

SHORT TERM SCIENTIFIC MISSION (STSM) SCIENTIFIC REPORT

This report is submitted for approval by the STSM applicant to the STSM coordinator

Action number: IS1405

STSM title: Parental Quality of Life after a very preterm birth: Rethinking family centredness

STSM start and end date: 26/06/2017 to 09/07/2017

Grantee name: Mariana Filipa da Silva Amorim

PURPOSE OF THE STSM:

This STSM, intrinsically related to the socio-cultural aspects of birth, is based on my mixed-methods PhD project about the effect of a very preterm birth on mothers' and fathers' quality of life (QoL); and the ethical and methodological challenges when interviewing couples about their experiences in Neonatal Intensive Care Units (NICU) after a very preterm birth.

The specific objectives of this STSM were: 1) to compare the policy, knowledge, attitudes and values that shape Family Centred Care in neonatal guidelines in Portugal, France and in Europe in order to support debates on expectations for public health services; and 2) to discuss ethical and methodological issues regarding sampling and data collection when interviewing parental couples about their QoL after a very preterm birth, focusing on dependability and transferability. The STSM addressed this agenda through four key tasks:

1. Presentation and discussion of a paper regarding ethical and methodological challenges involved in mixed-methods couple-based research.
2. Mapping out French, Portuguese and European guidelines regarding Family-Centred Care in Neonatology, through the analysis of the inclusion of parental information.
3. Visiting a French NICU.
4. Attendance of the 3rd International Neonatology Association Conference with an e-poster presentation.

DESCRIPTION OF WORK CARRIED OUT DURING THE STSM

The birth of a very preterm infant and his/her subsequent hospitalization in NICU constitutes a stressful life event for mothers and fathers (1-3), which may influence parental QoL. However, it may be possible to mitigate its negative effects through the implementation of Family Centred Care. This approach advocates the promotion of individualized and flexible care, suitable to the specific

needs of each family, being grounded on the provision of information and family support, and on the establishment of effective communication between healthcare professionals and family members (4-6). In the last decade, there has been a strong focus on the translation of scientific knowledge into evidence-based practice when dealing with very preterm births, aiming to standardise and rationalise healthcare (7). However, the development of guidelines for neonatal intensive care is mainly carried out by specialists and based on their own perspectives (8) and the incorporation of parents' needs and perspectives with respect to the organisation of care is needed (6, 9-11).

Parental informational needs included in the NICU guidelines were analysed at two levels: European and national (Portugal and France). The flow diagram of the guidelines selection process is presented in Figure 1. Specifically:

1. We searched all the guidelines freely available in June 2017 at the following websites:
 - European Society of Paediatric and Neonatal Intensive Care (<http://espn-online.org/Education/Standards-and-Guidelines>)
 - Portuguese Neonatal Society (<http://www.spneonatologia.pt/documents/consensuses/>)
 - French Pediatric Society (<http://www.sfpediatricie.com/recommandations-de-bonne-pratique>)
2. Documents regarding guidelines specific for neonatal care, that included at least one of the words: Mother(s), Father(s), Parent(s), Family(ies), Parental, Maternal, Paternal, Siblings, Brother(s), Sister(s), and comprising data concerning the type and characteristics of the information to provide to parents/families during the hospitalization period, were selected.
3. According to the protocol from Stemler (12) for content analysis, the guidelines eligible were coded line-by-line and then synthesized into descriptive a priori categories related to parental information needs, emerging from literature (8): Infant's health status; Jaundice; Breastfeeding; Visits Regulation; Preparation to discharge; Neonatal palliative Care. Data analysis was performed using NVIVO software.
4. If new categories emerged they were included.

Additionally, to understand the socio-cultural context of the French neonatal guidelines, I visited the NICU at Hôpitaux de Toulouse.

Listening to parental couples raises several ethical and methodological challenges regarding sampling, data collection and analysis (13, 14). Family researchers have recognized the need for discussing ethical challenges drawn from couple-based studies embedded in researchers' experiences (15). However, the sparse work around these topics has been mainly grounded on qualitative data covering dilemmas regarding informed consent, voluntary participation,

confidentiality and privacy; questions regarding study design and sampling; and difficulties in data analysis and interpretation.

