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FMUP FACULDADE DE MEDICINA
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Sara Catarina Fernandes

Síndrome da Morte Súbita no Lactente: o
que sabem os profissionais de saúde e os pais
sobre a sua prevenção / *Sudden Infant Death
Syndrome: What healthcare professionals and
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Faculdade de Medicina da Universidade do Porto, 27/02/2020

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TÍTULO DISSERTAÇÃO/MONOGRAFIA (riscar o que não interessa)

Sudden Infant Death Syndrome: What healthcare professionals and parents know about how to prevent it

ORIENTADOR

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Gostaria de dedicar este trabalho a todos os que estiveram ao meu lado durante estes 6 anos.

Aos meus pais e à minha irmã Mimi.

Aos meus tios Conceição e Augusto e aos meus primos.

A todos os amigos que a faculdade me deu.

Aos amigos que já me acompanhavam antes da faculdade, especialmente as cinco amigas de sempre.

Sem eles não teria chegado aqui com o mesmo sentido de realização que sinto agora.

**Sudden Infant Death Syndrome: What healthcare professionals and parents know about
how to prevent it**

Sudden Infant Death Syndrome Prevention

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Abbreviations: SIDS – Sudden Infant Death Syndrome; CHUSJ – Centro Hospitalar Universitário São João; SUID - Sudden Unexpected Infant Death; ASSB - Accidental Suffocation and Strangulation in Bed; ALTE - Acute Life-Threatening Event; SUPC - Sudden Unexpected Postnatal Collapse; BTS – Back to Sleep; SPP - Sociedade Portuguesa de Pediatria

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Abstract

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 including necropsy. In developed countries, SIDS is the first cause of mortality in the first year of life, excluding the neonatal period (first 28 days), and is the third leading cause of infant death in the world. Risk factors related to SIDS have already been identified, most of them related with the infant's sleep position and environment.

Objective: This study aims at assessing the knowledge about SIDS risk factors of parents of infants born in the Centro Hospitalar Universitário São João (CHUSJ) and of healthcare professionals in care of new-borns in the same hospital.

Materials and Methods: This study used two structured self-administered questionnaires aiming at evaluating the knowledge of parents and healthcare professionals about SIDS prevention and its risk factors.

Results: Overall, 67.7% of parents and 100% of healthcare professionals know what SIDS stands for. Besides, 82.3% of healthcare professionals and 47.5% of parents recognized the supine position as the safest sleep position 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 7 questions were correctly answered by the majority of respondents.

Discussion and Conclusion: Healthcare professionals are not as well informed about SIDS as they should and have little confidence in discussing SIDS-related issues. This highlights how crucial the training of healthcare professionals about this topic is, and that their role of (partial) gatekeepers of this information for parents should be strengthened with appropriate support to 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. [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 together with 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 important definition is Acute Life-Threatening Event (ALTE), that is the collapse of an infant that requires at least one hour of ventilation [6] or Sudden Unexpected Postnatal Collapse (SUPC). This 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 (first 28 days), and is the third leading cause of infant death in the world. [9] Although this syndrome mortality rate decreased in the 1990's, it has not been decreasing in the recent years. Countries such as Japan, the United States, the United Kingdom and New Zealand reported rates of 0.8, 0.57, 0.41, and 0.09 deaths per 1000 livebirths, respectively. [10] However, 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 0.1 to 0.2 deaths per 1000 livebirths, with the lower limit obtained from data reported to Eurostat in 2015 (notoriously underestimating this type of cause of death) and the higher limit suggested by the University of Porto. [12,13]

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. [14] These can be broadly grouped in two groups: factors related to the context of the infants and factors related to the behaviour of their parents.

