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Sleep Problems in Adults with Intellectual Disabilities: An Exploratory Analysis of Support Workers' Causal Attributions, Sleep Quality and Treatment Acceptability.

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TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

Systematic Review

Major Research Project

Sleep Problems and Challenging Behaviour in Adults with Intellectual Disabilities: Is there an Association? A Systematic Review

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Abstract

Background Sleep problems affect cognitive, emotional, social and physical aspects of functioning. Adults with intellectual disabilities (ID) may be particularly vulnerable to the effects of sleep disruption, given that they have more limited cognitive and social resources to draw upon. As challenging behaviour (CB) has been suggested as a potential indicator of underlying distress, in some cases, it is possible that disrupted sleep may be associated with increased levels of CB.

Method A systematic review of published literature was undertaken to identify studies that addressed CB and sleep quality in adults with ID.

Results A limited number of studies were retrieved, with none considered to be of substantial quality. Those studies that were identified suggested that sleep disturbance may be associated with increased levels of self-injurious behaviour and stereotypical behaviour. Sleep disturbance was also associated with identified mental illness.

Conclusions Sleep disturbance in adults with ID may be associated with increased levels of CB and mental illness. However, conclusions are limited by the scarcity and low level of quality of existing studies. Further research is required to provide clear evidence of any association between sleep problems and CB.

Introduction

There is increasing evidence that sleep disturbance affects cognitive, emotional and physical health, and contributes to reduced work performance, social activity and lower life aspirations (Kyle et al. 2010). Adults with insomnia have consistently reported withdrawing from activities, lacking energy and experiencing increased levels of anxiety and irritability (Leger et al. 2005; Nakata et al. 2004). Morin et al. (2003) showed that adults with insomnia perceive their lives to be more stressful and report higher levels of pre-sleep arousal than good sleepers, who experience similar levels of daytime stress. Pre-sleep arousal and coping skills were important mediating factors in insomnia in this study.

Whilst an individual's well-being may be adversely affected by sleep disturbance, disrupted sleep may, in itself, be an underlying symptom of a mood disorder (Peterson & Benca, 2008). Indeed, Perlis et al. (1997) suggested that insomnia may be prodromal to individual relapses into depression. The extent of sleep disturbance has also been found to correlate with the severity of mood disturbance (Taylor et al. 2005). Hence, it is possible that there is an inter-dependent relationship between sleep and mood disorders, where mood problems predispose a person to sleep problems and vice versa. Furthermore, Manber et al. (2008) found that treatment of insomnia enhanced depression outcomes in patients with co-morbid depression and insomnia. These studies suggest a joint underlying pathway between mood and sleep problems.

Adults with Intellectual Disabilities and Sleep Disturbance

Research in sleep in people with intellectual disabilities (ID) has highlighted some differences from the general population (Espie et al. 1998). A greater proportion of individuals with ID (47%; Brylewski & Wiggs, 1998) are considered to have sleep problems than the general adult population (30%; Espie, 2000). Piazza et al. (1996) reported that children and adults with ID experience less total sleep and more night-time disruptions than their typically developing peers. Furthermore, adults with severe and profound ID have significantly different sleep architecture, with less REM sleep, more night wakening and poor sleep-efficiency (Espie et al. 1998).

It has been suggested that adults with ID may have fewer coping resources, such as limited communication skills, less ability to use and availability of social support, and social status inequalities that lead to negative self-evaluation and social comparison (Cooper et al. 2007; Dagnan & Waring, 2004). Adults with ID may also have less social contact, more disruption in relationships and experience of separation and loss than the general population. The cognitive limitations that result from having an ID may lead to difficulties in conceptualising problems and developing problem solving skills (Bird et al. 1989). They tend to have a lower capacity for coping with stressful circumstances as a result of the psychological complexity of making sense of difficult circumstances. They therefore experience physiological and psychological stress more readily (Emerson et al. 1998; Reiss & Benson, 1984).

Given the underlying social and cognitive difficulties that a person with an ID may experience, it is possible that the consequences of sleep disturbance may be exacerbated in this population. As a result of fatigue, reduced tolerance to task demands, irritability and frustration, adults with ID may also reduce their engagement with activities when they experience sleep problems. Similar to the general adult population, it is possible that an adult with ID and a sleep problem will experience further impairments to their memory and reasoning ability, as well as mood instability, increased anxiety and irritability (Banks & Dinges, 2007).

Despite the potential exacerbation of a sleep problem to an adult with an ID, there has not been a vast amount of research in this area. It is possible that the invasive nature of the gold standard sleep assessments and concerns regarding issues of consent have deterred researchers from investigating this important field. Even with informed consent, measuring sleep in the adult with ID is not a straight-forward process.

Assessment of Sleep Quality

Sleep can be measured in a variety of ways; observation, self-report, actigraphy and polysomnography (PSG). Observation of participants' sleep is open to error, in that the observer cannot know, definitively, whether or not the individual is asleep. Frequent observations may also disrupt the individual's sleep. Self-report measures can include questionnaires or sleep-diaries. Questionnaires can be a useful screening tool as a measure of an individual's perceived sleep quality. Sleep diaries can be kept over several nights and allow for measurement of more than one time point. In research with adults with ID, it is often someone else who reports on the person's sleep quality; this reduces the potential accuracy of the assessment (Espie et al. 1998). General psychiatric screening tools such as the DASH-II (Sturmey et al. 2004) and PAS-ADD (Moss et al. 1997) include items that enquire about sleep.

Objective assessment of sleep can be carried out using actigraphy. Actigraphy involves the use of a small accelerometer worn by the individual, usually in the form of a 'wrist-watch'. The actigraph detects the presence or absence of movement and stores this data. An algorithm is then employed to estimate whether the movement is indicative of wakefulness or sleep. Continuous data can be stored for up to 60 days. PSG is a multi-parametric test that measures physiological changes during sleep including: brain activity, eye and muscle movements, heart rhythm and breathing. Several electrodes are placed on the head and torso and send data to an attached computer where a technician can interpret the individual's sleep stage. As well as being an objective measure of sleep, PSG also provides information on abnormalities in sleep architecture and levels of arousal (Perlis & Lichstein, 2003).

As adults with ID may have fewer cognitive and social resources to manage and communicate their emotional states, additional sleep disturbance may potentially exacerbate these difficulties and lead to the development, or escalation, of CB. Several studies have sought to explore this possibility, but have drawn differing conclusions. For example, Symons et al. (2000) found that sleep disturbance correlated with self-injurious behaviour (SIB). On the other hand, Rojahn et al. (2004) found no such correlation and Chaney et al.

(2004) found that the relationship between SIB and sleep disturbance fell just outside significance in their sample. It is unclear from the literature whether these differences reflect different methodologies or different functions of CB in the individuals who participated.

Challenging Behaviour

CB is one of the main causes of referral to mental health services for people with ID (Cooper et al. 2007; Bouras & Drummond, 1992). There are many possible explanations for the function of CB for an individual; these may include attempts to communicate with others, distress as a response to changes to the environment or daily activities (McGill et al. 2003). It has also been suggested that the presence of CB is indicative of mental health problems (Boyle et al. 2010). These behaviours can easily escalate and become entrenched if they are not properly understood and addressed (Iwata et al. 1994).

SIB is one of the more distressing types of CB, both for the adult with ID and those around them (Mitchell and Hastings, 2001). This has led to a substantial body of research into the causes and functions of SIB. SIB includes a variety of behaviours that involve a person inflicting harm on their own body, for example: scratching, biting, hitting, head-banging or pica (Carr, 1977). It is estimated that around 17.4% of adults with ID exhibit some level of SIB, (Collacot et al. 1998). Iwata et al. (1994) examined the function of SIB in adults with ID and found that two thirds of the SIB in the sample was learned, and therefore socially maintained, by way of a tangible reward or escape from a task demand. A quarter of the sample used SIB for sensory stimulation. Although speculative, it is possible that the soothing nature of sensory stimulation or tangible rewards might result in an increase in CB following sleep disturbance when individuals have a reduced tolerance for coping with stressors in their environment.

Physically aggressive behaviour has been found in around a quarter of adults with ID (Crocker et al. 2006; Deb et al. 2008) and can include physical and verbal aggression as well as aggression towards property. Other problematic behaviours reported in the literature such as “non-compliance” may also increase when sleep disorders are present as individuals will have less energy and motivation to comply with activities that they are offered. A known function of some aggressive behaviour is communication. When an individual’s cognitive resources are stretched by disturbed sleep, it may be more difficult for the individual to communicate. This may then result in an increase in CB.

Measuring CB is not an easy task for researchers. There are different definitions of severity, intensity and frequency of aggression. For example measuring an episode of aggression where an outburst may involve one strike or several can be difficult to compare. There is also potential for observer bias and results can be skewed by the time of day when observations take place.

Assessment of Challenging Behaviour

One of the main difficulties in exploring aggression and SIB, in people with ID, is completing sufficient observations of the behaviours in a large enough sample (Iwata et al. 1994). Frequency and severity measures can also be somewhat subjective, particularly where questionnaire methodology is used, or observers are the participants’ support workers. Furthermore, the majority of studies have been undertaken with samples of adults with ID who are referred to services; hence, studies may not have included those with less significant forms of CB who are unlikely to be referred to services (Iwata et al. 1994).

Research studies often separate different types of CB, but occasionally aggressive behaviours are grouped together, and can include behaviours such as screaming and SIB. It is crucial that studies clearly define individual behaviours for measurement. The ‘gold-standard’ method of measuring frequency and severity of CB includes the use of unobtrusive video observation. Recordings can then be reviewed by more than one person at a later time. Live observations are also useful but are unable to be reviewed and are therefore more open to observer error and bias. More than one observer allows for measurement of inter-rater reliability. Observers are most objective when they are blind to the experimental condition and do not know, or work with, the participant they are observing (Emerson, 1995).

Subjective methodology is commonly used in the literature by informant reports and questionnaires. Measures such as the Aberrant Behaviour Checklist (ABC; Aman et al. 1985), Diagnostic Assessment for Severely Handicapped (DASH-II) and Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) have been widely used and validated on populations and therefore provide more generalisable results than unvalidated questionnaires. However, when the severity and intensity of CB is measured subjectively it can be difficult to compare individual informants and different studies. The management of the behaviour can also influence the subjective severity experienced by the informant. For example, it is possible that a support worker with a good behaviour management plan and adequate support from colleagues may not report the same aggressive behaviour to be as challenging, compared with a support worker who has a poor management plan and no support.

Sleep and Challenging Behaviour in Adults with ID

As stated previously, there may be a potential link between sleep disturbance and CB in adults with ID. Despite the methodological challenges involved in assessing adults with ID for sleep problems, the potential consequences of untreated sleep problems are great. Evidence documenting the impact of sleep problems on overall functioning in adults with ID is emerging. However, studies into the relationship between sleep, mood and CB in adults with ID appear, on the surface, to provide conflicting evidence. This review aims to investigate whether there is evidence of an association between sleep problems and CB in adults with ID.

Method

Inclusion and Exclusion Criteria

Articles that were published in the English language and in a peer-reviewed journal were included in this review. Each article assessed sleep and CB in adults with ID over the age of 16 years. Studies that focussed specifically on children, adolescents and the elderly were excluded due to the significant developmental changes that occur in sleep duration and architecture during childhood development and in older adults (e.g. Coble et al. 1984). Articles were also excluded if they included participants with dementia due to changes in sleep and behaviour that often occur from organic processes in this condition (e.g. Scarmeas et al. 2007). These groups were excluded as it would be difficult to distinguish sleep and behavioural changes that were developmental or organic as compared with changes in sleep and behaviour that were linked to each other.

Search Strategy

The electronic databases Ovid, EBSCOHost and Web of Knowledge were searched from the data-base start date to March 29th 2010: MEDLINE (from 1950), EMBASE (from 1980), Health and Psychosocial Instruments (from 1985), EMBASE Classic + EMBASE (from 1947), PsycINFO (from 1800s), Web of Science (from 1898), BIOSIS Previews (from 1926), Journal Citation Reports (from 1997), CINAHL (from 1981), Health Source: Nursing/Academic Edition, International Bibliography of the Social Sciences, Professional Development Collection, PsycARTICLES, Psychology and Behavioural Sciences Collection and Research Starters – Sociology.

Keyword searches of these databases were carried out using *(Sleep or Insomnia or Parasomnia)* and *(intellectual disabilit* or learning disabilit* or learning disorder* or mental* handicap* or mental* retard* or developmental disabilit*)* and *(middle age* or adult*)*. These searches yielded 1039 papers, many of which were found to be irrelevant to the current review. Therefore the following keywords were removed from the search using the NOT Boolean: *(child* or infan* or adolescen* or youth or teen* or pre?school* *or toddler* or aged or older or geriatric* or elder* or treat* or therap* or dementia or mouse or mice or rat or rats or drosoph* or animal*).*

Each inclusive search term was then matched to the subject headings in the relevant databases: EMBASE, MEDLINE, PsycINFO and CINAHL. The Ovid multidatabase search yielded 148 results. The EMBASE subject heading search yielded 462 results. The MEDLINE subject heading search yielded 124 results. The Web of knowledge search yielded 125 results. The multidatabase search in EBSCOHost yielded 290 results. Subject heading search in CINAHL yielded 6 more results. A subject heading search of PsycINFO did not yield any further results.

Duplicate results were removed and further irrelevant articles were removed where, from the abstract, it was clear that inappropriate samples were the subject of the study. Further articles were removed that did not measure sleep or CB, leaving a total of 21 papers; full text copies of these were obtained. However, eleven of these did not fulfil criteria due to inclusion of children (six), inclusion of individuals who did not have learning disabilities (two), no measure of CB (two), no measure of night-time sleep (one) or full text article not being available in the English language (two). These articles are reported under “Excluded Articles” (see References). This left a total of eight papers that were suitable for the current review.

Hand searches of *Journal of Applied Research in Intellectual Disabilities*, *Sleep*, *American Journal on Intellectual and Developmental Disabilities*, *Journal of Intellectual and Developmental Disabilities, American Journal of Mental Retardation, Intellectual and Developmental Disabilities and Mental Retardation* from 2000-2010 did not yield any further relevant articles. Neither did reference and cited references searches of the retrieved papers.

Quality Rating

Study quality was rated on a quality rating tool (see Table 1), adapted from the SIGN guidelines for Methodology checklists (SIGN 50, 2010). Specific reference to the different methods of assessment of sleep and challenging behaviour were added to emphasise the importance of the studies' methodology. This provided guidance on study quality to raters, in order to facilitate objective assessment of overall quality. The full quality criteria are listed in Table 2.

{Insert Table 2 here}

Five of the eight (63%) included papers were rated by two reviewers. Full agreement on the overall quality rating was achieved on four of the five papers; rating of the remaining paper was resolved following discussion.

