

Ethical Responsivity and Pediatric Parental Pedagogy

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Abstract

This article explores the experience of ethical responsivity from the perspective of the parent whose child requires medical care. 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. Examples are taken from the practice of neonatal-perinatal medicine where newborns require hospitalization for issues such as prematurity, transitional problems, congenital abnormalities, and so forth. Here, the condition of the child and the techno-medical environment itself have the potential of complicating the touching contact of parent and child.

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 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 1969/1961, 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 (1969/1961), 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, 1981/1974, 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, 1989/1949, 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 responsiveness 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, 1962/1945, 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 responsiveness 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, 1998/1946). 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, 1968/1964, 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, 2005/2000, 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 (1962/1927), 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, 1981/1974, 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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