In the first group there is prematurity, as SIDS is responsible for more than double the rate of deaths of preterm infants born before 37 weeks of gestation when compared to term infants. [15] Furthermore, ethnicity differences have been reported, since more non-caucasian infants die from SIDS compared to caucasian infants. However, scientists believe that this does not happen because of inherent racial population differences, since both rates for caucasians and non-caucasians show a downward trend. [16] The socioeconomic and educational status of the families also determined some differences in the rate of SIDS, since this was observed to be higher in families with poorer education and socioeconomic status. [17] Multiparity, single mothers, young mothers and mothers with few educational qualifications were all associated with an increased risk of SIDS, together with absence of perinatal care. [18] Although there is no strong evidence of a heritable contribution to SIDS, some genetic factors were proven to be responsible for the deaths of infants dying with SIDS, however, the percentage of SIDS deaths affected by these anomalies is still unknown. A study conducted by Campusano 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. [19] 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 gene alterations of importance in the pathophysiology of SIDS are associated with sodium and potassium channelopathies in the cardiac muscle that result in long QT syndrome. Other 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 development. [20–22]

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. These campaigns, often called “Back-to-Sleep” (BTS), promoted this position for infants to sleep, and led to decreases in SIDS mortality rate where they were carried out. For example, in the United States SIDS rate showed a reduction of 53% during the 10 years after the implementation of the first BTS campaign in 1992 (from 120 to 56 deaths over 100000 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 behaviours. [23] In Portugal, no BTS campaigns have ever been implemented. Nevertheless, in 2009 the Sociedade Portuguesa de Pediatria (SPP) elaborated recommendations for parents on how 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. [24]

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, potentially leading 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 and bed sharing, especially with smoking individuals, is also in the risk factors list for SIDS,

since a smoking environment is also related to SIDS, both before and after the birth of the infant. The same rule applies to the use of illicit drugs and alcohol during pregnancy. Even though bed sharing, especially when the infant is aged less than four months old 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. [14,25] The "feet to foot" position, where bedding is made up in a way that the infant's feet reach the foot of the crib, although considered an attractive idea to protect against SIDS since it reduces the chances of head covering, has not been proven to reduce the risk of this syndrome, even though the 2000, 2004 and 2005 United Kingdom Department of Health recommendations for SIDS prevention considered this a protective factor. [26]

Some protective factors appear to be connected with the decrease of the risk of postnatal mortality. Several studies showed that breastfeeding is considered a protective factor against SIDS and ideally infants should be exclusively breastfed for the first six months of life since the effect of breastfeeding is even stronger when done exclusively. An analysis of the German Study of Sudden Infant Death conducted by Vennemann revealed that breastfeeding can reduce the risk of SIDS by 50%. Independently of its duration, breastfeeding leads to a lower wake-up threshold compared to artificial milk nutrition and confers maternal immunoglobulins and cytokines that help in the prevention of infections, which are thought to be associated with increased risk of SIDS. [27,28] The use of a pacifier is also considered a protective factor for SIDS when it is offered to infants older than 3-4 weeks if breastfed (and only once breastfeeding is well established), or immediately after birth to bottle-fed infants. [29] Moreover, it was demonstrated that immunization of infants reduces in half the risk of SIDS. [30] The use of cardiorespiratory surveillance monitors could 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 showing that this equipment can reduce the number of deaths caused by SIDS. [31]

Numerous studies focusing on the knowledge about SIDS and recommendations made in the hospital setting of healthcare professionals were executed internationally. [32–37] The implementation of BTS campaigns over the past 20 years have 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 as the one with more benefits in reducing the incidence of SIDS. However, in parallel, the percentage of healthcare professionals aware that any non-prone position is associated with less risk of SIDS than prone position decreased over time. Contextually, campaigns focusing on changing the sleep position of infants from prone or lateral to supine in several countries revealed an immediate reduction of postnatal mortality rates by up to 50%. [23] There is not much information about the knowledge of parents and health professionals about the prevention of SIDS in Portugal, nor evidence of a validated questionnaire to assess this topic. In 2007, Fernandes et al. conducted a study where 44 questionnaires were administered in the Child Health/Pediatrics practices of two health centres in Lisbon to mothers of babies aged between 29 days and 12 months 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 lead by Ferreira et al. in 2004 analysed 150 healthcare providers and pre-

school caregivers in two health centres and one nursery in Vila Nova de Gaia, and proved that healthcare and educational professionals lacked valid and recent information about SIDS. [38] These studies, conducted more than ten years ago, suggest 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 information on whether campaigns were implemented after the negative results of these studies.

Therefore, this study aims at assessing the knowledge about SIDS risk factors of parents of infants born in the Centro Hospitalar Universitário São João (CHUSJ), and of healthcare professionals caring for new-borns during their stay in the same hospital.

