

ORIGINAL CONTRIBUTION

Sudden Infant Death Syndrome: What Healthcare Professionals and Parents Know About How to Prevent it in Portugal

Sara C. Fernandes^{a,*}, Federico de Luca^b, Sara M. B. V. P. Fonseca^c, Filipa S. D. F. L. C. Oliveira^{a,c}, and Maria H. F. G. P. Areias^{a,d}

^aFaculty of Medicine of the University of Porto, Porto, Portugal; ^bDepartment of Social Statistics and Demography, Faculty of Social Sciences, University of Southampton, United Kingdom; ^cNeonatal Intensive Care Unit, Centro Hospitalar Universitário São João, Porto, Portugal; ^dCardiovascular R&D Unit, Faculty of Medicine of the University of Porto, Porto, Portugal

Background: Sudden Infant Death Syndrome (SIDS) is defined as the death of an infant of less than 1 year, that is unexpected and unexplained after an extensive investigation. Risk factors related to SIDS have been identified, and most of them concern the infant's sleep position and environment. **Objective:** Our objective was to conduct a survey with parents and healthcare professionals at the Centro Hospitalar Universitário São João (CHUSJ), in order to assess their knowledge of SIDS and its risk factors. **Materials and Methods:** This study used two structured self-administered questionnaires aimed at evaluating the knowledge of parents and healthcare professionals about SIDS prevention. **Results:** Overall, 100% of healthcare professionals and 67.7% of parents were aware of SIDS. Besides, 82.3% of healthcare professionals and 47.5% of parents recognized the supine position as the safest to prevent SIDS. For each of the 13 questions in the questionnaire about SIDS risk factors, the majority of healthcare professionals identified the correct answer whereas among parents, only seven questions were correctly answered by the majority of respondents. **Discussion and Conclusion:** Healthcare professionals are not as well informed about SIDS as they should be and have little confidence in discussing SIDS-related issues. Therefore, this study highlights the paramount importance of ensuring that their training on this topic is up-to-date, especially due to their crucial role of (partial) gatekeepers of this information for parents, and that providing them with appropriate support could likely contribute to a substantial decrease in the number of SIDS cases.

INTRODUCTION

Sudden Infant Death Syndrome (SIDS) is defined as the death of an infant of less than 1 year that is unexpected and unexplained after an extensive investigation including necropsy, investigation of the death scene, and

review of the medical history [1]. A literature revision put together by Alfilali *et al.* showed the potential infectious etiologies of SIDS. This syndrome has its peak incidence during colder months, which is consistent with the higher prevalence of respiratory viruses during this period of the year [2]. Also, markers of infection and inflammation to-

*To whom all correspondence should be addressed: Sara Catarina Fernandes; Rua das Laranjeiras 70, 4710-851 Braga, Portugal; Tel (+351) 916182654; Email: sara_cf6@hotmail.com; ORCID iD:0000-0001-7366-6549.

Abbreviations: SIDS, Sudden Infant Death Syndrome; CHUSJ, Centro Hospitalar Universitário São João; SUID, Sudden Unexpected Infant Death; ASSB, Accidental Suffocation and Strangulation in Bed; BRUE, Brief Resolved Unexplained Event; SUPC, Sudden Unexpected Postnatal Collapse; NICU, Neonatal Intensive Care Unit; BTS, Back to Sleep; SPP, Sociedade Portuguesa de Pediatria.

Keywords: Sudden Infant Death Syndrome, Prevention, Risk Factors, Knowledge, Healthcare professionals, Parents, Questionnaire

gether with the colonization of specific bacteria and viruses were found in autopsies of infants that died from SIDS, however, no specific organism was found to be directly associated with SIDS [3]. Another important definition is Sudden Unexpected Infant Death (SUID), described as the death of an infant of less than 1 year that occurs in a sudden and unexpected way and has no immediate or obvious cause. The latter includes all infants' sudden and unexpected deaths and not just SIDS related deaths [4]. The definition of SUID includes three sub-groups: SIDS, Accidental Suffocation and Strangulation in Bed (ASSB, including all infant deaths caused by suffocation and asphyxia in a sleeping environment), and the group of Infant Deaths of an Unknown Cause [5]. Another related concept is the one of Brief Resolved Unexplained Event (BRUE), that is a sudden, brief, and resolved episode, with no explanation for a qualifying event after appropriate history and physical examination is conducted, with at least one of the following in an infant with less than 1 year of age: cyanosis or pallor; absent, decreased or irregular breathing; marked hypertonia or hypotonia; altered level of responsiveness [6]. Finally, Sudden Unexpected Postnatal Collapse (SUPC), that was defined by the British Association of Perinatal Medicine as "a term or near-term infant who is well at birth, assigned to routine postnatal care and who collapses unexpectedly within the first 7 days of life, requiring resuscitation with intermittent positive pressure ventilation, and who either dies, requires ongoing intensive care or develops an encephalopathy [7,8]." Besides the different definitions, all the above-mentioned terms have similar risk factors and share the same etiologies.

In developed countries, SIDS is the first cause of mortality in the first year of life (excluding the neonatal period), and is the third leading cause of infant death in the world [9]. Although this syndrome's mortality rate decreased in the 1990s, it has not been decreasing in recent years. Countries such as Japan, the United States, the United Kingdom, and New Zealand have reported rates of 0.8, 0.57, 0.41, and 0.09 deaths per 1000 livebirths, respectively [10]. Unfortunately, SIDS is not a disease with mandatory focus in Portugal, so its prevalence in the country remains unknown [11]. A reasonable estimate could range between 0.04 and 0.2 deaths per 1000 livebirths, with the lower limit obtained from data reported to Eurostat in 2015 (which notoriously underestimates this cause of death) and the higher limit suggested by the University of Porto [12,13]. As Portugal registers between 80,000 and 90,000 annual livebirths, this would correspond to approximately three to 18 SIDS victims a year in the country [14].

