Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder or Down Syndrome

AND

CLINICAL RESEARCH PORTFOLIO

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Systematic Review

The relationship between carer's responses on the Illness Perception Questionnaire and psychological distress: a systematic review

Written according to guidelines for submission to *British Journal of Health Psychology* (See Appendix 1.1)

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Abstract

Purpose: This review aimed to address whether a relationship exists between the illness perceptions of carers, as measured by the Illness Perception Questionnaire (IPQ), and their levels of psychological distress.

Methods: The databases PsychINFO, EMBASE, MEDLINE, All EBM reviews, CINAHL and Web of Science were systematically searched, with 10 papers meeting the final inclusion criteria. Quality criteria were developed to rate the studies and the results were reviewed using a narrative synthesis approach.

Results: Relationships between carer's illness representations on the dimensions of the IPQ and their psychological distress were found, but these were inconsistent both within and between different health conditions. Variance in the adaptation of the IPQ may have contributed to these findings, in addition to other illness, patient, carer and relationship factors.

Conclusions: This review found inconsistent relationships between carer's illness representations on the dimensions of the IPQ and their psychological distress. Further research is required to explore other salient factors which may help explain why illness representations appear to have a relationship with psychological distress in some instances and not others.

Keywords Illness Perception; Common Sense Model; IPQ; Carer; Spouse; Parent

Introduction

The Illness Perception Questionnaire

The Illness Perception Questionnaire (IPQ; Weinman et al., 1996) is a widely used tool measuring cognitive illness representations (Broadbent et al., 2006). The publication of the IPQ and demonstration of its efficacy in predicting attendance at rehabilitation clinics is believed to have led to a sharp increase in research in this area (French & Weinman, 2008). The IPQ measures five dimensions of cognitive illness representations, developed from Leventhal et al.'s (1980) Common Sense Model of Illness Representation and confirmed across a range of conditions (Skelton and Croyle, 1991). These five dimensions are illness identity, cause, timeline, consequences and cure/control. The identity dimension examines the symptoms that the patient associates with the illness. The cause dimension refers to what the patient believes is the likely cause or causes of their illness. Timeline concerns the patient's perception of the likely duration of their illness, consequences reflects beliefs about the severity and impact of the illness on the patient's life and the cure/control dimension examines the patient's beliefs about the extent to which they believe the illness is amenable to cure or control.

A revised version of the Illness Perception Questionnaire (IPQ-R) by Moss-Morris et al. (2002) added and elaborated to these five dimensions; the cure/control dimension was separated in to two subscales of "personal control" and "treatment control", examining to what extent the patient believes they have control over their illness and to what extent they believe that treatment will be effective. The timeline dimension was divided in to

chronic and episodic/cyclical, to reflect the episodic or cyclical nature of the symptoms of some chronic conditions. Two further dimensions were added; illness coherence and emotional representations. Illness coherence aimed to evaluate to what extent the patient believed they had a coherent and useful understanding of their illness and emotional representation aimed to examine the patient's emotional response to their illness.

Cognitive illness representations exist within the more complex Common Sense Model of Illness Representation, shown in fig 1. This is a popular model for studying responses to health threats (Leventhal et al., 2007). The model contains two parallel streams of cognitive and emotional representations, which lead to coping strategies, appraisal of strategies, and outcomes, which feed back in to illness representations. Models which describe this dynamic process of a person modulating their thoughts, emotions and behaviours to achieve goals in a changing environment, with adaptation following appraisal and feedback are considered to be models of self regulation, and as such, this is a self-regulation model (Cameron & Leventhal, 2003).

(INSERT FIG 1 HERE)

Different patterns of illness representations may occur across different conditions, which Leventhal et al. (1980) acknowledged. Some researchers have suggested that a factor analysis should be performed on measures of illness representation to determine what clusters may occur for a particular condition (Turk et al., 1986; Heijmans et al., 1999). However, factor analysis usually extracts the dimensions in Leventhal's model (Hagger & Orbell, 2003), providing evidence for its use.

Illness representations and psychological distress

Hagger and Orbell (2003) conducted a meta-analytic review on studies using Leventhal et al.'s (1980) Common Sense Model of Illness Representation. They examined the relationship of illness representations in relation to a range of coping behaviours and illness outcomes. They found that the dimensions of consequences, identity and timeline were significantly positively correlated with psychological distress, suggesting that those who had perceived a stronger illness identity, more severe consequences and an increased chronic timeline scored higher on measures of psychological distress. The cure/control dimension was negatively correlated with psychological distress, suggesting that stronger beliefs in the treatability and controllability of the illness resulted in less psychological distress.

The use of the IPQ with carers

Although the Common Sense Model of Illness Representation focuses on the person's beliefs about their illness, Leventhal and colleagues (1985) also noted the importance of people's social context, and the influence and impact of health perceptions on the family unit and beyond. The illness perceptions of family members have received increasing attention and how carers represent the patient's illness is thought to influence their own behaviours and coping strategies (Weinman et al., 2003).

About one in ten of the population of England and Wales is a carer (Office for National Statistics, 2001 Census), and about one in eight adults in Scotland provides unpaid care

to someone (Harkins & Dudleston, 2006). The caring role may place strains on relationships and may reduce the physical, emotional and financial resources of the carer, potentially impacting upon their quality of life (Oyebode, 2003). It is therefore not surprising that carers present with higher levels of psychological distress than non-carers, and increased distress is associated with longer hours of care and with living with the person (Hirst, 2003). The need to ensure the well-being of unpaid carers is highlighted in recent government documents (e.g. Carers strategy, 2008; Shaping the future of care, 2009).

As a relationship exists between psychological distress and illness representations (Hagger & Orbell, 2003) and carer's illness representations may influence their behaviours and coping strategies (Weinman et al., 2003), it could be helpful to understand any relationship between carer's illness representations and psychological distress. This could inform future research and help to target intervention and resources which could be of benefit to both the carer and the patient. For example, if carer's illness representations were predictive of psychological distress, this could be a target for intervention.

Despite the potential importance of carer's illness representations and psychological well-being, there has not been a review of the literature in this area examining any relationship which may exist. Focussing on a quantitative measure of illness representation, such as the Illness Perception Questionnaire, may allow for comparability across studies in this area.

The research project in the next chapter of this thesis examines parental attributions. This would have been an interesting area in which to conduct a systematic review. However, this literature is diverse in both themes and terminology; studies have examined attributions as part of a wider examination of beliefs, or used the term "cause" instead of "attribution", making it difficult to systematically retrieve all relevant literature within the time constraints. As both the IPQ and the Hospital Anxiety and Depression Scale (HADS) were administered to parents in the research project in the next chapter, it was of interest to better understand any potential relationships between carer's responses on the IPQ and psychological distress to inform the research.

Aim

A review of studies using the IPQ or IPQ-R with carers, using this term to encompass any unpaid person supporting someone with an acute or chronic illness or health condition, may highlight relationships between dimensions of the IPQ and psychological distress. This review addresses the following question:

Does a relationship exist between the illness perceptions of carers, as measured by the IPQ, and their levels of psychological distress?

Method

Search Strategy

Studies were identified by searching the following electronic databases:

PsychINFO

EMBASE

MEDLINE

All EBM reviews

CINAHL

Web of Science

The following keyword search terms were used to identify research which may have used the Illness Perception Questionnaire or the Illness Perception Questionnaire-Revised:

IPQ

IPQ-R

Illness perception

Illness representation

Illness cognition

Common sense model

Self regulation theory

Self regulation model

These terms include the keywords used by French & Weinmann (2008), who sought to identify research on illness cognitions. The terms also include all of the keywords used by Hagger & Orbell (2003) to conduct a meta-analytic review of research using the Common-Sense Model of Illness Representations.

The above search terms were combined with the following, to restrict the research to the representations of carers:

Spous*

partner

husband

wife

wives

family

mother

father

parent

caregiver

carer

significant other

The term “relative” was not used due to its frequent use as an adjective describing any connected phenomena outwith a family context.

In addition to the database search, references from key articles and relevant book chapters were examined and a hand search of the following key journals was conducted:

Psychology & Health

British Journal of Clinical Psychology

British Journal of Health Psychology

Inclusion and exclusion criteria were defined as follows:

Inclusion

- Use of the IPQ or IPQ-R to measure the beliefs of an unpaid carer (e.g. parent, spouse, significant other)
- English language
- Research article with primary data

Exclusion

- Research published prior to 1996, as the IPQ was not published until 1996.
- Non-english language
- Qualitative research, reviews, dissertations, meeting abstracts & book chapters
- Research which examined the beliefs of medical professionals or those with a primarily professional relationship, for example, a Doctor-patient relationship
- Research which examined the illness perceptions of others who were not necessarily in a current relationship with that person, e.g. illness perceptions of people whose deceased relative had a hereditary disease.

Search Process

A diagram of the search process is available in Appendix 1.2. Computerised searching identified 358 results, although 126 of these were duplicates across databases. The

remaining 232 articles were searched in accordance to the inclusion and exclusion criteria above. Eighteen papers which met the criteria were retrieved.

Secondary exclusion

Basic descriptive information regarding these 18 papers is given in table 1. Of these 18 papers, 6 had a sole focus on patient or illness-related outcome measures including management of conditions or recovery rates and did not measure or report on the wellbeing of the carer, aside from their perception of the patient's illness (Heijmans et al., 1999; Law, 2002; Figuerias & Weinman, 2003; Keenan et al., 2007; Searle et al., 2007; Sterba et al., 2008). These papers were excluded. In addition to this, 2 papers were excluded as the main variables of interest were Expressed Emotion and Support/Undermining behaviours and therefore focussed on the dynamics of the relationship, rather than the carer's psychological distress (Lobban et al., 2006; Benyamini et al., 2007). This left 10 papers.

(INSERT TABLE 1 HERE)

Review strategy

Due to the diverse range of conditions examined using the Illness Perception Questionnaire and a variety of adaptations to the measure including use of different subscales, a meta-analysis was not viable and a narrative synthesis approach was adopted. The process was guided by the work of Popay et al. (2006) on narrative synthesis, which is outlined in guidance published by the University of York NHS

Centre for Reviews and Dissemination (2008). The guidance produced by Popay et al. (2006) attempts to increase the rigour of narrative synthesis and divides this approach in to four components; developing a theory, developing a preliminary synthesis, exploring relationships in and between studies and assessing the robustness of the synthesis. They suggest tools which may help at the different stages of this process. The benefit of narrative synthesis as opposed to a meta-analysis can be an increase in the range of implications for future research, although these approaches are not mutually exclusive (Rodgers et al., 2009).

Quality rating

Data extraction tables were used to allow for initial consideration and comparison of the methodology of the studies. Most of the studies had adopted a cross-sectional survey design, with an aim of characterising the population, in addition to other aims. Standardised tools developed for controlled trials were therefore only partially appropriate for reviewing the quality of this research. General methodological standards were combined from consultation of a variety of tools including the Clinical Trial Assessment Measure (CTAM; Tarrier & Wykes, 2004), Scottish Intercollegiate Guidelines Network Methodology Checklist (SIGN, 2004) and the Critical Appraisal Skills Programme (CASP; PHRU, 2004). From consultation of these guidelines, criteria covering the following core areas was derived:

- aim
- design
- sample
- measures

- analysis
- discussion

In addition to general indicators of quality, specific details pertinent to the research area and review question were considered in conjunction with the above; for example, a lack of detail concerning the duration and severity of the illness, no information on level of "caseness" of psychological distress or complete exclusion of any of the 5 core dimensions of the IPQ were considered to reduce the conclusions which could be drawn from the study. Measurement of other potentially relevant variables, for example regarding the carer-patient relationship or carer's view of caring, and analysis which considered the impact of other variables on any relationship with illness representations and psychological distress were viewed to enhance the conclusions which could be drawn. The final quality criteria are presented in appendix 1.3.

Each study was scored out of a possible 45 points and a percentage calculated based on this. Studies were arbitrarily assigned a quality rating of "high" if they achieved ≥75%, "Moderate" if they achieved 60% – 74% and "low" if they achieved <60%, to allow for comparability. Another Trainee Clinical Psychologist rated the studies and 97% agreement between raters was reached.

Results

Description of study characteristics

Table 2 and table 3 provide descriptive information about the 10 studies selected. This table allowed for initial comparison of characteristics across studies. Each column was reviewed and clusters and subgroups were identified, as described below:

(INSERT TABLE 2 & 3 HERE)

- **Patient condition**

The papers selected examine a range of chronic conditions, 4 of which could be grouped as having a primarily physical origin (Huntington's disease, Diabetes, Psoriasis, Rheumatoid Arthritis) and 6 of which could be grouped as having a primarily psychological origin (Alcohol dependency, Psychosis, Eating disorders). However, it is acknowledged that this distinction would be open to debate, with the origins of some conditions unclear and both physical and psychological aspects present across all conditions.

- **Relationship with patient**

Six papers examined the views of mixed groups, termed "carers", "relatives" or "significant others", and these groups predominantly consisted of parents or partners/spouses. Four papers focus on a specific relationship with the patient, including mother, husband, spouse and partner. Of note, studies considered to be examining a condition with a primarily physical origin (as described above), all examined a specific relationship (e.g. mother, husband). In comparison, studies examining a condition with a primarily psychological origin examined perceptions of mixed groups of "carers". This could possibly reflect a greater likelihood of impairments in social & family functioning present within those with a "psychiatric" condition, compared to those with a "physical" condition.

- **Age & sex of carers**

The mean age of the significant others appeared similar across conditions, ranging from 47 years to 57 years (standard deviation range 6yrs – 14yrs). Two studies examined the perceptions of only males (husbands) or females (mothers). Of the other 8, there were roughly equal numbers of males and females when spouse or partner perceptions were examined (Helder et al., 2002; Richards et al., 2004), and more females than males across studies where perceptions of mixed groups of carers were examined, including parents and spouses. There was a slightly higher female to male ratio of carers for those with psychosis (63% - 69% female), with the highest proportion of female carers present for those with eating disorders (82%).

- **Concepts measured and measurement tools adopted**

Concepts related to psychological distress were measured, including relationship quality, self-esteem and quality of life. Coping or carer burden was directly measured in 50% of the studies. In order to enhance comparability across studies, only measures of carer's psychological distress were considered. Where the Medical Outcomes Study Short Form (MOS SF-36; Ware & Sherbourne, 1992) was used to assess quality of life, only the mental health subscale was considered.

The most popular measure of psychological distress was the General Health Questionnaire (GHQ-12 & GHQ-28; Goldberg & Williams, 1988), with 50% of the selected studies employing one of the versions of this measure. The 12-item version gives an overall total psychopathology score, and the 28-item version gives details on four subscales of somatic symptoms, anxiety/insomnia, social dysfunction and severe depression. Measures of anxiety and depression included the Hospital Anxiety & Depression Scale (HADS; Zigmund & Snaith, 1983), Beck Depression Inventory (BDI;

Beck, 1988), Penn State Worry Questionnaire (PSWQ; Meyer et al.., 1990), the Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), and the Positive and Negative Affect Scale (PANAS; Watson et al., 1988). Two studies combined measures to produce a score of psychological adjustment (Olsen et al., 2008; Sterba & DeVellis, 2009) and one examined a total HADS score rather than separate anxiety and depression scores (Fortune et al., 2005).