Materials and Methods

This study used two structured self-administered questionnaires aiming at evaluating the knowledge of parents and healthcare professionals about SIDS prevention and its risk factors. Both instruments were based on the questionnaire constructed by Federico de Luca in the context of a cross-country survey in the early 2010s. This questionnaire has already been administered in Spain and the United Kingdom, and built upon the experience of a previous instrument used for a national healthcare campaign in Italy. [34,36]

The questionnaires for parents and healthcare professionals are similar and gather information on participants' knowledge about SIDS and about 13 of its risk factors. Furthermore, they also collect 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 healthcare professionals' questionnaire had some additional questions concerning specific medical knowledge about SIDS and the recommendations that they provided to parents during their hospital work.

The questionnaires for parents were delivered by hand to mothers and fathers of babies born in the Obstetrics and Neonatology wards of CHUSJ hospital between 30 June, 2019 and 27 September, 2019. During the same period, questionnaires were handed out to healthcare professionals working in the Obstetrics, Gynecology and Neonatology wards of CHUSJ. In this hospital, there are approximately 2600 births per year, of which about 400 are admitted in 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 since we were interested in surveying both specialists and interns, and the latter will often do internships also in the Gynecology ward. 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 participated in the study because some questionnaires were administered during ward meetings, which are also attended by emergency unit nurses. In total, the population of health care 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. T-tests were used to compare parents and healthcare professionals in terms of continuous variables, while Kruskal-Wallis tests were used when the variables of interest were ordinal. All statistical analyses were performed in STATA.

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 42 years old, 71 were nurses and 40 were doctors. Of these, 78 had a specialty in Obstetrics and Gynecology or in Paediatrics and Neonatology. 74 respondents had children, and 25 of these had children of less than 5 years. The average seniority of the respondents was of 18 years. [Table 1]

Overall, 138 parents (67.7%) and 113 healthcare professionals (100%) stated that they knew about SIDS and thus continued with the rest of the questionnaire. Parents stated that their main sources of information about SIDS were the Internet (53.7%), nurses (34.5%) and doctors (25.9%). Among healthcare professionals, the majority stated that they got their information about SIDS during university courses (86.7%). Less relevant sources of information for them were the Internet (15.9%) and work experience (10.6%). Few respondents (3 parents and 11 healthcare professionals) had a direct experience with a case of SIDS. The vast majority of parents rated their knowledge level about SIDS and its risk factors as moderate (42.5%) and low or very low (43.9%), while healthcare professionals were more distributed between high or very high (30.1%), moderate (48.7%) and low or very low (21.2%). The confidence to discuss SIDS-related issues was also self-assessed by parents and healthcare professionals. Similarly, to the self-assessment of their knowledge, the majority of parents described their confidence as moderate (39.6%) and low or very low (47.5%). Healthcare professionals, instead, were more evenly distributed between high or very high (21.2%), moderate (46.9%) and low or very low (31.9%). [Table 2] Healthcare professionals had both a higher self-perceived knowledge about SIDS and a higher confidence in discussing it than parents ($p < 0.001$ and $p = 0.003$, respectively).

When asked about the sleep position associated with the lowest risk of SIDS, 82.3% of healthcare professionals and only 47.5% of parents recognized the supine position as the safest

sleep position to prevent SIDS. Furthermore, the majority of healthcare professionals (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, the majority of healthcare professionals (46.9%) reported giving recommendations to parents about SIDS prevention more than once a week, while 53.1% of them considered themselves as qualified to advise parents about SIDS and its risk factors. [Table 3]

Tables 4a and 4b show the responses given by parents and healthcare professionals about SIDS risk factors. For each of the 13 questions about SIDS risk factors, the majority of healthcare professionals identified the correct answer, with the exception of the items about the “feet to foot” position (where only 14.2% responded correctly) and room sharing (40.7%). However, among parents, only 7 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.

The proportion of correct answers to the 13 questions about SIDS risk factors is presented in table 5 for both parents and healthcare professionals. Only 37.2% of the healthcare professionals and 8.7% of the parents responded correctly to 75% or more of the 13 questions about SIDS’ risk factors. Healthcare professionals have, on average, a higher knowledge about SIDS risk factors than parents ($p < 0.001$).