The mechanisms behind the deaths caused by SIDS are not well known, but several risk factors related to SIDS have already been identified. The *Task Force on*

Sudden Infant Death Syndrome of the American Academy of Pediatrics, published an update on the *Recommendations for a Safe Infant Sleeping Environment* in 2016, in order to reduce the risk of all sleep-related infant deaths [15]. These can be broadly grouped in two groups: factors related to the infants and their context, and factors related to the behavior of their parents.

In the first group there is prematurity, as the SIDS rate among preterm infants is more than double than that of term infants [16]. Furthermore, ethnicity differences have been reported, with more non-Caucasian infants dying from SIDS compared to Caucasian infants. This difference has been observed despite recent downwards trends in SIDS rates for both groups, which are likely attributable to the effects of Back to Sleep (BTS) campaigns [17]. The socioeconomic and educational status of the families also plays a role, with higher SIDS rates observed among families with less education and socioeconomic status [18]. Multiparity, single mothers, young mothers, and mothers with few educational qualifications are all factors associated with an increased risk of SIDS, together with the absence of perinatal care [19]. Although there is no strong evidence of a heritable condition that may contribute to SIDS, some genetic factors were proven to be responsible for the deaths of infants dying from SIDS. However, the percentage of SIDS deaths due to these anomalies is still unknown. A study conducted by Campuzano *et al.* reported that at least one rare gene mutation related to sudden cardiac death was found in 90.9% of the autopsies of infants that died unexpectedly [20]. The most vigorous of the findings relates to abnormalities in genes involved in the serotonergic transport in the brainstem, an area of the brain that plays an essential role in respiratory, arousal, and other autonomic functions. Other relevant gene alterations in the pathophysiology of SIDS are associated with sodium and potassium channelopathies in the cardiac muscle that result in long QT syndrome. Finally, some genes related to the embryologic development of the autonomic nervous system, inflammation, energy production, hypoglycemia, and thermal regulation have also been described as having a potential impact on SIDS [21-23].

In the second group of risk factors, the most known and strongest one is the sleep position of the infant. Supine position was proven to be the safest position for sleeping infants, a message which has been relayed and reinforced by several campaigns around the world since the late 1980s. These campaigns, often called "Back-to-Sleep" (BTS), led to substantial decreases in SIDS mortality rate where they were carried out. For example, in the United States SIDS rate showed a reduction of 53% in the 10 years following the implementation of the first BTS campaign in 1992 (from 120 to 56 deaths over 100,000 livebirths). Nonetheless, this was followed by a period where

the rate of SIDS reached a plateau, highlighting the need for further prevention campaigns to promote the adoption of other identified protective behaviors [24]. In Portugal, no BTS campaigns have ever been implemented. Nevertheless, in 2009 the Sociedade Portuguesa de Pediatria (SPP) elaborated recommendations for parents to reduce the risk of SIDS, and the Infant's Healthcare Report Card, which is used to document infant development in Portugal, includes a statement about the supine position as the preferential sleeping position for infants [25].

Other risk factors related to the environment and how infants sleep were also identified, such as the use of a soft mattress in the crib, which can leave gaps between the mattress and the sides of the crib and potentially lead to entrapment of the infant. Loose bedding, duvets, and soft objects also contribute to the risk of entrapment or suffocation since they can cover the infant's face, increasing the risk of inhalation of expired gases, hypoxia, and overheating. Overheating, bed sharing (especially with smokers), a non-smoke free environment (both before and after the birth of the infant), maternal use of illicit drugs and alcohol during pregnancy are all recognized risk factors for SIDS [15,26].

Some protective factors, though, have also been identified. Several studies showed that breastfeeding is a protective factor against SIDS, and ideally infants should be exclusively breastfed for the first 6 months of life. An analysis of the German Study of Sudden Infant Death conducted by Vennemann revealed that breastfeeding can reduce the risk of SIDS by up to 50%. Independently of its duration, breastfeeding leads to a lower wake-up threshold compared to artificial milk nutrition. It also confers maternal immunoglobulins and cytokines that help in the prevention of infections, which are thought to be associated with an increased risk of SIDS [27,28]. The use of a pacifier is also considered a protective factor for SIDS. Breastfed infants should be offered one only once breastfeeding is well established, while bottle-fed infants should be offered one immediately after birth [29]. Even though bed sharing is considered to be a risk factor for SIDS, it is advisable for children to sleep in the same room as the parents, in a crib next to the parents' bed [30]. Moreover, it was demonstrated that immunization of infants reduces the risk of SIDS by half [31].

The "feet to foot" position, where bedding is made up in a way that the infant's feet reach the foot of the crib, has long been considered an attractive method to protect against SIDS, since it is believed to reduce the chances of head covering [32]. In the United Kingdom, for example, it has been included among the Department of Health recommendations for SIDS prevention since 2000 [33,34]. However, its protective effect towards SIDS has not yet been conclusively proven, as it does not prevent the infant from turning to the side and consequently getting covered

by blankets if the crib is wide enough [33]. Thus, for the purpose of this article – and similarly to other studies previously carried out on this subject [35-37], it was included among the factors that do not affect the risk of SIDS. The use of cardiorespiratory surveillance monitors could also be considered a valid strategy to prevent SIDS, since they can detect at-risk situations such as bradycardia and apnea. However, there is no evidence indicating that this equipment can reduce SIDS rates [38].