Only 4 of the 10 studies (40%) reported the number of probable cases suggested by the scores on the measures (Richards et al., 2004; Fortune et al., 2005; Bamford et al., 2007; Whitney et al., 2007). Caseness varied across studies, with 57% of significant others of those with alcohol dependency and 35.7% of those caring for someone with an eating disorder reaching caseness, as measured by GHQ-12 scores (Bamford et al., 2007; Whitney et al., 2007). Within one study of relatives of people with psychosis, 54% scored over the clinical cut-off for an anxiety disorder and 38% scored over the cut-off for depression (Fortune et al., 2005). In contrast, only 1.7% reached caseness for probable depression, 10.3% for probable anxiety and 10.3% for pathological worry amongst partners of people with psoriasis (Richards et al., 2004).

Methodological considerations

Studies were reviewed using the quality criteria previously discussed.

- **Aims and design**

All studies had clearly focussed objectives. Three studies aimed to develop a version of the IPQ for use with carers of specific conditions, and examined the impact of

psychological distress as part of this (Barrowclough et al., 2001; Lobban et al., 2005; Sterba & DeVellis, 2009). Four studies focussed on the impact of divergent beliefs between patient and carer on outcomes, one of which was psychological distress (Richards et al., 2004; Bamford et al., 2007; Kuipers et al., 2007; Olsen et al., 2008). The three remaining studies focussed on the relationship between illness perceptions and distress in carers, with two also examining how these related to coping and one examining how these related to appraisals of caring (Helder et al., 2002; Fortune et al., 2005; Whitney et al., 2007).

Eight of the ten studies (80%) adopted a cross-sectional design, with two using a longitudinal design to examine illness representations over time (Lobban et al., 2005; Sterba & DeVellis, 2009). Items appeared stable at 4 or 6 month follow-up in both studies, except for an additional blame subscale used by Lobban et al. (2005) which was omitted from further analysis.

- **Sample**

Three studies recruited from consecutive referrals to services (Barrowclough et al., 2001; Bamford et al., 2007; Kuipers et al., 2007). Four studies used convenience samples from clinics, supplementing this with recruitment through charities in some cases (Helder et al., 2002; Richards et al., 2004; Lobban et al., 2005; Sterba & DeVellis, 2009). Two studies recruited using convenience samples from non-statutory organisations including a carer's support group and a carer's volunteer database (Fortune et al., 2005; Whitney et al., 2007), which may limit the generalisability of their findings, although this method allowed for carers to be contacted directly rather than

through patients. The remaining study recruited using participants who were part of a past research project, of which no further details are reported (Olsen et al., 2008).

In 8 of the studies, patient – carer dyads were recruited. This may have impacted on the representativeness of the sample, as patients consented in to the study prior to carers being approached. In half of the studies reviewed, the participants were recruited as part of larger studies, which may also have influenced their representativeness, although this is unclear.

No studies reported power calculations or justified their sample size, although 6 mentioned power briefly as a possible limitation to their research (Barrowclough et al., 2001; Helder et al., 2002; Fortune et al., 2005; Bamford et al., 2007; Whitney et al., 2007; Olsen et al., 2008).

Studies differed in the level of detail they provided about inclusion and exclusion criteria, with three studies not explicitly stating their criteria (Helder et al., 2002; Fortune et al., 2005; Olsen et al., 2008). The remaining studies stated their criteria, with variation in how restrictive this criteria was.

All studies stated their response rate, except for Richards et al. (2004) and Sterba & DeVellis (2009). Differing levels of detail were available on non-participants and eligibility.

- **IPQ**

The IPQ and IPQ-R require some adaptation in accordance to the illness or condition of interest. As they were designed for use with patients rather than carers, adaptations to the measure to account for this were also necessary. Psychometric properties were reported for 70% of the studies, with 30% not reporting this analysis (Helder et al., 2002; Richards et al., 2004; Bamford et al., 2007).

Core dimensions of the original IPQ were left out of some studies, with four studies not attempting to measure all five original dimensions (Barrowclough et al., 2001; Kuipers et al., 2007; Olsen et al., 2008; Sterba & DeVellis, 2009), in particular the cause and identity subscales. A number of reasons were given for this, for example, to reduce participant burden. These decisions were usually listed as limitations of the studies and areas for future research.

Dimensions of identity, cause, timeline and the subscale of treatment control were focussed on the illness and therefore were adapted by re-wording items by all authors who used them. However, the dimensions of consequences, coherence, emotional representation and the subscale of personal control were interpreted differently across studies, as to whether they referred to the patient or the carer or both. For example, personal control could be the control that the carer has over the outcome of the condition or the control they think the patient has over this. The scales were defined adequately in 80% of studies, either in the text or from example items, but were not defined clearly in two studies (Bamford et al., 2007; Richards et al., 2004).

- **Analysis**

Analysis varied depending on the aim of the study; two studies focussed on the psychometric properties of the scale (Barrowclough et al., 2001; Lobban et al., 2005), one study compared means and examined correlations (Kuipers et al., 2007) and the remaining seven studies used regression analysis, in addition to other types of analysis. The analysis appeared appropriate in all cases. Regression analysis allowed for the impact of other variables to be accounted for, strengthening confidence that significant relationships with psychological distress were a product of illness perceptions and not other confounding variables.

Quality Rating

The ratings for each study using the quality criteria described earlier are available in appendix 1.4 and a table of the ranked scores is available in appendix 1.5. The studies ranged in score from 60% to 82%, with a median of 68%. Using the rating system previously described, three studies were considered high quality, (Barrowclough et al., 2001; Fortune et al., 2005; Whitney et al., 2007) and the remaining seven studies were considered of moderate quality. There was limited variation in the quality of the studies.

Findings

Table 4 shows the univariate relationships reported between psychological distress (or adjustment) and the dimensions of the IPQ. Eight papers examined the relationship between the dimensions of the IPQ and the significant other's level of psychological distress. The majority of studies reported correlations, and ones which reached

significance are given in bold, red type. Correlations that did not reach significance, if provided, are given within parentheses.

(INSERT TABLE 4 HERE)

The remaining two papers only examined dissimilarities between the IPQ scores of patient and carer, and the relationship of this dissimilarity score to significant other's psychological distress. These were Bamford et al. (2007) and Richards et al. (2004). Two papers examined dissimilarity scores in addition to individual scores (Kuipers et al., 2007; Olsen et al., 2008). Table 5 shows the relationships between psychological distress and dissimilarity scores reported in these four studies.

(INSERT TABLE 5 HERE)

- **Identity**

Only 5 (50%) of the studies examined identity in relation to significant other's psychological distress. Two found a significant relationship, with both of these studies looking at carer's perceptions of psychosis (Barrowclough et al., 2001; Fortune et al., 2005). These studies indicated positive correlations between identity and psychological distress, suggesting the greater frequency of symptoms, the higher the level of carer psychological distress. Lobban et al. (2005) did not find a significant correlation between identity and carer's psychological distress in carers of people with psychosis.

Both of the studies which found significant relationships measured the identity subscale using frequency of symptoms calculated from the Family Questionnaire (Barrowclough

& Parle, 1997). Fortune et al. (2005), who found the highest correlation, used a score derived from the presence and frequency of a list of 45 symptoms. Barrowclough et al. (2001) used only the total count of the presence or absence of 49 listed symptoms. Lobban et al. (2005) measured the number of experiences which had ever been a problem for the patient since the onset of mental health problems, from a list of 58 items. These differences in measurement might suggest that both range and frequency of current symptoms contribute to carer's psychological distress, rather than only the variety of possibly infrequent symptoms, or historical symptoms.

- **Cause**

The cause scale was only completed in 6 studies (60%) and only analysed in 4 studies (40%). No significant independent relationships were found between the cause scale and carer's psychological distress.

- **Timeline**

Two studies found significant positive correlations between chronic timeline and carer psychological distress, both within carers of people with psychosis (Fortune et al., 2005; Kuipers et al., 2007). The two other studies of carers of people with psychosis did not find significant correlations, (Barrowclough et al., 2001; Lobban et al., 2005). It is possible that a specific construct of psychological distress may be relevant to the relationship between timeline and chronicity; scales specifically measuring depression did not find a significant correlation. However, the GHQ subscale termed "stress" by Kuipers et al. (2007) and described as anxiety/insomnia by the scale authors (Goldberg & Williams, 1988) was positively correlated, as was the HADS, which contains an

anxiety subscale. It is possible that for carers of people with psychosis, there is a relationship between anxiety and timeline chronicity, reflecting worries about the future.

Richards et al. (2004) also found a relationship between psychological distress and chronic timeline, with dissimilarity scores on this dimension independently associated with depression in partners. Partners who believed the condition would have a more chronic timeline than the patient were more likely to score higher on a measure of depression.

Two studies found a significant relationship between psychological distress/adjustment and episodic timeline (Richards et al., 2004; Olsen et al., 2008). Olsen et al. (2008) found that mother's negative adjustment was associated with the view of the adolescent's diabetes being cyclical. It is possible that this relationship with maternal negative adjustment is due to adolescent's difficulties in managing their condition and hence the condition is fluctuating. Richards et al. (2004) found that discrepancies between partner's and patient's beliefs about the cyclical nature of psoriasis were associated with worry in partners, with partners who held a lesser belief that the condition was cyclical than their partners, being more likely to score higher on a measure of worry.

- **Consequences**

Four studies had examined carer's beliefs about the consequences of the condition to the patient, 1 study had examined carer's beliefs about the consequences to themselves, and 3 studies had examined both. It was unclear to whom the consequences were

concerning in Richards et al. (2004) and one study examined the consequences for both partners on a single scale (Sterba & DeVellis, 2009).

Richards et al. (2004) found that divergence in beliefs about consequences was significantly associated with worry in partners of people with psoriasis, with partners believed the consequences of psoriasis to be more severe compared to the patient reporting higher levels of worry. This is explained by the authors in terms of partners engaging in rumination to as a result of the mismatch in perceptions to prevent or avoid negative consequences.

Sterba & DeVellis (2009) found severity of consequences to be negatively correlated with psychological adjustment scores and positively correlated with negative affect in husbands of wives with Rheumatoid Arthritis. This suggests higher psychological distress in husbands who perceive more severe consequences as a result of the condition, which appears logical.

A further two studies found positive correlations between consequences for the patient and psychological distress (Barrowclough et al., 2001; Fortune et al., 2005), in carers of people with psychosis. However, the same result was not found across all measures of psychological distress or consistently across studies of carer's illness perceptions of psychosis. Lobban et al. (2005) amended the consequences scale to include more items, covering a broader range of consequences than Barrowclough et al. (2001) and Kuipers et al. (2007). This could explain the differing results in this study. Kuipers et al. (2007) analysed individual subscales of the GHQ which may have contributed to the differing results. Mean scores on the GHQ and level of caseness is unknown for Kuipers et al.

(2007) and Lobban et al. (2001) so it is not known if differing levels of distress amongst samples could have contributed to the conflicting results.

Of the five studies which examined consequences to the carer specifically, three of them found a significant positive correlation with measures of psychological distress, all within carers of people with psychosis (Barrowclough et al., 2001; Fortune et al., 2005; Lobban et al., 2005). The two that did not find this relationship found no independent relationships between carer's psychological distress and any of the IPQ dimensions (Helder et al., 2002; Whitney et al., 2007). It appears logical that there is a correlation between the severity of the consequences that carers perceive to themselves and reported psychological distress, although the direction of causality is not known.

- **Cure/Control**

Seven of the ten studies found no independent association between individual or dissimilarity scores on any aspect of this dimension and psychological distress. Of the five studies that specifically examined carer's views of their control of the patient's condition, no relationship with psychological distress was found.

Studies within the same condition found differing results; a significant positive correlation was found between the view of the patient's level of control and psychological distress of the carer, suggesting that when carers perceived the patient as having more control of their condition, they themselves were more distressed (Fortune et al., 2005). Conversely, a negative correlation was found between beliefs about treatment control and carer psychological distress in the same study, indicating that carers who view treatment to be less effective are likely to be more distressed. Another

study with carers of people with psychosis, using the single cure/control scale from the original IPQ did not find significant correlations (Barrowclough et al., 2001). It is possible that this insignificant result was due to cure and control correlating in differing directions and cancelling each other out. However, Lobban et al. (2005) found no significant correlations between carer's level of psychological distress and separate scales of the patient's control, the carer's control and treatment control. In a further psychosis study, Kuipers et al. (2007) found significant negative correlations between the combined cure/control scale and subscales of depression and stress, indicating that the greater the carer's beliefs of control, by the patient and the treatment, the less distressed the carer was likely to be.

It is unclear why there is so much variance across illness beliefs of carers of people with the same condition, with specificity of measurement of both illness perceptions and psychological distress possibly contributing, in addition to possible differences in the levels of carer psychological distress within the samples. Fortune et al. (2005) recruited through carers support groups and recruited carers directly rather than patient-carer dyads. Their sample may therefore represent a distinct subset of carers of people with psychosis compared to the other studies, which recruited patients through clinics. This study also had a higher proportion of carers who were parents compared to the other psychosis studies, which contained a more mixed group of parents and partners.

Bamford et al. (2007) found a significant relationship between carer's psychological distress and dissimilarity scores on the treatment control scale; when carer's had a stronger belief in the efficacy of treatment, they were less likely to have a clinically significant level of distress. Out of the five studies which examined treatment control as

a separate entitity, two indicated an association between greater beliefs in treatment control and reduced psychological distress in carers (Fortune et al., 2005; Bamford et al., 2007).

- **Coherence**

Six of the ten studies (60%) examined the coherence subscale, with only one finding a significant correlation (Olsen et al., 2008). In two of the studies, the carer's coherence had been enquired about (Lobban et al., 2005; Olsen et al., 2008), in one study, the carer's perception of the patient's coherence had been enquired about (Sterba & DeVellis, 2009) and in the remaining three studies, it is unclear if the questions referred to the patient or the carer's coherence (Richards et al., 2004; Fortune et al., 2005; Bamford et al., 2007).

Olsen et al. (2008) was the only study to find a significant negative correlation between coherence and psychological distress. This suggests mothers with a less coherent view of their child's diabetes have higher levels of psychological distress. It is possible that having a coherent view of a condition is more important for parents caring for children and young people than carers of adult patients, which could explain why a significant result was only found in this study. Alternatively, it could be a condition-specific relationship.

- **Emotional representation**

Six of the ten studies (60%) used the emotional representations scale, although it has been used in different ways; two studies examined the carer's view of the patient's emotional representation (Fortune et al., 2005; Sterba & DeVellis, 2009), three studies

examined the relative's own emotional representation (Lobban et al., 2005; Bamford et al., 2007; Olsen et al., 2008) and one study did not specify whose emotional representation they enquired about (Richards et al., 2004).

