

# What do Carers Undertake to Reduce the Risk of Sudden Infant Death Syndrome?

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## Abstract

**Introduction:** Sudden infant death syndrome is a major cause of post-neonatal death in several countries. The aim of our study was to evaluate the carers knowledge and compliance regarding international recommendations for the prevention of sudden infant death syndrome.

**Methods:** Observational, transversal and analytical study through the analysis of anonymous survey applied to pregnant women and carers of children followed in a Family Health Unit.

**Results:** Of 163 eligible carers, 60 were included in the study. The mother filled out the survey in 51 (85%) cases. Sixteen (27%) carers had no previous knowledge on this matter, one (2%) disclosed smoking in the baby household or room and 41 (68%) placed the baby to sleep in supine position. Families with mothers over 30 years old ( $p = 0.043$ ), with employed parents ( $p = 0.026$ ) or with undergraduate diploma (father  $p = 0.016$ , mother  $p = 0.006$ ) placed the baby to sleep in supine position. When the mother was unemployed, she more frequently shared the bed with the baby ( $p = 0.047$ ). Overheating was a concern when the parents had better education (father  $p = 0.021$ , mother  $p = 0.031$ ).

**Discussion:** Younger parents, unemployed or with lower educational status did not follow the recommendations for the prevention of sudden infant death syndrome. Efforts should be done in order to raise awareness on sudden infant death syndrome.

**Keywords:** Infant Care; Health Knowledge, Attitudes, Practice; Parents; Portugal; Sleep; Socioeconomic Factors; Surveys and Questionnaires; Sudden Infant Death/prevention & control

## Introduction

Sudden Infant Death Syndrome (SIDS) is a major public health problem. In addition to being the leading cause of post-neonatal death in developed countries, it is a

devastating, tragic and unexpected event that remains unexplained even after detailed investigations of it.<sup>1,2</sup>

Its rate varies between 0.09 and 0.57 cases per 1,000 live births in countries like Japan and the United States of America (USA).<sup>1</sup> In Portugal, the incidence of SIDS remains unknown.

SIDS is more frequent in the male gender, between 2 and 4 months of life, and is rare during the neonatal period.<sup>1</sup>

The cause of SIDS remains unclear, but it appears to be multifactorial. The triple risk hypothesis argues that SIDS occurs in vulnerable infants (with specific brain, autonomic nervous system, metabolic or response to infection abnormalities) who are subject to a potentially asphyxiating or overheated environment (prone position and airway obstruction) during a critical phase of the development of the central nervous or immune systems and immaturity of the autonomic cardiorespiratory drive, culminates in the inability to wake up after progressive asphyxia, bradycardia, hypotension, metabolic acidosis and ineffective ventilation, leading to death.<sup>1-3</sup>

In the USA and Europe, in the 1990s, epidemiological studies showed that prone sleeping was an important risk factor.<sup>4-6</sup>

Table 1 presents the recommendations of the American Academy of Pediatrics for a safe environment for a sleeping infant,<sup>6</sup> also adopted by the Portuguese associations, which includes the avoidance of prenatal and postnatal smoke exposure, placement of infants in the supine position in their own cradle in the parents' room, avoiding overheating, with a firm mattress covered by a well-fitted sheet, no loose objects in the cradle and the use of a pacifier. Breastfeeding should be promoted as it is associated with a reduced risk of SIDS and its protective effect increases if it is exclusive up to 6 months of age.<sup>1,2,6-10</sup>

The implementation of these recommendations is known to significantly reduce the prevalence of SIDS. A number of developed countries have implemented awareness-raising campaigns on risk factors and practices associated with SIDS, following which there was a

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decrease in the incidence of SIDS by 53% and post-neonatal mortality by 39%.<sup>4-6</sup>

In Portugal, there are recommendations from the Portuguese Society of Paediatrics and the Portuguese Directorate-General of Health for the prevention of SIDS. However, awareness campaigns have not been carried out, and the level of knowledge of carers is not known. In addition, there is a shortage of methodologically robust studies on adherence to these measures in our country.<sup>7-9,11-13</sup>

This study aims to evaluate the knowledge of the recommendations for the prevention of SIDS and adherence by the carers, to analyse the attitudes and knowledge of carers regarding the international recommendations and to evaluate the factors associated with noncompliance with the recommendations.

