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BMJ Open Perceptions and expectations of parents regarding their position in a French NICU: quantitative and qualitative approaches

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ABSTRACT

Objectives To assess perceptions, expectations, and concerns of parents of preterm infants regarding their position during hospital admission in the neonatal intensive care unit.

Design Data were analysed from two studies, using complementary methods (quantitative and qualitative). Study I surveyed parents via a questionnaire, and study II was a reanalysis of interviews with fathers, collected in a previous study.

Setting Neonatology department in a French tertiary care university hospital that promotes the Newborn Individualised Care and Assessment Program (NIDCAP).

Participants In both studies, participants had a premature child admitted for any level of care in the neonatal intensive care unit.

Results For study I, about half (33) of eligible families participated in the questionnaire survey, and for study II, we reanalysed interviews with 20 fathers. In both analyses, parents were satisfied overall with their involvement in the care of their child. In both studies, however, they expressed that they had expected to be better informed about their child's condition and more involved in medical decision-making. Parents also reported relational issues with some healthcare practitioners who made them feel judged, unheard or not competent to discuss their child's case. These concerns were not reported for NIDCAP staff. Respondents in both studies also described insufficient contact with physicians and an inability to obtain rest in the room with their child.

Conclusion Provision of training to healthcare practitioners regarding information that parents request and doing so respectfully might be keys to fulfilling parent-reported needs. Such improvements could facilitate parental empowerment and involvement.

INTRODUCTION

Premature birth may lead to parent-child separation, a long hospital stay in neonatology and frequent readmission. Under these conditions, parents often experience high levels of stress, which can compromise interactions with their infant, lead to parental depression and contribute to impairments in child development.¹

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Despite differing methodological approaches, consistent findings across the two studies suggest robust results.
- ⇒ Investigating parent needs in a department where some staff are already familiar with individualised care may not be generalisable to all French neonatal intensive care units.
- ⇒ Our samples included parents of lower weight and younger preterm babies, which may have led to overestimations of average parental needs in these units.

A family-centred care (FCC) approach is hypothesised to decrease parental stress by fostering the parent-healthcare professional (HCP) relationship through principles of mutual respect and dignity, parental participation in care for and decisions about their baby, information sharing and collaboration with professionals.² As long as parent perspectives and preferences can be heard, one opportunity for applying the FCC approach is during medical rounds when HCPs routinely share information and make decisions.³ Thus, the American Academy of Pediatrics recommends family-centred rounds (FCRs) as a standard practice.⁴ FCR is defined as a multidisciplinary round inside or near the patient's room, involving physicians, residents, nurses, allied professionals, patients and families.⁵ Research mainly from North American paediatric settings has shown that FCRs positively affect family satisfaction and foster communication, relationship building and collaboration between families and HCPs.^{6,7}

FCR implementation is complex because it requires changes in stakeholder behaviour as well as in unit routine, which both challenge staff and unit functioning. Although FCR seems to have been widely implemented in US institutions,^{8,9} few studies are available



that describe it in neonatology departments in cultural environments outside of North America.^{1 10 11}

To the best of our knowledge, FCR has not been implemented in France, but our neonatal department, which admits more than 300 newborns per year, is willing to implement this practice. The project is consistent with the department's promotion of the Newborn Individualised Developmental Care and Assessment Program (NIDCAP) since 1998.¹² This program acknowledges parents as primary nurturers of the child and aims to implement a cue-based nursing and medical approach. Thus, parents in the unit are supported, familiarised with their child's behaviour and their permanent presence (24-hour access) as well as participation in care are encouraged. Although progress has been achieved in developmental care, room for improvement remains with respect to FCC, as indicated by current practices in our 12-bed level III and 12-bed level II units. For instance, all department medical rounds take place after residents and medical students have conducted walk-rounds in their respective units, obtaining data, examining babies, writing notes and giving preliminary orders. In the level II unit, the medical round is performed 5 days a week in a staff room with participation of a senior neonatologist, residents, nurses and students. Once a week, this round is replaced by a grand medical round in the conference room where the head nurse, clinical psychologist, developmental nurse and social worker also are involved. Nurses present case reports on the babies in their care. In the level III unit, the round is performed in the hallway, in front of each room, with the participation of a senior neonatologist, residents, students and occasionally nurses. Additionally, a staff meeting is held each morning in a conference room in the presence of residents, attending physicians, nurses and medical students. Finally, discussion with families occurs only after a round, typically in a private room.

