

**‘Like Walking in A Fog’ - Parents' Perceptions of Sleep and Consequences of Sleep
Loss When Staying Overnight with Their Child in Hospital**

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Summary

Disruption of parental sleep in hospital, with frequent awakenings and poor sleep quality, limits the parents' resources to meet the child's needs and maintain parental wellbeing. The aim of the study was to explore and describe how parents perceive their sleep when staying overnight with their sick child in hospital. A further aim was to explore and describe parents' perception of what circumstances influence their sleep in the hospital. Twenty-two parents who were accommodated with their sick child (0-17 years) in pediatric wards in Norway and Sweden participated. Interviews were conducted during the hospital stay to elicit their perspectives. Phenomenography was used to analyze data. Two descriptive categories were found: 1) "Perceptions of sleep", with two sub-categories: "Sleep in the pediatric ward" and "Consequences of sleep loss", and 2) "Circumstances influencing sleep in the pediatric ward" with three sub-categories: "The importance of the family", "Information and routines at the pediatric ward", and "Accommodation facilities". Parents' sleep and needs must be acknowledged in pediatric wards. An individual plan of care for the upcoming night could be a valuable tool for both the parents and nurses. The child's medical needs must be met with respect to the parents' willingness to take part in the child's care during the night and the need for rest and sleep for both parent and child.

Keywords: Children, Hospitalized; Family-Centered Care; Pediatrics; Pediatric nursing

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Introduction

According to Article 9 in the Convention of the rights of the child (United Nations, 1989), children must not be separated from their parents against their will. To prevent separation and to comply the child's need of safety, many hospitals offer accommodation for parents during the child's hospital stay. In Scandinavian countries, it is a policy that at least one of the parents stays together with the child 24 hours a day. This improves the child's experiences and coping during the hospitalization (Coyne, Hallström, & Söderbäck, 2016; Shields et al., 2012). However, there is little qualitative research on how parent's overnight stay at hospitals is experienced.

Sleep is essential for health and recovery. Good sleep quality has been defined by the National Sleep Foundation as sleeping at least 85% of the total time in bed, falling asleep in 30 minutes or less, a maximum of one perceived nocturnal awakening and being awake for 20 minutes or less after initially falling asleep (Ohayon et al., 2017). Sleep deprivation may lead to health problems such as decreased cognitive performance, memory deficits, and depressive mood (Koren, Dumin, & Gozal, 2016; Morin & Jarrin, 2013; Porkka-Heiskanen, Zitting, & Wigren, 2013).

It is psychological factors, e.g. stress, anxiety, worries and difficult thoughts, as well as poor accommodation facilities, noise, bright lights and ward activity that hinder parents' sleep in hospital (Edéll-Gustafsson, Angelhoff, Johnsson, Karlsson, & Mörelius, 2015; Nassery & Landgren, 2018; Stremmler, Dhukai, Wong, & Parshuram, 2011; Stickland, Clayton, Sankey, & Hill, 2016). In addition, participation in care may increase the number of disturbances during the night. A recent study reports that parents were less alert and had reduced concentration

when they had stayed overnight at their child's bedside in hospital compared to at home. However, the child's age or diagnosis were not significant factors for their sleep disruption (Angelhoff, Edéll-Gustafsson, & Mörelius, 2018).

Good sleep is necessary for the parents' and the child's health and well-being. The disruption of parental sleep during the night for a long period, with frequent awakenings and poor sleep quality, affect and limit the parents' resources to meet the child's needs and maintain parental wellbeing (Angelhoff, Edéll-Gustafsson, & Mörelius, 2015; Lee, Chai, & Ismail, 2012; Meltzer & Mindell, 2006; Meltzer, Davis & Mindell, 2012; Stickland et al. 2016). To find interventions that could improve parents' sleep when staying overnight with their child in hospital it is important to get a deeper knowledge of the subject. The aim of this study was to explore and describe how parents perceive their sleep when staying overnight with their sick child in hospital. A further aim was to explore and describe parents' perception of what circumstances influence their sleep in the hospital.

