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Current attitudes and beliefs toward perinatal care orientation before 25 weeks of gestation: The French perspective in 2020

Short title: Perinatal care before 25 weeks in France

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Abstract

The survival rate of infants born before 25 weeks of gestational age in France is extremely low compared with that of many other countries: 0%, 1%, and 31% at 22, 23, and 24 weeks' in the last national cohort study. A non-optimal regionalization and variations in practice are prevalent. Some parents in social media and support groups have reported feeling lost and confused with mixed messages leading to lack of trust. These data kindled a major debate in France around perinatal management leading to an investigation exploring neonatologists' perspectives and ways to improve care. The majority (81%) of the responding neonatologists reported more active care and higher survival rates than in 2011, although others continued preferring delivery room comfort care and limited NICU treatment at or before 24 weeks. The desire to improve was an overarching theme in all the respondents' answers to open-ended questions. Barriers to active care included an absence of expertise and of benchmarking to guide optimal care, and limited resources in the NICU and during follow-up - all leading to self-fulfilling prophecies of poor prognosis. Optimization of regionalization, perinatal teamwork and parental involvement, fostering experience by creating specific perinatal centers, stimulating benchmarking, and working with policy makers to allow better long-term outcomes could enable higher survival.

Introduction

The survival rate of infants born extremely preterm in France, compared with that of many other countries with the same access to medicine, technologies, and expertise, is low.¹⁻⁷ In the nationwide EPIPAGE-2 cohort study in 2011, survival to discharge was 0%, 1%, and 31% at 22, 23, and 24 weeks' gestation, respectively; survival rates before 25 weeks did not change between the original EPIPAGE cohort in 1997 and EPIPAGE-2, although it increased significantly after that gestational age.^{8,9} The French medical system is a public system where the population has access to medical care. Neonatal care is not regionalized in an optimal fashion, with many neonatal intensive care units (NICUs) caring for a large number of extremely preterm infants, while several other NICUs have a small number of such babies admitted. Extremely preterm infants can be cared for in dedicated NICUs or in mixed NICU/PICU units, where the attending physician/nurse is not uniquely dedicated to neonatal care. Several studies have sought to better understand these results by exploring the variability of practices among French perinatal centers. All found distinctly unstandardized practices for the management of infants born before 26 weeks.²

Active antenatal care, defined as either the administration of corticosteroids or magnesium sulfate or cesarean delivery for fetal rescue, varied widely with the place of birth, increased with gestational age (GA), and was not associated with individual characteristics.² Rates of withholding or withdrawal of intensive care in the delivery room (DR) also varied between units (from 0% to 100%),¹⁰ with DR management apparently based mainly on GA and intensive care withheld or withdrawn in more than 90% of babies born at 22-23 weeks' gestation compared with 38% at 24 and 8% at 25 weeks. Non-pharmacological comfort care and parental support were nonetheless all provided routinely.¹¹ In 2011, DR comfort care was performed in nearly all

cases before 24 weeks without involving the parents; at 24 weeks, parents were consulted prenatally in only half the cases about DR care orientation.¹¹ Sensorimotor outcomes for survivors of extremely preterm birth at 2 years of age did not differ with the intensity of perinatal care provision, but active management of periviable births was associated with increased survival without sensorimotor disability.¹²

"When is a baby viable? I'm hospitalized at 23 weeks' gestation. The doctor tells me that I have to last up to 25 weeks for the level-3 neonatal intensive care unit (NICU) to take care of me and my son. I'm really scared."

Comments like this, extracted from the Facebook discussion forum of SOS Préma, the French parents' association¹³, illustrate a recurrent theme among families faced with extreme prematurity. Answers to this question are often diverse, with differences in representations and practices among French perinatal teams (comprising neonatologists, obstetricians, nurses, and midwives). This discordance retrospectively raises doubts among parents about the appropriateness of decisions to "not resuscitate" babies at birth before 24 weeks or at less than 500 grams. Some parents also report being told that "23 weekers never survive", while other parents show pictures of their baby born at 23 weeks who was admitted in an NICU close by. This can have a big impact on parental trust in a unit. Moreover, questions about the child's outcome and future quality of life (QoL) appear crucial to parents and often influence their prenatal choices.^{11,14} In 2011, a French study on prenatal counseling reported that at 24 weeks' gestation, the message physicians wanted to give parents was mostly "pessimistic" (54%) or "uncertain" (42%), and rarely optimistic (5%). In SOS-Préma's forum, parents report that some doctors highlight suffering and disabilities without any balance by positive possibilities and sometimes imposes or attempts to convince them to opt for DR palliative care. Parents wonder

