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Prematurity-related knowledge among mothers and fathers of very preterm infants

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Abstract

Objective: Empowering parents as health promoters may contribute to decrease the costs associated with prematurity. In Portugal, 8% and 1% of the births occurring in 2018 were preterm and very preterm, respectively. This study aimed to assess prematurity-related knowledge with regard to its prevalence, causes and consequences, according to sociodemographic, obstetric and offspring's characteristics, among mothers and fathers of very preterm infants.

Methods: Between May and July 2017, mothers and fathers of very preterm infants were invited to participate through the Portuguese association of parents for support to the premature baby, with 196 parents being included. Knowledge on prematurity (prevalence, causes and consequences) was collected through a structured online questionnaire. Reporting of this research follows STROBE guidelines for cross-sectional studies.

Results: Parents estimated a median prevalence of preterm and of very preterm delivery in Portugal of 15% and 8%, respectively. However, approximately 20% did not provide an estimate. More than 90% of the participants acknowledged placental complications, hypertensive disorders of pregnancy, multiple pregnancy and intrauterine growth restriction as causes of preterm delivery, whereas only 24.2% identified low socioeconomic status. Cardiac complications and respiratory morbidity were recognised as the main consequences of prematurity by more than 80% of the parents. Overall, parents with a higher socioeconomic status tended to provide correct responses more frequently than those with a low socioeconomic status.

Conclusions: The results revealed the existence of knowledge gaps regarding the prevalence, causes and consequences of premature delivery. Understanding the main facilitators and barriers to the achievement of prematurity-related knowledge may contribute for the global improvement of preventing this condition.

Relevance to clinical practice: It is crucial to include the improvement of parents' knowledge about prematurity as a complementary dimension during the provision of medical care, with nurses playing a key role as main sources of information.

KEYWORDS

attitudes, health information management, health knowledge, parents, practice, premature birth

1 | INTRODUCTION

Prematurity is the worldwide leading cause of neonatal death and morbidity in children up to five years of age (World Health Organization, 2012, 2018), accounting for nearly 18% of all deaths in children in this age range and 35% of deaths among newborns (Liu et al., 2016). In 2016, preterm birth was responsible for 2.5% of all Disability Adjusted Life Years (DALYs), which is more than the DALYs for tuberculosis, HIV and malaria (GBD, 2016 DALYs, & HALE Collaborators, 2017).

The global average preterm birth prevalence in 2014 was 10.6%, with estimates ranging from approximately 8.7% in northern Europe to 13.4% in North Africa (Chawanpaiboon et al., 2019). Very preterm births, occurring before 32 weeks of gestational age, account for about 1% of live births and represent a proportion of 15.6% of all preterm births (World Health Organization, 2012). There has been a wide variation in preterm birth trends across European countries. Although many European countries maintained or reduced the rates of singleton preterm birth over the last two decades, the rising preterm birth rate for multiple births contributed to an increase in the overall preterm birth rate (Zeitlin et al., 2013). In Portugal, the prevalence of preterm birth has increased from 7.4% to 8.0% between 2011 and 2018 (Instituto Nacional de Estatística, 2019), while the prevalence of very preterm birth remained at 1% during the same period (Instituto Nacional de Estatística, 2018).

Although the survival of preterm infants improved markedly over recent decades, mainly due to medical advances in neonatal care (Saigal & Doyle, 2008), preterm birth sequelae can be lifelong (Platt, 2014), with impacts on individuals, families and society, as well as on the healthcare costs associated with perinatal care and long-term disability (Amorim, Alves, Kelly-Irving, Ribeiro, & Silva, 2018; Frey & Klebanoff, 2016; Platt, 2014). In this context, preterm birth is considered a major public health priority (Vogel et al., 2018), and as such, innovative strategies to prevent preterm birth and to reduce the burden of prematurity are needed (Chawanpaiboon et al., 2019; Frey & Klebanoff, 2016; McLoughlin, 2019). A successful prevention of preterm birth requires a multifaceted approach, combining public health and educational interventions, lifestyle modification, and the optimisation of obstetric healthcare (Newnham et al., 2017). However, current strategies to prevent preterm birth tend to focus on managing risk factors (Chang et al., 2013), while neglecting the assessment of prematurity-related knowledge of mothers and fathers, and its inclusion in the design and implementation of strategies regarding prematurity and co-production of care (Horvath et al., 2017).

