

## Preterm Infants: Parenting Implications and Perspectives in Early Childhood Special Education

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### **Abstract**

Preterm birth is an event that affects about 30,000 children a year, only in Italy. The great progress carried out in the context of neonatology (especially in recent decades) drastically reduced the risk of mortality. However, it should be reminded that these children may have a high risk of developing such serious complications which could potentially lead to permanent pathologies or disabilities, especially for those born to lower gestational ages (WHO, 2015). This contribution intends to analyze the phenomenon of prematurity according to the parenting and educational-teaching dimension. Premature parents, in fact, are immersed in a situation to which they were not prepared and which could interrupt or threaten the harmonious relationship with the newborn. For this reason, interdisciplinary synergistic actions should also be promoted in a way which calls Special Education both in direct support to families and in the preparation of generative welfare actions affecting educators and teachers, as valuable allies in early intervention and in the implementation of fully inclusive and efficient educational services for early childhood.

**Keywords:** Preterm birth; Parenting; Special Education, Quality of Life.

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### 1. Special Education view on preterm births

The World Health Organization (2015) defines preterm births as those events in which delivery occurs before the 37th week of gestational age.

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Moreover, newborns can be classified according to their birth weight in low (< 2500 grams), very low (< 1500 grams) and extremely low (< 1000 grams). Those born between the 23rd and 33rd week of gestation and weighing less than 1000 grams are defined as “extremely preterm” and have the most difficulties and complications related to the event of prematurity.

The reasons behind a preterm birth are not fully known. Nevertheless, pathological conditions could interest either the mother (chronic diseases, infections, smoking, alcohol and drugs abuse, hypo/hypertension, etc.) or the foetus (multiple pregnancies, placental or uterine causes, foetal distress), increasing the risk of a preterm birth.

Neonatological science has made undoubted progress over the last few decades which has, in fact, dramatically reduced the risk of mortality from over 70% in the 1970s to less than 15% in the 2000s (Amatori, 2021). We have, in particular, been witnessing a process of “humanisation” of neonatal intensive care, which has also involved the restructuring of dedicated wards from an increasingly family-centred perspective. In order to fully understand the scientific progress underpinning the processes of care and attention to a preterm infant, it is enough to remind that up to thirty years ago small newborns were considered not able to feel pain (or rather this pain was not localised and, therefore, not “conscious” and not to be remembered in the future). For this reason, surgical operations were performed without anaesthesia on newborns, particularly on preterm ones (Aite, 2017).

However, it has later been proved that newborns not only feel the painful stimulus, but also retain a memory of it and that their pain threshold is similar or even lower compared to older children. Moreover, it has been shown that repeated painful stimuli, but also simple *discomfort*, and, more generally *stress*, can lead to harmful repercussions (physical and psychological) which can be demonstrated at a later stage and can worsen the disease state and/or hinder the healing process. (Aite, 2017, p. 14)

In Italy, preterm infants account for about 7% of annual births (Cedap/ISTAT, 2016). The extensive scientific literature and, particularly, the studies carried out by Bowlby (1999), Winnicott (1987) and Stern (1998) have proven the need of contact between the newborn baby and its mother in the first hours and days of life, in order to enable the bonding and attachment processes, which are needed for good maternal containment and care and the normal development of the child.

The preterm infant must be regarded in respect of its abilities: it is not a term newborn with a deficit, but rather an individual whose functioning is suitable for the uterine environment and unsuitable for the extra-uterine environment.

Newborns depend on adults' decisions, from which the thread of their existence will unravel. The very event of birth itself represents in an unmistakable and blatant way the start of a planning and educational process, which is, however, not likely to be perceived in terms of awareness, expression and sharing by parents. Particularly in the case of a preterm birth, the parental couple may be strongly affected by the situation experienced beforehand, with implications that may concern both their perceptions of themselves and their role (also in terms of self-efficacy), and their relationship with the baby. In other contexts (Amatori, 2021), we have defined the mothers and fathers of preterm infants as "glass parents", precisely to emphasise the emotional and identity vulnerability characterising the family ecosystem in its intra- and inter-systemic relationships, which can affect all protagonists' quality of life.

Therefore, a preterm birth does not itself embody a direct link to the development of any form of disability or deficit, but it is undoubtedly a condition of vulnerability involving all protagonists for a shorter or longer period of time, affecting their quality of life. In this dimension, Special Education fits rightfully the role of *care* science, in the deepest meaning of a competent guidance (Gaspari, 2021) gradually leading to new points of view on the world, of rediscovered planning skills, whose endless variety is not only related to the mutability of personal stories, but also to the diverseness of past experiences and representational alternatives, originating from the encounter with the self and with the other.

