Emilia Afrange

We Need to Talk About Prematurity

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Preface

It is essential to talk about prematurity, especially in a country where this issue is present in 11% of families – there are approximately 320,000 premature births per year in Brazil. They comprise a very heterogeneous group of children, ranging from the threshold of viability, with extreme immaturity, to near the end of pregnancy.

The occurrence of premature birth is always striking, but fortunately, for most parents, this repercussion will be transitory. The baby is more mature and, having overcome only a few initial difficulties, its parents will be able to take it home when discharged from the maternity hospital.

For others, however, this experience will be much more complex and begins in the delivery room, when the feeling of joy at birth is accompanied by the tension of parents and professionals. The contact with the baby is very brief and surrounded by uncertainties.

Later on, it comes the daily participation in the routine of a neonatal intensive care unit, an unknown and frightening universe, but fundamental for the survival and future quality of life of the premature baby. Seeing your child in an incubator with various equipment – tracheal tube, respirator, feeding tube, catheters for medications and monitors, among others – means a sadness that can only be overcome with a lot of resilience and with the support of health teams and family members.

For some this situation means months of hospitalization, and a roller coaster of emotions. Arrivals at the neonatal intensive care unit are surrounded by uncertainties, like, "How was its night?", "Is it breathing any better?", "Got an infection?", "Accepted the milk well?", "Started to gain

weight?". Each answer may mean a deepened concern or a renewed hope.

Alongside personal feelings, there are these bonds that form between families and the sharing of emotions. Each loss is felt by everyone, but any achievement also impacts and cheers the families and the team. And there are plenty of these achievements during the hospitalization – breathing unaided, suckling, leaving the incubator. Until the long-awaited moment – hospital discharge!

Then, other concerns arise, "Will we know how to take care of the baby?", "Will it get sick?", "Will the baby grow up, walk, talk?", "How well will the child do at school?". These questions will only be answered in time and, fortunately, in most cases, there will be favorable answers.

However, when looking at the premature baby after hospital discharge one needs to be very careful so that the necessary therapies are initiated at the right time. Monitoring by a multidisciplinary team is essential for many prematurely-born babies and, ideally, this should include professionals in the areas of pediatrics, neurology, ophthalmology, physiotherapy, speech therapy, occupational therapy, psychology, neuropsychology, nutrition, dentistry, nursing and social work. Thus, the integrated work of the team with the family is essential for the child to fully achieve its potential for growth and development.

This book is the result of the work developed with much dedication by Emilia at the Outpatient Clinic for Prematurely-Born Children at the São Paulo School of Medicine of the Federal University of São Paulo (UNIFESP), where children and adolescents born prematurely up to the age of 20 are assisted by a multidisciplinary team. Most of them are at high risk of biological, psychological and social

complications. While working together and integrating with the various professional categories (twelve people in all) we have all learned a lot, thus gradually improving patient care and assistance to family members, so we feel now that we are certainly contributing to the promotion of the quality of life of children, adolescents and their families.

In this publication, the relevant aspects of prematurity are presented, ending with the psychological issues that the author knows in depth and shares with readers, providing them with a very interesting and pleasant text, which will certainly contribute to the dissemination of this theme, which for us is so vital.

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Introduction

The first concepts, to support our conversation: babies born alive before the 37th week of pregnancy are considered premature. In addition, based on the number of weeks of pregnancy, prematurely-born babies can be classified into three types: **extremely premature**, born before the 28th week of pregnancy; **very premature**, those born between the 28th and the 32nd week of pregnancy; and **late premature** babies, for those born between the 32nd and 37th weeks of pregnancy.

I take this opportunity to make a remark: although the most common denomination is "premature" when people refer to these children who are born before the 37th week of pregnancy, I always try to use the expression "prematurely-born babies." My intention is not to endorse a stigma associated with the word "premature" that, if used improperly, could become a way to justify any future commitment.

Prematurity is a global and growing public health issue. Over the past few years, the issue of prematurely-born babies has gained more attention in several spheres worldwide. So much so that initiatives such as the creation of the European Foundation for the Care of Newborn Infants (EFCNI) emerged in 2008; the institution of World Prematurity Day (November 17) in 2011, to raise awareness about the millions of babies that are born prematurely each year; in addition to *Born Too Soon*, a report published in 2012 gathering a set of information, initiatives, commitments and actions, prepared by the World Health Organization, which coordinated a work conducted by 30 worldwide organizations focused on the well-being of prematurely-born babies.

All this because prematurity is the main cause of neonatal mortality (children aged up to 28 days old) and infant mortality (children aged up to 5 years old) worldwide. If that were not enough, more than one million children die each year from complications during premature birth.

Prematurity is known to be an important cause of high morbidity (risk of being affected by diseases), and it is also associated with long periods of hospitalization. Prematurely-born babies who manage to survive may have to live with health problems for life, as some of them tend to have complications in their physical, cognitive, emotional and behavioral development, which result in difficulties for their families and society as a whole.

Experience shows that prematurely-born babies are at increased risk of malnutrition, anemia and respiratory complications, hearing and visual problems, as well as changes in the development of their nervous system – including retardation of motor and speech skills. Prematurity potentially brings with it a greater risk of cases of autism, attention deficit and hyperactivity, not to mention psychiatric disorders.[1]

Consequently, the outcomes of prematurity are not restricted to the period immediately after birth. Coming into the world before the 37th week of pregnancy can affect the biological, psychological and social development of the baby, since biological birth does not imply psychological birth – they do not coincide chronologically. In fact, they lie on different substrates. And it happens naturally in the development of any baby, whether they were born prematurely or not.[2]

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1 Institute of the Prematurely-Born Child – Living and Smiling. 2018 Annual Report. Available on: <institutodoprematuro.org.br>. Accessed in January 2021.

2 Institute of the Prematurely-Born Child – Living and Smiling. <https://www.institutodoprematuro.org.br/publicacoes-e-documentos>. Accessed in January 2021.

Biological birth is a delimited and observable event, which implies the necessary physical separation of the baby from its mother in order for the development of the child to happen in a progressive manner. But psychological birth is different. It is a gradual process in which the illusion of merging the child with the mother is necessary, which leads to a special "psychic birth." I need to emphasize this again, this is true for all babies, not only for babies born prematurely. The experience of separation can happen only if this special condition is met. Thus, the baby will have elements to realize that its mother is not an extension of itself, but someone else, distinct from it.

PART 1
STATISTICS

1. The Relevance of the Subject

2. The Figures Concerning Brazil and the World

3. Fetal Development

1

The Relevance of the Subject

According to the World Health Organization (WHO), an estimated 15 million babies are born prematurely every year in the world. This is more than 1 child in 10, that is, more than 10%. Approximately one million babies die each year from complications due to their premature births. And many of the survivors will have to face a life with physical complications, such as learning disabilities and hearing or sight problems. Not to mention the psychological aspects, which we will see later.

Economic and social inequality around the world directly affects the survival rates of babies born prematurely. In low-income settings, **half** the number of babies born before the 32nd week of pregnancy end up dying due to a lack of resources and care, such as lack of care in the face of breathing difficulties, human affection, breastfeeding and precaution against infections, among other causes.

In turn, in high-income societies, virtually all babies born prematurely survive. Between these extremes, even considering babies born prematurely in the homes of middle-class families, who survive, there has been an increase in complications and deficiencies due to the underutilization of technologies and resources.

The Solution

According to the World Health Organization, more than three-quarters of babies born prematurely can be saved with basic and relatively affordable care, such as providing steroid injections during the prenatal period (given to pregnant women who are at risk of premature delivery) , under

certain conditions, to strengthen the lungs of the babies); appropriate care during birth and throughout the postnatal period for all mothers and babies; antibiotics for the treatment of infections in newborns; and the "kangaroo" method (where the baby is carried by its parents with skin-to-skin contact).[3]

The prevention of deaths and complications in the lives of babies born prematurely start with a healthy pregnancy. Quality care before and during pregnancy should ensure that all women have a positive experience during this period. The guidelines for the prenatal period, issued by the World Health Organization, include specific indications to prevent premature births, such as advice on food and nutrition, to be kept at optimal levels; the use of tobacco, alcohol and other substances is not recommended; measurements of the dimensions of the fetus, by means of ultrasound examination, to determine the period of pregnancy and a possible multiple pregnancy; and a minimum of eight contacts with health professionals, during pregnancy, to identify and act on risk factors. In addition, more access to contraceptive methods and increased empowerment of women could lead to a reduction in the number of premature births, according to the organization.

[3] The "Kangaroo Mother" method, devised by Colombian physician Héctor Martínez. This method has the advantages of increasing the mother-child bond, avoiding long periods without sensory stimulation by decreasing the mother-child separation time; it stimulates breastfeeding, which favors its greater frequency, precocity and duration; improves thermal control, due to a higher rate of change of beds; decreases the number of newborns in intermediate care units; decreases the rate of nosocomial infection and allow for shorter hospital stays.

