet, how could we kill him? How could we have a part in ending his life? We avoided the staff to avoid the discussion. We avoided coming in to see our son, just to avoid being confronted with the predicament of having to make the decision. We just wanted to give him a chance. If he was to die, he would die on his own. We did not want to take his death away from him.

What is a decision for the professional may not be a real choice for the parent. After all, for a choice to be a genuine possibility, it ostensibly needs to be seen by the parent as something that he or she could freely conceive of making. The experience of choice need not only be constrained by religious or cultural convictions. Instead, it may be that the offered choice is just too different from the path that a parent envisions for his or her child. The decision to withdraw treatment may be incommensurate with what a parent may feel that he or she can do as a parent. So it may happen that in this moment perhaps all a parent is able to do is choose to give his or her child a chance.

The ethical decision as looking for a way out
There are other situations that seem to demand information. The decision is not simply resolvable in the moment, but instead may ask for reason, calculation, deliberation, and even meditation. So the parents may think it through, looking for evidence to clear away uncertainty.

The choices were that we could keep her on the ventilator without giving her dexamethasone knowing she was going to deteriorate slowly; that we could give her the dexamethasone and see where that takes us; or, that we could withdraw treatment. The first was not a decision for us. We did not want her to suffer. We so wanted to help her, but at what cost? I remember taking a walk with my husband after talking with the doctors. We talked about quality of life. We knew that while the dexamethasone could be good for her lungs, it could be bad for her brain. We talked about what we were prepared to live with. We knew that if she was severely disabled that we would be unable to handle that. We did not want that for our child. We talked about what we knew and what we didn't know—the uncertainty of it all. It really felt like there was no clear right answer. And we felt like we did not have time, there was no time to make a clear decision. Time was pressing, we almost decided to withdraw treatment. But we really did not want to let her go. Perhaps we were kind of looking for an excuse to give her the dexamethasone. As we were walking back, still unsure, my husband brought up, well, what about if we ask for a head ultrasound to

confirm that she does not have a brain bleed? Cause if she had had a brain bleed, we were not going to go on with it, cause then we would know that there was brain injury. So we said if there is no brain bleed, we will go ahead with it. We did not want her to have the life of a wheelchair.

As the parents try to work out an answer, the ethical decision may be the experience of a problematic that offers an elusive solution. What the parents may look and long for is not just the raw information of how dexamethasone may effect the lungs and brain. The existential meanings of choices are crucial—to cause our child suffering, to let our child go, or to carry on with our child. And the parents may wonder: What will life be like for our child? What will life be like for us? What can we live with? Although uncertainty in the future may be unresolvable, meaning may be dwelled on in a time marked by urgency and anticipation as parents seek answers.

If a solution is not forthcoming, the decision may be deferred by appealing to the "fateful" outcome of an investigation, the head ultrasound. Perhaps the ultrasound provides the parents with more time, a hopeful situation where everything may still turn out all right, by showing them a child who has no definitive evidence of brain injury. After all, to withdraw treatment on their child, as she currently appears, may not be a real option to think through.

The decision as thinking and feeling oneself through the consequences

In the thinking through of a decision, rational calculation may not resolve uncertainty. Instead, one may need to feel oneself through what is to come.

They told us that it would be for the best if we were to discontinue life support. Our answer was "No." We were just not ready. It was a shock. And we had not had time to discuss it. We felt so rushed, pushed to come to a decision. They wanted an answer. We went back to our room. I was thinking, he is my little boy. I pictured him in the isolette as I stared at the pictures of him on the table. He was with us in that room. We searched the Internet, pulled everything up on the computer on what he had and what the outcome could be. We looked at the worst of the worst given his brain injury. Asking ourselves, can we handle it? It is going to be a daily-life thing for us, and if that is how he is going to be, can we deal with it constantly day-in and day-out? We started talking about different home situations and stuff. Even to the point of bedroom space and such—room colors, pictures, bedding. We were putting him at home in our thoughts. I don't think we were deliberating and weighing things, it was just, can we do this? And it was at that point, as his parents, we knew we could do anything, that, no matter what, we could handle it. And if he wanted to go, he would have to go on his own.