1.1 | Background

The sparse literature on prematurity-related knowledge focuses on perceptions about preterm birth and describes, mainly,

> **What does this paper contribute to the wider global clinical community?**
>
> - There are knowledge gaps regarding the prevalence, main causes and consequences of premature delivery, especially among mothers and fathers with low socio-economic status.
> - Understanding the facilitators and barriers to the achievement of appropriate prematurity-related knowledge may contribute for the global improvement of preventing prematurity.
> - It is crucial to ensure the implementation of structural changes in caregiving, by considering parents' education and knowledge transfer as an essential dimension of care, complementary to the provision of medical care.

information about the definition and possible causes of preterm delivery (Antony et al., 2019; Giurgescu, Banks, Dancy, & Norr, 2013; Gondwe, Munthali, Ashorn, & Ashorn, 2014; Levison et al., 2014; Ling, Lian, Ho, & Yeo, 2009; Tolhurst et al., 2008). Despite the report of important gaps on participants' knowledge of preterm birth, as well as the existence of some misconceptions, a recent study concluded that 3 years after the implementation of a community health worker-based patient education programme, the majority of the participants expressed improved understanding of the definition and strategies to prevent and manage preterm birth (Antony et al., 2019). However, these studies were performed in specific settings, among populations with a high prevalence of prematurity, and with different groups of stakeholders, which impair data generalisation.

The occurrence of a very preterm delivery constitutes a disruptive life event for mothers and fathers, with short- and long-term impact on the health and well-being of the family (Amorim et al., 2018; Baía et al., 2016; Gondwe, White-Traut, Brandon, Pan, & Holditch-Davis, 2017; Mughal, Ginn, Magill-Evans, & Benzies, 2017). These parents frequently report the need to obtain clear and consistent information as a way to increase their sense of control (Alves, Amorim, Baía, & Silva, 2017). Therefore, assessing the prematurity-related knowledge among this population would contribute for the development of interventions to assist the families through this difficult experience, and also to implement interventions to raise awareness on prematurity that could possibly lead to better lifestyle choices and/or health-seeking behaviours.

This study intends to contribute to current literature by assessing the prematurity-related knowledge with regard to its prevalence, main causes and consequences, according to sociodemographic, obstetric and offspring's characteristics, among mothers and fathers of very preterm infants.

2 | METHODS

2.1 | Design and participants

The current study adheres to the STROBE checklist for reporting cross-sectional studies (Supplementary File 1).

Between 1 May and 31 July 2017, mothers and fathers who had experienced at least one very preterm delivery, before 32 weeks of gestation, were invited to participate in the study through the Portuguese association of parents for support to the premature baby with the highest number of associates: XXS—Associação Portuguesa de Apoio ao Bebé Prematuro. The study was approved by the Ethics Committee for Health of the Centro Hospitalar de São João/Faculdade de Medicina da Universidade do Porto. All participants were informed of the study objectives, as well as the confidentiality and anonymity of the data.

The invitation to integrate the study was assured by XXS, who was responsible for sending an e-mail to all associates appealing for participation, explaining the main objectives of the study and with the link for the online questionnaire. This information was also available on the association's official website (http://www.xxs-prematuros.com/) and on their Facebook page (https://www.facebook.com/xxs.prematuros/). Overall, 266 parents accepted to participate and completed the online questionnaire. After the exclusion of 70 participants with missing data on prevalence, causes or consequences of prematurity, 196 participants were included in the present analysis. There were no significant differences between participants who answered the questions on prematurity-related knowledge and those who did not regarding the time after the very preterm delivery, multiple pregnancy, and the existence of other nonpreterm children in the household, while fathers were less likely to answer these questions (6.1% vs. 15.5%; p = .016).

2.2 | Data collection

Data on sociodemographic characteristics (sex, age, educational level and household monthly income), reproductive history (time after preterm delivery, multiple pregnancy and existence of other nonpreterm children), health of the very preterm offspring (offspring's health perception, offspring's health problems) and knowledge on prematurity (prevalence, causes and consequences) were collected through a structured online questionnaire.