Why Premature Births Do Happen

There are several causes for babies to be born prematurely. Most of these births happen spontaneously. But some of them are the result of an anticipation of labor or caesarean sections, sometimes for medical reasons, sometimes not. It is known that women who have had this experience before, as well as those pregnant with twins or multiple pregnancies, are at greater risk of premature birth. Also included are women with a history of cervical or uterine problems, or even with infections and chronic conditions, such as diabetes and a high blood pressure.

In addition, certain factors can lead to a premature birth: absence of prenatal exams, smoking, alcohol consumption, drug use, stress, urinary tract infections, vaginal bleeding, diabetes, obesity, low weight, high blood pressure or pre-eclampsia, clotting disorders, some congenital anomalies of the baby, very close pregnancies (less than 6 to 9 months between the birth of a baby and the next pregnancy), pregnancy as a result of *in vitro* fertilization, and age under 17 or over 35 years old.

However, it is very common that there is no specific and identifiable reason. It may even be that there is a genetic influence. A greater understanding of the causes and mechanisms involved in this issue should lead to an advance in the development of solutions for the prevention of premature births.

The Figures Concerning Brazil and the World

According to data collected by the World Health Organization, more than 60% of premature births occur in Africa and South Asia. But the organization points out that this is a truly global issue. In countries with low-income populations, on average, 12% of babies are born prematurely. In the case of rich countries, this rate drops to 9%. A constant fact for all nations is that the poorest families are those who are most at risk of premature birth.

According to official data for 2010, the 10 countries with the highest number of premature births are the following:

1. India: 3,519,100
2. China: 1,172,300
3. Nigeria: 773,600
4. Pakistan: 748,100
5. Indonesia: 676,700
6. United States: 517,400
7. Bangladesh: 424,100
8. Philippines: 348,900
9. Congo: 341,400
10. Brazil: 279,300

On the other hand, the 10 countries with the highest rates of premature births per 100 live births are the following:

1. Malawi: 18.1 premature births per 100 live births
2. Cameroon: 16.7
3. Congo: 16.7
4. Zimbabwe: 16.6
5. Equatorial Guinea: 16.5
6. Mozambique: 16.4
7. Gabon: 16.3
8. Pakistan: 15.8
9. Indonesia: 15.5
10. Mauritania: 15.4

There are countless conclusions that can be drawn from the data presented above. But it is important to highlight one fact: there is a significant difference in the survival of premature babies depending on where they are born. For example, more than 90% of extremely premature babies (born before the 28th week of pregnancy) who are born in low-income countries die during their first few days of life, but where income is high, this percentage drops to less than 10%.

Brazil

One of the most relevant recent studies on the issue of motherhood in our country was the survey "Childbirth in Brazil," coordinated by the Sergio Arouca National School of Public Health (ENSP) of the Oswaldo Cruz Foundation (FIOCRUZ), which brought together researchers with training in epidemiology, obstetrics, perinatology, pediatrics and obstetric nursing from several institutions. The survey consisted of observing 23,984 women and their babies in public health establishments, affiliated to the Unified Public Health System provided by the Brazilian government or to private healthcare networks, from all Brazilian states, in which more than 500 births occurred each year, between February 2011 and October 2012.

Part of the results were published in December 2016 and, according to the study, the excess of obstetric interventions and the low use of good practices in childbirth care continued to be common practices in Brazil. Furthermore, the rate of prematurity in our country reached 11.5%, almost twice as high as that observed in European countries, with 74% of these babies being late premature (born between the 34th and 36th week of pregnancy). In absolute numbers, there are about 340 thousand babies born prematurely in Brazil each year, according to the Ministry of Health (data for year 2019).

At the time, the coordinator of the study, researcher Maria do Carmo Leal, warned of the possible consequences of this reality. "Prematurity is the biggest risk factor for the newborn to get sick and die, not only immediately after birth, but also during childhood and adulthood. The damage goes beyond the field of physical health, reaching the cognitive and behavioral dimensions, making this

problem one of the biggest challenges for contemporary Public Health," she stated.

Costs

Recent data indicate that in a period of four years (between 2012 and 2016), there was a 56% increase in premature births in Brazil – and nothing indicates that there was a decrease or even stabilization in this trend.[4] It is important to note that the impact of the birth of a prematurely-born baby goes far beyond the sequelae, both physical and psychological, that this type of delivery usually leaves on children and their families.

I will now address the issue of costs. Between October 2016 and June 2019, the Brazilian Association of Parents, Family Members, Friends and Caregivers of Prematurely-Born Babies (NGO *Prematuridade.com*) conducted a survey with 2,900 families who had babies born prematurely. The objective was to identify possible actions for the prevention of prematurity in the country.

Among the most outstanding results, it was found the following: the average period of hospitalization of babies born prematurely in Neonatal Intensive Care Units, after birth, was 51 days. However, 63.7% of babies stayed longer than 60 days in hospital after birth, and 26% of them stayed in the Intensive Care Unit between two and five months. This is a long time.

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[4] National School of Public Health (ENSP) of the Oswaldo Cruz Foundation (Fiocruz) <https://portal.fiocruz.br/noticia/taxa-de-bebes-prematuros-no-pais-e-quase-o-dobro-do-que-em-paises-da-europa>. Accessed on February 2021.

Regardless of the country, the daily cost of a prematurely-born baby admitted to an Intensive Care Unit is very high. We must remember that we are dealing with newborns, very fragile, who can only survive with the help of sophisticated equipment and expensive medicines. From the survey conducted by the São Paulo Center for Health Economics at the Federal University of São Paulo (UNIFESP), between 2009 and 2011, it was known that the average daily cost of a premature baby was BRL 497.84. Considering the average period of 51 days of hospitalization, the total average cost would be around BRL 25,000 per child. This means that, based on a conservative estimate, making a data projection for the reality of 2020, premature births would cost BRL 8 billion (or BRL 8 thousand million) a year in Brazil.

In turn, a more recent study, conducted by hospital *Santa Casa de Misericórdia e Maternidade* of Rondonópolis, in the state of Mato Grosso, which was presented at the 24th Brazilian Congress of Costs, in 2017, revealed that the average daily costs per patient in the Neonatal Intensive Care Unit was BRL 934.48. Thus, based on the average interval of 51 days of hospitalization for each Brazilian premature patient, the total in the period would reach more than BRL 47,000, which, extrapolating to the approximately 340,000 cases of premature babies born annually, would represent a total cost of more than BRL 15 billion a year for the intensive care of these children.

Fetal Development

During a normal pregnancy, there is a sequence of developmental stages that the fetus goes through. In general, they would be as follows:

1st month

In the beginning, fertilization gives rise to the zygote, a cell formed by the union of the male and female gametes. From a sequence of cell divisions, the embryo will be formed and sheltered inside the uterus. At this stage, the placenta also begins to form, surrounding the embryo with amniotic fluid. It is this liquid that will assist in the feeding of the embryo and protect it in case of an accident (for example, if the mother falls).

2nd month

The heart of an embryo beats rapidly, about 150 times a minute. It is at this stage that the nervous, digestive, circulatory and respiratory systems begin to form. The eyes, mouth, nose, arms and legs also begin to form.

3rd month

The fetal period, which begins in this third month of pregnancy, is marked by the development of the fetus, starting with its skeleton, including its ribs, fingers and toes.

4th month

At this stage, the baby measures approximately 16 cm and starts to move, suck and swallow. The fetus is also able to perceive changes in light and differentiate bitter and sweet tastes.

5th month

The first hair strands, eyelashes and eyebrows appear. The development of the fetus happens in a more intense and clear way. It is when the ovarian tubes and the uterus form in girls. The genitals of boys can be viewed on the ultrasound imaging examination.

6th month

At this stage, the fetus is 32 cm long and is able to recognize external sounds, especially the voice and breathing of its mother.

7th month

Here, the fetus will be between 35 cm and 40 cm long. Inside the uterus, it yawns, opens its eyes, sleeps and moves. The mother-baby relationship, both in the real and in the imaginary aspects, becomes closer and increasingly present.

8th month

In the eighth month of pregnancy, the fetus is between 40 cm to 45 cm long and begins to prepare itself to be in the birthing position, in other words, it is upside down. The bones are already more resistant, and the lungs are almost ready. Meanwhile, the mother-baby relationship grows stronger and broader.

9th month

This is the final stretch. In the ninth month, the baby is between 45 cm and 50 cm long, fully capable of controlling breathing and has all its organs fully formed. The separation is about to happen. From the 37th week onwards, if the entire formation process goes as expected, the baby is ready to be born.

PART 2
THE APPROACH

4. The Consequences for Babies, Families and Society

5. Multidisciplinary Treatment

4

The Consequences for Babies, Families and Society

The issue of prematurity gains increased relevance when we analyze its consequences, in several aspects. Here we will focus our attention on just three of them: the immediate consequences for the babies themselves, their families and society as a whole.

