Siblings’ experiences of sleep disruption in families with a child with Down syndrome

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Objective: Adverse effects of sleep disruption are identified in parents who live with a child with Down Syndrome (DS), yet there is no research on siblings’ experiences. This study addresses this knowledge gap.

Methods: Semi-structured sibling interviews explored what it was like to have a sibling with DS and sleep difficulties; the participant’s own sleep; how their sleep affected how they felt during the day; how sleep impacted their family; and advice that they would give to other siblings. Parent interviews included similar topics; here we report on excerpts in which parents reference siblings. Interviews were audio recorded, transcribed verbatim, and analyzed using a reflexive thematic analysis.

Results: Siblings and parents acknowledge sleep disruption for siblings; yet sleep disruption is normalized, viewed with acceptance and inevitability. Siblings report adverse effects from sleep disruption, view sleep in a relational way, and cope with sleep disruption. Parents can underestimate siblings’ sleep disruption and are uncertain whether siblings’ symptoms result from sleep disruption or other causes.

Conclusions: Siblings of a child with DS experience sleep disruption and may be at risk of developing long-term health problems without focused support.

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experiences. Siblings report feeling acceptance, love, and pride toward their sibling with DS, and many describe becoming more patient, considerate, caring, compassionate, appreciative of human variation, and understanding of disability. Siblings also encounter challenging experiences, such as extra chores and caregiving responsibilities, parental stress, and negative societal views toward their sibling. Missing in this literature are accounts of siblings’ experiences of sleep disruption deriving from the night behavior of children with DS.

Sleep disruption among young carers

Sleep is a vital health and well-being indicator, as important to health as diet and exercise, and critical to many functions, such as memory, learning, immunity, emotion, and mood. Given its significance, sleep among young carers is gaining attention. Recent survey, qualitative, and phenomenological studies in Australia and the United Kingdom found that child carers engage in age-inappropriate night-time caregiving, which they often normalize. This entails frequent awakenings and ongoing worrying, alertness, and monitoring of the care recipient, and care provision. Adverse consequences include shortened sleep, poor sleep quality, impacts on well-being and daytime functioning, and stress and tiredness that impede education and social opportunities, particularly at school.

Sleep in families of children with Down syndrome

In the general literature on sleep in families, little research addresses how siblings affect one another’s sleep, outside the context of bed sharing. Studies on families of children with DS have focused on day-time and parental caregiving, with parent reports more common than sibling reports. Research finds that these parents evaluate their conceptualizations of “normality”; framing their child as a “normal baby” is key to parents’ sense making and adaptation to a “new normal”. A qualitative Danish study described parents’ need to be alert to their child with DS, resulting in less attention for siblings. Notably, families often scheduled time when their child with DS was away (eg, a night with grandparents) to spend time with their other children and to have a good night’s sleep. Importantly, a recent study identified that parents’ normalizing extends to the domain of sleep, with parents conceptualizing their tiredness as synonymous with parenting, rather than relating it specifically to their child with DS.

Study aim

This qualitative study is underpinned by (1) an interpretivist approach that seeks to understand how child siblings interpret and ascribe meaning to their experiences, and (2) a child rights approach, informed by The United Nations Convention on the Rights of the Child, which states that children have a right to have input on matters that affect their lives. In addition to a child voice imperative, there is a health rationale underpinning this study, as self-reported sleep characteristics correlate with health outcomes and may reflect self-appraisal of overall health, which is an important health and well-being domain. How siblings of children with DS and their parents interpret siblings’ experiences of sleep disruption will significantly influence support for siblings’ sleep. This study aims to answer the following research question and sub-questions:

How do child siblings experience sleep disruption in families with a child with DS who has sleep difficulties?

How do child siblings view their experiences of sleep disruption?

How do parents view child siblings’ experiences of sleep disruption?

Methods

Sample and data collection

This qualitative study is part of a larger mixed-method study, *Sleep Difficulties in Children with Down Syndrome: An Evaluation of Parent/Carer and Family Quality of Life*, which included semi-structured interviews with 31 families with a child with DS and sleep difficulties. We report on a subset of this sample: 8 families where a sibling(s) of the child with DS was interviewed. We conducted 9 interviews with 11 siblings: one sibling each from 5 families, 2 siblings each from 2 families in a joint interview, and 2 siblings from 1 family in separate interviews.