To assess knowledge about the prevalence of preterm and of very preterm delivery in Portugal, participants were asked "Out of every 100 deliveries, how many occur before 37 weeks of gestation?" and "Out of every 100 deliveries, how many occur before 32 weeks of gestation?", respectively. The quantitative estimate was used as a continuous variable in data analysis.

Knowledge on causes of prematurity was obtained through the question "Please indicate whether, in your opinion, the occurrence of a preterm birth is more frequent among people with the

following characteristics." A list of 17 options, all described in the literature as possible causes of prematurity, was then presented. The question also allowed participants to select "Other" as an option and to specify the other cause. All other causes referred were categorised in one of the 17 options previously presented. For each option, participants could select the answer "Yes," "No" and "Does not know"; for data analysis, the latter option was recoded as "No". To assess the main determinants of knowledge on the causes of prematurity, the possible causes were grouped in two categories: reproductive and obstetric causes, including "placental complications," "hypertensive disorders of pregnancy," "multiple pregnancy," "intrauterine growth restriction," "premature rupture of membranes," "infections during pregnancy," "uterine contractions," "uterine malformations," "previous preterm delivery," "previous vascular disease" and "assisted reproductive technology conception"; and maternal sociodemographic and lifestyle causes, comprising: "violence during pregnancy," "smoking during pregnancy," "inadequate prenatal care," "maternal age below 18 years or above 35 years old," "maternal underweight or obesity," and "low socioeconomic status." The answer was considered correct if participants considered all options included in each category as possible causes.

To assess knowledge on the potential consequences of prematurity, participants were asked to indicate whether each of the eight options, namely "cardiac complications," "respiratory morbidity," "visual impairment," "learning disabilities," "hearing impairment," "cerebral palsy," "cognitive impairment" and "behavioural problems," could result from a premature delivery. Also, participants could select "Other" as an option and specify the other consequence. The answer "Does not know" was recoded as "No" for data analysis. The associations between sociodemographic, obstetric and offspring's characteristics with knowledge on consequences of prematurity were described assuming participants recognised all possible consequences.

2.3 | Statistical analysis

Statistical analysis was performed using Stata 15.1 (College Station, TX, 2017). Sample characteristics were presented as counts and proportions. The prevalence of preterm and of very preterm delivery was presented as medians and percentiles (P25-P75), and compared using the Mann–Whitney test or the Kruskal–Wallis test for ordinal variables. The proportion of parents who recognised all causes and consequences of prematurity were presented according to sociodemographic, obstetric and offspring's characteristics, and compared using the chi-squared test or Fisher's exact test, as appropriate.

3 | RESULTS

The characteristics of the study's participants are summarised in Table 1. The majority of the participants were women, and

approximately 37% were aged between 35 and 39 years old. The place of residence of the participants was distributed across all regions of mainland Portugal and its insular territory (NUTS III), with predominance on the Lisboa Metropolitan Region. Nearly 70% of the respondents reported an educational level above 12 years, with 58.3% stating a household monthly income above 1,500€. The very preterm delivery occurred in the last two years for 34.7% of the parents, less than 20% reported a multiple pregnancy and approximately a third had other non-very preterm children in the household. Less than 15% of the participants perceived the health of their very preterm children as fair or poor, but more than 30% reported a previous diagnosis of disease.

Overall, 18.9% and 21.0% of the participants did not provide an estimate for the occurrence of preterm and of very preterm delivery, respectively (data not shown). Parents of very preterm infants stated that, among 100 deliveries in Portugal, a median of 15 (P25–P75: 10.0–40.0) and 8 (P25–P75: 4.0–20.0) would occur before 37 and 32 weeks of gestation, respectively (Table 2). The estimated prevalence of preterm birth was statistically higher among participants aged below 40 years old ($p = .005$) and with 12 or less years of education ($p = .002$). Regarding very preterm delivery, participants with 40 or more years ($p = .007$), more than 12 years of education ($p < .001$) and with a household monthly income above 1,500€ ($p = .026$) provided significantly lower estimates. There were no statistically significant differences according to obstetric and offspring's characteristics.