To address both cultural preferences and effectiveness in implementing FCR in this French neonatology department, we chose the intervention mapping protocol.¹³ This protocol is relevant for addressing complex changes rooted in societal practices. It involves multiple stakeholders (patients, HCPs, multilevel administrators and researchers) across a six-stage iterative process. The present work is part of the first stage of the protocol, which includes a detailed needs assessment for users (families and HCPs) and implementers (HCPs and administrators). Results of the needs assessment regarding HCPs have already been published.¹⁴

The aim of this paper is to report on the needs assessment for parents. Specifically, the objectives were to define (1) parent perception of the current parental position in the department and satisfaction, with a focus on medical rounds and (2) parental expectations and concerns related to healthcare in the department. This needs assessment relied on two studies, both conducted in our department within two separate research projects funded by short-term governmental support. The first study, using a questionnaire approach, was designed

within the specific purpose of developing FCR. The second, with a qualitative approach, was originally designed to explore how fathers perceive breastfeeding.¹⁵ Here, a secondary analysis of these interviews provided an opportunity to enrich results from the questionnaire study. Both studies were conducted by PhD researchers (MD and VT) external to the department.

METHODS

Study I

For study I, we conducted a cross-sectional survey of a convenience sample of families whose child was admitted to our level II unit between July and the first week of November 2014. Research staff approached parents if they were fluent in French and over age 18 years and had a premature child (gestational age <37 weeks). For this survey, we developed a three-part questionnaire based on the current medical literature that combined closed and open-ended questions (online supplemental material). First and second parts were filled in during admission, third part was completed 1 month after returning home.

A midwifery student coordinated the data collection. For the descriptive analyses of the recruitment process of this survey, data related to admissions during the study period and to basic parental demographics (age, occupation, home distance from hospital), hospitalisation duration and infant characteristics at birth (gestational age, birth weight, breastmilk intake) were retrieved from the level II unit database.

Data were analysed with Epi-Info V.3.5.4 (CDS Atlanta, Georgia). Content thematic analyses of open-ended questions were performed manually: sentences were screened, and all ideas were listed, coded and grouped under specific themes. Frequencies were calculated. Themes were counted only once per respondent. To compare ordinal variable frequencies between groups, we used non-parametric tests. Normality assumptions were checked prior to comparing continuous variables to ensure use of the appropriate statistical tests. The traditional (two-tailed) 5% level of significance was used to indicate statistically significant differences, but clinical significance was also considered by gestational age and birth weight.

Study II

To complement study I results, we turned to data from 20 interviews conducted between September 2014 and June 2015 in our neonatal intensive care unit (NICU) for another research project on how fathers perceive breastfeeding. Social representations theory guided the qualitative approach we used in study II.¹⁶ Primary analyses were carried out with textual data analysis by Alceste software, which allowed automatic generation and quantification of discourse classes through a descending hierarchical classification. These primary analyses showed that the second most important discourse class for fathers was related to healthcare staff.¹⁵ Based on this finding, for the

