

Premature Birth and Quality of Life between Present and Future. Family Constellations and Relational Dimensions in Special Education

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Abstract

Preterm birth is an event that affects about 30,000 babies a year, in Italy alone. The great advances made in neonatology (especially in recent decades) have drastically reduced the risk of mortality. The contribution intends to analyze the phenomenon of prematurity according to the parental and family dimension. Premature parents, in fact, are immersed in a situation for which they were not prepared, and which could interrupt or threaten the harmonious relationship with the newborn. In particular, the analysis will focus on the maternal and paternal pathways, in accordance with international literature. The goal is to promote interdisciplinary synergistic actions, which involve Special Education, both in direct support of families, and in the preparation of generative welfare actions as well as in the preparation of welcoming and family-centered environments within the Neonatal Intensive Care.

Keywords: preterm birth, glass parents, motherhood, fatherhood, NICU.

Abstract

Il parto pretermine è un evento che colpisce circa 30.000 bambini l'anno, solo in Italia. I grandi progressi compiuti in neonatologia (soprattutto negli ultimi decenni) hanno ridotto drasticamente il rischio di mortalità. Il contributo intende analizzare il fenomeno della prematurità secondo la dimensione genitoriale e familiare. I genitori, infatti, sono immersi in una situazione alla quale non erano preparati, e che potrebbe interrompere o minacciare il rapporto armonioso con il neonato. In particolare, l'analisi si concentrerà sui percorsi materno e paterno, in accordo con la letteratura internazionale. L'obiettivo è quello di promuovere azioni sinergiche interdisciplinari, che coinvolgano la Pedagogia Speciale, sia nel sostegno diretto alle famiglie, sia nella predisposizione di azioni di welfare generativo, nonché nella predisposizione di ambienti accoglienti e centrati sulla famiglia all'interno delle Terapie Intensive Neonatali.

Parole chiave: prematurità, genitori di vetro, maternità, paternità, Terapia Intensiva Neonatale.

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1. *Parenting and premature birth*

Although it is still difficult to explain, in terms ordinarily used in developmental psychology, how a child's genes can interact with the surrounding environment to guide its development, we can support, with some certainty, the decisive role represented by parenting on present and future well-being, especially in the first three years of a child's life. The intentionality and planning of parents represent two of the most powerful educational dimensions, which are experienced through the performance of three important duties: a reflexive one, a relay (or community) one, and an orchestration one. These duties are permeated, in a transversal way, by a protective one, which concerns the satisfaction of the child's needs, that is the ability to give love and protect him from fears (Lacharité, 2015a; 2015b; Milani, 2018).

Parents are not born, but become parents, through an evolutionary process involving major identity changes that affect the individual and the couple.

It may happen that the physiological time span of gestation, for various reasons linked to genetic, epigenetic, or environmental factors, does not reach the physiological end of 39-40 weeks, but is interrupted by the preterm birth of the baby (WHO, 2015). The prematurity of the newborn can be a critical event for development since the baby has an organism that is still suitable for uterine life and not yet ready for external life (Aite, 2017; Stefana, Lavelli, 2016). However, in addition to the baby, there is also a couple of premature parents: a father and mother who find themselves taking on their parental role before they are ready, at a delicate stage when the psychological and pedagogical processes of pregnancy have not yet been completed.

It is therefore evident that preterm birth does not constitute the direct and safe contingency for the acquisition of forms of disability or difficulty, but represents a condition of fragility that concerns, for a more or less long time, the baby born and also his/her family. The parental couple, in fact, can be strongly affected by the situation experienced by the unexpected anticipation of the birth event, with implications that may affect both perceptions about the self and one's sense of parental self-efficacy, and the relationship with the baby. We are faced with "glass parents" (Amatori, 2021), not only for the explicit reference to the machines that guard the newborn and that give continuity to the uterine environment within the Neonatal Intensive Care Unit, in addition to intervening in the first contacts, and above all for the emotional condition of the parental couple, so fragile and delicate.

In fact, glass risks being a real filter capable of conditioning the Quality of Life of all the protagonists, in the form of prejudices, fears, worries, which can last for some time, even when the pain and the worry have now been transformed into memory.

2. *Maternal constellations*

The transition to parenthood is a crucial event for the entire family unit. However, we can say with some certainty that it is particularly so for the mother. During pregnancy, in fact, the woman's body becomes a welcoming home, «a sacred space for physiological care and emotional protection» (Amatori, 2019, p. 26). While the body is engaged in the baby's "physical" gestation, a new identity is gradually built in the mother's mind, which inevitably involves two ideal images: one linked to the idea of the type of mother one wants to become, the other to the mental image of the child who will come into the world. In agreement with Stern and collaborators, we can affirm that «in a certain sense, there are three pregnancies that proceed at the same time: the physical fetus that grows in the womb, your psychic structure that is oriented towards motherhood and the imaginary child taking shape in your mind» (Stern *et al.*, 1999, p. 31).