Results

Studies Using Objective Measures

A summary of the included papers, including measurements used, quality rating achieved, main findings and limitations is presented in Table 3.

{Insert Table 3 here}

Quality Levels 1 and 2

No studies were found that utilised objective measures such as polysomnography or actigraphy to measure sleep. Furthermore, studies that used observational methodology to measure sleep or CB did not state whether the researchers were blind to participants' group. Therefore no relevant studies achieved a quality rating of category 1 or 2.

Observational Studies

Quality Levels 3a and 3b

One study (Symons et al. 2000) met criteria for category 3a. This utilised observational assessment of sleep and CB using well matched groups (on age, gender, level of ID and medication), with an adequate number of participants. Symons et al. (2000) used 30 minute observations, by institution staff, over 8 hours between 11pm and 7am, for between 60 and 330 nights. They investigated the night-time sleep patterns of 30 adults with profound ID and self-injurious behaviour (SIB), as compared to 30 well matched controls, who did not display SIB. Although observations are not considered to be a truly objective measure, clear guidelines for coding wakefulness and sleep were provided to assessors. Those with medical illness or who were diagnosed or treated for sleep disorder were excluded.

Symons et al. (2000) found that those who displayed SIB were asleep for fewer intervals and showed more variability in their sleep pattern than those who did not show SIB. Age and medication factors did not explain the variance in duration of sleep. The study did not state whether the observations caused the residents any disruption, and there is a possibility that those who show SIB may have been lighter sleepers who were more easily roused by the observation process. There is also the possibility that participants may have slept outside the hours of 11pm to 7am, which would not have been recorded.

One study (Chaney et al. 1994) was found that obtained a quality rating of category 3b, that is a small study where observations of sleep and CB were made by non-blind researchers or support workers.

Chaney et al. (1994) selected a sample of adults with moderate to profound ID from a residential centre in the USA. The “sleep disturbance” group included 30 participants whose IQs were in the severe to profound range. Annual surveys were carried out for 5 years to determine which residents may have circadian disturbances in sleep and behaviour. Ten control participants who displayed other regulatory dysfunctions were also included. Observations were carried out every 5 minutes over a period of 24 hours by undergraduate researchers. The authors did not report whether the raters were blinded to the group of participants they were observing.

Chaney et al. (1994) found that patients with sleep disturbance displayed significantly more stereotypical behaviour. In line with Symons et al. (2000), the sleep disturbance group showed a tendency towards more self-injurious behaviour that fell just outside significance (p=0.056). They found no conclusive evidence of medication causing or preventing insomnia in the sample.

A limitation of this study is the short duration of measurements. For example, the authors stated that one of the participants slept for 9.4 hours on the day of the study while having been awake for three consecutive nights preceding the study. A valid measurement of a circadian rhythm would require more than one period of 24 hours. Furthermore, the method of sample selection is not clearly stated and the authors did not report whether there were other residents with sleep disturbance in the centre who may have been eligible for inclusion in the study.

Questionnaire/ Informant Report Studies

Quality Level 3c

Four studies were found that met criteria for category 3c as they used validated questionnaires to measure sleep and CB.

Matson et al. (2008) compared 168 adults with ID and Autistic Spectrum Disorder (ASD) to 166 adults with ID alone in relation to sleep disturbance and related difficulties. Participants came from two development centres in the US that provided 24-hour supervision. They interviewed daytime staff to gather information on psychopathology (using the DASH-II) and behaviour problems over the preceding two weeks, using the Autistic Spectrum Disorder- Behaviour Problems for Adults (ASD-BPA; Matson & Rivet, 2007), which is a measure of CB developed specifically for people with ASD.

The sleep items on the DASH-II are “difficulty staying awake during the day”, “wakes frequently during the night”, “difficulty getting to sleep”, “sleepwalks” and “wakes crying or screaming”. Matson et al. (2008) defined sleep disturbance as scoring on at least one of these five items. They found that 44.7% of adults with ASD and ID had a sleep problem compared to 13.7% of adults with ID alone. Those with ASD had significantly higher scores on all sleep items except “sleepwalks”. No participant scored higher than 6 out of 10 on the sleep items. When matched on level of sleep disturbance, participants with ASD showed more behavioural problems than those with ID alone. Both groups showed an increase in problem behaviours in moderate sleep disturbance compared with mild sleep disturbance. However, this difference was not found between the moderate to severe sleep disturbance samples. The authors speculate that this may be due to daytime staff having limited knowledge of participants’ sleep, or that the severe sleep disorder group were too tired to engage in problem behaviours.

The authors conclude that the combination of ASD, ID and sleep disturbance leads to a high risk of having problem behaviours. However, there were key differences between the ASD and ID alone groups that may have influenced their results. The ASD group had more severe levels of ID, which may account for some of the large increase in both sleep and CB. The ASD-BPA may have inflated the CB scores in the ASD group by screening for behavioural abnormalities that are specific to ASD, e.g. social interaction deficits. There is also the possibility that the sample did not contain participants with clinically severe sleep problems as no participants scored in the upper range for sleep disturbance on the DASH-II.

Another study that used the DASH-II to assess psychopathology and sleep problems was Rojahn et al. (2004). They recruited 226 adults with ID and a psychiatric diagnosis who lived in a development centre. The BPI was also used; it provides three subscales that measure problem behaviours over the preceding two months: SIB, stereotyped behaviour and aggressive/destructive behaviour.

Rojahn et al. (2004) found that sleep disorder on the DASH-II was significantly correlated with stereotyped behaviour on the BPI but not SIB or aggression. However, Rojahn et al. (2004) merged the sleep and stereotypy subscales together into a “sleep disorder factor”. Subsequent calculation of risk ratios showed that the sleep disorder factor did not increase the risk of behaviour problems or psychopathology on the BPI.

Brylewski and Wiggs (1999) carried out a questionnaire study to explore the associations between sleep problems and daytime CB in adults with moderate to profound ID. They recruited 79 (39.5%) adults with ID and sleep problems and 121 adults with ID and no sleep problems (as measured by a modified version of the Simmonds and Parraga (1982) Sleep Questionnaire). A sleep problem was defined as trouble settling or night-wakening. This may have resulted in reduced identification of sleep problems as it does not include daytime sleepiness or early morning wakening. Participants were not matched on level of ID as this information was not available. Participants with parasomnias were excluded from the control group only (n=5). Differences between the groups were assessed, and the sleep disturbance group was reported to be older and comprised of fewer adults with Down Syndrome.
The group with sleep disturbance scored higher on the Aberrant Behaviour Checklist (ABC) for irritability, stereotypies and hyperactivity. There was no difference on the speech or lethargy subtests. Individual items on the ABC were analysed to compare specific types of CB. Brylewski & Wiggs (1999) found that aggression, SIB and 'screaming' were more severe in the sleep problem group. Adults with sleep problems were more likely to have daytime behaviour difficulties but this study could not address the aetiology of this association.

Further support for an association between sleep problems and CB was found by Boyle et al. (2010), who measured sleep problems in 1023 adults with ID as part of a population-based health screening. Sleep problems were measured using the sleep items on the PAS-ADD (initial insomnia at least 1 hour, early morning wakening of at least an hour and broken sleep, waking up for 1 hour or more) and they derived a "significant sleep problem" variable which comprised of a score of at least one severe, or more than one type of, sleep problem. It seems that people with ID were included in the interview process as far as possible, supported by their carers, although only subjective measures were used and proportions of adults with ID who were able to contribute were not reported.

Boyle et al. (2010) found that the 4-week prevalence of sleep problems in the sample was 9.2% and that those with sleep problems were more likely to have mental health problems and problem behaviours. People with severe/profound ID were significantly more likely to have a sleep problem than those who had a mild/moderate ID although multivariate analysis showed that there was no independent association. All types of sleep problem were strongly associated with mental ill-health. Boyle et al. (2010) also found that problem behaviours were significantly related to sleep problems, broken sleep and early morning wakening, but not sleep onset difficulties.

The authors suggest that the prevalence of sleep problems is lower in their sample than previous studies as they have a more representative sample than studies that have taken samples from group homes or clinic populations. However, it seems that the 1 hour cut-off that was used may have led to identification of only the most severe sleep problems and may have missed lesser, but clinically significant problems. The International Classification of Sleep Disorders (American Academy of Sleep Medicine, 2001) use a 30 minute cut off to define sleep disorders, which may have led to a greater prevalence of sleep disorders in Boyle et al.'s (2010) study.

Quality Level 4a

One study met criteria for category 4a, as the measures used were unvalidated. Patti and Tsiouris (2006) monitored a clinic sample of 206 adults with Down Syndrome over an 8 year period. This review only includes data for the 48 participants in the sample who were under the age of 40 years, because a high proportion of individuals in the sample, who were older than 40 years, were found to show signs of dementia.

Patti and Tsiouris (2006) found that half of 20-39 year olds showed signs of sleep disturbance. However they did not define their inclusion criteria for sleep disturbance. This figure is much higher than other studies (Brylewski and Wiggs, 1999) that have found fewer people with Down Syndrome to have sleep problems than other adults with ID, and is possibly the result of a over-inclusive definition that incorporates more milder sleep difficulties. Patti & Tsouris (2006) found that half of adults aged 20-39 showed physical aggression, 8% showed verbal aggression, 17-25% showed SIB and 42% showed disruptive behaviour. There was also a high rate of mood disturbance in the sample, 50-72%. Unfortunately, comparative analysis between sleep disturbance and CB was not carried out.

Retrospective studies

One further study met inclusion criteria for this review although did not specifically compare measures of sleep and CB. Hurley (2008) carried out a retrospective record review of 300 adults with ID who were referred to a specialist clinic. Those with dual diagnosis were excluded, leaving 212 participants. Control participants were those referred for assessment of service provision and for whom no “mood symptoms” were reported. Different “complaints” from the records were categorised and compared. Aggression was the most common “chief complaint” in 69 cases.

Hurley (2008) found an association between night-time wakening and depression and bipolar disorder, in comparison with those with anxiety or no psychiatric diagnosis. Furthermore, compared to controls, those with depression or bipolar disorder were significantly more likely to have sleep onset difficulties and early morning wakening. Hurley (2008) also found that patients with bipolar disorder showed more aggression, over-activity, self-stimulation, tantrums and impulsivity than those with depression. Those with depression showed more aggression and impulsive behaviour than those with anxiety. Compared with controls, patients with depression reported more aggression, SIB, under-activity, rituals, self-stimulation, tantrums and impulsivity.

A clear limitation of this study is that the absence of a symptom in the notes was assumed to be equivalent to a genuine absence of that symptom in the individual. It is possible that carers were not aware of symptoms and therefore did not report them (e.g. Espie et al. 1998). Unfortunately, no comparison was made between sleep disturbances and CB. Although there was more sleep disturbance and CB in the groups with bipolar disorder and depression, it is not possible to determine whether these are correlated.

Discussion

Perhaps one of the most marked findings from this review is the relative dearth of high-quality literature that addresses this area. Furthermore, differing methods of assessment, reporting and definition of sleep disturbance and CB between studies, make the comparison and interpretation of authors' findings difficult. The differences between studies are such that it has not been possible to undertake a meta-analysis. Nonetheless, some trends within the literature do emerge. It is noteworthy that seven of the eight articles reviewed, reported behavioural differences in adults with ID and sleep disturbance.

Studies of relatively higher quality, in terms of the objective measurement of sleep, tended to find associations between sleep problems and SIB. For example, Symons et al. (2000) found that those individuals who exhibited SIB were more likely to have disturbed sleep than those who did not self-injure. Chaney et al. (2004) found a tendency for those who had disturbed sleep to show more SIB than those whose sleep was not disturbed. Rojahn et al. (2004) did not find an association in their subjective questionnaire study. However, Espie (1998) has shown that support workers tended to underestimate sleep problems when compared with objective measures. It is possible that Rojahn et al.'s (2004) informants did not notice the sleep problems that the sample was experiencing, whereas the more objective observations of Symons et al. (2000) and Chaney et al. (2004) may have detected sleep problems that the subjective informants had missed.

Brylewski and Wiggs (1999) found that adults with ID and sleep problems showed more severe CB and higher rates of irritability, stereotypy and hyperactivity. Rojahn et al. (2004) and Chaney et al. (2004) also found associations between sleep problems and stereotypical behaviour. Boyle et al. (2010) also found that more participants with sleep problems had problem behaviours. These studies are measuring a variety of CBs from physical aggression to non-compliance. Furthermore, the heterogeneous population which encompasses a variety of genetic syndromes, ages and levels of ID does not allow for a meaningful comparison of sleep problems with problematic behaviour from the literature that has been published so far.

Studies have, as yet, been unable to find a causal link between sleep disturbance and CB (Boyle et al 2010; Hurley 2008), instead focussing on the link between CB and mental health problems. Similar to CB, those with sleep disturbance have been found to have a higher incidence of mental health problems, particularly depression and bipolar disorder (Boyle et al 2010; Hurley 2008). This may indicate that sleep problems can be a prodrome for mental health problems in adults with ID, as in the general population.

There is some evidence that suggests that the level of ID has an impact on sleep problems. Chaney et al. (2004), Boyle et al. (2010) and Brylewski and Wiggs (1999) all reported a higher prevalence of sleep problems in the participants with more severe levels of ID. In addition, the article that reported the lowest prevalence of sleep disturbance (9.2%; Boyle et al. 2010) included the highest proportion of participants with mild ID. It is possible that the organic causes of more severe ID have an impact on the architecture of sleep itself and hence its overall quality (Espie, 2000). Future research should control for level of ID when measuring sleep disturbance and ensure experimental groups are well matched on level of ID.

It is possible that researchers have been reluctant to undertake ‘gold-standard’ studies using PSG to investigate sleep quality in adults with ID. PSG is an expensive and time-consuming methodology that can also be quite uncomfortable for the participant. Ethically, it would not be justifiable to perform such procedures on healthy adults who may not be able to provide informed consent. This particularly applies to those with severe and profound ID who would be less able to fully understand the procedure, and may even be reluctant to wear an actiwatch. However, where consent can be provided or full compliance is freely attained, it would be of significant value to fully investigate the sleep quality of adults with ID in relation to CB.

Although not the focus of this review, consideration of the effect of genetic syndromes and specific conditions may also be worthy of comment. Matson et al. (2008) reported that adults with ASD displayed significantly more CB and sleep problems than adults with ID alone. There was conflicting evidence of the prevalence of sleep problems in Down Syndrome with high rates of sleep problems and mood disturbance reported by Patti and Tsouris 2006) but a lower prevalence of sleep problems reported by Brylewski and Wiggs (1999). It is possible that Patti and Tsouris (2006) have used a more inclusive definition of a sleep problem in their sample of adults with Down Syndrome. However, this was not reported.

