

## **Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families**

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### **Background to research:**

The majority of research on sleep concentrates on the biological and psychological aspects of this phenomenon. However, in recent years it has been recognised within the field of sociology that sleep is worthy of exploration. There is now an expanding collection of studies recognising sleep as embedded in the social context of people's lives. Such research has explored sleep from the point of view of children, women, men, and couples (Williams et al. 2007; Moran-Ellis and Venn, 2007; Hislop and Arber, 2003; Meadows et al. 2008; Hislop, 2007). However, the experiences of sleep from the multiple perspectives of children and parents of the same family have not, as yet, been explored. Furthermore, sociological research exploring sleep has not extended to children with disabilities and their families.

The literature on sleep and children with disabilities is dominated by the medical realm with the majority of research describing the high prevalence rates of sleep problems in this population. The majority of this research has relied on parental responses to sleep questionnaires and sleep diaries.

This research has also sought to describe the negative impact of 'sleeplessness' on the child themselves and on their primary caregivers (specifically mothers). However, it is argued in line with Wiggs (2007) that, as with sleep, the definition of sleeplessness is bound up within a social context and depends on individual, familial and cultural aspects including access to coping resources and strategies.

Children with cerebral palsy (CP) make up the largest group of children with a physical disability in the UK (Rosenbaum, 2003), yet there is very little research focusing on their sleep or the possible impacts of this on other family members. The only research specific to the sleep of children with CP has been concerned with the presence of sleep problems and the diagnosis of sleep disorders with problems pertaining to sleeplessness (i.e. problems initiating sleep, night time waking and early morning waking) being commonly found in this group (Khan and Underhill, 2006; Newman et al. 2006). It is concluded in this research that factors associated with CP such as the inability to change one's own position during the night and pain associated with muscle spasms and postural deformities, as well as possible co-existing problems such as epilepsy, gastro-intestinal problems and sensory impairments will all lead to a higher likelihood of sleep problems in this group.

However, there remains a huge gap in our understanding of the *experience* of sleep for children and young people with CP themselves. Furthermore, there has been no in depth research exploring the experience of sleep from multiple family members' perspectives from within the same family. This is despite the assertion that sleep is embedded within family life and that potentially an exploration of sleep could provide novel information pertaining to family life.

### **Aims and Objectives:**

Given the lack of in-depth research the primary focus of this study was to qualitatively explore the experiences of sleep for children and young people with CP and for members of their immediate family (i.e. parents and siblings).

This research aimed to meaningfully involve all family members in the research and aimed to allow participants to explore and describe their lived experiences and opinions of sleep from their own perspectives.

Therefore, the study aimed to:

- Obtain an in-depth understanding of the sleep of young people with cerebral palsy (CP) and the sleep of their parents and siblings.
- Explore and compare family member's constructions of 'good sleep' compared to 'poor sleep'.
- Obtain an understanding of the impact of 'poor sleep' on the lives and relationships of young people with CP and their families and the coping strategies used.
- Explore how experiences of sleep change or vary when young people with CP regularly spend nights away from home i.e. in respite care.
- Develop recommendations and resources about sleep for young people with CP and their families on the basis of the research findings.

### **Design:**

The study was designed by the researcher and advice regarding the study was gained from 2 young people with CP, 1 sibling and 1 mother of a child with CP.

For a family group to be included in the study there had to be at least one index young person (i.e. young person with CP aged 6-15 years) and one parent, agreeing to participate in the study. 10 families participated in the research (34 participants). Given the depth and variety of data collected this was deemed as the maximum manageable number of participants, and is an acceptable number of participants for qualitative research.

### **Methods:**

Multiple methods were selected in order to explore the "complex, multifaceted, multidimensional phenomenon" of sleep (Williams, 2002, p178). The primary focus of this study was to qualitatively explore the lived experiences, perspectives and opinions related to sleep of children and young people with cerebral palsy (CP) and that of their families. Quantitative methods supplemented the qualitative approach for the purpose of complementarity (Greene et al. 1989, cited in Alexander et al. 2008). Complementarity refers to the use of multiple methods to explore the different dimensions of a complex phenomenon (Alexander et al. 2008).

Furthermore, the use of multiple methods goes some way in redressing the power imbalance existent in adult-child research by promoting the view that children are social actors in their own right. By not relying on one method alone more opportunities are available for children to relay their experiences in different ways that can compliment their differing competencies.

The qualitative methods employed were:

- in-depth individual interviews,
- sleep diaries (2 weeks),
- self-directed photography (children/young people inc. siblings only).

The quantitative methods were:

- sleep quality questionnaires;
- actigraphy (2 weeks).

Communication difficulties are common in cerebral palsy so all these methods were adapted in consultation with the children and in accordance with their preferred methods of communicating.

### **Results and Conclusions:**

The data for this research has now been collected and is currently being analysed. The project will be written up for PhD thesis submission and results will be disseminated to the families involved and to wider audiences through reports, journal articles and conference presentations. A resource for children with CP and their families about sleep will be developed and provided through Chailey Heritage Clinical Services.

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*This study is Jessica's PhD doctoral research. The PhD is being carried out part-time and collaboratively between Chailey Heritage Clinical Services and the University of Surrey.*

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