It is Stern (1995) who defines the *maternal constellation* as the mental state of the woman who becomes a mother, which allows her to prepare herself adequately for the new role she will play. This precious passage causes the child to begin to occupy a space in the mind of the mother who already physically welcomes him through the changes in her own body. The precious time of this phase is necessary to order and manage desires, fears, and fantasies that revolve around the maternal function in the culture of our society. It is a discontinuous and unsystematic time, which is experienced in alternating phases during the long months of pregnancy.

Research in the psychological field (Stern, 1995; 1999; Brazelton, 1973) highlights a precise excursus that unites the cycle of construction of the maternal identity: from a representational void in the first weeks of gestation, we arrive at the birth of the child in the maternal psychic world starting from the third month, thanks also to the reassurances on the normal progress of pregnancy that are combined with the perception of the first movements of the fetus within itself. Between the fourth and sixth month, the mother's fantasies become more and more specific to

reach, then, the maximum elaboration between the seventh and eighth month: it is in this moment of pregnancy that the representations begin to form about the child's behavioural traits and temperament. The fantasies come to a halt with the eighth/ninth month and with the approach of childbirth: an important psychic process that facilitates the encounter with the real baby and detaches from the imaginary one, which originates in the very desire for motherhood.

The premature birth of a child interrupts the regular path described so far. The birth, in fact, takes place in a very delicate phase, in which the imaginary child is still very vivid in the mother's mind. This condition has repercussions in maternal life through a real elaboration of bereavement, in which the loss is connected to the imaginary child but also to the image of oneself as a good mother. In fact, "glass mothers" often experience a feeling of incompleteness, given by the impossibility of being able to adequately carry out a pregnancy, even if the conditions of the event are to be considered totally beyond their control.

The traumatic reality of prematurity combined with a damaged and damaging vision of the parental self - as well as of one's own child - implodes the parental function. High levels of anxiety and sadness, as well as a sense of learned helplessness, can hinder the processes of reparation and resilience.

These complex and delicate aspects can compromise the initiation of the mother-child relationship.

In particular, the experience that the mother has to face following the birth of a premature baby can be divided into three main moments.

The first is temporally placed in the moments immediately following childbirth, when the conditions of fragility and transience of the child lead the mother to an oscillating emotional experience between hope and optimism (also linked to the need to continue to hope) and feelings of guilt, fear, and anxiety. The "primary maternal preoccupation", described by Winnicott (1981) as the state of mind that allows the mother to identify with her child and to respond to her basic needs, is undermined by the sudden separation that takes place at birth when the baby needs intensive care.

The second moment, often related to the first, leads the mother to have to deal with the sense of failure for not being able to carry the pregnancy to term, a feeling that can also be generalized to the idea of not being a "good mother".

In the third phase, the increased chance of survival of the newborn and the effective possibility for the mother to play a more active role

in the care of the child, allows the re-construction of the relationship interrupted abruptly with the birth and facilitates a “rekindling” of affectivity.

To ensure the start of this last, precious phase of resilience, it is appropriate to underline the importance of hospital policies and practices, as well as the training of operators, to which, however, we will return later. Unlike what happened in the past, in fact, in which the fear of infections, as well as the delicacy of technological machinery (combined with very little attention to the preparation of health personnel on a psychopedagogical level), implied a marked separation between the newborn premature baby and his/her parents (especially the mother), care practices today take into account parental and family dynamics, embracing a holistic vision that sees, in the neonatal setting, the entire family unit as a subject of attention (Negri, 2012; Aite, 2011; 2017).

The meetings with glass mothers conducted by Candelori and collaborators (2013) have, once again, confirmed the prevailing trends in the experience of parenting after premature birth. Among these, the sense of guilt and the fear of loss which, often, intensifies when the mother is discharged and returns home without the child.

In the words of some mothers interviewed it is possible to find almost a sense of strangeness towards the child born, combined with a feeling of unreality. The dependence of the newborn on the machines and the care of the medical-health staff slows down the building of an intimate and exclusive relationship with their child, to the point that many mothers do not seem to feel completely “responsible” for their child yet, almost like if this did not belong to them and every time, they had to ask permission to be near them.

Glass mothers have often been deprived of the first “sensorial” encounter with the baby, which represents the line of continuity with that physical containment that had the baby’s first growth, made up of hugs, eye contact and the privileged and exclusive relationship between mother and child symbolised by the breast attachment, «in which all the preverbal expression of love is concentrated, which has a vital meaning for every child» (Musi, 2007, p. 192). The birth did not represent an encounter, but a separation, significantly affecting identity and parental planning. To paraphrase Winnicott (1987), the mother’s care for the baby started inside her body but did not arrive in her arms.