Prematurely-Born Babies

The first important fact is that a premature baby is born with an incomplete body. If there is a standard of time considered normal for the proper formation of all the organs of a person (39 or 40 weeks), any anticipation in that time of pregnancy will result in an unfinished development of that organism. The degree of this poor formation of the body will be directly related to the time of the pregnancy. Thus, babies born extremely premature (before the 28th week) will be those with the most fragile bodies, compared to the very premature (born between the 28th and the 32nd week) and the late premature (between the 32nd and the 37th week).

This implies that, in general, these babies are born with organs that have not yet reached sufficient maturity for extrauterine life – and the Intensive Care Unit (when necessary) or Neonatal Unit will function as an external uterus. Thus, if this baby survives, not only will it have to mature in a very different context from that of its mother's womb, but it may also need intensive therapies of various types to ensure its survival. For this reason, babies born

prematurely usually suffer from several types of health problems, which can negatively affect their vitality, education and their family resources.

In general, the physical characteristics of a premature baby are as follows:

- Low weight at birth;
- Thin, shiny and pink skin;
- Visible veins;
- Little fat under the skin;
- Little hair;
- Thin and soft ears;
- Head disproportionately large in relation to the body;
- Weak muscles and little motor activity;
- Few suction and swallowing reflexes;
- Genitals not fully formed.

In addition to the bodily fragility, health issues must be considered. Babies born prematurely tend to have breathing problems, since they are born with a lack of surfactant, a protein produced by the lungs that allows them to be filled with air. Pulmonary surfactant is a liquid that has the function of facilitating the exchange of respiratory gases in the lungs. Its action allows the pulmonary alveoli – which are small bags responsible for gas exchange – to remain open during breathing. As this protein is produced throughout the maturation of the baby's lungs, around 28 weeks of pregnancy, it is common for babies born prematurely to come into the world without having a sufficient production of pulmonary surfactant. As a result, their clinical condition

may progress to **Pediatric Acute Respiratory Distress Syndrome (ARDS)**, which causes increased respiratory distress. If a baby is born without the ability to breathe on its own, it may be necessary to use mechanical ventilation until the lungs mature. Another treatment is the administration of the surfactant in order to open the pulmonary alveoli and facilitate gas exchange, thus preventing the so-called *apnea* (pause in breathing).

Furthermore, babies born prematurely can also have heart problems. The most common of these complications is the **Patent Arterial Duct (PAD)**, which is the persistence, after birth, of the fetal connection (arterial duct) between the aorta and the pulmonary artery. Normally, this vessel closes shortly after birth, thus allowing blood to reach the lungs. However, in babies born prematurely it is common for these ducts not to close properly, leading to heart failure. For the treatment of milder cases, medications are usually sufficient, but the most serious situations often require surgery.

Another common problem among about 90% of babies born prematurely is **Necrotizing Enterocolitis (NEC)**, an intestinal inflammation in which portions of the intestine undergo necrosis (cell death). This disease is related to the immaturity of the layer that lines the intestines of the baby and is associated with symptoms such as having difficulty feeding, abdominal swelling, blood in the stools, diarrhea, fatigue, unstable body temperature and vomiting. In general, the treatment consists of suspending oral feeding and replacing it with intravenous nutrition, in addition to the intake of antibiotics. In extreme cases, surgeries are required. This is estimated to be the second most common cause of mortality in newborns who were born prematurely.

There are records that, in babies born extremely premature, it is possible to occur cerebral hemorrhages during the first days of life. In most cases, these are minor hemorrhages that are usually spontaneously reabsorbed by the body, without serious consequences. In the most severe cases there may be some damage to the brain tissue.

Another dysfunction commonly found in babies born prematurely is **Retinopathy of Prematurity** (**ROP**), in which there is an alteration in the growth of the retina. It is a major cause of preventable childhood blindness. The proportion of blindness caused by this disease is greatly influenced by the level of neonatal care (which includes availability of expert personnel, equipment, quality and access to neonatal care), as well as the existence of effective screening and treatment programs. Due to this condition, an abnormal growth of the blood vessels in the retina occurs, which can result in the formation of scars and retinal detachment. In mild cases, the disease regresses spontaneously; however, in extreme situations it can lead to blindness.

Last but not least, it was found that premature birth poses significant risks of negative consequences for the brain. The technologies and intensive treatments needed to save the lives of these babies compromise their fetal brain development. The double stress of being separated from the mother and experiencing daily pain and discomfort tend to result in neurotoxic episodes that alter the functioning of the brain.

For this reason, the risks of neurodevelopmental deficiencies in babies born prematurely are significant. Studies in this area have rightly focused on the motor and cognitive sequelae of prematurity. However, research had initially paid less attention to issues related to mood, behavior and emotional disorders of babies. Recent data suggest that children

born prematurely are also vulnerable to changes in behavioral and social development, which can be precursors to learning disabilities and psychiatric disorders that would manifest about the middle of childhood.

Studies on these issues were already conducted, indicating that a good percentage of children born prematurely manifest problems at school and affective difficulties. One of the causes for these difficulties would be the fact that, when hospitalized for long periods, babies would be separated from their parents for a long time, which would lead to increased anxiety and a possible interference with the parents-child bond.

Despite the small number of studies in this area and the consequent lack of data for more accurate conclusions, it is considered that, as a group, children born prematurely are described as more introspective, less adaptable, less persevering and less stable from the point of view of mood, during their first years of life, when compared to children who were not born prematurely.[5]

It is worth highlighting an important psychological aspect: "(...) babies, like children, have strong primitive needs for safety and satisfaction of their instincts, which pediatricians and psychiatrists call *anaclitic needs* (from the Greek *anaklinein*, which means "to lean upon"). These involve the need to be hugged and feel skin contact, be caressed, comforted, play and be the center of attention. When these needs are not met, there are serious negative consequences for the future of the individual."[6]

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[5] Riese ML. Temperament in Full-Term and Preterm Infants: Stability over Ages 6 to 24 Months. *Journal of Developmental & Behavioral Pediatrics*. 1988;9(1):6-11.

[6] *The Way of the Psychonaut: Encyclopedia for Inner Journeys*, by Stanislav Grof, MD.

Families

The consequences of having a prematurely-born baby, for parents, unfold in several aspects. Starting with the suffering of seeing your baby fighting for life in an incubator, with limited access to it. The mortality rate of babies born prematurely is much higher than that of babies born from a pregnancy considered normal, and this information becomes a ghost to haunt the lives of the parents during the stay of their baby inside the incubator. Thus, it is common for parents to feel guilty, who assume responsibility for the precarious situation of the newborn child. Another important aspect to consider is the collapse of parents' dreams, who had fantasized during pregnancy about the future relationship with the new baby and that, suddenly, everything turns into nightmarish moments. In fact, this impact goes beyond the relationship, which can be translated into a question like, "But, which one is my baby?". The fantasy created during pregnancy falls apart, giving way to a mourning for the idealized baby who did not appear, who was not born.

In addition, as the baby's permanence in recovery inside an incubator can vary from days to months, the family routine is affected and it needs to adapt to the new circumstances. This means reorganizing not only the parents' professional activities, but also the care of their other children and relatives (if any) and their most immediate plans. Until the baby is free from the risk of death and fully recovered, part of the parents' life is kept in a state of suspension.

This new situation also includes additional financial costs. It is not just the expense of staying in the maternity hospital for longer than expected. It is necessary to take into account that, in more severe cases, a premature birth

can lead the child to be affected by motor, language, hearing and vision disorders, in addition to suffering from behavioral changes and a delay in schooling. In this scenario, the development of a prematurely-born baby usually requires time and money to be invested in professionals such as pediatricians, nutritionists, physiotherapists, speech therapists, neurologists, psychotherapists and social workers – not only during the child's first 1,000 days of lifetime – considered critical – but also during early childhood and often during adolescence.

Society

The consequences of the birth and development of each prematurely-born baby also fall on society as a whole. Take into account, for example, the increase in the survival rates of these children. This implies an increase in costs for health systems, which need to make use of incubators and other resources, in addition to professionals for the care of these babies, sometimes for months.

In addition, if there are negative physical, mental, emotional or behavioral consequences, a concentrated effort must be made, so that this child can grow and become a citizen adapted to social life. When these children enter school, for example, new challenges reveal other difficulties. The rates of learning disabilities in prematurely-born babies are usually higher, and mathematical reasoning seems to be the most affected. In addition, good school performance is more compromised in the presence of Attention Deficit Disorder, whose rates tend to be much higher in babies born prematurely.

Finally, by imagining a thread of life that unfolds itself month by month, year by year, it is possible to have a clue

of how much time, energy and financial resources should be invested in order to ensure that a prematurely-born baby will have a life that is both worthy for itself and productive for society.

5

Multidisciplinary Treatment

With so many difficulties to be faced by a prematurely-born baby, as well as by its family and society itself, it is necessary to organize a whole infrastructure so that this child can grow and develop properly. But, first of all, for the baby born before the 37th week of pregnancy the first big challenge is to survive.