## Methods

### Study population

Pregnant women expecting delivery during the study period and carers of children up to 12 months of age were followed in a maternal or child surveillance visit of a Portuguese Family Health Unit. The exclusion criteria included carers with difficulty understanding the Portuguese language and questionnaires with contradictory or incomplete answers.

### Study period

The data were collected from November 2016 to September 2017 through anonymous surveys applied during maternal or child surveillance visits in the Family Health Unit.

### Study design

Observational, transversal and analytical study based on an anonymous SIDS survey. The studied characteristics of the infants/children were sex, age, race, biometry, perinatal history (pregnancy and childbirth) and psychomotor growth and development. Regarding family history, the age of the parents, education, parity, profession and employment situation were collected. For the study of attitudes and knowledge of SIDS risk reduction, the variables studied were the place where the infant sleeps, the position in which the infant is put to sleep, the sharing of the bed with the parents to sleep and the presence of objects inside the cradle. The family was considered to be a single parent family when the infant lived most of the time with one of the parents and to be a large family when the infant lived with more than three relatives in the same house.

### Data collection

Before each maternal surveillance or child visit at the health unit, pregnant women and carers of children up to 12 months of age were asked to complete an anonymous SIDS survey. After an explanation of the study objectives, clarification of doubts was provided and free informed consent was signed, the subjects put the filled in survey in a sealed box. Later and regardless of the adherence of the carers to the completion of the survey, the carers were made aware of the actions that reduce the risk of SIDS and, at the end of the medical appointment, they received an information leaflet on the subject.

### Data analysis

Data were collected and encoded in Excel®, version 2011 (Microsoft Corporation, USA) for statistical treatment, supplemented with IBM SPSS® software, version 20 for Mac (SPSS, IL, USA).

**Table 1. American Academy of Pediatrics Recommendations for a Safe Infant Sleeping Environment**

#### A-level recommendations

Back to sleep for every sleep.

Use a firm sleep surface.

Room-sharing with the infant on a separate sleep surface is recommended.

Keep soft objects and loose bedding away from the infant's sleep area.

Pregnant women should seek and obtain regular prenatal care.

Avoid smoke exposure, alcohol and illicit drug use during pregnancy and after birth.

Breastfeeding is recommended.

Consider offering a pacifier at naptime and bedtime.

Avoid overheating.

Do not use home cardiorespiratory monitors as a strategy to reduce the risk of sudden infant death syndrome.

Expand national campaigns to reduce the risk of sudden infant death syndrome.

#### B-level recommendations

Vaccination according to the American Academy of Pediatrics guidelines.

Avoid the use of commercial devices that are inconsistent with safe sleep recommendations.

Supervised, awake tummy time is recommended to facilitate development and to minimize development of positional plagiocephaly.

#### C-level recommendations

Health care providers, staff in newborn nurseries and NICUs, and child care providers should endorse and model the sudden infant death syndrome risk-reduction recommendations from birth.

Media and manufacturers should follow safe sleep guidelines in their messaging and advertising.

Continue research and surveillance on the risk factors, causes, and pathophysiologic mechanisms of sudden infant death syndrome and other sleep-related infant deaths, with the ultimate goal of eliminating these deaths entirely.

Adapted from: American Academy of Pediatrics Task Force on Infant Positioning and SIDS. Pediatrics 1992;89:1120-6.<sup>3</sup>

