

Behavioural interventions to help parents manage sleep problems in young disabled children

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Sleep problems are common and persistent in disabled children. However, many families do not receive help to deal with the problem. A rapid review of evidence on the effectiveness of behavioural interventions was carried out.

Key findings

- Evidence was identified on three different behavioural approaches which were carried out by parents at home: interventions using multiple behavioural techniques (non-specific behavioural interventions), extinction, and sleep restriction.
- There were two types of non-specific behavioural interventions evaluated: general information giving, and individually tailored intervention combining information giving to parents with an individual treatment plan for each child based on an assessment of the sleep problems.
- There is evidence that the provision of information to parents of children with a severe learning disability and a severe behavioural sleep problem, either in a single face-to-face session or through a booklet, is a promising approach.
- There is evidence that a detailed assessment of the child's sleep problem in combination with an agreed written behavioural programme delivered by parents and provision of information on behavioural techniques is a promising intervention for children with severe learning disabilities.
- Although several studies evaluated extinction, no controlled studies were identified. In the absence of a control group it is not clear whether the improvement found in the studies was a direct result of the intervention.
- As with extinction, there were no controlled studies of sleep restriction. The studies showed improvement in sleep but because of the study design it is unclear whether this can be directly attributed to the intervention.
- Most of the studies did not report the views of parents, therefore it is unclear what parents' views were about some of the approaches and what aspects of the interventions they found most helpful.

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Background

Sleep problems are common among all children but more common among disabled children. For these children problems appear to be very persistent, and are not likely to disappear without intervention. A number of reasons have been suggested for the high prevalence of sleep problems in disabled children. Physical and medical conditions associated with disability may affect sleep. Problems in learning may hinder the establishment of appropriate routines for settling and staying asleep and parents may also have low expectations of the child's ability to learn such routines.

Sleep problems can have a number of effects on the child and family. For parents, they are associated with high levels of stress and irritability. For children, they are associated with poor concentration and increased probability of daytime behaviour problems. However, only a minority of families who have a disabled child with a severe sleep problem appear to receive help in dealing with the problem.

It is important to note that it is normal for young children to wake a number of times during the night. What distinguishes normal sleep from a sleep problem is what children do when they awaken. In normal sleep, children wake briefly and resume sleep themselves. Children with sleep problems may cry or shout out when they wake and elicit a response from parents, this can act as a reward and result in the child needing parental attention to go back to sleep. Intervention is aimed at the child learning to go back to sleep without parental attention. Young children also often spend some time settling themselves to sleep when put to bed. However this becomes a problem when a child makes repeated calls on parents after being put to bed. Again the aim of intervention is to teach the child to fall asleep alone.

Sleep problems found in studies of disabled children are broadly of two types: a) 'behavioural' problems relating to settling into and maintaining sleep and b) 'physical' problems, such as upper airway obstruction and other physiological factors. However, these often co-exist, and it is important that a full assessment of the problems and their causes is carried out to inform the choice of intervention.

This rapid review focused on interventions for behavioural sleep problems in young disabled children (up to age eight years), specifically interventions that can be carried out by parents in the home.

Findings

There are a number of types of behavioural interventions that can be used for sleep problems in children (see Box 1). Six studies included in this review evaluated a non-specific behavioural intervention – using a number of different techniques as appropriate for the child and family; seven evaluated extinction or graduated extinction; two evaluated sleep restriction. Three studies evaluated bedtime fading with response cost but all were carried out in hospital settings. It is not clear what the effects of this intervention may be in the home setting. Therefore, it is not considered further here.

Non-specific behavioural interventions

In the six studies of non-specific behavioural intervention, the majority of children involved had severe learning disabilities. Most appear to have had severe and long-standing sleep problems, usually difficulties in settling at bedtime and related disruptive behaviour, night waking leading to disrupted sleep for parents and sleeping in the parents' bed. The studies

Box 1 Types of

Sleep scheduling/ restriction:

instituting fixed bedtime and waking time, avoiding sleep outside scheduled times. In sleep restriction, the amount of time the child sleeps is restricted to around 90 per cent of the time s/he normally slept before the intervention. Bedtimes and wake times can then be adjusted by set amounts of time per day until the appropriate times for sleep and waking are reached.

Bedtime routine and gradual distancing from parents:

establishing bedtime routines. Reducing parental involvement gradually, for instance reduction of sleeping in the same bed as parents by the parent moving from bed to sitting next to the bed until child is asleep, then gradually moving the chair further away until the parent is out of the room.

interventions

Bedtime fading with or without response cost:

retraining bedtime habits by setting bedtime at a time when the child will fall asleep quickly, then gradually bringing bedtime forward. Response cost involves the child being taken out of bed for a set time if s/he doesn't fall asleep within a specified time.