Survival

Good news: the continuous medical and assistance advances in the field of Neonatology (a branch of Pediatrics that deals with babies, from birth to 4 weeks of age) have allowed a considerable improvement in the survival rates of prematurely-born babies. Neonatal Intensive Care Units, which function as an extracorporeal uterus, promoting an artificial continuation of pregnancy, are increasingly better structured – both in terms of equipment and in the training of professionals allocated there.

Several studies to monitor the development of prematurely-born babies indicate that the chances of survival of these children are conditioned by the following factors: gestational age, the weight of the baby at birth and the complications that it undergoes when it comes to the world. Among all these factors, the most important is gestational age, since it determines the maturity of its organs.

It is still quite difficult to predict the future disability of a baby born before full term, but there are factors that lead to an increased risk of sequelae. Unfortunately, some of them can only be diagnosed through the child's developmental stages.

Research has shown that, for premature babies born at 22 weeks of pregnancy, survival rates range from just 2% to 15%.[7] As few babies born in this condition manage to survive, there is still not enough information about the possible sequelae for this group of children.

As for the group of babies born at 23 weeks of pregnancy, the survival rates rise to somewhere between 15% and 40%. And for those at 25 weeks, the rates rise even further: between 55% and 70%. For these cases, the data indicate that somewhere between 30% and 40% of these children should develop normally, without major health problems or disabilities. But it is estimated that between 20% and 35% of them are likely to suffer from severe disabilities, such as cerebral palsy, severe intellectual disability, blindness, deafness, or a combination of these problems, which will require significant medical care. In turn, a fraction between 25% and 40% of these babies may have disabilities classified as mild to moderate, such as subtle forms of visual impairment, mild cerebral palsy (which compromises motor control), chronic asthma, learning difficulties and behavioral problems, such as Attention Deficit Disorder.

It is already known that the survival rates increase substantially, to a level between 75% and 85%, in cases of babies born between the 26th and 28th weeks of pregnancy. For this group, approximately between 10% and 25% of them are expected to suffer from severe disabilities, such as cerebral palsy, severe intellectual disability, blindness, deaf-

[7] Brazilian Association of Parents, Family, Friends and Caregivers of Prematurely-Born Babies (*Prematuridade.com*).<https://www.prematuridade.com/index.php/interna-post/prematuro-taxa-de-sobrevivencia-e-prognostico-de-acordo-com-a-idade-gestacional-6648>. Accessed on: February 2021.

ness, or a combination of them. However, studies indicate that between 50% and 60% of them will tend to suffer from mild disabilities, such as subtle forms of visual impairment, mild cerebral palsy (which compromises motor control), chronic asthma, learning difficulties and behavioral problems, such as Attention Deficit Disorder; while between 25% and 40% of these babies are expected to suffer from disabilities of the same types, but ranging from mild to moderate.

In the case of babies born between the 29th and 32nd weeks of pregnancy, survival rates reach a level between 90% and 95%. In this group, between 60% and 70% tend to develop normally, without any problems considered serious. However, between 10% and 15% of these children will be at risk of developing serious disabilities, such as cerebral palsy, severe intellectual disability, blindness, deafness, or a combination of these impediments, a fact that will require considerable medical care. Finally, between 15% and 20% of these babies should be diagnosed with difficulties considered mild or moderate, such as subtle forms of visual impairment, mild cerebral palsy (which compromises motor control), chronic asthma, learning difficulties and behavioral problems such as Attention Deficit Disorder.

The survival rate for babies born prematurely between the 33rd and 36th weeks of pregnancy is over 95%. For this group of preterm children, the risk of developing severe disabilities is about the same as that of children born in due term. However, these babies are at increased risk for mild cerebral palsy, developmental delay and learning difficulties.

The Issue of Breastfeeding the Prematurely-Born Baby

Nothing is more important to the health of babies, during the first days and months of their lives, than breastfeeding. For the case of children born prematurely, this issue is even more relevant, since they come into the world with an organism not fully formed.

However, it is quite common for mothers of babies born prematurely not to be able to breastfeed them to meet their needs – in most cases, it is a hormonal problem. In addition, the learning of these small babies regarding breastfeeding is usually slow and gradual, and it depends a lot on the gestational age at birth, the size of the baby and its health.

It is always good to remember the benefits of breastfeeding, both for the mother and her baby. In the case of the mother, breastfeeding tends to lead to a decrease in postpartum bleeding, a reduction in the likelihood of her developing anemia, breast and ovarian cancer, diabetes and infarction, and favors a faster loss of the weight that has been gained during pregnancy, in addition to favoring the emotional bond with the baby. In turn, breastfeeding causes the baby to receive antibodies from its mother, which help protect it from diarrhea and various types of infections, and also reduces the likelihood of developing allergies, high cholesterol, diabetes and obesity, and increases the likelihood of a sound physical and emotional development of the child, favors the development of its face and speech, as well as the formation of strong and healthy teeth, in addition to favoring the development of good breathing.

In the case of babies born prematurely, there is a fundamental issue: in general, soon after birth they are taken to a Neonatal Intensive Care Unit, so that their health evolution

can be closely monitored there. In this peculiar nursery, the newborn undergoes a series of procedures:

a. first, it will be placed inside an incubator, so that its body temperature remains at an ideal level;
b. from then on, there will be a constant monitoring of its vital signs, such as blood pressure, heartbeat rate and breathing;
c. it is likely that, during the first days of life, the baby will be fed intravenously (parenteral feeding., or that it receives breast milk through a tube that enters its nose and goes to the stomach – this is so until it acquires the reflex of sucking and swallowing (enteral feeding.;
d. constant monitoring of the levels of sodium, potassium and fluids of the baby, so that they can be replaced whenever necessary;
e. if the newborn is unable to produce red blood cells on its own, then it must receive blood transfusions. In addition, depending on the complications that it presents, it will be necessary to administer medications or, in some cases, subject it to surgery.

In an ideal situation, during the stay of the baby born prematurely in the Neonatal Intensive Care Unit, a complete team of health professionals is supposed to care of it. Even after hospital discharge, a series of precautions must be observed at home, especially during the first months. The guidance regarding this care is the responsibility of the multidisciplinary medical team. Taking into account the variety of problems that the baby born prematurely can

undergo – related to feeding, incomplete organic formation, extreme fragility, etc. – it is necessary to keep in mind a holistic approach, that is, an integral view of the child as a patient. At this point, we are referring to a team of specialized professionals: physiotherapists, pediatricians, dentists, psychologists, speech therapists, nutritionists, physiatrists, ophthalmologists, psychopedagogists and social workers, to name the most usual.

The assistance and constant monitoring provided by these professionals, from birth, should provide the prematurely-born baby with the best conditions for its physical, mental and psychological development.

PART 3

PSYCHOLOGY AND PSYCHOTHERAPY

6

Theoretical Foundation Winnicott, Bowlby, Piontelli and Bion

At the beginning of my professional career, I followed the precepts commonly adopted by most of the highly experienced therapists. For example, I knew that my performance would be linked to the following activities:

- Watch the patient closely;
- Work towards developing a degree of tolerance to frustration;
- Bear in mind the emotion/thought relationship;
- Assist in the reconstruction or construction of personal stories, identities and the capacity for emotional resonance.

For us, professionals who deal with the health of the mind, its disorders and dysfunctions, it is essential to be aware of certain precepts and paradigms that are part of our work. Although they seem commonplace issues, we know that we live with them all the time:

- Accept the inevitable limitations of each period of life;
- Accept the inevitability of death;
- Develop the capacity to fight for goals;
- Develop a "feeling of the world" (in a book of the same name, Brazilian poet Carlos Drummond de Andrade

disclosed his feelings of limitation and powerlessness in the world);[8]

- Develop a sense of citizenship, social and family responsibility;
- Develop the capacity to enjoy beauty and moments of happiness;
- Be aware that emotional states fluctuate between moments of greater or lesser psychic integration;
- Develop the capacity to tolerate a varying degree of psychological distress;
- Develop the capacity to work through unavoidable mourning due to evolutionary and accidental losses;
- Develop the capacity to enjoy life.

As it is the case with almost everyone, throughout my academic and professional career I have had contact with several authors, including psychologists, psychiatrists, pediatricians, psychoanalysts and psychotherapists. All of them contributed to my training, but some of them were more important and had a strong influence on the way I understand and practice psychotherapeutic work, especially with children and their parents.

It was from studying the approach and understanding of these professionals, with whom I identified myself a lot, that I ended up developing my view of psychotherapy, which I call "The 3 Pillars." Before presenting my work process, I would like to share a little of the life and works of the therapists who have helped me so much.