The draft of a paper on ethical and methodological issues regarding sampling and data collection when interviewing couples about their experiences in NICU after a very preterm delivery, was presented and discussed during the INSERM UMR1027 Social Epidemiology team meeting.

The attendance of the 3rd International Neonatology Association Conference allowed the dissemination and discussion of the results of my PhD thesis regarding family-integrated care in Neonatology.

DESCRIPTION OF THE MAIN RESULTS OBTAINED

From all the identified guidelines (n=92), 6 European, 6 French and 9 Portuguese reported data on information to provide to parents/families during NICU hospitalization. Overall, the guidelines available on the websites were updated and exclusively written by specialists (Table 1), contradicting the recent trends to integrate individual patient values and preferences in clinical practice guidelines (16).

Parental information regarding resuscitation, breastfeeding, therapy side-effects, and infant's health status were highlighted (Table 2). European guidelines emphasized the information during resuscitation process adapted to parental beliefs, values and rituals; as well as the discussion about organ donation with parents/relatives. However, such issues are absent at the national level guidelines.

French NICU professionals are mainly concerned with the provision of information on breastfeeding, which is probably associated with its connotation of servitude for women in France (17). French culture has privileged the advertising of hiding the nourishing breast, resulting in negative speeches and misconceptions of breastfeeding (17). Also, the low proportion of Baby-friendly Hospitals (18) in France comparing to Portugal (5% vs. 35%, in 2015) (19), may justify the focus on breastfeeding education. Portuguese NICU professionals underline the importance of providing parental genetic counselling and information about jaundice and to prepare parents for caring for their infant after discharge.

The discussion of ethical and methodological challenges regarding sampling and data collection when doing mixed-methods couple-based research is informed by fieldwork conducted in Portugal (9), based on: NICU-based surveys of parents of very preterm infants admitted to the 7 level III NICU of North of Portugal; and semi-structured couple interviews, conducted 4 months

after birth. A reflexive analysis of questionnaires, interviews and researcher's field notes was undertaken.

Ethically important decisions occurred when choosing the criteria for sampling and opting to conduct separate or joint couple interviews. Participants were purposively sampled to include parents of extremely and non-extremely low birth weight infants, based on evidence from ethnographic observation, suggesting infant's birth weight as a proxy of the infant's vulnerability for parents. Nevertheless, health professionals suggested the use of gestational age, invoking evidence-based knowledge. In fact, our analysis showed that father's occupation was the main variable influencing the couples' narratives about parental roles and knowledge in NICU. Men working in health and teaching professionals enacted an "emotionally-driven narrative"; men with occupations in artisanal or skilled manual jobs and clerical support roles presented an "emotionally-silenced narrative"; and finally, men working in business, civil construction and armed forces a "control-need narrative".

Additional issues included informed consent and how to deal with spouses' discordant self-reports of couple-level variables (household monthly income and length of marital relationship). Consent of the two spouses can become a "deformed consent" and dilemmas regarding privacy emerged in joint interviews.

There is a need to include family perspectives on European and National NICU guidelines to promote family-centred neonatal services. National guidelines include parental information rooted on country needs, not following directly the European hot topics. Ethical issues involved in studies with couples need to be systematically discussed in the literature, and embedded in researchers' experiences.

FUTURE COLLABORATIONS (if applicable)

This short report is a preliminary and descriptive exploration of the data analysed and discussed during this STSM.

Regarding the NICU guidelines, further investigation, with an in-depth analysis, including the hospital level guidelines (NICU from hospital of Toulouse and NICU from a hospital of Porto), will be performed in collaboration with the host institution. The analyses and results will be structured into a scientific paper in an international peer-reviewed journal in collaboration with Michelle Kelly-Irving and Flora Koliouli during 2018.

The paper concerning the ethical and methodological challenges in mixed methods couple-based research is ongoing, and is expected to be submitted to an international peer-reviewed journal at the beginning of 2018, in collaboration with Michelle Kelly-Irving.