Situated within the sociology of childhood paradigm, we conceptualized children as competent social agents who need to be understood in relation to the social order of intergenerational relations, which shapes how children are listened to. Accordingly, we sought to understand children’s and parents’ views, to provide important contextual insights into children’s experiences and voices within a family. Sibling interviews were semi-structured, with open-ended questions focusing on what it was like to have a sibling with DS and sleep difficulties; what participants’ own sleep was like; what it was like to be woken up by the child with DS; how they felt waking up in the morning; how they felt during the day after a good or bad night’s sleep; how they noticed a bad night’s sleep affecting their family during the day; and what advice they would give to other siblings of children with DS (full interview guide available upon request).

We interviewed 8 mothers and 3 fathers from the 8 families. We report only on instances where parents reference siblings, usually in response to questions about how sleep disruption affects family dynamics. Further details regarding parent interviews are reported in a separate paper on parents’ experiences (Table 1).

The first author, who has expertise in research with children, interviewed children over Zoom or phone between May and August, 2021. Parents talked to their children about the interview to gauge interest, and if the child was interested, the parent provided written consent. At the start of the interview, the interviewer explained the purpose of the interview using child-centric language and asked for children’s informed verbal assent. Ethics approval was obtained from Children’s Hospital Queensland Hospital and Health Service Human Research Ethics Committee HREC/20/QCHQ/65571.

Informed by child-centric methodology, the interviewer adapted their language, intonation, and expression to suit the needs of child participants, who were aged between 5 and 15 years old. In families where the child with DS had multiple siblings participating, to ensure that children felt comfortable and empowered, each child chose whether they participated in an individual interview or a joint interview with their sibling. Younger children participated with their parent/s sitting next to them, to make them feel more comfortable, and so that they were not talking to a stranger on a device by themselves. Older children preferred to participate without their parents sitting next to them (ie, parent(s) in a separate area of the home). The length of the interview was child-determined: when the child began to show signs of disinterest, the interviewer concluded the interview. Children had some control over the direction of the semi-structured interview; the interviewer had key interview questions but followed children’s lead to build rapport. The interviewer asked follow-up questions to elicit in-depth descriptions. Interviews lasted 12-34 minutes and were audio recorded, transcribed verbatim, and de-identified. Pseudonyms were assigned to maintain children’s sense of personhood while protecting their identity.

Data analysis

A reflexive thematic analysis (TA) was led by author Emma Cooke (EC) who is a sociologist with expertise in qualitative
methodologies. In reflexive TA, themes refer to meaning-based patterns across a data set. Author EC followed the 6 steps for reflexive TA: (1) data familiarization and note-taking, (2) data coding, (3) generating initial themes, (4) developing and reviewing themes, (5) refining and defining themes, and (6) producing the report. During the initial stage of data familiarization, author Caitlin Smith (CS) assembled a table to record quotes pertaining to sibling’s sleep, with quotes from siblings in 1 column and quotes from the corresponding parents in another column. This comparative approach supported the identification of discrepancies in parents’ and siblings’ accounts of siblings’ sleep disruptions, with author CS recording these initial observations. Author EC read and re-read the interview transcripts and made notes. Author CS and EC’s notes informed the initial coding, which they then used to generate initial themes.

In reflexive TA, the researcher’s subjectivity is an important analytic resource. Author EC has expertise in the sociology of childhood and author Maria Carmen Miguel (MM) has worked as a clinical nurse for over 20 years, including 9 years as a sleep clinical nurse, and has 2 neurodiverse children. Researchers’ subjectivity was particularly significant in the developing and reviewing, and the refining and defining of themes, as authors sought to identify ‘latent’ level meanings, that is, underlying ideas, assumptions, and conceptualizations that shaped participants’ accounts. Key to the lengthy analytic process of developing and reviewing themes were the conversations between authors EC and MM as they immersed themselves in the data and questioned, analyzed, and wrote together, which often involved author MM drawing upon her lived experience. For instance, MM’s knowledge of sleep shaped the development of themes and especially the health-focused theme implications. Reflexivity was also integral to the defining themes; for example, while it was grounded in the data that siblings’ sleep was interconnected and influenced by other family members, author EC’s knowledge of the sociology of childhood contributed to the naming of this theme: ‘siblings view sleep in a relational way’.

