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Research article

Needs of parents of very preterm infants in Neonatal Intensive Care Units: A mixed methods study

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ABSTRACT

Objectives: To explore needs of parents of very preterm infants hospitalised in Neonatal Intensive Care Units according to their socioeconomic position, obstetric history and infant's characteristics.
Methodology: Sequential explanatory mixed methods study. Individual quantitative questionnaires (n = 118 mothers; 89 fathers) during infants' hospitalisation; couples-based semi-structured interviews (n = 26) four months after childbirth (July 2013–June 2014).
Setting: All level III public neonatal intensive care units in North Portugal.
Results: Mothers valued more information needs than fathers and their overall scores were mainly influenced by age and educational level, while fathers' needs perceptions were influenced by previous children. Despite gender differences, the assurance and proximity needs of parents apply across sociotechnical environments. Qualitative findings added the following needs: instrumental support from the government; regular emotional support from psychologists and social workers; enhancement of privacy to assure family-centred information and comfort; and availability of peers and health professionals as mediators in the provision of coherent information.
Conclusions: The promotion of family-friendly and gender-equality policies is crucial to support family integrated healthcare services. This study raises awareness for developing sensitive conceptual frameworks and instruments to assess parents' needs considering their socioeconomic position and reproductive trajectories, as well as privacy and regular emotional support in the neonatal intensive care unit.

Implications for clinical practice

- Nurses, neonatologists and peers are important health mediators in the provision of detailed and coherent information about all neonatal intensive care daily procedures.
- Health professionals should enhance privacy in information provision and in the ward.
- Parents need regular emotional support from psychologists and social workers during their stay.
- Support from the government facilitates the presence of both mothers and fathers in the neonatal intensive care unit and their involvement in child care.

Introduction

Time is ripe to identify, understand and address parental needs during infants' hospitalisation in Neonatal Intensive Care Units (NICU) by listening to both mothers and fathers' perspectives (Wang et al., 2016; Ward, 2001). Addressing parental needs

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is widely recognised as a keystone to guide quality family-centred and integrated healthcare services (O'Brien et al., 2018; World Health Organization, 2015, 2016a), as well as to improve parental quality of life (Cleveland, 2008). These issues are particularly pertinent for parents of preterm infants due to child's vulnerability, increased risk of morbidities and prolonged length of stay (Manuck et al., 2016). The incorporation of parents' perspectives on the organisation of care and health governance is especially relevant considering the mismatches between the perceptions of health professionals and parents (Lantz and Ottosson, 2014; Latour et al., 2010), and the differences between the support provided to family-friendly and gender-equality policies in Western and Nordic European countries (Hansen, 2012). These phenomena could led to a gap between the care expected by parents and the care actually provided (Ladani et al., 2017), as well as discrepancies between guidelines and families' needs (Amorim et al., 2016).

The literature on parental needs in NICU is mainly based on a qualitative assessment of mothers' experiences and has been focused on dimensions related with shared health and care (e.g., information and communication, assurance, proximity, social support, comfort) (Cleveland, 2008; De Rouck and Leys, 2009; Staniszewska et al., 2012), and not with the shared governance for health, limiting the opportunities of co-producing family centred and integrated healthcare systems (Kickbusch and Gleicher, 2012). Parents consistently prioritise infant-centred needs and undervalue parents-centred needs (Mousavi et al., 2016), but the scarce existing quantitative studies show that such needs may vary according to parents' socioeconomic characteristics (gender, age, marital status, educational level, income) (Mundy, 2010; Sargent, 2009; Wang et al., 2016), their previous experiences in NICU (Mundy, 2010), infants' illness trajectories (De Rouck and Leys, 2009) and length of stay (Sargent, 2009), as well as the design, organisational rules and regulations of each NICU (Baylis et al., 2014). These findings suggest that both parental and infants' characteristics and the environment of NICU influence the type of needs experienced by parents.

Hence, the comprehensive identification and mapping of both mothers' and fathers' needs simultaneously related to shared care and governance would benefit from a mixed methods approach. This knowledge is crucial for promoting quality healthcare systems and services centred on families and enabling their involvement in co-production of health in neonatology (Kickbusch and Gleicher, 2012). By integrating quantitative and qualitative data, this study aims to explore needs of mothers and fathers of very preterm infants hospitalised in NICU according to their socioeconomic position, obstetric history and infant's characteristics.

Methods

This observational mixed methods study used a sequential explanatory design, whereby the quantitative data were first collected to provide a general overview of the most valued needs and gender specific differences, followed by an interpretation of qualitative data to refine, explain and expand those statistical results (Creswell, 2015). The approach comprised individual quantitative questionnaires during infants' NICU hospitalisation, applied 15 to 22 days after delivery, and qualitative semi-structured couple interviews four months after. Clinical records were reviewed by researchers to retrieve data on pregnancy complications, multiple pregnancy, and each infant's gestational age and birth weight. Extremely low birth weight was defined as birth weight bellow 1000 g and extremely premature infants were those with gestational age under 28 completed weeks of pregnancy (World Health Organization, 2016b).