Furthermore, we are discussing the possibility of translating into French and validating the Short form of the Neonatal Intensive Care Unit Family Needs Inventory developed by Alves et al. (20) for use within the *Bulle NéoMat* Project in Toulouse; and to translate into Portuguese and validate the Healthcare team Satisfaction/stress Questionnaire which the *Bulle NéoMat* team is using in their project in a NICU of Porto.

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Figure 1. Flow diagram of the guidelines selection process

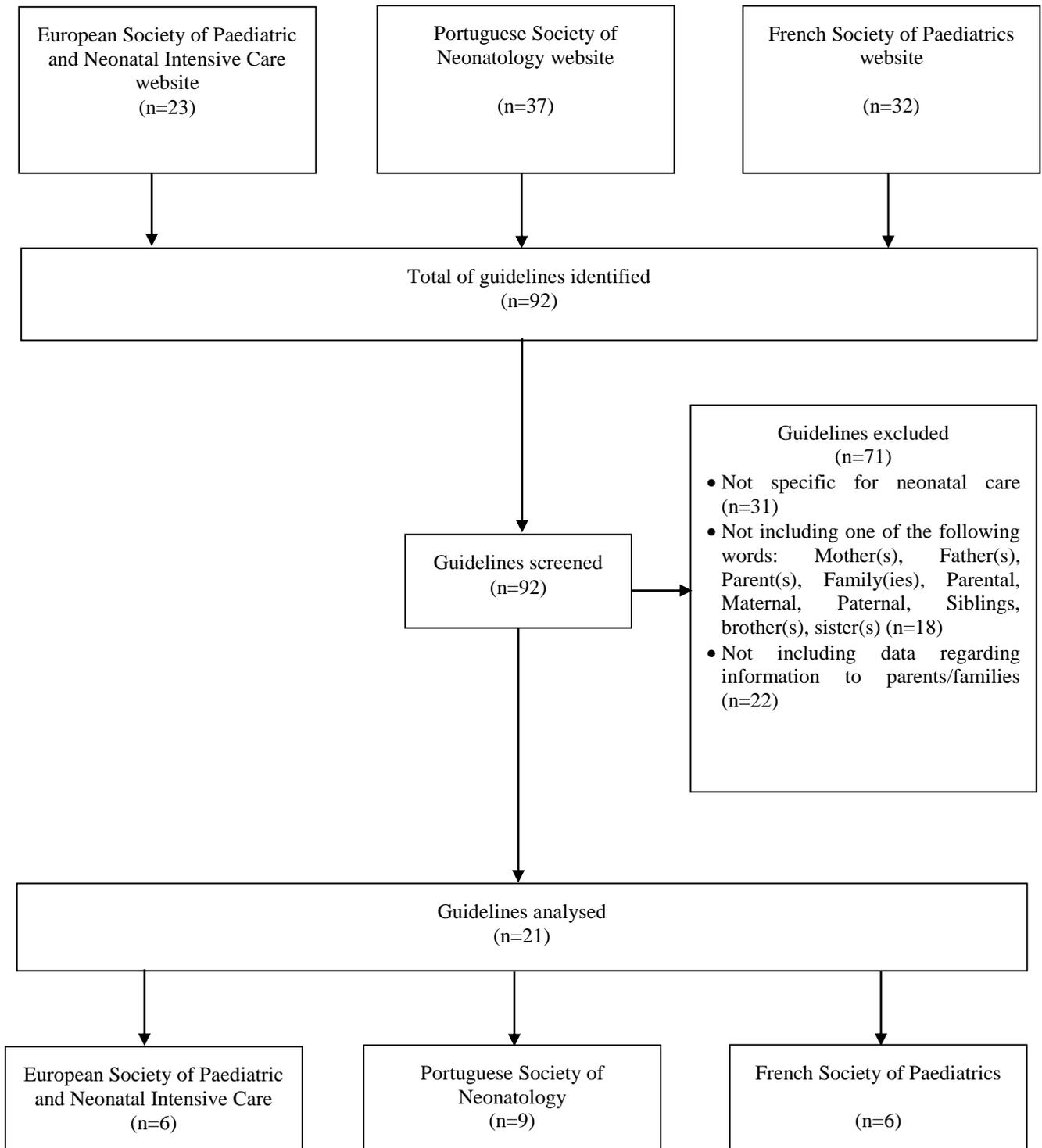


Table 1. Characteristics of the analysed guidelines

Code	Authors	Year	Title
E2	Wyllie et al.	2015	Resuscitation and support of transition of babies at birth
E3	Maconochie et al.	2015	Paediatric life support
E6	Monsieurs et al.	2015	European Resuscitation Council Guidelines for Resuscitation 2015 - Executive summary
E7	Bossaert et al.	2015	The ethics of resuscitation and end-of-life decisions
E13	Fulbrook et al.	2007	The presence of family members during cardiopulmonary resuscitation
E16	European Society of Paediatric and Neonatal Intensive Care	Not described	Standards for End of Life Care including Organ/Tissue Donation
F4	Pietremen et al.	2016	Diagnostic et prise en charge de la maladie rénale chronique de l'enfant: recommandations de la Société de néphrologie pédiatrique (SNP)
F9	Turck et al.	2013	Allaitement maternel: les bénéfices pour la santé de l'enfant et de sa mère
F15	Gaudelus et al.	2014	Le nouveau calendrier vaccinal est-il adapté à l'ancien prématuré?
F17	Chappuy et al.	2014	Recommandations pour la conduite et la publication de travaux de recherche en pédiatrie.
F22	Meau-Petit et al.	2009	Hypothermie contrôlée du nouveau-né à terme après asphyxie périnatale
F24	Ministère de la Santé et des Solidarités	2006	Comment bien recueillir, conserver et transporter le lait maternel en toute sécurité
P2	Taborda et al.	2010	Neuro-imagiologia neonatal
P9	Mendes e Justo da Silva	2013	Cuidados paliativos neonatais e em fim de vida
P12	Quintas e Ramires	2013	Icterícia neonatal: Avaliação e tratamento no recém-nascido de termo e pré-termo
P15	Martins et al.	2013	Recém-nascido hipotónico – Algoritmo de orientação diagnóstica
P17	Vasconcellos et al.	2013	Trombocitopenia no recém-nascido
P21	Gonçalves et al.	2014	Hiperplasia congénita da suprarrenal no período neonatal
P23	Gonçalves et al.	2014	Hipertensão pulmonar persistente do recém-nascido
P24	Freitas et al.	2014	Atuação no micronato
P30	Branco e Mimoso	2014	Limite da viabilidade

Note: E= European Guidelines; F= French guidelines; P= Portuguese guidelines

Table 2. Extracts of type and characteristics of the information to provide to parents/families during the hospitalization period