The ethical decision may be experienced not so much as a deliberative affair of weighing benefits and burdens but rather an asking, "can we do this?" The

answer may not simply be a response to a question of feasibility. Instead the answer also involves feeling the expected consequence of the decision "day-in and day-out." The eidetic meaning of the ethical decision may then be found in the experience of feeling the appeal, the child's face, that un-makes the looming end-of-life decision. In this way the decision may be un-made from what was perceived initially as an option.

The ethical decision as indecision

For the parent, the decision moment may be an ethical encounter that places him or her in a situation of irresponsible responsibility.

We were asked to make a decision about Isaiah. We needed to decide whether to carry on, or whether to stop. They told us that, if he survived, he would almost certainly be severely impaired: never walk, never talk, and likely never see. He would not share our world at least in the way that we live it. Thinking of Isaiah, I thought of my other children. I remembered their faces when they were young. I thought of the dreams we had for them. What continuing on with Isaiah would mean for them. We would have less time for them. There would have to be sacrifices. Sacrifices that I would never want my children to have to make. Still, Isaiah is also my child. His face is no different!

What ought he to decide *for* Isaiah? How many challenges are too many for a child to face? How much is too much for Isaiah to bear? As the ethical appeal of the child transcends rationality, the father is faced by the faces of all of his children. In his ethical response to their faces is a deep sense of responsibility. He knows himself to be responsively responsible for Isaiah. And he is also responsible for all of his other children. The responsibility does not originate from himself but from the others: his children. Consequently, the significance of the decision may be in the experience of being held in indecision: the father cannot satisfy the demands of responsibility for all his children at once. Perhaps all the father can responsibly do is defer the decision as indecision, to endure the indecision.

Deciding the decision

A decision may haunt the parent and require more decision.

I find myself coming back to the decision. I go to brush my teeth, and I find myself thinking about it. It is like a mood that does not seem to go away. Even though I made my decision. I still think of it as not closed, not finished, not done. I still see it as a possibility. This morning we were eating our breakfast, but I just found myself distracted. Their conversation seemed to interrupt me as some kind of deliberation goes on. Really, whatever activity I am caught up in—eating, drinking, driving, whatever—I am still in this moment of decision. It is

exhausting but I am just not ready to let it go. To accept my decision. To remain decided. I am, and I am not, where I need to be. I am back there beside the incubator looking at her. I am back there looking at her face. I am reliving the discussions, reliving the decision, I am revisiting the decision as if unmaking it. It is like the decision is a place that I cannot get settled in but also cannot leave.

Here is a NICU situation where a mother still seems to live in-decision: distracted, preoccupied, and torn. The decision will not settle.

Yet when a child continues to get worse and an ethical decision is forced, we may wonder if the decision—uncalculable and unthinkable—may be resolved not by thinking but rather by appealing to chance, leaving it to another, or even by taking a leap.

I do not know at what moment it was, but at some point, I stopped hearing the risks of transplantation, and I finally knew what we had to do. We had been struggling, trying to understand what we should decide. We were going through the process again—how they would qualify her for listing, what being listed would mean, the risks of transplantation, the benefits—all of it. I was listening to what they were saying when I remember suddenly feeling settled. It was done, completed. I was moving on. The decision between palliative care and heart transplantation was made. I had to give her the chance of transplantation no matter the risks, no matter what she may have to go through, even if she died on the waiting list. I had to do that as her mother. I went back to her bedside after the meeting and sat there, looking in her eyes, seeing her face. She was my daughter needing a transplant.

Discussion

It would seem that what we consider as an ethical decision may be experienced by parents in a complex variety of ways.

For some parents, there are ethical decisions that are not quite decisions. And if there is no perceived choice, the healthcare professional's need for a decision may turn into a moment when the parent can only express his or her wants and desires for his or her child. So although the decision may come from the parent, owned as "my" decision, we may wonder if the decision is truly a decision at all, or rather simply a documentation of the wishes of a parent for his or her child. Of course, from a rational perspective, this kind of "nondecision" can be seen as a decision as well. But the point is that medical professionals need to understand that this kind of nondecision decision is a possible experience that some parents may encounter.