More than 90% of the parents acknowledged placental complications, hypertensive disorders of pregnancy, multiple pregnancy and intrauterine growth restriction as possible causes of preterm delivery, however, less than a quarter identified low socioeconomic status (Figure 1). Only 9.3% of the participants added other causes, referring cervix disorders or cancer, maternal stress and congenital disorders.

Table 3 summarises knowledge on the two main groups of causes and on the consequences of premature delivery, according to sociodemographic, obstetric and offspring's characteristics. Approximately 20% of the parents identified all items included in the reproductive and obstetric causes, and in the maternal sociodemographic and lifestyle causes. Regarding reproductive and obstetric causes, there were no consistent differences according to sociodemographic characteristics, obstetric and offspring's characteristics, while parents with a household monthly income above 1,500€ were more likely to acknowledge maternal sociodemographic and lifestyle causes than those with a household monthly income equal to or below 1,500€.

Regarding knowledge on the consequences of prematurity, more than 80% of the respondents identified cardiac complications and respiratory morbidity, but the percentage was lower for cognitive impairment (66.0%) and behavioural problems (65.5%) (Figure 2). Other consequences were named by 10.8% of the parents and included developmental impairment, motor impairment, gastrointestinal diseases, drug consumption, anaemia and death (data not shown). Almost half of the participants identified all possible consequences

of prematurity, with mothers ($p = .005$) and parents with higher levels of education ($p < .001$) being more likely to acknowledge them (Table 3).

TABLE 1 Participants' characteristics ($n = 196$)

	n (%)
Sex	
Female	184 (93.9)
Male	12 (6.1)
Age (years)	
<35	54 (30.2)
35–39	67 (37.4)
≥40	58 (32.4)
Place of residence (NUTS III)*	
North	45 (28.3)
Centre	20 (12.6)
Lisboa Metropolitan Region	64 (40.3)
Alentejo	11 (6.9)
Algarve	5 (3.1)
Autonomous Region of Madeira	8 (5.0)
Autonomous Region of the Azores	6 (3.8)
Educational level (years)	
≤12	57 (31.8)
>12	122 (68.2)
Household monthly income (€)	
≤1,500	70 (41.7)
>1,500	98 (58.3)
Time after very preterm delivery (years)	
<2	68 (34.7)
2–4	68 (34.7)
≥5	60 (30.6)
Multiple pregnancy	
No	162 (85.7)
Yes	34 (17.3)
Other non-very preterm children	
No	129 (65.8)
Yes	67 (34.2)
Offspring's health perception	
Excellent/very good	113 (58.0)
Good	55 (28.2)
Fair/poor	27 (13.8)
Offspring's health problems[b]	
No	134 (68.7)
Yes	61 (31.3)

Note: In each variable, the total may not add 196 due to missing values.
[a]Nomenclature of territorial units for statistical purposes.
[b]Respiratory morbidity, visual impairment, developmental impairment, hearing impairment, behavioural problems, neurological impairment, motor impairment, gastrointestinal diseases, allergies, hormonal dysfunction, cardiac diseases, kidney diseases, hernias, skin diseases, autoimmune diseases and cancer.

TABLE 2 Perceived risk of preterm and of very preterm delivery, according to sociodemographic, obstetric and offspring's characteristics