Table 2. Characterisation of the study sample

<b>Filled surveys</b>	Mother n = 51 (85%) Father n = 9 (15%)
<b>Characterisation of the pregnant women n = 12</b>	
Gestational age	1st trimester n = 2 (17%) 2nd trimester n = 4 (33%) 3rd trimester n = 6 (50%)
Prenatal care	With prenatal care n = 12 (100%)
Smoke exposure	Yes n = 1 (8%) No n = 11 (92%)
Alcohol exposure	No n = 12 (100%)
Illicit drug use	No n = 12 (100%)
<b>Characterisation of infants n = 48</b>	
Age	Median 4 months, interquartile range (1.7), minimum 4 days, maximum 12 months 0-6 months n = 34 (71%) 7-12 months n = 14 (29%)
Gender	Male n = 23 (48%) Female n = 25 (52%)
Race	Caucasian n = 47 (98%) Other n = 1 (2%)
Pregnancy	
Gestational age	Term n = 43 (90%) Preterm (minimum 36 weeks) n = 5 (10%)
Twin	Two twin pairs
Adequate Prenatal care	Adequate care (at least 6 visits) n = 48 (100%)
Smoke exposure	Yes n = 2 (4%) No n = 46 (96%)
Alcohol exposure	Yes n = 1 (2%) No n = 47 (98%)
Illicit drug use	No n = 48 (100%)
Delivery	
Type	Normal n = 20 (42%) Caesarean section n = 12 (25%) Vacuum/Forceps n = 12 (25%) No response n = 4 (8%)
Birth weight	Mean 3054 g, minimum 2390 g, maximum 3970 g
National vaccination programme	Up to date n = 48 (100%)
Key-stage visits	All n = 46 (96%) Partial n = 2 (4%)
<b>Family history n = 60</b>	
Mother	
Age	Mean 32 years, minimum 22 years, maximum 40 years
Education	4th grade n = 0 (0%) 9th grade n = 5 (8%) 12th grade n = 16 (27%) Undergraduate degree or higher n = 39 (65%)
Profession (Graffar scale)	1st class n = 29 (48%) 2nd class n = 14 (23%) 3rd class n = 1 (2%) 4th class n = 14 (23%) 5th class n = 1 (2%) Not applicable n = 1 (2%)
Unemployed	Yes n = 4 (7%) No n = 56 (93%)
Smoker	Yes n = 2 (3%) No n = 58 (97%)
Father	
Age	Mean 34 years, minimum 25 years, maximum 49 years
Education	4th grade n = 1 (2%) 9th grade n = 10 (17%) 12th grade n = 19 (31%) Undergraduate degree or higher n = 30 (50%)
Profession (Graffar scale)	1st class n = 26 (43%) 2nd class n = 11 (18%) 3rd class n = 1 (2%) 4th class n = 14 (23%) 5th class n = 2 (4%) Not applicable n = 6 (10%)
Unemployed	Yes n = 4 (7%) No n = 56 (93%)
Smoker	Yes n = 16 (27%) No n = 44 (73%)
Siblings	None n = 43 (71%) One n = 16 (27%) Two n = 1 (2%)
Close relative death with up to 12 months of age	n = 2 (4%) - cousin and sibling No answer as to the cause of death
Household	
Rooms	Two n = 15 (25%) Three n = 35 (58%) Four n = 10 (17%)
Number of people living with the infant	One n = 7 (11%) Two n = 32 (54%) Three n = 16 (27%) Four or more n = 5 (8%)

Table 3. Attitudes of carers to reduce the risk of sudden infant death syndrome (n = 60)

Attitudes of carers on the infant sleep environment	Never (0 days/week)		Sometimes (3-4 days/week)		Always (7 days/week)	
	n	%	n	%	n	%
	Putting your baby to sleep belly up?	8	14	11	18	41
Putting your baby to sleep belly down or on their side?	37	61	20	34	3	5
Using a firm mattress in the baby's bed?	0	0	1	2	59	98
Using lightweight sheets and covers tightly attached to the cradle and under your baby's shoulders?	3	5	5	8	52	87
Offering a pacifier at bedtime?	18	30	30	50	12	20
The baby sleeps in a shared bed with an adult?	47	79	11	18	2	3
The baby sleeps in the room of the carers in their own cradle?	1	2	6	10	53	88
The baby sleeps on the couch with an adult?	57	95	3	5	0	0
The baby sleeps in a room separated from the carer before 6 months of age?	55	92	5	8	0	0
The baby sleeps in a room separated from the carer after 6 months of age?	26	43	16	27	18	30
Do you place a cushion under the baby's head when they are sleeping?	49	82	9	15	2	3
Do you put diapers, plush toys or soft objects inside the cradle when the baby is sleeping?	47	79	8	13	5	8
Do you/another carer smoke in the baby's bedroom or at home?	59	98	1	2	0	0
Do you avoid overheating the baby (sleeping with more clothes than adults)?	16	27	2	3	42	70
Do you keep the room temperature of the baby around 20°C-22°C?	3	5	8	13	49	82
			Yes		No	
			n	%	n	%
Do you obtain adequate and regular antenatal care?	60	100	0	0		
Did you avoid smoke exposure, alcohol and illicit drug use during pregnancy as well as after the birth of the baby?	59	98	1	2		

The data analysis was both descriptive with frequency distribution and inferential. Chi-square and Fisher's exact tests were used to test associations between variables. A significance level of 0.05 was considered.