Categories	Number of guidelines	Number of references coded	Extracts
Resuscitation	5 (5E, 0P, 0F)	17	“Family members should be warned that on occasions they may be asked to leave the bedside if at any time it is thought to be in their or the patient’s best interests, for example, for the purpose (...) of the resuscitation team. Europe is multi-culturally diverse, and the resuscitation team should take the individual patient’s and family’s beliefs, values and rituals into account.” (E13)
Breastfeeding	3 (0E, 1P, 2F)	15	“The decision to breastfeed, of course, belongs to the parents, [we have to make sure] they are fully informed about the benefits of breastfeeding. The legitimate concern of not blaming mothers who do not want to breastfeed does not justify the lack of information of those who plan to breastfeed. It is up to health professionals to inform the parents, while scrupulously respecting their choice. The information should not be too medicalized. The message should be based on 2 issues: 1) breast milk is the reference; 2) breastfeeding is valuable for the mother and gives her a real pleasure in contacting with the baby.” (F9)
Side-effects of a therapy	3 (0E, 2P, 1F)	6	“The parents, or legal guardian, should sign an informed consent sheet, after being informed about the possible benefits and risks of complications associated with [the use of] ECMO.” (P23)
Infant’s health status	3 (1E, 2P, 0F)	4	“(…) It is important that the team caring for the newborn baby informs the parents of the baby’s progress (...) If resuscitation is required inform the parents of the procedures undertaken and why they were required (...)” (E6)
Limit of viability	2 (1E, 1P, 0F)	9	“One of the fundamental aspects in the viability weighted is the involvement of parents in this process. Careful and mutually empathetic, repeated and coherent information and discussion, preferably simultaneously with both parents, will compose the basis of that involvement, which will lead to a strong and healthy relationship of trust between them and the team. The information to the family must be sensitive to its cultural essence and appropriate to its level of understanding.” (P20)
Neonatal palliative care	2 (1E, 1P, 0F)	8	“Compassionate communication with patients and loved ones is essential when dealing with end-of-life-care (...) The grieving process may be supported by allowing unrestricted visiting, provision of clear verbal and written information, providing the opportunity to visit the deceased and facilitating religious procedures (...) Clinicians should be honest about what can and cannot be achieved. Sharing the truth of the