Other decisions may be experienced by parents as problems in need of deliberation. These dilemmas may require not only a "thinking through," but

also a "feeling through." Resolution relies not just from weighing benefits and burdens but also from parents fundamentally asking of themselves: What do we feel comfortable with? Does the decision feel right? And ultimately, can we live with it? This manner of questioning does not necessarily position an ethical decision away from the "best interests of the child." Instead, it may situate the decision relationally in the parent's encounter with his or her child as the parent asks: What ought "I" to do for my child?

If in the end a parent cannot settle into a decision—necessitating the appeal to technology, nature, or fate—the health professional may find him or herself drawn deeper into the ethics of the decision. These situations emphasize the need for a collaborative, or even at times a delegated, decision-making whereby the professional assumes a greater role (Madrigal et al., 2012).

These insights about parental decision-making need no generalization but instead an acknowledgement that different parents may experience the moments of ethical decisions contingently in different ways. And just as an ethical decision may be a complex predicament for the parent, much is also demanded from the healthcare professional confronted with the responsibility of helping a family navigate difficult life predicaments.

The problem remains that physicians, who often take the professional guiding role in decision-making, may not feel adequately prepared for this critical area of practice (Boss, Hutton, Donohue, Pamela, & Arnold, 2009). Even seasoned practitioners may experience gaps and lacks of understanding between the worlds of healthcare provider and patient-family as professionals and parents approach collective decision-making differently (Alderson, Hawthorne, & Killen, 2006). As such, it would seem that medical practitioners and other healthcare team members need to gather and develop nuanced understandings of the possible experiences that different parents may encounter in differing and contingent ethical decision circumstances. This study has aimed to contribute to filling this gap.

Further research is needed into the experience of ethical decision-making especially as the medical landscape changes incorporating advanced technologies, often in the context of differing or conflicting cultural values, and so forth. While studies have identified factors that may be important for professionals to consider in parental decision-making such as medical prognosis, race, and religion, these analyses have not revealed how parents are relationally informed or directed by their own experiences of parental responsibility (Arad, Braunstein, & Netzer, 2008; da Costa, Ghazal, & Al Khusaiby, 2002; Doron, Veness-Meehan, Margolis, Holoman, & Stiles, 1998; Moseley et al., 2004). In other words, they do not provide insights into how parents are situationally affected by the vulnerability, singularity, and alterity of their newborns. For the professional, empathic understanding of possible

parental decision-making experiences may be important in meeting the communicative needs of parents in collaborative decision-making (Boss, Hutton, Sulpar, West, & Donohue. 2008, Brosig, Pierucci, Kupst, & Leuthner, 2007; Kent, Casey, & Lui, 2007).

While the focus of this study has been on "major" decisions, there are also day-to-day choices such as holding, breastfeeding, and other events that may constitute significant ethical responsibilities (Alderson et al., 2006). These latter decisions may be so ordinary that they are not overtly acknowledged as decisions even though they may be felt by the parent as of great consequence.

Conclusions

Although theoretically the ethical decision tends to be understood as a rational, deliberative affair striving to be based on the patient's best interests, the actual lived experience of this event is more complex. Decision experiences cannot be conceptually simplified for generalization nor be necessarily fitted into a resolution framework. Healthcare practitioners instead may do well to develop critical yet nuanced understandings of the possible experiences that parents may encounter in in the moment of the ethical decision. On the basis of more refined phenomenological understandings of parental experiences, practitioners may be able to muster a personal ethical response.

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8. Conclusion and apologies to Uranus

Perhaps up to this point, this very time in history, we have misunderstood Uranus.

> Loathed from the first by their very own father, who, when they were infants,
> Tucked them away in a hole in the earth and prevented their coming
> Up to the light; and Uranus rejoiced in his own evildoing.
>
> (Hesiod, 2005, p. 58)

In retelling the myth of Uranus we may wonder: Can we see more to his action than rejection? Was he so solely filled with hatred and loathing? Or did his burying gesture perhaps reflect a measure of care? After all, Uranus did not destroy his children. He did not commit murder. Instead, he tucked each one away, concealed them, in a safe place: the protective place of their own gestation. Perhaps Uranus' experience, his understanding, only differed from that of Gaia.