what the criteria are for active or palliative care, and if prognostic descriptions come from individual convictions or the current state of knowledge. The medical community too has questions about the disparities in practices and the reasons for these inequalities. A clearly conceived and supported consensus with information including uncertainty would allow parents who want to be involved in this decision to better appreciate what is at stake and to participate in the decisions that concern their child's life and their family's future.

Interestingly, no evidence indicated that the intensity of perinatal care for extremely preterm babies had any effect on births at a higher GA.¹⁵ These data kindled a major debate in France around perinatal management, reinforced by questions from neonatologists from other countries.^{16,17} New proposals to harmonize French practices were presented at a national congress in 2017⁷ and were recently published.¹⁸ The objective of this study was to describe the current attitudes of senior French neonatologists towards active care before 25 weeks and explore the opportunities available to improve outcomes. Our ultimate goal is to investigate how a country with very low rates of survival before 25-weeks can improve care for these fragile patients.

Methods

Survey of reported practices and their motivations

To explore the changes that have occurred and care practices before 25 weeks, we conducted a mixed-methods observational study, collecting two types of data. First, we sent an anonymous web survey to one senior neonatologist responsible for frontline counseling and care of extremely preterm neonates, in each level-3 French NICU. Most questions were multiple-choice, while others concluded with an open-ended question asking the participant to justify their answer

("briefly explain why"). The questionnaire evaluated changes in practices since 2011 and then presented fictitious clinical vignettes of imminent birth at 22 to 24 weeks, in which parents requested active care. To understand the teams' motivations and barriers, we also interviewed 7 expert neonatologists from NICUs or NICU/PICUs in 5 French regions. They were chosen because of their role as local leaders, representing a specific unit type (regional mixed PICU/NICU (n=1), exclusively NICU (n=3), expert perinatal center (n=2), recently-created NICU (n=1), to represent various French settings. A neonatologist familiar with these questions and with techniques for qualitative research interviews and thematic analysis (LC) conducted the interviews (semidirective, average 45 minutes) and performed the qualitative discourse analysis.¹⁹ It covered prenatal and postnatal practices, decision criteria, parental involvement, and the teams' motivations, barriers, and follow-up care for survivors. The participants, after information about the purpose of the research and the data anonymization, consented to participate.

Results

The survey was emailed in June 2020 and followed up by four reminders until August 2020. Senior neonatologists from 53 of the 65 French NICUs responded (81%). Table 1 presents the participants' responses. According to 37 respondents (70%), mortality in their units had probably changed since 2011 for the population born before 25 weeks' gestation; 16 (43%) noted an improvement in survival rates, 20 (54%) in the quality of postnatal care), and 7 (10%) in prenatal care. They reported that 3.5% of babies born at 22 weeks of gestation were admitted to the NICU, 32% at 23 weeks, and 88% at 24 weeks.

Responses from neonatologists at NICUs and NICU/PICUs did not differ significantly except for the median annual number of live-born babies at 24 weeks, which was higher in hospitals with NICUs than with NICU/PICUs (10.1 vs 4.6, $P = 0.014$) and a trend to a higher median of those admitted to NICUs than NICU/PICUs (9.2 vs 4.8, $P = 0.053$).

Table 2 reports the local practices for all 3 vignettes where parents requested active care.

Comments from the respondents are described in a Supplementary Material table. Globally, most respondents chose active prenatal care: 77%, 98-100%, and 100%, respectively, for the vignettes at 22, 23, and 24 weeks. The themes most often mentioned to justify decisions for antenatal transfer to a level-3 center and antenatal steroids were GA, adequate estimated weight, parents' wishes, other prognostic factors, need to optimize care, and information by experts. Some underlined the need to dissociate the decision about antenatal steroids from that about resuscitation. Similar arguments were invoked for intubation/NICU transfer (43%, 91%, and 100% at respectively 22, 23, and 24 weeks). Nevertheless, before 24 weeks, GA was mentioned to justify the absence of active care for 50% of babies born at 22 and 60% of babies born at 23 weeks. At 24 weeks, 100% choose proactive prenatal and postnatal attitudes, but GA was not the theme most often mentioned to justify active care (24%).