			situation (...) will allow the patients to make informed decisions about the choices available to them at the end of their lives.” (E7)
Genetic counselling	2 (0E, 2P, 0F)	2	“The treatment of the new-borns with hypotonia is out of this protocol scope (...) but it should be offered genetic counselling to the family.” (P15)
Jaundice	1 (0E, 1P, 0F)	3	“At hospital discharge [it is] important, in the case of late preterm infants, oral and written information to parents about jaundice.” (P12)
Participation in research studies	1 (0E, 0P, 1F)	2	“(…) [the authors should guarantee] that the patient (or his or her parents or guardian) has given written informed consent for the publication. Informed consent, in this case, requires that the identifiable patient (or his or her parent or guardian) have consulted the manuscript to be published.” (F17)
Dealing with chronic kidney disease	1 (0E, 0P, 1F)	2	“Access to information should be facilitated to family by providing them documents, when they exist, and by indicating the names of associations, discussion forums, websites [with experiences of other families caring for infants with chronic kidney disease].” (F4)
Organ donation	1 (1E, 0P, 0F)	1	“Discussion about organ donation with parents/relatives should occur with experts in donation. Collaborative discussion with the family by both [N]ICU team and the organ donation team together, is preferred, though the organ donation team alone can approach if the [N]ICU team supports this (...)” (E16)
Preparation to discharge	1 (0E, 1P, 0F)	1	“Before discharge, it should be ensured that there is parental competence and adequate home conditions to receive the infant. Parents should feel prepared for discharge and confident in their role as parents. They should be educated to recognize signs of illness, take measures to prevent infection and promote a smoke-free environment and avoid overcrowded places. The family should be instructed on safe practices for the prevention of sudden infant death syndrome, cardiorespiratory resuscitation training, and car seat safety.” (P24)
Transport	1 (0E, 0P, 1F)	1	“The information given to parents before transport should be very conservative.” (F22)
Vaccination	1 (0E, 0P, 1F)	1	“Beyond the basic hygiene rules, certain vaccinations of parents, grandparents, siblings and staff (...), carried out before or just after birth, can considerably reduce the risk of illness. It is therefore necessary to check and if necessary to update the

			<p>vaccinations of the entourage especially for the pertussis and the flu. Due to the high risk of severe pertussis complications in children born prematurely, the major role of parents and siblings in pertussis transmission highlights the particular interest of booster vaccination of parents (...), and the update of the vaccines of the grandparents, brothers and sisters.” (F15)</p>
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Note: E= European Guidelines; F= French guidelines; P= Portuguese guidelines