As we will demonstrate, our findings provide critical insight into why parents and siblings of children with DS normalize siblings’ sleep disruptions and may not seek support for these disruptions.

### Findings

The overarching finding from our TA was that siblings’ sleep disruption is normalized; both siblings and parents acknowledge—to varying degrees—that sleep disruption for siblings results from behaviors of the child with DS in the family, yet they concurrently view such disruption with a sense of acceptance and inevitability. Below we present 5 key themes under 2 domain headings: “Siblings’ experiences of sleep disruption” and “Parents’ views of siblings’ experiences of sleep disruption”.

#### Siblings’ experiences of sleep disruption

Siblings’ experiences of sleep disruption were characterized by 3 related themes: (1) siblings experience adverse effects from sleep disruption, (2) siblings view sleep in a relational way, and (3) siblings cope with sleep disruption. The combination of the second 2 themes results in sleep disruption being normalized for siblings.

#### Siblings experience adverse effects from sleep disruption

Siblings reported a variety of ways that they were affected by sleep disruption, including negative impacts on their emotional regulation, bodily fatigue, and difficulties with focusing and functioning during the day, particularly at school.

Sean reported adverse emotions and schooling impacts from sleep disruption: “I usually wake up at 12 [am], because my [brother with DS] wakes up at 12… turns on my light and wakes me up… I just go back to sleep, but he always jumps on me.” This made him feel “angry… upset… very, very tired”. This sleep disruption leads to sleeping in and school tardiness: “I always get to be late for school… because we’re sleeping until eight, like 59.” He said that when he feels tired at school, “it makes me feel angry.”

Jenny’s start to the day is also negatively impacted by sleep disruption as she experiences depleted motivation and physical energy:

When I wake up, I just don’t want to move any bit of my body or do anything. And then eventually, if it’s a school day, mum will go like, you have to get up, it’s a school day… when I stand up, I might feel wobbly and stuff on my feet.

Similarly, upon waking from a night with disrupted sleep, Mitch says that he will “feel a bit groggy…” I find it a bit harder to focus at school and getting ready.” This also resonated with Jacob who said that, “sometimes when I don’t really go to sleep I want some energy.” When asked how he then felt at school, he said “going slow… talking slow”.

Siblings described the negative impacts of sleep disruption affecting them across the school day. Kalina explained how sleep disruption diminished her capacity to focus at school and socialize with her friends, intimating feelings of isolation:

When I’m at school, I sort of lose interest in the stuff we’re doing or just zone out and—or just play games on my laptop and sort of not participate or not include myself in many things… I tried to tell my Japanese teacher but she told me it was just an excuse… my teachers don’t really understand… Then at lunchtime, I sort of just don’t really speak to anyone so I just hang around with my friends but not really be involved in much of the conversation.

#### Parents’ views of siblings’ experiences of sleep disruption

<table>
<thead>
<tr>
<th>Table 1 Demographic information of the interviewed siblings and their families</th>
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<tbody>
<tr>
<td>Sub-category</td>
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<tr>
<td>Gender of sibling</td>
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<tr>
<td>Male</td>
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<tr>
<td>Age of sibling (n = 11)</td>
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<tr>
<td>Jacob, Jolie</td>
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<td>Jenny, Jeremiah, Mitch, Sean, Skylar</td>
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<tr>
<td>Danika, Delilah, Kalina, Kendra</td>
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<tr>
<td>Sub-category</td>
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<tr>
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<td>5-8 years</td>
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*Pseudonyms are used, and exact ages are not disclosed to protect participants' anonymity.*

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Kalina’s description resonates with her older sister, Kendra, who illustrates that her functioning and mood is impacted by sleep disruption: “I kind of start zoning out more than I normally would [at school], and I sometimes start getting more anxious.” Jenny’s quotes illustrate the stark difference in her capacity to function and learn at school depending on her sleep quality: “A bad night’s sleep, I fall behind and start daydreaming a lot … I just want to sit down or lie down,” yet, after a good night’s sleep, “I won’t stop asking questions … I’m really energetic.”