Method

Design

This study was explorative and descriptive. A purposeful sample was used to find parents of children with a variation of ages and diagnoses, accommodated in the same room as their child at a pediatric ward for at least one night.

Setting

One pediatric ward in a general hospital in Norway and one pediatric surgical ward in a university hospital in Sweden were included in the study. According to organizational routines at the wards, the child's care during the hospital stay is depending on parental

participation 24 hours a day. Both countries offer temporary parental leave from the government when their child needs hospital care, which gives parents the opportunity to stay.

The accommodation facilities differed between the two pediatric wards; one ward offered single or shared patient rooms with a plastic mattress at the child's bedside for the parents, the other ward offered single patient rooms with wall-hung folding beds for the parents.

Procedure

In Norway, the study was registered in The Norwegian Center of Research Data (NSD-58428), after recommendation from the Regional Committee for Medical Research (REK 2017/2152). In Sweden, ethical approval for the study was obtained by the Regional Committee for Medical Research (DNR 2017/473-31).

The parents were contacted by nurses and nurse assistants at the pediatric wards, who gave them written and oral information about the study. After receiving an informed consent form, the parents were contacted by one of the authors (CA, HS or BL) to arrange time for the interview. All interviews (eleven in each country) were conducted at the hospitals in the patient's room or in a room close to the pediatric ward to ensure privacy for the conversation, between January and March 2018. The interviews were recorded digitally and lasted between 12-45 minutes.

Data Analysis

Data analysis was performed in seven steps according to phenomenography (Sjöström & Dahlgren, 2002). Phenomenography describes both similarities and differences in how a phenomenon is experienced and conceptualized by the individual. The researcher aims to constitute not just a set of different perceptions, but a relation between the different

perceptions. The descriptive categories constituted by the researcher to represent different ways of experiencing a phenomenon are thus referred to as the outcome space, i.e. the result of a phenomenographic study (Marton, 1981; Marton & Booth, 1997). Credibility within phenomenography involves people's different ways of describing their perceptions. To enhance trustworthiness, all steps of the analyzing process are described together with a presentation of the parents and the interview guide. The interview guide consisted of following questions: How would you describe your sleep at home? What does good sleep mean to you? Do you perceive that your sleep/sleep loss affects you as a parent? How would you describe your sleep in the hospital? How does your sleep differ between sleeping at the hospital and sleeping at home? Do you have previous experiences of staying overnight at a pediatric ward? What would facilitate and improve your sleep in the hospital? Additional probing questions were added during the interviews to enrich the data. No specific question about factors that hinder sleep was needed as the parents talked about them without asking.

Scandinavian languages have similar linguistic characteristics and major differences between Norwegian and Swedish are few (Faarlund & Haugen, 2011). To capture nuances in the languages and cultural differences that may occur in the different countries, the authors discussed the questions carefully before a consensus of the interview guides were taken.

The researchers' unique backgrounds and values are inherent in all steps of the analysis process (Cope, 2004). The authors of this study have expertise in pediatric nursing (CA and EM), psychiatric nursing (BL) and sociology (HS). The authors discussed and reflected to avoid inclusion of their own perceptions. The first three steps of the analysis (familiarization, compilation and condensation) were given high priority to understand the material. The interviews were transcribed verbatim and read several times by the authors in Norway (BL, HS) and Sweden (CA, EM) separately, to find and condense the most significant answers. Thereafter all authors discussed the content and started the grouping of the condensed

perceptions (step 4) and compared sub-categories to reduce them (step 5). The sub-categories were discussed and revised iteratively, before descriptive categories were found and named (step 6). The descriptive categories were finally described in an outcome space (Figure 1), that constitute the result of a phenomenographic study (step 7). Quotations are used to support the findings (Sjöström & Dahlgren, 2002).

Findings

Twenty-two parents (eighteen mothers and four fathers) participated in the study. The parents' age ranged between 26-52 years (mean 38.9 years, sd 7.8). The median length of stay was two nights (range 1-10 nights). The children's ages ranged between four weeks and 16 years (mean 8.4 years, sd 5.8). There were variations in the diagnoses and severity of the children's illnesses, and of acute and planned admissions (Table 1).