Conclusions

Although some of the literature reviewed suggested that there is an association between sleep problems and CB, the findings are inconsistent. Associations between sleep disturbance and challenging behaviour were anticipated because the consequences of sleep disturbance are similar to some causes of CB (Carr 1977; Kyle et al. 2010). However, this review concludes that there is no clear evidence for this supposition.

A particular difficulty when drawing conclusions for this review was the limited literature, in both quality and quantity that directly addressed this issue. Articles that utilised objective measures tended to suggest there may be a link between sleep problems, SIB and stereotypical behaviour. However, again these studies are not conclusive. It was hypothesised that disturbed sleep might lead to an increase in CB. Prospective studies have not been carried out in this area therefore it is not possible to confirm or refute this hypothesis.

Prospective, blind observational studies of CB that use objective measures of sleep quality over the entire 24 hour period, for a sufficient number of days and nights, are required before it can be concluded that sleep has a direct causal relationship to CB. Such studies would show whether CB could be predicted by disturbed sleep or vice versa. From the current evidence, it is possible that sleep disturbance and CB may co-occur due to underlying reasons that are not directly causal, such as mental ill-health. It is important that future research in this area controls for confounding factors such as participants age, gender, medication, psychiatric diagnoses, genetic syndromes and their level of ID.

In terms of individual clinical work, further research will help to clarify the extent to which sleep should be taken into account when formulating an individual's CB or suspected mental health problems. Furthermore, this information will help in directing appropriate staff training that could help support workers to identify these difficulties earlier and help to raise awareness of the impact of sleep problems on adults with ID.

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Table 1: Quality Rating Tool

	Quality Rating Tool		
	Study identification: (Author, year, title)		
	Checklist completed by:	**Covered (✓)**	**Not covered(✓)**
1	The study addresses an appropriate and clearly focused question		
2	A description of the methodology used is included.		
3	What is study design?	*RCT/Controlled Trial* *Cohort Study* *Case-Controlled Study*	*Other: (please describe)*
4	How was learning disability assessed?	*Validated measure* *Confirmed by researchers*	
5	How was participants' sleep measured?	*PSG/Actigraphy* *Sleep diaries/ observations* *Validated sleep questionnaire*	*Unvalidated sleep questionnaire* *carer report*
6	How was challenging behaviour measured?	*Video/ live with inter-rater reliability check* *live with 1 rater* *Validated questionnaire*	*Unvalidated questionnaire* *Carer report*
7	The cases and controls are taken from comparable populations		
8	Are attempts made to exclude or match cases where there are confounding stressful life events? (recent change of environment, bereavement etc.)		
9	Are attempts made to match or exclude cases where other psychiatric illness/medication might account for sleep disturbance or CB?		
10	The same exclusion criteria are used for both cases and controls		
11	Cases are clearly defined and differentiated from controls		
12	Where the study is carried out at more than one site, results are comparable for all sites		
13	What is the sample size?	*Cases:* *Controls:*	
14	The outcomes are clearly defined.		
15	Evidence from other sources is used to demonstrate that the method of outcome assessment is		

	valid and reliable.		
16	Exposure level or prognostic factor is assessed more than once.		
17	Have confidence intervals or mean and standard deviation have been reported?		
18	How well was the study done to minimise the risk of bias or confounding, and to establish a causal relationship between exposure and effect? *Code ++, +, or –*	++ + -	
19	Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the exposure being investigated?	*Yes* *Partially* *No*	
20	Overall study rating	*1a 1b 1c 2a 2b 3a 3b 3c 4a 4b*	

Table 2: Quality Criteria

1a	Sleep measured by polysomnography (PSG) Challenging behaviour measured by video obs rated by more than one independent observer (blind to sleep status). Validated measure of ID. Participants screened for potential confounds eg. Life events, bereavement, meds, illness. Large randomly selected sample, well matched groups
1b	Sleep measured by PSG/Actigraphy Video or live obs of CB rated by at least one independent observer (blind to sleep status). Validated measure of ID. Participants screened for potential confounds eg. Life events, bereavement, meds, illness. Large randomly selected sample, well matched groups
1c	Sleep measured by PSG/actigraphy Live obs of CB rated by at least one independent observer (blind to sleep status). Validated measure of ID. Participants screened for potential confounds eg. Life events, bereavement, meds, illness. Small randomly selected sample, well matched groups.
2a	Objective measure of sleep e.g. PSG/actigraphy Video or live obs of CB rated by one independent observer (blind to sleep status). No validated measure of ID. Participants screened for potential confounds eg. Life events, bereavement, meds, illness. Larger sample or well matched groups
2b	Objective measure of sleep e.g. PSG/actigraphy Video or live obs of CB rated by one independent observer (blind to sleep status). No validated measure of ID. Participants screened for potential confounds eg. Life events, bereavement, meds, illness. Smaller or opportunistic sample, poorly matched groups
3a	Objective measure of sleep e.g. PSG/actigraphy/observation Challenging behaviour measured by video or live observation by non-blind observer. No validated measure of ID. Participant screened for some recent life events that may influence sleep or behaviour. Adequate sample size
3b	Objective measure of at least one of sleep or challenging behaviour e.g. PSG/actigraphy/observation/questionnaire/carer report. No validated measure of ID. Participant screened for some recent life events that may influence sleep or behaviour. Smaller sample size, well matched groups
3c	Subjective measure of sleep e.g. validated sleep questionnaire/carer report Challenging behaviour measured by validated questionnaire. No validated measure of ID. Minimal or no reported attempt to control for potentially confounding life circumstances. Smaller sample size, poorly matched groups
4a	Subjective measure of sleep e.g. sleep questionnaire/carer report Challenging behaviour measured by unvalidated questionnaire/carer report. No validated measure of ID. No reported attempt to control for potentially confounding life circumstances. Adequate sample size, well matched groups
4b	Subjective measure of sleep e.g. sleep questionnaire/carer report Challenging behaviour measured by unvalidated questionnaire/carer report. No validated measure of ID. No reported attempt to control for potentially confounding life circumstances. Smaller sample size or single case study, poorly matched groups

Table 3: Summary of included papers

Study	Type of study	Quality rating	n	LD measure	Sleep measure	CB measure	Main results	Limitations
Boyle et al. 2009	Cohort	3c	1023	Not reported	PAS-ADD	PAS-ADD	9.2% had sleep disturbance. They were more likely to have mental health problems and problem behaviours.	No control group. 1-hour cut offs may be under-representative of sleep disorders.
Brylewski et al. 1999	Case-controlled	3c	79 SD 121 no SD	Not reported	Modified sleep questionnaire	ABC	SD group had more severe CB and more irritability, steretypies and hyperactivity.	Only mod-severe ID included. No causal link could be established
Chaney et al. 1994	Cohort	3b	30 (10 controls)	CDER	5min obs over 24 hours.	CDER	Those with sleep disturbance showed more stereotypical behaviour.	Sleep group lower IQ and differentiated by historical insomnia.
Hurley 2008	Case-controlled	-	212	Record review	Record review	Record review	More sleep disturbances found in DEP and BIP groups.	Did not compare sleep and challenging behaviour.
Matson et al. 2008	Case-controlled	3c	168 (166 controls)	Stanford-Binet	DASH-II	ASD-BPA	ASD - 44.7% sleep disturbance. ID alone -13.7%. ASD group had more CB.	Day staff completed ratings.
Patti et al. 2006	Cohort	4a	48 of 206 adults with DS included in this review	Not reported.	PSP	BPI, PSP and staff interview	Sleep disturbances found in 50-53% of 20-39yrs. Non-compliance common to all age groups.	No definition of sleep disturbance.
Rojahn et al. 2004	Cohort	3c	226	Not reported	DASH-II	DASH-II and BPI	Sleep disorder correlated with stereotypy but not SIB or aggression.	No detailed analysis carried out on problem behaviours.
Symons et al. 2000	Cohort	3a	30 with SIB and 30 controls	Not reported	2hr obs	2hr obs	Well-matched controls. ID and SIB slept less at night than controls.	Ratings by care staff 11pm-7am only.

BIP-Bipolar disorder, SIB – Self-injurious behaviour, DEP – Depression, ABC – Aberrant Behaviour Checklist, DASH-II – Diagnostic Assessment of the Severely Handicapped, PAS-ADD – Psychiatric Assessment Schedule for Adults with Developmental Disability, CDER –Client Development Evaluation Report, PSP- Psychiatric Signs Profile, , BPI – Behavioural Problems Inventory, ASD-BPA – Autistic Spectrum Disorders – Behaviour Problems for Adult

MAJOR RESEARCH PROJECT

Sleep Problems in Adults with Intellectual Disabilities: An Exploratory Analysis of Support Workers' Causal Attributions, Sleep Quality and Treatment Acceptability

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Abstract

Background Sleep has been found to have an important restorative function. Any disturbance to sleep can be detrimental to both physical and mental health. Between 9-50% of adults with intellectual disabilities (ID) are reported to experience sleep disturbance. Support workers have a key role in identifying and responding to difficulties in the people they work with. Support workers' attributions towards the cause of these difficulties are crucial in mediating their decision to seek treatment. Their attributions may also mediate their adherence to a recommended treatment. Hence, their awareness and beliefs regarding sleep difficulties may influence their ability to recognise and seek help for sleep problems in adults they support.

Method This study utilised an exploratory vignette and questionnaire design. Questionnaires were given to 120 support workers, based in community settings, to measure their attributions to negative behaviour change and sleep problems. Support workers' attributional style was compared to their views on the acceptability of a variety of treatments for sleep disturbance. Support workers' own sleep quality was measured and compared to their attributions.

Results Support workers attributed negative behaviour change to sleep and mental health problems most strongly. Sleep problems were believed to be internal, uncontrollable and unintentional. Support workers were optimistic about treatment, particularly non-pharmacological treatments. Support workers' own sleep quality did not correlate with their attributions towards sleep problems or views on the different types of treatment.

Conclusions Support workers are optimistic that sleep problems in adults with ID can be treated, however further work is necessary to understand barriers to seeking out assessment and treatment for clients with ID.

Introduction

Sleep allows restoration of the physical and mental processes of the body and has an important role in immune function and regulating circadian rhythms such as body temperature and hormone release (Morin & Espie 2003). Acute sleep disturbance leads to various difficulties in daytime functioning, such as slowed reaction time, poor judgement, and reduced ability to learn and consolidate memories (Banks & Dinges, 2007; Chee & Chuah, 2008). Furthermore, long term sleep problems have been associated with increased stress and reduced perceived quality of life across five domains: physical, psychological, social, energy and cognitive (Leger et al 2005).

Recent interest in sleep in people with intellectual disabilities (ID) has highlighted some differences from the general population. A greater proportion of individuals with ID (47%) are considered to have sleep problems than the general adult population (30%; Brylewski & Wiggs 1998; Espie, 2000). Piazza et al. (1996) reported that children and adults with ID experience less total sleep and more night-time disruptions than their typically developing peers. Furthermore, Espie et al. (1998) found that adults with severe and profound ID have significantly different sleep architecture, with less REM sleep, more night wakening and poor sleep-efficiency.

Adults with ID and sleep problems may show signs of stress as a result of their sleep problem. Lack of sleep may lead to reduced tolerance and ability to cope with the demands that are placed on them during the day. For example, it has been found that individuals with ID and sleep problems show increased hyperactivity, stereotypy, daytime irritability and higher levels of challenging behaviour than those without sleep problems (Boyle et al. 2010, Brylewski & Wiggs, 1999).

The role of support workers in ID

There is some evidence that support workers do not recognise sleep problems in the people they support. Espie et al. (1998) compared support workers' reports of sleep quality to an objective measure, in this case, actigraphy. They found that support workers typically overestimated the sleep quality of people with ID. Brylewski & Wiggs (1998) reported that links between poor sleep and daytime functioning were not commonly acknowledged in their sample of carers. They suggest that carers may have minimised or overlooked sleep problems in their clients.

Support workers may have a key mediating role as they are often responsible for determining the times their client settles and wakens, facilitating a night time routine and providing sufficiently stimulating activity during the day. People with ID seldom refer themselves to mental health services, but instead rely on others to notice when they need specialist intervention. Therefore, support workers play an important role in identifying difficulties that their client is experiencing. They are required to make interpretations about the cause of these changes, often based on subtle alterations in the client's mood or behaviour. This can be a challenging task, particularly with problems, such as sleep disturbance, that may not be as obvious to the observer as other difficulties (Leger et al. 2005).

Following a population health screen for people with ID (Boyle et al. 2010), 94 of 1,023 individuals were identified as having a "significant sleep problem". This is lower than previous studies and may reflect the strict criteria for sleep disturbance used in this study, such as defining sleep disturbance as being present when sleep onset difficulties, night-wakening and early morning wakening were greater than an hour. As a result, the study may have captured only the most severe sleep problems. Despite a detailed sleep assessment being offered to individuals identified as experiencing difficulties, none of the services providing support accepted the offer of further assessment (Melville, 2009). The reasons for this were not explored by the authors of the study.

Attribution Theory

Distress can be difficult to fully understand and appreciate in a verbal, articulate adult; therefore it may be even more difficult to understand the distress that a person with ID may be experiencing. Once a change in mood or behaviour is noted there may be a variety of explanations that can be attributed to the change. According to attribution theory, a person's causal attributions and emotional responses will influence their response to another person's behaviour (Weiner, 1986). The perceived cause that is attributed to behaviour change may affect how likely they are to offer help to an individual (Willner & Smith, 2008). The support worker's explanation, or attribution, for change they observe in their client's behaviour may be fundamental in determining the course of action, if any, that they take.

Previous research has applied attribution theory to the study of staff reactions to challenging behaviour. Mitchell and Hastings (1998) suggested that the type of emotion produced in support workers by challenging behaviour (fear/anxiety and depression/anger), mediated the link between attribution and behaviour. Dagnan et al. (1998) found that staff attributions fitted Weiner's (1986) model and that optimism, negative emotion and controllability predicted helping behaviour. However, Bailey et al. (2006) used observations of carers' behaviour and found that their results did not support the model; instead, negative affect predicted negative behaviour from carers. Challenging behaviour can evoke strong emotions in support workers, which may alter causal attributions. However, more subtle negative behaviour change might be more predictive of helping behaviour, using Weiner's (1986) attributions model, as the emotional response may be less likely to affect causal attributions.

For attributions to be made towards a behaviour, the behaviour must first be noticed (Weiner, 1986). Although support workers are likely to notice changes in the mood or behaviour of their clients, it is possible that they do not notice their clients' sleep quality (Brylewski & Wiggs, 1998). Espie et al. (1998) demonstrated that support workers over-estimated their clients' sleep quality, as compared with objective measures of their clients' sleep. If support workers are not aware of sleep disturbance in their clients, they may have difficulty associating the cause of behavioural change with disturbed sleep. Support workers' own sleep quality may influence their attributions towards the sleep problems of the adults they work with. For example, support workers with poor sleep quality themselves may not recognise their clients' poor sleep as problematic.