Annex 1
Full description of daily activities

Day	Task
26/06/2017	Arrival at Toulouse
27/06/2017	<p>1) Little tour on UMR 1027 building guided by Michelle Kelly-Irving in order to meet the staff and to introduce myself.</p> <p>2) Meeting with Michelle Kelly-Irving to discuss the progress of my PhD and the draft of the paper regarding ethical and methodological challenges involved in mixed-methods couple-based research.</p> <p>3) Presentation of my PhD results, with a special focus on the ethical and methodological challenges faced when doing mixed-methods couple-based research, on the INSERM UMR1027 team meeting.</p> <p>4) Attending a meeting about the new French regulations on nutritional health.</p>
Notes	<p>It was very helpful to have comments and suggestions about my work in order to improve it.</p> <p>I had an informal conversation with a Postdoctoral researcher who had a very preterm baby. It was a very helpful conversation once it helped me to understand the hospitalization process in a NICU in France.</p>
28/06/2017	<p>1) Mapping out the guidelines from French Pediatric Society.</p> <p>2) Meeting with Michelle Kelly-Irving to receive their feedback about the draft of the paper on ethical and methodological challenges in mixed methods couple research.</p>
Notes	Today I have met a Medical Doctor Master student in Public Health from Paraguay interested in maternal health. It was a good networking especially due to the differences between our countries in maternal health and family planning practices.
29/06/2017	1) Meeting with Dr. Olivia Troupel-Cremel, PI of the project “Bulle NéoMat”, Lecturer in developmental psychology, Université Toulouse II Jean Jaurès, about the project in which she is the principal investigator. They are implementing a model of care in which the mother and the premature baby (>33 weeks of gestation) are hospitalized in the same room. They are interested in the attachment, skin-to-skin, breastfeeding, stress and satisfaction with care variables.

	<p>They developed peers support groups, workshops to help parents in the transition to parenthood and developed a program to train the healthcare staff for having a common, coherent and comprehensive information delivery. She is developing a project based on the experience of the siblings of hospitalized premature babies.</p> <p>2) Meeting with Dr. Flora Koliouli, Postdoctoral researcher in developmental psychology Université Toulouse II Jean Jaurès, working on projects: “Bulle NéoMat” and “1,2,3 Préma”, about the possibility to writing a paper in collaboration regarding the analysis of the inclusion of parents/families information needs in NICU guidelines – European Union, Countries (France and Portugal) and specific hospitals (Toulouse and Porto) as case studies. The aim is to see if the concerns that came up from a bottom up perspective (like the development of the family integrated care, including the family in the NICU norms and routines) are including in the guidelines that are developed in a top down perspective.</p>
Notes	I found common research interest between me and Flora, namely the study of satisfaction and the stress among NICU healthcare professionals. It will discuss with my team from Porto the possibility of designing a collaboration project.
30/06/2017	<p>1) Development of the protocol for content analysis of the NICU European, French and Portuguese guidelines and a grill in order to standardize the analysis made by me and Flora.</p> <p>3) Attending the essay of the Thesis presentation “<i>Stress dans la petite enfance et maladies atopiques: Approche biopsychosociale dans la cohort de naissance ELFE</i>” from a Master student. The work assessed the association between parental stress (perinatal and psychosocial), and the development of atopic diseases in children at two years of age.</p> <p>3) Literature review of studies aiming to analyze qualitatively guidelines and documents.</p>
01/07/2017	Visit to the city center.
02/07/2017	<p>Lunch with Michelle Kelly-Irving and her family.</p> <p>Visit to two museums: Natural history museum and Augustin museum.</p>
03/07/2017	<p>1) Import all the guidelines to the NVIVO.</p> <p>2) Analysis of the Portuguese guidelines.</p> <p>3) Informal analysis of the documents regarding the hospitalization of the Postdoctoral’s son in the NICU of Toulouse:</p> <ul style="list-style-type: none"> - booklet for fathers - pamphlet about breastfeeding - brochure on skin-to-skin mother care