	Preterm delivery		Very preterm delivery	
	Median (P25–P75)	p	Median (P25–P75)	p
Overall	*15.0 (10.0–40.0)*		*8.0 (4.0–20.0)*	
Sex				
Female	15.0 (10.0–40.0)		8.0 (4.0–20.0)	
Male	20.0 (10.0–70.0)	.281	8.0 (3.0–30.0)	.649
Age (years)				
<35	16.0 (10.0–30.0)		9.0 (3.5–16.5)	
35–39	20.0 (10.0–55.0)		10.0 (5.0–30.0)	
≥40	10.0 (9.0–20.0)	**.005**	5.0 (3.0–10.0)	**.007**
Educational level (years)				
≤12	30.0 (10.0–60.0)		17.5 (5.0–40.0)	
>12	10.0 (10.0–30.0)	**.002**	6.0 (4.0–10.0)	**<.001**
Household monthly income (€)				
≤1,500	20.0 (10.0–60.0)		10.0 (4.0–30.0)	
>1,500	10.0 (10.0–30.0)	.056	7.0 (5.0–10.0)	**.026**
Time after very preterm delivery (years)				
<2	20.0 (10.0–45.0)		9.5 (4.5–20.0)	
2–4	10.0 (10.0–30.0)		6.5 (4.0–12.5)	
≥5	10.0 (10.0–45.0)	.340	8.5 (5.0–20.0)	.518
Multiple pregnancy				
No	15.0 (10.0–40.0)		8.0 (4.0–20.0)	
Yes	18.0 (10.0–30.0)	.697	8.0 (5.0–20.0)	.843
Other non-very preterm children				
No	13.0 (10.0–32.5)		8.0 (4.0–20.0)	
Yes	20.0 (10.0–50.0)	.267	8.0 (4.0–20.0)	.907
Offspring's health perception				
Excellent/very good	10.0 (10.0–30.0)		8.0 (4.0–15.0)	
Good	20.0 (10.0–60.0)		10.0 (5.0–30.0)	
Fair/poor	18.5 (10.0–45.0)	.141	6.5 (2.5–27.5)	.144
Offspring's health problems[a]				
No	15.5 (10.0–40.0)		8.0 (5.0–20.0)	
Yes	10.0 (10.0–30.0)	.301	9.5 (3.0–15.0)	.495

Note: Bold type indicates statistically significant associations.
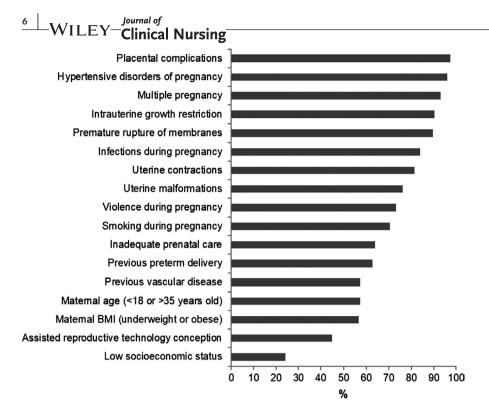
[a]Respiratory morbidity, visual impairment, developmental impairment, hearing impairment, behavioural problems, neurological impairment, motor impairment, gastrointestinal diseases, allergies, hormonal dysfunction, cardiac diseases, kidney diseases, hernias, skin diseases, autoimmune diseases and cancer.

4 | DISCUSSION

The present study provides a characterisation of the main aspects of prematurity-related knowledge among mothers and fathers of infants born before 32 weeks of gestation. The results revealed the existence of knowledge gaps regarding the prevalence, main causes and consequences of premature delivery, especially among parents with low socioeconomic status. There were no statistically significant differences in prematurity-related knowledge according to obstetric and offspring's characteristics.

Understanding the current status of prematurity-related knowledge can be useful to respond to international recommendations that call for the implementation of integrated people-centred approaches (European Commission, 2017), by putting the needs of people and communities at the centre of health and social systems.

Despite the previous experience of delivering a very preterm infant, approximately one fifth of the participants did not provide an estimate for the occurrence of preterm or of very preterm delivery in Portugal. Among those who provided an answer, the

FIGURE 1 Knowledge on the main causes of preterm delivery (%)[†]. [†]Percentage of participants identifying each option as a potential cause of preterm delivery

