# Neonatal & Infant Care

# Midwives' experiences of safer infant sleep discussions at a southwest London hospital: a work-based learning project

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# **ORIGINAL**

#### Introduction

Sudden infant death syndrome (SIDS) is defined as 'the sudden unexpected death of an infant under one year of age, with onset of the fatal episode apparently occurring during sleep, which remains unexplained after thorough investigation' (Willinger et al 1991). The aim of this work-based learning (WBL) project was to review how the maternity workforce at a southwest London trust undertakes Safer Infant Sleep Discussions (SISD). Women's and midwives' experiences of SISD were explored to identify barriers and facilitators, alongside a review of interventions to assist midwives with SISD. Analysis of the results enabled quality improvement and practice-based recommendations with a reflection on the learning process.

#### **Background and rationale**

The rationale for this project arose because the author, who works as a community midwife, observed an increased number of unsafe sleeping practices while carrying out postnatal home visits, which all pose a significant risk of SIDS (Royal College of Midwives (RCM) 2021). Despite this, the actual rates of SIDS worldwide remain low and this is largely due to the success of the Back to Sleep (BTS) campaign. BTS was launched in the UK in 1991 and is widely acknowledged to be one of the most successful public health campaigns of the 20th century, achieving considerable reductions in the rates of SIDS in the UK and worldwide. This can be attributed to the simplicity of the message and change required — of putting babies to sleep on their backs (Moon & Hauck 2018).

In England, the rates of unexplained deaths, which include sudden infant deaths and unascertained deaths, continue to follow a downward trajectory, as the reported incidence for 2020 was 0.24 deaths per 1,000 births (Office for National Statistics (ONS) 2022) versus 0.27 in 2019 (ONS 2021). In London, the rates of unexplained deaths in 2019 were lower than the national average or 0.20 per 1,000 live births (ONS 2021).

Nevertheless, the hospital at which this WBL was undertaken is located within a London borough that experienced the fifth-highest incidence of unexplained infant deaths from 2018–2020 and this was noted to be above the national average during this time frame (Trust for London 2022). For this reason — and due to the increasing number of unsafe sleep practices that the author has recently observed — the rationale for this quality improvement/WBL project is highly justified.

#### Literature review

# 1. Risks

Although the exact mechanisms of SIDS are still unknown, there are many known risk factors strongly associated with it (Kroll et al 2018, Sidebotham et al 2018, Blair & Pease 2019, Child Safeguarding Practice Review Panel (CSPRP) 2020). Approximately 75 per cent of babies who die from SIDS have two or more risk factors present and 91 per cent have at least one risk factor (Horne et al 2014). Filiano & Kinney (1994) devised the most widely accepted framework for the mechanisms of SIDS, including both intrinsic and extrinsic risk factors occurring concurrently: 1) physical vulnerability; 2) the age of the infant (0-4 months — a time of rapid development); and 3) unsafe sleeping environment, known as 'the triple risk model'. The model is effective in grouping the broad range of risk factors; however, it is lacking, in that it does not acknowledge socio-economic risk factors, which are closely linked to SIDS and reported in

contemporaneous literature (Sidebotham et al 2018, CSPRP 2020).

# 1.1 Intrinsic risk: physical vulnerability and age of the infant

The age of the infant poses an intrinsic risk, as the incidence of SIDS peaks between two and four months of age (Kinney 2009). Gender can also increase susceptibility, as a greater proportion of male infants (55.3 per cent) succumb to SIDS, even though the gender gap has decreased in recent years (ONS 2021). Moreover, babies that are premature or small for gestational age/intrauterine growth restricted and weigh below 2.5 kg have a fourfold risk of SIDS (Blair & Pease 2019). Additionally, a substantial number of influential studies consistently link both maternal/parental smoking, alcohol and illegal drug use during pregnancy and after birth with an increased risk of SIDS, even in term and well-grown infants (Blair et al 1996, Fleming & Blair 2007, Zhang & Wang 2013, Horne 2018).

## 1.2 Social, economic factors and ethnicity

SIDS is common in families of low socio-economic status, with overcrowding and deprivation being evident (Bartick & Tomori 2019). Moreover, infants born to teenage mothers are four times more likely to experience SIDS for reasons including a lack of parenting skills, immaturity and insufficient support (RCM 2021).