In conclusion, therefore, the possible negative influence on the attachment dimension between mother and child is not necessarily the event of the infant’s hospitalization in the Neonatal Intensive Care Unit

(NICU), but rather the architecture of a value and individual system that oscillates between ambivalent feelings of hope and anticipated mourning, between waiting for resignation and role anxieties. It is, therefore, appropriate to act on family cohesion, on the quality of the hospital environment and, therefore, on the implementation of pedagogical support – as well as psychological – within the wards, in order to reduce the feelings of learned helplessness and involve actively the mother in the care of the child and in the re-construction of his role identity.

3. *Where is the father?*

In situations of preterm birth, in which newborns are hospitalized in NICU, the role of the father assumes a specific relevance, because new mothers are often bedridden due to the physical conditions in which they find themselves after the childbirth. As Colombo (2011) suggests, fathers are almost always the first to be able to interact with their child, albeit through the incubator and to perform a series of specific tasks, for example: talking to neonatologists, reporting to their partners information they were able to perceive (often in a filtered way), accompanying the new mothers, once recovered, to get to know their respective children (Stefana, 2016). Therefore, there is an evident reversal of roles: while, in ordinary situations, birth brings the baby closer to the loving gaze of the mother, who can finally hold him/her in her arms, and only then to the paternal gaze, in preterm births the father suddenly finds himself filling a physical and emotional distance that separates the newborn from his mother, both in need of attention and care. According to Fava Vizziello (2010), these men, often in total loneliness, experience “stress without rest”, to alleviate – as far as possible – the situation of their partners, burdened, moreover, by work commitments from which they cannot escape.

Emotional reactions related to stress, anxiety and depression are therefore not completely uncommon in fathers, as well as in mothers. However, it is a question of «a state of emotional distress that [...] is not immediately evident because the symptomatic-logical manifestations of the fathers are different and more difficult to observe than those of the mothers» (Stefana, 2016, p. 485). Furthermore, there is still little scientific evidence regarding this question, probably because men tend to be less willing to participate in research (because they are more reluctant to disclose their emotional problems).

Further studies have shown that many fathers within the NICU do not feel free to let themselves go on an emotional level. Some fathers have expressed constant worry and an inability to relax, others also describe an effort to appear calm and show nothing on the outside, in line with the masculine ideals of independence and self-reliance (Candelori *et al.*, 2015).

Furthermore, a recent American study (Garfield *et al.*, 2017) founds that, at discharge, the cortisol levels recorded in the fathers showed that they were more stressed than the mothers, even if this emotional state was not reported in the questionnaire they had filled out on perceived stress. The fathers interviewed stated that their main role was to meet the needs and requirements of the mothers and that they did not expect mutual support from them.

The role of health professionals within NICU turns out to be rather delicate and important. It is they, in fact, who, through a semeiotic gaze (Stefana, Gamba, 2014), can grasp signs of emotional malaise and intervene to safeguard father-child and father-mother relationships.

NICU can turn out to be a privileged space for observation, since the operators have an institutional space-time setting that is particularly suitable for this purpose.

It is becoming increasingly clear, therefore, that NICU represents a context of attention to the whole family and not just to the baby. In fact, putting the family at the center of the entire care project means respecting the rights and dignity of the newborn and his/her parents but also building the basis for a healthy and harmonious growth of a new family and its individual members.

Conclusions

In conclusion, we believe it is fundamental to reiterate the perspective of Special Education within the founding dimensions of “being in the world”, especially in situations of fragility and vulnerability. «The “difference” is, in fact, an ontological attribute and an essential phenomenological datum pertaining both to the natural sphere and to the anthropological and cultural dimension» (d’Alonzo, 2019, p. 298).

Especially for what concerns preterm birth and NICU, the sharing experience can represent the central element of taking care of the fragile person (in this case, the newborn and his/her family) through processes of awareness very far from the idea of determinism and predetermination (Bocci, 2019).

The encounter between the medical, psychological, and pedagogical dimensions can make the difference (here the importance of prevention) in supporting vulnerable parents in premature births. This translates into a support towards the contingent needs of the protagonists (mothers, fathers, hospitalized child, any siblings), and the dimension of family planning, in that delicate process that connotes parenting in the transition phase from sharing as a couple to planning for the family.

Special Education has the task of supporting the planning capacity of parents towards their children in difficulty, firstly, and of the protagonists themselves, then, who, by exposing themselves to confrontation and the continuous need for reorganisation, without succumbing or giving up, will overcome disorientation through continuous and regenerated learning.

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