[Place Table 1 here]

The result consists of two descriptive categories answering the aims of the study: 1) "Perceptions of sleep", with two sub-categories "Sleep in the pediatric ward" and "Consequences of sleep loss", and 2) "Circumstances influencing sleep in the pediatric ward" that includes three sub-categories "The importance of the family", "Information and routines at the pediatric ward", and "Accommodation facilities" (Figure 1).

[place Figure 1 here]

Theme 1. Perceptions of Sleep

This category describes how the parents perceived their sleep in the hospital and consequences of sleep loss in the hospital.

Sleep in the pediatric ward. There were great variations in how the parents described perceptions of their sleep in the pediatric ward, often with a reference to their habitual sleep in home. Parents with good sleep quality at home described better sleep quality in hospital than those with poor sleep at home.

Several parents described how they woke up during the night in hospital because their child needed their attention due to crying and/or pain, but also just to check that the child was all right.

...well, it has been a bit better at times, and then, well, then I've, you know, I've slept with her in my arms here and it- As long as she's sleeping tightly and is not in pain, well, then I can sleep, but then, well, then, of course, she wakes up, but, for some periods, in any case. (P5)

Parents who described that their child slept well during the night found it easier to relax and achieved better sleep themselves. One mother described that she got even more hours of sleep in the hospital as she went to bed at the same time as her child, instead of being up late as she used to at home.

Parents staying for a longer time at the pediatric ward described how they had adapted to the situation and slept better after a few nights at the hospital. A mother of a 16-year-old child described how she laid on the bed with her clothes on during the first nights, ready to get up if the child needed help or if someone in the staff should enter the room. After a couple of nights, she could relax and slept like she did at home. A mother of a four-weeks-old baby described how she awakened several times during the first nights when the staff came in to administer medication to the child but after a couple of nights, she did not take any notice of them and slept through the night even if the staff was in the room. Another mother who had stayed at the hospital for seven nights said,

I noticed this the first days, when I was by the [child's] bed the whole time. I slept maybe two-three hours, that's it. And the day is just as hard. But it gets better after some time because you see that it's moving forward, and then you sleep better. (P15)

Almost all parents said that they could deal with shorter sleep duration at the hospital as they knew it was for a short time and best for the child. Parents of children with planned admissions described that they were prepared for a time of poor sleep. Even though they were tired they put up with sleep loss as they had no other choice. One mother expressed that "as long as my girl gets better, it doesn't matter. Then I can probably be here for several months, if it's necessary" (P6).

Consequences of sleep loss. Most parents described negative effects of sleep loss, such as decreased ability to concentrate, solve problems and to receive and understand information. They lacked the energy to care for their child and described difficulties to meet their child's needs. "It's like I'm completely drained, I get so exhausted. I am done, completely done" (P16). Two mothers of teenagers described, independently of each other, that they had no acceptance for their children's teenage-manners as their patience wore thin due to sleep loss.

Loss of energy and exhaustion led to negative mood. It was difficult to accept that they could not be as alert and productive as they were used to. A mother of a 16-year-old child described how her son's sleep loss led to negative mood, which in turn affected her mood as well:

I'm more affected by the fact that we're not in phase with each other, because normally we have quite a lot of fun together you're never able to sleep properly. And it's the same for him, of course, because he's not able to sleep either The whole situation means that you, you know, it just gets you down a bit. (P1)

Inactivity at the ward during the day led to feelings of passivity and isolation. Most of the day, the parents sat idle, waiting for examinations and information, or accompanied their tired and, sometimes, sleeping child. They felt apathetic and dull, "like walking in a fog" (P10).

You feel more exhausted at a place like this, I think. I feel more tired, you don't do very much, there's not much to do. And partly [child's name], he spends more time in bed, he's more tired. I mean, he needs sleep to help him recover a bit better, so you end up mostly sitting, and it, it makes you apathetic. (P8)

To recover from the nights' sleep loss and cope with the situation some parents used the inactive time to take day naps.