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[8] https://www.culturagenial.com/livro-sentimento-do-mundo-de-carlos-drummond-de-andrade

Donald Woods Winnicott

(April 7, 1896 – January 28, 1971)

Winnicott was a British pediatrician, psychiatrist and psychoanalyst who became known for his ideas related to a "true" and a "false" self, to the theory of "good enough" parents and, in partnership with his second wife, Clare Winnicott, developed the notion of "transitional object." Leading member of the British Independent Group of the British Psychoanalytical Society, and President of the British Psychoanalytical Society itself on two occasions (1956 and 1959), Winnicott published several books and articles, and his work was considered an indisputable theoretical and practical advance in the field of child psychology and psychiatry. His ideas focused almost exclusively on the bond between mother and child. For him, the maternal figure was the essential psychological support for the child to develop an authentic, healthy and happy self.

According to experts, these would be Winnicott's main contributions to the field of pediatrics:

- The baby does not exist without its mother – the mother's availability and her safe and affectionate proximity help form the child's psychic identity. The baby needs this physical and psychic envelope to be able to grow, in every way;
- The importance of play – by playing, the child comes into contact with its sense of existence and its identity. From the possibility of imagining, learning, sharing, idealizing and experimenting, the child creates conditions to grow and evolve.

- The upbringing of a child – for Winnicott, it is necessary to trust the mother's instinct, because only she knows what is best for her children at all times.
- The "false self" – this danger arises in the child when it does not feel it is being cared, understood and loved. In this case, it chooses to be "someone else," someone with plenty of needs, who seeks the attention of others.

Propositions by Winnicott:

"The first mirror of the human creature is the mother's face: her expression, her look, her voice. [...] It is as if the baby thought: I look and I am seen, therefore, I exist!"

"The child plays to express aggression, acquire experience, control anxieties, establish social contacts as integration of the personality, and for pleasure."

"For babies to finally become healthy adults, independent individuals, but socially concerned, they totally depend on being given a good principle, which is ensured, in nature, by the existence of a bond between the mother and her baby."

Edward John Mostyn Bowlby

(February 26, 1907 – September 2, 1990)

John Bowlby was a British psychologist, psychiatrist and psychoanalyst, notable for his interest in child development and for his pioneering work on the "Attachment Theory." The idea of the importance of attachment in childhood is usually present in different societies, but it was only consolidated after the creation of the theory devised by Bowlby, who studied and analyzed the effects of its presence or absence. His legacy is vast: although his theory has undergone several modifications and has been interpreted and reinterpreted by several authors, Bowlby's ideas continue to have a major influence on psychology, especially since they emphasize the importance of the emotional bond with our parental figures in childhood.

Key Concepts Developed by Bowlby:

- Humanization of hospitals – The term "hospitalism" designates a state of profound, physical and psychological alteration, which gradually settles in very young children, during their first 18 months of life, due to an abandonment or a prolonged stay in a hospital institution. The signs of hospitalism are manifested by delayed body development, an inability to adapt to the environment and, sometimes, a mutism that resembles autism and can lead to psychosis. In cases of total lack of affection, linked to the lack of any kind of maternal bond, the disorders can reach severe depression and death. From the research and

articles of John Bowlby and other psychoanalysts, in the 1940s, in all countries of the world, there was a reform of hospitalization conditions for very young children.[9]

- Attachment, loss and separation – According to Attachment Theory, babies establish bonds with adults who are sensitive and responsive in social interactions and who remain consistent caregivers for the period from 6 months to approximately 2 years of age. Parental responses lead to the development of attachment patterns which, in turn, lead to "internal working models" that will guide the individual's feelings, thoughts and expectations in later relationships. More specifically, Bowlby explained in his 3-volume series on attachment and loss that all humans develop an internal working model for the self and another internal working model for the others. Both the self-model and the other's model are built from initial experiences with their primary caregiver and shape an individual's expectation of future interactions with others. The self-model will determine how individuals see themselves, which will affect their self-confidence, self-esteem and dependence. The other's model will determine how individuals see the others, which will affect their bonds or approaches, their options for loneliness or social interactions. In Bowlby's approach, it is considered that the human child needs a safe relationship with adult caregivers, without whom normal social and emotional development will not occur. According to the Attachment Theory, the child instinctively

[9] *Revista Educação*, Issue 245, December 2017.

establishes a bond with those who care for it, in order to survive, and its physical, social and emotional development depends on it. The attachment process is not gender-specific, as babies form bonds with any consistent caregiver who is sensitive and responsive in social interactions. The quality of social engagement appears to be more influential than the amount of time spent.[10]

Propositions by Bowlby:

"In a happy partnership there is a constant giving and receiving."

Alessandra Piontelli

(January 17, 1945)

Is an Italian physician, specialized in neurology and psychiatry. She spent a year as an intern in India and then 3 years working and researching at the Children and Parents Department at the Tavistock Clinic, in London. Back in Italy, she became a visiting lecturer at several universities, always in the department of maternal and fetal medicine.

In 1995 she published the book "From Fetus to Child," a description of the analysis of very young children and ultrasound observations of the behavior of the fetuses before

[10] *Revista Educação*, Issue 245, December 2017.

they are born, which suggests a relationship between pre-birth life and the most common childhood psychoses. The advent of ultrasound made it possible to observe the fetus undisturbed in its natural environment. In this book, Dr. Piontelli describes in moving details her observations of the behavior of various children from the earliest stages in the womb, through birth to childhood. The first longitudinal study of this type, this work shows how observation and psychoanalytical data can offer different, but complementary, insights, in an attempt to answer fundamental questions of human development.

Wilfred Ruprecht Bion

(September 8, 1897 – November 8, 1979)

Was an influential British psychiatrist and psychoanalyst who conducted research on group formation and phenomena, among other topics. He began his studies in the British army and continued them in groups at the Tavistock Institute, comprised of people with diverse backgrounds.

He wrote "Experiments with Groups," an important guide to the movements of group psychotherapy and encounter groups, which began in the 1960s and quickly became the cornerstone for the work of applying Group Theory to a wide range variety of fields. Bion's general thinking fits in with the school of Object Relations Theory. He was president of the British Psychoanalytic Society between 1962 and 1965. Many of the concepts developed in his research became relevant to the understanding of work groups and the emotional phenomena underlying them.

Theories by Bion:

- **Theory of Groups** – Each group has a mental activity that has two levels of functioning: conscious and unconscious. While the first is rational and driven by the reality principle, the second is emotional and works through the pleasure principle, that is, the group is oriented towards avoiding activities that are not to their liking. There is also the aspect of Group Mentality, by which the group members meet according to common goals and seek to establish, among themselves, relationships of similarity. In addition, the groups symbolize the feeling of belonging to a family, with the consequences of search for and loss of affection.
- **Theory of Thinking** – For Bion, thinking serves as an outlet to deal with frustration, including the consequences resulting from the capacity of the ego of being able to overcome, or not, the hatred resulting from a certain disappointment. In other words, he says that thinking is the result of a process based on sensory and emotional experiences. Emotion is at the very heart of the meaning of psychic life, and not just an intellectual process. Bion described two types of mental functioning, the "automatic mind" or "proto-mind," and the "symbolic mind." For Bion, thoughts precede thinking and they exist independently of the thinker. He believed that in order to think, it was essential to build a mechanism that would result from the mother-baby relationship: she operating with *reverie*, that is, with the capacity to receive projections from the baby, elaborate them into meanings and return them to the baby, so that it can assimilate the mother's mental functioning.

- **Theory of Transformations** – When an emotional experience has a value of learning and security, thus providing a greater capacity to accept pain.

In other words, Bion expanded the concepts of memory and desire in relation to the practice of psychoanalysis. He even recommended that the analyst let go of these elements when in front of the patient, that is, that he let go of the desire to heal the patient and, moreover, that he went to the office without keeping memories of the previous session.

Propositions by Bion:

"The purpose of an analysis is not that the patient will become just like the analyst, and be cured just like his analyst, but rather that he will become someone in the process of becoming someone!"

"A good analyst is always dealing with an unknown, unpredictable and dangerous situation."

"(...) the only thing that seems to be basic is not so much what we do, but rather what we experience, what we are."

7

My View
The 3 Pillars

Introduction

I was once preparing a paper to be presented at the 2nd Congress on Mental Health: Meeting the Needs of the 21st Century (October 19 to 21, 2018, in Moscow, Russia) – an important world congress on mental health. It would be my second participation in that event, since I was present at the first congress, also organized in Moscow, two years earlier. My intention was to present the sequence of a work that I had already exposed. I realized, then, that the continuation should not be repeated, and that I would need to demonstrate, in 15 minutes, my experience on the topic within the Outpatient Clinic of Premature Children at the Federal University of São Paulo (UNIFESP).

How could I summarize my experience of six years, until then (nine years, in 2021) in terms of what I offered within this service, with a focus on children who were born prematurely? I chose to address the "problem," the issue, in different ways, expressed within a multi-professional team. A team that deals with children who were born before the 37th week of pregnancy and underweight.

I could see that many situations were complicated regarding what to do. How could I manage them? In a way, I had a hard time understanding, and gradually I got acquainted with that – I recognize that I needed to have a dose of patience. Certainly, patience! For one of the first signs that I noticed, in me, is that I wanted to do everything that I thought was necessary to do for those children.