Kroll et al (2018) found that, in the absence of traditional risk factors, the highest risk of SIDS in babies was found in Black Caribbean, mixed Black African/Caribbean and White ethnicities, with White British being at intermediate risk and Indian, Bangladeshi, Black African and Pakistani infants at lowest risk. They maintain that this is thought to be related to cultural differences in infant care.

# 1.3 Extrinsic risk: unsafe sleeping position and environment

Many high-level epidemiological studies carried out in the 1980s found that placing babies in the supine position led to decreased rates of SIDS, and that the prone or side position led to a considerable increase in SIDS (Hauck et al 2003, Li et al 2003, Bergman 2015, Wu et al 2017).

Following this, the BTS campaign was launched. Even though it has made significant reductions in SIDS worldwide overall, the rates of infant mortality attributed to hazardous co-sleeping have risen (Blair et al 2006). Co-sleeping is a normal phenomenon for many mothers and approximately a quarter of mothers in the UK bed share in any one night (Fleming & Blair 2015). It is linked to improved settling and mother–baby bonding, reduced crying, higher breastfeeding success rates and increased arousals, and these factors are known to be protective against SIDS (Ball et al 2016).

Moreover, in 2014 Blair et al presented strong new evidence that co-sleeping can be safe, in the absence of certain hazardous conditions. These include prematurity, alcohol, drugs, smoking and co-sleeping on chairs or sofas, which poses one of the greatest dangers — increasing the risk of SIDS by up to 50 times (Blair et al 2009).

# 2. SIDS prevention

#### 2.1 Women's experiences of SISD

As a result of the new evidence, the National Institute for Health and Care Excellence (NICE) updated its postnatal care guideline in 2014 with recommendations that health care professionals (HCPs) carry out conversations with parents about safe co-sleeping (NICE 2021). Yet this has failed to make a significant impact, as an influential report published by the CSPRP in 2020 found that in 38 of the 40 cases of sleep-related infant mortality they reviewed, hazardous co-sleeping was the cause of death.

Similarly, according to a survey carried out by The Lullaby Trust in 2020, 46 per cent of parents admitted that they had co-slept with their babies on sofas and chairs, and up to a third had also settled their babies in the prone or side position to sleep. The main reasons given for this were tiredness, an inability to settle the baby, disrupted routines and unrealistic expectations for how long a newborn should sleep at night.

In the wider literature, these and other barriers to safe sleep adherence were reported by mothers, for example, inconsistent and confusing messages; a complete lack of advice or inadequate explanations of the consequences of not following safe sleeping advice from HCPs; the use of an ineffective didactic and impersonal approach; and false reassurance from having had other children or monitors/sleep equipment (De Luca & Hinde 2016, Salm Ward & Balfour 2016, Pease et al 2017, Pease et al 2018). For all these reasons, it is now recommended that safer infant sleep practices (SISP) initiatives are multifaceted, targeted and culturally sensitive (Salm Ward & Balfour 2016, Sidebotham et al 2018).

Furthermore, SIDS prevention should adopt the health promotion approaches of education, empowerment, enforcement and environment modification, to motivate positive behavioural change, as they have effectively demonstrated reductions in morbidity and mortality when used as part of injury prevention campaigns (Deal et al 2000, Rivara & Johnston 2013).

# 2.2 Midwives' experiences of SISD

According to CSPRP (2020) and RCM (2021), midwives should commence SISD at the earliest opportunity during the pregnancy or the booking

appointment at eight-10 weeks and this should be reinforced during both the antenatal and postnatal periods. A literature search of midwives' experiences of delivering SISD yielded no papers, therefore the search was widened to midwives' experiences of communicating health-promotion messages. The barriers identified included a lack of time; inability to remember all items to discuss; inadequate resources to assist them to deliver messages effectively to women of low health literacy or poor English; a lack of training or up-to-date knowledge; and a fear of upsetting the women (Wilmore et al 2015, Hodges et al 2018, McLellan et al 2019, Bright et al 2021, Dayyani et al) 2022. Despite the obstacles, midwives reported being highly motivated to carry out SISD to benefit the long-term health of the mother-baby dyad (McLellan et al 2019).