frequency of these events tended to be overestimated, especially in the case of a very preterm delivery. The participants tended to double the probability of occurrence of a preterm birth (Instituto Nacional de Estatística, 2019), while a prevalence eight times higher than the one described for very preterm birth among the Portuguese population was estimated (Instituto Nacional de Estatística, 2018). Such an overestimation may be related to the specificities of our sample, since all participants experienced a very preterm delivery. Therefore, it is possible that they tended to be more familiar with the occurrence of prematurity, because they know other families that also experienced such event, and they may be more attentive to news and information regarding this issue. A similar effect was previously described in a study assessing health-related knowledge on hypertension, where participants with a previous diagnosis of hypertension tended to overestimate the prevalence of the disease (Alves, Costa, Moura-Ferreira, Azevedo, & Lunet, 2018). These results emphasise the need to invest in knowledge translation techniques, such as multidisciplinary teams, educational meetings, workshop interventions (with didactic and interactive components) (Albrecht, Archibald, Snelgrove-Clarke, & Scott, 2016), online discussion forums, blogs and the use of social networks (Mairs, McNeil, McLeod, Prorok, & Stolee, 2013), that foster interaction between various stakeholders (mothers, fathers and their babies; doctors, nurses and other healthcare providers; community-based organisations; researchers; and policymakers), and assist in the sharing of ideas and knowledge within the health field (Yamey, Horváth, Schmidt, Myers, & Brindis, 2016).

Preterm delivery results from the interplay of multiple factors, including sociodemographic, nutritional, medical, obstetric, foetal and environmental characteristics (Goldenberg, Culhane, Iams, &

Romero, 2008; Vogel et al., 2018), although its aetiology remains incompletely understood (Vogel et al., 2018). In the present study, most mothers and fathers recognised the occurrence of placental complications, hypertensive disorders of pregnancy, multiple gestation and intrauterine growth restriction as possible causes of preterm birth, which may be explained by the high percentage of preterm births attributable to these factors (Boyle, Rinaldi, Norman, & Stock, 2017). Conversely, parents identified maternal sociodemographic and lifestyle characteristics less frequently, especially a low socioeconomic status. Previous literature on prematurity-related knowledge supports these results, emphasising mainly diabetes, hypertension, depression, sexually transmitted infections, smoking, alcohol intake and domestic violence as perceived causes of preterm delivery (Giurgescu et al., 2013; Levison et al., 2014; Ling et al., 2009; Tolhurst et al., 2008).

It has been previously described that during the hospitalisation of a premature infant, feelings of self-blame and guilt may emerge, especially among mothers, due to uncertainties regarding the specific causes of their children's preterm birth (Alves et al., 2017). However, our results described a focus on the acknowledgement of risk factors that are outside the mothers' control, which may be an unconscious defence mechanism (Cramer, 2015). Despite the recognition of such a mechanism as an important psychological strategy used to deal with the occurrence of a very preterm delivery, we argue that it is also essential to improve the understanding of maternal sociodemographic and lifestyle characteristics as possible causes of preterm delivery. In fact, the increase observed in the last decades regarding maternal age at the birth of the first child (Instituto Nacional de Estatística, 2019), the higher prevalence of overweight and obesity in younger ages (Carreira, Pereira, Azevedo, & Lunet, 2012), and the more frequent use of assisted reproductive technologies in Portugal (European, Geyter,