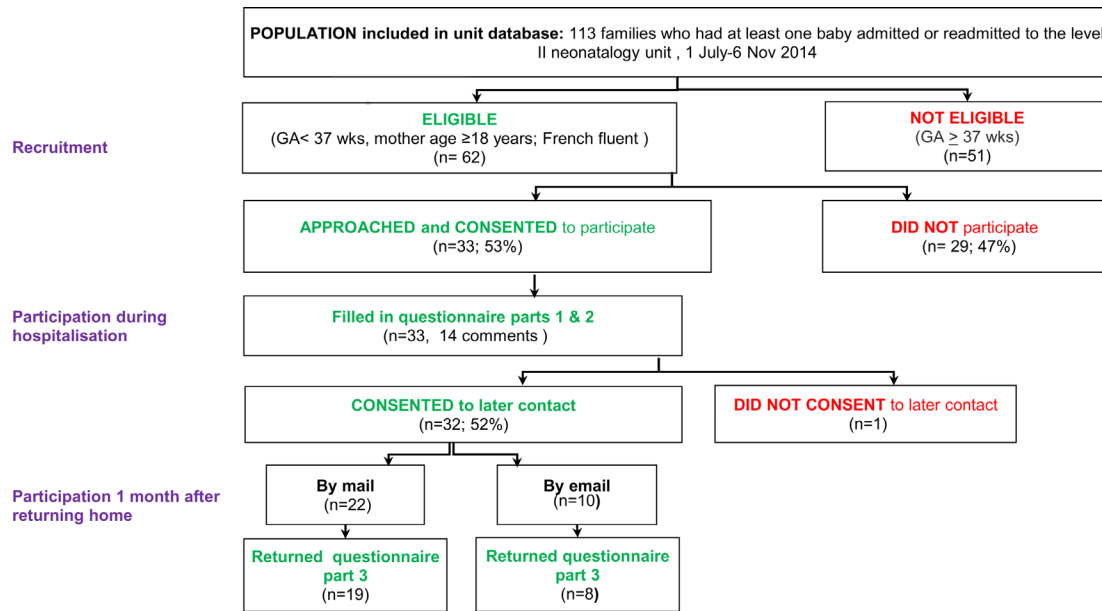


Figure 1 Flowchart for study I participation.

current work, we decided to examine more deeply how fathers talked about HCPs and performed a secondary analysis¹⁷ of interviews, via content analysis. We extracted all excerpts of Alceste software related to the healthcare staff discourse class for this content analysis.

Patient and public involvement

No patient was involved in both studies.

RESULTS

Study I participation

Figure 1 details the participation process, participation rate among eligible participants, and number of participants included in the study I analyses. There were 27

mothers, 3 fathers and 3 couples who responded together. Table 1 outlines the characteristics of the participating families, who were comparable to non-participating families except for gestational age, birth weight and hospital duration. The infants of participating families were statistically younger. They were also clinically, but not statistically, lighter and stayed longer in the hospital than infants from non-participating families.

Study I: Parental satisfaction and perception of position in the NICU

Most study I participants were satisfied overall with their position in the NICU (24/27), their involvement in the care of their child (25/27) and the information

Table 1 Comparisons of study I participants and non-participants

	Participants (N=33)		Non-participants (N=29)		P values
	n	n	n	n	
Parental characteristics					
Mother age (years), mean (SD)	33	30 (4)	29	29 (6)	0.63*
Father age (years), mean (SD)	31	33 (1)	0		na
Distance from home (km), median (min; max)	28	24 (0; 402)	20	30 (0; 90)	0.11†
Siblings (yes), frequency (%(95% CI))	31	19 (61.3%(42.2% to 78.2%))	0		na
Infant characteristics					
Gestational age at birth (wk), mean (SD)	33	33.1 (1.7)	29	33.9 (2.8)	0.03†
Birth weight (g) ‡, mean (SD)	33	1729 (596)	29	1932 (422)	0.12*
Hospital duration¶ (d), median (min; max)	27	25 (3; 59)	16	13 (0; 63)	0.09†
Receive breastmilk, frequency (%(95% CI))	29	25 (86.2%(68.3% to 96.1%))	25	20 (80.0%(59.3% to 93.2%))	0.72§

*ANOVA
 †Kruskal-Wallis test
 ‡Within twins only the lightest baby has been considered
 § χ^2 test.
 ¶Only calculated for babies who leave the unit to return home.
 ANOVA, analysis of variance.

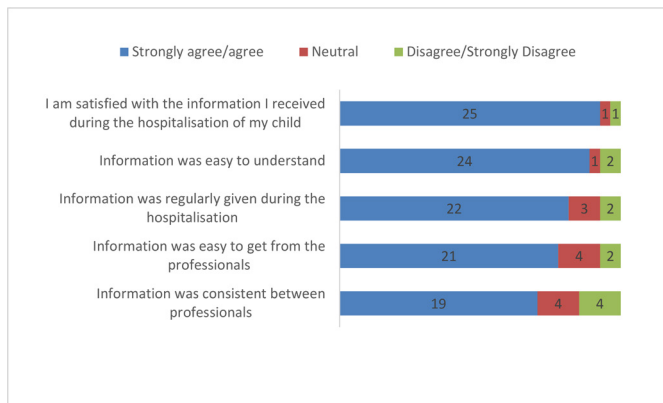


Figure 2 Study I participant satisfaction regarding information, 1 month after returning home (n=27).

they received (figure 2). Comments from 10 families at 1 month after returning home reinforced this finding of overall satisfaction, as shown by following comments:

Comment of participant 10: very good position given to parents

Comment of participant 33: regarding healthcare involvement, I find it is great we are able to take part, this limits somehow suffering and worry

In contrast, participants were moderately (15/27) satisfied with their involvement in the healthcare decision-making process.