There is only limited evidence of attribution theory being applied to workers who support people with ID who experience sleep problems. Keenan et al. (2007) found that parents of children with developmental disabilities, who were seeking treatment for their child's sleep problems, believed that the sleep problem was chronic, yet they were optimistic that it was also controllable. Keenan concluded that parents' beliefs might influence their choice and adherence to treatment. Parents most commonly attributed their child's sleep problem to their disability; this is in line with previous research from Didden et al. (2002). If professional carers have similar attributions they may therefore have similar vulnerabilities to non-adherence to treatment strategies that do not fit with their causal attributions. For example, a support worker who believed a person's learning disability was the cause of their sleep problem would make less effort with a behavioural sleep intervention, than a support worker who attributed the sleep problem to a behavioural cause.

Treatment Acceptability

Treatment acceptability is the judgement, by the client or consumer, about the appropriateness and suitability of the proposed treatment (Wolf, 1978). Ensuring a treatment is acceptable to the client is fundamental in managing adherence. This is the case in the sleep literature, as in treatments for other conditions. For example, Vincent & Lionberg (2001) found that clients who rated a cognitive behavioural therapy (CBT) group intervention for insomnia as favourable were more likely to adhere to the treatment. Perlis et al. (2004) used a drug treatment to increase the acceptability of the side effects (daytime sleepiness) of CBT for insomnia and found that this resulted in greater adherence to the treatment protocol.

A perceived absence of acceptable treatment options may influence support workers' willingness to seek treatment for their client's sleep problem. Once they have decided that treatment is necessary, their views on the cause of the sleep problem will influence the type of treatment that they find acceptable. Receiving a treatment in a similar domain to their causal attribution may make them more likely to adhere to the treatment.

It is important to gain a better understanding of the factors that impact on a support worker's tendency to identify sleep disorders as a potential cause of behaviour change and also the factors that may influence their willingness to seek help for their client. The current study will explore support workers' causal attributions of a negative behaviour change, in relation to sleep problems and other factors, as well as their own sleep quality. Furthermore, support workers' attributional style for sleep problems, treatment optimism and views on the acceptability of different types of treatment for sleep problems will be explored.

Hypotheses

1) Support workers will attribute negative behaviour change to other factors, to a greater extent, than to sleep problems.
2) Support workers' with poor sleep quality will attribute negative behaviour change to sleep problems to a lesser extent than support workers who sleep well.
3) The attributional style of support workers will be associated with their optimism and views on treatment acceptability.

Method

Design

A within subjects questionnaire design was used to investigate support workers' attributions to negative behaviour change, views on the acceptability of various treatments for sleep problems and to measure their own sleep quality.

Recruitment

Participants were recruited from four care providers in Glasgow and Lanarkshire. One further care provider agreed to participate but did not provide access to participants following several unreturned attempts at contact. Recruitment methods included distribution of questionnaires by managers and the researcher attending staff meetings and training events to request participation and provide copies of the questionnaires. Support workers volunteered to complete the questionnaires with no incentive. A training session on sleep problems in adults with ID was offered to care providers as a gesture of appreciation for participating in the study.

Measures

Vignette Development

Vignettes are typically used to assess causal attributions of behavioural change (e.g. Tynan & Allen, 2002). The content of the vignettes presented in this study consisted of consequences that people with sleep problems regularly and reliably report; these were derived from Leger et al. (2005). The first vignette described an adult with ID whose behaviour had changed recently (see Appendix 1). The behavioural changes were designed to be ambiguous and therefore attributable to several different factors; for example "decreased motivation" and "increased frequency of sleeping" (McClure et al. 2008). The second vignette explicitly described a man with ID and a sleep problem. The vignettes were matched in terms of length, readability and information provided. The character's level of ID was not stated in either vignette as this has been shown to influence attributions (Stanley & Standen, 2000).

Causal Attribution Questionnaire (CAQ)

The CAQ (see Appendix 1) was adapted from Hastings' (1997) Challenging Behaviour Attributions Scale, with specific items relating to self-injury removed. It was designed to measure the causal attributions to sleep problems as compared with other factors. Leger et al.'s (2005) model of quality of life in sleep disturbance was adapted into new subscales within the CAQ. Physical, cognitive, environmental and emotional domains were retained. A social domain was created from items in Hastings' (1997) "Stimulation" domain and Leger et al.'s "Relationships" domain. Leger et al.'s (2005) energy domain was used to describe the character's difficulties in the vignette and was therefore not reproduced in the CAQ. The final question on the CAQ allowed participants to state their own reason for the behavioural change, if they perceived that this had been omitted from the questionnaire. Items were scored on a Likert scale from one to seven: a score of four represented equal or no attribution; a score of more than four represented a positive attribution; and a score below four represented a negative attribution to each item.

Treatment Acceptability and Attributional Style Questionnaire (TAASQ)

The TAASQ (see Appendix 1) focussed explicitly on sleep problems and used a 7-point Likert scale to measure participants' responses on attributional dimensions of stability, controllability, globality, intentionality and locus. Similar Likert scales were used to measure optimism and treatment acceptability for CBT, relaxation techniques, medication from the doctor, medication from the chemist and a sleep schedule.

Pittsburgh Sleep Quality Index (PSQI)

The PSQI is a self-rated measure that assesses sleep quality over the preceding month. It is considered to be a good screening measure for a wide spectrum of sleep disorders (Buysse et al. 1988).

Demographic information

Participants' age, gender, length of experience working with adults with ID and hours worked each week were collected to characterise the sample. Participants were also asked whether they had received training specific to sleep problems in adults with ID, and whether they had experience of working with someone with a sleep problem.

Procedure

Participants were asked to read the information sheet (see Appendix 1) then read the first, ambiguous, vignette and complete the CAQ. The TAASQ was sealed in an envelope with instructions stating it was not to be opened until the CAQ was completed. Prior to this point, support workers were not aware that the study was specifically concerned with sleep. They then read the second vignette which described an adult with ID who had a sleep problem, completed the TAASQ, PSQI and Demographics Questionnaire, and then returned both questionnaires to the researcher in a sealed envelope.

Pilot Study

The vignettes and questionnaires were piloted with sixteen support workers, clinical psychologists and allied health professionals. All participants in the pilot reported that the vignettes were realistic. However, several requested further information to be included in the vignette in order to allow them to make more informed judgements about the underlying cause of the behaviour change. This was not provided as the limited information presented was an attempt to elicit participants' attributions without priming.

Participant responses on the original version of the TAASQ were made on a visual analogue scale. Following the pilot study, this scale was changed to a Likert scale because participants appeared to utilise only three points on the scale (the extreme ends and the mid-point). Hence, a seven-point Likert scale was adopted. No changes were suggested or made to the CAQ following the pilot study.

Approval and Consent

Ethical approval was granted from West of Scotland Research Ethics Committee Five. Site approval was granted from both NHS Lanarkshire and NHS Greater Glasgow and Clyde departments of Research and Development. Care providers consented to participate in the study. Individual participants provided their consent by completing and returning the questionnaires.

Results

Demographic Information

A total of 195 questionnaires were distributed to four care providers across Glasgow and Lanarkshire, with 120 completed questionnaires returned. This gave a response rate of 61.5%. Table 4 outlines demographic characteristics of the sample. Support workers ages ranged from 18 to 63 years with a range of 3 months to 29 years experience working with adults with ID. This sample is of similar age to the sample in Hastings (1997), although the current sample has a higher ratio of males.

{Insert Table 4 here}

1) Support workers will attribute negative behaviour change to other factors, to a greater extent, than to sleep problems.

Frequency and percentages of participants responses to the 24 items on the CAQ are displayed in Table 5. All items were completed by a minimum of 110 participants. Participants used the full range of responses on the Likert scales.

Factor Analysis of CAQ

An exploratory principal component analysis was carried out to investigate the factor structure of the CAQ. All assumptions for this analysis were met. Six components were extracted with eigenvalues greater than 1 (Table 6). Factors were rotated using varimax orthogonal rotation in order to improve interpretability. Items that loaded to each factor by more than 0.4 were included in each component, displayed in Table 7.

Items in Component One consisted of *don't talk to him, left alone, no activities, unpleasant surroundings, rarely goes outside, bored, noisy, weight*, *medication* and *sleeping at the wrong times of day*. Together these items seem to measure environment and living circumstances. Therefore this factor was labelled 'Milieu'.

Items in Component Two consist of *clumsy, forgetful, poor attention, weight, too hot* and *circadian disruption* items, representing a ‘Physiological’ component. Component Three consists of *difficulty concentrating, learning disability, unwell* and *scared* and is labelled ‘Well-being’. Component Four consists of *tired, trouble sleeping* and *bored* and is labelled ‘Sleep’. Component Five consists of *worried, stress, bored* and *unhappy* and is labelled ‘Mental Health’. Items in Component Six include *medication*, *unwell* and *nightmares* and appear to be ‘Unrelated’.

Reliability Analysis

Reliability analysis was carried out for each component using Cronbach’s α. Five of the six scales reached an acceptable level of reliability α >0.7 and are therefore included in further analysis (see Table 8). The Unrelated component, number six, was excluded from further analysis as it appeared to be measuring an unclear and unreliable mix of constructs.

{Insert Table 8 here}

None of the five components were significantly correlated with each other, support workers’ age, experience or PSQI scores. This suggested that the CAQ was measuring five distinct themes of attribution to negative behaviour, which are not mediated by support workers’ age, experience or sleep quality.

Additional Attributions

Participants were also asked whether they thought there was another reason for the negative behaviour change that was not mentioned in the CAQ. Sixty participants (50%) responded, with 41 (34.2%) of those stating that another reason was likely. Some of the suggestions appear to reflect existing CAQ items (e.g. loneliness), however, external factors such as bullying/abuse and health problems were identified by the majority who suggested an additional reason for the behaviour change.

{Insert Table 9 here}

Differences between attributions

Differences between the mean scores on each of the components were calculated for each participant in order to determine whether participants attributed the behaviour change to any particular components more than others. One-sample t-tests were used to compare the differences. Post-hoc Bonferroni corrections were applied as there were ten comparisons, and resulted in a significance level of $p<0.005$. Attributions to sleep problems were significantly more positive than to milieu ($t(118)= 9.26$, $p<0.001$), physiological ($t(118) = 12.45$, $p<0.001$), well-being ($t(118) = 11.28$, $p<0.001$), but not significantly different to mental health ($t(119) = 0.443$, $p>0.05$). Mental health attributions were significantly more positive than milieu ($t(119) = 11.613$, $p<0.001$), physiological ($t(118) = 13.99$, $p=0<0.001$), and well-being ($t(118) = 11.51$, $p<0.001$). Attributions to milieu were significantly more positive than to physiological factors ($t(118) = 7.01$, $p<0.001$) and well-being ($t(118) = 3.16$, $p=0.002$). Attributions to well-being were not significantly different to physiological factors ($t(117) = 2.45$, $p=0.016$).

Overall, the CAQ showed that support workers attributed negative behaviour change to ‘sleep’ and ‘mental health’ problems most strongly. They also attributed the change to ‘milieu’ more than ‘well-being’. Physiological factors were endorsed at a lower level than any of the other factors. Hence, hypothesis one was not supported.

2) Support workers’ with poor sleep quality will attribute negative behaviour change to sleep problems to a lesser extent than support workers who sleep well.

Support Workers’ Sleep Quality

The PSQI was completed by 92 (77%) participants; 28 participants were excluded from analysis due to incomplete questionnaires. The mean score was 5 (±3.3), with 59 (64.1%) of respondents scoring 5 or below (range 0-16) (see Figure 1). Scores of six and above are considered to suggest an increased likelihood of the presence of a sleep disorder (Buysse et al. 1988). The PSQI scores suggest that 28% of the sample may have an existing sleep disorder, which is in line with other prevalence studies (Espie et al. 2000).

Spearman's rho correlations were carried out to examine any relationship between support workers sleep quality and their attributions to the sleep component on the CAQ. No significant correlation was found which suggested that support workers' own sleep quality was not related to their attributions to sleep in the adult with ID. Hence, hypothesis two was not supported.

3) The attributional style of support workers will be associated with their optimism and views on treatment acceptability.

Support Workers' Attributions to Sleep Problems

Table 10 shows the frequency and percentage of responses to the attributional style questions. There was a spread of attributions displayed on the *locus* measure (median=5) indicating that there was a tendency towards attributing the sleep problem to internal factors, which has been associated with increased helping behaviour (Dagnan & Cairns, 2005). The *stability* dimension showed that support workers did not consider the sleep problem to be stable or unstable (median=4). The *globality* dimension also showed that support workers did not attribute the sleep problem to generalise across situations or to be confined to one situation alone (median=4). The *controllability* dimension was skewed towards uncontrollable (median=2), which has been associated with increased helping behaviour (Dagnan et al. 1998). The *intentionality* dimension was skewed towards the sleep problem being unintentional (median=2).

{Insert Table 10 here}

Support workers made attributions about the sleep problem along the full scale of each attributional dimension. Overall, their attributions represent the sleep problem as an internal process that changes, but is not controllable or intentional.

Treatment Optimism

Participants were asked to what extent the character in the vignette could be helped with his sleep problem. Dagnan et al. (1998) found optimism to be important in carers' willingness to help. Frequency and percent responses are displayed in Table 11. The vast majority of support workers believed that the character could be helped, n=113 (94.2%). Three support workers (2.5%) believed that he could not be helped and a further three were "not sure".

{Insert Table 11 here}

Treatment Acceptability

Support workers were asked how acceptable specific treatments would be for the vignette character's sleep problem (see Table 12). *Relaxation techniques* (median=6) and CBT (median=6) were the most acceptable of the treatments listed. M*edication from the doctor* (median=5) was also acceptable to support workers.

The responses to the *Sleep schedule* treatment showed a bimodal distribution. This may reflect agreement from those who understood the rationale for this intervention and disagreement from those who did not. Responses to *medication from the chemist* were binomially distributed and slightly skewed towards unacceptable, (median=5, mode=1). Although highly speculative, it may reflect the fact that support workers would not be allowed to purchase over the counter medicine for the people they support or that they do not think medication is effective for sleep problems. As only ten support workers (8.3%) had taken sleep medication themselves in the last month, it was not possible to provide a reliable estimate of this potential relationship.

{Insert Table 12 here}

Attributional style and treatment acceptability

Spearman's rho correlations were calculated to compare attributional style with optimism and treatment acceptability (see Table 13).