TABLE 3 Knowledge on causes and consequences of preterm delivery, according to sociodemographic, obstetric and offspring's characteristics
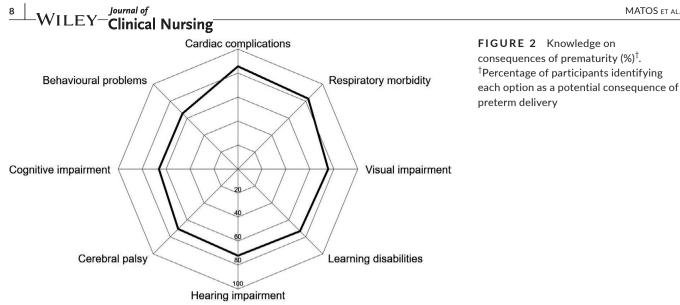
	Causes				Consequences	
	Reproductive and obstetric[a]		Maternal sociodemographic and lifestyle[b]			
	n (%)	p	n (%)	p	n (%)	p
Overall	39 (20.1)		36 (18.6)		93 (47.5)	
Sex						
Female	37 (20.3)		34 (18.7)		92 (50.0)	
Male	2 (16.7)	.553	2 (16.7)	.609	1 (8.3)	**.005**
Age (years)						
<35	12 (22.2)		8 (14.8)		26 (48.2)	
35–39	12 (18.5)		13 (20.0)		33 (49.3)	
≥40	11 (19.0)	.861	14 (24.1)	.464	28 (48.3)	.991
Educational level (years)						
≤12	7 (12.7)		7 (12.7)		14 (24.6)	
>12	27 (22.1)	.142	26 (21.3)	.175	72 (59.0)	**<.001**
Household monthly income (€)						
≤1,500	13 (18.8)		9 (13.0)		30 (42.9)	
>1,500	20 (20.4)	.802	25 (25.5)	**.049**	54 (55.1)	.118
Time after very preterm delivery (years)						
<2	14 (20.6)		11 (16.2)		36 (52.9)	
2–4	11 (16.4)		13 (19.4)		33 (48.5)	
≥5	14 (23.7)	.589	12 (20.3)	.814	24 (40.0)	.335
Multiple pregnancy						
No	35 (21.9)		29 (18.1)		73 (45.1)	
Yes	4 (11.8)	.182	7 (20.6)	.737	20 (58.8)	.144
Other non-very preterm children						
0	25 (19.7)		22 (17.3)		67 (51.9)	
≥1	14 (20.9)	.841	14 (20.9)	.543	26 (38.8)	.081
Offspring's health perception						
Excellent/ very good	18 (16.1)		19 (17.0)		56 (60.2)	
Good	14 (25.5)		12 (21.8)		25 (45.5)	
Fair/poor	7 (26.9)	.240	5 (19.2)	.749	12 (44.4)	.826
Offspring's health problems[c]						
No	23 (17.3)		22 (16.5)		60 (44.8)	
Yes	16 (26.7)	.133	14 (23.3)	.262	33 (54.1)	.227

Note: The answer "does not know" was recoded as "no" for data analysis; Bold type indicates statistically significant associations.

[a]Placental complications, hypertensive disorders of pregnancy, multiple pregnancy, intrauterine growth restriction, premature rupture of membranes, infections during pregnancy, uterine contractions, uterine malformations, previous preterm delivery, previous vascular disease and assisted reproductive technology conception.

[b]Violence during pregnancy, smoking during pregnancy, inadequate prenatal care, maternal age below 18 years or above 35 years old, maternal underweight or obesity, and low socioeconomic status.

[c]Respiratory morbidity, visual impairment, developmental impairment, hearing impairment, behavioural problems, neurological impairment, motor impairment, gastrointestinal diseases, allergies, hormonal dysfunction, cardiac diseases, kidney diseases, hernias, skin diseases, autoimmune diseases and cancer.

FIGURE 2 Knowledge on consequences of prematurity (%)[†]. [†]Percentage of participants identifying each option as a potential consequence of preterm delivery

Kupka, & Goossens, 2017) support the need to implement strategies that improve reproductive health-related knowledge.

Almost half of the participants identified all the main consequences of prematurity. The most identified consequences were those related to cardiac complications and respiratory morbidity, perhaps because they entail severe complications in the development of children born prematurely (Bayman, Drake, & Piyasena, 2014; Urs, Kotecha, Hall, & Simpson, 2018). A previous study assessing knowledge on the consequences of prematurity among adults attending a parenting-related public forum reported difficulties in breathing and weaker resistance to infections as the main consequences of prematurity (Ling et al., 2009). These results, as well as the fact that behavioural problems were the least identified consequences of prematurity, suggest that parents are more likely to acknowledge conditions that are more frequently associated with an immediate risk of life.

Globally, parents with a higher socioeconomic status tended to provide correct responses more frequently than those with a low socioeconomic status, which may be explained by the association between educational level and health literacy (van der Heide et al., 2013). However, a study performed in 2015 reported that 49% of the Portuguese have limited health literacy (Espanha, Ávila, & Mendes, 2016), highlighting the need to improve health-related knowledge among the general population.

To the best of our knowledge, this is the first study to assess prematurity-related knowledge among mothers and fathers who experienced a very preterm delivery. The results may contribute for the adjustment of current preventive strategies on prematurity to mothers' and fathers' knowledge (Horvath et al., 2017), what is crucial for the development of a model of co-production of care, able to empower mothers and fathers as health promoters. However, some limitations should be discussed. Although the inclusion of fathers constitutes a main methodological advantage of the present study, since fathers are often excluded from studies focusing on prematurity, the small proportion of fathers that accepted to participate limits the statistical power to detect possible gender differences.

