A qualitative study of sleep quality in children and their resident parents when in hospital

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ABSTRACT
Objective Poor sleep quality impairs immune responses and pain tolerance, both key to recovery from acute illness. Hospitalised children and their co-sleeping parents also risk emotional lability and impaired coping skills when sleep-deprived. We aimed to study the experiences of children and parents during hospital admisions.

Design Semi-structured interviews were conducted with parents within a week of their child’s discharge. Questions explored parent and child sleep quality, factors contributing to this, perceived impact on day-time functioning and suggested improvements to ward sleep environment.

Setting Southampton Children’s Hospital, UK.

Patients 17 co-sleeping parents of 16 children aged 3–12 years completed interviews. Children admitted for surgical procedures and those with established sleep disorders or nocturnal seizures were excluded.

Main outcome measures Constant comparative methods identified themes within the data using a grounded theory approach.

Results Parents reported that they, and to a lesser extent their children, experienced reduced sleep quality. Noise and light as ward schedules were identified as key factors disrupting sleep. Parents reported that lack of sleep caused difficulties with their own emotional regulation and that of their child, affecting day-time parent–child relationships. Furthermore, they reported a negative impact of sleep deprivation on decision-making about their child’s medical care.

Conclusions Parents identified poor sleep in hospital as a significant additional burden to their child’s hospital admission. Importantly, they identified potential improvements to the ward sleep environment. Intervention studies that target modifiable, child-centred alterations to night-time ward culture are recommended, focusing on measurable child and parental outcomes.

INTRODUCTION
There are good reasons why children spend half of their lives asleep. Sleep promotes neural health,1 efficient cognitive function,2 memory consolidation3 and behavioural and emotional regulation.4 5 Sleep is the ‘oxygen’ of cellular homeostasis and impacts on a range of physiological functions. Some, such as immune function6 and pain perception,7 are particularly relevant to hospitalised or sick children.

There are compelling reasons why sleep should be promoted for children in hospital as well as for their co-sleeping parents. First considering the child: a high percentage of acute admissions in the UK are associated with infection.8 9 Restricted sleep impairs the immune response. Antibody titres decreased by >50% 10 days after influenza vaccine in 80 adults restricted to only 4 h of sleep the night before vaccination when compared to controls taking their usual amount of sleep.10 Similar levels of sleep restriction for 10 nights attenuated the febrile response to an endotoxin (Escherichia coli) challenge.11 Furthermore, poor quality sleep (both inadequate sleep duration and interrupted/fragmented sleep) can cause increased pain sensitivity,12 an important consideration for children in hospital who may be exposed to pain from illness and invasive procedures.

Second, to consider factors affecting both parent and child: poor quality sleep affects mood, emotional control, distress thresholds13–15 and flexible thinking and decision-making.16 Sleep-deprived parents are more likely to report parenting stress and mood disorder.17 Young children are particularly vulnerable to fatigue-induced mood disturbances and may express this as internalising behaviours (withdrawal, anxiety, depression) or/and externalising behaviours (irritability, aggression, hyperactivity).18 19 Sleep-fragmentation increases cortisol release, raising stress and exacerbating mood disturbance.20 Emotional control and difficult...
behaviours are important considerations in paediatric care, which requires skilled management of the parent–child dyad in already stressful circumstances. Parents of hospitalised children often have to process and understand complex new information and make informed decisions of importance regarding their child’s care. In this study we aimed to explore the experience of sleeping in hospital for children and their resident parents.

METHOD
Participants and setting
Families were recruited from the medical wards of Southampton Children’s Hospital, University Hospital Southampton NHS Foundation Trust. All parents had slept in a fold-down bed alongside their child’s standard hospital bed during their child’s admission.

Recruitment
Parents were recruited while their children were in hospital. Two groups of children were purposively sampled: those with chronic illnesses and those with acute illnesses. This sampling approach was adopted to ensure that we interviewed both parents of children who were familiar with the ward environment and those for whom this was a novel, unplanned admission. The inclusion of patients with chronic illnesses was also intended to limit confounding factors such as febrile illness, which may independently affect sleep quality.21 Exclusion criteria were as follows: children who were recovering from surgical procedures, and those with known sleep disorders identified by parental completion of the Child Sleep Habits screening questionnaire22 or nocturnal seizures. Parents were initially approached by nursing staff. Those expressing an interest were provided with participant information sheets which detailed the objectives of the study and outlined study requirements.

Measures
Child Sleep Habits questionnaire
Parents were asked to complete this 31-item screening instrument for school-aged children. Psychometric assessment of the questionnaire has demonstrated that it can distinguish between clinical samples of children with sleep disorders and community samples. The screening questionnaire was reviewed by a paediatrician with expertise in sleep medicine (CMH).