## 2. Relationship parent-child in preterm birth: attachment and emotional interactions as protective factors

Literature of various sciences, such as pedagogy, developmental psychology, clinical and social psychology and psychoanalysis, uses the term "parenthood" in relation to a broad construct of growth and care skills towards children, which has taken on different dimensions over time, depending on the theoretical frame of reference considered.

The parenthood process undoubtedly involves the process of generativity, but not necessarily in a unidirectional way. Generativity usually evolves towards parenthood, but in other circumstances the parenthood project itself triggers the individual's and the couple's generativity (Cena, Imbasciati, 2010). However, it may be impossible for generativity to be supported or to evolve towards parenthood due to complex, inner, intra-psychic, interpersonal or social adversities. What specifically defines this transition, in fact, is the dimension of planning allowing an evolution from the physiological aspects of procreation to the educational, social and role aspects, typical of the maternal

and paternal conditions. The very event of birth itself must be indeed considered inside a multidimensional and procedural logic which entails the restructuring of the couple at different levels: first of all, in terms of functioning, which from dyadic becomes triadic, but also representational in terms of interpretations and past experiences, as well as social, considering the transition from couple to family and from family to society (Amatori, 2021).

The gestational path involves a specific time in which the dream of generativity is idealised and then materialised at birth. During the nine months, the future parents are required to manage with balance the complex interaction between the child's narcissistic dimensions and object investments, as well as to "fill" this time with planning and projective perspectives regarding the care responsibility towards the child. In fact, it is the child being the parent.

Motherhood and fatherhood are, however, specific dimensions, complementary to each other but not similar, within which parenthood takes place. Women become mothers according to a "natural" order, which is part of a biological process. Men, on the other hand, become fathers through a symbolic system belonging mainly to the order of culture (Cena, Imbasciati, 2010). What the two paths have undoubtedly in common is the waiting time, during which the man and the woman face a series of changes related to the transition from the title of son/daughter and husband/wife to that of mother and father. Those transitions require the deconstruction of the previous balance and a long process of readjusting and reorganisation.

It can happen, however, that the physiological time of gestation is interrupted beforehand by a preterm birth. Prematurity is a vulnerable condition of the newborn, which carries also a premature couple of parents becoming mother and father before being ready, in a delicate stage in which the psychopedagogical processes of pregnancy have not yet been completed. Instead of a happy event, the parental couple is forced to face a reality which is very different from what they might have envisaged during the pregnancy. As pointed out by Cena and Imbasciati (2010), «preterm birth is an abrupt breach of the hopes and expectations also towards the families of origin: the "life debt" to one's own family cannot be fully discharged, and there may also be a certain difficulty in placing and welcoming the newborn child within one's own family history» (p. 156).

In such a delicate condition, the two dimensions of educational care on which the event of a preterm birth might place considerable strain, are those involving relationships and planning. As a matter of fact, parents have lost the space needed to process the experience ahead of time (Stefana, Lavelli, 2016). In particular, mothers and fathers feel deprived of the possibility to provide their children with medical and basic care (such as breastfeeding, cuddling, changing their nappies...), thus creating a separating space which might put

couple's resilience, their planning capacity and the process of identification with the parental function and attachment to test (Stefana, Lavelli, 2016). A great deal of studies has shown, in this regard, that the emotional impact of a preterm birth on the parent and the way the parent copes with it, are crucial in influencing the child's behaviour and emotional development (Macey et al., 1987; Latva et al., 2008).

The painful emotions experienced by the mother and the father during the hospitalisation in the neonatal intensive care unit can jeopardise the stability of an early and harmonious relationship with the baby. In this sense, the path seems to be rather diversified between mother and father.

Specifically for the mother, the experience of prematurity can be experienced in three substantial moments. The first can be found in the moment immediately after the delivery, when the vulnerable condition of the newborn leads the mother to live an oscillating experience between optimistic and hopeful urges and discouragement, fear, anxiety. At a second stage, guilt induces the mother to interpret the experience as feeling responsible for not having been able to regularly carry the pregnancy to term. These interpretations, accompanied by feelings of incompleteness, can even be generalised to the point of developing the idea of not being a good mother, affecting the sense of self-efficacy and identification in the new role. The third stage, which is undoubtedly more resilient, reignites affection and it is strongly determined by the actual possibility for the mother to play a more active role in the child care. The rediscovered sensorial contact with the baby, experienced, for example, through the increasingly widespread practice of kangaroo-care, allows the restoration of the physical relationship between mother and baby, thus fostering a rediscovery of the experience.

In preterm birth situations, the father's role is particularly important, as mothers are often bedridden due to their postnatal conditions. These men often experience 'stress without rest' (Fava Vizziello, 2010) in the difficult attempt to support their partners – often filtering the information received from the medical team or accompanying them to meet the newborn for the first time once physically recovered – but burdened by work duties from which they cannot escape.