Study I: parental expectations and reported concerns

Although once they were at home, participants appeared rather satisfied about the information they received, 10 of 33 commented that when their child was still in the hospital, they should have been consistently and systematically informed about decisions, changes and the schedule for medical rounds, so that they could plan to attend. Also at 1 month after returning home, a minority (4/27) commented, as shown below, that clear and consistent nursing instructions to parents would have helped to improve their involvement in the care of their child.

Comment of participant 18: A logbook in the room would allow medical staff to write down decisions: parents would be assured they get the information

Comment of participant 33: It had happened that I was informed about a specific nursing care or an X-ray or something else, the day after or after it has been completed: thus, I could not accompany my baby. It would be better to communicate in advance this kind of event. [...] Regarding our participation in nursing care, I found it was great, limiting pain and anxiety. But sometimes there were inconsistencies between staff: one would tell you to do thing in one way, while another would disagree.

Another theme was about interaction with HCPs. Most participants (30/33) wished to attend medical rounds, and a minority (11/33) felt that HCPs on rounds had

been ‘always or often’ present. As followed, some participants (8/33) commented on their need to interact with the physician.

Comment of participant 11: In level III unit, there was daily medical round at bedside: it reassured me. I could ask questions related to physical examination. In level II unit, there is no daily medical round at bedside and only a few physician visits. It’s a shame because we have lots of questions. Meeting once a week to review the situation, would be great.

Comment of participant 25: I did not notice a daily medical round or even any short feedback from the physician regarding the follow-up of my twins. I think that follow-up and healthcare are carried out by the nurse and the child nurse. Who knows who the referee is—I don’t really know who is in charge, to whom I should contact...?

Nine respondents mentioned difficulty being heard by staff and having their opinions and concerns addressed. For example:

Comment of participant 34: please listen to parents’ feelings and suggestion.

Comment of participant 29: acknowledge that parents with other children cannot spend all their time in hospital.

Comment of participant 34: Some physicians should better adapt their speech to parents’ comprehension. Fortunately, nurses are here to translate.

Finally, a minority of participants reported barriers to parental involvement, such as difficulties obtaining rest in the unit (7/33) because of a lack of bed for parents (6) and because of the noise (1) as well as limited staff resources to guide parents (1) and exclusion of fathers from the infant care (1).

Study II participation

Table 2 outlines the characteristics of the 20 fathers whose interviews were reanalysed. They were comparable with non-participating fathers of the original study, except for their infant’s birth weight, duration of hospital stay and hospital distance from home. The infants of participating fathers were statistically and clinically lighter and stayed longer in the hospital, and the families travelled a longer distance from home.

Fathers’ satisfaction and perception of their role in the NICU

Most (12/20) fathers appreciated the human approach taken in the NICU and felt grateful to HCPs. Specifically, they appreciated the permanent access to the unit, relative staff attention, comprehension and care of their needs. Fathers appeared convinced of the benefits of such an approach for their premature child and complied with the type of delivery care offered. Two of the fathers even specified that this kind of approach was best for premature children.

Table 2 Comparisons of study II participants and non-participants

	Participants (N=20)	Non-participants (N=24)	P values
Parental characteristics			
Mother age (years), mean (SD)	31 (5)	30 (6)	0.59*
Father age (years), mean (SD)	34 (6)	33 (7)	0.69*
Distance from home (km), median (min; max)	26 (0; 71)	12 (0;70)	0.03*
Siblings (yes), frequency (%(95% CI))	12 (60.0%(36.1% to 80.9%))	13 (54.2%(32.8% to 74.4%))	0.69†
Infant characteristics			
Gestational age at birth (wk), mean (SD)	30.2 (2.8)	31.5 (2.7)	0.12*
Caesarean delivery, frequency (%(95% CI))	15 (75.0%(50.9% to 91.3%))	19 (79.2%(57.8% to 92.9%))	0.51†
Birth weight (g) ‡, mean (SD)	1363 (352)	1636 (503)	0.05*
Hospital duration¶(d), median (min; max)	43 (19; 128)	29 (5; 96)	0.03§
*ANOVA.			
† χ^2 test.			
‡within twins only the lightest baby has been considered.			
§Kruskal-Wallis test.			
¶Only calculated for babies who leave the unit to return home.			
ANOVA, analysis of variance.			