Between July 2013 and June 2014, mothers and fathers of very preterm infants admitted to all public level III NICU in Northern Health Region of Portugal (n = 7) were consecutively and systematically invited to participate in the study by the healthcare team. Eligible parents were those whose infants survived, were present in NICU during the hospitalisation period, and were able to speak and write in Portuguese (Alves et al., 2014). Among the 126 eligible couples, 122 (96.8%) agreed to participate in the questionnaire and among the latter, 117 (95.9%) accepted to be contacted for the qualitative interviews.

Questionnaire: participants and data collection

Five trained interviewers, all members of the research team outside the NICU healthcare staff, conducted face-to-face interviews, using structured questionnaires, to mothers and fathers, separately but within the same timeframe. Self-reported data on sociodemographic characteristics (sex, gender, educational level, marital status, occupation and subjective social class), as well as the existence of previous children were collected.

Occupations were classified according to the Portuguese Classification of Occupations 2010 (Statistics Portugal, 2018) and grouped in three categories: upper-white-collar, including executive civil servants, industrial directors and executives, professionals and scientists, middle management and technicians; lower-white-collar, including administrative and related workers, and service and sales workers; and blue-collar, which includes farmers and skilled agricultural, fisheries workers, skilled workers, craftsmen and similar, machine operators, assembly workers and unskilled workers.

Each participant was georeferenced according to home address, using the ArcGIS Online World Geocoding Service and Google Maps, to be matched to the contextual variable: distance in minutes from residence to NICU. The shortest road distance from participant's residence to NICU was calculated using ArcGIS version 10.4.1 and the Network analyst extension. The street network, required to calculate road distances, was provided courtesy of Environmental Systems Research Institute.

Additionally, mothers and fathers completed the NICU Family Needs Inventory (Ward, 2001), a self-report scale consisting in 56 need statements designed to measure the importance attributed to family needs. Each item ranges from 1 to 4: (1) Not important, (2) Slightly important, (3) Important and (4) Very important, being grouped into 5 subscales: "Assurance", "Proximity", "Information", "Support" and "Comfort". There is one open-ended question in which parents can describe other needs than those asked in the Inventory. The Portuguese version of the Inventory has shown a good internal consistency (Cronbach's $\alpha = 0.92$). After excluding participants with >20% of missing values, 118 mothers and 89 fathers (86 couples) were included in quantitative analysis.

Statistical analysis

Scores of the NICU Family Needs Inventory were calculated as the sum of all items of each subscale divided by the number of items for each subscale. In the case of having $\leq$20% of items classified as non-applicable or missing values, the scores were calculated as the mean of all items answered in each subscale.

Statistical analysis was performed using Stata 11.0 (College Station, TX, 2009). Sample characteristics are presented as counts and proportions and compared by Chi-square Test. The overall score of each subscale is presented as medians and interquartile range (IQR), according to socioeconomic, obstetric and infant's characteristics, and the comparison between mothers and fathers were computed using the Mann-Whitney test.

Qualitative interviews: participants and data collection

Between November 2013 and April 2014, parents who had previously accepted to be contacted four months after childbirth were systematically invited to participate in a couple-based interview. Parents whose infants were still hospitalized (n = 1) or died (n = 3) were excluded from this phase of the study. Participants were purposively sampled to include parents of infants with extremely and non-extremely low birth weight. In addition, a heterogeneity sampling was used for maximum variation of views and experiences, until no new themes emerged from interview data – thematic saturation (Braun and Clarke, 2006). Among 49 couples invited, 23 refused to be interviewed by lack of interest in the study (n = 12), unwillingness of one member of the couple to participate (n = 5), infant's illness (n = 3), lack of time (n = 2) and psychological unavailability (n = 1). Thus, semi-structured qualitative interviews were conducted with a subsample of 26 parental couples with a joint mode of interviewing.

The interviews took place at the most suitable venue for the participants, respecting their preference and assuring that there were no financial/time constraints for them, being conducted at parents' homes (n = 19), at the university department responsible for the study (n = 6) and in a private hospital room (n = 1). Interview duration ranged from 20 to 72 min (mean: 39 min). All interviews were audio taped and transcribed verbatim and accuracy has been checked. The interview guide covered the following areas: how parents deal with uncertainty and doubts and how they made their decisions concerning parental care, treatment options and uses of information sources; their understandings of medical facts, of technologies applied to perinatal care and of prognosis; their views of life and living with handicaps; and information and communication needs of parents. Data related to parental needs during infants' NICU hospitalisation will be discussed by exploring the entire content of each interview.

