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ORIGINAL ARTICLE



## Digits and narratives of the experience of Italian families facing premature births

Maria Giulia Marini<sup>a</sup>, Paola Chesi<sup>a</sup>, Martina Bruscagnin<sup>b</sup>, Monica Ceccatelli<sup>b</sup> and Elisabetta Ruzzon<sup>b</sup>

<sup>a</sup>ISTUD Foundation, Milan, Italy; <sup>b</sup>VIVERE Onlus, Padua, Italy

### ABSTRACT

The objective of the research was to understand the experience of families living a premature birth and to outline the current care plan in Italy. The survey was addressed to 150 parents of children born under the 34<sup>th</sup> week of pregnancy. Topics of the investigation were the implications on their family, social and working contexts, determined through a questionnaire enriched by a collection of narratives. Written testimonies were clustered through a Narrative Medicine method and matched with quantitative information. The main respondents were mothers of severe and moderate preterm children. Except for the Kangaroo Care, services were not uniformed amongst the centers and few home care supports resulted available for families. Sixty-seven percent of the mothers could not obtain a prolonged maternity leave and described the impacts on their working activities. Narratives revealed a low level of prevention, information and awareness on the risks of prematurity amongst families, few local networks among Neonatal Intensive Care Unit (NICU) teams, gynecologists and pediatricians, and the shortage of support for parents at work; these actions were collected in a Position Paper. Findings showed the integration between families' coping strategies and the offered care services for preterm births. Narrative tools could represent the bridge between families and health care teams.

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Family care; narrative medicine; preterm birth

## Introduction

According to the World Health Organization, births before the 37th week of gestation are preterm. Every year in the world about 15 millions of preterm children are born and about 500 000 in Europe (10%) [1]. Preterm birth is the first cause of childhood mortality and congenital disabilities both in advanced and least developed Countries, although with different rate variation [2]. In Italy, from 6.5 to 7% of the preterm births/year are estimated [3,4]. Premature birth is considered a growing phenomenon [5] which depends on pathophysiological, genetic and environmental factors, together with mother's wellbeing [6,7]. Improvements in neonatal care have led to an increased rate of very premature children's survival, but the risks of adverse effects to child's health and development are still high [8]. These conditions require prolonged hospitalizations at the Neonatal Intensive Care Unit (NICU) and continuous care during the early years of the child's life. Different levels of prematurity, related to the gestational age, are classified by the European Lung Foundation [9].

Although, different possibilities of screening during pregnancy, tests, and treatments to predict and

prevent spontaneous preterm birth in asymptomatic women are still poor [10]. Consequently, families are not prepared to face a preterm birth and the care plan, for the lack of information. After the traumatic event of the birth, a sense of frustration might increase in parents and cause psychological repercussions, which can persist and affect their caregiving, up to obstacle the child's development [11].

This survey had the aim to understand the experience of Italian families living a premature birth and identify the available service, to define a Position Paper addressed to health decision makers for the improvement of care. Narrative Medicine was used to pinpoint families' feelings, thoughts, needs, expectations and awareness towards premature births.

The use of narrative research is recommended by the World Health Organization to improve health care policies through a value-based approach [12]. Narratives from patients, caregivers and healthcare professionals allow to understand how the person and the family live a condition of illness and give meaning to the care plan with the healthcare team [13,14].

While the Evidence Based Medicine (EBM) cares for the monitoring of clinical pathophysiological

processes, Narrative Based Medicine (NBM) includes the person's judgement when coping with distress caused by clinical, social, relational, emotional issues and their real needs [15]. The difference between the words "disease" and "illness" reflects the integration between EBM and NBM. "Disease" means an objective alteration of the biological structure or functioning of the body; "illness" refers to the human experience of living a physical condition, including perceptions, feelings and thoughts [16].

Furthermore, Narrative Medicine is a systemic approach to improve the organization of care and is a catalyst for generating sustainability [17,18].

## Materials and methods

The research was carried out by Vivere Onlus – Italian Coordination of Associations of Preterm Newborns' Parents – and ISTUD Foundation.

The aim of the survey was to collect 150 written interviews from families who lived the experience of a preterm birth to obtain a picture of the experience of care. The narratives were about premature children born under the 34<sup>th</sup> weeks of gestation and not older than 4 years, with focus on severe and moderately severe preterm births.