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, that can be seen in table 6. It emerged that healthcare professionals with children aged 5 or less are more likely to have stronger knowledge about SIDS risk factors than the other respondents ($p = 0.032$). Additionally, we found that doctors are more likely to have less correct knowledge about SIDS risk factors, and to give worse recommendations about the safest sleep position than nurses ($p = 0.028$ and 0.012 , respectively).

Discussion

In this study, we assessed the knowledge of parents and healthcare professionals about SIDS risk factors and its prevention. Since the majority of the risk factors is associated with preventable actions, informing parents better about SIDS prevention should help reduce its incidence. This becomes even more relevant given that our results show that there is still a great share of parents that have never heard of SIDS before (31.8%). 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, and there was about 15% of healthcare professionals who reported not recommending the best sleep position to parents. This is very relevant, because healthcare professionals are one of the most significant vectors to inform parents about this topic (for more than 60% of parents), and should pass on the right message.

A possible solution to this lack of knowledge among parents could be to organize campaigns and workshops in order to inform them about SIDS risk factors. However, these campaigns are generally very complex to implement, due to the high number and diversity of the target group. On the other hand, campaigns aimed at better informing healthcare professionals, and reinforcing their role in the prevention of SIDS through their relationship with parents, should lead to results that would last over time and still result in increasing 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 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 recommendations' follow-up as the infants get older. Other recommendations showed satisfying results, such as 83.1% of infants being breastfed and 84.1% using a pacifier. [39] 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 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. This study 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. [40] Additionally, according to Carla Patton et al., the uniformity of actions across all informed healthcare professionals will make parents less confused about the best practices to reduce SIDS. [32,41]

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 the parents is mostly centred on nurses. Hence, since nurses represent the category of healthcare professionals that has more contact with parents during their stay in the hospital after delivery, they should be the focus of SIDS prevention campaigns targeting healthcare professionals. Also, data from this study reveals that doctors are more likely to have less correct knowledge about SIDS risk factors, and to give worse recommendations about the safest sleep position than nurses, which again reveals the importance of nurses in the transmission of this important message to parents which should be done as early as possible, since this syndrome occurs during the earlier months of life of the newborn. However, this should not exempt doctors from the responsibility of instructing parents about SIDS risk factors, a preventive action that should begin in the prenatal period because some risk factors happen during this time (e.g. maternal smoking during pregnancy). Besides, general practitioners working in health centres and pediatricians other than neonatologists 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. In our study, only 61.9% of parents and 77.0% of healthcare professionals responded that smoking during pregnancy increases the risk of SIDS. This is quite

concerning, as both parents and healthcare professionals should be more aware of the harm that tobacco produces in the organism.

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. Furthermore, 6.2% of them consider that this is the safest position to prevent SIDS, while 4.4% admit both supine and lateral positions as the safest to prevent SIDS. These numbers are even higher in parents, with 23.7% of them considering the lateral position as the safest. Besides, there is a non-negligible share of healthcare professionals (9.8%) recommending this 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. [42]

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 recognised that putting infants to sleep in the “feet to foot” position does not affect 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 to turn to the side and consequently get covered by blankets if the crib is wide enough. [26]

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% 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. These questions concerning the sleep position and conditions of the infant are the ones where more wrong answers were observed, and should thus be kept in mind when planning eventual SIDS prevention campaigns.

A similar study by de Luca, Gómez-Durán and Arimany-Manso involved 552 healthcare professionals from three different cities in Catalonia region in Spain. [36] Although the participants involved and the questionnaires’ delivery process was differently (pediatricians and via mail and email delivery), 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, representing numbers quite different from the ones in this study, with 53.1% of healthcare professionals considering themselves confident enough to discuss SIDS related topics and 82.3% recognizing the supine position as the safest in preventing SIDS. [36] Two studies were carried out in Portugal to assess the awareness about SIDS among healthcare professionals and parents separately. In the study conducted by Ferreira et al. in 2004, 47 doctors and 52 nurses from one health centre and one hospital, and also 65 educational professionals from a nursery, all in Vila Nova de Gaia participated. Only 16% of the participants in the study recognized the supine position as the safest to prevent SIDS and the authors concluded that healthcare and educational professionals lack information about this topic. [38] The study by Fernandes et al. applied to 44 infants’

mothers showed that only 30% put the infants to sleep in the supine position and that generally mothers lacked knowledge about SIDS risk factors. [11] To our knowledge, this study is the first to be conducted in Portugal that analyses concomitantly the knowledge of both parents and healthcare professionals.