Table 3 summarizes the themes raised by the expert neonatologists in the interviews: two trends in care since 2011 were identified. The first trend was essentially one of stability: delivery room comfort care was generally offered before 24 weeks' gestation. For babies born at 24 weeks, these teams often proposed intensive care, possibly limiting treatment if complications developed. The second trend involved a notable change in practices towards more active care, with decisions based on multiple prognostic criteria rather than GA only. In these teams, the neonatologist reported working hand in hand with the obstetrics team, using obstetrics-pediatrics

meetings to write up the individual situation and recommendations to the parents; they generally offered resuscitation at 23 weeks, but only rarely at 22. These teams nonetheless described some reluctance due to the difficulty in reducing these babies' complications and improving their survival despite strong efforts; colleagues also had divergent positions, which led sometimes to moral distress or conflicts. Some doctors involved in follow-up of survivors emphasized the lack of availability and long waiting times for the care of children with specific needs²⁰ related to extreme prematurity and noted that this absence of services contributed substantially to their reluctance to care for babies at high risk.

Discussion

Towards a change in practices

This survey shows that more than two-thirds of the participating neonatologists (responsible for prenatal consultations and processes in the NICUs) considered that the practices for care of the most premature babies in France can - and should - evolve. A majority reported that mortality has changed in their centers since 2011, mainly with higher survival, more active management before 25 weeks, and individualized decisions based on prognostic criteria rather than GA thresholds. Conditions for improving prenatal care include: obstetric-pediatric consultations, communication with parents, more proactive behavior, and the dissociation of prenatal care from resuscitation decisions for decision-making. Around 20% reported no change in mortality, and 9% had no information. The reported changes in practice are confirmed by the proportion of live-born infants reported to have been admitted to NICUs, which indicates a trend towards active care for one third of the babies born at 23 and nearly 90% of those born at 24 weeks, far higher

rates than in the EPIPAGE-2 study in 2011.¹¹ The unanimous agreement by physicians about antenatal corticosteroid therapy at 23 weeks revealed fairly recent changes, in accordance with the new proposals,¹⁸ different from the previous (2010) recommendations, which did not support antenatal steroids independently of care orientation.²¹ It is also notable that 91% of the participating neonatologists considered that it is acceptable to intubate and transfer babies born before 24 weeks to the NICU.

Self-fulfilling prophecy

An important barrier to the neonatologists' desire to offer of intensive care involves their representations of these patients' outcomes. In particular, representations of low likelihood of survival and a high risk of severe adverse neurodevelopmental outcomes and adverse quality of life have a strong impact on teams' motivations and confidence in the results of their actions and may generate a self-fulfilling prophecy. Their experiences frame a vision that influences future beliefs, attitudes, and care decisions in their unit. Repeated negative outcomes may result from preventable complications, mortality occurring after treatments were limited, or a negative image of these children's futures.

Moreover, the team's conviction that their care actions will be successful may be influenced by the willingness - or lack of willingness - of local leaders to instill the motivation to treat these patients in a coherent path through post-discharge follow-up. Our interviews showed that elements that may hinder a change of attitudes in some centers are the experience and habit of proposing DR comfort care if prognosis is deemed unfavorable, or of withdrawing/withholding treatments in the NICU, when severe complications occur. In France, the Claeys-Leonetti Act²² prohibits prolonging treatment beyond a reasonable chance of success and requires both a

multidisciplinary meeting and parental involvement in cases of doubts. Some doctors fear they will be considered unreasonable in saving these children.

Lack of regionalization, lack of experience,

Hospitals that have modified their practices toward active individualized care at the request of parents tend to offer interventions according to global prognostic factors, but from 23 weeks of gestation onwards only, not before. Our results show that even if neonatologists say they individualize more, GA still has a huge psychological impact on them, although it is still a “plus or minus 5 days” diagnosis. For example, in Scenario 2 baby could be the same GA as Scenario 1 (23+5, plus or minus 5 days). Therefore, recommendations should avoid mentioning GA but rather use outcomes, for which GA is only one factor in combination with others.