Siblings cope with sleep disruption

Siblings cope with their sleep disruption by adopting an attitude of resignation and implementing strategies to settle their sibling with DS and to self-soothe. Siblings were asked what advice that they would give a friend to have a good night’s sleep if they had a new baby brother or sister with DS. This question prompted rich responses and a variety of coping strategies.

Siblings coped with sleep disruption by becoming resigned to it, as Danika indicates in her advice “[Expect that] they will wake you up in the night.” This resonates with Kendra’s experience: “I just kind of got used to it … just know that there could be moments where you might get woken up, but just to go back to sleep.” Likewise, Delilah said to expect that “[Your sleep] is never going to be how it was before,” later elaborating on her own resignation: “On the weekends he gets up at the crack of dawn … and if I wanted to sleep in, well, it’s not going to happen.” Jenny also offered advice that implied that sleep disruption was inevitable “If you have a lock on your door, lock it, which sadly I don’t.”

Interestingly, many siblings coped with their own sleep disruption by settling and soothing their sibling with DS because when their sibling went back to sleep this would then help them to get back to sleep. Danika described the different settling strategies that she uses:

- Usually when Beau wakes up, he usually gets back to bed with his dummy (pacifier) and we would tuck him in and have him like—got his head on a pillow and everything and just, yeah, try and make him comfortable.
- Kalina also offered multiple strategies:
  - Stay away from sleeping in the same room or bed with them. Or if they do try and wake you up, if you don’t give them attention … if they are trying to wake you up, try and offer for them to lie in your bed with you. I feel like that works a bit with Narelle
  - This method of trying different settling strategies was echoed by Jenny “try different things that they like that help them go to bed, like go to sleep.”
  - Some siblings also reported self-soothing strategies that they implemented to cope with sleep disruption. On nights when Danika had woken up a few times and was trying to go back to sleep, her strategy was to “chill (relax) ’til I’m tired.” In response to a question about how he made himself feel better for sleeping at night, Sean said “I make myself feel better when I go and do my own thing and do my, give myself some space.”
  - Jeremiah explained that, to prevent being woken up by his sister with DS, “I’ve got my door closed and I’m listening to audio books.”
Mitch also used audio distraction to self-soothe and help with sleep: “I just try and focus on another sound ... it helps me ... Sometimes I hear the rushing of blood through my ear when I'm lying down ... I try and focus on that.”

**Parents’ views of siblings’ experiences of sleep disruption**

Parents’ views of siblings sleep disruption were characterized by 2 themes: (1) parents can underestimate siblings’ sleep disruption (2) parents are uncertain whether siblings’ symptoms result from sleep disruption or other causes. We posit that such minimization and possible misattribution results in the normalization of siblings’ sleep disruption.

**Parents can underestimate siblings’ sleep disruption**

We found that some parents underestimate, to varying extents, siblings’ sleep disruption. While some parents’ accounts of siblings’ sleep disruption resembled siblings’ accounts, in about half of our sample, there were instances where parents noticeably underestimated the frequency and extent of siblings’ sleep disruption (eg, performing night-time caregiving). For example, one mother stated “[child with DS] doesn’t affect Kendra at all ... she just sleeps.” Yet, Kendra reported, “most of the time, [child with DS] is up at, like, four or five [am] ... She’ll either wake me up or she’ll just wake Kalina (younger sister) and Mum up.” Similarly, another mother reported that being woken up by the child with DS “doesn’t happen very often with Delilah and Skylar (the siblings). It’s lately more me.” While this account resonated with Delilah’s perspective: “It doesn’t happen as much as used to, now,” it conflicted with Skylar’s account of being woken up “once or twice a week.” This example illustrates how siblings in the same family can have different experiences of sleep disruption.

Parents also underestimated—to varying degrees—the extent to which siblings are providing care for, and settling, their sibling with DS during the night. In the following quote, the mother acknowledges that the child with DS disrupts his sibling, Jenny’s, sleep; however, the mother frames this as something that happened in the past, and only sometimes, with the disruption being quickly resolved: “I think [child with DS] used to try and go into her bed, he'd try to sleep with her sometimes. Thankfully she would just chase him out, tell him to go back to bed.”