Above the ethical decision

Uranus, the sky, in many respects was hovering above the ethical encounter of Gaia and her children. He was afforded another perspective, from a heavenly order, to see what was occurring below. Imaginably it was an observing, examining, or even contemplating look as he appraised the situation, just as he saw it, from a distanced view.

To Uranus, the children perhaps appeared unprepared for the world. They were relatively feeble and weak compared to Uranus' own immensity and strength: unable to challenge him. Challenge not in the sense of defy; but rather challenge in the sense of *come up* to him as an equal. Gestation had not yet equipped them to thrive.

Uranus never had a father. And so he did what an inexperienced father might do. He made a choice of reason. Notwithstanding the suffering that he knew it would cause his partner, Uranus prudently placed immature child after child back into the safety of the womb. Still we may wonder, was this rational choice ethical? And if so, in what sense?

Consider in comparison the notion of the transitional figure: the advocate, the therapist, the teacher, or the researcher (Waldenfels, 2011).[1] The transitional figure properly lives in distanced proximity, neither outside nor wholly within the encounter between self and other. And from this third place, while the figure may have the capacity to be touched by the other, he or she is also limited from wholly transgressing a certain order. The order is not an institutional framework, a professional code, or some other form of rule-contracting convention. The order is ontologically the vocation as lived: being the advocate, the therapist, the teacher, or the researcher. The transitional figure occupies a special place in that he or she is simultaneously close and distant from the other in their care.

Uranus as the sky is depicted as of a heavenly rational order: above, yet exposed to, the down-to-earth encounters below. But his distance from his children is different. He simply cannot descend to feel what is contained within the depths of the earthen world. After all, to come in contact with his children, he would cease being the untouchable sky. So Uranus is the inexperienced parent, close but not being able to benefit from the distance of the transitional figure.

In contrast, the physician, the nurse, the social worker, and other health professionals may be considered as transitional figures. Their disciplines necessitates a certain closeness but also a degree of professional distancing from the patient. Unlike the mythical figure of Uranus, real world professionals are not so divine and omnipotent. We may hear such phrases as "he is too close" or "she is too involved" used forebodingly to appraise the professional figure who comes near to breaking from their clinical order to assume a position of un-orderly ethical responsivity.

So order does not mean that the health professional may not be ethically addressed by the child. Nor does it mean that the professional may not experience responsivity to the parent. The figure is "always transgressing the limits of the order it represents" (Waldenfels, 2011, p. 157). But it does mean that the professional may experience a different ethical response afforded by virtue of his or her lucidity and distance.

The ability of the health professional to experience some sort of genuine human encounter with the child or the parent is still necessary to his or her humanity. After all, to suffer through the experiences of the child and the

[1] Transitional figure speaks to a figure whom is situated impermanently in-between the ethical encounter of the self and the other. The word transitional is perhaps unfortunate as it may also imply that this figure is temporary or inconsequential in the lives of others. Transitional figures such as teachers, nurses, and doctors clearly may leave lasting impressions on people.

parent may in the end allow the professional to draw nearer to the meanings inhering in the ethical decision—to muster his or her own nonprofessional professional moral response.

A different description

Is this all we ought to say? That as physicians, nurses, social workers, and other health professionals we enjoy an unusual third position? Or is there more disorder to this order?

I recall a clinical colleague taking care of a very premature child. The child was very fragile, not only in the critical illness sense, but also the baby's body itself was fragile—thinly skinned, softly boned, and delicately featured. As the child became sicker, it became necessary to view the heart to gain a sense of its function. My colleague appropriately obtained an ultrasound machine, unbundled the child to expose the chest, and pressed the probe against the sternum to look at the filling, contractility, and ejection fraction of the organ. When she was satisfied, having finished the ultrasound study, she removed the probe. Then she looked at the chest: it was bruised. The pressure of the probe had been too much. She was horrified by what she had done.