The neonatologists' feelings that they are not improving their patients' condition may be due to any one or more of several factors: a lack of evidence-based knowledge available, their failure to translate research findings and reviews into practice and policy,²³ peer group barriers, with the prerequisite necessary care not always provided,^{5,24} and the persistence of local standards of care, inconsistent with current recommendations. Active prenatal care has been proven effective, but this first step toward better outcomes is not always taken. Neonatologists could probably improve their cooperation and antenatal discussions with obstetricians. Systemic barriers beyond physicians' control may also exist: lack of the necessary facilities and equipment or inappropriate skill mix or expertise. Finally, although experience is a key factor in improving outcome in this population, some units in France have too few extremely preterm patients to treat the number necessary to acquire this experience.

All these factors are effects of a lack of regionalization. The EPICURE study has shown that improvement of outcomes may pass through closing small units and portions of NICUs in mixed

units. Such decisions need strong political commitment and changes that threaten the stability of smaller units.

Integrating parental perspectives

A central point in parents' interrogations and physicians' arguments involves the child's best interests, subjectively perceived by some to justify active treatment, and by others as an argument for comfort care. Parents report that some physicians adopt a "pessimistic" paternalistic attitude in prenatal consultations, describing a poor future quality of life (QoL) for the soon-to-be-born child. QoL is a subjective notion and may indeed influence professionals' treatment choices in French NICUs.²⁵ People with impairments can have a good QoL; QoL is intimately linked to each person's capacity for resilience but also, and above all, to that person's support and place in society.²⁶⁻²⁹ The evaluation of extremely preterm infants' future QoL depends on many uncertain and dynamic factors (health, social, environmental, and emotional contexts). Some difficulties may appear later or subsequently improve, in a given environment, which itself changes through adaptation and the implementation (or not) of compensatory actions and interventions. The QoL reported by children born extremely preterm seems to have little relation to cognitive performance, or specific motor or neurological impairment.^{30,31} Moreover, QoL assessment should not be used to stigmatize life as good or bad or for making life-or-death decisions, but rather as a reflective item, to reflect on what a "good life" is, not only influenced by medical diagnoses, but also by the well-being of families and children. A commitment to implement ways to reduce the impact of complications and better support families is also essential. This argument has resulted in formalizing the importance of personalized decision that allows parents to include their perspective on both uncertainty and a life worth living.^{32,33} At the

same time, some families find it difficult to determine or express their wishes. It is important to make clear to parents that they can defer to the health care team's proposal.²²

This survey offers an inventory of current practices and beliefs in France. It has limitations: the questionnaire was sent to only one neonatologist per unit, obstetricians were not directly involved, and the vignettes may differ from real situations, especially the parents' unequivocal wish for active care. Moreover, the sample size for the qualitative part was small, and respondents and interviewees might have reported their "ideal" and/or a research-induced attitude that they could not implement in reality, because their choice was locally neither usual nor feasible. For these reasons, the results may not always reflect the reality.

Implications for the future

These findings have implications for future perinatal care in France. The first, key concept is the perinatal teamwork: collaboration between obstetricians, midwives, neonatologists, and nurses, with formal joint agreement on decisions from the prenatal to the postnatal period. The recent French proposals for optimized and uniform prenatal care are being widely disseminated. Changes will have to be organized regionally, at the level of perinatal networks: the decision for transfer to the level-3 referral center, the timing of corticosteroids, and the consistency of the parental information provided by the teams from each center must be discussed and determined consensually in obstetrics-pediatrics meetings to increase equity in access to consistent perinatal care. The second point relates to clinical care, politics and regionalization. Experience is necessary to optimize prenatal and postnatal care. To avoid dilution of experience with many centers having few patients, nationally identified specific units for potential less-than-25-week infants. Proximity to the family's home is nonetheless a challenge in reducing the number of