Numerous studies have focused on healthcare professionals' knowledge about SIDS and the recommendations they give [35-37,39-41]. The implementation of BTS campaigns over the past 20 years has led to an increased percentage of healthcare professionals recommending parents a supine or, at least, non-prone position to put their babies to sleep. About 80% of healthcare professionals seemed to recommend exclusively the supine position. However, in parallel, the percentage of healthcare professionals aware that any non-prone position is associated with less risk of SIDS than the prone position decreased over time. Contextually, campaigns focusing on changing the sleep position of infants from prone or lateral to supine revealed an immediate reduction of SIDS rates by up to 50% in several countries [24]. There is not much information about the knowledge of healthcare professionals and parents about the prevention of SIDS in Portugal, nor any validated questionnaire to assess this topic. In 2007, Fernandes *et al.* conducted a study in the practices of Child Health/Pediatrics of two health centers in Lisbon with 44 mothers, in order to evaluate their knowledge about SIDS and its risk factors. This limited evidence suggested that most mothers in the study sample had little knowledge of SIDS as well as of its associated risk factors [11]. Another Portuguese study led by Ferreira *et al.* in 2004 analyzed 150 healthcare professionals and pre-school caregivers in two health centers and one nursery in Vila Nova de Gaia, and showed that healthcare and educational professionals lacked valid and recent information about SIDS [42]. These studies, conducted more than 10 years ago, suggested that both parents and healthcare professionals were not properly informed about SIDS risk factors and prevention, and concluded that active campaigns were necessary to inform both groups about this topic. However, there is no evidence that these campaigns were implemented.

Therefore, this study conducted a survey with parents and healthcare professionals at the Centro Hospitalar Universitário São João (CHUSJ), in order to assess their knowledge of SIDS and of its risk factors.

MATERIALS AND METHODS

This study used two structured self-administered questionnaires based on the questionnaire constructed by

Federico de Luca in the context of a cross-country survey in the early 2010s. This questionnaire was administered in Spain and the United Kingdom, and built upon the experience of a previous instrument used for a national healthcare campaign in Italy [36,37].

The questionnaires for parents and healthcare professionals were similar and gathered information on participants' knowledge about SIDS and 13 of its risk factors. Furthermore, they also collected data on the respondents' self-perception of their knowledge about SIDS, confidence in discussing it, and demographic and professional background. Some small differences existed between the two questionnaires, mostly consisting of adaptations to make sure that questions were clearly understood by both target populations (*e.g.* the supine position was described as "sleeping with the belly facing the ceiling" in the questionnaire for parents). Besides these differences, the questionnaire for healthcare professionals included some additional questions concerning specific medical knowledge about SIDS and the recommendations that they provided to parents during their hospital work.

Two of the authors delivered the paper-based questionnaires to parents of babies born in the Obstetrics and Neonatology wards of CHUSJ hospital between 30 June 2019 and 27 September 2019. In the Obstetrics ward, questionnaires were delivered two to three times a week, as most post-partum hospital stays in Portugal last at least 3 days. In the Neonatology ward, instead, questionnaires were delivered only once a week, given that in this ward, the average stay is usually longer (about 15 days). In both cases, questionnaires were delivered during the family's stay in the hospital. If parents agreed to participate, they were given 2 hours to complete the questionnaire, which was later collected by one of the two authors. During the same period, one of the authors handed out the questionnaires to healthcare professionals working in the Obstetrics, Gynecology and Neonatology wards of CHUSJ. In the Obstetrics ward, the head nurse helped to distribute them to nurses. In all wards, questionnaires were handed out during service meetings and shift changes, and respondents were given 10 minutes to complete them. The CHUSJ hospital sees approximately 2600 births per year, of which about 400 are admitted to the Neonatal ward. In terms of medical staff, 22 doctors and 37 nurses work in the Obstetrics ward, 34 doctors and 28 nurses in the Gynecology ward, and 18 doctors and 39 nurses in the Neonatal ward. Doctors from the Gynecology ward were included in this study because in Portugal the specialties of gynecology and obstetrics are not separated, which implies that gynecologists are also involved in obstetrics (especially during their internships). On the contrary, nurses from the Gynecology service were not included in this study. Furthermore, 59 additional nurses working in the emergency unit of the Obstetrics ward also partic-

ipated in the study. In total, the population of healthcare professionals consisted of 74 doctors and 135 nurses.

We performed a descriptive analysis of the responses, and logistic regressions and odds ratios were used in order to investigate the relationship between variables. All statistical analyses were performed in *Stata* 16.1.

RESULTS

A total of 204 parents and 113 healthcare professionals filled out the questionnaires. In the case of healthcare professionals, this corresponds to a response rate of 54.1%, while for parents, a response rate was not available.

Of the 204 parents that responded to the questionnaire, 147 were women, their average age was 33 years old, the majority did not hold a higher education degree (132), 172 were employed and 102 had more than one child, with 69 of these having children of less than 5 years.

Among healthcare professionals, 101 of the 113 participants were women, the average age was 41 years old, 71 were nurses, and 40 were doctors. Of these, 78 had a specialty in Obstetrics and Gynecology or in Pediatrics and Neonatology. Seventy-four respondents had children and 25 of these had children of less than 5 years of age. The average seniority of the respondents was of 18 years (Table 1).

Overall, 138 parents (67.7%) stated that they knew about SIDS and thus continued with the rest of the questionnaire. Of them, only three had a direct experience with a case of SIDS. Parents declared that their main sources of information about SIDS were the Internet (53.7%), nurses (34.5%), and doctors (25.9%). The vast majority of parents rated their knowledge about SIDS and its risk factors as moderate (42.5%) or (very) low (43.9%). Similarly, the majority also described their confidence to discuss SIDS-related issues as moderate (39.6%) or (very) low (47.5%).