Father 1: When we're not here, we can call the unit to know how he's doing. A moment of anxiety, we call, or we come. The unit is opened for parents (...). We do think that it is necessary that one of the parents be present at night (...) it was obvious for us.

Study II: Fathers' expectations and reported concerns

The most frequent theme (15/20) that fathers mentioned was related to how information was transmitted to them. Although 6 of these 15 fathers expressed satisfaction about information transmission, nine reported dissatisfaction and explained that information was either lacking, present but inaccessible or had to be requested.

Father 5: I need to get information ... I mean I want to understand. I am a technician; I need to understand. If I don't understand, I don't feel I get the thing, be in control (...) I'm not in control, I trust the team though, but I need to understand what's going on around me otherwise I don't like this, and I really don't like this.

Father 9: We often heard about medical round for instance, but (...) we never had any feedback about it. (...) maybe a transmission summary, I don't know, a tool that could be useful (...), not necessarily that parents could attend medical round, because it's a medical business (...) a paper with questions on which responses could be written down during staff and returned to parents (...). It should be better that any information about the baby stays in the room, by leaving the medical file in the room.

Another theme that the fathers raised was about their interactions with HCPs. One father commented on the need to interact with the physician, suggesting the need for parents to attend medical rounds:

Father 5: I would like to meet a paediatrician, even a resident. Once a week, it would be great. Because now, we feel a bit abandoned.

Of 10 fathers who brought up interactions with HCPs, eight specifically pointed out that the NIDCAP team comforted and supported them, helped them to better understand their baby's condition and played a mediation role between them and other HCPs.

Father 10: The NIDCAP team helped us and comforted us with all of their explanations and when they talked about our baby's condition evolution, yeah they knew how to reassure us and (...) to show us the positive or negative aspects that occur with respiratory pause or things like that. They had always been able to provide us with explanations in lay language.

Nevertheless, five fathers described difficulties in establishing rapport with some HCPs or that they had felt judged.

Father 10: It is more a matter of communication. (...) They come if it is for a milk bottle that should be given or something else, they come to give it to us, then, there is no real exchange, no communication with the staff.

Father 17: Concerning breastfeeding, it is different. Some nurses put you under pressure. (...) but with a premature child, you should respect parental choices.

DISCUSSION

With a focus on medical rounds, the aims of this paper were to report on parent perception of and satisfaction with their position in the NICU, parental expectations and concerns related to healthcare. Our results from



both analyses (studies I and II) suggest that parents were rather satisfied with the healthcare approach, their involvement in the care of their child and staff attention. These findings are consistent with the needs of 'contact with the infant' and 'inclusion in the infant's care' that Cleveland described in a systematic review based on a 32-study content analysis of parent needs and behaviours supportive of parenting in the NICU.¹⁸ We note that Cleveland cited other needs, including reporting accurate information, vigilant oversight and protection of the infant, a positive perception by the nursery staff, individualised care and a therapeutic relationship with the nursing staff.

Nevertheless, our participants expected better transmission of information related to their child's medical condition, would have preferred more involvement in medical decision-making and expressed a willingness to attend medical rounds. These results also are consistent with Cleveland¹⁸ and with other studies that have assessed parental satisfaction when attending FCR.^{11 19–21} Finally, they are consistent with Muething *et al*²² who reported that approximately 85% of families would choose active involvement in rounds. These parental desires, however, contrast with the perceptions of HCPs in the same unit at the same period.¹⁴ Indeed, although HCPs were rather positive about parental proximity to the infants and acknowledged that parental attendance at rounds could offer benefits for some parents, the HCPs also viewed FCR as stressful for parents and as breaking confidentiality. NIDCAP-trained professionals did not share these views. Similarly contrasting perceptions between parents and professionals were described in a study of 32 parents and 68 HCPs in a Canadian paediatric intensive care unit.²³

In addition, the analyses of studies I and II showed that parents raised two issues that could impede their involvement: the impossibility of resting in-room with their child, and interaction issues with HCPs that range from a lack of relationship to difficulties in liaising with them. As others have suggested,^{11 18 24} parent complaints about insufficient contact with physicians may be interpreted as a need to be directly informed by a fully trained physician and reassured. This need is congruent with the desire that some of our participants expressed for reassurance from a senior physician as well as with their willingness to attend medical rounds. Another implication is that medical residents, who visit the child at least two times a day, are not fully acknowledged as physicians, making the information they deliver uncertain for parents.