Content analysis

Thematic content analysis (Braun and Clarke, 2006) was performed using the software NVivo11 (QSR International, USA, 2015). A triangulation strategy was used to guarantee the rigour and quality of research - the first author led the analysis by identifying, sentence by sentence, parental needs experienced in NICU, and the last author collaborated on the development of coding framework. Firstly, quotations with similar meanings were inductively synthesised into categories, based on parents' perceptions about their needs in NICU. Secondly, using theoretical sensitivity in consultation with the existing literature about parental needs in intensive care (Leske, 1991; Ward, 2001), the categories were grouped into the following themes: support, assurance, comfort, proximity, and information and communication. The content of open-ended question of the NICU Family Needs Inventory was analysed using the same coding scheme. The most illustrative verbatim quotes were selected by two authors and revised by an English native speaker.

Ethical approval

The study was approved by the National Data Protection Commission (7136/2013) and the Ethics Committees of all seven hospitals where data was collected. Written informed consent was obtained from all participants according to the World Association's Declaration of Helsinki.

Results

Needs evaluation through parent questionnaire

The majority of participants were less than 35 years of age, married or lived with a partner, had no previous children and lived at less than 15 minutes distance from NICU (Table 1). About three quarters were parents of singletons and more than two quintiles experienced complications during pregnancy. The majority of parents did not have an extremely low birth weight or an extremely preterm delivery. Fathers were significantly less educated, were less likely to have lower white-collar occupations and considered themselves as belonging to a low/medium-low social class more frequently than mothers.

Participants attributed high importance to all NICU family needs subscales, increasing slightly from comfort (Median (IQR): 3.3 (3.0–3.6)) to assurance (Median (IQR): 3.9 (3.8–4.0)) needs. Mothers revealed a statistically significant tendency to value more information needs than fathers (Median (IQR): 3.8 (3.6–3.9) vs. 3.7 (3.5–3.9)).

Mothers and fathers without previous children rated support needs higher than those with previous children (Table 2). First-time fathers also revealed a significant tendency to value assurance and information needs, in comparison with fathers with previous children. Fathers of twins reported more frequently higher rates of comfort needs than fathers of singletons. Mothers aged 35 years or more attributed more importance to the needs of proximity, information and comfort than younger mothers. Less educated mothers were more likely to rate support and comfort needs as more important than more educated mothers. Support and assurance needs were also higher scored, respectively, by mothers living at a 15 minutes distance or more from NICU and those without pregnancy complications, in comparison with their counterparts.

The majority of needs considered as very important by $\geq$90% of parents were related to assurance and proximity (Table 3). Additional needs regarding support (n = 5), comfort (n = 3) and information (n = 1) were reported by 3 mothers and 6 fathers who responded to the open-ended question.

Semi-structured interviews with a subset of parents

All interviewed parents referred support, and information and communication needs. They mentioned the importance for extending parental leave for both mothers and fathers, covering the period of hospitalization, to facilitate their presence in NICU, as well as for having access to financial assistance for parking expenses, for both parents staying overnight near NICU, and for all recommended vaccines independently of infant's gestational age at birth:

> *"Mother: I should have the right to have a bigger parental leave* [100% instead of 65% of the salary], *at least during the hospitalisation period. Mother stays there [NICU] for a lot of hours alone in a very difficult situation. At least during the hospitalisation in NICU, the father and the mother should have the right to stay both with a* [full parental] *leave (...).*" (I21)

> *"Father:* [Our home] *It's too far [from NICU]. We have the car expenses, the tolls (...) Mother: The problem is that we have to pay the car parking* [at the hospital] *(...) Father: We can't* [manage it]." (I6)

> *"Father: For parents who lived far away* [from NICU] *there was a house for mothers to stay but (...) Mother: Perhaps allowing the father to stay as well.*" (I24)

> *"Father: They* [politicians] *should include all the* [recommended] *vaccines for all the babies* [in the National Program for Vaccina-

Table 1
Participants' characteristics and NICU Family Needs Inventory scores, stratified by gender.