All of the 113 healthcare professionals were aware of what SIDS is, and 11 of them had had a direct experience with a case of SIDS. The majority of respondents stated that they got their information during university courses (86.7%), while less relevant sources of information were the Internet (15.9%) and work experience (10.6%). Healthcare professionals were more evenly distributed in rating their knowledge level about SIDS between high or very high (30.1%), moderate (48.7%), and low or very low (21.2%). However, their confidence to discuss SIDS-related issues was more skewed towards the lower categories, as they rated it high or very high in 21.2% of the cases, moderate (46.9%), and low or very low (31.9%).

When asked about the sleep position associated with

Table 1. Demographic and professional background of the sample.

Parents (n=204)	
Women, n (%)	147 (72.1)
Age, mean (SD)	32.6 (5.9)
Schooling, n (%)	
Degree, Master, Doctorate, Bachelor's degree	69 (33.8)
12th grade or less	132 (64.7)
Unknown	3 (1.5)
Occupation, n (%)	
Employed	172 (84.3)
Unemployed	30 (14.7)
Unknown	2 (1.0)
Has previous children, n (%)	102 (50.0)
<5 years old, n (%)	69 (33.8)
Healthcare Professionals (n=113)	
Women, n (%)	101 (89.4)
Age, mean (SD)	41.7 (9.7)
Professional category, n (%)	
Doctor	40 (35.4)
Nurse	71 (62.8)
Other	2 (1.8)
Professional specialty in Obstetrics and Gynecology or Pediatrics and Neonatology, n (%)	
Yes	78 (69.0)
No ^a	30 (26.6)
Unknown	5 (4.4)
Has children, n (%)	74 (65.5)
< 5 years old, n (%)	23 (20.4)
Working years, mean (SD)	17.8 (9.8)

^a It includes intern doctors that have not yet completed a specialty.

the lowest risk of SIDS, only 47.5% of parents recognized the supine position as the safest sleep position. Among healthcare professionals, this percentage rose to 82.3%, and the majority of respondents (85%) reported recommending exclusively the supine sleep position to parents. Interestingly, 14 healthcare professionals reported recommending a different position than the one they believed to be the safest. In terms of the frequency of recommendations given to parents, 46.9% of healthcare professionals reported giving recommendations to parents about SIDS prevention more than once a week, while only 53.1% of them considered themselves as qualified to advise parents about SIDS and its risk factors (Table 2).

Tables 3a and 3b show the responses given by parents and healthcare professionals about SIDS risk factors. Among parents, only 7 out of 13 questions were correctly answered by the majority of respondents, with the items about lateral position, "feet to foot" position and room temperature being the ones that fewer parents answered correctly. In terms of single respondents, only 8.7% of parents responded correctly to 75% or more of the 13 questions about SIDS risk factors.

Among healthcare professionals, however, the majority of respondents identified the correct answer for all questions about SIDS risk factors, with the exception of the items about the "feet to foot" position (where only 14.2% responded correctly) and room sharing (40.7%). Worryingly, only 37.2% of healthcare professionals responded correctly to 75% or more of the 13 questions about SIDS' risk factors.

We then investigated if there was any relationship between our variables of interest (knowledge about the safest sleep position, about SIDS risk factors, and recommendations about the safest sleep position) and the demographic and professional characteristics of healthcare professionals. The results indicated that healthcare professionals with children aged 5 or less were more likely to have stronger knowledge about SIDS risk factors than the other respondents ($p = 0.032$). Additionally, we found that doctors were more likely to have less correct knowledge about SIDS risk factors than nurses, and also to give worse recommendations about the safest sleep position ($p = 0.028$ and 0.012 , respectively) (Table 4).

Table 2. Respondents' answers about the safest sleep position, the recommendations and its frequency given to parents by healthcare professionals, healthcare professionals qualification to give recommendations to parents and believes about home apnea monitor in at-risk patients to decrease the risk of SIDS (respondents could choose multiple positions).

	Variable	n, (%)
Position that parents believe to be the safest	Supine position	66 (47.5)
	Lateral	33 (23.7)
	Supine+Lateral positions	19 (13.7)
	Other	13 (9.4)
	Don't know	5 (3.6)
	Unknown	3 (2.2)
Position that healthcare professionals believe to be the safest	Supine position	93 (82.3)
	Lateral	7 (6.2)
	Supine+Lateral positions	5 (4.4)
	Other	6 (5.3)
	Don't know	2 (1.8)
Position that healthcare professionals recommend to parents	Supine	96 (85.0)
	Lateral	8 (7.1)
	Lateral + Supine	3 (2.7)
	Other	1 (0.9)
	Don't recommend a position	5 (4.4)
Frequency of given recommendations to parents by healthcare professionals	More than once a week	53 (46.9)
	Two-four times a month	18 (15.9)
	About once a month or less	15 (13.3)
	Never	25 (22.1)
	Unknown	2 (1.8)
Healthcare professionals that consider themselves as a qualified person to advice about SIDS		60 (53.1)
Healthcare professionals that believe that home apnea monitor in at-risk patients does not decreases the risk of SIDS		33 (29.2)

DISCUSSION

In this study, we assessed the knowledge of parents and healthcare professionals about SIDS and its risk factors. Since the majority of risk factors are associated with preventable actions, making sure that parents are well informed about SIDS prevention should help reduce its incidence. This becomes particularly relevant as our results show that there is still a large portion of parents that have never even heard of SIDS (31.6%). Furthermore, among those parents who are aware of what SIDS is, only 8.7% answered correctly to at least 75% of the questions about SIDS risk factors. As many parents mentioned healthcare professionals as one of their main sources of information about SIDS, it was also particularly worrying to find out that 15% of healthcare professionals participating in this study reported not recommending exclusively the supine position to parents.

A possible solution to this lack of knowledge among parents could be to organize campaigns and workshops in order to inform them about SIDS and its risk factors. However, these campaigns are generally very complex to implement due to the size and diversity of the target group. Not to mention that they would need to be cycli-

cally organized in order to cover all the new cohorts of parents. On the other hand, campaigns aimed at better informing healthcare professionals, and at reinforcing their role in the prevention of SIDS, would lead to sustainable results and still increase parents' knowledge about this topic.