Many of them had survived situations that I could not even conjecture that a human being could endure, having to remain in these conditions of fragility, vulnerability and, often, between life and death for several seconds, minutes, hours, days, weeks, months, sometimes years on end.

I noticed that my listening tried to achieve what was not said, neither by the mother, nor by the team, nor by the child, nor by myself. Those days spent in the incubator, in the Intensive Care Unit, in the Neonatal Unit, with varied needs. Many times, it seemed very distant to me what this child, this family and the medical team had been through – I mean, how that scenario was being set up.

One of my first patients was 4 or 5 years old. He could not speak or walk. He had cerebral palsy. His paternal great-aunt had adopted him. She took care of him and his needs. She brought him in her baby carriage, taking oxygen and a gastric tube to feed him. It was a very striking picture: that paternal great-aunt, of a certain age, fragile and with bones visible in her small stature, was no longer able to carry him as she used to do before. So, his life was like that, since his discharge from the hospital. After he was born, he underwent several hospitalizations due to the consequences of his extreme prematurity.

And I thought: what can I do in this scenario?

The great-aunt was looking for me, as she was referred by a nutritionist who, attentively, noticed the anguish and anxiety interfering in the child's health. I listened carefully to the whole story she wanted to tell me. With each sentence, my heart sank. And, frankly, that was what I felt I should do: welcome both the pain and the hope that she could take care of the child in the best possible way.

And so, we had many meetings. My distress was giving way to observing the child's gaze towards his caregiver.

And the gaze of the paternal great-aunt, caressing him on her lap, while we talked.

I would usually hear the distress in her speech, for she feared she would die before her child's life came to an end. I was listening to the child's grunts subside at the same time that the paternal great-aunt began to breathe calmly and slowly. And, in a way, I was in the presence of a pair that seemed to work in a complementary way. One needing the other, like communicating vessels. And so, I started noticing and naming these three items: Observation, Listening and Therapeutic Presence.

And, from that example, my practice grew richer and objectively more accurate. These three formulations were developed and recaptured in order to demonstrate, in that congress, the need for a psychotherapist or clinical psychologist during the monitoring and integration of a multidisciplinary team.

Now, by revisiting my history within that service, I was able to analyze, in a succinct way, this conjecture. Probably, my uncertainty on how to deal with this issue was finding a place. The assumptions studied, administered and experienced, since my graduation, have given way to the maintenance of hope.

The place where I found myself could be the scenario to continue the study of bringing hope to those who have been struggling to survive, to stay alive. And, for those who have collaborated in this struggle for survival, to go on living their lives. Be it the medical team, the family and the prematurely-born baby itself.

OBSERVATION, LISTENING and THERAPEUTIC PRESENCE are the pillars of my professional and personal action. Let's discuss them now.

Observation – Perception Of Light

(in a way, this comes close to photography)

It may seem simple – and it is simple, of such simplicity that it gets complex. And so, it resembles human complexity. What is involved in this observation?

These are divergent and converging aspects that, if we can wait, we will see, and we will discover a new path. It is as if the ineffable could be identified, narrated, shared.

It is a simple look – but not too simple – which, by association of ideas, can guide and indicate the sun of understanding. It is a concentration of the spirit driven by attention, prudence and investigation that guides the formulation of the analysis. Almost like a gold-digging field where the gold nuggets keep on emerging, thus indicating their evidence.

Eventually, we can also make a mistake. For what reason? In what way? Perhaps because of the inaccuracy and attempt to get it right – the observation is both active and attentive. The error may indicate the need for a "reorientation," a new return to the path – and, in fact, the error itself may be the need for reorientation. It is also a sign. And the observation that the error occurred indicates that we can be very close to an emotional situation that is both dense and conflictive. Thus, observing what has been observed is an important ancillary tool.

Observation-based recognition means commitment to the stated "truth." Responsibility with a committed duty, based on observation, indicates a break with what does not want to be evidenced.

In the same way, we could think of observation as a command in the sense of something to be carried out. I

think that an observation to be provided would be the staging itself on the scene.

And how to identify it?

Well, that identification is an internal source of content for emotional experiences that throb within us. It is a strong indication that is developed during training at work and the accumulated introjection both from experiences and reflections or analyzes.

Following the reasoning, we interpret what is observed. We give meaning to our observation. And we must also not forget that our found meaning is based on both our theoretical and experiential background – the result of personal analysis, study and articulation of these contents.

We can think about and assume that the more we know about ourselves, the more we can expand our perception and understanding of what is going on around us.

However, there is a risk – we can think of biased observations. Here, I think that the possibility of error and deception would apply. There is intuition – the result of the experience acquired and that "must" also be observed. Guessing, divination, inspiration – there must be an internal space to welcome what is observed. And thus, intuition and observation can both be analyzed and oriented towards the absence of reasoning.

Accepting – Waiting – Observing.

We can think that, in fact, the one who observes is also a spectator, the one who contemplates, watches and witnesses, in addition to witnessing a scene, an event, is also a participant in it – by interacting with what was manifested internally, based on what was observed and felt. One comes to have one's understanding of oneself, almost like a sponsor of the scene.

When observation is in action, some things happen. For example: attention, where the senses are active and can be activated.

Listening

By listening, we approach sounds that can touch us, because those that do not touch us, we do not even notice.

Thus, paying attention to our surroundings is something that enriches us for both good and evil. I say this because we perceive things and they are not always related to what we want to notice. On the other hand, at work, every sound, every silence noticed has a sense and a meaning.

Being attentive is the way and the indication of where to go. Noticing or sensing something is the result of listening attentively, and that speaks to us.

Listening also promotes a closer emotional experience. What the person is feeling or experiencing.

How to discriminate the sound that produces contact with what is just siren song? The discrimination proposal is already a type of contact.

Listening is about what is perceived, as it presents a field of knowledge and information or light and clarification. Listening to a perceived, both captured and felt. Care and also expectation. Well, when we talk about expectation, a boundary is established as a watershed. Expectation makes room for error, for the siren song again. My self-knowledge is the watershed between research and determinism.

Listening is about opening the door to what is unknown and ineffable. A type of negative capacity to withstand what is surreal, the blank space peppered with novelties – with or without expression. Negative capacity – lurking

and waiting, waiting for the formulation, waiting for the (apparently) magical and intuitive touch of the ideational construction.

Listening is about paying attention, finding what is hidden, what is not apparent, what is concealed. In order to make paths appear and illuminate, and thus, perhaps, offer a likelihood of hope.

Listening is also about finding the ignorance we hide – the erased times, surrounded by nonsensical stupidity.

Listening promotes, illuminates what is manifestly hidden – what is dormant and repressed, what has made us suffer by means of experiencing.

Presence – Therapeutic Presence

To be in the presence of someone, with someone and for someone is about witnessing visually, in person and ocularly, breathing the same air as this someone.

Lend yourself to that witnessing, to be someone's screen and receiver, living in the same environment, being able to make yourself available to someone. And we can even think about that for ourselves.

It requires a great deal of self-knowledge to be able to abdicate yourself, to be present beyond your difficulties and needs.

Being present in this way can be something like sharing the experience, in the same environment with what is presented to us by someone.

It is interesting to realize that being in this situation for a certain time allows us to make observation and listening more lively, more attentive, more up-to-date.

And that brings relief to the other, gives the other existence and truth in what is being felt, that is, suffering, feeling, emotion, whether present or absent. Perceive and include what is absent, forgotten, ethereal and ineffable. What is misunderstood now has a place to manifest and be welcomed.

Absence causes forgetting; the therapeutic presence is open to observing and listening to those nuances that are presented, even if not so evident, even the hidden and invisible ones.

These 3 propositions, combined, potentiate and, thus, increase the receptivity of what may be happening in the meeting, during the session, during the visit, in the conversation, in the surroundings.

Make room for the new in each one, or rather, enable the transformation for the reception and restructuring of pain, suffering, difficulty. This helps us get ready to take action.

In other words, an expectation, a door, a hope for the future is opened. For what has not yet occurred, for what is to come, tomorrow, the future.

The proposal that I conceived is to look for a chance for what can be done and not to worry too much about what cannot be done, or when we cannot do anything.

Guiding us to move on, accepting our faults, sins and crimes that we have committed, forgetting this, as this is a very insignificant part of the whole of history.

Creating memories for the future, as other things will come towards us and the therapeutic presence has the potential to collaborate with this movement – they are often difficult to bear alone.

These three propositions feed the reasoning, the reflection, the analysis, establishing and/or providing inspiring hypotheses of thoughts, through imagination – bringing openings and abstractions to continue dealing with the situation and expanding the space to exist and live, finding a *raison d'être*, a sense.

PART 4
THE IDEA

8

The Inspiration – Réd Methot

In 2019, as a student of a photography course, I thought about doing an essay inspired by the work of Canadian photographer Red Méthot,[11] who gained worldwide prominence with his album *Les Premas*.[12] After the birth of his first child, he got enchanted by the perseverance and daily struggle of small babies for survival. "Before my children were born," – his two children were born premature – "I knew nothing about premature birth. So, I decided to carry out a photographic project to give people more knowledge on this topic. I was looking for a way to show how premature babies are brave fighters."