A review of the literature to explore the effectiveness of interventions designed to assist midwives with SISD also yielded limited results. This has been linked to the fact that, overall, the rates of SIDS are low and therefore it is difficult to evidence the impact in the reduction of any intervention campaign on the primary outcome of reducing SIDS (Sidebotham et al 2018).

Alternatively, increased knowledge of SISP with HCPs was reported in nine of 11 studies in a systematic review of Safe Sleep Interventions in 2016 by Salm Ward & Balfour. This was achieved through traditional educational tools, including visual displays (posters, pictures, written materials such as leaflets), multimedia (such as videos), signposting to web-based public materials, and training and education sessions. It should also be noted that a strategy recommended in various papers — motivational interviewing — can assist HCPs to avoid ineffective and closed health promotion-based conversations and it has subsequently been proven to empower individuals to make positive behavioural change (Pease et al 2017, Zabolypour et al 2020).

Finally, a recent paper by Polavarapu et al (2022) and the CSPRP report (2020) both call for rigorous SIDS risk-assessment tools to be introduced to assist HCPs with identifying and supporting families at high risk of SIDS.

#### Literature review summary

Due to the findings of this literature review, which has highlighted the plethora of risks for SIDS, the complexity of tailored prevention and the challenges that midwives can face while carrying out SISD, the author decided to undertake a survey with the maternity workforce. An online survey instrument via SurveyPlanet was selected, as it incurred minimal costs, was quick to create, easy to distribute and aligned to the timeline for the project (Toepoel 2016).

The aim of the survey was to provide insight into the experiences of the staff. Moreover, it also facilitated a co-production approach, which is widely acknowledged to be highly effective in motivating behaviour change in quality improvement or WBL projects (Vennik et al 2016, Hawkins et al 2017).

# Survey design and methodology

An email was sent to the lead midwife to request permission to carry out the survey with all staff, who are all involved in SISD. The design was guided by recommendations in *The SAGE Handbook of Online Research Methods* to provide a robust structure, maximise validity and reliability, and address ethical issues (Toepoel 2016).

To minimise non-response bias, nine short questions were formulated, which were unambiguous, not leading and mandatory to avoid inconsistency. Closed questions were used for the demographics and the remaining questions were open, so that the responses did not become biased through the provision of a choice of answers. A mixture of descriptive statistics and thematic analysis was used to interpret the findings, allowing for themes and patterns of meaning to emerge, as analysis of experiences is an essential part of this project (Clarke & Braun 2017).

To increase reliability, a pilot study was carried out with a small sample of participants (n=3) (Misro et al 2014). No major modifications were deemed necessary, except it was noted that there was no option for one of the participant's ethnicity (Indian other) and this was amended.

To facilitate informed consent and address the ethical dimensions of survey design, a participant information sheet was included at distribution. It detailed the aims of the project, benefits, duration to complete, offered full anonymity to participants and permitted withdrawal, and supplied a contact email address for the author in case of questions or concerns (Toepoel 2016). To maximise accessibility and distribution, and to enable a representative sample to be achieved, the link to the survey was posted on a private social media group for all maternity staff and shared via work WhatsApp groups (Aerny-Perreten et al 2015). In accordance with the Data Protection Act (2018), the anonymised data were stored securely via a password-protected account.

## **Survey results**

The survey remained open for 14 days and 58 responses were received by the closing date, equating to a 40 per cent response rate from a sample of approximately 145 staff.

Four overarching themes were identified: 1. Advice; 2. Communication barriers; 3. Equipment; 4. Desire for visual aids.

## Theme 1: Advice

Despite only 48 per cent of survey respondents stating that they carry out SISD in both the antenatal and

postnatal periods, not all staff worked in all settings. Therefore, of the 44 per cent who reported that they carry out SISD during the postnatal period only, the majority were identified as working exclusively in postnatal settings. However, 10 per cent of those respondents were midwives who work in rotational roles and should carry out SISD antenatally as well as postnatally. Of those who discuss it antenatally, 69 per cent do so only once and mainly at the 34- or 36-week follow ups; 18 per cent do it twice, 13 per cent discuss it three times. The booking appointment was when the most SISD were carried out and this equated to 19 per cent of the respondents.