{Insert Table 13 here}

Within the attributional style dimensions there are significant correlations between *internal* and *unstable*, implying that support workers who thought the sleep problem was internal to the character also thought that it was a changeable, rather than a fixed or chronic problem. Stability was negatively correlated with globality, which is a logical conclusion whereby the sleep problem is changeable therefore not all-encompassing. Controllability was positively correlated with globality, which indicates that those who believed the sleep problem was outwith the character's control also believed that it did not generalise across every situation. Controllability also correlated with intentionality, suggesting that support workers who believed the sleep problem to be uncontrollable also believed that it was unintentional. This correlation has also been found with attributions to challenging behaviour and it has been noted that these dimensions may not be separate entities (Stanley & Standen, 2000; Weiner, 1979).

The majority of the statistically significant correlation co-efficients, which represent the relationship between the different treatment options and attributional style, are small and indicate that there are other unknown modulating factors impacting on these relationships. The *locus* dimension was positively correlated to *medication from the doctor, CBT,* and *a sleep schedule*. This may indicate that support workers believe that an internal, possibly medical or biological, problem would require an intervention that is targeted directly at the internal processes of that person. *Stability* correlated with *relaxation* and this may show an awareness of sleep difficulties increasing under times of stress, when relaxation can have the greatest impact. *Controllability* correlated with *sleep schedule* and may indicate an agreement with the implementation of increased structure for an individual who is able to sleep appropriately but has fallen out of a routine.

Treatment optimism was positively correlated with the three non-pharmacological treatments, which suggests that support workers may be more optimistic about the outcome of non-pharmacological interventions for sleep problems. Hence, there is some, albeit limited, support for hypothesis three, which would warrant further investigation.

Discussion

Results of this study suggested that support workers attributed a negative behaviour change, as presented in a fictional vignette, to be the result of underlying sleep or mental health difficulties. Other explanations, such as physical health problems or general environmental factors, were seen as being less likely to be the cause of these changes in behaviour.

This is an important finding, as the first stage of Ajzen's (1985) theory of planned behaviour has demonstrated that the attitude and attribution towards the behaviour has a significant influence on the response. The sample of support workers was showing an awareness and positive attributions towards the person's sleep problem. Hence, according to Ajzen's (1985) model, support workers would not be inhibited from helping while holding these attributions.

There was evidence that the support workers tailored their responses to the specific vignette, as items that were not referred to in the vignette were rated as less likely to have caused the behavioural change (e.g. such as the individual being 'clumsy', or over-weight). Results suggest that the majority of support workers identified and discriminated between the different types of sleep problem within the original sleep subscale. There is no suggestion in the vignette that the character is experiencing nightmares or circadian problems. Accordingly, support workers rejected these items while accepting the more appropriate sleep items. This also suggests that future research should carefully separate different types of sleep problems with insomnias, early morning wakening, delayed sleep phase syndrome and parasomnias as separate items.

The current study found that support workers' own sleep quality was unrelated to their causal attributions or attributional style towards an adult with ID who had a sleep problem. It is reassuring to find that any cognitive distortions that may apply to their own sleep do not transfer to others.

Overall, support workers believed the sleep problem to be uncontrollable and unintentional; attributions that have been shown to increase helping behaviours in support workers dealing with challenging behaviour. (Sharrock et al. 1990; Dagnan et al. 1998). Sharrock et al. (1990) found that external and unstable attributions also increased helping behaviour. However, support workers in the current study did not make strong attributions to the sleep problem on either of these dimensions. It is possible that locus and stability dimensions do not apply as easily to sleep problems as they do to challenging behaviour. Globality was not attributed to in either direction and, as the question with the lowest response rate in the questionnaires (82.5%) it is likely that the phrasing of this question has been difficult to interpret.

In contrast with Keenan et al. (2007) and Didden et al. (2002), who found that parents of children with sleep problems attributed them to the child's problem/ disability, the current study found that professional support workers did not make attributions regarding the locus of the sleep problem. In line with Keenan's (2007) sample of parents, who believed their child's sleep problem could be treated, the current sample showed high levels of optimism for the treatability of the character's sleep problem. This is important as the challenging behaviour literature has shown that optimism is a key factor in adherence to behavioural interventions (Dagnan et al. 1998). However, these results are not in line with the findings of Boyle et al. (2010) whereby no carers came forward for further assessment of identified sleep problems (Melville, 2009).

It is possible that there are other factors, not measured by this study, that mediate the decision to seek treatment for an adult with ID and a sleep problem. It would be useful to measure the support workers' emotional responses to the sleep problem and whether or not helping behaviour occurs as a result. Wanless & Jahoda (2002) showed that vignette studies did not elicit a realistic emotional response, compared with a real situation. Therefore, further research should investigate support workers' emotional responses and attributions to their clients' sleep problems as compared to any actions they may take in order to help. Furthermore, research could investigate the other stages of Ajzen's (1985) theory of planned behaviour. This would include assessing support workers' perceived behavioural control over the sleep problem and the social norms, in relation to sleep, in the environment in which they work.

CBT, relaxation and, to a lesser extent, a sleep schedule, were acceptable to the majority of the sample. The differing responses may reflect differing levels of knowledge or familiarity with each intervention. The response pattern may also reflect the assumption that it would be support workers themselves who would be responsible for implementing the sleep schedule. The interventions that were deemed most acceptable required delivery by someone else: a therapist or doctor. Speculatively, this may suggest a lack of confidence in managing sleep problems and may be explained by the fact that only 13% of those sampled have had training in this area and only half have worked with someone with an identified sleep problem.

The response to the sleep schedule treatment is interesting, as this treatment would be targeting external causes, such as the day and night sleep routine. This does not fit with the support workers attributions, which tended to be that the sleep problem was internal, this may explain the lower agreement with this treatment. Furthermore, the sleep schedule treatment correlated with controllability, meaning that those who supported a sleep schedule believed that the sleep problem was under the character's control. Conversely, those who did not support the sleep schedule believed the sleep problem was uncontrollable. It appears that support workers believed this treatment to be a restrictive intervention for those who were deliberately challenging in the way they choose to sleep. This suggests that support workers' attributions to the sleep problem are in conflict with the rationale for the treatment and would require to be addressed if this intervention was to be adhered to and used effectively (Bromley & Emerson, 1995). For example, support workers could be trained to understand that a sleep schedule helps to mediate the circadian timing of sleep and improves behavioural cues for sleep onset rather than being viewed as an aversive intervention.

Limitations

A key limitation of applying attribution theory within this study is the implicit suggestion of an underlying problem in the vignette. According to the attribution model, in order for attributions to be made, the behaviour must first be noticed (Weiner, 1979). Espie et al. (1998) showed that support workers do not notice sleep problems; hence it would be useful to investigate whether this remains the case. There may also be interventions that could increase support workers' awareness of the sleep quality and daytime consequences of poor sleep in the adults they support.

Every effort was made to avoid priming participants that the focus of the study was on sleep difficulties. However, there remains the possibility that those participants who had already completed the study, discussed its focus on sleep with those who were yet to participate. Therefore, it is possible that attributions to sleep problems may have been inflated, despite these efforts to conceal the purpose of the study for the duration of the first questionnaire.

Although commonly used in exploratory research, a known limitation of vignette designs is that they do not always correlate with similar investigations using other research methods (Wanless & Jahoda, 2002). In particular, they do not produce the emotional responses to scenarios that occur in real life. Therefore, without further research it is not possible to generalise the findings of this study to real-life settings in the community, where support workers may overlook sleep problems more easily. Further research should be carried out to investigate support workers' opinions on, and emotional responses to the presence of sleep problems in the individuals they work with. Sleep quality could then be assessed, objectively, to determine the rate of agreement.

Principal Component Analysis of the CAQ highlighted five separate components of attribution. However, some items proved to be ambiguous, loading onto more than one component. Before the CAQ is used in further research it is important that consideration is given to removing or replacing the weaker and ambiguous items with others that identify another clear component, such as bullying or, family difficulties, both of which were suggested as potential causes of the behaviour by support workers. In addition, it may be worthwhile to investigate other potential sources of attribution through qualitative methods.

In relation to Ajzen's (1985) model, the current study did not measure actual or predicted behaviour or how support workers would really respond if they witnessed the negative behavioural changes in their clients in real life. It is possible that they have the knowledge and awareness, but for some other reason choose not to act. This could be further explored by prospective investigation that measured the behavioural changes and sleep quality of adults with ID and support workers' responses.

In conclusion, contrary to the findings of Espie et al. (1998) and Brylewski and Wiggs (1998), support workers in this study consider sleep and mental health problems to be the best explanation of behaviour change in the presented vignette. Support workers are optimistic that sleep problems can be treated, and rate CBT and relaxation techniques to be the most acceptable treatments of those presented. Support workers attributed sleep problems to internal and uncontrollable factors, both of which have been shown to be associated with increased helping in the challenging behaviour literature (Dagnan et al. 1998).

The results of the current study suggest that support workers' attributions and optimism are not preventing them from seeking further assessment and treatment. Therefore, further research should investigate the very limited acceptance of sleep assessments (Melville, 2009) which would help clinicians to tailor interventions and training to support staff in this area. This may involve consideration of whether systemic factors, such as diffusion of responsibility, lack of confidence or a presence of other barriers are preventing support workers from making the step between being aware of sleep problems and helping their client to seek treatment.

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Table 4: Demographic Information

	Frequency (%)	**Missing**
Male	38 (31.7%)	18 (15.0%)
Female	64 (53.3%)	
Worked nights	81 (64.2%)	8 (6.7%)
Daytime shifts only	35 (29.2%)	
Experience of working with an adult with ID and a sleep problem	60 (50.0%)	11 (9.2%)
Received training on sleep problems in adults with ID.	16 (13.3%)	8 (6.7%)
Good sleeper	59 (49.2%)	28 (23.3%)
Poor sleeper	33 (27.5%)	

Frequencies displayed with % total sample.

Table 5: Frequency and Percentage responses to items on the CAQ

Attribution	Very Unlikely	Unlikely	Fairly Unlikely	Equally Likely	Fairly Likely	Likely	Very Likely	Missing
He is often unwell	13 (10.8%)	31 (25.8%)	15 (12.5%)	27 (22.5%)	15 (12.5%)	14 (11.7%)	3 (2.5%)	2 (1.7%)
He is rarely given activities to do	7 (5.8%)	21 (17.5%)	22 (18.3%)	25 (20.8%)	20 (16.7%)	16 (13.3%)	2 (1.7%)	7 (5.8%)
He has difficulty concentrating	5 (4.2%)	22 (18.3%)	28 (23.3%)	31 (25.8%)	18 (15%)	9 (7.5%)	2 (1.7%)	5 (4.2%)
He is having trouble sleeping	3 (2.5%)	1 (0.8%)	8 (6.7%)	16 (13.3%)	26 (21.7%)	32 (26.7%)	34 (28.3%)	0
He gets scared	7 (5.8%)	16 (13.3%)	25 (20.8%)	27 (22.5%)	20 (16.7%)	17 (14.2%)	3 (2.5%)	5 4.2%)
He rarely goes outside	10 (8.3%)	27 (22.5%)	22 (18.3%)	22 (18.3%)	16 (13.3%)	8 (6.7%)	5 (4.2%)	10 (8.3%)
He has a learning disability	30 (25%)	38 (31.7%)	15 (12.5%)	15 (12.5%)	5 (4.2%)	5 (4.2%)	8 (6.7%)	4 (3.3%)
He gets too hot	23 (19.2%)	31 (25.8%)	18 (15%)	26 (21.7%)	11 (9.2%)	4 (3.3%)	3 (2.5%)	4 (3.3%)
He is tired	6 (5%)	10 (8.3%)	13 (10.8%)	20 (16.7%)	17 (14.2%)	29 (24.2%)	20 (16.7%)	5 (4.2%)
He can be clumsy and break things	29 (24.2%)	41 (34.2%)	24 (20%)	15 (12.5%)	2 (1.7%)	2 (1.7%)	3 (2.5%)	4 (3.3%)
He is unhappy	3 (2.5%)	4 (3.3%)	8 (6.7%)	27 (22.5%)	25 (20.8%)	33 (27.5%)	17 (14.2%)	3 (2.5%)
He is bored	7 (5.8%)	12 (10%)	19 (15.8%)	25 (20.8%)	21 (17.5%)	17 (14.2%)	13 (10.8%)	6 (5%)
He sometimes gets forgetful	12 (10%)	35 (29.2%)	29 (24.2%)	20 (16.7%)	12 (10%)	3 (2.5%)	5 (4.2%)	4 (3.3%)
He lives in unpleasant surroundings	15 (12.5%)	22 (18.3%)	29 (24.2%)	25 (20.8%)	15 (12.5%)	9 (7.5%)	3 (2.5%)	2 (1.7%)
He does not cope well with high levels of stress	5 (4.2%)	5 (4.2%)	17 (14.2%)	27 (22.5%)	30 (25%)	17 (14.2%)	14 (11.7%)	5 (4.2%)
He has nightmares	8 (6.7%)	11 (9.2%)	24 (20%)	31 (25.8%)	23 (19.2%)	13 (10.8%)	6 (5%)	4 (3.3%)
Of the medication he is given	7 (5.8%)	11 (9.2%)	23 (19.2%)	32 (26.7%)	18 (15%)	17 (14.2%)	7 (5.8%)	5 (4.2%)
People don't talk to him very much	8 (23%)	23 (19.2%)	27 (22.5%)	21 (17.5%)	15 (12.5%)	15 (12.5%)	5 (4.2%)	6 (5%)
Because his attention can be poor	10 (8.3%)	23 (19.2%)	29 (24.2%)	32 (26.7%)	13 (10.8%)	5 (4.2%)	3 (2.5%)	5 (4.2%)
He sleeps at the wrong times of day	6 (5%)	15 (12.5%)	18 (15%)	33 (27.5%)	21 (17.5%)	13 (10.8%)	10 (8.3%)	4 (3.3%)
Of his weight	12 (10%)	29 (24.2%)	34 (28.3%)	27 (22.5%)	2 (1.7%)	4 (3.3%)	3 (2.5%)	9 (7.5%)
He gets left on his own	11 (9.2%)	17 (14.2%)	23 (19.2%)	33 (27.5%)	16 (13.3%)	6 (5%)	8 (6.7%)	6 (5%)
He is worried about something	2 (1.7%)	0	7 (5.8%)	22 (18.3%)	26 (21.7%)	34 (28.3%)	26 (21.7%)	3 (2.5%)
He lives in a noisy place	8 (6.7%)	9 (7.5%)	23 (19.5%)	31 (25.8%)	17 (14.2%)	18 (15%)	12 (10%)	2 (1.7%)

Table 6: Principle Component Analysis

Component	Eigenvalue	Percentage of variance
1	4.770	19.9
2	3.705	15.4
3	2.442	10.2
4	1.955	8.1
5	1.820	7.6
6	1.427	6.0

Table 7: Questionnaire items in each component

Component	Questionnaire items	Factor loadings
1 Milieu	*People don't talk to him very much*	0.817
	He gets left on his own	0.799
	He is rarely given activities to do	0.790
	He lives in unpleasant surroundings	0.679
	He rarely goes outside	0.676
	He is bored	0.575
	He lives in a noisy place	0.551
	His weight	0.507
	Medication he is given	0.492
	He sleeps at the wrong times of day	0.455
2 Physiological	*He is clumsy*	0.758
	He gets forgetful	0.746
	His attention can be poor	0.655
	His weight	0.651
	He gets too hot	0.643
	He sleeps at the wrong times of day	0.543
3 Well-being	*He has difficulty concentrating*	0.747
	He has a learning disability	0.610
	He is often unwell	0.608
	He gets scared	0.479
4 Sleep	*He is tired*	0.822
	He is having trouble sleeping	0.811
	He is bored	0.402
5 Mental Health	*He is worried about something*	0.776
	He does not cope with high levels of stress	0.620
	He is bored	0.467
	He is unhappy	0.446
6 Unrelated	*He has nightmares*	0.685
	He is often unwell	0.492
	The medication he is given	0.408

Table 8: Cronbach's α values for each component

Component	α
Milieu	0.892
Physiological	0.867
Well-being	0.742
Sleep	0.696
Mental health	0.733
Unrelated	0.551

Table 9: Further suggestions of attributions not covered by the CAQ.