He then photographed 22 children, teenagers and adults holding black and white photos of themselves when they were newborns. Most were oblivious to the difficult beginnings of their lives. Méthot soon realized that the initial idea of photographing premature babies in the hospital would be logistically difficult. Premature babies (children born before the 37th week of pregnancy and weighing less than 4.4 pounds) are usually kept in Intensive Care Units until their organs are fully developed.

So, his first models were his own children; but soon other parents of premature children became interested in the project. "They are special because I was there to take a picture of them. And I am very happy that people are talking about prematurity and the photos can be seen by people who are experiencing it now. There may be people

[11] *Red Méthot – Photographe à Québec*. Available on: <https://redmphoto.ca/>. Accessed on February 2021.

[12] *Les Prémas*. Available on: <https://redmphoto.ca/les-premas/>. Accessed on February 2021.

who have a small child in the hospital at the moment, and I hope it can help them," he stated.

So, I contacted him, through a social network, to tell him about my intention to, inspired by his work, do something similar to what he has already done.

9

The Project

My project is called: "Born Again: A Photo-Essay."[13] The place where I carried out the project was the Premature Outpatient Clinic of the Department of Pediatrics (discipline of Neonatal Pediatrics) at the University Hospital of the School of Medicine of the State of São Paulo at the Federal University of São Paulo (UNIFESP), in partnership with the non-governmental organization Institute of the Prematurely-Born Child – Living and Smiling (in Portuguese: *Instituto do Prematuro – Viver e Sorrir*), both based in the city of São Paulo, in the state of the same name, in the southeastern region of Brazil.

This clinic is a center specializing in following-up prematurely-born children. It was instituted in 1981 with the objective of providing multi-professional assistance to these children, aiming at promoting their growth and development, from hospital discharge until the end of adolescence.

Outpatient follow-up is provided by an interdisciplinary team, which enables the collaboration of several specialties with different knowledge and qualifications, a situation that allows for the diagnosis and early treatment of possible sequelae of prematurity, thus minimizing their present and future repercussions.

The Start of the Project

Since October 2012 I have worked as a psychologist and volunteer psychotherapist at the Premature Outpatient

[13] A "photo essay" means a collection of photos taken about the same topic or by the same author.

Clinic, providing care (in group and individual) to children, upon admission, as well as to the mother-baby pair, accompanying them in pediatric and physical therapy visits and, in specific cases, also at school and at home (on site). And I also assist adolescents until they reach the age of 21.

The Course of the Project

The Cases

I started the project with the approval and authorization by the coordinator of the Premature Outpatient Clinic and also by some mothers, who accepted the invitation to participate.

Those were the goals of the project:

- Disseminate the discussion on the topic of prematurity, as the number of premature births is high, and this information is unknown to society in general. The report *Born too Soon*: *the Global Action Report on Preterm Birth,*[14] points out that 15 million children worldwide are born prematurely each year.
- Disseminate and make society aware of the imperative needs regarding children born prematurely to ensure their good physical and mental development, since advanced technologies, modern equipment in hospital treatment, the presence of specialized professionals and the improvement in the postnatal approach, as well as psychosocial support to families, contribute to increase the survival rates of premature babies.

[14] *Born Too Soon*. Report. Available on: <https://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf>. Accessed on February 2021.

Many mothers had not photographed their children at this stage of life, as they thought "they might not survive, and having a photo would be too painful." Therefore, many of the children and adolescents involved did not know this chapter of their history.

So, before the photo-essay, I promoted a day of conversations with mothers, children and teenagers about these facts and other pertinent subjects. It was an important resource in an attempt to recover a significant part of their personal trajectories, integrating part of themselves through the stories told, opening new horizons and strengthening the force of Life.

With the beginning of the photo-essay, I noticed that the children and adolescents were expanding their self-perception and there was a readjustment of their own view of themselves. I believe that the initiative has been a success.

The Setbacks

Due to the confidentiality agreement that exists between therapist and patient, I will not present here the details of the children and adolescents who agreed to participate in the project with the approval of their families. But, in order for readers to have a general idea of the profiles of each of them, I inform you that I carried out the project with the following people: non-identical pre-adolescent quadruplets; a young boy who was born only on his mother's fourth pregnancy, at the 26th week of pregnancy, weighing 2.3 pounds; an adolescent girl who has been between life and death on more than one occasion; a family in which four births were of premature babies: two twin births, one of triplets and another of quadruplets; a pre-adolescent girl

who has lived with her father and paternal grandmother since she was very young; a pre-adolescent girl who witnessed a murder, was born at the 30th week of pregnancy and was hospitalized for 28 days; an adolescent boy who is usually quiet, silent, shy, looking scared.

Not all of them had photographs from the time they were born. With different degrees of acceptance and resistance, everyone took photos of themselves, holding the pictures they had of the time they were in the incubator, a process that proved to be quite revealing and contributed to the advance of our therapeutic work.

The new coronavirus pandemic that changed the world in 2020 also affected my work with these children, adolescents and their families. Initially, due to restrictions imposed by the authorities, contact with patients was interrupted for three months. However, starting in June 2020, I resumed contacting all of them remotely, via computer, and so our joint work continued.

10

Preliminary Results

Even with all the difficulties imposed by the new coronavirus pandemic, my work with premature patients, despite being momentarily interrupted, continued in 2020. It is worth making a remark here: unlike some segments of the medical field, which presuppose the physical presence of the patient and physical contact with the doctor, psychotherapeutic work can be carried out remotely, via telephone or computer. This is not the ideal situation, of course. But whether to continue the treatment in this "imperfect" way or to interrupt contact with the patients entirely, I had no doubt about how I should proceed.

At the start of the project, I asked people for a photograph that would be the first photo of their lives. Many did not have them, because it would be very sad for parents to have the memory of something they wanted to forget – they wanted not to be able to remember. Even the fact that I asked for it generated some anxiety and nervousness. People started to wonder:

- Why does she want this?
- What does she intend to do?

These questions were part of what was not said. But I understood the need to identify, name, produce and relate ideas. For it is necessary to combat hopelessness, by recovering the hope necessary for people to live and develop, preparing for the future, with their own choices. With my way of looking, feeling and seeing, I report here some situations experienced during work. I am a psychologist,

psychotherapist and in-training psychoanalyst. One of my first concepts, learned during my professional life, as I mentioned in other moments, is that the emotional experience can be both the generator and driver of changes. I am always thinking about the relationship and how I believe it develops: by observing, listening and participating with and in presence.

Until the completion of this book (April 2021), I could mention, in general, the following results achieved with the project "Born Again: A Photo-Essay:"

- Some patients, when they heard the proposal of the photographs, seemed euphoric. Others even decided to set up a stage, bringing accessories (toys and masks, among other objects, for their interpretations) – but even though this was not requested, they considered it important.
- There were those among them who did not recognize themselves in the photos as babies, seeming to be in front of their pictures for the very first time, demonstrating both curiosity and strangeness.
- In one of the cases, a patient and I, in front of several unidentified photos, searched for the one that could be hers and, together, we chose the same photo! This is because, in some way, we associated the picture of a chubby baby with the silhouette of the girl at that moment. Then I found out that we were both wrong: that photo was not hers. When faced with the real picture, seeing herself as a newborn in the Intensive Care Unit, she expressed a certain distress, showing shortness of breath and pallor. "You're not like that anymore," I said, to reassure her. And we got on with the work.

- I have been building a very interesting relationship with a patient. We did three photo shoots, in different places. We were able to talk several times about her life situations, and the photos were important guiding threads in the rescue of her memory and history. The photographic records served as an instrument that articulates, correlates affections and emotions, bringing them up in a playful way. No, perhaps "playful" is not the best word. It would be more appropriate to think that, yes, photographic records can update, at present, affections and emotions in a more spontaneous, simple, genuine way.
- Some children did not have photos from the time of their birth, but decided to participate in the photo-essay, as they showed interest and eagerness to be photographed. They are children with strength and willpower.
- A patient was very tenacious and sensitive. She brought me a photo in which she appears on her mother's lap, held by the Kangaroo Mother Method. She restarted psychotherapeutic follow-up at her mother's request and demonstrates that she is a poetic, dramatic, talkative and smart girl. She has been able to "endure" her fears to the point of staying awake for several hours, as if, by doing so, she could protect her family, like a night watchman.

11

Concluding Remarks

I have been working with babies born prematurely, and their families, since 2012. Over these nine years (until 2021), I learned a lot from this universe that I knew so little, and I believe that I am already able to make some considerations on this topic.

First, we need to get some thinking about a few things.

If everything that happens in the therapeutic setting[15] can promote changes, then, the 3 combined methodological resources, which I called the "3 Pillars" – Observation, Analytical Listening and Therapeutic Presence – are potentiated and, thus, increase the receptivity of what can happen in the meeting, during the session, during the visit, in the conversation and in the surroundings.