A Swedish study aimed at assessing if parents who had just had a baby followed SIDS prevention recommendations given by healthcare professionals from maternal and child healthcare services. This study found that the adherence of parents in following national SIDS prevention recommendations was generally good, with only 1.3% of parents placing their infants to sleep in a prone position. Nonetheless, 14.3% still placed them in the lateral position, a share that rose with the increasing age of children (5.6% and 23.6%, respectively, at 3 and 5 months of age), possibly showing a less rigorous follow-up to the recommendations as the infants get older. Other recommendations showed satisfying results, such as 83.1% of infants being breastfed and 84.1% using a pacifier [43]. Furthermore, a study conducted by Colson *et al.* aimed at identifying the barriers to following the recommendations about the safest sleep position for infants in order to prevent SIDS, and showed that 60% of

Table 3a. Parents' answers to the effect of different behaviors on the risk of SIDS (the correct answers are shown in bold).

	Increases the risk (%)	Does not affect the risk (%)	Lowers the risk (%)	I do not know (%)	Does not reply (%)
Placing infants to sleep in a supine position	19.4	11.5	56.1	10.1	2.9
Smoking during pregnancy	61.9	5.0	0.7	30.2	2.2
Smoking in the infant's environment	68.4	3.6	0.7	25.2	2.2
Breastfeeding	0.7	41.7	30.2	25.2	2.2
Encouraging tummy time when the infant is awake and observed	13.7	32.4	20.9	30.2	2.9
Placing infants to sleep in a lateral position	18.0	22.3	34.5	23.0	2.2
Making up the bedding so that the infant's feet reach the foot of the crib	7.2	18.0	40.3	32.4	2.2
Placing infants to sleep in a soft mattress	38.1	8.6	3.6	46.8	2.9
Placing soft objects such as pillows, quilts and stuffed toys in the crib	75.5	6.5	1.4	13.7	2.9
Allowing infants to sleep in the same room as their parents	3.6	41.7	41.0	10.8	2.9
Allowing infants to sleep in the same bed as their parents	59.7	14.4	5.0	18.0	2.9
Sleeping with an infant on a couch/armchair	47.5	20.9	0.7	28.1	2.9
Maintaining the room temperature below 20°C	22.3	11.5	17.3	46.8	2.2

Table 3b. Healthcare professionals' answers to the effect of different behaviors on the risk of SIDS (the correct answers are shown in bold).

	Increases the risk (%)	Does not affect the risk (%)	Lowers the risk (%)	I do not know (%)	Does not reply (%)
Placing infants to sleep in a supine position	5.3	3.5	88.5	1.8	0.9
Smoking during pregnancy	77.0	6.2	0.9	13.3	2.7
Smoking in the infant's environment	87.6	1.8	0.9	8.9	0.9
Breastfeeding	0.0	34.5	58.4	4.4	2.7
Encouraging tummy time when the infant is awake and observed	19.5	61.1	7.1	12.4	0.0
Placing infants to sleep in a lateral position	61.1	14.2	15.0	8.0	1.8
Making up the bedding so that the infant's feet reach the foot of the crib	5.4	14.2	67.9	12.5	0.0
Placing infants to sleep in a soft mattress	74.3	8.0	0.9	15.9	0.9
Placing soft objects such as pillows, quilts and stuffed toys in the crib	89.4	4.4	0.9	5.3	0.0
Allowing infants to sleep in the same room as their parents	2.7	51.3	40.7	4.4	0.9
Allowing infants to sleep in the same bed as their parents	81.4	11.5	0.9	4.4	1.8
Sleeping with an infant on a couch/armchair	70.8	15.0	2.7	10.6	0.9
Maintain the room temperature below 20°C	12.4	20.4	43.4	21.2	2.7

Table 4. Correlation between selected covariates and the variables of interest among healthcare professionals.

Covariates	Odds ratio (significance)		
	Correct knowledge about the safest sleep position	Knowledge about SIDS risk factors (proportion of correct answers over 13 items)	Correct recommendations about the safest sleep position
Age	0.955 (0.097)	0.996 (0.483)	0.963 (0.200)
Has children aged 5 or less	1.626 (0.495)	1.281 (0.032)	2.250 (0.326)
Is a doctor (vs nurse)	0.435 (0.103)	0.778 (0.028)	0.227 (0.012)
Has a specialty in pediatrics or obstetrics/gynecology	1.522 (0.426)	0.917 (0.493)	0.846 (0.788)
Seniority	0.967 (0.178)	0.997 (0.611)	0.975 (0.363)

the mothers using the supine position to put their babies to sleep had observed healthcare professionals using this same position while they were hospitalized after giving birth [44]. Another study focusing on neonatal intensive care units (NICU) revealed that the most important factors affecting parents when choosing the sleep position for their child were the recommendations received from healthcare professionals and nursery practices [45]. The study by Colson *et al.* also showed that while mothers were more eager to follow recommendations from friends and relatives (rather than from healthcare professionals), those who developed a trust relationship with healthcare professionals were more likely to follow the advice of the latter. The belief that the infant might choke in the supine position, that the prone position is more comfortable for the infant and that sleeping with an adult prevents SIDS were within additional barriers identified by parents to follow the supine position recommendations [44]. According to Pease *et al.* the previous experiences of mothers can also create a conflict between what they believe is safe and promotes a greater amount of sleep for the child, since it worked previously, and the current evidence given to them about safe sleep strategies. The stress of looking after a baby and the disruption of routines may lead mothers to prioritize sleep and settling over safety on occasion. Besides, the credibility of advice also plays an important role in the decision making of mothers regarding the infant's sleep position. They prefer a more individual approach rather than a didactic one since they are given more time to process the information and ask questions to better understand a logical physiological link between the recommendations and the reduction of risk. Whenever mothers are not satisfied or convinced with the advice given, they tend to provide their own strategies to reduce risk by using monitors, frequent checking, and their perceived increased awareness during sleep [46]. Discussion