	Total n = 207	Mothers n = 118	Fathers n = 89
Age (years), n (%)			
<35	145 (70.1)	84 (71.2)	61 (68.5)
≥35	62 (29.9)	34 (28.8)	28 (31.5)
Educational level (years), n (%)			
≤12	129 (62.3)	66 (55.9)*	63 (70.8)*
>12	78 (37.7)	52 (44.1)*	26 (29.2)*
Marital status, n (%)			
Single/Divorced/Widower	27 (13.0)	16 (13.6)	11 (12.4)
Married/living with a partner	180 (87.0)	102 (86.4)	78 (87.6)
Occupation, n (%)[a]			
Upper white collar	82 (42.7)	44 (41.1)*	38 (44.7)*
Lower white collar	56 (29.2)	40 (37.4)*	16 (18.8)*
Blue Collar	54 (28.1)	23 (21.5)*	31 (36.5)*
Subjective social class, n (%)			
Low/Medium-low	161 (78.9)	85 (73.9)*	76 (85.4)*
Medium-high/High	43 (21.1)	30 (26.1)*	13 (14.6)*
Distance from home to NICU (minutes), n (%)			
<15	106 (52.7)	58 (50.9)	48 (55.2)
≥15	95 (47.3)	56 (49.1)	39 (44.8)
Previous children, n (%)			
No	149 (72.0)	84 (71.2)	65 (73.0)
Yes	58 (28.0)	34 (28.8)	24 (27.0)
Multiple pregnancy, n (%)			
No	159 (76.8)	91 (77.1)	68 (76.4)
Yes	48 (23.2)	27 (22.9)	21 (23.6)
Pregnancy complications[b], n (%)			
No	118 (57.0)	69 (58.5)	49 (55.1)
Yes	89 (43.0)	49 (41.5)	40 (44.9)
Extremely low birth weight delivery[c], n (%)			
No	145 (70.0)	81 (68.6)	64 (71.9)
Yes	62 (30.0)	37 (31.4)	25 (28.1)
Extremely preterm delivery[d], n (%)			
No	162 (78.3)	93 (78.8)	69 (77.5)
Yes	45 (21.7)	25 (21.2)	20 (22.5)
NICU Family Needs Inventory Subscales[e], median (IQR)			
Assurance	3.9 (3.8–4.0)	3.9 (3.8–4.0)	3.8 (3.7–4.0)
Proximity	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.8 (3.6–3.9)
Information	3.7 (3.6–3.9)	3.8 (3.6–3.9)*	3.7 (3.5–3.9)*
Support	3.5 (3.1–3.8)	3.5 (3.1–3.8)	3.4 (3.2–3.7)
Comfort	3.3 (3.0–3.6)	3.3 (2.9–3.6)	3.4 (3.0–3.6)

Notes: IQR – Interquartile range; In each variable, the total may not add 207 parents, 118 mothers or 89 fathers due to missing values; *p value < 0.05 for the comparison between mothers and fathers.

[a] Unemployed (n = 36) and retired participants (n = 1) were classified considering their previous main occupation. Students (n = 2), housewives (n = 4) and armed forces occupations (n = 3) were excluded from this classification.

[b] Infectious, placental, haemorrhagic and cardiovascular complications.

[c] <1000 g.

[d] <28 completed weeks of pregnancy.

[e] Scale ranging from 1 – not important to 4 – very important.

tion], *not only for those with less than 28/30 weeks, even because we have a lot of expenses with them* [twins]." (I25)

Interviewed parents also referred to the need for having a technician available in the hospital to help them with "the social security bureaucracy and for explaining [what kind of] papers they need to deliver" (Mother, I10). They felt that the medical equipment, such as "the ventilators" (Father, I16), and the ratio of nurses per baby, "especially during the night" (Mother, I6), needed to be updated. Parents also requested a "[public] human milk bank" (Mother, I7). The support of extended family, in particular the grandparents, was highlighted as an important need to spread information about the infant's development to "*the rest of the family*" (Father, I25) and to help them dealing with daily activities like "cleaning the house and cooking" (Father, I26). Interviewees reported the need for regular support from psychologists and social workers beyond weekly meetings, which tended to be provided by nurses:

> "*Father: The psychologist and the social worker only approach us* [parents] *for that* [weekly] *session and the parents need them on a daily basis, when the difficulties happen (…) when we are unhappy. Mother: We need them* [psychologist and social worker] *to be more present.*" (I24)

> "*Mother: The Neonatology* [unit] *has a psychologist (…) but the nurses gave us a lot of support, every time we needed they gave us a lot of support.*" (I20)

The emotional support from other parents of infants hospitalised in NICU also emerged as an important need, mainly because the feeling of sameness facilitates mutual understanding and dialogue:

> "*Mother: The other mothers know what we are feeling because they are feeling the same (…) and we are more comfortable to talk with them* [instead of a health professional]." (I6)

Interviewees highlighted the role of other parents on the provision of practical information about the expected infants' hospitalisation trajectory and emotional experience, both orally or in-books:

> "*Mother: At the beginning (…) it was the other parents that explained to us what happened with their children, while the doctors were only saying that he* [son] *was stable.*" (I19)

> "*Mother: When they* [twin children] *were in NICU I have read a book of testimonials of parents of preterm twins, people who know what I'm going through (…) and this was very important.*" (I10)