In contrast, Jenny relayed that she regularly engages in night-time caregiving, albeit a recent reduction in the frequency of disruptions:

Sometimes like he’ll wake up and he’ll come into my room and just won't shut up pretty much ... I walk him to his bed. Then tell him he’s got to go to sleep and everything and if he doesn’t fall asleep ... sometimes I’ll read him a story ... Other times I’ll pretend I’m asleep next to him ... Other times I cuddle him and he will just go to sleep ... at least does it once a week now ... last year he did it like every day.

Danika’s mother recognizes that her children are involved in some night-time caregiving; her account implies that these practices are normalized in her family and that the resulting sleep disruption is insignificant:

I don’t know that it impacts the kids a lot. I think they’ve just grown up with Beau (child with DS) doing this. So, as far as Beau getting out a lot, they’re just like, Beau’s out his cot, and they’ll go put him back in. That’s not particularly worrying to them.

Yet, the eldest sibling, Danika, described that Beau was “very loud” during the night, she would “find his dummy (pacifier) and give it to him”. She also shared “[he] jumps on me in the morning”, and this sleep disruption made her “tired”. Following a discussion about her brother being “grumpy” in the morning when he woke up during the night and how she would then “cuddle him until he’s okay,” the interviewer asked Danika how she felt about making her brother feel better when he was tired: “I feel okay about it. I kind of feel worried, but okay ... hoping Beau is going to be okay and his stomach isn’t hurting.”

This illustrates that, contrary to the mother’s view, the child with DS’s sleep disruption is worrying to at least one of her other children.

**Parents are uncertain whether siblings’ symptoms result from sleep disruption or other causes**

A second theme, which is connected to parental minimization of siblings’ sleep disruption, is that parents are uncertain whether siblings’ symptoms result from sleep disruption or other causes. Specifically, parents interpret siblings’ adverse symptoms—anger, irritability, impatience, and tiredness—as potentially being caused by sleep disruption, mental health difficulties, hormones, temperament, age, or stress.

Parents’ accounts highlight that sleep disruption, and its associated symptoms, can be easily attributed to other causes. For example, Jolie’s mother states:

I’ve currently got her seeing a counselor at school ... She is definitely going through something ... Jolie has anxiety ... a very stressed, angry child ... She will just cry and say she’s tired ... A lot of it is obviously because day-to-day life with [child with DS]. ... When she has time away, so she’ll go to my mum’s house or something ... She’s just this totally different child, more happy, not stressed, sleeping, actually sleeping into a normal time.

 Likewise, another mother indicates how signs of sleep disruption can be attributed to other causes: “Kalina can get cranky but then I don’t know if it’s the sleeplessness or the fact that she’s hormonal.” This mother also shares that her eldest child is in therapy, “Kendra really struggles. Kendra’s not got the patience that Kalina has;” yet, the mother does not temper this assessment with a reference to how sleep can impact patience, thereby implying that impatience is primarily linked to temperament. While this could be true in this case, sleep disruption being overlooked is still problematic because sleep disruption could exacerbate other issues.

The mother in the subsequent example is aware of the sleep disruption and the resulting day-time tiredness that her daughter, Jenny, experiences. Yet, when she discusses Jenny’s struggles with sleep onset, she does not link it to the sleep disruption that Jenny experiences, but rather hypothesizes that this may be due to her age or general stress from her brother.

I don’t know if it’s her age ... just a change ... but she struggles to go to sleep at night ... she has a fair amount of stress going on with her brother. It can be hard for her.

While parents were not denying that their children experienced sleep disruption and associated symptoms, they frequently reported that they were uncertain about the cause of the adverse symptoms. Therefore, parents view siblings’ sleep disruption as difficult to isolate from other conditions and, accordingly, challenging to identify and address.

**Discussion and conclusion**

This study focuses on child siblings’ experiences of sleep disruption in families with a child with DS, and to our knowledge is the first of its kind. The findings alert clinicians to the importance of family dynamics and family sleep disruption and can inform much-needed clinical practice improvements. This study demonstrates how the sociology of childhood paradigm is useful for gaining rich and contextualized insights into children’s views, as children are conceptualized as competent social agents that need to be understood within their social order and generational relations—that is, in
this study, their parents. While this is a qualitative study limited by a small sample size of English-speaking, primarily nuclear families, and mostly female siblings, the findings from this study are striking enough to prompt improvements to clinical practice. We highlight the need for further research, particularly into families with more diverse cultural backgrounds and family structures. Below we outline how each of our 5 findings compare to, and extend upon, the existing literature.