The research was performed between September and December 2014, throughout the website [www.medicinanarrativa.eu/nascere](http://www.medicinanarrativa.eu/nascere) of ISTUD Foundation. The tool allowed to reach families in a short time and to let participants directly access to the survey. Narratives were collected on a voluntary basis and after releasing online written informed consent, according to the Italian Privacy Law [19].

### Research tool

A quantitative questionnaire was integrated to the narrative tool. The survey contemplated the whole care plan, from pregnancy to follow-up during the first years of childhood, with focus on parents' work condition and possible consequences (ATTACHMENTS A, B, C and D).

### Analysis of data and narratives

Data from questionnaires were analyzed with descriptive statistics, as means, ranges and frequencies.

The qualitative analysis was carried out through the methodology of independent reading from at least two researchers, to limit subjective interpretation of

texts; in case of conflict, a third researcher was involved. Narratives have been clustered according to the following classifications:

1. Kleinman: disease/illness/sickness stories. The "disease narratives" focus on the clinical evolution of the condition, with a strictly technical language. The "illness narratives" focus on emotional and relational experience the subjects, with an open language and a flowing narration. Sickness is the perceptions of the society with respect to a given condition [20].
2. Launer & Robinson: progressive/stable/regressive narratives. This classification is based on the individual's ability to cope under a difficult and uncertain situation. Coping is defined as the conscious effort to solve problems [21,22]. Progressive narratives show coping strategies, while in stable and regressive narratives the person does not find the way to master the situation [23].

The semantic clustering of narratives was carried out through NVivo 10 program (Melbourne, Australia), a textual analysis software based on the approach of the Grounded Theory, which assumes to carry out the analysis without any previous hypothesis [24,25].

Crossing between quantitative and qualitative information were carried out to integrate all the emerged components.

Finally, the methodology of the Consensus [26] was used to write a Position Paper.

## Results

Among the 150 collected interviews, 90% were mothers' contributions. The remaining 10% was shared between fathers (8%) and grandparents (2%).

The age of the mothers at the preterm birth was mainly between 33 and 40 years. Parents stated to have one child (67%), or two (28%). As a result, first-preterm born children were observed in 73% of the cases.

The premature children were almost evenly distributed between males (53%) and females (47%). The average age of the children was 21.7 months, with an equal distribution amongst the age groups; this means that narratives concerned both very recent care pathways and almost concluded cares. The children's level of prematurity was between moderate to severe and their weight at birth was 1174 g, in a range between 430 and 2900 g (Table 1).

**Table 1.** Children's data.

Children's age	Not survived (12) 7%	0–11 months (44) 26%	12–23 months (44) 26%	24–35 months (34) 20%	36–48 months (37) 21%
Children's weight			Range (g) 430–2900 1300–3500	Average weight (g) 1174 2248	
Level of prematurity					
Born before the 28th week of gestation					(60) 41%
Born between the 29th and the 32th week of gestation					(76) 51%
Born over the 33th week of gestation					(12) 8%
Ventilation support			Yes (53) 90% (52) 67% (2) 17%	No (6) 10% (26) 33% (10) 83%	
Respiratory prophylaxis			Yes (47) 81% (43) 56% (5) 42%	No (11) 19% (34) 44% (7) 58%	

### The pregnancy

Preterm birth risk during pregnancy was diagnosed in 28% of cases. The main reference during pregnancy was the gynecologist. Information on risks of preterm birth was communicated to 37% of the parents, while prenatal screening was done in 62% of the cases. Hospitalizations during pregnancy were 43%.

The pregnancy was lived by 45% of the mothers with happiness, tranquility, optimism, until the onset of symptoms of premature delivery, while 42% of women described this period as complicated and lived with concern and anxiety, fear up to terror; the remaining 13% did not mention emotions. Fifty-seven percent of the women gave positive feedback on care during pregnancy, describing good and reassuring health care professionals: "My physicians were very careful, they monitored every exam and test, and when they were not convinced about something, they adopted preventative measures". In other narratives (43%), negative judgments were stated on professionals unable to identify a pregnancy at risk: "My gynecologist knew about the increase of my pressure and my backache, but he considered all this as normal"; "My gynecologist was a little hasty and superficial in the visits".

### The premature birth

The birth in 83% of the parents was described as sudden and unexpected, requiring an emergency intervention. The caesarean section was carried out in 78% of the cases.