Regarding difficulties in liaising with HCPs, parents reported that they felt judged, not respected, or unequipped for the discussion. Others have reported similar findings. Among 270 parents surveyed in a Sweden NICU, most reported satisfaction with staff communication but half also reported that the nurses and doctors did not understand their emotional situation well.²⁵ Among 1500 parents of premature children in France, 15% of them felt judged by nurses.²⁶ Such difficulties are consistent with the need for staff to have

a positive attitude towards parents and the therapeutic relationship reported by Cleveland.¹⁸ The latter refers to a relationship that requires HCP genuineness, empathy and respect.²⁷ We note again that in our studies, parents pointed out that their relationship with NIDCAP trained staff was not an issue.

Here, we report two analyses that represent the first new data in France on perceptions and expectations of parents of premature children in a NICU. It is also one of the few analyses of fathers' needs.²⁴ Given our complementary methodological approaches, which allow for method triangulation as suggested by Denzin,²⁸ and the consistency of findings across these two different but complementary study populations, our results appear robust. We also acknowledge some limitations. The needs that we report may be specific to the surveyed population. First, we investigated the needs of parents in a department where some staff were already familiar with FCC principles and applying vigilant oversight and individualised care through the NIDCAP approach. These factors could explain the overall satisfaction among parents with care in the NICU. Second, by including only fluently French-speaking parents, we could not explore the needs of non-native French speakers. Third, only half of eligible families participated in study I, and we could not compare this participation rate with other French data in the hospital because they are not available. We did not obtain the reasons for not participating, which could range from dysfunction at recruitment to parental refusal. Nevertheless, a comparison between participants and non-participants highlighted the specific characteristics of these two groups, which did not differ substantially in most features. Compared with non-participants, participants in study I were more likely to have more vulnerable babies, with statistically significant younger gestational ages and clinically significant lighter birth weight. Similarly, compared with non-participants, study II fathers appeared to have more vulnerable babies, a longer travelling distance from home and longer periods of hospital stay. Interpreting why parents chose to participate or not is complicated. For parents in the most vulnerable conditions, participation might be an opportunity to express concerns or acknowledge the care they received. Although these parents do not represent all NICU parents, their insights and experiences provide interesting information about parental involvement in medical decision-making.

Finally, we believe that the four nursing behaviours that Cleveland¹⁸ identified to support meeting parent needs may be applicable to our French context. These behaviours are (a) emotional support, (b) parent empowerment, (c) a welcoming environment with supportive unit policies and (d) parent education with an opportunity to practise new skills through guided participation. Because of consistently positive parental feedback about NIDCAP-trained staff of our unit, we believe that these staff members already have adopted these behaviours. Thus, ideally every HCP in the unit should follow a similar training or at least undergo specific training on

information delivery to parents. Consistent with other suggestions,²⁹ such training should detail the kinds of information parents seek, ranging from the infant's medical condition to the planning of tests and the role of each staff member, including medical residents. Such training also should highlight that information needs evolve as the child's condition evolves. Additionally, the training should address best communication practices in information delivery to avoid parental discomfort. FCR has been suggested to increase family understanding of information^{11 19 20 30} and improve communication between families and HCPs,^{11 20 21 31} so this period of training could be an opportunity to introduce FCR to French HCPs as a strategy to facilitate information sharing. All these suggestions should support fulfilling the first wishes of parents that we and others^{18 24} have reported (need for information, better involvement in decision-making, interaction with physicians) as well as facilitating parental empowerment and involvement.

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Competing interests Dr. Thébaud reports grants from Fondation de France and from the French Ministry of Health during the conduct of the study. All authors declare no relationships or activities that could have influenced the submitted work.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Study I was approved by the Ethics Committee of the University Hospital of Brest on 09/12/2014. Study II was approved by the Commission number 6 for Patients Protection (Comité de Protection des Personnes -Ouest 6): 2014-A00456-41. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Qualitative and quantitative data are deidentified. They can be requested to MD and VT.

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