Parents mentioned the need for receiving coherent information provided by different health professionals about NICU rules and routines "during the admission time" (Father, I11) and seemingly daily "insignificant" procedures, medical procedures and discharge decision-making:

> "*Mother: One day, I arrived at NICU and I saw the incubator empty… I was in shock. I didn't ask any question, I just started crying. When a nurse saw me* [crying], *she ran to tell me that my daughter was moved to be closer to her twin. She should have been more careful and call me (…) or to the father. This could seem the most insignificant thing in the world but it's not, it's very important [for us].*" (I7)

> "*Father: When the doctor was going to do the ultrasounds nobody informed us.* (I7)

> "*Mother:* [When] *I came to the unit, the nurse told me the babies* [twins] *will go home (…) nothing predicted that because they didn't feed properly (…) suddenly they were going to be discharged.*" (I7)

They praised the provision of "the necessary information in a non-shocking way, in a way that did not over concern" them (Mother, I12), but reported the need for reinforcing privacy when receiving information about infants' health status inside the neonatal ward, in order to do not "listening all the information about the baby besides" them (Father, I22). The awareness of the division of work between nurses and neonatologists was seen as an important information to improve communication: "Basically, on a daily basis we talked with the nurses (…) if it was a more serious thing [infection, heart problems], we talked to the doctor" (Father, I2). However, some interviewees claimed for more frequent interactions and a closer parent-neonatologist relationship:

Table 2
NICU Family Needs Inventory subscales scores stratified by gender, according to participants' characteristics.