These resources enable the transformation for the reception and the restructuring of pain and suffering, thus opening doors of hope for a better-quality future life.

Regarding the role of the psychologist /psychotherapist, these resources – Observation, Analytical Listening and Therapeutic Presence – are tools that feed reasoning, reflection and analysis, by establishing and/or providing inspiring hypotheses of thought and imagination, thus bringing openings and abstractions in order to continue expanding the meaning and space of existence.

In the various meetings with prematurely-born babies, I was able to perceive some situations that could develop in a way to reassure the patient. Each meeting was – and is – a possibility. For example: I receive a request to meet

[15] A space in which the relationship between therapist and patient takes place.

and talk to a mother who is very apprehensive, distressed and tormented, as her son has difficulties to feed himself. The request comes from the outpatient professional who identifies something that may be contributing to this mother's unrest. She and I scheduled an appointment to talk and what I realize, during the course of the contact, is that she internally experiences a feeling of loneliness, anguish, suffering, helplessness, confusion and distress – all these due to the various ill-accommodated memories that she keeps. And all this discomfort ends up creating, in the relationship with the child, a bond which is both symbiotic and fusional.

In this sense, our conversations started to have a prominent place in the mother's speech and, little by little, the symptoms, which were frequent in her son, became scarce. The moment the mother felt welcomed, contained in her affliction, she was able to broaden her observation of her surroundings and establish a more realistic contact with them. She was able to identify elements in herself that can be worked on to expand her ability to tolerate vicissitudes.

Thus, the work involves the efficiency of being available to observe, listen and be present in and during the experience. This triad, in the exercise of the profession, allows for the articulation of what is known, by inspiring the expansion of the art of waiting.

What I saw in my visits, regardless of whether or not they were linked to prematurity, was the creation of an internal space to support and tolerate what is unbearable. A space that helps patients think about their problems, finding new ways to deal with them. With this, individuals can favor significant changes in their way of thinking and thus significantly improve their lives.

Now, I would like to share some of the conclusions I have reached as a result of that journey.

If mothers could be supported psychologically and feel such support, not as a recrimination, but as genuine help, this would help them to deal with the anguish and guilt due to the baby's birth. The mother is not "guilty" for the premature birth of the baby.

In general, mothers are more present in the treatment and care of prematurely-born babies than fathers. In my experience, I have had only two cases of very present fathers – far more than mothers.

Most of the time, the main reason for patients to drop out of treatment is the financial issue: there is not always enough money for transport to the clinic, and the mother is not always able to take the child there, because of work. However, with the pandemic, this situation could be overcome, and the great difficulty became the remote connection (available phone, internet quality, etc.) – the other side of financial limitations.

I have had cases of children who decided to stop treatment because they felt they could move forward on their own, with "their own legs." On the other hand, I noticed that, in some cases, some children did not realize that they were no longer sick – and I had to help them see this reality. The feeling of death, sometimes, remains and impacts the lives of children, without them realizing it.

Many mothers repeat their own stories – they described several attempts to get pregnant, even with cases of abortions and the death of prematurely-born babies. As previously mentioned, mothers keep, in themselves, issues, anxieties and yearnings due to premature birth.

Depending on the functioning of each mother, the degree of this feeling of guilt and incompetence varies, due

to having given birth to a premature baby. Especially in situations where the mother finds herself unable to feed her child – in most cases due to its own conditions, when the child is unable to suck. An intense frustration then arises: "I am unable to feed my baby" – which, in turn, triggers a frustrating and helpless feeling, which generates anguish.

One of the ways that mothers find to deal with this is try to escape, by projecting on the world and in the closest relationships, often in the medical team, this feeling of helplessness.

So, many times the mother tries to expel her undesirable feelings of guilt and frustration, among other equally destructive ones, by throwing them towards the medical team. Because it is the closest to the situation presented, which ends up receiving all the emotional discharge.

In turn, the medical team can react in several ways. We can understand this whole scenario. It is, in a way, expected. However, all of us human beings ("whose blood is not that of a cockroach"), have and feel anguish. Therefore, it is expected that the team, understanding the mother's emotion, can deal with it. But how? By welcoming her, minimizing conflicts, giving meaning – thus spotting the anguish and reducing anxiety.

Depending on the emotional and psychological maturity of the mother, as well as the medical team, the outcome of this scenario can collaborate to or hinder the baby's development. For example: by providing an adequate reception, the uterus can be reconstituted outside the mother – with the Neonatal Unit functioning as an extracorporeal uterus. We must consider that the birth of a premature baby is accompanied by a mother who is also premature.

The 3 Pillars proposal is opportune as it proposes the creation of a space to identify and welcome the anxieties,

fears and fantasies involved, until they can be recognized and worked on. The multi-professional team is a powerful tool to strengthen this performance. And the psychologist, as I said, is a member of this team. It is like gears: each one with its unique role, function and objective, unanimously, for the healthy biopsychosocial survival of this prematurely-born human being.

Important: depending on the degree of difficulty experienced in the situation of prematurity, emotions and feelings of fear in everyone involved can be triggered – because, in a way, everyone suffers. A premature birth can be understood as "unidentified, unprocessed violence" and, thus, there is a risk of misunderstandings.

My experience has shown that, in many cases, the psychotherapist acts as a conductor who leads mothers and medical staff. He/she bridges the gap between these two extremes, which at times have great difficulty in making themselves understood. There were several occasions when the doctors asked me for assistance in this regard – and also to be able to understand a little better the psychological condition of the mothers.

In this book, after presenting the situation of the reality of prematurely-born babies and my work with some of them, I tried to gather a set of ideas on the way towards a whole. For it is in interpersonal contact that a relationship and the proposal for expansion are formed, in which the psychotherapist helps the patient to move from the sensory towards the psychological, thus expanding the promise of mental health in the other and in the psychotherapist himself. From there, we move on.

Appendix

On November 17, 2020, as a tribute to the World Day of Prematurity, I decided to write a text and distribute it among friends, professionals and entities related to therapies.

VIOLET NOVEMBER[16]
INTERNATIONAL MONTH OF RAISING AWARENESS ABOUT PREMATURITY

NOVEMBER 17
WORLD DAY OF PREMATURITY

DO WE NEED TO TALK ABOUT PREMATURITY?
CERTAINLY!

1. **Because** prematurity is a global public health problem, as it affects 15 million children every year: one (1) out of ten (10) babies worldwide.[17]
2. **Because** prematurity is the main cause of neonatal death (from 0 to 28 days) and infant mortality (under 5 years) in the world. More than 1 million children die each year from complications from premature births.

[16] The violet color symbolizes sensitivity and individuality, characteristics peculiar to children born prematurely. Violet also means transmutation (change), the art of transforming something into another form or substance – transformation.

[17] Born Too Soon. Report. Available on: <https://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf>. Accessed on 2021.

3. **Because** prematurity is an important cause of serious morbidities, associated with long hospitalizations.
4. **Because** premature birth survivors may face adverse health consequences throughout their lives, related to physical, cognitive, emotional and behavioral development.
5. **Because** the consequences of prematurity generate a significant burden for families and society.
6. **Because** there are countless causes that lead to premature birth, but not all of them are known yet, and in many instances, it is not possible to associate it with a specific cause.
7. **Because** prioritizing preventive action, diagnosis and provision of adequate care, as well as awareness of the effects of prematurity, are urgent and necessary measures to face the problem.
8. **Because** it is a way of drawing the attention of the government, corporations and society in general about the seriousness of the issue and the need for preventive measures, humanization of care, adequate and egalitarian treatment.
9. **Because** there is still much inequality among the survival rates in the world and this situation requires urgent and effective measures, being one of the main challenges inherent in the provision of services. In developing countries, half of babies born before the 32nd week of pregnancy die due to the lack of essential measures, such as support for breastfeeding and basic care to prevent infections and breathing difficulties.[18]

[18] Brazil ranks 10th in the list of countries with the most premature births in the world. The births of premature babies correspond to 12.4% of live births.

10. **Because** it is necessary to get parents and family members involved in the care, stimulation and interaction as essential factors for the physical, cognitive and emotional development of children born prematurely.
11. **Because** it is necessary to invest in the training of health professionals in primary care and in improving the postnatal approach, for early identification and initiation of treatment.
12. **Because** it is necessary to invest in the functionalization and equipment of Neonatal Inpatient Units and in advanced technologies to minimize the consequences of preterm births.

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Emília,

I read your book under my conditions at the moment.

I really liked the content and the presentation. Very clear, objective, succinct, as relevant information must be.

If it was aimed at a more academic readership, it would need some developments and more bibliographic references.

My admiration for your interest in our fragile travel companions on this planet of ours, for your investigative look on the issue, and especially for your dedication to the prematurely-born.

May all of this be very useful for everyone interested in this issue so relevant to everyone!

A warm hug,

J.A. Pavan

in memoriam

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