How is it that the professional touches and is touched by the child? On the one hand, the professional needs to probe to understand and manipulate pathophysiologic processes. And on the other hand, he or she must also stand back to encounter and relate to the actual patient he or she is responsible for. Consider two opposing gestures of the hand:

> The hand that grasps and shapes confronts *obstacles* and stands under the sign of a struggle with nature; while the hand that greets and blesses operates under the aegis of a *threshold* which makes possible a meeting of persons. (Jager, 1996, p. 29).

From the scientific attitude, the clinician perhaps encounters an *obstacle* aiming to penetrate, breach, and expose: the child as a heart. Yet from a non-scientific attitude, the clinician may stand on a *threshold* to encounter the human: the child as a child.

Perhaps it is only in removing the ultrasound probe that the look of the child as a child is revealed. In this moment, the clinician is not seeing the discolored chest as marked by a lesion, an ecchymosis, or other dermatologic description. Instead, the physician sees the bruise meaningfully: a mark that has been inflicted. It is perhaps only from this ordinary attitude where the conditions for an encountering ethics, the appearance of the other, exist.

From this duality, we can perhaps begin to be sympathetic to the clinician who finds him or herself reaching coincidentally in two opposing gestures to touch the child: the gnostic and the pathic touch (van Manen, 1999). Still, are these divisions so clear? And do they allow us to appreciate what is outside of subjectivity?

The ethical technical encounter

Let us now return to the phenomenality of the phenomenon of neonatology as expressed in its *givenness*. The given understood not as the what, the eidetic cause, of the given experience; but rather the given as its *coming forth* into *visibility* (Marion, 1997/2002).

In the mythical encounter of Gaia and Uranus with their newborns, the children do not simply come into being as immaterial objects, without significance, to be accepted or rejected by their parents. The children are not simply bodies, impoverished of meaning, that the mother subjectively intends. Instead, the children have an effect on their parents: effect understood in the fullest sense of sentiment, feeling, and emotion. For in encountering the children, the phenomenality of the phenomenon of neonatology comes forth in the responsivity of the parent as responsibility. And as considered, responsibility seems to be of a different order for Uranus than for Gaia.

We are not only interested in the experience of Gaia and Uranus. It is also the lived experience of the (re)born technical children, exemplified by Kronos, that concern us. How do they experience responsibility? And what are the latent possibilities of the way in which the initial encounter between parent and child is facilitated or hindered?

Surely, Kronos in carrying the serrated sickle is unlike his mother (and father). He is a technical being whereby his thriving, his very being, is dependent on his ability to embody the tool. And perhaps by virtue of his technicality, his lived experience is inundated by the technological. Recall Kronos' encounter with his father:

> Ushering night in, Uranus visited Gaia, desiring
> Amorous intimacy; he extended himself all around and
> Over the earth, while his son from his ambush protruded his left hand;
> Taking the formidable broad serrated blade in his right, he
> Hastily cut off his own father's privates and cast them behind him.
>
> (Hesiod, 2005, pp. 59)

As Kronos stood in ambush, he carried the long, serrated sickle, with the capacity to do what his mother had been unable to do. The capacity came not

from the tool, but from his ability to hold the sickle. For in holding the sickle, his hand, his arm, his very being became the instrument. He became capable of the gesture of slicing, cutting, and maiming: a gesture that was beyond the nature of his mother. And so he came forth, encountering his father, sickle *as* hand.

The image of Kronos provides a metaphor for the modern human as a technical being. In the NICU, neither the health professional nor the parent's ethical experiences of the child can be fully understood without also considering the various effects that the different medical technologies may infuse and latently carry into the encounter between self and other. For example, the child may come forth into the visibility by the clinician holding the ultrasound probe, a modern sickle, not as a child but instead as a heart to be seen. And it may only be in laying down the probe that the child may come forth into visibility in unmediated responsibility. Again, while it may be tempting to consider technologies as simply either present or absent, we might recall the neonatal monitor screen, which massages the parent's sensibilities in complex ways (van Manen, in press).

So while the focus of the papers in this dissertation have explored the ethical experience of the child from the perspective of the parent, we should also remember that these technologies are also formative of the experience of the professional.[1] Still we should not look at technology despairingly. The modern human not only is constituted by the technological, humans may also (re)design the technologies that constitutes them: these are ethical-moral acts.