Extinction:

parent leaves the room after bedtime routine. In gradual extinction, the parent can re-enter the room and encourage the child to sleep at set intervals (for example, 3–5 minutes). These intervals are extended on subsequent nights. In non-graduated extinction, the parents do not respond to the child after the bedtime routine.

were similar in that they all provided parents with information on more than one behavioural technique, but they varied in how the intervention was implemented and the design of the study. Two randomised controlled trials (RCTs) provided single general information sessions for parents on behavioural techniques. One of these, which was a well designed study, showed statistically significant improvements in sleep problems for children in the intervention groups (face-to-face information and information through a booklet) at the end of the intervention and six months later, but no change for those in the control group (that is those who did not receive the intervention). For the majority of children in the intervention groups, problems were reduced by at least half, which was the level that had been defined by parents as one which would make the intervention worthwhile. The other study did not find a difference between the intervention and control group, but this study used children with and without sleep problems. It is not possible to judge how effective the intervention might have been for those who did have sleep problems, as those without sleep problems would have had little room for improvement.

One RCT and three before and after studies provided individual treatment plans for each child based on a detailed assessment of the child's sleep problems. In the RCT, parents implemented the plan over four weeks and their progress was monitored through regular telephone calls. The group receiving the intervention showed statistically significant improvements in sleep one and three months after the intervention, with average problem scores showing drops of almost half at one month and over half at three months, whereas there was no change in the control group. This study also looked at effects on parents. It found that after the intervention mothers slept longer and had reduced levels of stress, and mothers and fathers were more satisfied with their own sleep.

The before and after studies measured children's sleep problems before the intervention took place and after it had been implemented but did not have any control group so it is not clear whether any change is due to the intervention. In these studies, parents received a considerable amount of support from professionals whilst they implemented the intervention, through home visits in two studies and through telephone support in the third. One study noted that some parents needed time to develop trusting relationships with the professionals, and to contemplate changing their routines, before they could carry out the intervention. All three studies showed improvement in children's sleep after intervention, demonstrated by average reductions of over half in time taken to settle at night, number of night wakings and duration of night waking. Two of the studies measured effects on parents and found positive changes.

Extinction

Seven small before and after studies evaluated extinction. One used graduated extinction, six used non-graduated extinction. All of the studies reported improvement in children's sleep problems following the intervention, although because of the studies' design it is unclear whether improvement can be directly attributed to the intervention. Three studies explored parents' views. Responses varied, although most parents were satisfied with the outcomes of the intervention, some found it very time consuming or did not like ignoring their child when s/he called.

Sleep restriction

In two very small before and after studies, sleep restriction was used in conjunction with consistent bedtime routines. Both studies reported

improvements in children's sleep problems, although again it is unclear whether improvement can be directly attributed to the intervention. The authors of both studies stated that parents found the intervention easy to implement. They suggest that the intervention is suitable for parents who are uncomfortable about using extinction methods.

Implications for policy and practice

Overall, there is sufficient evidence to conclude that the provision of information on behavioural techniques for dealing with sleep problems to parents of children with a severe learning disability, either in a single face-to-face session or through a booklet, is a promising approach. Further research across a range of children with different disabilities is required. It seems reasonable to suggest that such techniques would be transferable to other disabled groups. However, a key question is whether parents who participated were more highly motivated and/or felt more confident to deliver such an intervention with their children compared to a general population.

Provision of information in conjunction with individual treatment plans is also a promising approach. Studies of this approach provided more intensive support to parents. It is likely that information provision alone would not be an appropriate approach for all families, and some may prefer to have to a tailored intervention to implement rather than trying to apply general information to their own specific situation. Equally some parents may prefer to avoid the time commitment of a more intensive intervention. It may be appropriate, where practical, to make available the less intensive approach to all families in the first instance and to provide the more intensive approach to families who feel that they need the extra support or for whom the less intensive approach is not effective.

Although there were several studies evaluating extinction, no controlled studies were identified, so it is not clear that the improvement found in the studies was a direct result of the intervention. However, given that sleeping problems in children with learning disabilities can be long-standing and unlikely to improve without intervention, these studies indicate that extinction may be a feasible approach. The two studies using sleep restriction also showed improvement in sleep outcomes, but again it is unclear whether this can be directly attributed to the intervention. Sleep restriction may be suitable for parents who are uncomfortable about using extinction.

Further research is needed on interventions for behavioural sleep problems in young children with disabilities, particularly studies with a control group and studies which investigate interventions with children with a range of disabilities. Research is also required on longer-term outcomes following intervention, on evaluating the cost-effectiveness of different interventions, and exploring parental preferences.

Methods

A range of electronic databases were searched for relevant publications in English since 1985; 1,314 papers were identified. Twenty-five papers, reporting 19 individual studies, met the inclusion criteria for the review. Full details could not be obtained for one study, so 18 were included in the review. Study designs were assessed on the Maryland Scale of Scientific Methods. Studies with a control group were also appraised using criteria from the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies.

Further information

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