with healthcare providers about these concerns, may have a positive impact on parental attitudes towards negative approaches regarding the sleep position and location. The development of a trust relationship between parents and healthcare professionals is essential to address barriers to compliance of recommendations for safe sleep and discuss fears and personal beliefs parents may have about this matter. All discrepancies between nursery practices that take place in NICU and recommendations that should be followed at home, should also be pointed out in the context of a trust relationship. This would therefore contribute to invalidate any wrong idea that parents might develop based on what they observed during their infant's stay in NICU [45]. Additionally, according to Patton *et al.*, the uniformity of actions across all informed healthcare professionals will make parents less confused about the best practices to reduce SIDS [39].

In the Portuguese context, doctors are in contact with parents during pregnancy consultations. However, in the period immediately after the delivery, the relationship between healthcare professionals and parents is mostly centered on nurses. Hence, nurses should be the focus of SIDS prevention campaigns, targeting healthcare professionals. This is reinforced by data from this study, which reveals that doctors are more likely to have less correct knowledge about SIDS risk factors than nurses, and also to give worse recommendations about the safest sleep position. However, this should not exempt doctors from the responsibility of instructing parents about SIDS risk factors, a preventive action that should begin during the prenatal period because some risk factors happen at this time (*e.g.* maternal smoking during pregnancy). Furthermore, general practitioners working in health centers and pediatricians can also play a key role in the prevention of this syndrome, as they are usually the ones with the earliest contact with parents after they leave the hospital.

Our results show that there are still too many healthcare professionals (29.2%) that believe that the lateral position lowers or does not affect the risk of SIDS. 6.2% of them consider that this is the safest position to prevent SIDS, while 4.4% believe that both supine and lateral positions are the safest to prevent SIDS. Furthermore, there is a non-negligible share of healthcare professionals (9.7%) recommending the lateral position to parents. This is probably due to the fact that, before proving that the supine position was the most effective in reducing the risk of SIDS, there was a belief that the lateral position was the best position to reduce the risk of aspiration in case of vomiting [47].

The questions regarding the “feet to foot” position seems to be the one with the highest rate of wrong answers. In fact, only 18% of parents and 14.2% of healthcare professionals recognized that putting infants to sleep in the “feet to foot” position does not reduce the risk of SIDS. However, 40.3% of parents and 67.9% of healthcare professionals believe that this position is related with a decrease in the risk of SIDS, which could be explained by the idea that this position can be associated with prevention of head covering. However, this was never proved to be a protective factor since it does not prevent the infant from turning to the side and consequently, getting covered by blankets if the crib is wide enough [33].

Although the majority of parents and healthcare professionals answered the item on bed sharing correctly, the same did not happened with the item about room sharing, with only 41.0% of parents and 40.7% of healthcare professionals answering that this is a protective factor for SIDS. Furthermore, only 17.3% of parents knew that room temperature should be maintained below 20°C/68°F. These questions concerning the sleep position and conditions of the infant are the ones for which more wrong answers were observed and should thus be kept in mind when planning eventual SIDS prevention campaigns.

A similar study carried out by de Luca, Gómez-Durán, and Arimany-Manso in 2012/2013 involved 552 healthcare professionals from three out of four provinces in Catalonia, Spain [37]. Although the participants involved and the delivery process of the questionnaires were different (pediatricians were the target group and both mail and email were used to deliver the questionnaires), some comparisons can be made. Overall, 94% of the respondents self-perceived themselves as qualified to give advice about SIDS to parents and only 58% considered the supine position as the safest to prevent SIDS. These numbers are quite different from the ones in this study, with healthcare professionals feeling less qualified to give advice about SIDS (53.1%) but with many more of them (82.3%) recognizing the supine position as the safest in preventing SIDS [37]. The results of the studies previously carried out in Portugal date back more than

10 years and assessed the awareness about SIDS among healthcare professionals and parents separately. In the study conducted by Ferreira *et al.* in 2004, only 16% of healthcare professionals recognized the supine position as the safest to prevent SIDS [42]. In the study by Fernandes *et al.*, only 30% of mothers stated that they put infants to sleep in the supine position, and generally lacked knowledge about SIDS risk factors [11]. To our knowledge, this is the first study to concomitantly analyze the knowledge of parents and healthcare professionals about SIDS in Portugal.

However, this study has some limitations. Questionnaires were handed out two to three times per week for almost 3 months and most parents agreed to participate. Nonetheless, it was not possible to obtain an accurate response rate for parents because the number of parents that decided not to fill out the questionnaire was not noted. We attempted, however, to estimate these numbers based on the number of births per year in the center (approximately 2600 births per year, including twins) and the frequency of delivery of the questionnaires. This led to a total of approximately 210 questionnaires, which is very close to the 204 questionnaires filled out. But this is only an estimate. The short period of time for the delivery of the questionnaires and the fact that this study was carried out in a single center makes it impossible to generalize the results of the whole target population. Furthermore, pediatricians had to be excluded from the study for logistic reasons, although including them would have provided additional interesting information as they play a relevant role in the prevention of SIDS. It should also be mentioned that not all risk factors for SIDS were included in the questionnaire. It is well-known that the use of a pacifier and the immunization of infants reduce the risk of SIDS, and that the consumption of alcohol and illicit drugs during pregnancy increase it. However, these behaviors were excluded from the questionnaires during the item selection phase. Finally, we were able to observe some imbalance in terms of participants' gender, as most of the respondents, in both groups, were women. This could be partially structural, as most of the time fathers are not present in the hospital ward and most of healthcare professionals in this medical branch are women. Nonetheless, we could not assess if this distribution was an accurate representation of the one in the underlying population.