	Mothers (n = 118)					Fathers (n = 89)				
	Assurance Median (IQR)	Proximity Median (IQR)	Information Median (IQR)	Support Median (IQR)	Comfort Median (IQR)	Assurance Median (IQR)	Proximity Median (IQR)	Information Median (IQR)	Support Median (IQR)	Comfort Median (IQR)
Age (years)										
<35	3.9 (3.8–4.0)	**3.8 (3.5–3.9)**	**3.7 (3.6–3.9)**	3.4 (3.0–3.8)	**3.3 (2.9–3.4)**	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.5 (3.2–3.8)	3.4 (3.0–3.6)
≥35	3.9 (3.8–4.0)	**3.9 (3.6–4.0)**	**3.9 (3.7–4.0)**	3.6 (3.1–3.8)	**3.6 (3.1–3.9)**	3.8 (3.5–3.9)	3.7 (3.6–3.9)	3.6 (3.5–3.9)	3.4 (3.1–3.7)	3.4 (3.0–3.6)
Educational level (years)										
≤12	3.9 (3.8–4.0)	3.8 (3.6–4.0)	3.8 (3.7–3.9)	**3.6 (3.3–3.8)**	**3.4 (3.1–3.7)**	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.9)	3.4 (3.2–3.8)	3.4 (3.0–3.6)
>12	3.8 (3.8–4.0)	3.8 (3.5–3.9)	3.8 (3.6–3.9)	**3.2 (3.0–3.7)**	**3.1 (2.9–3.4)**	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.8)	3.4 (3.1–3.7)	3.2 (2.9–3.6)
Marital status										
Single/Divorced/ widower	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.5 (3.1–3.8)	3.3 (2.9–3.6)	3.8 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.8)	3.4 (3.2–3.7)	3.4 (3.0–3.7)
Married/living with a partner	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.6 (3.2–3.8)	3.1 (2.9–3.6)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.5 (3.2–4.0)	3.3 (3.0–3.6)
Occupation[a]										
Upper white collar	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.3 (3.0–3.7)	3.2 (2.9–3.5)	3.9 (3.7–4.0)	3.7 (3.6–3.9)	3.7 (3.5–3.9)	3.5 (3.0–3.7)	3.3 (2.9–3.6)
Lower white collar	3.9 (3.8–4.0)	3.8 (3.5–3.9)	3.8 (3.6–4.0)	3.5 (3.1–3.8)	3.3 (2.9–3.7)	3.9 (3.7–4.0)	3.9 (3.6–3.9)	3.7 (3.6–3.9)	3.4 (3.3–3.9)	3.4 (3.1–3.5)
Blue Collar	3.9 (3.8–4.0)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.5 (3.2–3.8)	3.4 (3.0–3.7)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.6 (3.5–3.8)	3.4 (3.2–3.7)	3.3 (3.0–3.6)
Subjective social class										
Low/Medium-low	3.9 (3.8–4.0)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.5 (3.1–3.8)	3.3 (3.0–3.7)	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.9)	3.4 (3.2–3.8)	3.4 (3.0–3.6)
Medium-high/High	3.8 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.5 (3.0–3.8)	3.3 (2.9–3.4)	3.8 (3.7–3.9)	3.8 (3.6–3.8)	3.7 (3.6–3.9)	3.6 (3.0–3.7)	3.3 (2.9–3.5)
Distance home-NICU (min)										
<15	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	**3.4 (3.0–3.8)**	3.3 (3.0–3.6)	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.4 (3.1–3.8)	3.4 (3.0–3.7)
≥15	3.9 (3.8–4.0)	3.8 (3.6–4.0)	3.9 (3.7–4.0)	**3.6 (3.2–3.9)**	3.3 (2.9–3.7)	3.8 (3.5–4.0)	3.8 (3.5–3.9)	3.6 (3.5–3.8)	3.5 (3.2–3.7)	3.3 (3.0–3.5)
Previous children										
No	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–4.0)	**3.6 (3.1–3.8)**	3.3 (2.9–3.7)	**3.9 (3.8–4.0)**	3.8 (3.6–3.9)	**3.7 (3.6–3.9)**	**3.6 (3.3–3.8)**	3.4 (3.0–3.6)
Yes	3.8 (3.8–4.0)	3.8 (3.5–4.0)	3.7 (3.5–3.9)	**3.3 (3.0–3.5)**	3.3 (3.0–3.6)	**3.7 (3.5–3.9)**	3.7 (3.6–3.8)	**3.5 (3.4–3.8)**	**3.2 (2.9–3.5)**	3.2 (2.9–3.5)
Multiple pregnancy										
No	3.8 (3.8–4.0)	3.8 (3.5–3.9)	3.8 (3.6–3.9)	3.4 (3.0–3.8)	3.3 (2.9–3.6)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.9)	3.4 (3.1–3.7)	**3.3 (2.9–3.6)**
Yes	3.9 (3.9–4.0)	3.9 (3.6–4.0)	3.9 (3.7–4.0)	3.6 (3.2–3.8)	3.4 (3.0–3.7)	3.8 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.8)	3.7 (3.3–3.9)	**3.6 (3.1–3.7)**
Pregnancy complications[b]										
No	**3.9 (3.8–4.0)**	3.8 (3.6–4.0)	3.8 (3.7–4.0)	3.6 (3.1–3.8)	3.4 (2.9–3.7)	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.5–3.8)	3.4 (3.2–3.7)	3.4 (3.1–3.6)
Yes	**3.8 (3.7–3.9)**	3.8 (3.5–3.9)	3.8 (3.5–3.9)	3.4 (3.0–3.8)	3.3 (3.0–3.6)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.6 (3.1–4.0)	3.4 (2.9–3.7)
ELBW delivery[c]										
No	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.7–4.0)	3.6 (3.1–3.8)	3.4 (2.9–3.7)	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.4 (3.2–3.8)	3.4 (3.0–3.7)
Yes	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.3 (3.1–3.8)	3.2 (2.9–3.4)	3.8 (3.6–3.9)	3.7 (3.5–3.9)	3.6 (3.5–3.8)	3.4 (3.2–3.6)	3.3 (3.0–3.4)
Extremely preterm delivery[d]										
No	3.9 (3.8–4.0)	3.8 (3.6–3.9)	3.8 (3.6–3.9)	3.5 (3.1–3.8)	3.3 (2.9–3.7)	3.9 (3.7–4.0)	3.8 (3.6–3.9)	3.7 (3.6–3.9)	3.5 (3.2–3.8)	3.4 (3.0–3.7)
Yes	3.9 (3.8–4.0)	3.8 (3.6–4.0)	3.8 (3.6–3.9)	3.4 (3.1–3.8)	3.3 (2.9–3.6)	3.8 (3.5–3.9)	3.6 (3.5–3.9)	3.6 (3.4–3.8)	3.4 (3.1–3.6)	3.1 (2.9–3.5)

Notes: ELBW – Extremely low birth weight; IQR – Interquartile range; Scores are based on rating scale ranging from 1 – not important to 4 – very important; Bold types represent significant differences ($p < 0.05$).

[a] Unemployed (n = 36) and retired participants (n = 1) were classified considering their previous main occupation. Students (n = 2), housewives (n = 4) and armed forces occupations (n = 3) were excluded from this classification.

[b] Infectious, placental, haemorrhagic and cardiovascular complications.

[c] <1000 g.

[d] <28 completed weeks of pregnancy.

Table 3
Summary of the most important needs reported by parents of very preterm infants.