Theme 2. Circumstances Influencing Sleep in the Pediatric Ward

For some parents, the feeling of being in a hospital was enough to affect their sleep and mood. One mother expressed: "I don't like hospitals at all, so it's about the whole combination of things, it's not like you're there without a reason" (P13). However, there were a variety of circumstances that influenced the parent's sleep in positive, as well as negative, ways.

The importance of the family. It was important to feel safe and secure to be able to get a good night's sleep. This included security for the child as well as for the parents themselves and the whole family. One mother declared, "The safer you feel, the better you sleep. If you feel unsafe, I don't think you can sleep in all" (P6). Many parents emphasized the importance of being together with their sick child and expressed satisfaction with the opportunity of being accommodated at their child's bedside. Being close to their child did not only give them control over the situation but also a chance to support and speak up for the child. A father reflected,

I thought it worked surprisingly well to sleep here, even so, and then I think that it feels safe to sleep with the child as well, simply the fact that they know that I'm here I think that closeness is important, actually And it's good that you can sleep in the hospital to be close to your child: I think it's important, or actually, I think it's necessary. (P9)

The child's age did not affect the parents' wish to stay at the hospital. One mother described how her 16-year old son usually lived by himself in an own apartment, as he studied in another town. She stated that she, even though her son was a teenager and used to stay by himself, wanted to be by his side when he was ill and needed hospital care.

Some families chose to take turns during the nights in hospital to get a chance to recover and regain energy. A father described how he and his wife took turns, to manage work and the home situation during the hospital stay:

There was an idea that things would be better workwise, I mean, we both have jobs to go to, and there was a suggestion that it would be good to. But we'll just have to see how we do things next time. It may be better to have a couple of nights in a row, or something, but there's also the fact that you want to be with the other child, you know, so then you have to take it in turns. (P10)

Being away from the rest of the family and the home was perceived as depressing for many parents as they missed their partner and their other children. Many mothers described that they lacked support from their partner, whereas others expressed that they did not want to leave the responsibility to the other parent. They perceived that they were the primary source of safeness for the child or did not expect the other parent to handle the situation.

Information and routines at the pediatric ward. For most parents, information regarding nightly routines at the ward, an individualized plan for the child's care during the

night, and clarity in who was responsible for the child's care during the night was a prerequisite for sleep. Worries about the child's health and uncertainty about the future affected the parents' sleep negatively. Not knowing how long they were going to stay at the hospital or what was going to happen during the day was frustrating and worsened the parents' mood. Some parents described these feelings as more exhausting and demanding than the sleep loss.

The parents requested information about the upcoming night's doings and asked for a plan of care with the nursing staff for the night. "I think that it's good, sort of, to know that, well, when they're coming, and so on, you know. It makes you calmer and such, so it means that I can sleep soundly" (P2). Some parents had found written information about routines at the pediatric ward but asked for oral information and an individualized plan customized after their child's needs. There were also differences in the nightly routines depending on who was working on the shift. This affected the predictability of what was going to happen during the night and gave the parents a sense of insecurity.

The parental role and responsibility during the night was not always clear to the parents. They were unsure of who had the main responsibility of the child's medical care during the hospital stay and especially during the nights. Most parents felt that they should be the ones to comfort, console and care for the child's wellbeing. They wanted to do what they could as they were the child's parent and had primary responsibility for the child's basic care. As one father described,

And they've made the offer as well, because it was, you know, the first evening and I had to walk with her in the corridors for hours and carry her, so that she could settle down, and so on. But then, they said that they could take her, but no, I don't think that it's- I don't want to let go of her, you know Your dad's your dad, and your mum's

your mum They don't know them, do they, even if they have got good contact, even so it's not the same thing It's my role. (P5)

In contrast, some parents described that they did not want to be awakened if the nurse came into the room; they thought it was the nurse's responsibility to do the regular vital sign checks and administer medications during their rounds.

For some parents, the nightly rounds caused several nocturnal awakenings, even if the staff tried to be quiet. They experienced that the staff did not show respect for their or their child's sleep when they entered the room.

Some of the nursing staff working at night put the lights on in the room by the sink so that half the room is lit, while the others have a little light on their uniform that disturbs as little as possible. And that is a major difference to having the lights suddenly turned on, because I know that I wake up. (P12)

Others described that they slept through the night and did not hear when the staff came into the room.