Thus, further studies should implement innovative strategies to increase the participation of fathers. Non-Portuguese speaking mothers and fathers are probably missed in our sample. However, taking into account that more than 60% of migrants in Portugal came from Portuguese speaking countries (PORDATA, 2020) and that approximately 10% of the total births in 2018 occurred among migrant mothers, we expect a very small number of preterm deliveries among non-Portuguese speaking migrants, which should not significantly affect the results described.

The relative small sample size and the focus on parents of very preterm infants, who were expected to have higher prematurity-related knowledge than the general population, preclude the generalisation of the results. Still, taking into account the knowledge gaps regarding the prevalence, main causes and consequences of premature birth described in our study, as well as the previous reports of limited health literacy among the Portuguese population (Espanha et al., 2016), we believe that the improvement of knowledge on prematurity in Portugal remains a current need.

Data on causes and consequences of prematurity were obtained from the recognition of possible options, which could lead to an overestimation of knowledge in these domains. It has been shown that close-ended questions in general yield higher percentages of response than open-ended questions for answers that are identical in both question forms (Reja, Manfreda, Hlebec, & Vehova, 2003). In fact, the lower proportion of responses regarding the prevalence of preterm and of very preterm delivery seems to support this assumption.

Finally, the participants' selection strategy can have introduced some selection bias. First, although XXS—Associação Portuguesa de Apoio ao Bebé Prematuro—is the association of reference for parents of very preterm infants in Portugal, we cannot ensure that all mothers and fathers follow their page. Second, the online mode of data collection might have excluded some parents since not all may have access to Internet. However, in 2017, 97% of Portuguese families with children had access to the Internet at home (Instituto Nacional de Estatística, 2017). Also, a recent study performed with

parents of children aged below four years old concluded that although online questionnaires presented slightly lower response rates when compared with paper questionnaires, the analyses of socioeconomic variables showed almost no difference between nonrespondents in both groups (Ebert, Huibers, Christensen, & Christensen, 2018). Thus, a lower response rate to an online questionnaire may not necessarily increase the level of selection bias. Therefore, we considered that our participants' selection strategy can be a good low-budget approach to reach the parents of very preterm infants.

5 | CONCLUSION

Considering the economic, societal and family costs associated with prematurity (Frey & Klebanoff, 2016), innovative and interdisciplinary strategies of prevention are needed. The results of the present study highlight the need for promoting prematurity-related knowledge among mothers and fathers of very preterm infants, thus empowering families as health promoters. Understanding the facilitators and barriers to the achievement of appropriate prematurity-related knowledge may contribute for the global improvement of preventing this condition.

6 | RELEVANCE TO CLINICAL PRACTICE

Experiencing a very preterm delivery constitutes an adverse life event for mothers and fathers (Amorim et al., 2018; Baía et al., 2016; Gondwe et al., 2017; Mughal et al., 2017), with parents frequently reporting the need to obtain clear and consistent information as a way to increase their sense of control and confidence on making decisions about the infants' care (Alves et al., 2017). Given the reliance on health professionals as the main sources of information in NICU (Gallagher, Shaw, Aladangady, & Marlow, 2018), nurses may play a key role in improving knowledge among mothers and fathers of very preterm infants. Thus, it is crucial to ensure the implementation of structural changes in caregiving, by considering parents' education and knowledge transfer as essential dimensions of care, complementary to the provision of medical care.

CONFLICT OF INTERESTS
The authors have no conflict of interests to declare.

AUTHOR CONTRIBUTIONS
All authors have made a substantial contribution to the submitted manuscript and approved the final version. Joana Matos collaborated in the acquisition, analysis and interpretation of the data, and wrote the first draft of the article. Mariana Amorim, Susana Silva and Conceição Nogueira collaborated in the analysis and interpretation of the data, and reviewed the article critically. Elisabete Alves designed the study, collaborated in the acquisition, analysis and interpretation of the data and reviewed the article critically for important intellectual content.

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