	I was also able to see some photos of the NICU and as far as I could see it's not very different from Portugal regarding infrastructures (e.g. just one chair beside each incubator).
04/07/2017	1) Analysis using NVIVO software of the European and French guidelines.
05/07/2017	1) Analysis using NVIVO software of the French guidelines. 2) Meeting with Flora to compare our preliminary analysis and to settle the following steps regarding the writing the paper draft. 3) Visit to a French Neonatal Intensive Care Unit at Hôpitaux de Toulouse, hosted by Dr. Melinda Benard, a neonatologist.
Notes	It was really interesting to see the similarities and the differences between the neonatal cares in two different countries and to have the opportunity to ask some questions about it. The main difference, in addition to the organization of care in 5 steps, was the absence of parents in neonatology. I have seen much less parents caring for their babies or just sited beside the incubator in France than in Portugal. I asked Dr. Melinda the reason why parents are not present in neonatology and she said that possibly is because they live far away from hospital, they have other children to take care and they do not want to see their babies suffering. I audio recorded my observations, thoughts and feelings during the visit to the French NICU. It will be helpful in the writing of a little comment comparing my experience in NICU's of two different countries.
06/07/2017	1) Meeting with Michelle Kelly-Irving to: - discuss the preliminary results of content analysis of guidelines, - examine whether the aims of my visit were fulfilled; - discuss the roadmap for next steps on our research collaboration. 2) Travel to Lyon.
07/07/2017	Attendance of the INAC opening ceremony, the symposium "Human milk fortification: Benefits of an exclusive human milk diet for premature infants" and the abstract session.
08/07/2017	Attendance of the session: "Birth defect, ethical issues and Neonatology in Future", the plenary session: "Neonatal challenges", the abstract session and the symposium: "Intensive & critical care – information systems".
Notes	A medical doctor, specialized in neonatology, wanted to know more about my work. She works at a French Neonatal Unit and she is very interested in the results of our work. We shared our e-mail contacts.

09/07/2017	<p>1) Attendance of the symposium: “Meet the expert: how to successfully implement the SPO2 CCHD screening” and the session: “Hot topics in Neonatology”.</p> <p>2) Travel to Porto</p>
Notes	<p>Topics about parents and family are not in the agenda of neonatal healthcare professionals, which contradicts the recent movement to integrate individual patient values and preferences in care in NICU. The only two abstract (including mine) regarding parental issues were presented as E-Posters.</p>

Annex 2

Photo Gallery



Photo1. The arrival at Université Toulouse III, INSERM UMR 1027.



Photos 2 and 3. Walking around Toulouse: on the Place du Capitole and on the bank of the Garonne River.



Photo 4. At the 3rd International Neonatology Association Conference, besides the E-Poster.

Annex 3

The e-poster presented at the 3rd International Neonatology Association Conference



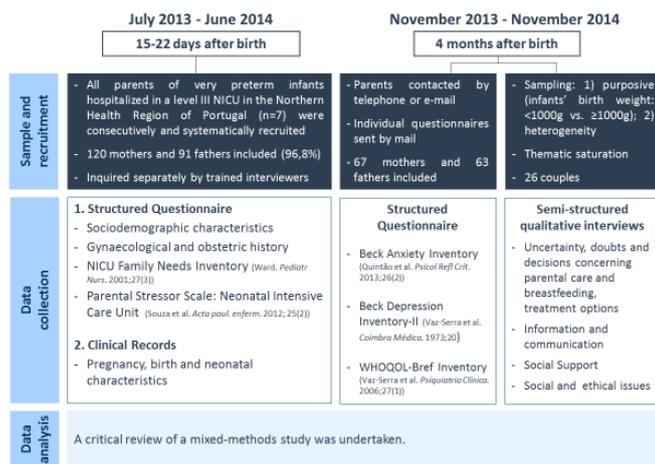
Family-integrated care in Neonatology: a needs-driven and socio-ethical sensitive approach

Mariana Amorim, Elisabete Alves, Michelle Kelly-Irving, Susana Silva



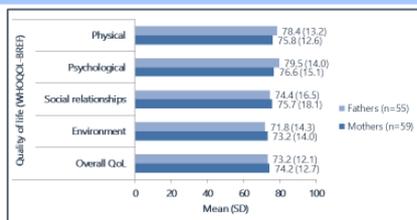
FCOMP-01-0124-FEDER-019902; PD/BD/105830/2014; IF/01674/2015; SFRH/BPD/103562/2014

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Alves E, Amorim M, Fraga S, Barros H, Silva S. Parenting roles and knowledge in neonatal intensive care units: Protocol of a mixed methods study. *BMC open.* 2014;4(7):e005941.