To conclude, healthcare professionals are not as well informed about SIDS as we would like them to be. Furthermore, and possibly due to their self-awareness, they have little confidence in discussing SIDS-related issues. This study highlights the paramount importance of ensuring that their training on this topic is up-to-date, especially due to their crucial role of (partial) gatekeepers of this information for parents. In this way, they could effectively pass on to parents the correct messages about SIDS

prevention, and consequently contribute to a decrease in the number of SIDS cases.

Therefore, we believe that more studies, similar to this one are needed in order to assess the knowledge of pediatricians and family doctors about SIDS, since they also have direct contact with parents in the early months of their children's lives. Furthermore, studies on the effectiveness of training programs for healthcare professionals in terms of SIDS prevention, should also be carried out. In both cases, we would recommend the use of representative samples in order to be able to generalize the findings to bigger populations.

REFERENCES

- Willinger M, James LS, Catz C. Defining the sudden infant death syndrome (SIDS): deliberations of an expert panel convened by the National Institute of Child Health and Human Development. *Pediatr Pathol*. 1991 Sep-Oct;11(5):677–84.
- Kinney HC, Thach BT. The sudden infant death syndrome. *N Engl J Med*. 2009 Aug;361(8):795–805.
- Alfelali M, Khandaker G. Infectious causes of sudden infant death syndrome [Internet]. *Paediatr Respir Rev*. 2014 Dec;15(4):307–11.
- Moon RY, Darnall RA, Feldman-Winter L, Goodstein MH, Hauck FR; TASK FORCE ON SUDDEN INFANT DEATH SYNDROME. SIDS and other sleep-related infant deaths: evidence base for 2016 updated recommendations for a safe infant sleeping environment. *Pediatrics*. 2016 Nov;138(5):e20162940.
- Centers for Disease Control and Prevention. Sudden Unexpected Infant Death and Sudden Infant Death Syndrome [Internet]. 13 September. 2019. Available from: <https://www.cdc.gov/sids/data.htm>
- Tieder JS, Bonkowski JL, Etzel RA, Franklin WH, Gremse DA, Herman B, et al. Brief resolved unexplained events (formerly apparent life-threatening events) and evaluation of lower-risk infants. *Pediatrics*. 2016;137(5).
- Monnelly V, Becher JC. Sudden unexpected postnatal collapse [Internet]. *Early Hum Dev*. 2018 Nov;126:28–31.
- Guidelines for the Investigation of Newborn Infants who suffer a Sudden and Unexpected Postnatal Collapse. British Association of Perinatal Medicine. 2011.
- Maged M, Rizzolo D. Preventing sudden infant death syndrome and other sleep-related infant deaths. *JAAPA*. 2018 Nov;31(11):25–30.
- Harper RM. Sudden Infant Death Syndrome. *Encycl Respir Med Four-Volume Set*. 2006;370:132–4.
- Fernandes A, Fernandes C, Amador A, Guimarães F. Síndrome da morte súbita do lactente: o que sabem os pais? *Acta Pediátrica Port* [Internet]. 2012;43(2):59–62. Available from: <http://actapediatrica.spp.pt/article/view-File/1102/895>
- Knoema. Total infant mortality rate in Portugal - Sudden Infant Death Syndrome. 2015.
- Metis. Síndrome da Morte Súbita no Lactente. 2018.
- Instituto Nacional de Estatística - Statistics Portugal. Estatísticas Vitais Nados-vivos, óbitos e casamentos decrescem em 2019 [Internet]. 2020. Available from: https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_destaques&DESTAQUESdest_boui=411265794&DESTAQUESmodo=2
- Moon RY, Darnall RA, Feldman-Winter L, Goodstein MH, Hauck FR. SIDS and other sleep-related infant deaths: Updated 2016 recommendations for a safe infant sleeping environment. *Pediatrics*. 2016;138(5). <https://doi.org/10.1542/peds.2016-2940>.
- Dowling DA, Barsman SG, Forsythe P, Damato EG. Caring about Premies' Safe Sleep (CaPSS): An Educational Program to Improve Adherence to Safe Sleep Recommendations by Mothers of Preterm Infants. *J Perinat Neonatal Nurs*. 2018 Oct/Dec;32(4):366–72.
- Randall B, Thompson P, Wilson A. Racial differences within subsets of Sudden Unexpected Infant Death (SUID) with an emphasis on asphyxia [Internet]. *J Forensic Leg Med*. 2019 Feb;62(62):52–5.
- Saugstad OD. 50 Years Ago in The Journal Of Pediatrics: Sudden Unexpected Death in Infancy: A Statistical Analysis of Certain Socioeconomic Factors [Internet]. *J Pediatr*. 2018 Sep;200(September):149.
- Nunes ML, Pinho AP, Aerts D, Sant'Anna A, Martins MP, Costa JC. [Sudden infant death syndrome: clinical aspects of an underdiagnosed disease]. *J Pediatr (Rio J)*. 2001 Jan-Feb;77(1):29–34.
- Campuzano O, Beltramo P, Fernandez A, Iglesias A, García L, Allegue C, et al. Molecular autopsy in a cohort of infants died suddenly at rest [Internet]. *Forensic Sci Int Genet*. 2018 Nov;37:54–63.
- Machaalani R, Say M, Waters KA. Serotonergic receptor 1A in the sudden infant death syndrome brainstem medulla and associations with clinical risk factors. *Acta Neuropathol*. 2009 Mar;117(3):257–65.
- Opdal SH, Vege A, Rognum TO. Serotonin transporter gene variation in sudden infant death syndrome. *Acta Paediatr*. 2008 Jul;97(7):861–5.
- Garcia AJ 3rd, Koschnitzky JE, Ramirez JM. The physiological determinants of sudden infant death syndrome [Internet]. *Respir Physiol Neurobiol*. 2013 Nov;189(2):288–300.
- de Luca F, Hinde A. Effectiveness of the 'Back-to-Sleep' campaigns among healthcare professionals in the past 20 years: a systematic review. *BMJ Open*. 2016 Sep;6(9):e011435.
- de Pediatria SP. Proposta de consenso para a redução do risco de SMSL [Internet]. 2009. Available from: <https://www.spp.pt/noticias/default.asp?IDN=116&op=2&ID=132>
- Blair PS, Fleming PJ, Smith IJ, Platt MW, Young J, Nadin P, et al. Babies sleeping with parents: case-control study of factors influencing the risk of the sudden infant death syndrome. CESDI SUDI research group. *BMJ*. 1999 Dec;319(7223):1457–61.
- Vennemann MM, Bajanowski T, Brinkmann B, Jorch G, Yücesan K, Sauerland C, et al.; GeSID Study Group. Does breastfeeding reduce the risk of sudden infant death syndrome? *Pediatrics*. 2009 Mar;123(3):e406–10.
- Hauck FR, Thompson JM, Tanabe KO, Moon RY, Vennemann MM. Breastfeeding and reduced risk of sudden infant death syndrome: a meta-analysis. *Pediatrics*. 2011