Family Needs	Quantitative data		Qualitative data
	Needs considered very important by ≥90% of participants	Needs identified in open-ended question	Needs added by parents during interviews
Assurance (reflecting the parental need to feel confident, secure and hopeful about their infant's outcomes, which stems from their trust in the health care system)	• Parents: to have questions about their infants answered honestly; to know that their infant is being handled gently by healthcare providers; to be assured that the best care possible is being given to their infant; to feel that the hospital personnel care about their infant • Mothers: to be told specific facts concerning their infant's progress; to feel there is hope; to know the expected outcome for their infant • Fathers: to know the expected outcome for their infant		• To put babies in the "first place", above parents
Proximity (including the parental need to remain near the infant, both emotionally and physically)	• Parents: to see their infant frequently • Mothers: to receive information about their infant at least once a day; to hold their infant in their arms and against their skin as soon as they can • Fathers: to be called at home about important changes in their infant's condition		• Taking care of the infant like "normal" parents do (change diapers give bath, measure body temperature)
Information and communication (including parental need to obtain realistic information about their infant health and care and about the NICU environment)	• Parents: to know how the infant is being treated medically	• Father: "To have information about the meaning of all NICU machines' beeps"	• Practical information provided by other parents • Reinforcement of consistency and privacy • Be aware of the division of work between nurses and neonatologists; more interactions and a closest parents-neonatologists relationship • Information about all daily "insignificant" procedures
Support (encompassing references to resources, systems and structures needed by parents)	• Mothers: to be given directions about how they can provide care to their infant in the NICU	• Parents: "To have financial support on meals and parking" • Mother: "To have psychological support when parents lost a child" • Father: "To have religious support in decision-making process about blood transfusions" • Father: "To support mothers with special physical health conditions after delivery"	• Support from the Portuguese government: extend parental leave for mothers and fathers; help with social security bureaucracy; create a human milk bank • Support from extended family: inform relatives/friends; helping in daily activities • Regular support from psychologists and social workers
Comfort (including references to personal comforts that are important to parents)	• Parents: to see that the NICU staff provide comfort to their infant	• Father: "The noise in NICU does not help to the rest of babies and parents" • Father: "To have an entrance for health professionals away from baby's incubators" • Mother: "To have a private room for mothers with infants hospitalised in NICU away from the full-term mothers' regular ward"	• To enhancing privacy in NICU ward (barriers between the incubators, a single room per family near NICU, a mourning room, a setting for breast-feeding and kangaroo care) • Natural light and thermal insulation • A sitting room with comfortable furniture and eat and drink facilities

"*Mother: The nurses responsible for them* [twin children] *talked a lot with us* [parents] *(. . .) if we asked to talk to the doctor, he also came but he was more distant* [from us]. *I felt the need for the doctor be more* [often] *in contact with us.*" (I26)

Almost all interviewed parents underlined the importance for proximity needs (25/26 couples). They pointed out the need for taking care of the infant like "normal" parents do, by "changing diapers, giving bath or measuring body temperature" (Mother, I1), while reinforcing the need for physical contact (e.g. touching and holding the baby, kangaroo care) to develop parental bonds and for parental presence in the NICU without time restrictions:

"*Mother: I couldn't verbalise the word "son" during the first days (. . .) I only started to internalise this from the moment I could touch him, starting to feel him (. . .) the first time they* [nurses] *put him in skin-to-skin contact with me it was the moment I felt: this is real, he is mine.*" (I11)

"*Mother: We* [parents] *were there* [NICU] *just beside her* [daughter], *nothing more (. . .) and this is important (. . .). The fact that the hospital let the parents be there* [NICU] *24 hrs a day is great (. . .) it's a tremendous luxury for parents.*" (I3)

More than a half of the interviewed parents (15/26 couples) revealed assurance needs. To "put babies first, above parents" (Mother, I3), and to develop trustworthy parent-provider relationships were frequently mentioned. To feel confidence when leaving "the infants in doctors' hands" (Mother, I10) emphasised, which may feel threatened when healthcare professionals didn't tell parents "the truth". Some interviewees talked about the need for having opportunity to decide whether they are willing or unwilling to stay beside the baby during painful procedures, such as "the transfontanelar ultrasounds performed by medical residents" (Mother, I7).

"*Mother: He* [son] *had two cerebral haemorrhages (. . .) Father: Yes, they* [doctors] *said to us that he had two little points in the ultrasound (. . .)* [and then] *in the morning they said to me that it was a little haemorrhage, without importance (. . .) after that we couldn't trust* [the doctors] *because they didn't tell us the truth (. . .)*" (I8)

A few interviewees (6/26 couples) mentioned comfort needs, calling for more privacy in NICU ward. Parents reported the need for having "physical barriers between the incubators" (Father, I25), a "single room per family" near NICU (Father, I8), a "mourning room for parents" (Father, I25) and an appropriate setting for breastfeeding and for doing kangaroo care. They also mentioned the importance of natural light and thermal insulation in NICU ward, as well as a sitting room, with comfortable furniture and eat and drink facilities, to rest or to talk with other parents:

"*Mother: The space for breast pumping and for doing the kangaroo care is very small (. . .) I was always being pushed because it was a passing area (. . .) and I would like a more private space.*" (I1)