## Results

Of the total of 163 eligible respondents, both carers with infants up to 12 months of age or pregnant women whose delivery occurred during the study period, a total of 68 agreed to enter the study (response rate 42%). Eight (12%) surveys were excluded due to improper completion (conflicting responses or incomplete surveys).

Table 2 shows the characterisation of the sample. Seven (11%) families were single-parent families and five (8%) were large families. Concerning attendance at visits on the key stages of growth (first week, first month, 2, 4, 6, 9 and 12 months of age), 46 (97%) had a complete follow-up. Mothers expressed their willingness to breast-feed as long as possible in 27 (45%) of the cases.

Table 3 summarises the attitude of carers to reduce the risk of SIDS.

Regarding information about SIDS, 16 (27%) carers

reported not receiving information on the subject. Of those subject to patient education, it was provided by at least one health care professional, namely nurse (n = 43, 72%), family doctor (n = 20, 33%), obstetrician (n = 17, 28%) and paediatrician (n = 15, 25%). Five (8%) carers obtained information from the Internet and seven (12%) from television. Carers who received information on the subject most frequently placed the infant to sleep adequately (Table 4).

Nuclear families ( $p = 0.068$ ), mother over the age of 30 ( $p = 0.043$ ), mother ( $p = 0.006$ ) or father ( $p = 0.016$ ) with higher education or mother with a first or second Graffar scale profession ( $p = 0.001$ ) or families with employed parents ( $p = 0.026$ ) placed the child to sleep more frequently in the supine position (Table 4).

Infants younger than 6 months old were less likely to prone sleep ( $p = 0.005$ ). Employed mothers reported less frequently infant sleeping in a shared bed ( $p = 0.047$ ). Carers frequently placed the infant to sleep in their own cradle in their room (n = 53, 88%). Employed parents more frequently kept the child sleeping in the same room as the carer during the first six months ( $p = 0.013$ ), but this did not occur in the following months ( $p = 0.379$ ). In families with a non-smoker parent, the

**Table 4. Comparison between categorical variables (prior information on sudden infant death syndrome, family type, age, education, profession Graffar score, employability, smoking of carers and the age of the infant) and response to questions**