Qualitative data were collected using a semi-structured interview undertaken by female students AS and EC as part of their undergraduate curriculum. Both received training in qualitative methods. The interview was designed and piloted with five parents, and addressed three main themes: first, the parent’s sleep quality during their child’s admission; second, the quality of sleep experienced by the child (as observed by the parent); and finally, how the hospital environment had affected quality of sleep.

Interviews were conducted privately, either in the hospital prior to discharge or at the family home within 1 week of discharge. Interviews lasted around 30 min. Each interview was recorded using a standard digital audio-recording device and subsequently transcribed. A grounded theory approach was used in data analysis.23 Transcripts were subject to open coding, and statements grouped into emergent major themes, initially independently by AS, reviewed and modified in discussion with EC and CMH into minor themes.

Procedure
Ethics approval for the research was obtained from the UK National Research Ethics Committee (reference 10/H0502/82). Informed written consent was obtained from the parent prior to interview and parents had an opportunity to meet the researchers ahead of their scheduled interview.

RESULTS
Participants
Thirty-five parents were invited to participate, of whom 18 declined, mostly due to the burden of hospital admission. Seventeen parents (16 mothers and 1 father) completed interviews to the point of data saturation (the point at which no new themes were recorded). They reported on the experience of sleep in their 16 children, aged 3–12 years (mean age 7 years), of whom 8 were boys. The diagnoses of the children and reasons for admission are shown in table 1.

All interviewees had slept alongside their child’s bed within the ward area throughout their child’s admission. Eleven children were admitted with acute illnesses, predominantly respiratory tract infections, while six had chronic illnesses including leukaemia and cystic fibrosis. Key themes are discussed. Quotes included in these results are identified by a code assigned to each participant. Inclusions by the researcher are denoted by square brackets.

Parents’ experience of sleep
In response to the question ‘Can you tell me how well you slept when X was in hospital?’, 15/17 parents gave brief negative responses, for example:

| Table 1 Diagnoses of the children and reasons for admission where known |
|-----------------|----------------|-----------------|-----------------|
| Age (years) | Established diagnosis | Reason for admission | Length of stay (days) | Location |
| 4 | Healthy, typically developing | Empyema | 8 | Open bay |
| 12 | Healthy, typically developing | Peri-tonsillitis | 4 | Open bay |
| 10 | Previously healthy, typically developing | Acute myeloid leukaemia | 29 | Open bay |
| 5 | Asthma | Exacerbation requiring intravenous antibiotics | 11 | Single room |
| 12 | Asthma | Exacerbation of asthma | 15 | Open bay plus PICU |
| 5 | Cystic fibrosis | Infective exacerbation | 10 | Single room |
| 8 | Congenital leg shortening | Traction | 5 | Open bay |
| 11 | Cystic fibrosis | Infective exacerbation | 9 | Single room |
| 12 | Primary ciliary dyskinesia | Infective exacerbation | 14 | Single room |
| 9 | Cystic fibrosis | Infective exacerbation | 15 | Single room |
| 8 | Asthma | Acute exacerbation | 4 | Open bay |
| 7 | Acute myeloid leukaemia | Relapsed acute myeloid leukaemia | 12 | Single room |
| 5 | Nephrotic syndrome | Wheeze (viral) | 1 | Open bay |
| 7 | Healthy, typically developing | Acute sepsis and empyema | 17 | Single room |
| 3 | Healthy, typically developing | Acute admission | Missing | Missing |
Terribly actually. #4
Not at all. No, not as well as at home. #15
Not very well at all, very broken sleep. #5
Not well at all really. I didn’t really feel comfortable enough to sleep because of the people around and the environment you are in ... I think I got about an hour’s sleep. #14
I won’t get any sleep till we get out of here. #9

Parents were asked ‘Did you think your sleep quality affected how you felt in the day when X was on the ward?’. Some parents felt that their tiredness during the hospital admission had a direct impact on their ability to function cognitively and specifically noted that decision-making was more difficult:

I noticed in conversations with the medics that I took longer to absorb information and making trivial decisions became harder. I realised being tired did not help. #1

Yeah definitely, the more tired you are the more difficult it is to function in general. It’s difficult to take into account everything that’s been said with regards to her condition. Not being able to think straight, relying on caffeine and Red Bull to get through the day. #6

Parents commonly reported emotional instability following lack of sleep:

I think it makes you a bit more emotional and I think it makes it harder to deal with things ... your reflexes are slower, you’ve got the feeling that you don’t really want to be doing anything. I think it affects you a huge amount, you’re grumpy and a bit more ‘why are we doing this now’ kind of thing. It’s that mental kind of build-up, it eats away at you eventually. #5

If I don’t get enough sleep, I’m very cranky the next day. #3

For others this led to a more general inability to cope:

I struggled to stay awake the following day. My wife was in there for 12 nights on the trot and couldn’t handle any more. She wouldn’t have chosen to come home, but she just couldn’t go on any more, surviving on a couple of hours sleep every night for a couple of weeks. #14

Child’s experience of sleep in hospital

When asked ‘Can you tell me how well X slept when in hospital?’, 8 out 17 parents reported that their child’s quality of sleep was not affected by the hospital environment:

She didn’t seem too bad actually. #10

She was pretty good really. We tried to keep it quite similar to home. #7

He slept ... as normal really. #11

However, an equal number reported that their child experienced alterations in mood and behaviour and specifically related this to the child’s sleep quality:

He did not sleep enough during the night and was very cranky and miserable the next day. #3

Two parents felt this, in turn, affected how their child coped with the hospital situation:

We have had misbehaving during the day and reaction to treatments that we wouldn’t have had if she had had a good night’s sleep. #15

The more tired she is the more difficult it is to cope with what’s going on sort of with her body and that. #6

Another theme which emerged was alteration in the scheduling of children’s sleep. A number of parents noticed that their child went to sleep later in hospital than at home:

She always tries to stay up as long as possible because there is so much going on in hospital. #4

He found it hard to settle down ... he would normally be in bed by 8, it was more like 10:30–11 pm in hospital. #5

It was noticed by some parents that their child was more difficult to rouse in the morning while in hospital, indicating insufficient night-time sleep:

He was more difficult to wake each morning ... as he’s always not ready to wake up, bit more drowsy. #3

Some parents noted that their child slept in the day, suggesting some compensation for inadequate night-time sleep:

She usually had some naps during the day, but that was partly her illness ... I’m sure her quality of sleep at night would have an impact on that as well. #1

She has been catching up on sleep during the day. #6

Factors influencing sleep

Parents were asked both with respect to their own sleep and that of their child: ‘Remembering your experience of sleeping in the ward, are there any things you would like to mention that helped you/your child sleep or made it more difficult for you/your child to sleep?’.

A pervasive theme (emerging from 100% of interviews) was noise levels during the night.

The noise came from three main sources.

Noise from other patients/visitors

I found a lot of other patient’s parents kept me awake talking and calling the nurses. #10

You could hear the young babies during the night, they were moaning and screaming. #4

My main concern is people talk on their mobile at 10 o’clock at night. #10

It’s very noisy at night. I don’t think there’s much of an effort made to be quiet. Sometimes you can hear the bins slamming and the talking, the babies crying, and you know it’s very hard to sleep. #8

Noise from hospital staff

Being on shifts [the hospital staff] obviously spoke at the same level during the night as they would [in the day]. #1

The noise [made it difficult to sleep]. The nurses carry on as if it’s a day job for them. #8

The nurses don’t always help as they are banging about quite early in the morning. #7

The staff do not seem to make a distinction between night and day ... particularly with the assessment unit that’s going 24 hours, people talk very loud, you can actually hear what they’re saying: discussing a case, or a television programme. #5

Conversely some parents reported positive experiences of staff noise levels:
in this study. Nonetheless, a majority of parents reported that their child’s sleep was impaired in hospital and of these, six associated this specifically with deterioration in their child’s behaviours. Five of these children had chronic illnesses and were familiar with hospital routines and environment. In line with previous research by Wiggs highlighting negative mood following lack of sleep, parents used terms such as ‘misbehaving’, ‘grumpiness’ and ‘crankiness’.4

Our data suggest a number of adverse effects on cognition and mood for parents that were attributed to poor quality sleep. Mothers of children who sleep poorly may have increased anger towards their children.29 30 This finding was consistent across both acute and chronic admissions. Mood disturbance, low frustration thresholds and fractious children increase the burden of hospitalisation. One parent described her tiredness which resulted in her “giving [her daughter] a hard time” despite the fact that the child was ill and in need of nurture. Negative parental affect may inflict further stress upon the child, exacerbating his/her behavioural responses.

While ultimately the urge to sleep is difficult to suppress, given the opportunity, most children will delay bedtimes. Settling to sleep is a learned behaviour best supported with a consistent structured bedtime routine and a quiet, low light, familiar sleep environment where the child feels safe and comfortable.27 28 Hospital wards challenge this ideal. Some aspects, such as the unfamiliar ward environment and natural anxieties that the child and parent will experience, are inevitable. However, aspects such as ward routines are potentially modifiable. A distinction should be made between ward routines governed by staff convenience or tradition and those centred on the child’s welfare and recovery. The timing of medication administration was reported by 10 parents to be a cause of disrupted sleep. In support of this experience, a study of 201 hospitalised Italian children under 2 years of age, reported that 50.5% had their sleep interrupted by nursing care.27 An interesting insight was given by a parent in our study who was also a doctor. Her child was receiving twice daily urokinase via a chest drain for a pleural effusion:

I appreciate the logistics of staff and timing, but ideally it would have been better in terms of sleep if [the urokinase] could have been administered in the morning. I know it has to be administered 12-hourly, but if that could be done at say 8 am and 8 pm … that would better than midday and 12 pm. #1

The introduction of strict ward routines and curfew hours for visiting could help children maintain their sleep routines. This is supported by evidence from Brazil where hospitalised children were reported to sleep more efficiently than at home and the difference was attributed to strict bedtime routines in paediatric wards.27 European paediatricians have called for changes to hospital routines to promote sleep hygiene.28 Were a clear ‘bedtime’ to be encouraged by hospital staff, both patients and the staff themselves may be more inclined to ensure that the ward environment is quiet, thus promoting sleep.29

Parents referred to several notable features of the physical ward environment. Night-time ambient light levels were reported by five parents to impair sleep as 24 h nursing and medical care necessitates minimal levels of lighting in open ward areas. Light can compromise sleep quality through two mechanisms. Exposure to early evening or night-time blue light results in circadian phase delay, encouraging progressively later sleep onset.30 At the same time, light suppresses production of the sleep-inducing pineal hormone melatonin. Deregulated ward lighting is therefore likely to exacerbate difficulty falling asleep...
in the evening and naturally delay sleep onset. Lighting solutions that minimise both lux and blue wavelength light components would be a solution.

Environmental noise, from a variety of sources, including patients, staff and medical equipment, was identified by all parents as a cause of poor sleep. This was true irrespective of whether children were in single rooms or open four-bedded bays:

Better sound insulation in the rooms would be nice … because I could hear … next door talking quite late and it was very clear, you could hear every single word. #11

Noise is a potent arousing stimulus from sleep. A polysomnographic study of adults in hospital settings identified that certain sound stimuli, namely electronic alarms from medical devices, pagers and staff conversations, resulted in a 50% chance of awakening.31 The WHO recommends that median noise levels in hospitals at night should not exceed 30 dB.32 Linder and Christian33 demonstrated abrupt increases in sound level and constantly elevated sound levels throughout the night on a paediatric oncology ward. Similar studies in adult hospital settings have demonstrated an association between noise and poor sleep, furthermore identifying avoidable sources of noise, such as noisy conversations among staff.34 While improving sound insulation would be expensive, staff behaviours during night shifts, as well as regulations around appropriate visiting times and television and electronic media curfew hours, could make a measureable difference.35 Prompt attention to alarms at night or alarms that sound directly at the nurses’ station could also reduce this source of noise.

LIMITATIONS

Qualitative research can be influenced by researcher bias. This was minimised by using the same semi-structured questions for all interviewees. Inevitably however, the presence of the researcher during data collection influences the participants’ responses.36 The fact that differences were anticipated but not found between children with acute and chronic illnesses and, similarly, the perception by a number of parents that children’s sleep quality was not overall a problem, suggests that bias was not a major problem in this study. The sample size of 17 enabled key recurring themes to be identified. As the interviews progressed, it became apparent that the data had reached saturation, that is, the majority of parents discussed previously explored points rather than raising new issues. Selection bias is a possibility when small samples are involved. Parents wishing to participate may have had more negative experiences of sleeping in hospital. However, the fact that families were generally recruited within the first 24–48 h of admission, and that some reported positive experiences, suggests that this was not a significant problem. We did not screen parents in the study for sleep disorders and, while no parents related a personal history of sleep difficulties during interviews, such a history could have potentially led to a negative emotional response bias. Future studies could usefully include data on parental sleep history.

Data may not necessarily be transferable to other settings. Surgical wards, other UK hospitals and international settings may differ. However, consistent with our findings, other authors have reported the negative impact of excessive noise and light levels in both adult and paediatric ward settings on sleep.37 A study carried out in Massachusetts demonstrated the disruption caused by a range of hospital sounds on sleep, thereby underlining the importance of improvements to the acoustic environment of healthcare settings to optimise sleep quality.38 Furthermore, the stringent bedtime routines in paediatric wards in Brazil enabled children to experience better quality sleep in hospital than at home.22 Future studies could usefully replicate our findings in other settings and combine objective measures of sleep quality with measures of environmental factors, such as noise and light, identified by parents in this study as major obstacles to sleep.

CONCLUSION

Parents reported poor sleep quality when co-sleeping with their children in hospital. Importantly, they identified modifiable factors in the hospital environment which affected their sleep quality. Intervention trials targeting environmental and cultural modifications in paediatric night-time care are needed to establish the benefit of such changes to child and parent alike. Hospital staff are advised to ‘wake up’ to the importance of sleep for child and parent wellbeing.

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Arch Dis Child  published online March 24, 2016

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