Limitations

This study has some limitations. Questionnaires were handed out two to three times per week during almost three 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 in the questionnaire was not noted. We did try, however, to estimate this number based on the number of births per year in the hospital (approximately 2600 births per year, including twins) and the frequency of questionnaires delivery. 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 centre makes it impossible to generalize the results of whole target population. Furthermore, pediatricians other than neonatologists were not included in the study, which contributed to making the sample of healthcare professionals smaller. Although we consider them as an essential part in the prevention of SIDS, we opted not to include them in the study for logistic reasons. 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 the 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.

Conclusion

In conclusion, healthcare professionals are not as well informed about SIDS as we would like them to be and possibly due to their self-awareness of this, they have little confidence in discussing SIDS-related issues. This highlights how crucial the training of healthcare professionals about this topic is, and that their role of (partial) gatekeepers of this information for parents should be strengthened with appropriate support. 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 cases.

Therefore, we believe that more similar studies are needed in order to assess the knowledge of pediatricians and family doctors about SIDS, since they are an integral part of the group of healthcare professionals that have direct contact with parents in the early months of their children's lives. Furthermore, studies on the effectiveness of healthcare professionals training programs 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.

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Tables

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 speciality in Obstetrics and Gynecology or Pediatrics and Neonatology, n (%)	
Yes	78 (69.0)
No*	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)

* It includes intern doctors that don't have completed a speciality yet

Table 2: Parents' and healthcare professionals' answers regarding knowledge about SIDS, source of information, a direct experience with a case of SIDS, the safest sleep position.

	Parents (n=204 for the first question, n=139 for the rest of the table)	Healthcare Professionals (n=113)
Knows what SIDS is, n (%)	138 (67.7)	113 (100.0)
Unknown	1 (0.5)	0 (0.0)
Source of information, n (%) *		
Doctor	36 (25.9)	-
Nurse	48 (34.5)	-
Internet	76 (53.7)	18 (15.9)
University course	-	98 (86.7)
Work experience	-	12 (10.6)
Other	35 (25.2)	16 (14.2)
Unknown	1 (0.7)	4 (3.5)
Had a direct experience with a case of SIDS, n (%)	3 (2.2)	11 (9.7)
Self-perceived knowledge level about SIDS and its risk factors, n (%)		
Very high - High	18 (13.0)	34 (30.1)
Moderate	59 (42.5)	55 (48.7)
Low - Very low	61 (43.9)	24 (21.2)
Unknown	1 (0.7)	0 (0.0)
Confidence to discuss SIDS related issues, n (%)		
Very high - High	15 (10.8)	24 (21.2)
Moderate	55 (39.6)	53 (46.9)
Low - Very low	66 (47.5)	36 (31.9)
Unknown	3 (2.2)	0 (0.0)

* Participants could give more than one answer

Table 3: 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)

Table 4a: Parents' answers to the effect of different behaviours 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 4b: Healthcare professionals' answers to the effect of different behaviours 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 5: Distribution of respondents in terms of percentage of correct answers given to the 13 items about SIDS risk factors

Proportion of correct answers	Group of respondents	
	Parents, n (%)	Healthcare professionals, n (%)
25% or less	31 (22.5)	5 (4.4)
25 - 50%	56 (40.6)	16 (14.2)
50 - 75%	39 (28.3)	50 (44.3)
75% or more	12 (8.7)	42 (37.2)
Total	138 (100.0)	113 (100.0)

Table 6: 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)

Agradecimentos

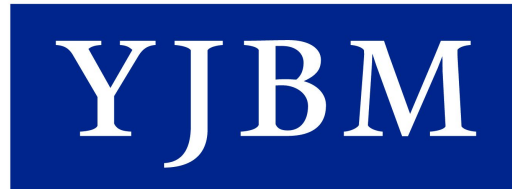
Concluída esta dissertação, resta-me expressar os meus mais sinceros agradecimentos a todas as pessoas envolvidas que possibilitaram a realização da mesma.