Reason	N (%)
Sleep Problem	1 (4.2%)
Family problems	2 (8.3%)
Too many people around	4 (16.7%)
Lonely	2 (8.3%)
Health problems	6 (25%)
Upset	2 (8.3%)
Trying to communicate	1 (4.2%)
Bullying/abuse	5 (20.8%)
Changes to environment	1 (4.2%)

Table 10 – Attributions to sleep problems

	Completely disagree	Mostly disagree	Slightly disagree	Neither	Somewhat agree	Mostly Agree	Completely Agree	Missing
Something about him *(locus)*	12 (10.0%)	15 (12.5%)	11 (9.2%)	13 (10.8%)	36 (30.0%)	16 (13.3%)	10 (8.3%)	7 (5.8%)
Changes from day to day (*Stability*)	5 (4.2%)	18 (15.0%)	18 (15.0%)	22 (18.3%)	33 (27.5%)	10 (8.3%)	4 (3.3%)	10 (8.3%)
Under his control *(Controllability)*	36 (30.0%)	34 (28.3%)	14 (11.7%)	7 (5.6%)	13 (10.8%)	4 (3.3%)	2 (1.7%)	10 (8.3%)
There in every situation *(Globality)*	12 (10.0%)	6 (5.0%)	19 (15.8%)	22 (18.3%)	18 (15.0%)	13 (10.8%)	9 (7.5%)	21 (17.5%)
Sleeps this way on purpose *(Intentionality)*	49 (40.8%)	23 (19.2%)	17 (14.2%)	11 (9.2%)	7 (5.8%)	2 (1.7%)	2 (1.7%)	9 (7.5%)

Table 11 – Treatment Optimism

	Definitely Not	Probably Not	Possibly Not	Not sure	Possibly	Probably	Definitely	Missing
Treatment optimism	0	2 (1.7%)	1 (0.8%)	3 (2.5%)	28 (23.3%)	53 (44.2%)	32 (26.7%)	1 (0.8%)

Table 12 – Treatment acceptability

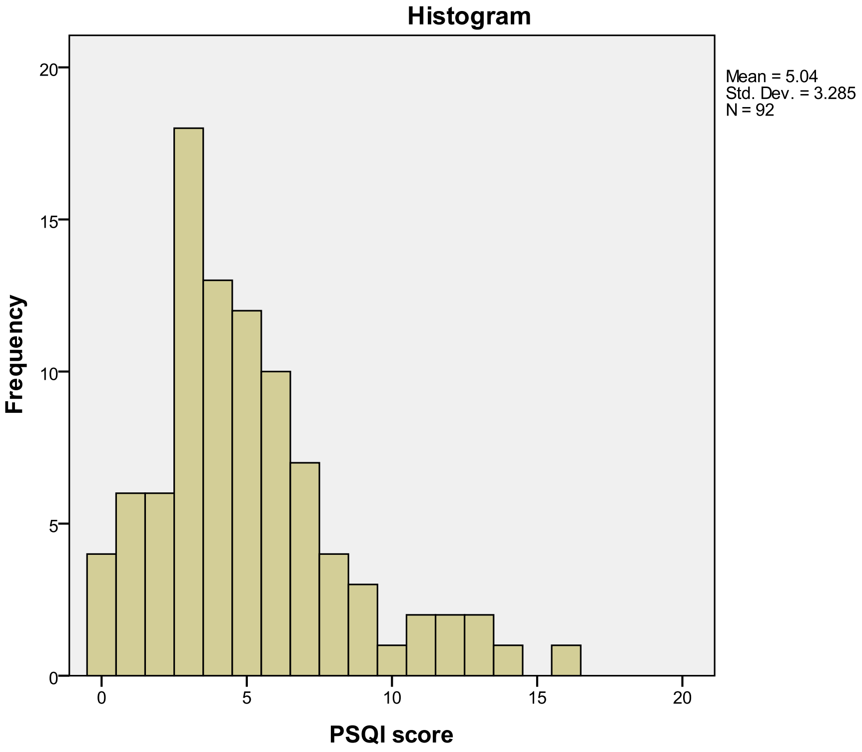
	Completely Unacceptable (1)	Mostly Unacceptable (2)	A little unacceptable (3)	Neither acceptable or unacceptable (4)	A little acceptable (5)	Mostly acceptable (6)	Completely acceptable (7)	Missing
Medication from the doctor	2 (1.7%)	7 (5.8%)	6 (5%)	19 (15.8%)	47 (39.2%)	32 (26.7%)	6 (5%)	1 (0.8%)
CBT	1 (0.8%)	5 (4.2%)	4 (3.3%	12 (10%)	27 (22.5%)	43 (35.8%)	27 (22.5%)	1 (0.8%)
Sleep schedule	14 (11.7%)	14 (11.7%)	9 (7.5%)	11 (9.2%)	33 (27.5%)	28 (23.3%)	10 (8.3%)	1 (0.8%)
Relaxation techniques	1 (0.8%)	2 (1.7%)	2 (1.7%)	3 (2.5%)	18 (15%)	51 (42.5%)	43 (35.8%)	0
Medication from the chemist	27 (22.5%)	21 (17.5%)	11 (9.2%)	21 (17.5%)	23 (19.2%)	14 (11.7%)	3 (2.5%)	0

Table 13 Correlation Matrix

	Internal	Unstable	Controllable	Global	Intentional	Optimism	Meds from Doctor	CBT	Sleep schedule	Relaxation techniques	Meds from chemist
Internal	1.000	**0.330****	0.081	0.104	-0.015	0.089	**0.196***	**0.210***	**0.227***	0.153	-0.011
Unstable		1.000	0.054	**-0.227***	-0.029	-0.157	-0.049	0.170	0.147	**0.188***	-0.064
Controllable			1.000	**0.238***	**0.436****	-0.053	0.063	0.035	**0.226***	-0.136	0.012
Global				1.000	0.183	0.085	0.112	0.030	0.092	0.118	0.056
Intentional					1.000	0.008	-0.052	-0.201	0.039	-0.211	0.213
Optimism						1.000	-0.069	**0.329****	**0.207***	**0.236****	0.058
Meds from Doctor							1.000	-0.024	**0.204***	-0.029	**0.270****
CBT								1.000	**0.296****	**0.534****	-0.036
Sleep schedule									1.000	0.163	**0.230***
Relaxation techniques										1.000	-0.079
Meds from chemist											1.000

** correlation significant at the 0.01 level
* correlation significant at the 0.05 level

Figure 1: PSQI scores



Appendix 1: Questionnaires and Information Sheet

Part 1

Exploring the Causes of Behavioural Change in Adults with Learning Disabilities

Please read the description of Charlie. Try to form a picture of what you think Charlie is like. Keep Charlie in mind as you answer the questions. You may read the description of Charlie as many times as you like.

Please answer all questions. There are no right or wrong answers; we are interested in what you think about Charlie.

Your answers will be treated confidentially.

Charlie is a man with a learning disability. He lives in the community in a supervised setting with other adults with learning disabilities. He requires support in some tasks of daily living. Over the last few weeks he seems to have less energy than usual and easily becomes irritable. He has been lying awake in bed at night. Charlie's care workers have noticed that he is spending less time with his friends.

The following section is a list of possible reasons for the change in Charlie's behaviour. Please use the scale to show your opinion of how likely it is that each reason explains the change in Charlie's behaviour.

For example if you thought it was "likely" that Charlie was behaving like this because he doesn't like the rain you would complete the table like this:

This change in Charlie is:	***Very Unlikely***	***Unlikely***	***Fairly Unlikely***	***Equally Likely***	***Fairly Likely***	***Likely***	***Very Likely***
Because he doesn't like the rain	*1*	*2*	*3*	*4*	*5*	[✓ *6*]	*7*

Please turn over.

Please circle each one response for each reason.

	This change in Charlie is:	***Very Unlikely***	***Unlikely***	***Fairly Unlikely***	***Equally Likely***	***Fairly Likely***	***Likely***	***Very Likely***
1	Because he is often unwell	*1*	*2*	*3*	*4*	*5*	*6*	*7*
2	Because he is rarely given activities to do	*1*	*2*	*3*	*4*	*5*	*6*	*7*
3	Because he has difficulty concentrating	*1*	*2*	*3*	*4*	*5*	*6*	*7*
4	Because he is having trouble sleeping	*1*	*2*	*3*	*4*	*5*	*6*	*7*
5	Because he gets scared	*1*	*2*	*3*	*4*	*5*	*6*	*7*
6	Because he rarely goes outside	*1*	*2*	*3*	*4*	*5*	*6*	*7*
7	Because he has a learning disability	*1*	*2*	*3*	*4*	*5*	*6*	*7*
8	Because he gets too hot	*1*	*2*	*3*	*4*	*5*	*6*	*7*
9	Because he is tired	*1*	*2*	*3*	*4*	*5*	*6*	*7*
10	Because he can be clumsy and break things	*1*	*2*	*3*	*4*	*5*	*6*	*7*
11	Because he is unhappy	*1*	*2*	*3*	*4*	*5*	*6*	*7*
12	Because he is bored	*1*	*2*	*3*	*4*	*5*	*6*	*7*
13	Because he sometimes gets forgetful	*1*	*2*	*3*	*4*	*5*	*6*	*7*
14	Because he lives in unpleasant surroundings	*1*	*2*	*3*	*4*	*5*	*6*	*7*
15	Because he does not cope well with high levels of stress	*1*	*2*	*3*	*4*	*5*	*6*	*7*
16	Because he has nightmares	*1*	*2*	*3*	*4*	*5*	*6*	*7*
17	Because of the medication he is given	*1*	*2*	*3*	*4*	*5*	*6*	*7*
18	Because people don’t talk to him very much	*1*	*2*	*3*	*4*	*5*	*6*	*7*
19	Because his attention can be poor	*1*	*2*	*3*	*4*	*5*	*6*	*7*
20	Because he sleeps at the wrong times of day	*1*	*2*	*3*	*4*	*5*	*6*	*7*
21	Because of his weight	*1*	*2*	*3*	*4*	*5*	*6*	*7*
22	Because he gets left on his own	*1*	*2*	*3*	*4*	*5*	*6*	*7*
23	Because he is worried about something	*1*	*2*	*3*	*4*	*5*	*6*	*7*
24	Because he lives in a noisy place	*1*	*2*	*3*	*4*	*5*	*6*	*7*
25	Because of another reason: __________________________ (please state)	*1*	*2*	*3*	*4*	*5*	*6*	*7*

Please put this page into envelope A and seal it.

Then open envelope B.

Part 2

Exploring the Causes of Behavioural Change in Adults with Learning Disabilities: the Role of Sleep

We are specifically interested in the role of sleep in negative behaviour change. At this stage, we're not sure how much sleep influences behaviour. We'd like to know what you think.

Please read the description of Kevin. Try to form a picture of what you think Kevin is like. Keep Kevin in mind as you answer the questions. The description is repeated on each page.

Kevin has a learning disability. He seems to have a major problem with his sleep. Kevin finds it hard to get to sleep at night and can become quite frustrated. It takes him over an hour to get to sleep. Then sometimes he will wake up too early and not be able to get back to sleep. Kevin is usually tired during the day. He sometimes has a nap in the afternoon.

Please circle a number to show how much you agree with each of the following statements about Kevin.

Completely Disagree	***Mostly Disagree***	***Somewhat Disagree***	***Neither Agree nor Disagree***	***Somewhat Agree***	***Mostly Agree***	***Completely Agree***
1	*2*	*3*	*4*	[✓ 5]	*6*	*7*

Kevin has a learning disability. He seems to have a major problem with his sleep. Kevin finds it hard to get to sleep at night and can become quite frustrated. It takes him over an hour to get to sleep. Then sometimes he will wake up too early and not be able to get back to sleep. Kevin is usually tired during the day. He sometimes has a nap in the afternoon.

To what extent do you think…

	Kevin's sleep problem	***Completely Disagree***	***Mostly Disagree***	***Slightly Disagree***	***Neither***	***Somewhat Agree***	***Mostly Agree***	***Completely Agree***
1	Is because of something about him.	*1*	*2*	*3*	*4*	*5*	*6*	*7*
2	Changes from day to day	*1*	*2*	*3*	*4*	*5*	*6*	*7*
3	Is under his control.	*1*	*2*	*3*	*4*	*5*	*6*	*7*
4	Is there in every situation	*1*	*2*	*3*	*4*	*5*	*6*	*7*
5	Is because he sleeps this way on purpose.	*1*	*2*	*3*	*4*	*5*	*6*	*7*

Please circle a number to show how much you agree with each of the following statements about Kevin.

1) To what extent do you think Kevin can be helped with his sleep problem?

Definitely Not	***Probably Not***	***Possibly Not***	***Not Sure***	***Possibly***	***Probably***	***Definitely***
1	*2*	*3*	*4*	*5*	*6*	*7*

2) How acceptable would a sleep medication from the doctor be in helping Kevin?

Completely Unacceptable	***Mostly Unacceptable***	***A little Unacceptable***	***Neither acceptable or unacceptable***	***A little Acceptable***	***Mostly Acceptable***	***Completely Acceptable***
1	*2*	*3*	*4*	*5*	*6*	*7*

Kevin has a learning disability. He seems to have a major problem with his sleep. Kevin finds it hard to get to sleep at night and can become quite frustrated. It takes him over an hour to get to sleep. Then sometimes he will wake up too early and not be able to get back to sleep. Kevin is usually tired during the day. He sometimes has a nap in the afternoon.