The professionals at delivery were mainly operators on shift (54%) and only in 16% of the cases birth was carried out under the reference of the gynecologist. Fear was the dominant emotion (36%), followed by

sadness, confusion, helplessness, frustration, desperation, guilty feelings, shock: "I could not understand what was happening"; "I was afraid that me and my baby could die"; "*I had no idea what was going on and I never thought that the stomach ache were contractions*". The same feelings were described by fathers: "It is still hard to have a sharp memory of those moments. We were chatting quietly, then everything crashed"; "*I was shocked, I almost lost both my wife and my son, and in less than two hours*". However, there were also happiness, trust and a willing not to give up (9%): "*I could not give up. My daughter still needed my energy and positivity!*".

### The recovery at NICU

The health care facilities for premature children were mainly close to the residence, although not in the same municipality for almost 70% of parents. Hospitalization lasted longer than 50 days in 52% of cases, or with ranges from 31 to 50 days (24%), 11–30 days (21%), within 10 days (3%).

Ventilation was applied in 71% of the newborn and lasted mainly within 5 days (50%), although situations of more than 25 days with respiratory support (20%). The recourse to ventilation was correlated with severe (90%) or moderate prematurity (67%). Prophylaxis for respiratory complications was provided in 62% of the cases, in the most severe cases of prematurity (81%), but also applied for prematurity within 29–32 weeks of gestation (56%) and above 33 weeks (42%) (Table 1). These data are consistent with the Italian Guidelines, which recommend respiratory prophylaxis not only on the basis of the gestational age, but also on singular clinical conditions [27].

Regarding the NICUs care services, the kangaroo care was practiced in almost 80% of the cases, while inside beds for parents were less present (37%).

The NICUs were described in 61% of the narratives as adequate to care, well equipped and organized: "The department was nice and comfortable, suitable to parents who, like us, spent all the day close to the incubator"; "Our NICU was really nice, comfortable, clean, it was my second house for 6 months". The remaining 39% of narratives described crowded NICUs, with too few areas for family's privacy: "I really didn't like that people could go backwards and forwards continuously"; "The room was really small. There was little privacy for parents".

The imposed visiting hours were not appreciated (15%): "Since I could see my son only at specific times, I did not feel a complete mother, but a 'half mother'"; "I could go to the NICU only twice a day for 1 h, and the hospital was far from my house".

Although the emotions described during the period at NICU presented a progression, fear, sadness and concern still prevailed (74%): "Pain ... fear ... sadness ... anxiety. You don't know if you'll see your daughter".

### **The discharge**

The predischarge training was offered in 28% of the cases. The children's weight at discharge ranged between 1300 and 3500 g, with an average of 2248 g (Table 1). Gestational age was between 31 and 50 weeks. After the discharge, home care was given only in 10% of the cases, while the remote support from centers was reported in 44% of the questionnaires.

The prevailing emotion was happiness for having overcome the most critical phase, and the first days were mostly positively described (40%). Nevertheless, fear and anxiety for the possibility that the child's health condition could worsen still persisted (30%); 21% of the mothers described this period as "very difficult" and "demanding": "The first days were the most difficult ones, because of the fear. After a so long period at the hospital, you feel safe only there and the lack of physicians and nurses was difficult to face".

Fathers played a key role: they were the first contact with the NICU's operators and the only ones to have access to the ward, together with mothers. They managed the daily family and work life: "During the days after the birth, my wife was confused, she did not realize what had happened. Our families couldn't do anything in that period. I was the only point of balance".

Follow-ups were considered supportive (60%).

### **Living the premature birth today**

In 78% of narratives, mothers finally felt happy, serene, stronger, proud, lucky: "I am happy, my daughter is healthy and I don't have any regrets"; "Today I feel fine, I am a happy mother, proud of her son. I am enthusiastic for his progresses". On the contrary, 22% of mothers revealed sadness, fear, anger and regret: "I'm still very angry about the normal pregnancy and for my child's losses. I feel robbed".

### **The focus on parents' work condition**

Seventy-six percent of the mothers and 92% of the fathers were employed. Sixty-seven percent of mothers used the standardized maternity leave, as for normal births, and 69% had consequences on their work (Table 2). The paternity leave was given only in 9 and 83% of the fathers revealed constraints on their job because of the preterm birth. A common dissatisfaction towards the current Italian maternity and paternity law – L0.53 n 8 March 2000 – was revealed and evaluated as poorly protective. (70% of mothers and 69% of fathers). Comments mainly concerned the need to extend the period of maternity leave in case of preterm birth (54%).