Leading on from this, the survey revealed that none of the staff gave advice on all six of the recommended subjects for SISD according to The Lullaby Trust (2022): 31 per cent of respondents discuss three topics; 20 per cent discuss a single topic; 19 per cent discuss two topics; 15 per cent discussed four topics. Only seven per cent of respondents mentioned five topics.

'Give your baby a clear, safe sleeping place in the same room' was the most discussed topic (by 85 per cent of respondents) and 'Feet to foot' was the most mentioned preventative individual measure relating to this theme (mentioned by 62 per cent). 'Bedsharing more safely' was the second most frequently discussed topic (by 56 per cent of respondents) and some survey participants detailed what they advise, such as not bed sharing when under the influence of alcohol, drugs or smoking. 'Always place your baby on their back for sleep' was the third most mentioned topic (39 per cent of respondents), followed by 'Keep your baby smoke free' (25 per cent).

'Never sleep with your baby on a sofa or armchair', mentioned by 24 per cent of those who took part, which addresses one of the highest risks for SIDS, was the second-least discussed subject. 'Breastfeeding' came in last place and was mentioned by just 10 per cent.

The inconsistencies and omissions in advice correlate closely to the experiences reported by women in the literature review, who stated that they do not always receive adequate, consistent or tailored safer sleep advice, especially during the antenatal period (de Luca & Hinde 2016, Salm Ward & Balfour 2016, Pease et al 2017, Pease et al 2018).

In the same way, the staff described how carrying out SISD was limited by time constraints and the fear of being patronising or because, as Participant 28 put it, they 'Don't want to panic mums'. Furthermore, advice from family and friends (mentioned by 25 percent of respondents) and cultural influences (cited by 24 per cent) that runs counter to current safe sleep recommendations were the most frequently mentioned barriers to SISD. As Participant 17 states:

'Non-evidence based advice from family/friends. Advice given to nanny when she had kids changed'.

#### Theme 2: Communication

Sub-themes of 'language barriers' and 'parents feeling too tired and too much information for parents' were repeatedly highlighted.

Participant 53 stated that there was 'A lot of information to take in, often discussing when parents are tired and overwhelmed' and 'previous experiences' also influenced parents: Participant 57 said 'they have the idea of their previous experience stuck in their thoughts'.

### Theme 3: Equipment

Survey respondents described in some circumstances, how they 'Feel guilty advising them to spend money' (Participant 3) to buy the baby its own bed.

Conversely, the team described their frustration at the plethora of equipment that some wealthy parents bought, in the hope of settling the baby for longer periods of time, even though it was unsafe, such as: 'Sleep positioners that make babies sleep longer but are not safe' (Participant 30).

All the above barriers correlate strongly to the issues identified by the midwives in delivering health promotion messages in the wider literature (Wilmore et al 2015, Hodges et al 2018, McLellan et al 2019, Bright et al 2021, Dayyani et al 2022).

#### Theme 4: Desire for visual aids

Finally, to overcome these obstacles, the survey respondents overwhelmingly mentioned the desire for visual aids, including leaflets, flash cards, pictures, posters and information packs, available in various languages or with infographics, such as 'Visual tick and cross pictures so no language barrier' (Participant 37), to assist them in delivering SISD that were thorough and understandable for all women. As Participant 10 states, these aids would be useful in 'Ensuring that it is part of antenatal conversations & that all staff are saying the same thing'.

# Practice development and reflection

The findings of this survey justify a need for change. The package of intervention will be based on the suggestions from the survey findings and the health promotion principles of education, empowerment, enforcement and environment modification. These have been effective in reducing mortality and morbidity in injury prevention campaigns (Deal et al 2000, Rivara & Johnston 2013).

Despite the use of a co-production approach, disseminating innovation in health care settings can prove complex and resistance to change is common (Greenhalgh & Papoutsi 2019). Therefore, as per the guidance from the NHS Leadership Academy 2013

and NHS England 2018, which calls for leaders to 'share the vision', 'engage the team' to combat the 'human dimensions of change', a summary of this report will be shared via email with all staff and students, with the full report also included for reference.