I think it's about the nurses. That's what I think. Because the one who was there on the nights I slept better, is very calm. She comes inside and talks to me and makes me feel safe when I talk about the things that worry me. That way I get to calm down and then go to sleep. (P21)

Parents with earlier experiences of being accommodated at the pediatric ward knew what was expected from them and found it easier to tell the staff how they wanted the night to be. This did not only affect their sleep during the night positively, it also increased their satisfaction with the hospital care.

Accommodation facilities. The accommodation facilities were mentioned in both negative and positive terms. They described how they appreciated single patient rooms as

they, as well as their children, needed some peace and quiet and the opportunity to be by themselves.

It's so nice to have your own room and just look after yourselves, and not have to think about someone else, that you might be disturbing someone else, or anything, because there are so many things among everything else, when you're here you want to have a bit of peace. (P4)

Parents in shared room described difficulties to sleep and relax due to snoring, coughing and noises from the other individuals in the room, and they expressed a lack of privacy.

Many of the parents that slept on a mattress on the floor expressed dissatisfaction as they perceived this as both unhygienic and uncomfortable. They pointed out that they were not at the same level as the child. This negatively affected their ability to see the child and answer to the child's needs negatively. Some parents with younger children chose to have the child with them at the floor to be closer to the child or because the child did not want to sleep by themselves in a bed. At the other hospital, some parents with younger children chose to move the patient bed close to the parents' bed so that they could reach the child during sleep.

We arranged it so that it was just beside my child's bed, so that it was easier just to calm the child by stroking, or something Sleeping beside may have a calming effect as well, so that, mmm I think I've not slept as well because of this, but it feels right to do it anyway, mostly to be able to hear a bit about, eh, what happens during the night. (P10)

The parents' perceptions of the accommodation facilities also included the room environment, such as temperature (too warm and too cold), pillows, unfamiliar medical equipment and lack of colors.

Discussion

The findings of this study provide new information about parents' perception of sleep in the pediatric ward, consequences of sleep loss, and positive as well as negative factors influencing their sleep in the hospital. The parents described negative effects of sleep loss leading to decreased ability to concentrate, lack of energy, less patience and apathy. This is consistent with results from previous qualitative studies of parents' sleep in hospital (Edéll-Gustafsson et al. 2015; Nassery & Landgren, 2018). Moreover, the parents described how mood was negatively affected by tiredness and passivity during the days. Time spent inactive between the child's treatment and investigations at hospital has previously been described by parents as time of anxiety, stress, fear and boredom (Corsano, Majorano, Vignola, Guidotti, & Izzi, 2015). Trimm and Sanford (2010) have reported waiting as the most stressful aspect of the hospital experience for family members, with a constant struggle to maintain a balance between negative and positive thoughts. In the current study, uncertainty was another source of stress which affected the parent's ability to fall asleep. This could be eased by regular communication and information by the nursing staff.

The parents appreciated the opportunity to be accommodated at their child's bedside so that they could be there to comfort and console their child when needed, regardless of the child's age. Single patient rooms were highly appreciated and facilitated sleep, while parents in shared rooms complained about noises and disturbances from other patients interrupting their sleep. Single patient room is reported as significant for improving sleep in parents (McCann, 2008) and beneficial for stress reduction, relaxation and privacy, leading to better sleep during the hospital stay (Edéll-Gustafsson et al., 2015; Nassery & Landgren, 2018), but could also be a source of isolation for the parents (Edéll-Gustafsson et al., 2015). When renovating or rebuilding pediatric wards, single patient rooms with beds for the parents to stay in the room should be highly considered. However, when single rooms are used, other facilities that can give parents opportunities, if they want, to meet with parents in similar

situations for peer support, may be needed. At hospitals where single rooms cannot be offered, it is important to find other ways to make sure the parents are given the opportunity to find some peace and quiet. Some hospitals offer accommodation at Ronald McDonald House, which facilitates parents' attendance during their child's admission and provide opportunities for essential sleep for the parents (Franck et al., 2014).