units, as parental presence is the basis of the infant- and family-centered developmental care appears essential for these infants.³⁴ Both experience and outcome perception can be improved by physicians using benchmarking and quality improvement strategies, for example visiting centers with the best results to share treatment decisions and follow-up, and to discuss conviction/confidence and uncertainty issues. The third point is prenatal parental involvement. Ideally, the team that will care for the mother and infant should communicate with the family. Young neonatologists and obstetricians are receiving educations based on updated data and areas of uncertainty, but decision tools would be helpful. Training in personalized communication in this specific context would be useful to help parents imagine the situation and construct their own positions, to the degree they personally would like. Fourth, exchanges between experts and parents' associations could help parents to understand medical proposals and gain insight into their wishes, by having knowledge about the outcome and variability of courses in and after the NICU. Finally, schools and healthcare professionals must increase their focus on children's outcome evaluations and supportive services that might help improve their functioning. Substantial development of these supportive services is required at the national level to end the waiting lists and unavailability of these services about which some doctors involved in their follow-up complain. Medical, but also organizational, political, and social issues require consideration, from the local up to the national level.

Tables

Table 1. Description of trends in practices

	53 responses N (%)
Do you know the differences in survival results for 22-24 weekers in France vs. other countries, Yes, n (%)	51 (96%)
Is this something that can change in France, Yes, n (%)	41 (77%)
Conditions for such a change are (open-ended question):	<i>Among 32 comments:</i>
- Different NICU philosophy/culture of care, n (%)	7 (22%)
- Proactive antenatal management, n (%)	4 (12%)
- Individualized decisions, n (%)	4 (12%)
- Increased NICU expertise, n (%)	3 (9%)
- Need for clear limits in care provided, n (%)	3 (9%)
- Other (more material and human resources, better disability management, individual goodwill), n (%)	5 (16%)
Are you familiar with the 2010 French recommendations (21), Yes, n (%)	46 (87%)
Do you use them in your prenatal counseling discussions, Yes, n (%)	21 (40%)
Compared to 2011 (EPIPAGE-2), is the mortality of babies born alive before 25 weeks in your hospital be different at this time?	
Yes, today's mortality would be different, n (%)	37 (70%)
<i>Comments:</i>	<i>Among 37</i>

<ul style="list-style-type: none"> - Improved survival, n (%) - Due to changes in postnatal practices, n (%) - Due to changes in prenatal practices, n (%) - Due to change of vision, change of organization, n (%) <p>No, today's mortality is identical to that in 2011, n (%)</p> <ul style="list-style-type: none"> - Because the same treatment choices are made, n (%) - Because prognosis has not changed, n (%) <p>I don't know, n (%)</p>	<p><i>comments:</i></p> <p>16 (43%)</p> <p>20 (54%)</p> <p>7 (19%)</p> <p>2 (5%)</p> <p>11 (21%)</p> <p>4 (36%)</p> <p>2 (18%)</p> <p>5 (9%)</p>
<p>Annual number of babies live-born at 22 weeks in the DR, mean (SD)</p> <p>Annual number of babies live-born at 22 weeks admitted to the NICU, mean (SD)</p> <p>Proportion of babies live-born at 22 weeks admitted to the NICU (%)*</p>	<p>4.0 (4.4)</p> <p>0.1 (0.5)</p> <p>2.5%</p>
<p>Annual number of babies live-born at 23 weeks in the DR, mean (SD)</p> <p>Annual number of babies liveborn at 23 weeks admitted to the NICU, mean (SD)</p> <p>Proportion of babies live-born at 23 weeks admitted to the NICU (%)*</p>	<p>5.4 (4.6)</p> <p>1.4 (1.4)</p> <p>26%</p>
<p>Annual number of babies live-born at 24 weeks in the DR, mean (SD)</p> <p>Annual number of babies live-born at 24 weeks admitted to the NICU, mean (SD)</p> <p>Proportion of babies live-born at 24 weeks admitted to the NICU</p>	<p>8.8 (6.5)</p> <p>8.1 (6.6)</p>

(%)*	92%
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n: number; SD: standard deviation; DR: delivery room;

*number of babies admitted to NICU divided by the number of live-born babies in delivery room
in each center's delivery room