"*Father: In other hospitals the light is artificial, here the light is good [natural] (. . .) but we can see that the windows, the air conditioning. . . Mother: Through those windows comes such a cold! Father: It's old (. . .) it* [physical environment] *could be better.*" (I26)

"*Mother: I think it's missing a room for parents. Father: Yes for, those who are there* [NICU] *all day, resting. The available room had only one chair, (. . .) without any furniture, only lockers. We need a coffee machine, a water machine (. . .) some chairs to talk to each other and get some rest.*" (I13)

Discussion

Results from this mixed methods study can be useful for assessing and implementing quality family-centred and integrated healthcare services. Quantitative data suggest gender differences in factors associated with the importance attributed to parental needs: mothers valued more information needs than fathers and their overall scores were mainly influenced by age and level of education, while fathers' perception of their needs was mainly influenced by previous children. These findings contribute to a growing but still scarce literature addressing the specific factors associated with needs of parents of very preterm infants in NICU and support the development of further research on the degree of gender sensitivity of family needs measures. This study also showed that, despite gender differences, the assurance and proximity needs of parents apply across sociotechnical environments. All interviewees mentioned the need for instrumental support from the government for facilitating the presence of both mothers and fathers in NICU, and for regular emotional support from psychologists and social workers. These qualitative findings draw attention to the role of public policies in supporting or hindering parental involvement in NICU. Qualitative data also revealed additional needs related with information and comfort, alerting for the enhancement of privacy in the NICU ward and highlighting the role of other parents, nurses and neonatologists as complementary health mediators in the provision of detailed and coherent information about all NICU daily procedures. This knowledge helps in developing respectful and responsive family-friendly and gender-equality policies and healthcare, while challenging the items and the conceptual framework underlying the quantitative Inventory.

Gender differences in the perception of parental needs in NICU have been previously reported (Mundy, 2010; Sargent, 2009; Wang et al., 2016). This study contributes to reveal how multiple femininities and masculinities intertwined with traditional gender roles, in the sense that persistence of mothers as primary caregivers (Noergaard et al., 2017) helps to explain why information regarding infants' health and NICU routines are more important for mothers than fathers, especially for the oldest ones. In addition, fathers without experience of parenting require being directly informed by staff, helping them to maintain control, to protect their family and to participate in childcare (Noergaard et al., 2017). Healthcare professionals should be aware of the importance for clear, constant and reliable information adapted to infant's illness trajectory phase, parental cultural background and previous experience during pregnancy (De Rouck and Leys, 2009; Noergaard et al., 2017).

In a context where parents of preterm infants tend to attribute higher scores to assurance and proximity needs worldwide (Mundy, 2010; Ward, 2001), this study draws attention not only to the crucial role of regular emotional counseling provided by a wider network of professionals within multidisciplinary teams but also of public healthcare policies beyond NICU staff's control (e.g., parental leave policies, social security bureaucracy, travel, family accommodation near the NICU and other financial implications). This knowledge will contribute to promote policies that would assist families in their proximity needs (Mousavi et al., 2016), while reducing social inequalities and the stress created by financial hardship and dealing with bureaucracy in caring for a very preterm baby. This is particularly significant in the context of the socio-economic situation that parents find themselves in. The need for reinforcing privacy during information provision as well as in NICU ward join the concern from recent studies revealing the importance of a consistent and continuous care (Toral-Lopez et al., 2016) and underlining the confidentiality guarantee during handovers and ward rounds in NICU (Banerjee et al., 2018). More-

over, it challenges the idea that parents tend to neglect their comfort needs (Mundy, 2010; Wang et al., 2016).

Limitations

A limitation of this study is the time discrepancy between the two moments of data collection (during hospitalisation and four months after). Although it may shape differences between quantitative and qualitative results, very preterm infants stay hospitalised for long periods and parental experiences remain vivid by several months (Colville et al., 2009). Moreover, joint couple interviews may have limited the emergence of some sensitive issues among participants who may felt themselves uncomfortable acknowledging them in the presence of the partner, while leading to greater agreement on a variety of attitudinal and behavioural items. Furthermore, the utility of the NICU Family Needs Inventory (Ward, 2001) for research and clinical purposes could be questioned due to its length and conceptual subjectivity underlying the placement of each item in its respective subscale (Nicholas, 2006).

Conclusion

This mixed methods study draws attention to family-friendly and gender-equality policies for supporting quality family-centred and integrated healthcare services in Neonatology. Grounded in a consecutive and systematic recruitment of both mothers and fathers from all public level III NICU in North of Portugal during one year, this study raises awareness for the need of flexibility and sensitivity in developing conceptual frameworks and instruments to assess parental needs that take notice of socioeconomic position and reproductive trajectories of parents, as well as issues of privacy and regular emotional support in NICU.

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Declaration of Competing Interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2019.05.003.

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