The ethical-moral act of the technological

How ought technologies be designed to mediate our ethical encounter with (an)other? How should we use technologies so that their applications may create or foster morally good effects? And how should we equip others with technologies to positively affect their being-in-the-world?

Imaginably these could have been the kind of moral-ethical questions that concerned Uranus and Gaia as they encountered their children. While the focus of this study has been the ethical encounter with (an)other, we may also consider what is moral:

> Moral experience encompasses a person's sense that values that he or she deems important are being realized or thwarted in everyday life. This includes a person's interpretations of a lived encounter, or a set

[1] And likely profoundly formative of the experiences of the NICU child in ways that we do not yet fully recognize.

> of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust. (Hunt & Carnevale, 2011, p. 659)

It is precisely because of the ethical, the lived encounter with (an)other, that the moral experience of the right-wrong, good-bad, or just-unjust may occur. And for this reason, technologies are not only critically interwoven with ethics but also with our morality.

Bernard Stiegler (1994/1998, 2003) deepens the relation of the human to technics by reminding us that our humanity is constituted by technology. The human being has always been a technical being. More so, he tells us that it is our prosthetic capacity to embody technologies—our original flaw, lack, or *défault*—is what makes us inimitably human. Technologies serve to supplement or defer this lack: the "flaw cannot be *made good,* the lack can never be *filled*" (Stiegler, 2003, p. 156). Our relationship with technology is co-original in the sense that the technical does not emerge out of the (already constituted) human nor does the human out of the (already constituted) technical. The fundamental moral question then becomes how are we to shape and design our technologies, to reinvent ourselves, as the inventive technical involves the becoming of our humanity.

> It is always in the play of exteriority that decisions are made. Questions which call for decisions arise only like this: they always go through exteriority, they are induced and led, more or less palpably, by exteriorization. (Stiegler, 2003, p. 163)

To equip or not to equip the child, to use or not use a technology, is a question of exteriority as it lies outside of self. While the *ethical* demand is felt formative of the "me," the *moral* decision presumes agency, makes me an "I." Technology thus requires a moral decision: the exteriorization and questioning of our prostheses imposed by our originary *défault.* And so the moral question comes to ask, what and how ought "I" to design, build, and use technologies? The "I" reflectively and interpretatively weighs benefits and burdens to deal with issues of justice, society, and so forth. It is the technical "I" that judges along the spectrums of right-wrong, good-bad, or just-unjust

And so we regard technologies in moral terms in the sense as to whether they play a "good" or "bad" role in our lives—even if it is not possible to blame them for the "bad" (Verbeek, 2011, p. 1). A morality of materiality, however, not only speaks to what possible human actions a technology will afford, but also what human actions will the technology promote, prescribe, or script (Achterhuis, 1995, Akrich, 1992; Latour, 1992). And while the question of what constitutes the "good" may move us closer to the domains of moral philosophy, the questions are never wholly separate from the experience of the other.

To consider the design of neonatal medical technologies in moral-ethical terms then asks, how do we want to design technologies such that they cultivate a particular manner of encountering the other? Ought we even to take advantage of this technomedical opportunity? Or perhaps, more reflectively, recognizing that technologies may have a formative effect on the relation of parent and child, how can we not consider ethical and moral dimensions in their design?

As technical human beings, professionals or parents, we are afforded to use, design, or build technologies that not only affect us and our relation to the other, but also the other and his or her relations to yet others. In this sense, we may be responsible for the latent effects of technologies on others. We may wonder how do neonatal technologies affect not only the professional and the parent but also the becoming of the child? What opportunities do they promote or discourage? What are their existential significances for the child of the now and the child of the future? What are the consequences of beginning life in a hospital place?

And so we see that while Gaia's decision was ultimately born from responsivity, in the end it became an ethical-moral act. These profound ethical-moral questions need further consideration and study in various clinical contexts. A critical thoughtfulness towards technology is clearly required whereby we do not only view technologies instrumentally but also as formative of our very humanity. And while the answers are unlikely to be solely founded within phenomenological inquiry, phenomenology may help to identify, explicate, and raise these issues. Phenomenology may reawaken us to their ethics.

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