As might be expected, emotional representations were significantly associated with psychological distress across almost all studies that used this dimension, with four out of five showing a significant relationship. The one study, which did not find a significant relationship, enquired about the patient's emotional representation, and no correlation value is available to indicate if the value may have been approaching significance (Fortune et al., 2005). Sterba & DeVellis (2009) found a significant negative correlation between husband's views of their wives' emotional representations and the husband's psychological adjustment and a positive correlation between emotional representations and husband's negative affect, suggesting that believing the patient to have a more emotional representation of their illness is related to a greater level of psychological distress.

In studies which examined dissimilarity scores, Bamford et al. (2007) found carers who maximised the emotional representations of the patient's condition, compared to patients, were more likely to have clinically significant distress. Richards et al. (2004) found that dissimilarity in emotional representations was independently associated with depression, although the direction of this dissimilarity is not stated.

Significant correlations were found by Olsen et al. (2008) and Lobban et al. (2005) between the carer's own emotional representation of the illness and psychological distress. Despite some differences and lack of clarity regarding the scale's use, it

appears to be fairly consistently associated with measures of psychological distress, which potentially lends support to the validity of the scale as one would expect such an overlap. However, the relationship between emotional representations and psychological distress could be viewed as circular as it could be argued that they are measuring the same construct, and hence this finding may be of limited clinical interest.

Discussion

This review aimed to address the question of whether or not a relationship exists between the illness perceptions of carers, as measured by the IPQ, and their levels of psychological distress. The results varied both across conditions and within conditions, possibly reflecting the impact of other patient, carer, relationship and illness factors between studies. It would appear that in some circumstances, a relationship exists between carer's illness representations and their psychological distress but there may be other influencing factors which explain why this pattern is not observed uniformly within and between conditions. Figure 2 below illustrates some of these possible influencing factors.

(INSERT FIGURE 2 HERE)

The greatest frequency of significant relationships between psychological distress and illness representations were found with the emotional representations dimension and the cure/control, although the relationship between emotional representations and psychological distress may be circular due to the high degree of similarity between these constructs. The results are not comparable with the findings of Hagger & Orbell

(2003) due to the inconsistency of findings, with no significant relationships found across some studies (Helder et al., 2002; Whitney et al., 2007) and several significant relationships found across different dimensions in other studies. As these studies examined associations, it was difficult to draw conclusive arguments from their results.

No studies found a relationship between causal attributions and psychological distress. There is evidence for a relationship between carer's causal attributions and critical responses to patients with psychosis (Barrowclough & Hooley, 2003), indicating that attributions are an important consideration in this area. However, Barrowclough et al. (1996) found no relationship between causal attributions and distress in relatives of people with psychosis. This could suggest that beliefs about cause have more impact on the relationship dynamics rather than a direct association with carer distress. Alternatively, the variety of approaches taken to record and surmise the cause scale across different conditions could have also masked significant relationships.

The number of comparable findings across studies was restricted due to the variety of adaptations of the IPQ and IPQ-R, which meant different subscales were employed. Some of the differences between studies may have also been due to different underlying dimensions of psychological distress, with differing results between measures focussed on anxiety and depression. The proportion of carers who met the clinical criteria for "caseness" may have also influenced the relationships observed, and level of caseness was often not reported.

This review raises important methodological issues in the use of the IPQ with carers which may help improve quality of research in the future. It highlights the importance

of thorough, detailed use of the IPQ with carers and a lack of consistency in its adaptation to date. Longitudinal research would help determine the direction of causality between correlated variables. A range of other potentially relevant factors influencing illness representations have been measured in various studies, including coping strategies and appraisals, expressed emotion, relationship quality and self-esteem, which would warrant further investigation.

Methodological considerations

An attempt was made to access all relevant literature using the search methodology described. However, it is acknowledged that further literature could be available. Research which did not produce significant results may not have been published and dissertations and other grey literature were not examined. No standardised tool for assessing the quality of the research reviewed was available, making the quality criteria employed subjective and more open to bias.

Conclusion

This review found inconsistent relationships between carer's illness representations on the dimensions of the IPQ and their psychological distress, both within and between different conditions. The most frequently observed relationships were between psychological distress and the emotional representations dimension and the cure/control dimension. It is possible that there are other illness, patient, carer or relationship factors which have influenced the findings and were not accounted for. Further research is required to explore other salient factors which may help explain why illness

representations appear to have a relationship with psychological distress in some instances and not others.

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Fig 1 – The Common Sense Model of illness Representation (from Hagger & Orbell, 2003)

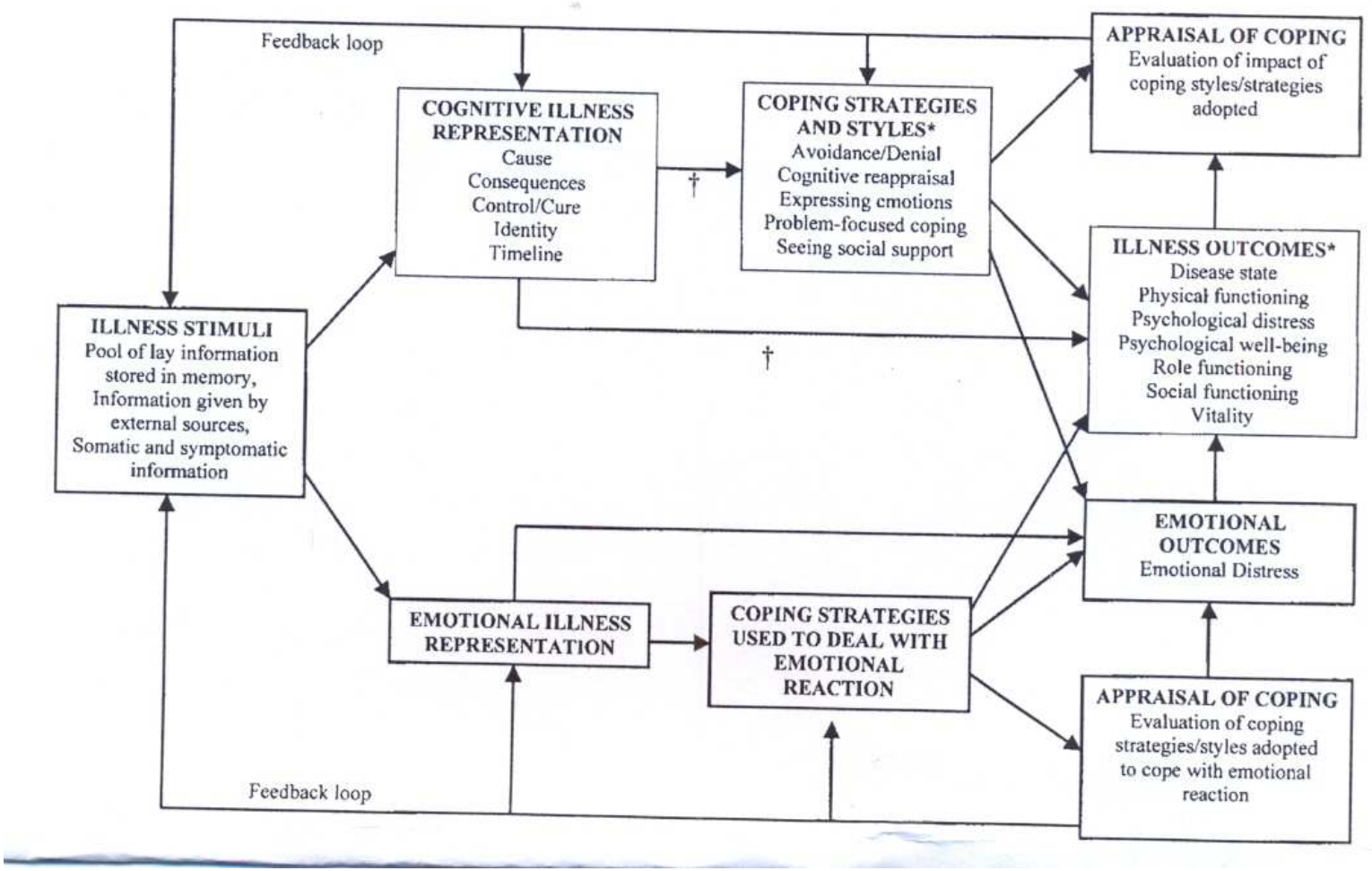


Fig 2 - A model of factors potentially influencing carer's illness representations

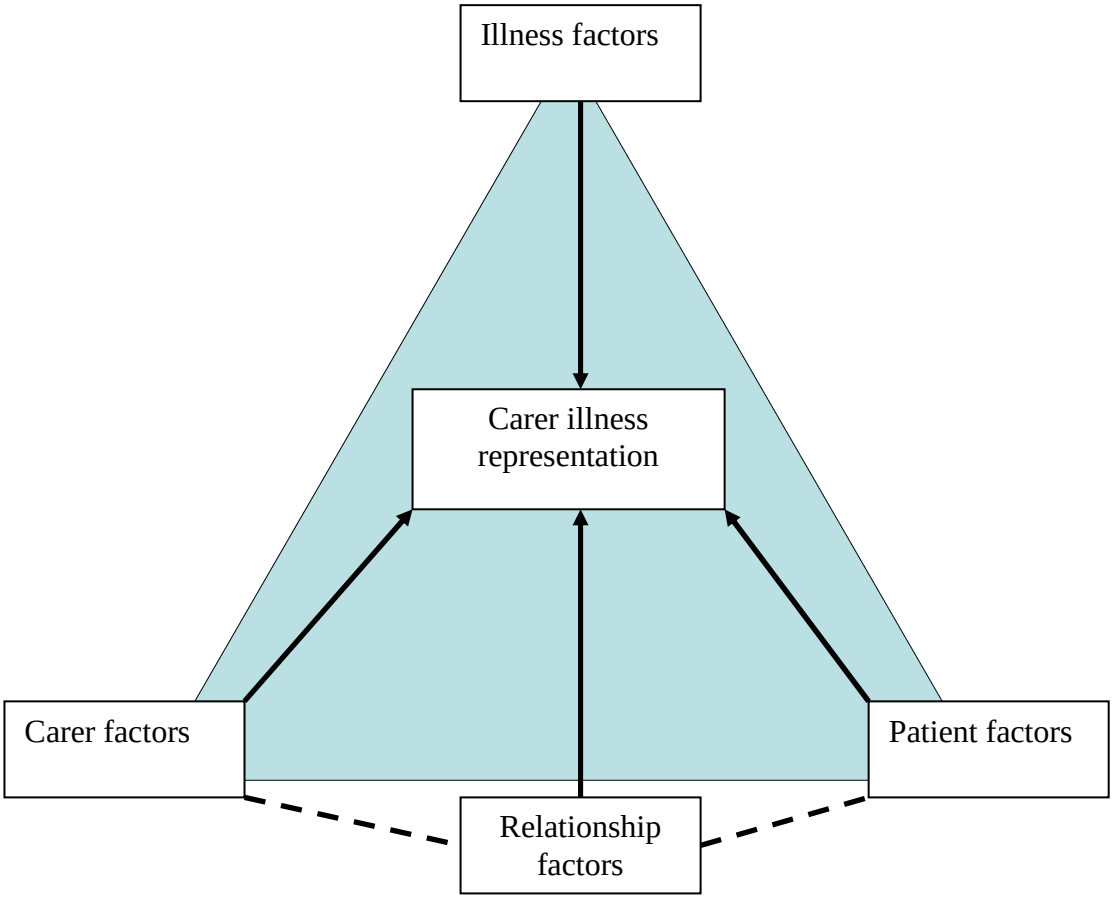


Table 1 – Selection of studies for inclusion

Author	Patient's condition	Relationship with patient	Main variables of interest	Include?
Bamford et al., (2007)	Alcohol dependency	Significant other (60% partners, 24% parents)	relationship quality, significant other distress, treatment attendance	✓
Barrowclough et al., (2001)	Schizophrenia	Carer (53% parent 28% Spouse)	Patient outcomes: symptom severity, social & general functioning; Carer outcomes: distress and burden	✓
Benyamini et al. (2007)	Heart disease	Spouse (38% male, 62% female)	Perceptions of spouse support and undermining (of both patient and spouse)	✖
Figueiras et al. (2003)	Myocardial Infarction	Partner/Spouse	Rate of patient recovery	✖
Fortune et al. (2005)	Schizophrenia	Relative (93% parents)	Relative's appraisals of psychosis, coping strategies and distress	✓
Heijmans et al. (1999)	Gp 1: Chronic Fatigue Syndrome Gp 2: Addison's Disease	Spouse	Patient's coping behaviour and adaptive outcome	✖
Helder et al. (2002)	Huntington's disease	Spouse	Quality of Life of spouses	✓
Keenan et al. (2007)	Sleep problems (children with developmental disabilities)	Parent (86% mothers)	Treatment acceptability	✖
Kuipers et al. (2007)	Non-affective Psychosis	Carer (50% parent, 34% partner)	Expressed Emotion (EE) and disturbed affect (in carers)	✓
Lobban et al. (2006)	Schizophrenia	Relative (53% parents, 36% spouse/partner)	Expressed Emotion (EE)	✖
Lobban et al. (2005)	Schizophrenia	Relative (59% parents, 24% spouse/partner)	Relative's emotional and behavioural responses	✓
Olsen et al. (2008)	Type I Diabetes	Mother	Negative emotional adjustment in both mother and child	✓
Richards et al. (2004)	Psoriasis	Partner/Couple	Psychological distress in both partners	✓
Searle et al. (2007)	Type 2 Diabetes	Partner/Couple	Patient self-management behaviour	✖
Sterba & DeVellis (2009)	Rheumatoid Arthritis	Husband	Sociodemographic & psychological variables	✓
Sterba et al. (2008)	Rheumatoid Arthritis	Husband	Wives psychological adjustment	✖
Urquhart Law et al. (2002)	Type 1 Diabetes	Mother	Adolescent psychological well-being	✖
Whitney et al. (2007)	Eating Disorder	Carer (80% Mothers)	Carer distress	✓