3) How acceptable would cognitive behavioural therapy (CBT) be in helping Kevin? (CBT is a therapy designed to challenge unhelpful thoughts and **look at ways to change** behaviours)

Completely Unacceptable	*Mostly Unacceptable*	*A little Unacceptable*	*Neither acceptable or unacceptable*	*A little Acceptable*	*Mostly Acceptable*	*Completely Acceptable*
1	*2*	*3*	*4*	*5*	*6*	*7*

4) How acceptable would a sleep schedule be in helping Kevin (where he is only allowed to be in bed when he should be asleep eg. 11pm-7am)?

Completely Unacceptable	*Mostly Unacceptable*	*A little Unacceptable*	*Neither acceptable or unacceptable*	*A little Acceptable*	*Mostly Acceptable*	*Completely Acceptable*
1	*2*	*3*	*4*	*5*	*6*	*7*

5) How acceptable would learning relaxation techniques be in helping Kevin?

Completely Unacceptable	*Mostly Unacceptable*	*A little Unacceptable*	*Neither acceptable or unacceptable*	*A little Acceptable*	*Mostly Acceptable*	*Completely Acceptable*
1	*2*	*3*	*4*	*5*	*6*	*7*

6) How acceptable would a sleep medication from the chemist be in helping Kevin?

Completely Unacceptable	*Mostly Unacceptable*	*A little Unacceptable*	*Neither acceptable or unacceptable*	*A little Acceptable*	*Mostly Acceptable*	*Completely Acceptable*
1	*2*	*3*	*4*	*5*	*6*	*7*

PITTSBURGH SLEEP QUALITY INDEX

INSTRUCTIONS:
The following questions relate to **your** usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

Please answer all the questions.

1. During the past month, when have you usually gone to bed at night?

USUAL BED TIME: ________________

2.During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

NUMBER OF MINUTES: ____________

2b. How long have you usually been awake during the night?

NUMBER OF MINUTES: ____________

3. During the past month, when have you usually got up in the morning?

USUAL GETTING UP TIME: __________

4. During the past month, how many hours of *actual* sleep did you get at night? This may be different to the number of hours you spend in bed.

HOURS OF SLEEP PER NIGHT: ________

4b. How many nights per week do you usually have difficulties sleeping?

NUMBER OF NIGHTS PER WEEK: _____

5. During the past month, how often have you had trouble sleeping because you:

		Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
(a)	Cannot get to sleep within 30 minutes				
(b)	Wake up in the middle of the night or early morning				
(c)	Have to get up and use the bathroom				

(d)	Cannot breathe comfortably				
(e)	Cough or snore loudly				
(f)	Feel too cold				
(g)	Feel too hot				
(h)	Had bad dreams				
(i)	Have pain				

(j) Other reason(s), please describe________________________________
____
____

How often during the past month have you had trouble sleeping because of this?

Not during the past month	____	Less than once a week	____	Once or twice a week	____	Three or more times a week	____

6. During the past month, how would you rate your sleep quality overall?

Very good ___ Fairly good ____ Fairly bad ____ Very Bad ____

7. During the past month, how often have you taken medicine (prescribed or 'over the counter') to help you sleep?

Not during the past month	____	Less than once a week	____	Once or twice a week	____	Three or more times a week	____

8. During the past month, how often have you had trouble staying awake while driving, eating meals or engaging in social activity?

Not during the past month	____	Less than once a week	____	Once or twice a week	____	Three or more times a week	____

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

No problem at all ____	Only a very slight problem ____	Somewhat of a problem ____	A very big problem ____

10. Do you have a bed partner or room-mate?

No bedpartner or room-mate ____	Partner/ room-mate in other room ____	Partner in same room, but not same bed ____	Partner in same bed ____

If you have a roomate or bed partner, ask him/ her how often in the past month you have had:

(a) Loud snoring

Not during the past month ____	Less than once a week ____	Once or twice a week ____	Three or more times a week ____

(b) Long pauses between breaths while asleep

Not during the past month ____	Less than once a week ____	Once or twice a week ____	Three or more times a week ____

(c) Legs twitching or jerking while you sleep

Not during the past month ____	Less than once a week ____	Once or twice a week ____	Three or more times a week ____

(d) Episodes of disorientation or confusion during sleep

Not during the past month ____	Less than once a week ____	Once or twice a week ____	Three or more times a week ____

(e) Other restless while you sleep; please describe

____

____

____

Not during the past month ____	Less than once a week ____	Once or twice a week ____	Three or more times a week ____

Finally, could you complete the details below for classification purposes:

1) Gender: **Male/Female**

2) Age: ______________

3) How long, in total, have you worked with adults with learning disabilities (include previous jobs): _______**years** ________**months**

4) How many hours a week do you work at the moment? ________

5) What shifts do you work at the moment? **daytime shifts / sleepover / waking nights** (please circle all that apply)

6) Have you ever worked with someone who has had a sleep problem before? **Yes/No**

7) Have you ever received any training specific to sleep problems in learning disabilities? **Yes/No**

Please put this questionnaire into the big return envelope C with envelope A and seal it.

Thank you very much for your time. Your help is greatly appreciated.

Information Sheet

Thank you for taking the time to read this sheet. I am asking for your permission to involve you in a research study. The study is looking at behaviour change in people with learning disabilities and I am looking for support workers to complete some questionnaires.

Why are you doing this?

As part of my training on the Doctorate of Clinical Psychology Course I am required to carry out a research project. I enjoy working with people with learning disabilities and am interested in support workers' opinions about what causes negative changes in behaviour.

What will I have to do?

The questionnaires are in two parts. The first part has a description of a person with learning disabilities and describes a change in their behaviour. You would be asked to read this and then read some statements about why the person's behaviour has changed and circle how much you agree with each statement. The statements cover reasons such as loneliness, pain, poor sleep, emotional or thought problems and living circumstances. The second part of the questionnaire is sealed in an envelope which you should open after you have finished the first questionnaire. The second part has a different description of a person with a learning disability and asks you to complete some more questions about them and about yourself.

How long will it take?

The questionnaires take between 15-20 minutes to complete.

Who will read my answers?

I will collect all the questionnaires and read them to put the information on the computer. When I read them I will not be able to tell who has completed each questionnaire. No one will be able to identify you from this information and we will not ask you for your name. Individual results from each questionnaire will not be reproduced. However, overall results from all the questionnaires together will be written up as a thesis and submitted to the University of Glasgow.

What happens if I decide not to participate?

Nothing. You do not have to give a reason. Participation is voluntary.

Contact for further information:

If you have any questions you would like to ask please do not hesitate to contact me or my research supervisor:

Mhairi Gervais, Trainee Clinical Psychologist, Dept. of Psychological Medicine, University of Glasgow, Gartnavel Royal Hospital, Glasgow. 01698 244 320. Mhairi.Gervais@nhs.net
Dr Rachel Wright, Clinical Psychologist, Kirklands Hospital, Bothwell.

Thank you for reading this information sheet.

Appendix 2: Major Research Project Proposal

MAJOR RESEARCH PROJECT PROPOSAL

Carer attributions of behaviour changes in adults with ID: a comparative analysis of attributions to environment, emotion, health, social, cognitive and sleep-wake regulation factors

Research Supervisor – Prof Colin Espie
Field Supervisor – Dr Rachel Wright
Date Submitted – 6th August 2009
Word Count – 3663

Abstract

Background

Studies have shown that people with ID are more likely to have sleep problems. Evidence suggests carers overestimate their client's sleep quality and overlook the relevance of sleep problems as a cause for behaviour change. Attribution theory has been applied to challenging behaviour in ID but not to everyday difficulties such as sleep problems. Carer attributions are important as they may be the difference between someone getting treatment, or not, for a sleep problem that is detrimental to their quality of life.

Aims

- To investigate care workers' causal attributions for negative behaviour change in adults with learning disabilities in relation to sleep, biological, environmental, psychological, cognitive and social factors.
- To investigate care workers' attributions for sleep problems in people with intellectual disabilities.
- To investigate whether care workers' attitudes towards treatment are linked to their causal attributions of sleep problems.
- To explore care workers' self-reported sleep quality in relation to their attributions concerning sleep problems in adults with learning disabilities.

Methods

A within subjects case vignette design will be used to investigate care workers' attributions for changes in behaviour. The vignette is followed by a series of questionnaires on attributions, treatment acceptability and insomnia.

Applications

There may be implications for staff training if it is found that carers do not consider sleep to be important. There may also be scope for understanding poor adherence to behavioural sleep interventions if it is found that this type of intervention is considered to be less acceptable to carers.

Introduction

Sleep allows restoration of the physical and mental processes of the body and has an important role in immune function and regulating circadian rhythms such as body temperature and hormone release (Morin and Espie 2003). Recent interest in sleep in people with intellectual disabilities (ID) has highlighted some differences from the general population. Sleep problems are reported by up to 30% of the general adult population (Espie et al. 2000) and in up to 47% of adults with intellectual disabilities (ID) (Brylewski and Wiggs 1998). Piazza et al. (1996) found that children and adults with ID have less total sleep and more night-time disruptions than their typically developing peers. Furthermore, Espie et al. (1998) found that adults with severe and profound ID have significantly different sleep architecture, with less REM sleep, more night wakening and poor sleep-efficiency.

Having a sleep problem leads to various difficulties in daytime functioning, such as slowed reaction time, poor judgement, and reduced ability to learn and consolidate memories (Banks et al 2007 and Chee et al 2008). Furthermore, long term sleep problems have been shown to increase stress and reduce perceived quality of life across five domains: physical, psychological, social, cognitive and energy (Leger et al 2005). Indeed, adults with both ID and sleep problems appear to display signs of stress as a result of their sleep problem and it has been found that they show increased hyperactivity, stereotypy, daytime irritability and higher levels of challenging behaviour than those without sleep problems (Melville et al. in press, Brylewski et al. 1999).

The role of care workers in ID

There is some evidence that carers do not recognise sleep problems in the people they work with. Espie (1998) compared carer reports to actigraphy and found that carers substantially overestimated the sleep quality of people with ID. Brylewski et al. (1998) report that links between poor sleep and daytime functioning were not commonly acknowledged in their sample of carers and imply that, prior to their intervention, carers may have minimised or overlooked sleep problems in their clients. Furthermore, carers have a key role in mediating their client's sleep problem as they are often responsible for determining the times their client settles and wakens, facilitating a night time routine and providing sufficiently stimulating activity during the day.

People with ID seldom refer themselves to mental health services, instead they rely on others to notice when they need specialist intervention. They often have poor verbal skills and are unable to tell their carers when they are experiencing problems. Therefore, carers play an important role in identifying difficulties that their client is experiencing. Carers need to make interpretations based on the behaviour the client exhibits. This is a challenging task with problems, such as insomnia, that have been shown to cause more subjective distress to the sufferer than would be perceived by others (Leger et al 2005).

Attribution Theory

Attribution theory states that people will attribute a cause to an event or behaviour. Firstly, the behaviour has to be observed, then considered to be intentional and then attributed to internal or external causes. Weiner (1986) classified attribution across three dimensions: locus of control (internal vs external), stability (change vs no change over time) and controllability (controllable vs uncontrollable cause). According to attribution theory, a person's causal attributions and emotional responses will influence their response to another person's behaviour. Their perceived cause can affect how likely they are to offer help to an individual, (Willner & Smith 2008). The carer's explanation or attribution for change they observe in their client's behaviour is potentially fundamental in determining the course of action, if any, that they take.

Previous research has aimed to apply attribution theory to staff reactions to challenging behaviour, in order to develop a model that will explain and predict carers' responses to different types of challenges. Carer response to challenging behaviour is important as it has been shown to maintain the behaviour (Hastings 1999) and even contribute to the development of new challenging behaviours (Hall, 2001), however little evidence has been found to fully support this model (Jones & Hastings, 2003, Willner & Smith, 2008). Mitchell and Hastings (1998) suggest that the type of emotion produced in carers by challenging behaviour (fear/anxiety and depression/anger), is mediating the link between attribution and behaviour, which may explain the mixed results in the literature. Attribution theory was originally applied to achievement and motivation, which would not seem to evoke as strong emotional responses as challenging behaviour and may, therefore, be more applicable to subtle negative behaviour change.

There is limited evidence of attribution theory being applied to carers of people with sleep problems. However, Keenan et al. (2007) found that parents who are seeking treatment for their child's sleep problems believed that the sleep problem was chronic yet potentially controllable. Keenan concluded that parents' beliefs might affect their treatment choice and acceptability. The attribution parents rated highest for their child's sleep problem in this study was "my child's main medical problem/disability", replicated from Didden et al (2002). It is possible that professional carers, who are responsible for seeking treatment for their client, have similar attributions.

Treatment Acceptability

Treatment acceptability is the judgement, by the client or consumer, about the appropriateness and suitability of the proposed treatment (Wolf 1978). The acceptability of a treatment depends on a variety of factors such as the severity of the problem, the speed of effectiveness and the side effects (Cross, 1990). Ensuring a treatment is acceptable to a patient is fundamental in managing adherence. Vincent & Lionberg (2001) found that patients who rated a CBT group treatment for insomnia as favourable were more likely to adhere to the treatment. Perlis (2004) used a drug treatment to increase the acceptability of the side effects (daytime sleepiness) of CBT for insomnia and found that this resulted in greater adherence to the treatment protocol.

Less acceptable treatment options are one reason that carers may not seek treatment for their client's sleep problem, however there are many other possibilities that should be considered. It is possible that the behavioural manifestations of a sleep problem are attributed by carers to social, psychological or other factors. Morin (1993) adapted Beck's (1976) cognitive behavioural model of depression, to fit the dysfunctional cognitions of people with insomnia. Morin argued that these dysfunctional cognitions about the negative impact of poor sleep can increase the likelihood of sleep disturbance. In line with Beck's model it may follow that previous experience impacts on future cognitions and attributions about sleep. Therefore, carers who are good sleepers may be less likely to consider sleep as a potential problem. Perhaps carers who are poor sleepers do not recognise their client's sleep problem as abnormal. Furthermore, it is possible that carers are aware of sleep problems in their clients and opt not to pursue treatment as they do not believe it would work or do not have the ability, confidence or time available to carry out the intervention.

Following a population health screen for people with ID (Melville 2007), 94 individuals were identified as having a "significant sleep problem". Despite a detailed sleep assessment being offered to these individuals, which would make carers aware of the difficulties their clients were experiencing, there was no response. The reasons for the nil response are unknown at this time. It is important to gain a better understanding of the factors that impact on a carer's decision to seek help for their client. The current study will explore carers' attributions of a negative behaviour change, in relation to sleep problems and other factors as well as examining carers' attributions for sleep problems and their own sleep quality.