In the current study, some parents moved the beds in the patient room so that they could sleep closer to their child during the night. The importance of being close to their child during the admission was not only perceived as beneficial for the child, but also for the parents themselves. This is in line with a study of parents in neonatal intensive care, reporting that being close to the child during the hospital stay improves parents' sleep (Edéll-Gustafsson et al. 2015).

Participation in the child's care gives the parent a feeling of control and is an important part of their child's recovery (Nassery & Landgren, 2018) as well as the parents' well-being (Darcy, Knutsson, Huus, & Enskär, 2014). However, there was an uncertainty and insecurity among the parents in the current study of what was expected from them regarding their child's care during the night, especially those parents who visited the pediatric ward for the first time. This insecurity meant that some parents did not fall into deep sleep or slept with their clothes on, ready to get up if the nursing staff would enter the room. According to Jones, Nowacki, Greene, Traul, & Goldfarb (2017), supporting parents during their child's hospital admission may increase the parents' ability to participate in hospital care and decrease psychological distress. An important aspect of this is for the parent to be familiar with care routines so that they feel secure and can provide comfort and security to the child (Dahav & Sjöström-Strand, 2018). The need for rest and sleep in the family and the variation in parents' willingness to take part in the child's care during the night must be acknowledged and asked for by the nurses at the ward. To get an opportunity to improve their sleep in the hospital, the

parents must receive adequate information about the upcoming nights' activities. This could be done by creating individualized plans of care for the upcoming night, so that the demands of the child's medical needs will be met. The individual plan of care should not only consist of what kind of medical or nursing care the child needs, but also be clear about how, when and by whom it will be performed, and written in consensus between the nursing staff and the parent. Moreover, nurses need tools and routines to talk about sleep with the parents, to find and support those parents that are at the hospital for the first time as they seem to have more need. Otherwise, in busy times it may be impossible to recognize the families in need of interventions to improve sleep.

A strength with this study was that it was performed in two different pediatric wards in two countries. This enhances transferability to other contexts of pediatric facilities. On the other hand, it was performed in countries where parents can benefit from temporary parental leave for their sick child, which may not be eligible in other countries. The parents were approached during their hospital stay, to capture their perceptions of sleep in the present moment. However, this could have stressed the parents, as they maybe wanted to return to their child as quick as possible. A limitation of the study is that a majority of the parents had stayed only for a few nights in the hospital. Perceptions of sleep could change over time when staying with a child in hospital. Those who had been in the hospital for just one night might have had a different perception if they had stayed for more nights. Regular review and discussions of the analysis with all members of the multidisciplinary research team increased the trustworthiness of the data (Korstjens & Moser, 2018). The Consolidated criteria for reporting qualitative research (COREQ) was used to ensure that all relevant information was included in the paper (Tong, Sainsbury, & Craig, 2007).

Conclusion

In summary, this study provides important information of parents' perceptions of sleep when they are accommodated at pediatric wards with their child and highlights the importance of being close to their child, regardless of age, during the hospital stay. An individual plan of care for the upcoming night could be valuable tools for both the parents and nurses, so that the child's medical needs will be met with respect to the parents' willingness to take part in the child's care during the night and the need for rest and sleep for both parent and child. However, more interventions directed to parents and children at hospital should be developed and evaluated, focusing on improving sleep and decreasing stress.