Table 2 – Study & carer characteristics

Author	Patient's condition	Relationship with patient	n	Age	Sex	Design	Concept measured	Measures related to psychological distress / wellbeing	Rate of Ψ distress / caseness
Bamford et al., (2007)	Alcohol dependency	Significant other (60% partners, 24% parents)	49	-	-	Cross-sectional	relationship quality, significant other distress,	GHQ-12	57%
Barrowclough et al., (2001)	Schizophrenia	Carer (53% parent 28% Spouse)	47	-	F (68%) M(32%)	Cross – sectional	Carer outcomes: distress and burden	GHQ-28 BDI (SBAS, +/- feelings)	M 6.36 (2) M 11.57(10)
Fortune et al. (2005)	Schizophrenia	Relative (93% parents)	42	M 57yrs SD 8 yrs	F(64%) M(36%)	Cross-sectional	Relative's appraisals, coping strategies and distress	HADS (COPE)	54% (Anx) 38% (Dep)
Helder et al. (2002)	Huntington's disease	Spouse	90	M 53yrs SD 10yrs	F (54%) M(46%)	Cross- sectional	QoL of spouses, Coping	MOS SF-36 (COPE)	_
Kuipers et al. (2007)	Non-affective Psychosis	Carer (50% parent, 34% partner)	82	M 52yrs SD 13yrs	F(69%) M(31%)	Cross-sectional	Expressed Emotion (EE) and disturbed affect	GHQ Rosenberg SE	-
Lobban et al. (2005)	Schizophrenia	Relative (59% parents, 24% spouse/partner)	62	M 53yrs SD 14yrs	F(63%) M(37%)	Cross sectional and longitudinal correlational	Relative's emotional and behavioural responses	GHQ-28 (SBAS)	_
Olsen et al. (2008)	Type I Diabetes	Mother	84	M 49 yrs SD 6 yrs	F(100% M(0%)	Cross-sectional	Negative emotional adjustment	-ve adj score (derived from PANAS & CES-D)	_
Richards et al. (2004)	Psoriasis	Partner/Couple	58	M 47 yrs SD 13yrs	F(49%) M(51%)	Cross-sectional	Psychological distress	HADS PSWQ	10.3%
Sterba & DeVellis (2009)	Rheumatoid Arthritis	Husband	190	M 51yrs SD 14yrs	F (0%) M(100 %	Longitudinal	Sociodemographic & psychological variables	Ψ adj score (derived from 4 measures)	_
Whitney et al. (2007)	Eating Disorder	Carer (80% Mothers)	115	M 52yrs SD 8yrs	F(82%) M(18%)	Cross-sectional	Carer distress	GHQ-12 (CANAM)	35.7%

Table 3 – Patient Characteristics

Author	Patient's condition	Age	Sex	Duration of illness	Carer's relationship with patient	Contact with patient
Bamford et al., (2007)	Alcohol dependency	M = 42 years; SD = 9.9 (range 25 to 63 years)	29% female; 71% male	M = 10 years; SD = 10 (range 6 months – 45 years)	Significant other (60% partners, 24% parents)	Unknown
Barrowclough et al., (2001)	Schizophrenia	M = 36.8 years; SD = 11.32	38.3% female; 61.7% male	M = 14.3 years; SD = 10.14	Carer (53% parent 28% Spouse)	Min. 10hrs face-to-face contact 70.2% living with patient
Fortune et al. (2005)	Schizophrenia	-	-	M = 6.1 years; SD = 3.2 (range 2 – 14 years)	Relative (93% parents)	Unknown
Helder et al. (2002)	Huntington's disease	-	-	-	Spouse	27.8% patient in nursing home 72.2% living with patient
Kuipers et al. (2007)	Non-affective Psychosis	M = 36.2 years; SD = 12.2	28% female 72% male	M = 11.2 years; SD = 10.26	Carer (50% parent, 34% partner)	Hrs face-to-face contact per wk M = 39.3hrs; SD = 24
Lobban et al. (2005)	Schizophrenia	-	-	-	Relative (59% parents, 24% spouse/partner)	Waking hrs spent together per week - M = 29.25 72% living with patient
Olsen et al. (2008)	Type I Diabetes	M = 14.16; SD = 1.7 (11.5 – 17.5 years)	47% female 53% male	M = 4.0 years; SD = 2.8 All > 1 year	Mother	Unknown
Richards et al. (2004)	Psoriasis	M = 44 years; SD = 12 years	49% male 51% female	M = 18 years; SD = 11 years	Partner/Couple	Unknown
Sterba & DeVellis (2009)	Rheumatoid Arthritis	-	100% female 0% male	M = 14 years; SD = 10.9	Husband	Unknown
Whitney et al. (2007)	Eating Disorder	M = 24.0 years; SD = 9.7	97% female; 3% male	M = 8.0 years; SD = 8.0	Carer (80% Mothers)	19% ≤ 21 hrs per week 70% > 21 hrs per week

Table 4 - Univariate associations between dimensions on the IPQ and measures of psychological wellbeing

Papers	Measure	IPQ dimensions											
		Identity	Cause	Timeline		Consequences		Control/cure			Coherence	Emotion	
				Chronic	episodic / cy	Patient	Relative	Personal control		Treatment		Pnt	Rel.
								Rel.	Pnt.				
[a]Barrowclough et al. (2001) Psychosis	GHQ-28	**0.30**		(-0.16)	(-0.01)	**0.30**	**0.39**	(-0.04)	(-0.12)				
	BDI	(0.12)		(-0.10)	(-0.13)	(0.13)	**0.35**	(-0.11)	(-0.20)				
[a]Fortune et al. (2005) Psychosis	HADS	**0.53**		**0.37**	(ns)	**0.38**			**0.36**	**-0.41**	(ns)	(ns)	
[a]Kuipers et al. (2007) Psychosis	GHQ-28 Depr			(0.13)		(-0.02)			**-0.26**				
	GHQ-28 Stress			**0.22**		(0.11)			**-0.25**				
[a]Lobban et al. (2005) Psychosis	GHQ-28	(0.18)		(0.21)	(0.13)	(0.12)	**0.26**	(0.06)	(-0.10)	(0.00)	(-0.13)		**0.50**
[a]Olsen et al. (2008) Diabetes	-ve adj			(0.04)	**0.24**	(0.03)		(0.10)	(-0.10)		**-0.30**		**0.48**
[a]Sterba & DeVellis (2009) Arthritis	Ψ adj			(0.09)	(-0.05)	**-0.28**			(0.11) (but predictive f-u)		(0.12)	**-0.22**	
	-ve affect			(-0.11)	(0.11)	**0.22**			(0.09)		(-0.14)	**0.26**	
[a]Whitney et al. (2007) Eating Disorder	GHQ-12		(ns)	(ns)	(ns)	(ns)	(ns)	(ns)	(ns)	(ns)			
[a]Helder et al. (2002) Huntington's disease	MOS-SF 36 (mh scale)	(ns)	(ns)	(ns)			(ns)	(ns)		(ns)			
[b]Bamford et al. (2007) Alcohol	GHQ-12		(ns)	(ns)		(ns)			(ns)	✓	(ns)		✓
[b]Richards et al. (2004) Psoriasis	HADS (Depr)	(ns)	(ns)	✓	(ns)	(ns)		(ns)		(ns)	(ns)	✓	
	HADS (Anx)	(ns)	(ns)	(ns)	(ns)	(ns)		(ns)		(ns)	(ns)	(ns)	
	PSWQ(Worry)	(ns)	(ns)	(ns)	✓	✓		(ns)		(ns)	(ns)	(ns)	

a = study examined relationship between individual carer scores and IPQ dimensions; b = study examined scores of divergence in beliefs only

As studies employed different aspects and versions of the measure, the elements not employed are shaded in grey and elements employed but not analysed are shaded with diagonal lines. For the two studies which only reported discrepancy scores, a red tick indicates that a significant relationship was found between discrepancy scores and carer's psychological distress.

Table 5 - Relationship between dissimilarity scores and psychological distress

Papers	Measure		IPQ dimensions											
			Identity	Cause	Timeline		Consequences		Control/cure			Coherence	Emotion	
					Chronic	episodic / cy	Patient	Relative	Personal control		Treatment		Pnt	Rel.
									Pnt.	Rel.				
Kuipers et al. (2007) Psychosis	GHQ	Depr							✓					
		Stress							✓					
Olsen et al. (2008) Diabetes	Ψ adj				(ns)	(ns)	(ns)		(ns)	(ns)		✓	✓	
Bamford et al. (2007) Alcohol	GHQ		(ns)	(ns)	(ns)		(ns)		(ns)		✓	(ns)	✓	
Richards et al. (2004) Psoriasis	HADS (Depr)		(ns)	(ns)	✓	(ns)	✓		(ns)		(ns)	(ns)	(ns)	
	HADS (Anx)		(ns)	(ns)	(ns)	(ns)	(ns)		(ns)		(ns)	(ns)	(ns)	
	PSWQ(Worry)		(ns)	(ns)	(ns)	✓	✓		(ns)		(ns)	(ns)	(ns)	

As studies employed different aspects and versions of the measure, the elements not employed are shaded in grey and elements employed but not analysed are shaded with diagonal lines. A red tick indicates that a significant relationship was found between discrepancy scores and carer's psychological distress.

Appendix 1.1 Guidelines for authors

Notes for Contributors

The aim of the **British Journal of Health Psychology** is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via our **online peer review system**. The Journal operates a policy of anonymous peer review. **Authors must suggest three reviewers**

when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper.

5. Manuscript requirement

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. Please see the document below for further details:

British Journal of Health Psychology - Structured Abstracts Information

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

6. Publication ethics

All submissions should follow the ethical submission guidelines outlined the the documents below:

Ethical Publishing Principles – A Guideline for Authors

Code of Ethics and Conduct (2006)

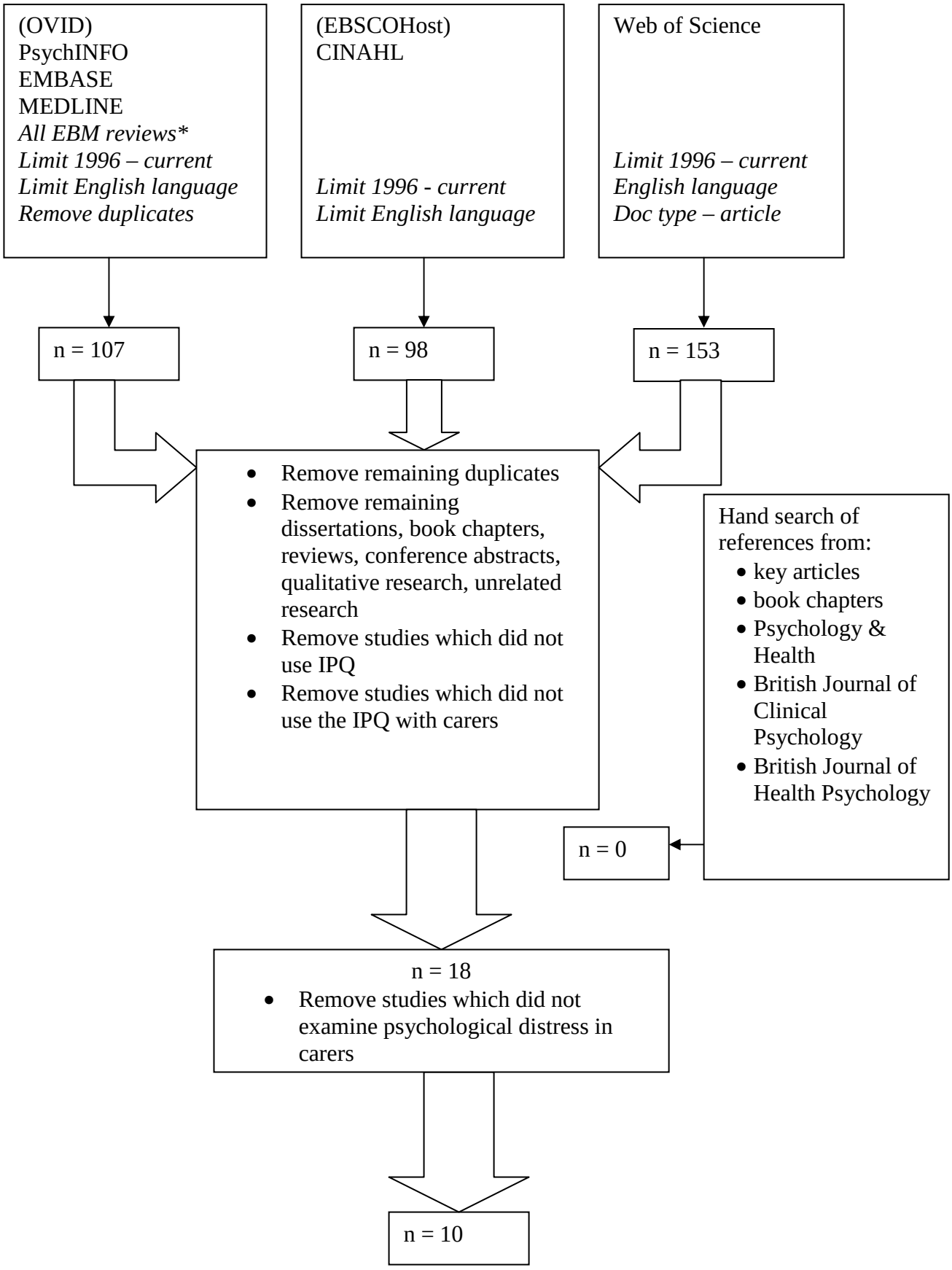
7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Copyright

On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form. To find out more, please see our **Copyright Information for Authors**.

Appendix 1.2 Search strategy



Appendix 1.3 Quality criteria

(1) Aim/Objective

2 The study has clearly focused objectives

1 The study has poorly focused objectives

0 The study does not report objectives

(2) Design

2 Longitudinal element to the design

1 Cross-sectional design

(3) Recruitment (carers) – where a combination has been used, rate highest

3 Consecutive patient referrals

2 Convenience sample within a statutory agency (clinic/service/other research project)

1 Convenience sample within a non-statutory agency e.g. support groups / including in combination with above

0 Highly selective sample (volunteers / advertisements) / unclear

(4) Justification of sample size

2 The sample size has been justified by either a power calculation or discussion of why it is of adequate size

1 Comment is made regarding the sample size as a limitation, or comment is made about sample size being adequate without justification.

0 There is no mention of the sample size being either adequate or inadequate.

(5) Inclusion/Exclusion criteria

2 Inclusion and exclusion criteria are clearly stated.

1 Inclusion and exclusion criteria are poorly stated, for example, just limited by patient diagnosis without consideration of other possibly relevant factors e.g. details regarding "carer" relationship.

0 No inclusion/exclusion criteria stated

(6) Significant other Demographics

Score 2 points for inclusion of each of the following:

- Age
- Gender
- Relationship with patient
- Amount of contact with patient
- Level of caseness or mean scores on measures of psychological distress
- Measure or indication of severity
- Duration of illness

(7) Response Rate

3 The study clearly indicates the participant response rate & provides information on non-participants.

2 The study clearly indicates the participant response rate but cannot give detail on non-participants

1 The study poorly indicates the participant response rate (e.g. lacks details on eligibility of those approached)

0 The study does not indicate the participant response rate

(8) Other measurements

Score 2 points for inclusion of each of the following:

- Measure reflecting relationship (e.g. Quality, EE)
- Measure reflecting caring role (e.g. Burden, Coping)

(9) Psychometric properties for IPQ/IPQ-R

2 Details of psychometric properties are given for use of the measure within the condition-specific population

1 Details of psychometric properties are reported from other studies, within different condition-specific populations

0 Not mentioned

(10) Exclusion of IPQ subscales

(Identity, Timeline, Consequences, cure/control and Cause)

2 Information on the 5 original subscales of CSM model gathered (or their adapted counterparts). This is regardless of whether this data was then analysed.