Aims

- To investigate care workers' causal attributions for negative behaviour change in adults with learning disabilities in relation to sleep, biological, environmental, psychological, cognitive and social factors.

- To investigate care workers' attributions for sleep problems in people with intellectual disabilities.
- To investigate whether care workers' attitudes towards treatment are linked to their causal attributions of sleep problems.
- To explore care workers' self-reported sleep quality in relation to their attributions concerning sleep problems in adults with intellectual disabilities.

Research Questions

- To what extent do care workers attribute negative behaviour change to sleep problems as compared with other sources of attribution?
- Can attribution theory be applied to carer's perceptions of the sleep problems of adults with intellectual disabilities?
- Do care workers view treatment as more acceptable if it is linked to their causal attribution of the sleep problem?
- Does the care worker's own sleep quality affect their attributions of sleep problems in adults with intellectual disabilities?

Plan of Investigation

Design

A within subjects design will be used to investigate care workers' attributions of negative behaviour change. In part 1, an ambiguous vignette design will be used to openly explore the causal attributions of sleep difficulties as compared with other causal factors. Before part 2, participants will not be primed to think about sleep problems specifically. In part 2, participants will be presented with a second vignette that explicitly describes someone who has a major problem with their sleep. They will be given questionnaires on their attributions to sleep problems, treatment acceptability of different types of sleep treatment and asked about their own sleep quality. At this stage, an exploratory study using hypothetical clients was deemed suitable to investigate whether a more detailed comparison is justified.

Recruitment procedures

Participants will be recruited by contacting carers' employers in the Greater Glasgow and Lanarkshire areas. Many carers work in the community supporting clients in their own homes. Furthermore, each organisation will be set up differently with some having regular meetings and facilities for a main staff base. The managers of each care provider will be contacted by telephone and/or letter/e-mail initially in order to request their participation and discuss the most effective recruitment procedure for them. It is expected that the researcher will meet with staff during training events, meetings or at set times where staff congregate to request their participation in the study. The researcher will continue to meet with staff until an adequate sample size is achieved.

As a secondary form of recruitment, or for care providers with infrequent staff meetings, the researcher will request to attend a forum where representatives from each care provider meet, in order to explain the study and request that they distribute the questionnaires to their staff. Care providers will be offered a training session for their staff on the subject of sleep in ID but asked to inform staff of a study and training in a relevant health area to avoid priming them about sleep. This will be made available within an agreed range of dates regardless of the response rate from each service.

The majority of the questionnaires are expected to be collected by the researcher at the time of completion. However, reply-paid envelopes will be made available and a box may be left on the site for completed questionnaires where this is practicable. The researcher will collect the questionnaires from the care providers where boxes are left. Telephone/e-mail contact will be made with the manager shortly before returning to collect the box in order to request that s/he reminds the staff to return questionnaires. Follow-up contact will be made to staff groups to provide further questionnaires with reply-paid envelopes if necessary.

Participants

A minimum of 82 carers of adults with intellectual disabilities will be required for the present study. North Lanarkshire council social work currently holds contracts with 14 care providers who employ approximately 1000 staff working with 16-64 year olds with ID. Previous studies in this field have received a response rate of 30-90% (Mappin 1998, Jones & Hastings, 2003). Allowing for a poorer response rate of 10-20%, it is estimated that up to 1000 questionnaires will be distributed.

Justification of sample size

A priori power analysis for a repeated measures ANOVA was carried out using G Power version 3.0.1 set to find a medium (0.25) (effect size (f), α error=0.05 and power of 0.8 (β-1) (Faul et al. 2007). The total sample size should be a minimum of 82 participants. A greater sample size of 150 is expected in order to maximise statistical power and enable valid post hoc regression analysis. A post hoc power analysis for multivariate regression will be carried out once the number of participants and predictors are known.

Inclusion and exclusion criteria

Participants will be paid carers who are currently working with adults with ID on either or both night and day shifts in the Greater Glasgow and Lanarkshire areas. Participants should be aged 16 or over, have a minimum of 3 months experience with this population and have a good command of the English language.

Measures

Vignette Development

The vignettes in this study were developed using the format of Tynan et al (2002) and details of the type of consequences that people with insomnia regularly and reliably report are derived from Leger et al (2005). The vignettes and follow-up questions (see appendix for current drafts) will be piloted and reviewed by five ID psychology experts in the context of the study aims. They will be asked to provide general feedback overall and specific feedback on each section of the vignettes and questionnaires. Following any refinements, the vignettes and questionnaires will be reviewed by a group of five support workers. The first vignette describes an adult with a learning disability whose behaviour has changed recently. The behavioural changes are designed to be ambiguous and therefore attributable to many different factors, for example "decreased motivation" and "increased frequency of sleeping" (McClure 2008).

Following the vignette, the causal attributions questionnaire asks participants to rate the likelihood of each cause of the behaviour change on a 7-point Likert scale. This questionnaire is adapted from Hastings (1997) Challenging Behaviour Attributions Scale, with specific items relating to self-injury removed. Leger's (2005) model of quality of life in insomnia has been adapted into new subscales within the current questionnaire. Physical, environmental and emotional domains are common to both. Hastings' "Stimulation" domain is similar to Leger's "Relationships" domain in terms of social contact. The energy domain was excluded from the questionnaire as the items are used to indicate difficulties in the vignette and a further domain was produced to include sleep-related difficulties. Leger used a cognitive domain, which was adapted into attributions and included in the current questionnaire. The final statement allows participants to state their own reason if they feel their main attribution has been missed from the questionnaire.

In part 2, participants are asked to consider sleep problems specifically. A second vignette will be used to facilitate description of a major problem with sleep. The next five questions use a visual analogue scale to investigate attributional dimensions. The third questionnaire asks about treatment acceptability for sleep problems, using a visual analogue scale and is based on biopsychosocial factors.

Insomnia Severity Index

Care workers will then be asked to complete the Insomnia Severity Index (ISI) to measure their own sleep quality (Morin 1993). Good sleepers will be asked to complete the ISI even if they do not currently have a sleep problem in line with standardised use of the measure (Morin et al. 2009). The ISI will be used to investigate whether there is an association between care workers' sleep quality and their attributions of sleep-related behavioural changes in their clients.

Demographic Information

Demographic information will be collected as part of the questionnaire and will include: age, gender, day/night shifts, length of time worked with adults with intellectual disabilities, whether or not they have worked with someone with a sleep problem and whether they have had any training specific to sleep problems. These variables will be used to control for any bias in the sample and ensure a representative range of respondents are available.

Research Procedures

The vignettes and questionnaires will be piloted on five professional staff working with learning disabilities. Following feedback from the group, changes may be made before a further pilot stage where five support workers are asked to comment on the content and procedure. Further changes in wording or style will be made before beginning full recruitment. The pilot support workers' data will be included in the main research if no further refinements are made.

Participants will be provided with an envelope containing the information sheet, questionnaire part one, envelope A to put it in and a sealed envelope B which contains part two of the questionnaire. They will be asked to read the information sheet, and complete part 1, then put it into envelope A and tick the box to indicate they have done this before opening envelope B. Then they should open envelope B, read the second vignette and complete the questionnaire part 2 which asks about attributions towards sleep problems, treatment acceptability, their own sleep and demographic information about themselves. Part 2 of the questionnaire is then placed into envelope A with part 1, sealed and returned to the researcher either at the time, in a reply-paid envelope or in a collection box.

Part 2 of the questionnaire is provided in a sealed envelope in order to avoid priming the participants to attribute the difficulties to sleep problems in part 1 of the questionnaire.

Settings and equipment

Settings will include care provider offices, staff bases and other places identified by care providers in the Greater Glasgow and Lanarkshire areas. Attempts will be made to ensure care workers are able to complete the questionnaires in a quiet place, without distraction and without interfering with their direct care work, where possible.

Paper will be required to produce questionnaires and envelopes to maintain anonymity. Reply-paid envelopes and/or a box will be provided for completed questionnaires.

Data Analysis

Quantative analysis will be carried out using SPSS for Windows on all data. Initial descriptive statistics will be presented and data will be checked for normality and homogeneity of variance for the demographic information and each questionnaire. Non-normal data will be transformed. The questionnaires will be checked for internal validity and visual checks will be carried out on graphical representations of the data for each questionnaire.

The causal attribution questionnaire will be examined for differences between the six factors using repeated measures ANOVA and post hoc tests. Pearson's correlations will be carried out to identify whether there are any relationships between domains on the attributional style questionnaire and between the main causal attribution and most acceptable treatment. A further Pearson's correlation will be carried out to identify whether there is a relationship between support workers' sleep and their attributions of sleep problems. If significant factors are found, following post hoc power calculations multivariate regression will be carried out in order to examine any predictive relationships between the different types of data.

Health and safety issues

Researcher safety issues

Meetings with support staff and care providers will be in community locations. The researchers work base will be kept informed of the locations to be visited and the researcher will adhere to the procedure of checking in with administrative staff by 5pm.

Participant safety issues

One possible stressor may emerge for care workers if they become aware of difficulties in their client that they had not realised were present. It is also possible that clinically significant sleep problems may be identified in the sample of support workers however due to the anonymous nature of data collection it will not be possible to alert individuals that this was found. Following data collection participants will be debriefed about the ambiguous nature of the case studies and they will be given an opportunity to attend the sleep training events to further discuss any questions they may have. Where more detailed information is required they will be directed to the relevant clinical services.

Ethical Issues

Ethical approval will be sought from committees in NHS Lanarkshire and NHS Greater Glasgow. Subsequently, permission will be sought to contact care providers from social work services and from care providers to arrange a suitable time and method of recruiting their staff. Each participant will be provided with an information sheet that explains the rationale and confidential nature of the study as well as a consent form detailing that participation is optional.

This study will not adversely affect the support workers or the people they care for, however if following the study they have further questions or concerns about someone they work with then they will be directed to contact the most suitable service in their area. The optional nature of the project will be stressed to support workers who are considering taking part.

No identifying information will be collected. Each participant's response will be anonymously returned in a sealed envelope with a code for their workplace noted on their questionnaire in order to examine any differences in working environment. Completed questionnaires will be kept in a locked filing cabinet and electronic information will be kept in accordance with the Data Protection Act and NHS data protection procedures.

Financial issues

Equipment costs, travel etc

Predicted costs include paper for the questionnaires and envelopes to maintain anonymity as well as reply-paid envelopes to return the questionnaires. The researcher will travel to care provider bases and other locations to meet with the teams during meetings or events and in order to collect questionnaires or meet with a staff team, as necessary.

Timetable

June 2009 – Aug 2009:	Application for ethics approval
Sept 2009 – Jan 2010:	Recruitment and data collection
Jan – March 2010:	Data Analysis
March – July 2010:	Write up

Practical Applications

Exploring carer attributions of behaviours linked to sleep problems in adults with ID will increase the understanding of the factors that carers take into account when trying to understand behaviour change in this client group. It will demonstrate whether carers have adequate knowledge and understanding to identify sleep problems and may have implications for staff training if it is found that they do not consider sleep to be important. There may also be scope for understanding poor adherence to behavioural sleep interventions if it is found that this type of intervention is considered to be less acceptable to carers.

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Appendix 3: Amendments to Proposal Prior to Pilot Study

The Insomnia Severity Index (Morin, 1993) was replaced with the Pittsburgh Sleep Quality Index (PSQI; Buysse et al. 1989) as the latter provides a broader measure of sleep difficulties in addition to insomnia.

Following piloting, a number of minor amendments to the layout of questionnaires were made:

Numbers were added to the Causal Attributions Questionnaire (CAQ) to assist in reading ease and reduce the number of missed responses. Minor wording changes were also made to the initial instructions for the CAQ. The centre item was also changed from “Not sure” to “Equally Likely” in order to reflect a more accurate centre point on the Likert scale.

The main instructions for the envelopes, which are copied at the bottom of the CAQ, were simplified and instructions, such as “Please Turn Over”, were added to the bottom of each page, in order to increase the probability of respondents completing all questionnaires fully.

Font size was increased on the vignette, to improve readability. The vignette was also repeated on the second section of Part Two to clarify that the questions related directly to the vignette.

Statistical analysis strategy was amended, from the original proposal, as a more extensive method was considered appropriate to the data collected. This is described within the major research study itself.

Appendix 4: Author Instructions for Target

Journal of Intellectual Disability Research

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4. MANUSCRIPT TYPES ACCEPTED

Original Research Article The main text should proceed through sections of Abstract, Introduction, Methods, Results, and Discussion.

Full Reports of up to 4,500 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions.

Brief Reports of up to 1,500 words are encouraged especially for replication studies, methodological research and technical contributions.

5. MANUSCRIPT FORMAT AND STRUCTURE

5.1. Format

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Abbreviations, Symbols and Nomenclature: Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of SI units.

It is important that the term 'intellectual disabilities' is used when preparing manuscripts.

Please note that 'intellectual disability', as used in the Journal, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some counties.

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All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

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The Journal follows the Harvard reference style. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood. Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* 24, 137- 41.
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Where more than six authors are listed for a reference please use the first six then 'et al.'

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We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

5.4. Tables, Figures and Figure Legends

Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and given a short caption.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

Service development in a Developing Service: Tolerating the Inability to Heal the World.

Abstract

This reflective account is based on my experiences of working in a specialist placement with a new Child and Adolescent Mental Health Service - Learning Disabilities. The service is still in a pilot phase and has been operational for just over a year. There is lots of ongoing service development work in this new, enthusiastic team. In this reflective account, I explore my learning about service development, the ethical issues faced by a service starting out with fewer resources than are required, the communication and the inter-disciplinary differences within a multidisciplinary team. I reflect on the importance of understanding my role as an individual within a team, within the wider context of mental health services as a whole, and the bi-directional influence with government strategy. I describe my thoughts on a prevention model and a reflective review of my thoughts on how to make a difference without burning yourself out.

The Mismanagement of Anger: Anger Referrals to Adult Mental Health Services in the West of Scotland.

Abstract

Adult mental health services in the NHS across the West of Scotland provide different levels of service to people with problematic anger. Many teams do not accept anger referrals at all. Occasionally some slip through the gate-keeping and we are able to help them, in the same way as other people with other types of emotion regulation difficulties. Anger is a normal emotion, but at extremes can cause suffering to the angry person, their family and local community, arguably, more so than most other mental health problems. Following a GP complaint to the team I worked in, the debate about whether or not to accept anger referrals was sparked once again. The arguments for and against opening the gates to anger referrals are discussed alongside narrative reflections on my personal experience of working with anger and the system's rejection of it. I reflect on the need for policy development and more clarity and equality in dealing with problematic anger in the West of Scotland, as well as the clinical psychologist's role in designing and implementing change.