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If human or animal subjects were used, either a) state that your institutional review board/ethics committee has approved the experiment and provide reference numbers as appropriate; b) state that IRB approval was not required and explain why; or c) if your institution does not have an IRB, state that the Declaration of Helsinki (<http://www.wma.net/e/policy/pdf/17c.pdf>) was followed. If informed consent was required, describe how it was obtained in the Methods section and include a copy of the informed consent form used.

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These should be on a separate page after the main body of the manuscript but before the References. Please do not put footnotes in the footer of the document. All footnotes in the main body of the text should be indicated by a superscript Arabic numeral in the order they appear in the text. The section should be clearly labelled “Footnotes” in bold and aligned to the left hand side of the document.

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References must appear after the main body of the manuscript after any footnotes that are included. References must be started on a new page and clearly marked as “References.” This title must be in bold and left justified. References must be double-spaced. If using citation software (i.e. EndNote), do not delete the field codes before sending the manuscript.

Our journal uses the format of the National Libraries of Medicine (http://www.nlm.nih.gov/bsd/uniform_requirements.html). Please cite references by sequential numbers as they appear in the text, using Arabic numbers in square brackets (e.g., [x]) on the line. References first cited in a table or figure legend should be numbered so they are in sequence with citations where the table or figure is first mentioned. Journal names should be abbreviated i.e. 'Journal of Pharmacology and Experimental Therapeutics' should be abbreviated as 'J Pharmacol Exp Ther.'

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1. Lee SH, Jung JY, Kim JC. Comparative Ocular Microbial Communities in Humans with and without Blepharitis. Invest Ophthalmol Vis Sci. 2012;53(9):5585–5593.
2. Peppercorn MA, Goldman P. The role of intestinal bacteria in the metabolism of salicylazosulfapyridine. J Pharmacol Exp Ther. 1972;181(3):555–562.

Please note if there are more than six authors for a particular reference please list the first six authors followed by et al.

Below is an example of how to reference a book:

1. Darnton R. Mesmerism and the end of the Enlightenment in France. Cambridge: Harvard University Press; 1968. p. 117.

Below is an example of how to reference a website or a report found online:

1. The Breast Cancer Research Foundation: Providing Critical Funding for Innovative Clinical and Genetic Research [Internet]. cited 2011. Jan 13. Available from: http://www.bcrfcure.org/action_accomplishments.html/.

FIGURES AND TABLES

Figures

Each figure must be submitted as an individual file, in either high resolution TIFF or JPEG format. Images in other file formats or embedded in documents such as Word or PowerPoint cannot be accepted. A resolution of at least 300 dpi will help ensure clear reproduction.

The name of the file should be named as such before being uploaded to Scholastica: the date submitted_last name of the first authors_Figure_x.TIFF/JPEG. For example: 06142011_Samji_Figure_1.JPEG.

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- To indicate levels of significance, use asterisks above each bar or portion of the figure. Define the level of significance in a footnote to the table (e.g., * $p < 0.05$). All p-values should be expressed as less or greater than one of the following levels: 0.25, 0.1, 0.05, 0.01, 0.001 (i.e., $p > 0.1$ or $p < 0.05$).
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All figure legends should be at the end of your document after the references. Figures must be interpretable from their legends without reference to the text. Do not include any details of methods in figure legends.

Begin legends with figure number, then title, both in bold. If several panels are present in the figure, label them as a, b, c, etc.

Provide a short description of each panel sequentially (**a.**, **b.**, etc.) and describe what symbols represent. When possible, include symbols in the legend (e.g., $[\leq]$ rather than “less than or equal to”). If error bars are included, specify what error they represent (standard deviation, SEM, etc.). If statistical significance is represented, define all asterisked symbols at the end of the figure legend.

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Each table should appear on a separate page at the end of your manuscript, after the references and figure legends. Each table should be one Word document page long. Include the title and table number above each table in bold. Each row and column requires a heading or title, with content (including units of measure) clearly indicated. Tables do not include legends; describe tables in the text as briefly as possible.

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Send a scanned copy of the letter in PDF format to Scholastica or forward the relevant message(s) to yjbm@yale.edu. Personal communications are cited in parentheses in the text and are not included in the references. *Example:* The protein is present at low abundance during embryogenesis (J. S. Smith, personal communication, 3.4.06).

Please direct all inquiries on manuscript submission to yjbm@yale.edu.