1 Exclusion of 1 subscale

0 Exclusion of 2 or more original subscales

(11) Definition of IPQ subscales

2 Adequate detail is given on all subscales used to determine who the questions refer to

1 Adequate detail is missing for one subscale

0 Adequate detail is missing for two or more subscales

(12) Analysis

1 Analysis is appropriate to the design

0 Analysis is not appropriate

(13) Analysis - consideration of confounding variables

2 Analysis controls for impact of other variables

0 Analysis does not control for impact of other variables

(14) Discussion – interpretation

2 The results are discussed with reference to the aims and hypotheses of the research

1 The results are discussed without clear reference to the aims and hypotheses of the research.

0 The results are only partially discussed with little reference to the research objectives.

(15) Discussion - generalisability

2 Generalisability of the research findings is discussed, with consideration of numerous factors.

1 There is brief comment on generalisability, focussing on a single factor.

0 There is no explicit discussion regarding the generalisability of the research findings.

Appendix 1.4 Quality ratings of studies

Study	Aim	Design	Recruitment	Sample size	Inclusion / Exclusion	Demographics	Response Rate	Other measures	Psychometric properties	Exclusion of IPQ subscales	Definition of IPQ subscales	Analysis	Confounding variables	Interpretation	Generalisability	Total	%
Bamford et al., (2007)	2	1	3	1	2	8	3	2	0	2	1	1	2	1	1	28	62
Barrowclough et al., (2001)	2	1	3	1	2	12	1	4	2	1	2	1	0	2	1	35	78
Fortune et al. (2005)	2	1	1	1	0	12	2	2	2	2	2	1	2	2	2	34	76
Helder et al. (2002)	2	1	2	1	0	10	1	2	0	2	2	1	2	2	2	29	64
Kuipers et al. (2007)	2	1	3	0	2	12	2	2	2	0	2	1	0	2	1	32	71
Lobban et al. (2005)	2	2	2	0	0	10	2	4	2	2	2	1	0	2	0	31	69
Olsen et al. (2008)	2	1	1	1	0	12	3	0	2	0	2	1	0	2	1	27	60
Richards et al. (2004)	2	1	2	0	2	12	0	0	0	2	0	1	2	2	2	28	62
Sterba & DeVellis (2009)	2	2	2	0	2	12	0	2	2	0	2	1	2	2	0	30	67
Whitney et al. (2007)	2	1	1	1	2	14	2	2	2	2	2	1	2	2	1	37	82

Appendix 1.5 - Studies ranked in order of quality rating

Score	Study	%	Rating
37	Whitney et al. (2007)	82	High
35	Barrowclough et al., (2001)	78	High
34	Fortune et al. (2005)	76	High
32	Kuipers et al. (2007)	71	Moderate
31	Lobban et al. (2005)	69	Moderate
30	Sterba & DeVellis (2009)	67	Moderate
29	Helder et al. (2002)	64	Moderate
28	Bamford et al., (2007)	62	Moderate
28	Richards et al. (2004)	62	Moderate
27	Olsen et al. (2008)	60	Moderate

Each study was scored out of a possible 45 points and a percentage calculated based on this. Studies were arbitrarily assigned a quality rating of "high" if they achieved ≥75%, "Moderate" if they achieved 60% – 74% and "low" if they achieved <60%, to allow for comparability. Another Trainee Clinical Psychologist rated the studies and 97% agreement between raters was reached.

Major Research Project

Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder or Down Syndrome

Shortened title: Parental attributions regarding sleep problems

Written according to guidelines for submission to *Journal of Sleep Research* (See Appendix 2.1)

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Submitted in partial requirement for the degree of Doctorate in Clinical Psychology (DClinPsy)

Summary

This study aimed to investigate any difference between the attributions parents made about their child's sleep problem, in parents of children with an Autism Spectrum Disorder and parents of children with Down Syndrome. Seventy-six parents of children with an Autism Spectrum Disorder and fifty-two parents of children with Down Syndrome completed a series of questionnaires on-line, regarding their child's sleep problem, their beliefs about their child's sleep problem and the parent's level of anxiety and depression. A significant difference was found between the groups on four of the causal items; other health problem, child's emotional state, child's personality and diet. Parents of children with Down Syndrome showed a higher level of agreement that their child's sleep problem could be attributed to another health problem compared to parents of children with an Autism Spectrum Disorder. Parents of children with an Autism Spectrum Disorder showed a higher level of agreement that their child's sleep problem could be attributed to their child's personality, their child's emotional state and their child's diet compared to parents of children with DS. There was a high level of agreement across all parents that their child's disability was a causal factor to their sleep problem and differences in attributions may reflect characteristics of the child's diagnosis. The results are consistent with previous findings that parents view disability as an important causal factor to their child's sleep problem and suggest a possible overlap in parent's views of their child's sleep problem and views of their disability.

Keywords: autism/autism spectrum disorder, down syndrome, attribution, illness perception, sleep, developmental disability

Introduction

Sleep problems are more prevalent in children with a developmental disability compared to typically developing children (Cotton & Richdale, 2006). However, parents of children with developmental disabilities often do not seek help for their child's sleep problem, despite the likelihood the problem will continue and become chronic without intervention (Wiggs & Stores, 1996; Robinson & Richdale, 2004). Therefore, it is particularly important for the well-being of children and their families within this group to understand the factors which influence the reporting of sleep problems and engagement with an appropriate intervention.

One such factor may be the causal attributions that parents make in relation to their child's sleep difficulties. Previous research has shown that how people explain events has consequences for how they think, feel and behave (Weiner, 1986). Heider (1958) described a "common sense" approach that people use to understand the behaviour of others, whereby a cause may either be attributed to dispositional factors within the person or situational factors outwith that person. Attribution theories examining how perceived cause impacts upon behaviour, affect and expectancy have been developed and applied within a number of areas including health, education and organisational settings (Kelley & Michela, 1980).

In previous studies involving children with a developmental disability and a sleep problem, parents have viewed the disability as an important contributing factor (Didden et al., 2002; Keenan et al., 2007). However, this research has not examined attributions within specific aetiologies of disability. Parents of children with differing disabilities

may have distinctly different experiences, and it is not known if attributions about sleep problems vary depending on the child's disability.

Autism Spectrum Disorder & Down Syndrome

Autism Spectrum Disorder (ASD) and Down Syndrome (DS) are among the most common developmental disabilities, and the experiences of parents of children with these diagnoses have frequently been compared. Parents of children with an ASD have been found to experience higher levels of anxiety, depression and stress, and a more external locus of control (Hamlyn-Wright et al., 2007) compared to parents of children with DS. Furthermore, higher rates of challenging behaviour are often found in children with an ASD (Eisenhower et al., 2005).

The family's experience of obtaining and adjusting to a diagnosis may also differ. A diagnosis of DS may be made prenatally, or soon after birth when the phenotype becomes physically apparent, with confirmation from a chromosomal test. Conversely, a reliable diagnosis of Autism cannot be made until a child is between 2-3 years of age, with diagnosis being less reliable for children on the broader Autism Spectrum at this age (Charman & Baird, 2002). The lack of clear genetic markers for Autism and a heterogeneous behavioural phenotype means that accurate diagnosis can sometimes be a complex and lengthy process.

There is evidence to suggest that parents of children with DS or an ASD differ in some of their perceptions, strategies and needs. Despite few differences in general beliefs about life, there were differences in strategies for day-to-day life, parents of children

with DS were more focussed on changing their child's environment, with parents of children with an ASD being more likely to take a new perspective (King et al., 2009). Parents of children with DS also reported higher cohesion, lower conflict, more positive appraisals and fewer negative appraisals compared to parents of children with an ASD (King et al., 2009). Parents with a child with an ASD perceived more of a need for professional support, compared to parents of children with DS perceiving more of a need for friendship opportunities for their child along with school and community supports (Siklos & Kerns, 2006). Siklos & Kerns (2006) suggest that parents of children with an ASD do not receive the same kind of "reinforcement" from parenting their child as parents of a child with DS do. In addition, Hoppes & Harris (1990) found that parents of children with an ASD scored lower on their perceived attachment to their child and gained less gratification from parenting their child than parents of children with DS and this was highlighted as a source of stress for parents. Overall, a trend exists which suggests poorer wellbeing in parents of children with an ASD compared to children with DS (Lewis et al., 2006).

Sleep problems in children with Autism and Down Syndrome

Although research often examines the sleep problems of children with developmental disabilities as a homogeneous group, the prevalence, nature and extent of these sleep problems may be dependent on the aetiology of the child's disability (Stores, 1992). For example, parents of children with an ASD have been shown to report sleep problems more frequently than parents of children with other developmental disabilities (Schreck & Mulick, 2000; Cotton & Richdale, 2006). Within a UK sample, Wiggs & Stores (2004) found that 67% of parents of children with an ASD considered their child

to have a current sleep problem. The majority were defined as having a sleeplessness problem, with problems initiating and maintaining sleep featuring prominently (Wiggs & Stores, 2004).

In a comparative study across disability groups, Cotton & Richdale (2006) found that children with Autism were more likely to have settling difficulties or sleep in their parent's bed whereas children with DS or presumed familial intellectual disability were more likely to have sleep maintenance problems. Prevalence of sleep problems across children with an ASD, DS or a familial disability were 73%, 40% and 46% respectively. A survey of parent's reporting of sleep problems in children with DS found 32% had problems maintaining sleep and 20% had problems settling (Stores et al., 1996). These rates were significantly higher than in siblings, where 10% experienced maintenance problems and 2% experienced settling problems. Children with DS are also particularly prone to sleep-related breathing difficulties. In a study by Stores (2001) fifty to eighty per cent of children with DS who underwent polysomnography were found to have Obstructive Sleep Apnea or hypoventilation.

Attribution Research

A number of models have been developed to suggest how attributions may influence management or treatment strategies adopted by the person. Weiner's (1986) model predicts that helping behaviour is most likely if stability and controllability are viewed as low, as these conditions generate optimism and sympathy, reducing feelings of anger. This model has been applied to care-staff's responses to challenging behaviour in people with intellectual disabilities, with inconsistent results (Willner & Smith, 2008).

With regard to children's behavioural problems, Morrisey-Kane & Prinz (1999) developed a model from a review of the research where parent's recognition of a problem led to attributions about both child and parent, causing an affective response and influencing expectations of change and engagement with treatment. Similarly, Leventhal's Common Sense Model of Illness Representation (Leventhal et al., 1980; Leventhal et al, 2003), which encompasses beliefs about cause along with identity, severity, controllability and consequences of a health problem, has been found to be predictive of affect, coping and adherence to treatment (Leventhal et al., 1984). This model has been employed to predict interest in Cognitive Behavioural Therapy for insomnia, with the dimension of causal attributions showing a robust association with interest (Cahn et al., 2005). In a qualitative study investigating parent's experiences of sleep disturbance in children with Rett's Syndrome, beliefs about the sleep problem were proposed to be a significant determinant of both emotional factors and coping (McDougall et al., 2005). These models differ in their detail, but essentially link attributions to emotional responses and subsequent behaviour.

This link between attributions and emotional response is also captured by theories of learned helplessness and hopelessness (Seligman, 1974; Abramson et al., 1989). It has been proposed that people who are depressed may make more global, internal and stable attributions about negative outcomes than those who are not depressed (Seligman et al., 1979). This negative attributional style may lead to learned helplessness, which combined with life stressors, may lead to depression (Peterson & Seligman, 1984). Furthermore, the expectation of helplessness may also create anxiety which can lead to co-morbid anxiety and depression, and hopelessness may develop (Abramson et al.,

1989). Therefore, there is a relationship between levels of anxiety, depression and attributions.

In their study of parent's beliefs about their developmentally disabled child's sleep problem and treatment acceptability, Keenan et al. (2007) found several causal items to be related to treatment acceptability, as measured by the Illness Perception Questionnaire (IPQ; Weinman et al., 1996). Positive correlations were found between the parent's views of behavioural treatment as acceptable and the bedroom environment and diet being identified as causal factors towards their child's sleep problem. Negative correlations were found between parent's views of behavioural treatment as acceptable and disability, fear for the child's safety during the night and the child's personality being identified as causal factors (Keenan et al., 2007). This indicates a possible relationship between attributions and treatment acceptability, therefore further exploration of attributions in this area may be helpful to inform engagement and intervention with parents of children with a developmental disability and a sleep problem. Keenan et al. (2007) did not investigate possible differences in parent's attributions about sleep problems depending on type of disability. As differences exist between parents of children with DS and parents of children with ASD, it may be important to understand how these differences could relate to engagement and choice in terms of intervention. As discussed, the literature has reported differences in the parents of children with DS and ASD, therefore, it is important to consider how these differences could relate to engagement and choice in terms of interventions for sleep difficulties.

Aim

The primary aim of this study was to investigate the attributions parents of children with an ASD or DS make about their child's sleep problem, and more specifically to test the hypothesis that a difference exists between these parent's attributions about their child's sleep problem, dependent on disability type. This was an exploratory, two-tailed hypothesis. It was intended to control for anxiety and depression scores as covariates.

Method

Design

The study employed a cross-sectional survey design with 2 levels of independent variable: parents of children with an ASD or parents of children with DS. The dependent variable was the parent's response on the cause subscale of the Illness Perception Questionnaire (IPQ). Measures of depression and anxiety were included as potential covariates.

Participants

Parents of children aged 5 to 11 with a diagnosis of an ASD or a diagnosis of DS and a current difficulty getting to sleep or staying asleep were invited to participate in the research. Potential participants were required to self-select and exclude themselves if they were under 18 years of age, had received a traumatic brain injury or had a current, diagnosed psychiatric disorder. Parents who reported that their child had a diagnosis

of co-morbid DS and ASD, epilepsy or a previous head injury were excluded. This was to control for epilepsy and/or head injury as potential important contributory factors in the child's sleep problem (Kohrman & Carney, 2000; Beebe et al., 2007).

Unfortunately, it was not possible to base a power calculation on the main measure of interest, the IPQ, as this measure had only been used with a similar sample population in a within-subjects design by Keenan et al. (2007). Therefore, a power calculation based on Hamlyn-Wright et al.'s (2007) study was performed as this study had also examined differences between parents of children with DS and ASD using a similar recruitment strategy. A power calculation was performed using G*Power software (Faul et al., 2007), based on Hamlyn-Wright et al.'s effect size *d* of 0.53 with alpha at 0.05 and power at 0.95, which gave a desired sample size of 94 participants in each group.

Measures

Demographics: Parents were asked for their child's age, gender, disability diagnosis, level of learning disability if known/present, any other diagnoses, medical conditions, medication and the severity of any behavioural problems. Parents were also asked to provide details of the first part of their postcode or home town and their relationship with their child (i.e. mother, father or other parental figure).