Both changes in the emotional structure of parents and relational difficulties may be overlooked by common observation with the risk of being underestimated. This is the fundamental reason why parents and children already need interventions aimed at promoting greater relationship intimacy as well as specific attention from professionals, during the hospitalisation in the neonatal intensive care unit.

The process of humanisation of neonatal intensive care and the attention which has been paid to family-centered approaches and to the early

reconnection of the family to the newborn (Bollini et al., 2009; Aite, 2011; 2017; Amatori, 2021) have undoubtedly and gradually brought to a deep transformation of spaces and contexts of neonatal care, transitioning from a kind of care oriented towards the “task” to another oriented towards the individual, from a vision of the parent as a “visitor” to parents considered partners in the whole care process. As a result, such approach is mainly oriented towards the person and takes the quality of life of the child and its family into consideration.

### 3. Prematurity and its educational and didactic implications

Studies in the field of neuroscience have shown how brain maturation, which was until recently considered an exclusive result of the genetic code, actually depends on the learning process of messages conveyed by the sensoriality of maternal and paternal contact, carried out by the neural networks of the foetus and the newborn (Cena, Imbasciati, 2010). A preterm infant must spend considerable time in the intensive care unit, which means, as mentioned above, that it is impossible for it to benefit from such sensoriality, which is instead the case for a term newborn. Moreover, studies in this direction have had the merit of bringing back to light the importance of the educational relationship, conceived as a practice «allowing each person to transcend a condition of incompleteness to transform and steer their own existence» (Maggiolini, 2021, p. 109), disconnecting it from a dimension of obviousness or innatism. The increasingly striking fact is that the quality of the parent-child relationship is responsible for each subsequent psychic and psychosomatic development of the child.

The separation from their own child, which parents have to undergo, can entail an emotional upheaval that research has shown to be essential to ensure that the child can optimally benefit from those silent learnings, essential for the functional maturation of the neural networks (Cena, Imbasciati, 2010).

International research data seems to be rather unanimous in considering preterm birth as a factor of greater vulnerability with respect to the potential outbreak of certain emotional, socio-affective, behavioural and/or learning difficulties.

In the United States, in particular, the preterm birth incidence accounts for 12%, which is why it is possible to estimate that there may be up to four children prematurely born in a class of a medium-sized US primary school (Hornby, Woodward, 2009).

Baron and colleagues (2012), in a review of late preterm birth neuropsychological and medical outcome literature, reports lower intelligence scores, more attention and internalizing problems, and poor academic achievement at age 5 years, with higher socioeconomic status and maternal education being protective. Baron and colleagues (2012) further identified risk of developmental delay even in children identified as “healthy latepreterm”. (Kelly, 2015)

According to the scientific literature review proposed by Battge and colleagues (2014), children born only a few weeks before their physiological term also seem to be at risk of having difficulties at school. This aspect increases in the case of male preterm infants, who have an extremely low birth weight (less than 1000g) and require on average an additional year of school before entering employment or higher education, and whose adult income is 25% lower compared to that of those born with a standard birth weight.

As a result, it would seem that low birth weight and low gestational age may be, in every respect, potential predictors of future special educational needs. The above-mentioned study carried out by Bettge et al. (2014) in Germany has, as a matter of fact, underlined the value of early childhood educational services (nurseries and pre-primary schools) in terms of early intervention, which is strongly able to limit the risk of developing learning difficulties in preterm children.

The work conducted by Michelle Kelly (2015) at Villanova University points out how preterm children are present in studies concerning children affected by learning difficulties, behavioural difficulties or medical conditions (for ex. asthma), without being indeed recognised as being preterm. This “omission” is not of minor importance, as it underlines how the experience of prematurity, after the event itself, is hardly taken into account, thus risking of not taking prompt and timely actions of prevention and of plans development to optimise the achievements of these children.

The learning difficulties experienced by preterm children by the time they enter school are associated with the fact that many of them, especially in pre-primary school, do not receive specific interventions, whereas teachers' assessments of learning progress can be particularly promising as a simple and effective means to identify these problems in a timely manner and, therefore, intervening in a targeted manner (Taylor et al., 2011).

The association between low birth weight and/or prematurity and the onset of Specific Learning Disorder has been recently object of investigation. The outcome associated with the occurrence of this risk factor is a below-average performance in reading, writing and calculation. However, this is not always sufficient to reach a relevant diagnosis of SLD. Yet, the Consensus Conference (2011) highlights that delays in reading, writing and calculation skills are

anyway associated with preterm births. These are difficulties particularly arising in the first years of school and persisting through adolescence. Reading difficulties are particularly noticeable and are characterised by the production of about twice as many mistakes. Difficulties in reading skills at school age may increase if medical complications are also associated with the preterm birth. For example, those affected by a bronchopulmonary dysplasia obtain lower results in reading skills (Kelly, 2016; Taylor et al., 2011). The studies conducted with preterm children have reported the occurrence of clear difficulties with the writing process. It has been shown that preterm children have lower performance in handwriting legibility and writing speed. This could be related to difficulties in sensorimotor skills, particularly fine coordination, skills of manipulation and of visual-motor integration.