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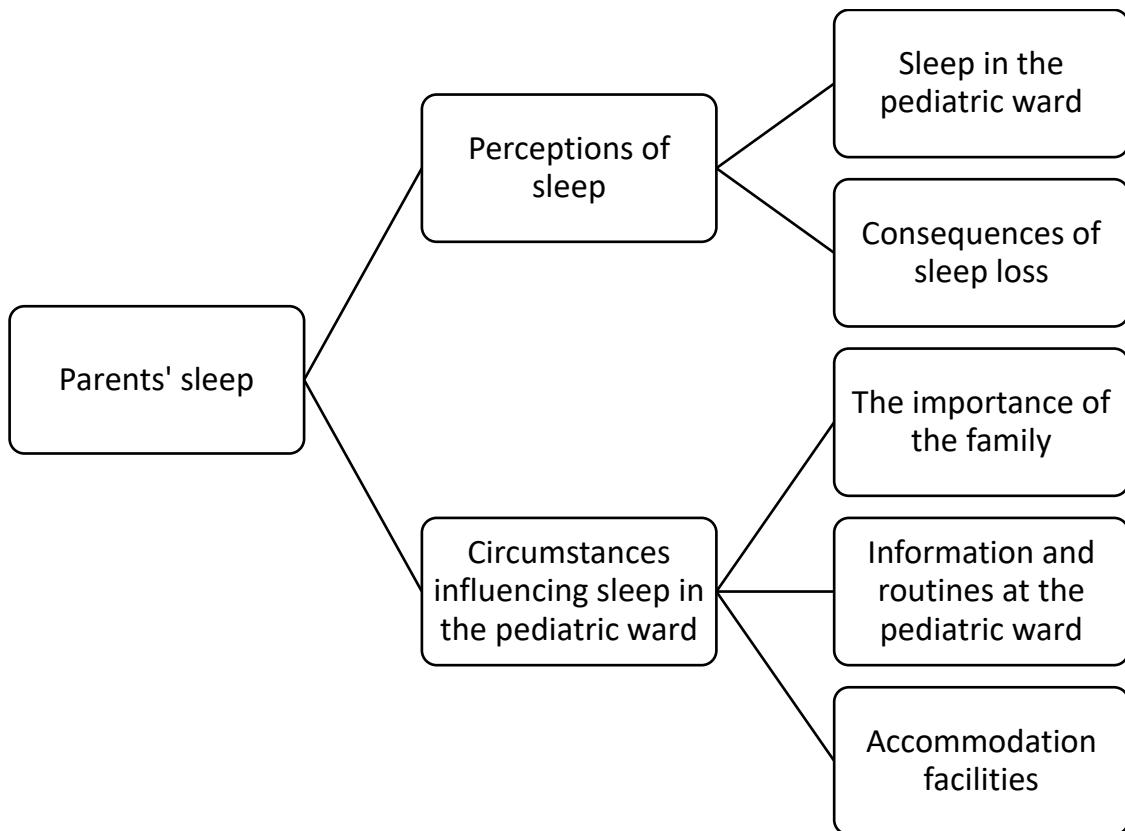


Figure 1. The outcome space, showing the different descriptive categories and the relation between them.

Table 1. Participant demographics.

Code	Mother(M) Father (F)	Marital status ^a	The child's age (years)	Reason for the child's admission	Number of nights (parent)	Number of nights (child)
P1	Mother	Single	16	Leg fracture	6	6
P2	Mother	Married	11	Surgery (spinal) ^b	3	3
P3	Mother	Married	15	Surgery (foot/heel) ^b	1	1
P4	Mother	Married	13	Urinary problems, treatment ^b	1	1
P5	Father	Married	2.5	Surgery (hip) ^b	2	4
P6	Mother	Married	11	Surgery (spinal) ^b	5	5
P7	Father	Married	14	Leg fracture	4	5
P8	Mother	Married	15	Surgery (foot/heel) ^b	1	1
P9	Father	Married	13	Surgery (spinal) ^b	2	4
P10	Father	Married	4	Surgery (foot/heel) ^b	3	6
P11	Mother	Married	9	Surgery Appendicitis	5	9
P12	Mother	Single	14	Myalgic encephalomyelitis, screening	4	4
P13	Mother	Married	5	Migraine	1	1
P14	Mother	Married	1.5	Respiratory disorder	1	1
P15	Mother	Married	7	Abdominal pain	1	1
P16	Mother	Married	2	Limping	1	1
P17	Mother	Married	15	Diabetes	1	1
P18	Mother	Married	1.5	Respiratory disorder	10	10
P19	Mother	Married	13	Myalgic encephalomyelitis, screening	1	1
P20	Mother	Married	1.5	Leukemia, treatment	2	2
P21	Mother	Married	1	Respiratory disorder	7	7
P22	Mother	Married	4 weeks	Respiratory disorder	4	4

^a including cohabitated with a partner, ^b planned admission