- Jul;128(1):103–10.
29. Horne RS, Hauck FR, Moon RY, L'hoir MP, Blair PS; Physiology and Epidemiology Working Groups of the International Society for the Study and Prevention of Perinatal and Infant Death. Dummy (pacifier) use and sudden infant death syndrome: potential advantages and disadvantages. *J Paediatr Child Health*. 2014 Mar;50(3):170–4.
 30. Scheers NJ, Rutherford GW, Kemp JS. Where should infants sleep? A comparison of risk for suffocation of infants sleeping in cribs, adult beds, and other sleeping locations. *Pediatrics*. 2003 Oct;112(4):883–9.
 31. Vennemann MM, Höffgen M, Bajanowski T, Hense HW, Mitchell EA. Do immunisations reduce the risk for SIDS? A meta-analysis. *Vaccine*. 2007 Jun;25(26):4875–9.
 32. Mitchell EA, Thompson JM, Becroft DM, Bajanowski T, Brinkmann B, Happe A, et al. Head covering and the risk for SIDS: findings from the New Zealand and German SIDS case-control studies. *Pediatrics*. 2008 Jun;121(6):e1478–83.
 33. Mitchell EA. Recommendations for sudden infant death syndrome prevention: a discussion document. *Arch Dis Child*. 2007 Feb;92(2):155–9.
 34. NHS. Sudden infant death syndrome (SIDS) [Internet]. 2018. Available from: <https://www.nhs.uk/conditions/sudden-infant-death-syndrome-sids/>
 35. Boccuzzo G, De Luca F. Sudden infant death syndrome: knowledge of its risk factors among Italian healthcare professionals. *Electron J Appl Stat Anal*. 2012;5(3):374–80.
 36. De Luca F, Boccuzzo G. General Practitioners' familiarity with Sudden Infant Death Syndrome in the UK: the results of the SIDS project. *Stat Appl*. 2017;29(1):29–47.
 37. de Luca F, Gómez-Durán EL, Arimany-Manso J. Paediatricians' Practice About SUDDEN Infant Death Syndrome in Catalonia, Spain. *Matern Child Health J*. 2017 Jun;21(6):1267–76.
 38. Keller K. American Academy of Pediatrics. *Encycl Obes*. 2014;111(4).
 39. Patton C, Stiltner D, Wright KB, Kautz DD, Ikuta L, Zukowsky K. Do nurses provide a safe sleep environment for infants in the hospital setting? An integrative review. *Adv Neonatal Care*. 2015 Feb;15(1):8–22.
 40. Bartlow KL, Cartwright SB, Shefferly EK. Nurses' knowledge and adherence to sudden infant death syndrome prevention guidelines. *Pediatr Nurs*. 2016 Jan-Feb;42(1):7–13.
 41. De Luca F, Boccuzzo G. What do healthcare workers know about sudden infant death syndrome?: the results of the Italian campaign "GenitoriPiù.". *J R Stat Soc Ser A Stat Soc*. 2014;177(1):63–82.
 42. Ferreira M, Gomes A, Pinto EM. Síndrome da morte súbita do lactente. Estaremos mesmo a prevenir? *Saúde Infantil*. 2004;26(1):13–22.
 43. Strömberg Celind F, Wennergren G, Möllborg P, Goksör E, Alm B. Area-based study shows most parents follow advice to reduce risk of sudden infant death syndrome. *Acta Paediatr*. 2017 Apr;106(4):579–85.
 44. Colson ER, Levenson S, Rybin D, Calianos C, Margolis A, Colton T, et al. Barriers to following the supine sleep recommendation among mothers at four centers for the Women, Infants, and Children Program. *Pediatrics*. 2006 Aug;118(2):e243–50.
 45. Esposito L, Hegyi T, Ostfeld BM. Educating Parents About the Risk Factors of Sudden Infant Death Syndrome The Role of Neonatal Intensive Care Unit and Well Baby Nursery Nurses. *J Perinat Neonatal Nurs*. 2007;21(2):158–64.
 46. Pease A, Ingram J, Blair PS, Fleming PJ. Factors influencing maternal decision-making for the infant sleep environment in families at higher risk of SIDS: a qualitative study. *BMJ Paediatr Open*. 2017 Sep;1(1):e000133.
 47. Jones SF. SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment. *Yearbook Pulm Dis [Internet]*. 2012;2012:197. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S8756345212000862>