Very few studies have, however, been carried out on calculation difficulties. General numerical and mathematical skills were examined using standardised tests. Once again, difficulties in mathematics are particularly noticeable when a medical complication is associated with the preterm birth.

Lastly, Farooqi and colleagues (2013) focused on the potential correlation between a preterm birth and difficulties involving executive functions. The Swedish researchers examined about 80 children, born very prematurely (before the 26th gestational week) at the age of 11 years old, with the aim of assessing the potential occurrence, frequency, characteristics and severity of behavioural problems related to executive functions and learning abilities. These children have been compared to a group of the same age, using a diagnostic tool of proven reliability.

The results revealed that children with a history of prematurity faced significantly more problems in behaviours related to executive functions (attention, hyperactivity/ipoactivity, impulsivity, planning and organisation, working memory) and a deficit in learning abilities compared to the control subjects. It should be emphasised that only a small portion of preterm infants (between 10 and 30% depending on the investigation modality) had a clinically relevant impairment.

The authors conclude by underlining that prematurity can be considered an 'overall' condition (without, therefore, alarmism or preconceptions), but they recall that it may be associated with certain "fragilities", of which it is necessary to be aware and which need to be addressed with an accurate diagnosis and appropriate, targeted and timely support interventions.

#### 4. Critical issues and research perspectives in Special Education

As far as the topic addressed in this contribution is concerned, we would



like, without any claim of exhaustiveness, to identify the problems and highlight possible solutions in terms of educational responses, which can be tested at a theoretical-practical level (Amatori, 2021).

First of all, we would like to draw the attention of Special Education to preterm births, together with the general dimension of birth and the perinatal period, which are still poorly investigated in our disciplinary framework. With regard to prematurity, it should be noted that, according to data from the Italian Society of Neonatology (SIN) the current global situation linked to the Covid-19 pandemic has led to a surge in preterm births, especially during the lockdown of March 2020. During the first wave (with an analysis ending on the 27th of July 2020) preterm births to Covid-positive mothers accounted for 19.7%. However, looking at the data up to the 15th of September the percentage dropped to 14%. According to the National Covid-19 Registry, this is more than double compared to the usual average (ANSA, 2020).

In the light of these data, the educational interest towards prematurity certainly deserves further attention in relation to ethical, as well as educational and didactic dynamics.

The coexistence of personal and family histories and care services implies, in fact, a moral competence that is first and foremost ethical, since it recalls basic values to be shared. It is precisely pedagogical ethics pushing us towards the virtuous reconciliation of protective and, at the same time, emancipatory drives with regard to fragility situations. In fact, this direction is the basis of any proper life project.

Educational issues primarily involve the family dimension also according to the logics of prevention and targeted intervention, which are triggered by awareness-raising practices in different, but always multidisciplinary, contexts and spaces (Giacconi, 2019). In that behalf, the role of Special Education is valuable and indispensable in a purely epistemological sense, as it is oriented towards foresight and feasibility of planning and methodologies.

From an educational point of view, several open questions remain, which are worth analysing firstly at the level of possibilities, then at that of implementation.

Ensuring quality social inclusion means promoting goals and results identified with children's belonging, engagement and learning. Participation is, therefore, a key process to reach those results and emphasises the crucial role played by early childhood education services. The predominant approach is indeed still focused on performance rather than services, as shown by 2019 ISTAT data concerning the mismatch between supply and demand fulfilment. The crisis endured by families with regard to the complex attempt to reconcile care tasks and work needs is exacerbated by the potential occurrence of difficulties connected to the weak health of their child. Moreover, it finds no

place in a social welfare system which is unable to enhance (in political, economic, structural and educational terms) the significance of nurseries and pre-primary schools. These are, in fact, safe and welcoming spaces, ensuring the quality of children growth and education and able to support social, emotional, physical and intellectual learning and to promote the development of new skills in a way that positively affects children development and quality of life.

In this framework, the preparation of educators and teachers is undoubtedly a relevant and particularly important aspect, as they are the first having the opportunity to observe children in their very first social interactions with their peers outside the domestic environment. Their contribution is key in providing appropriate, timely and inclusive intervention with regard to the development and growth of children.

In conclusion, despite progress in neonatological care, preterm birth continues to represent a risk factor for the child's development and a potentially stressful event for parents. It is, therefore, essential to more systematically implement interdisciplinary actions of prevention and intervention, in which the role of Special Education is valuable and crucial for the wellbeing of the child, its family and care professionals.

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