Sixty-three percent of mothers described their work as stressing during pregnancy: "At work, I found myself in the need to prove that the pregnancy was not a limit ... I remember I had a discussion with a colleague of mine just a few days before the preterm birth". In 21% of the cases mothers were forced to work even if their child still needed intense care: "the last days of hospitalization I had to go back to work"; "I was supposed to return three months after the child-birth, but my son was still in NICU". Fourteen percent of the mothers decided to give up work: "Not being able to send my son to the nursery school for his health problems, I just have to wait he gets older"; "I left my job to devote myself entirely to my son and I was able to return to work only after more than two years".

However, there were also cases of mothers who lived a calm pregnancy and a gradual return to work (17%): "I stayed at home from work immediately (upon my employer's request)"; "I have a good relationship with my boss who gave me very flexible and easy to manage schedules".

### **The clustering of narratives**

According to the Kleinman classification, in 62% of mothers' narratives disease and illness coexisted.

**Table 2.** Mothers' work condition.

Mothers' age	18–25 years	26–32 years	33–40 years	41–50 years
At preterm birth	(7) 3%	(53) 39%	(66) 54%	(4) 4%
At the moment of the interview	(5) 2%	(33) 25%	(79) 61%	(14) 12%
Mothers' work condition				
Stable employee			(36) 41%	
Temporary employee			(8) 9%	
Maternity leave			(23) 26%	
Household			(9) 10%	
Looking for a job			(7) 8%	
Withdraw from work			(3) 4%	
Student			(2) 2%	
Changes in mothers' work activities				
No			(17) 32%	
Yes			(35) 68%	
• I had to use all the available vacation days			(7) 13%	
• I had to ask for special permits			(2) 4%	
• I asked for a temporary replacement			(2) 4%	
• I changed my contract from full time to part time			(2) 4%	
• I had to stop working			(3) 6%	
• I gave up promotions and improvement of my career			(3) 6%	
• Several times I suspended my business			(3) 6%	
• My work activity decreased significantly			(10) 19%	
• I have been replaced			(2) 4%	
• I risked to close my activity			(1) 2%	

These stories tended to start with a focus on the disease, through the description of symptoms and health conditions, then gradually opened towards the illness, describing the evolution of feelings and the family life. Disease prevailed in fathers' stories (73%), more reluctant to tell about their emotional experience. Sickness was revealed in 44% of mothers' stories and 54% of fathers. Mothers told about the impacts on their work condition, while in fathers' narratives the predominant aspect was the issue of the "normality", meant as having a "like everyone else" child.

The Launer and Robinson's classification revealed that, despite the difficulties, in parents' narratives prevailed the progression (60% of mothers and 67% of fathers) for having adopted coping strategies: acceptance of the child's conditions, trust and gratitude towards the center of care and restoring of a new balance in their family, working and social life.

These outcomes resulted independent from the levels of children's prematurity, their age and the geographical origin.

### The position paper

A Position Paper was defined based on the collected testimonies. It includes recommendations concerning: 24 h opening of all the Italian NICUs; uniformed respiratory prophylaxis, based both on prematurity level and the child's condition; programs of prevention of risks and information on the whole care plan; a multidisciplinary follow-up with network between hospital and local health care services; the legal

acknowledgement of preterm birth through the extension of the maternity leave.

### Discussion

This research brought to light the parents' need to express themselves and be listened to. The respondents dedicated time and energy to write long and detailed narratives, opening to their inner emotions and reflections, and considerations on the organization of care. Narrative was a positive experience for 93% of mothers and 75% of fathers: "Rarely people are interested in what happens when a child is born before ... so, I was very pleased"; "For the first time I felt free to say that I was scared ... Thank you".

Premature birth is a trauma that shatters parents' expectations of parenthood; kangaroo mother care, breast-feeding and other family-centered cares are very meaningful for them [28,29]. The collected testimonies show parents' psychological distress, already seen in other Countries [29].

The crossing between quantitative information and narratives integrated the living of families with the organization of the care plan, with the outcome of the Position Paper to improve families' living of the experience and their long term caregiving. Narrative Medicine might represent a bridge between health care professionals, families and even health care managers.

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