Sleep: The Simonds and Parraga Sleep Questionnaire (Simonds & Parraga, 1982), as modified by Stores et al. (1996) for use with parents of children with developmental disabilities, was administered to gather descriptive information about the sleep problems. The modified version by Stores et al. (1996) is for use with children/adolescents aged 5

to 20 and covers the quantity and quality of the child/ adolescent's sleep, as well as identification of sleep disorders through rating of 32 items, covering four broad categories: disorders of initiating and maintaining sleep, parasomnias, sleep-related breathing problems and daytime sleep-related features. These items were rated on a six-point likert scale concerning the frequency of their occurrence ranging from "never" (0) to "daily"(5). This measure has previously been found to be acceptable to parents and has a test-retest reliability of between 0.83 and 1 (Wiggs & Stores, 1998).

From the Simonds and Parraga Questionnaire, a Composite Sleep Index (CSI) which takes into account the number and frequency of onset and maintenance problems can be calculated (Montgomery et al., 2004). This scale provides a score out of a possible 8 to give an indication of the severity of problems of onset and maintenance of sleep. A score of $\geq$4 was described by Montgomery et al. (2004) as indicating a severe sleep problem.

Parental attributions: In order to investigate parent's attributions about their child's sleeping difficulties, a modified version of the Illness Perception Questionnaire (IPQ), originally developed by Weinmann et al. (1996) and based on Leventhal's Common Sense Model of Illness Representation (Leventhal et al., 1980; Leventhal et al., 2003) was administered. This questionnaire was modified for use by parents of children with developmental disabilities by Keenan et al. (2007), and permission was granted to use this modified version. The IPQ contains five dimensions: Identity, Cause, Controllability/Cure, Timeline and Consequences. Parents had identified the symptoms they considered to be associated with their child's sleep problem through the Simmonds

& Parraga Questionnaire, and therefore this was considered to capture beliefs about identity and a separate measure of identity was not used.

In the present study, the Cause subscale was compiled utilising causes identified by McDougall et al. (2005) and further information was added following collaboration with an experienced nurse practitioner. Keenan et al. (2007) divided the cause dimension into internal and external subscales, however the internal subscale had an unacceptably low internal consistency of 0.17. It was therefore intended to use a different approach and sum the causal subscale on items reflecting psychological/emotional, biological and environmental causes, consistent with suggestions by Hagger & Orbell (2003). As the cause subscale was the dependent variable, 5 additional items were added to this dimension, consistent with those implemented by Moss-morris et al. (2002) in their revised IPQ, including "chance or bad luck" and "my child's emotional state". The adapted version of the IPQ is available in appendix 2.2.

Considering the sensitivity and specificity of the other dimensions, Keenan et al. (2007) reported Cronbach's alpha values of Consequences and Cure/Control to be 0.69 and 0.65 respectively, which were deemed adequate. The timeline dimension had a relatively low alpha of 0.54. It was suggested that this may be due to the small number of items on this dimension (Keenan et al., 2007).

Parental anxiety and depression: The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) was administered to measure anxiety and depression. This is a 14-item self-report questionnaire with two 7-item subscales measuring anxiety and

depression. This measure has been widely used in a variety of settings and populations, including the general population. A review of its validity found the mean Cronbach's alpha for the anxiety subscale to be 0.83 and the mean for the depression subscale to be 0.82, with sensitivity and specificity of both scales to be around 0.8 (Bjelland et al., 2002). The authors suggest that raw scores on either scale of 8 – 10 suggest a mild case, 11 – 15 is moderate and over 16 suggests a severe case (Snaith & Zigmond, 1994). Normative data from the general population considers a clinical cut-off score of 10 or 11 to be appropriate for both scales (Crawford et al., 2001).

Procedure

Participants were required to self-select via advertisements placed on relevant charities websites. Potential participants clicked on a web-link, which took them to a separate research website. They then viewed a letter of invitation and further information about the research, before giving consent to participate, by clicking on boxes on the screen. The site had navigation buttons to move forwards and backwards through the questionnaires and an exit button if participants opted to cease participating. Those who did not check the boxes to consent to participate could not navigate forward to view or complete the questionnaires. Participants completed demographic information, the Sleep Questionnaire, the IPQ, and the HADS in that order. Participation was anonymous; no information which could readily lead to a person being identified was requested, Internet Protocol (IP) addresses were not saved and Secure Sockets Layer (SSL) encryption was used to transfer data from the site for analysis. Ethical approval was granted by NHS Greater Glasgow & Clyde, as the website was administered and managed within this health-board area (see Appendix 2.4).

Analysis

The data were analysed using SPSS version 15. Descriptive statistics were produced. Kolmogorov-Smirnov and Shapiro-Wilks tests revealed that the majority of the data for analysis were not normally distributed. Accordingly, non-parametric methods were used to perform the main analyses. As the main outcome variable of interest, the Cause scale, was not normally distributed and could not be transformed due to the nature of the responses, a MANCOVA analysis could not be completed as previously planned. Therefore, Mann-Whitney U tests were performed to examine any difference between the attributions of parents with a child with an ASD and parents of a child with DS, regarding their child's sleep problem. Results were viewed to be significant if $p < 0.05$ and effect sizes were calculated to indicate the strength of any potential relationships. Correlations between Cause items and anxiety and depression scores were calculated using Kendall's tau, a non-parametric method of correlation, to allow for further exploration of this data. It is recommended that for small data sets with a large number of tied ranks, Kendall's tau should be used rather than Spearman's coefficient (Field, 2005), and despite the popularity of Spearman's coefficient in comparison, there is evidence to suggest that Kendall's tau is a better estimate of correlation (Howell, 1997).

Results

Participants

One hundred and ninety-two participants consented to take part in this study. Of these, 27 (14%) entered no data and 29 (15%) participants were excluded as they missed out at least one measure completely. One participant was excluded as the child was noted to have both Autism and Down Syndrome and 7 participants were excluded as the child scored <2 on the CSI and the parent did not consider the child to have a sleep problem. Therefore, the final sample consisted of 128 participants.

Descriptive information about the demographics of the sample is given in table 1. There were 76 parents of children with an ASD and 52 parents of children with DS in the final sample. The median age for both groups was 8 years, with no significant difference between the groups ($U = 1928.5$, $p = 0.817$, $r = -.02$). There was a high proportion of boys in the ASD group, as would be expected given the increased prevalence of ASD in males (Fombonne, 2005), and this difference was significant at the 0.05 level (χ^2 (1) = 9.03, $p = .011$), with a child being 3.2 times more likely to be a boy in the ASD group. The questionnaire was mainly completed by mothers, with only a low number of fathers completing it and no other parental figures participating.

(INSERT TABLE 1 HERE)

Sleep

Descriptive statistics relating to the sleep problems experienced by each group are shown in table 2. Duration of the children's sleep problems ranged from 1 month to 10 years in the ASD group, with a median of 2 years, and only 4 cases experiencing a problem for longer than 6 years. In the DS group, duration ranged from 1 month to 6 years, with a median of 2 years. Mean Composite Sleep Index scores, giving a measure

of the severity of problems initiating and maintaining sleep, was higher for children with an ASD (M = 4.7, SD = 1.9) than children with DS (M = 3.6, SD = 1.9), and this difference was statistically significant (t(126) = 3.04, p = .003).

A descriptive table of the frequency of further symptoms of disordered sleep experienced by each group is available in appendix 2.3. With reference to Wiggs et al. (1998) and the International Classification for Sleep Disorders (ICSD-2; American Academy of Sleep Medicine, 2005), these items were grouped into three categories of parasomnia-type symptoms, breathing-related symptoms and anxiety or behavioural type symptoms. Items where less than 10% in either group experienced the problem frequently were excluded.

There were significant differences between the groups on all three categories of symptoms of sleep disorders. Parents with children with DS reported more parasomnia type symptoms (U = 1143.0, p = .010, r = -.24), more breathing-related symptoms (U = 607.5, p = .000, r = -.53) and less anxiety/behavioural symptoms (U = 1054.0, p = .001, r = -.31) than parents of children with an ASD. A large effect size was observed concerning breathing related symptoms.

(INSERT TABLE 2 HERE)

Anxiety and Depression

On the Depression scale, the median score for both groups of parents was 8. There was no significant difference between the groups (U = 1926, p = .809, r = -.02). On the Anxiety scale, the median score for parents of children with an ASD was 10 and for

parents of children with DS was 9.5, again with no significant difference between the groups (U = 1703, p = .185, r = -.12). Using a cut-off score of ≥11, 23% of parents with a child with DS and 29% of parents with a child with an ASD met the criteria for caseness of depression. For anxiety, 40% of parents with a child with DS and 46% of parents with a child with an ASD met the criteria for caseness, using the same cut-off score of ≥11.

IPQ subscales Timeline, Consequences, Cure/Control

Cronbach's alpha was calculated as a check of internal consistency of the subscales of the IPQ. The timeline subscale was acceptable for both the ASD group (0.67) and the DS group (0.65). The consequences subscale demonstrated good internal consistency for the ASD group (0.86) and the DS group (0.78). Poorer internal consistency was found for the cure/control scale, for both the ASD group (0.59) and the DS group (0.48). Mann Whitney U tests were performed, showing no significant differences between the groups on these three subscales (Timeline: U = 1728.5, p = .273, r = -.10; Consequences: U = 1587.5, p = .164, r = -.13; Cure/Control: U = 1579, p = .087, r = -.15).

Cause

Table 3 shows the percentage of parents in each group who agreed or strongly agreed that the corresponding item was a cause of their child's sleep problem. On inspection of the data, the intended coding system appeared insufficient. There were several items on the cause scale with which the vast majority of parents did not agree were contributing causal factors to their child's sleep problem. It was therefore decided to remove any

item where less than 10% of parents in either group agreed that it was a contributing factor. This left 12 items, which were analysed individually.

(INSERT TABLE 3 HERE)

The two groups were compared using Mann Whitney U tests for each of the 12 remaining items on the causal scale. The results are presented in table 4. Significant differences were found on 4 out of the 12 items; child's emotional state, child's personality, other health problem and diet. Parents of children with DS showed a higher level of agreement with "other health problem" ($U = 1128.5$, $p = .000$, $r = - .36$) compared to parents of children with an ASD. Parents of children with an ASD showed a higher level of agreement with items "child's personality" ($U = 1353.0$, $p = .003$, $r = - .27$), "child's emotional state" ($U = 843.5$, $p = .000$, $r = - .50$) and "diet" ($U = 1530.0$, $p = .040$, $r = -.18$) compared to parents of children with DS. A large effect size was observed concerning the "child's emotional state", a medium effect size for "child's personality" and a small effect size for "diet", indicating that the strongest difference between groups was concerning the child's emotional state as a causal factor.

(INSERT TABLE 4 HERE)

Exploring the relationship between mood and causal variables

To explore the possible relationships between anxiety and depression scores and cause variables, Kendall's tau non-parametric correlations were performed.

Within the parents of children with DS group, anxiety scores were positively correlated with stronger beliefs that the sleep problem was hereditary ($N = 52$, $\tau = 0.248$, $p = .025$), caused by family worries related to the child's sleep problem ($N = 52$, $\tau = 0.232$, $p = .038$) and caused by the child's emotional state ($N = 52$, $\tau = 0.241$, $p = .025$). There was a negative correlation between anxiety score and belief in stage of development as a causal factor ($N = 52$, $\tau = -0.303$, $p = .006$). Depression scores were positively correlated with parent's reaction ($N = 51$, $\tau = 0.227$, $p = .039$) and child's personality ($N = 51$, $\tau = 0.225$, $p = .045$). The remaining correlations were not significant at the $p < .05$ level.

Within parents of children with ASD group, both anxiety and depression scores were positively correlated with causal beliefs about family worries (anxiety $N = 76$, $\tau = 0.271$, $p = .003$; depression $N = 76$, $\tau = 0.275$, $p = .002$) and parent emotion as a cause (anxiety $N = 74$, $\tau = 0.195$, $p = .032$; depression $N = 74$, $\tau = 0.198$, $p = .030$). The remaining correlations were not significant at the $p < .05$ level.

Parents were asked to state what they believed the main cause of their child's sleep problem to be. Consistent with results on the cause scale, parents frequently stated that they believed their child's disability to be the main cause of their sleep problem. Interestingly, some parents elaborated on how they felt their child's disability led to sleep problems, expressing a range of physiological and psychological mechanisms which they believed could lead to a sleep problem.

Discussion

It was hypothesised that there would be a difference in the attributions parents made about their child's sleep problem, between parents of children with an ASD and parents of children with DS. A significant difference was found between the groups on four of the causal items; other health problem, child's emotional state, child's personality and diet. Parents of children with DS showed a higher level of agreement that their child's sleep problem could be attributed to another health problem compared to parents of children with an ASD. Parents of children with an ASD showed a higher level of agreement that their child's sleep problem could be attributed to the child's personality, their child's emotional state and their child's diet. It is important to understand these results in the context of the scale used, which was ordinal rather than categorical; for example, although a higher level of agreement was found amongst parents of children with an ASD for the item Diet as a cause, it should be recognised that very few parents actually agreed that this *was* a cause.

As the data were non parametric, it was not possible to perform a MANCOVA so anxiety and depression scores were not controlled for as possible covariates. Nevertheless correlational analyses would suggest only a weak relationship with a few of the causal items, although these findings need to be interpreted with caution. Within the group of parents of children with Down Syndrome, anxiety appears to positively correlate with increased beliefs that the sleep problem is hereditary, caused by family worries related to the child's sleep problem and caused by the child's emotional state. This may reflect family dynamics. There was a negative correlation between anxiety and stage of development, which may suggest that less anxious parents more readily normalise their child's problem. Ly & Hoddapp (2002) noted that parents of children with DS made more "normalising-temporary" attributions than children with intellectual

disability of mixed cause, in a vignette study regarding behaviour. This could suggest a stronger tendency for parents of children with DS to normalise their child's behaviour. Depression scores within the DS group were positively correlated with parent's reaction and child's personality, potentially suggesting an increased frequency of internal, dispositional attributions to themselves and their child, consistent with Seligman et al. (1979). Within the ASD group, both anxiety and depression scores were positively correlated with causal beliefs about family worries and parent emotion as a cause, perhaps reflecting parent's insight in to how their worries and emotions may impact on their child.

In accordance with previous research these findings once again highlight parent's view of the importance of the child's disability as a major contributing factor. In addition, compared to Didden et al. (2002), where 25.3% stated the child's disability as the cause of their sleep problem; when directly asked during this research, 92% of all parents in the current study agreed or strongly agreed that this was a causal factor. This was further echoed by parent's statements about what they considered to be the most important cause. The differences between the other possible causal factors perhaps mimic parent's view of their child's disability; additional physical health problems are common in Down Syndrome and specific personality traits and emotional responses can be symptomatic of the impairments within social communication, interaction and flexibility which characterise Autism Spectrum Disorders. The findings may also indicate a high level of knowledge among the parents on the subject. However, it is also possible that the child's diagnosis overshadows their sleep problem, and this may prevent appropriate help being sought, although the majority of the parents in the study had received treatment or advice.