<b>A. Do you put the baby to sleep belly up?</b>		<b>Sometimes or always (n = 52)</b>		<b>Never (n = 8)</b>		<i>p</i>
		n	%	n	%	
Information on sudden infant death syndrome	Yes	40	77	4	50	0.188*
	No	12	23	4	50	
Family type	Single parent family	5	10	2	25	0.068*
	Nuclear	43	83	5	63	
	Extended	4	7	1	12	
Father's age	≤ 30 years	11	21	3	38	0.135 <sup>†</sup>
	> 30 years	41	79	5	62	
Mother's age	≤ 30 years	19	37	5	63	0.043 <sup>†</sup>
	> 30 years	33	63	3	37	
Father's education	≤ 9th grade	8	15	3	38	0.016 <sup>†</sup>
	12th grade	16	31	3	38	
	≥ Undergraduate	28	54	2	24	
Mother's education	≤ 9th grade	3	6	2	24	0.006 <sup>†</sup>
	12th grade	13	25	3	38	
	≥ Undergraduate	36	69	3	38	
One of the carers unemployed	Yes	4	8	4	50	0.026*
	No	48	92	4	50	
Father's profession - Graffar scale‡	1st or 2nd	31	67	6	75	0.803 <sup>†</sup>
	3rd, 4th or 5th	15	33	2	25	
Mother's profession - Graffar scale ‡	1st or 2nd	40	78	3	38	0.001 <sup>†</sup>
	3rd, 4th or 5th	11	22	5	62	
<b>B. Do you put your baby to sleep belly down or on their side?§</b>		<b>Sometimes or always (n = 21)</b>		<b>Never (n = 27)</b>		<i>p</i>
		n	%	n	%	
Infant age	≤ 6 months	11	52	23	85	0.005 <sup>†</sup>
	> 6 months	10	48	4	15	
<b>C. Do you put the baby to sleep in a shared bed with an adult?</b>		<b>Sometimes or always (n = 13)</b>		<b>Never (n = 47)</b>		<i>p</i>
		n	%	n	%	
Father unemployed	Yes	1	8	3	6	0.595*
	No	12	92	44	94	
Mother unemployed	Yes	3	23	1	2	0.047*
	No	10	77	46	98	
<b>D. Did you put the baby to sleep in a separate room of the carer before 6 months?</b>		<b>Sometimes or always (n = 5)</b>		<b>Never (n = 55)</b>		<i>p</i>
		n	%	n	%	
One of the carers unemployed	Yes	3	60	5	9	p = 0.013*
	No	2	40	50	91	
Father smoking	Yes	2	40	14	25	p = 0.284*
	No	3	60	41	75	
<b>E. Did you put the baby to sleep in a separate room of the carer after 6 months?</b>		<b>Sometimes or always (n = 34)</b>		<b>Never (n = 26)</b>		<i>p</i>
		n	%	n	%	
One of the carers unemployed	Yes	4	12	4	15	p = 0.379*
	No	30	88	22	85	
Father smoking	Yes	5	15	11	42	p = 0.040 <sup>†</sup>
	No	29	85	15	58	
<b>F. Do you avoid overheating the baby?</b>		<b>Sometimes or always (n = 44)</b>		<b>Never (n = 16)</b>		<i>p</i>
		n	%	n	%	
Father's education	≤ 9th grade	4	9	7	44	0.021 <sup>†</sup>
	12th grade	14	32	5	31	
	≥ Undergraduate	26	59	4	25	
Mother's education	≤ 9th grade	3	7	2	12	0.031 <sup>†</sup>
	12th grade	9	20	7	44	
Father's profession - Graffar scale‡	1st or 2nd	31	78	6	43	0.023 <sup>†</sup>
	3rd, 4th or 5th	9	22	8	57	
Mother's profession - Graffar scale ‡	1st or 2nd	36	82	7	47	0.022 <sup>†</sup>
	3rd, 4th or 5th	8	18	8	53	

\* Fisher's exact test.

† Chi-square test to test associations between variables.

‡ It does not include cases of the Graffar scale of the profession [not applicable] from Table 2.

§ Includes the group of carers of infants (n = 48) of Table 2.

infant was more likely to sleep in a separate room from six months of age ( $p = 0.040$ ) (Table 4).

Overheating of the child was a concern in 44 (73%) of the cases (Table 3) and it was associated with higher carers' education -father ( $p=0.021$ ) or mother's ( $p=0.031$ ) - and profession - father ( $p=0.023$ ) or mother's ( $p=0.022$ ). (Table 4)

## Discussion

These results show that there is still a low adherence to the recommendations for safe sleeping environments for infants up to 12 months. Our data are consistent with other published studies that reveal that parents may be influenced by the health care team and the media about the best position in which the infant should sleep.<sup>14,15</sup> Our study showed that nurses are particularly aware of this problem and doctors do not seem to approach this issue in regular surveillance visits as they should.

It is known that most cases of SIDS occur in families of low socioeconomic and educational status, as it is a group that has lower compliance with preventive measures.<sup>16,17</sup> The recommendations of the American Academy of Pediatrics advocate that the infant should sleep in their own cradle in the parents' room. As in other studies, our sample has shown that parents still share the bed with their child (20% answered affirmatively to the question "Does the baby sleep in a bed shared with an adult?" *versus* 33%-46% in other studies<sup>18-21</sup>). Respondents also report that they still put the infant to sleep on a couch with an adult and that, after 6 months of age, a large proportion already sleeps in their own room (57%).

Although 90% of SIDS cases occur in the first six months,<sup>5</sup> it is recommended that they sleep in their own cradle in their parents' room up to 12 months. Our study found that infants under 6 months of age were put to sleep in a shared room and in their own cradle adequately more frequently than older children. Parents may be reluctant to put younger infants to sleep in a separate room, as it is more difficult to monitor their sleep.