Results: Parental quality of life 4 months after delivery



Factors influencing negatively the QoL

- Loss of autonomy: constant surveillance; dependence of medical care; lack of institutional support
- Changes in lifestyles: sleeping disorders; no time for leisure activities; hygienisation (body and spaces); unhealthy diet
- Alterations in marital relationship: no time for being together

Factors influencing positively the QoL

- Redefining priorities
- Thinking positively
- Developing parental skills guided by specialists
- Support provided by partner, family and friends, peers and professionals
- Valuing small child achievements

Results: Parental needs and stress in NICU

	Parental needs' associated factors				
	Assurance	Proximity	Information	Support	Comfort
Overall (Median (IQR))	3.9 (3.8-4.0)	3.8 (3.6-3.9)	3.7 (3.6-3.9)	3.4 (3.1-3.6)	3.3 (3.0-3.6)
Sex (Female vs. Male)	0.06 (0.00; 0.12)	0.02 (-0.05; 0.09)	0.09 (0.02; 0.17)	0.10 (-0.01; 0.20)	-0.02 (-0.16; 0.11)
Age, years (<35 vs. >35)	0.01 (-0.06; 0.08)	0.05 (-0.03; 0.13)	0.08 (0.0; 0.16)	0.04 (-0.07; 0.15)	0.15 (0.01; 0.29)
Educational level, years (<12 vs. >12)	---	---	---	0.16 (0.05; 0.26)	0.22 (0.08; 0.35)
Multiple Pregnancy (Yes vs. No)	---	---	---	0.14 (0.02; 0.27)	0.21 (0.05; 0.37)
Gravidity (1 vs. >1)	---	---	0.11 (0.04; 0.19)	---	---

Interviewees highlighted the need for

- Daily "insignificant" procedures (e.g. changes in the localization of incubators)
- NICU's norms and routines
- Burden associated with prematurity and changes in parental roles
- Health care professionals
- Peers
- Portuguese Government
- Disclosure of information about infants' health

Maternal and paternal stress

Parental Stressor Scale	Mothers	Fathers	p
	Median (P25-P75)	Median (P25-P75)	
Overall Stress	4.0 (3.0-5.0)	3.0 (3.0-4.0)	0.004
Sights and Sounds	2.7 (2.2-3.4)	2.5 (1.8-3.0)	0.004
Baby Looks and Behaves	3.3 (2.5-4.2)	2.9 (2.2-3.6)	0.002
Changes in Parental Role	4.1 (3.2-4.7)	3.2 (2.4-4.0)	<0.001

Alves E, Severo M, Amorim M, Grande C, Silva S. *Jornal de Pediatria.* 2016; 92(1): 73-80.
Bala I, Amorim M, Silva S, Kelly-Irving M, de Freitas C, Alves E. *Early Human Development.* 2016; 101:3-9.

Conclusions

- Parents of very preterm infants hospitalized in NICU prioritized baby-centred needs (Assurance, Proximity and Information), emphasizing the need for information about changes in parental roles, which was the highest source of stress.
- Less educated parents and those with a twin pregnancy highlighted parents-centred needs (Social Support and Comfort).
- Interviewees valued: 1) the reinforcement of privacy when receiving health information; 2) the enhancement of parental autonomy; 3) and formal support to facilitate fathers' presence in NICU.
- Parents mentioned loss of autonomy, and changes in lifestyles and in marital relationship as the main factors influencing negatively their quality of life, while redefinition of priorities, valuing small achievements, and pragmatic and emotional support were considered facilitators.

Insights from *Family Integrated Care* in Neonatology call for the promotion of gender equity and ethical principles in coproduction of care.

The creation of hybrid spaces where mothers and fathers of very preterm infants hospitalized in NICU and health professionals can discuss opportunities and barriers to parental participation in care may improve healthcare governance.