No significant differences were found between parent's anxiety and depression scores on the HADS. Notably, scores were higher than those reported in previous research; Hamlyn-Wright et al. (2007) found mean scores of 7.53 and 5.06 for anxiety and depression respectively within parents of children with DS and mean scores of 9.63 and 7.20 for parents of children with an ASD. This was compared to the current study reporting medians of 8 and 9.5 for anxiety and depression in parents of children with DS and medians of 8 and 10 for anxiety and depression in parents of children with an ASD. It may be that for parents with a child with DS, having a child with a sleep problem increases the parent's level of anxiety and depression, but there appears little additional impact on levels of anxiety and depression in parents of children with an ASD. It is difficult to account for differences in levels of parental anxiety and depression observed between the groups in the current study and Hamlyn-Wright et al. (2007) as they did not investigate rates of sleep problems.

Clinical implications

Parents of children with an ASD showed a higher level of agreement that their child's sleep problem could be attributed to the child's personality compared to parents of children with DS. Considering Keenan et al.'s (2007) findings that acceptability of behavioural treatment was negatively correlated with the child's personality as a causal factor, there may be differences in treatment acceptability between these two groups in relation to this. This could potentially impact on help-seeking and engagement with interventions.

Keenan et al. (2007) also found a negative correlation between acceptability of behavioural treatment and the view that disability was a causal factor to the child's sleep problem. The high levels of agreement across parents that disability was a causal factor in their child's sleep problem could suggest that parents with children with an ASD or DS might find behavioural treatment less acceptable. Despite the existence of links between the child's disability and their sleep problem, there may be other important factors that are overshadowed by the disability or viewed to be part of it. Woolfson (2005) suggests that when parents attribute a child's behaviour problem to their disability, it may be helpful for psychologists to persuade them that some behavioural improvement could be possible. Considering the findings of this study, it may be helpful for those working with parents of children with developmental disabilities and sleep problems to address the attribution of the problem to the disability and consider other influencing factors, which may be amenable to intervention. However, there is a need to be mindful that sole attribution of the sleep problem to the disability could be a coping strategy for the parent. For example, a more authoritative parenting style could be more stressful for parents to implement (Woolfson & Grant, 2006).

Study limitations and implications for future research

The findings of the current study need to be interpreted with caution as the method employed has implications for the generalisability of the research. Participants are likely to be from higher income families, with higher levels of education (Sadeh et al., 2009), and may be more involved with supportive networks, and this might effect how representative the sample was of parents of children with DS or an ASD as a whole. However, other research has found similar results between internet-based surveys and

traditional methods when researching children's sleep (Sadeh, 2004; Sadeh et al., 2009). Additionally, the use of web-based questionnaires allowed for the recruitment of a large sample size and may also have reduced socially desirable responding. Given the target population, a possible alternative method would have been to approach education authorities to recruit parents via schools. However, the specificity of the target groups would mean recruiting widely across a variety of mainstream and specialist educational settings, with reliance on teaching staff to identify potential participants. Previously this method yielded a mere 5% response rate when all children with developmental disabilities were given study information to take home (Keenan et al., 2007). As the research was advertised within subsections of different webpages, it was not possible to provide a reliable estimate of the response rate.

Based on the a priori power calculations, the study was underpowered, which may have resulted in other differences not being detected. However, there was a lack of similar research on which to base the power calculation, and power appears to have been adequate to detect effects that might be clinically meaningful. Similarly, the conservative nature of non-parametric analysis may have reduced the number of significant effects found. The cause scale was analysed individually, due to difficulties encountered in grouping items. For example, "disability" could be viewed as biological or psychological, and items such as "hereditary" were relevant to both child and parent. Similar difficulties were encountered using other methods to categorise items. This prevented the use of a MANCOVA; Weinman et al. (1996) suggest that researchers perform a factor analysis on the cause scale, to identify suitable dimensions for analysis. However, the sample size was too modest to allow for this. The individual analysis of the cause subscale also led to multiple comparisons, which increased the chance of a

type I error. Attempts were made to reduce the number of comparisons by only analysing causal items where at least 10% of either group believed the item to be a contributory factor to their child's sleep problem.

Objective measurement of the child's sleep problem, level of intellectual ability or adaptive functioning, severity of Autistic traits, parent's level of self-efficacy and relationship between parent and child would have aided with the interpretation of the results, and should be considered for future research.

Parent's view of their child's disability may be an important factor in understanding their beliefs about their child's sleep problem, as well as understanding their views of the mechanisms by which disability causes the sleep problem. A greater level of detail regarding causal mechanisms and a richer sense of parent's experiences, as well as more insight in to the many possible influences on attributions might be gained from conducting qualitative research in this area. This method would also allow consideration of alternative models for understanding how parents represent their child's sleep problem. The Common Sense Model of Illness Representation (Leventhal et al., 1980; Leventhal et al., 2003) has been applied to a wide variety of health problems but it is possible that it is less applicable when a problem is viewed as part of a broader disability. Examining parent's attributions regarding children's sleep problems in typically developing children would also be of particular interest as disability would presumably not feature as a causal factor and so the impact of this could be better understood. Further understanding of parent's attributions, factors which are important in influencing these and how this impacts on management and

treatment strategies is also required. To what extent attributions serve as coping strategies in this area is another area that requires investigation.

Conclusion

Significant differences were found between parental attributions about their child's sleep problems in parents of children with an ASD and parents of children with DS. There was a high level of agreement across all parents that their child's disability was a causal factor to their sleep problem and differences in attributions may reflect characteristics of the child's diagnosis. Future research may wish to focus on a more in-depth examination of the relationship between parent's perception of the cause of their child's sleep problem and its relationship to their disability, possibly using qualitative methodology.

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Table 1 Demographics

	ASD	DS
N	76	52
Age (yrs) (Median)	8	8
Gender	82% male	60% male
Parent relationship to child	95% mother	92% mother
Level of LD:		
None	26%	2%
Mild	26%	19%
Moderate	22%	58%
Severe/profound	15%	15%
Missing data	11%	6%
% considered to have a behaviour problem	29%	23%
Median severity of the behaviour problem (1= mild, 5 = severe)	2	4
Any other medical problem stated:		
Hypothyroidism	0%	19%
Hearing impairment	1%	23%
Heart defect	0%	12%
Asthma	8%	8%
ADHD	11%	2%
Other	22%	27%
Medication:		
Melatonin	28%	14%
Any other medication	22%	44%

Table 2 Sleep problems

	ASD	DS
Mean CSI score	4.7 (SD 1.9)	3.6 (SD 1.9)
Total parasomnia score (median)	7 (range 0 – 21)	12 (range 0 – 23)
Total breathing-related score (median)	4.5 (range 0 – 22)	14.5 (range 0 – 25)
Total anxiety/behavioural score (median)	17 (range 0 – 32)	14 (range 0 – 23)
Duration of sleep problem (median)	24 months	24 months
% mentioning Sleep Apnea or obstructive sleep problem	0%	27%
% receiving previous treatment or advice	67%	79%
% believing this treatment / advice was helpful	75%	71%
% parents who believe they themselves do not get enough sleep	87%	77%

Table 3 % agreement that item is a cause in their child's sleep problem

		Agree or Strongly agree with item as possible cause		
		ASD	DS	Both
1	Disability	93%	90%	92%
2	Child's emotional state	76%	25%	56%
3	Child's personality	57%	37%	48%
4	Stage of development	32%	44%	37%
5	Parent's reaction	20%	37%	27%
6	Other health problem	12%	35%	21%
7	Hereditary	22%	6%	16%
8	Parent fears for child safety during night	13%	17%	15%
9	Parent's emotional state	15%	10%	13%
10	Chance or bad luck	15%	6%	11%
11	Family worries caused by sleep problem	11%	8%	9%
12	Diet	11%	8%	9%
13	Bedroom environment	9%	2%	6%
14	Parent's stress or worry	8%	2%	6%
15	Medication	5%	6%	6%
16	Accident or injury	7%	2%	5%
17	Poor medical care in child's past	5%	0%	3%
	Mean number of causal items agreed with	4.09	3.33	

Table 4 Mann Whitney U tests between groups on cause items

		U	Z	P (Exact sig, 2-tailed)	Effect size r
1	Disability	1935.5	-.223	0.829 (ns)	- .02
2	Child's emotional state	843.5	-5.685	0.000 (p< .05)	- .50
3	Child's personality	1353	-2.994	0.003 (p< .05)	- .27
4	Stage of development	1674.5	-1.524	0.128 (ns)	- .13
5	Parent's reaction	1621.5	-1.612	0.109 (ns)	- .14
6	Other health problem	1128.5	-3.974	0.000 (p< .05)	- .36
7	Hereditary	1696.5	-1.429	0.154 (ns)	- .13
8	Parent's fears for child's safety during night	1770.5	-1.057	0.293 (ns)	- .09
9	Parent's emotional state	1884.5	-.205	0.841 (ns)	- .02
10	Chance or bad luck	1653.0	-1.474	0.145 (ns)	- .13
11	Diet	1530.0	-2.055	0.040 (p< .05)	- .18
12	Family worries caused by sleep problem	1852.5	-.639	0.529 (ns)	- .06

Appendix 2.1 - Instructions for authors

Journal of Sleep Research

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Top**Author Guidelines**

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Kleitman, N. *Sleep and Wakefulness.* University of Chicago Press, Chicago, 1963 (second edition).

Webb, W. B. Theories about sleep and some clinical implications. In: R. Drucker Colin, M. Shkurovich and M. B. Sterman (eds) *The Functions of Sleep.*
Academic Press, New York, 1979: 1936.

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Appendix 2.2 Amended version of the IPQ

Parental attributions regarding sleep problems of children with

8. Views about your child's sleep problem (page 5 of 8)

We are interested in your own personal views of how you see your child's current sleep problem.

Please indicate how much you agree or disagree with the following statements about your child's sleep problem by ticking the appropriate box.

1. Views about your child's sleep problem:

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1. My child's sleep problem will last a short time	◯	◯	◯	◯	◯
2. My child's sleep problem is likely to be permanent rather than temporary	◯	◯	◯	◯	◯
3. My child's sleep problem will last for a long time	◯	◯	◯	◯	◯
4. My child's sleep problem is a serious condition	◯	◯	◯	◯	◯
5. My child's sleep problem has major consequences on their life	◯	◯	◯	◯	◯
6. My child's sleep problem is easy to live with	◯	◯	◯	◯	◯
7. My child's sleep problem does not have much effect on my life	◯	◯	◯	◯	◯
8. My child's sleep problem strongly affects the way others see my child	◯	◯	◯	◯	◯
9. My child's sleep problem has serious financial consequences	◯	◯	◯	◯	◯
10. My child's sleep problem strongly affects the way I see my child as a person	◯	◯	◯	◯	◯
11. There is a lot that I can do to control my child's symptoms	◯	◯	◯	◯	◯
12. What I do can determine whether my child's sleep problem gets better or worse	◯	◯	◯	◯	◯
13. My child's recovery from their sleep problem is largely dependent on chance or fate	◯	◯	◯	◯	◯
14. Treatment will be effective in curing my child's sleep problem	◯	◯	◯	◯	◯
15. My child's sleep problem will improve in time	◯	◯	◯	◯	◯
16. There is very little that can be done to improve my child's sleep problem	◯	◯	◯	◯	◯

Parental attributions regarding sleep problems of children with

9. Cause of child's sleep problem (page 6 of 8)

We are interested in what YOU consider may have been the cause of your child's sleep problem. As people are very different, there is no correct answer to this question. We are most interested in your own views about the factors that caused your child's sleep problem rather than what others, including doctors or family may have suggested to you. Below is a list of possible causes for your child's sleep problem. Please indicate how much you agree or disagree that they were a cause for your child by ticking the appropriate box.

*** 1. Cause of your child's sleep problem:**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. My child's disability	◯	◯	◯	◯	◯
2. Medication	◯	◯	◯	◯	◯
3. Other health problems (please state below)	◯	◯	◯	◯	◯
4. Bedroom environment	◯	◯	◯	◯	◯
5. Stage of development	◯	◯	◯	◯	◯
6. My stress/worry	◯	◯	◯	◯	◯
7. Hereditary (runs in the family)	◯	◯	◯	◯	◯
8. Diet/eating habits	◯	◯	◯	◯	◯
9. How I react to my child's sleep problem e.g. letting child sleep in my bed	◯	◯	◯	◯	◯
10. Family problems or worries caused by my child's sleep problem	◯	◯	◯	◯	◯
11. Fear for my child's safety during the night	◯	◯	◯	◯	◯
12. My child's inborn temperament / personality	◯	◯	◯	◯	◯
13. Chance or bad luck	◯	◯	◯	◯	◯
14. Poor medical care in the past	◯	◯	◯	◯	◯
15. Accident or injury to my child	◯	◯	◯	◯	◯
16. My child's level of stress or emotional state	◯	◯	◯	◯	◯
17. My level of stress or emotional state	◯	◯	◯	◯	◯

Please state other health problem for qu 3. if applicable

*** 2. Please state below the main factor that you believe caused your child to have their sleep problem. You may use any of the items from the table above or you may have additional ideas of your own.**

The most important cause for me is:

Appendix 2.3 Frequency of symptoms of disordered sleep

	Frequent (Daily or Many times a week)		Infrequent (Two to four times per month – less than once a month)		Never	
	ASD	DS	ASD	DS	ASD	DS
1. Talks in sleep	20%	29%	54%	40%	26%	25%
2. Walks in sleep	4%	19%	20%	19%	75%	56%
3. Grinds teeth in sleep	25%	39%	25%	21%	46%	40%
4. Bangs head at night	5%	17%	17%	15%	76%	65%
5. Has quick movements of arms or legs	34%	56%	24%	21%	41%	17%
6. Restless sleep	59%	85%	24%	14%	15%	2%
7. Bites tongue during sleep	5%	4%	9%	8%	83%	83%
8. Snores loudly during sleep	17%	48%	29%	31%	50%	17%
9. Gags, chokes or snorts loudly during sleep	9%	33%	17%	33%	71%	33%
10. Stops breathing	4%	29%	7%	14%	89%	50%
11. Wets bed during sleep	16%	17%	22%	29%	59%	52%
12. Nightmares	12%	6%	46%	35%	42%	56%
13. Night terrors	4%	0%	33%	4%	61%	90%
14. Afraid to go to bed	20%	0%	22%	20%	58%	77%
15. Fear die in sleep	5%	0%	9%	0%	84%	96%
16. Insists on sleeping with somebody else	37%	42%	20%	27%	43%	29%
17. Afraid of the dark	41%	27%	25%	17%	34%	50%
18. Needs security object	61%	39%	7%	6%	33%	50%
19. Insists on bedtime rituals	78%	71%	3%	8%	17%	19%
20. Needs sleeping medication	34%	15%	8%	4%	53%	77%
21. Loss of muscle tone	9%	4%	4%	10%	87%	83%
22. Sleep paralysis	1%	0%	3%	0%	92%	94%
23. During the day, has urges to go to sleep and can't stop	1%	10%	9%	23%	87%	64%

himself/herself						
24. Seems drowsy during the day, but can stop himself/herself from sleeping	20%	23%	28%	42%	51%	31%
25. During the day, appears more active than other children	61%	29%	22%	19%	17%	50%
26. Rolls from side to side rhythmically in sleep or while going off to sleep	9%	6%	12%	6%	79%	83%
27. Sleeps with head tipped right back	15%	44%	15%	15%	71%	39%
28. Breathes through mouth	36%	69%	26%	17%	34%	10%
29. Complains of headaches on waking up	5%	0%	24%	19%	68%	77%
30. Sweats a lot during sleep	43%	8%	30%	27%	26%	62%
31. Reluctant to go to bed	61%	29%	22%	33%	15%	35%
32. Wakes in the morning before 5am and stays awake?	41%	29%	33%	44%	21%	21%

Appendix 2.4 Ethical approval and Research & Development approval

Primary Care Division

Research Ethics
Primary Care, Community & Mental Health REC
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NHS Greater Glasgow and Clyde

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Date 11th November 2008
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 2811
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss MacQuarrie

Full title of study: **Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder and Down's Syndrome**

REC reference number: **08/S0701/135**

Thank you for your letter dated 2nd January 2009 in response to my letter dated 11th November 2008.