Sharing of the bed with the infant was less frequent if the parents were employed. On the other hand, employed parents more frequently kept the child sleeping in the same room as the carer during the first six months, and there were no differences after six months of age compared to families with an unemployed parent. Families with a non-smoker parent frequently placed the infant in a separate room from 6 months onwards. In fact, other studies have shown that bed sharing is related to poverty levels, such as low family income, adolescent mother, or parents with no higher education.<sup>22,23</sup> It should be noted that our sample has

infants exposed to smoke at home and multiple studies have shown that sharing the bed with the carer is particularly dangerous when one of the parents smokes.<sup>24-26</sup> In Western countries, the incidence of bed sharing has recently increased in higher socioeconomic classes, due to increased breastfeeding.<sup>18</sup> However, breastfeeding continues to be promoted and included in the risk reduction campaigns for SIDS.<sup>6</sup>

Only 68% of respondents prefer the supine position for putting the child to sleep. Although our data are substantially better than those reported by other national studies, they are still unsatisfactory.<sup>11-13</sup> Other studies have shown a progressive decrease in prone sleeping. After a US study analysed the circumstances of infant death by SIDS, a safe sleep campaign was implemented in 1994 wherein a decrease of this behaviour from 85.4% to 30.1% was observed.<sup>27</sup> They also found that the incidence of side positioning increased substantially even after the 2005 recommendations of the American Academy of Pediatrics, arguing it to be deemed a risk position as well, denoting the need to reinforce the carers' education to avoid both prone and side positions.<sup>27</sup> Studies in countries such as the US, Argentina, the United Kingdom and Sweden have shown that the prone sleeping rates varied between 0% and 32.3% and side sleeping rates varied between 14.3% and 40%, becoming more frequent with infant growth.<sup>16,17,28-31</sup> In our study, the infant was placed more frequently in the prone position in young parent families, families which one of the parents was unemployed or had a profession with a third to fifth class on the Graffar scale or education lower than higher education. It is important to note that we were able to verify that, as the infant grows, the position of the infant is changed, since carers of children over 6 months of age place them more frequently in the prone position. This is in accordance with other studies showing a significant decrease in compliance with recommendations with infant growth.<sup>2,13,27-31</sup>

Recommendations with higher compliance were those regarding the correct use of the mattress, sheets and bed covers. However, it is still a habit to place objects such as cushions or toys inside the cradle, although other studies have revealed a greater prevalence of this attitude (21% of our sample *versus* 68% in other studies).<sup>12,13</sup>

Giving a pacifier at bedtime was a common practice in our sample (70%).

A large part of the carers was aware of avoiding overheating the infant, and the higher the parents' education or profession of first and second class in the Graffar scale, the more importance was given to this aspect.

This study has some limitations, namely:

- The sleeping position was established by the carer and

not by direct observation, although the anonymous survey may reduce the response bias;

- The studied sample is not representative of the national population, since it is a convenience sample of patients followed in a Family Health Unit;
- The study included a small proportion of preterm infants, which is a population particularly vulnerable to SIDS.

The results show that all families should continue to be educated about the risk factors of SIDS, so that all infants can have a safe sleep.

In conclusion, there is unsatisfactory compliance with the recommendations for reducing the risk of SIDS. It is, therefore, important that health care professionals reinforce the education of families on this issue in the follow-up visits and that awareness campaigns are developed. We observed that certain characteristics were associated with preventive recommendations non-compliance, such as age, level of education, Graffar class of profession, employability and smoking. It is important for future studies to investigate the reasons for recommending noncompliance in order to effectively identify which interventions may alter the common practices of carers in the sleeping environment.

#### WHAT THIS STUDY ADDS

- Knowing the reality of what parents do to reduce the risk of sudden infant death syndrome allows the practitioner to adjust the approach and direct the intervention to the aspects that can be improved.
- It alerts for sociodemographic factors that put the infant at greater risk of sudden infant death syndrome.
- It reinforces the importance of the approach of this topic in the children's surveillance visits, not only to implement preventive strategies but also to demystify the subject.

#### Conflicts of Interest

The authors declare that there were no conflicts of interest in conducting this work.

#### Funding Sources

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#### Protection of human and animal subjects

The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki).

#### Confidentiality of data

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

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