Research has found that siblings in families with a child with DS report that their parents pay less attention to them than the child with DS in the family, and that siblings may avoid sharing their worries with their parents. Our study extends upon these pre-existing findings by highlighting potential adverse health impacts: lacking parental attention and siblings withholding information may contribute to parents underestimating siblings’ sleep disruption, thereby making it difficult to identify and address.

Previous studies have also found that young carers experience sleep disruption, our study provides new insights into how parents can be unaware of the extent of their child’s night-time caregiving and sleep disruption. Furthermore, we found parents are uncertain whether their child’s symptoms result from sleep disruption or have an alternative etiology. Such uncertainty is understandable given that the symptoms that may result from sleep disruption, such as for example, low mood and anxiety can also occur as a result of multiple other causal factors in children and it may be difficult to ascertain precisely the primary contributing factor. These findings highlight the importance of taking into account the social order of children’s lives when researching their perspectives as parents can impact how children are listened to and how their health issues are addressed. Sleep has been identified as an area where healthcare providers require further training to address prevalent sleep deficiencies that have health and economic costs. Our study demonstrates how it is important to consider poor sleep as a contributing factor to symptoms observed in a sibling of a child with DS as this may be modifiable if identified. We recommend that training and educational resources should include instruction around holistic healthcare that both seeks out siblings’ voices and raises parents’ awareness of sleep disruption symptoms and sleep health literacy, particularly around the benefits of addressing and seeking support for their child’s sleep disruption, even if other causes are also at play.

Our finding that siblings experience adverse effects from sleep disruption, including emotional dysregulation, bodily fatigue, and difficulties with focusing and day-time functioning, echoes findings from the medical literature on sleep disruption.

Young carers can experience sleep disruption with adverse consequences for day-time functioning, and our study is the first to explicitly identify siblings of children with DS as being a group at risk of sleep disruption. Siblings’ articulate accounts align with the conceptualization of children as competent social agents and illustrate that consultation with siblings is a viable option for improving holistic care for families. Targeted education about the consequences of sleep disruption and sleep health may benefit siblings and the people who care for and educate them (e.g., school counselors and teachers).

Siblings viewing their sleep in a relational way is a finding from our study that aligns with the literature on siblings of children with DS and makes a distinct, sleep-focused contribution. Like previous studies, the siblings in our study had caring relationships with their sibling with DS and made a distinct, sleep-focused contribution. Like previous studies, the siblings in our study had caring relationships with their sibling with DS and deepened understandings of others and of their sibling’s disability—our study extends these findings to demonstrate how such care and selflessness can impact siblings’ night-time caregiving and sleep. Healthcare professionals should be cognizant of how siblings’ sleep is interrelated with different family members. That is, addressing siblings’ sleep disruption may not be as simple as instructing siblings to abstain from night-time caregiving because that could be distressing for siblings and have unintended consequences for their family members. Given the inter-connectedness between family members’ sleep patterns and caring responsibilities, we recommend that siblings and parents should be included in the design of behavioral sleep interventions for children with DS.

Our finding that siblings cope with sleep disruption by becoming resigned, settling the child with DS, and self-soothing, raises concerns for siblings’ sleep health and may contribute to the normalization of sleep disruption, which has been found among parents of children with DS. More positively, siblings did describe, in their own words, mindfulness strategies that they used to fall asleep (e.g., focusing on certain sounds), which suggests that this could be an avenue to explore to support their rest and sleep. Nevertheless, our study raises the importance of addressing sleep health in these child siblings who may be at risk of developing long-term health problems from their early sleep deprivation without focused support.

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Credit authorship contribution statement

Emma Cooke: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. Caitlin Smith: Formal analysis, Writing – original draft. Maria Carmen Miguel: Formal analysis, Investigation, Writing – review & editing. Sally Staton: Conceptualization, Writing – review & editing, Funding acquisition. Karen Thorpe: Writing – review & editing, Funding acquisition. Jasneek Chawla: Conceptualization, Writing – review & editing, Supervision, Funding acquisition.

Declaration of Competing Interest

The authors have declared no conflicts of interest.

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