Table 2. Scenarios

<p>Scenario #1. Pregnancy after IVF. Premature labor with rupture of the membranes and cervix at 5 cm, at 22+6 weeks. Prenatal steroid initiated due to miscalculation of gestational age. Baby girl, estimated weight 510 grams. No sign of infection. Parents request active management of their child.</p> <p>- Should this patient be transferred to a level-3 perinatal center, Yes, n (%)</p> <p>- Is it acceptable to intubate this baby and transfer her to the NICU, Yes, n (%)</p>	<p>53 participants N (%)</p> <p>41 (77%)</p> <p>23 (43%)</p>
<p>Scenario #2. Cervical cerclage for incompetent cervix. Contractions at 23+5 weeks. Girl, estimated weight 610 grams. No sign of infection. Previous history of preterm birth at 22 weeks with neonatal death. Parents request active management of their child.</p> <p>- Should the patient receive antenatal corticosteroids, Yes, n (%)</p> <p>- Should this patient be transferred to a tertiary perinatal center, Yes, n (%)</p> <p>- Is it acceptable to intubate this baby and transfer her to the NICU, Yes, n (%)</p>	<p>53 (100%)</p> <p>52 (98%)</p> <p>48 (91%)</p>
<p>Scenario #3. Severe preeclampsia at 24+1 weeks. Baby boy, estimated fetal weight 600 grams. The delivery must take place within 12 hours for maternal reasons. No sign of infection. Parents request active care of their child.</p> <p>- Should the patient receive antenatal corticosteroids, Yes, n (%)</p> <p>- Should this patient be transferred to a tertiary perinatal center, Yes, n (%)</p> <p>- Is it acceptable to intubate this baby and transfer him to the NICU, Yes, n (%)</p>	<p>53 (100%)</p> <p>53 (100%)</p> <p>53 (100%)</p>

IVF: in vitro fertilization; n: number, NICU: neonatal intensive care unit, n: number.

A version of this table including the respondents' comments is available as a Supplementary Material.

Table 3. Current practices, perceived barriers to improving mortality and morbidity mentioned in the interviews

Type of perinatal centers: Centers reporting little change in their practices since 2011

No delivery room resuscitation offered before 24 weeks' GA

Life-sustaining interventions limited in infants with complications at 24 weeks' GA

Orientation of care towards delivery room comfort care before 24 weeks GA Routine of orienting care towards delivery room comfort care before 24 weeks; team experienced in this type of care

Lack of beds and motivation in mixed PICU/NICU units

- Lack of beds available for neonates, necessity to transfer out of the region for active intervention
- Discrimination toward the more premature patients in some mixed PICU/NICU units
- Lack of knowledge about outcome of these patients because no team involvement in follow-up consultations; if survival, a priori assumption of a high risk of disability and a poor quality of life

Simplification of care choices in the face of complexity and uncertainty

- Clear decision-making patterns for limiting treatment in cases of complication
- Lack of insight into the neurological or respiratory prognosis in the medium and long term

- Neonatologists' feeling of being unprepared to discuss prognosis when there is uncertainty

Type of perinatal centers: Centers reporting more active care since 2011

Intensive care is proposed to parents according to individual criteria, including at 23 weeks

Morbidity and mortality not improving sufficiently in the eyes of physicians; lack of clear evidence-based medicine answers and practical benchmarks to guide optimal care

If survival, representation of a positive outcome, follow-up by local teams

Insufficient medical and nursing expertise

- Lack of national training for nurses in the specific needs of the extremely premature infant, resulting in heterogeneous care practices and equipment
- Moral distress of professionals related to complications, length of stay and late deaths
- Iatrogenic complications perceived as unavoidable
- Lack of communication related to a positive philosophy of care of extremely preterm infants and its effects on development

Limited or inconsistent logistical and human resources

- Disparity between centers in terms of logistical, architectural, human and material possibilities in the delivery room and in NICU
- Lack of local leaders representing obstetrics and/or NICU

- Lack of specific neuro-developmental care facilities for children with special needs in France

Factors that may promote self-fulfilling prophecy toward a poor outcome

- Pessimistic prenatal counseling favoring delivery room comfort care
- Acceptance of complications as unpreventable, disbelief of the favorable results of other teams
- NICU culture valuing reorientation to palliative care in case of complications
- No involvement in follow-up, lack of representation of patients'/families' future

Author disclosure

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Author Contributions

LC initiated and designed the study. LC, SD, and AR generated the data collection. LC, SD and OD participated in the data analysis. LC, SD, OD, AR, VP, CG, PK, PHJ, FG participated in the data interpretation and writing of the manuscript. EL, PD participated in the writing of the manuscript. All the co-authors approved the final manuscript.

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