To capture the principle of enforcement, it will be stipulated that, as per the trust's guidelines, SISD should be carried out by staff at the booking appointment, at 28–40 and 34–40 week antenatal appointments, as well as at every opportunity postnatally, and this should be documented in the Badger Notes (Local Trust 2021). To encompass the approaches of empowerment and education, a visual aid (The Lullaby Trust 2022) will be printed in A4 colour, laminated and placed in antenatal clinics and on postnatal wards.

It is hoped that this A4 card will act as a prompt to help the staff to carry out SISD more consistently, succinctly and to utilise the principles of motivational interviewing, to cover all six of the necessary topics for SIDS prevention. In the same way, additional information relating to the pathophysiology of SIDS will be provided. It is hoped that this will assist the staff with providing simplified explanations to the women about the consequences of not adhering to the principles of SISP, as this was reported by the women as being a barrier to prevention (Pease et al 2017).

Safer Sleep for Babies (The Lullaby Trust 2022) can also be added to the woman's Badger Notes and signposted for her to read at home. An advantage of this leaflet is that it uses both text and infographics with ticks and crosses, which are effective at communicating health promotion messages to those of low health literacy or who are non-English speaking. Moreover, the infographics are culturally sensitive and inclusive, as they include illustrations of White-, Black- and Brown-skinned individuals (Health Education England (HEE) 2018). Finally, to fulfil the principle of environment modification and help the staff discuss SISD with those families who are of low socio-economic status, links to local charities who can provide equipment will be given.

Furthermore, to overcome language barriers, a simplified version of this leaflet is available on the Lullaby Trust website in 24 languages and links will be provided. A disadvantage of this version is that it does not have illustrations of safe bed sharing but the infographics from the full leaflet can also be used if necessary. Nonetheless, it will be stipulated that safer infant sleep advice should always be tailored and the English-language version of the simplified version would be more appropriate for discussions with parents at high risk of SIDS, as bed sharing should never be advised (Ball & Volpe 2013; Wilmore et al 2015, Pease et al 2017).

Leading on from this, the author personally believes that the idea of a risk-assessment tool could help the staff to identify those at high risk of SIDS more effectively and tailor support appropriately (Polavarapu et al 2022). As a result, a series of meetings were set up with key stakeholders, including the head of infant feeding, safeguarding and the digital midwives, to discuss how this could be implemented (NHS England 2018). The idea was welcomed and a rationale and change request for a proposed SIDS risk-assessment tool was submitted to the BadgerNet provider Clevermed, but unfortunately this remains in a queue and may take several years before it is developed.

Finally, even though the systematic review by Salm Ward & Balfour in 2016 demonstrated that leaflets were effective at increasing staff and patient knowledge of safer infant sleep, it will still be necessary to test effectiveness at this local site on a smaller scale, so that time and resources are not wasted. Therefore, all measures will be trialled on a small/pilot scale, using a PDSA cycle. If the findings demonstrate effectiveness, then this will justify a larger-scale roll out (NHS England 2018).

As a personal reflection, this project has been highly effective at increasing my own knowledge of safer infant sleep advice, which was largely based on my personal experiences of being a mother. Prior to this, I adopted a blanket approach of telling parents never to bed share, as I was unaware of the change in evidence to support safe co-sleeping, but I have now successfully updated my knowledge and commenced communicating this to families.

#### Conclusion

The survey carried out has effectively revealed that the maternity staff at this hospital encounter various barriers when carrying out SISD and consequently women may not always be receiving consistent and adequate advice regarding SIDS prevention. Consequently, an implementation package, which is based upon a collaborative approach, recommendations from wider literature and evidence-based health promotion principles will be trialled at the trust as an attempt to increase awareness and adherence to safer infant sleep advice.

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For more information on this topic see MIC database search packs: PN43 Sudden infant death: sleeping position; PN80 Co-sleeping / sharing a bed; PN125 Sudden infant death: smoking; PN51 Sudden infant death: environmental factors; PN23 Sudden infant death: physiology.

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Jolly L, Gregory J. MIDIRS Midwifery Digest, vol 33, no 3, September 2023, pp 278-284.

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