I can now confirm that you have met the conditions of the approval letter and you favourable opinion is now valid.

I have copied everything to R&D to keep them up to date.

Good luck with your proeject.

Yours sincerely

Liz Jamieson

Liz Jamieson
Research Ethics Co-ordinator

POSITIVE ABOUT DISABLED PEOPLE

D370787

Acute Services Division

NHS
Greater Glasgow and Clyde

Coordinator/administrator: Emma Cuthbertson
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R&D Management Office
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04 March 2009

Miss Jane MacQuarrie
Trainee Clinical Psychologist
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

R&D Management Approval

Dear Miss MacQuarrie

Project Title: Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder and Down's Syndrome
Chief Investigator: Miss Jane McQuarrie
R&D Reference: PN08CP435
Protocol no (including version and date): version 4, dated 14th July 2008

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Management Approval** for the above study.
As a condition of this approval the following information is required during the lifespan of the project:

1. SAES/SUSARS – If the study is a **Clinical Trial** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004 (CTIMP only)
2. Recruitment Numbers on a quarterly basis (not required for commercial trials)
3. Any change of Staff working on the project named on the ethics form
4. Change of CI
5. Amendments – Protocol/CRF etc
6. Notification of when the Trial / study has ended
7. Final Report
8. Copies of Publications & Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Yours sincerely

Professor Chris Packard
Director - Research and Development

Delivering better health

Appendix 2.5 MRP proposal

Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder and Down Syndrome

Jane MacQuarrie

Research supervisor: Dr Jason Ellis

Version 5 Protocol, with changes in bold type

Changes as follows:

- Page 1, para 4 regarding previous experience of sleep problems potentially affecting attributions
- Page 3, para 3 regarding aim to examine covariates, rather than mediating factors
- Page 4 last paragraph, page 5 1st paragraph – changes to analysis section
- Page 6 – additional reference

Parental attributions regarding sleep problems of children with an Autism Spectrum Disorder and Down Syndrome

Introduction

Sleep problems are more prevalent in children with a developmental disability compared to typically developing children (Cotton and Richdale, 2006). Sleep problems are under-reported in children (Blunden et al., 2004), and parents of children with developmental disabilities often do not seek help for their child's sleep problems (Robinson & Richdale, 2004; Wiggs & Stores, 1996a). Therefore, understanding the factors which mediate the reporting of sleep problems is important for professionals to recognise and engage parents with an appropriate intervention.

Attributions about the cause of an event or a problem have been shown to mediate the person's affect, expectations and future behaviour (Morrisey-Kane & Prinz, 1991; Weiner, 1986). This has also been applied to parent's attributions about their child when there is a problem with behaviour (Morrisey-Kane and Prinz, 1999). Leventhal's self-regulatory model of illness representation encompasses attributions and is also predictive of affect, coping and adherence to treatment (Leventhal, Nerenz & Steele, 1984). In a qualitative study investigating parent's experiences of sleep disturbance in children with Rett's Syndrome, beliefs about the sleep problem (which included attributions about the cause) were proposed to be a significant determinant of both emotional factors and coping (McDougall et al., 2004). It therefore seems plausible that the attributions parents make about their child's sleep problems would be an important factor relating to parental affect and help-seeking behaviour. Conversely, affect may also influence the attributions a person makes.

The link between parental affect and attributions made can be explained by theories of learned helplessness and hopelessness (Seligman, 1974; Abramson, Metalsky & Alloy, 1989). People who are depressed make more global, internal and stable attributions about negative outcomes than those who are not depressed (Seligman et al., 1979). This attributional style may lead to learned helplessness, which combined with life stressors, may lead to depression (Peterson & Seligman, 1984). The expectation of helplessness may create anxiety which can lead to co-morbid anxiety and depression and hopelessness may develop (Abramson et al., 1989). Considering this evidence, a parent's levels of stress, anxiety and depression may be important in mediating the relationship between attributions and expectations and behaviour.

As well as parental affect relating to parental attributions, **parent's previous experience of having a child with a sleep problem may impact on their attributions. Research examining staff attributions and emotional reactions to challenging behaviour in adults with a learning disability has shown that attributions and emotional reactions may differ according to level of experience (Hastings et al., 2003).**

The child's disability and the nature of the child's sleep problem may also impact on the attributions that a parent makes. In studies with children with a developmental disability and a sleep problem, parents have viewed the developmental disability as an important contributing factor (Didden et al., 2002; Keenan, Wild, McArthur and Espie, 2006). Although research often examines the sleep problems of children with developmental disabilities as a group, the prevalence, nature and extent of these sleep problems may be dependent on the aetiology of the child's disability (Stores, 1992). For example, parents of children with an Autism Spectrum Disorder(ASD) have been shown to report sleep problems more frequently than parents of children with other developmental disabilities (Schreck and Mulick, 2000; Cotton and Richdale, 2006). Cotton and Richdale (2006) found that children with Down Syndrome (DS) or presumed

familial intellectual disability were more likely to have sleep maintenance problems and children with Autism were more likely to have settling difficulties or co-sleep. Children with DS are particularly prone to sleep-related breathing difficulties and the occurrence of Obstructive Sleep Apnea or hypoventilation in children with DS who underwent polysomnography has range from 50 to 80 per cent (Stores, 2001). There is also evidence to suggest that adults with an ASD exhibit different sleep cycles than neuro-typical controls (Limoges et al., 2005) and around 60% of adults with ASD and without seizures showed abnormal EEG epileptiform activity during sleep (Chez et al., 2006).

Parent's well-being has also been shown to differ in accordance with the aetiology of their child's disability; Parents of children with an ASD have been found to have lower levels of internal locus of control and higher levels of anxiety, depression and stress, compared with parents of children with DS (Hamlyn-Wright, Draghi-Lorenz and Ellis, 2007). Considering the differences in sleep problems, parent's well-being and locus of control between children with an ASD and children with DS, parent's attributions about their children's sleep problems may also differ.

The aim of the study is to examine whether diagnosis of ASD or DS influences the attributions parents make, and the influence of **anxiety and depression scores as possible covariates.**

Method:

- **Design**

The study will employ a cross-sectional survey design with 2 levels of independent variable: parents of children with an ASD or parents of children DS.

- **Participants and recruitment**

Parents of children age 5 to 11 with a diagnosis of an ASD or a diagnosis of DS will be recruited through the National Autistic Society and the National Down Syndrome Association. These charities have participated in similar research projects before and will be approached following ethical approval. It is anticipated that parents will be recruited through opting to complete the questionnaires on-line on the relevant society's websites in the first instance, followed by a postal questionnaire sent to families in Scotland if the response does not meet the required sample size. A previous postal survey via the above charities received a response rate of 53% from parents of children with an ASD and 44.6% from parents of children with DS (Hamlyn-Wright et al., 2007). Children with a diagnosis of co-morbid DS and ASD, epilepsy or a previous head injury will be excluded. Parents who have a history of psychiatric illness or a traumatic brain injury will also be excluded.

- **Measures**

Demographics: The child's age, gender, diagnoses, other medical conditions, severity of learning disability if present, rating of behavioural problems on a visual analogue scale, and the parent's relationship with the child (e.g. mother, father, other guardian), and first part of post code will be sought.

Parent's attributions: A modified version of the Illness Perception Questionniare (IPQ), originally developed by Weinmann et al. (1996) and based on Leventhal's self-regulation model will be administered. The questionnaire was modified for use with parents of children with developmental disabilities by Keenan et al. (2006) and permission will be sought to use this modified version. The IPQ contains five dimensions of identity, cause, controllability/cure, timeline and consequences. The adapted version by Keenan et al. (2006) does not include the identity dimension as parents had already identified their child as having a sleep problem and the

cause subscale was compiled using causes identified by McDougall et al. (2005) and discussion with an experienced nurse practitioner. The need to alter this subscale dependent on illness group is acknowledged by Weinmann et al. (1996). Questions concerning controllability/cure, timeline and consequences were re-phrased to ask about the child's sleep problem, rather than the respondent's illness.

Sleep: The simmonds and parraga sleep questionnaire (Simmonds and Parraga, 1982), as modified by Stores et al. (1996) for use with parents of children with developmental disabilities will be administered to determine the type of sleep problem and level of daytime impairment to the child. The modified version by Stores et al. (1996) is for use with children age 5 to 20 and covers the quantity and quality of the child's sleep, as well as identification of sleep disorders, covering four broad categories: disorders of initiating and maintaining sleep, parasomnias, sleep-related breathing problems and daytime sleep-related features.

Parent's anxiety and depression: The Hospital Anxiety and Depression Scale (HADS, Zigmund & Snaith, 1983) will be administered to measure anxiety and depression.

Parent stress: The short form of the Questionnaire on Resources and Stress (QRS-F, Friedrich et al., 1983) will be used. This is a 52 item questionnaire which is frequently used with parents of children with developmental disabilities (Glidden and Floyd, 1997). It measures the dimensions of Parent and Family problems, Pessimism, Child characteristics and physical incapacitation. Use of this measure with parents of young children with Autism demonstrated good reliability (Honey, Hastings and McConachie, 2005).

Justification of sample size

Hamlyn-wright et al.'s (2007) study was selected to calculate the required sample size. This study was selected because of several similarities with the current study, for example, recruitment through voluntary organisations of parents with a child with DS or an ASD and completion of the HADS. It was also not possible to base a power calculation on the IPQ because this measure has only been used with a similar sample by Keenan et al. (2006), who employed a within-subjects design. The effect size for both the anxiety scale and the depression scale of the HADS were calculated and the standard deviation was pooled. This gave an effect size of 0.488 for the anxiety subscale and 0.5278 for the depression subscale. The smaller effect size was selected so that differences on both of these subscales might be achieved. An estimation of sample size was produced using Gpower software, taking alpha as 0.05, with a power of 0.8. This gave a sample size of 67 participants in each group.

Settings and equipment

Participants will be asked to complete the survey via internet or by post, therefore, participants will access the survey where they choose to use computer access or in the case of survey by post, in their own home. Therefore, participants will require access to a computer with internet facilities or a pen and posting facilities if they receive the survey by post. The researcher requires stationary, computer and printer access and access to a photocopier and will be undertaking the research in the Department of Psychological Medicine at the University of Glasgow.

Analysis

Descriptive statistics will be produced to describe the data.

A Multiple Analysis of Co-variance (MANCOVA) will be performed to examine if there is a difference between the attributions of parents with a child with an ASD and parents of a child with

Down Syndrome, regarding their child's sleep problem. Anxiety and depression scores as covariates.

Health and safety issues

Researcher safety issues

There is minimal risk to the researcher, as the method does not involve direct contact with participants.

Participant safety issues

The questionnaires selected have been deemed to be acceptable to participants in previous research and completion of these is not known to be associated with significant distress. Parents are being recruited via organisations that can offer support and direct parents to relevant services.

Ethical issues

Information about the aims of the research will be provided and informed consent will be sought prior to participation. The questionnaires will be anonymous and will be treated confidentially. Parents will be given guidance on where to find further help and information on their child's sleep problem and contact information for the Glasgow Sleep Centre. Additionally, when the results of the study are fed back to the participants, the feedback will advise parents with concerns about themselves or their child to contact their GP.

Financial issues

If enough participants complete the survey on-line, the costs of the research will be minimal (estimated at £12.10). However, if a postal survey is required, the estimated cost is £276.99, with a large proportion of this being on postage.

Timetable

May 2008	Submit proposal to University for approval to proceed
July 2008	Submit application to ethics committee
Autumn 2008	Following ethical approval, seek approval from relevant charities and post questionnaires on the website
Jan 2009	Monitor response rate and take measures as necessary
March 2009	Analyse data and write up

Practical applications

Understanding the attributions that parents make about their child's sleep problems may allow professionals to tailor their approaches to engage these parents with services. There are implications for predicting motivation to engage in treatment, treatment acceptability, and understanding parent's own well being and coping strategies.

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Advanced Clinical Practice I
Reflective Critical Account
(Abstract only)

Understanding staff reactions in a Community Mental Health Team

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Submitted in partial requirement for the degree of Doctorate in Clinical Psychology (D.Clin.Psy.)

Abstract

My main point of reflection involves a change of perception of other staff within a Multi-Disciplinary Team (MDT), but closely mirrors how my thinking developed with a client, and hence I will try to reflect on these parallel experiences in tandem. I became aware of shifts in my thinking about the attitudes of colleagues and the stress they were under, following increased personal experience of working with clients in the CMHT. With increasing experience of working with clients with complex difficulties, whilst balancing large workloads, I can better empathise with staff who feel stressed and overwhelmed, without necessarily condoning depersonalisation. I can see a role for myself, as a Clinical Psychologist, in conjunction with colleagues, to examine and develop systems to enhance team functioning, manage the impact of the job, define roles and secure appropriate resources.

Advanced Clinical Practice II

Reflective Critical Account
(Abstract only)

Risky business: learning to manage

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Abstract

Following a conversation on placement, I felt inspired to reflect upon referral criteria and service organisation and sought out relevant information and took note of experiences related to this. These experiences and issues raised a number of questions for me to reflect on; How do you manage referral criteria and limited resources? Who do you see and who do you not see? What are the pros and cons of specialist vs generic services? This led me to a discussion of the "Mediating Psychological Processes" model of mental disorder and it's implications for policy (Kinderman, 2005). For me, the outcome of the reflective process has been to increase my motivation for tackling service issues and managing professional risks. I critique my approach and conclude by considering the role of reflection in my professional development.