

Introduction

- Fifty to 80% of individuals with autism spectrum disorder (ASD) experience sleep problems, including insomnia, shortened sleep durations, frequent night wakings, bedtime resistance, difficulty sleeping independently (i.e. co-sleeping) and parasomnias [1-9].
- Longitudinal research suggests that two-thirds of children with ASD continue to experience sleep problems into their adolescence and adulthood [10].
- Persistent sleep difficulties impact not only the health and wellbeing of the individual with ASD but also their family. [17-19].
- The direct impact of child sleep on parental quality of life has not however been formally assessed in families of children with ASD.

Aim

- Establish a profile of sleep problems in children with ASD in Western Australia
- Examine the relationship between sleep problems in children with ASD and parent QoL.

Method

- Cross-sectional survey design
- Parent-reported questionnaire developed to investigate the experience of families of children with ASD in Western Australia.
- Responses gathered from January 2015 to July 2016
- Curtin University Human Research Ethics Committee approval (HR 123/2014).

Participants

- 204 primary caregivers of 219 children aged 2-18 years with a formal diagnosis of ASD living in Western Australia

Caregiver characteristics

- 92% mothers
- 90% have only one child with ASD
- 77% two-parent households
- 24% of mothers had secondary school education only, 40% had a university degree
- Mean household income: \$AU78-104,000
- Living in major city (47%), regional (45%) and remote areas (8%)

Child characteristics

- 82% males
- Mean age 8.8 years (SD 4.3)
- 55% had a diagnosis of autism, 33% Asperger's syndrome (DSM IV),
- Co-morbidities:
 - 13% had a history of seizures
 - 20% had an intellectual disability
 - 20% had a mental health condition
 - 19% had a physical/medical condition

Measurement

- Demographic profile of child and family
- Children's Sleep Habits Questionnaire**
- Caregiver perception of child's sleep [20]
- 33 sleep behaviour items
- Eight subscales (see Fig. 1), cut-offs for significant clinical problem set at 2 SD's above community norms [7,20]
- Total sleep disturbance score (>41); higher score = more significant sleep problems
- World Health Organisation Quality of Life (WHOQOL) BREF**
- Caregiver quality of life [21]
- 24 statements on 5-point scale e.g. "how satisfied are you with your personal self".
- Four domains: physical, psychological, social relationship and environment
- Mean score for each domain, higher scores = higher QoL; each scaled out of 100
- DSM IV/ICD-10 checklist**
- Autism symptoms - 19 items (y/n) [22]
- Item-level presence of symptoms across 3 domains: social interaction, communication, and restricted, repetitive and stereotyped patterns of behavior/interests/activities.

Analysis

- Percentage of children who were above clinical cut-offs for sleep scales and total sleep disturbance calculated (established by [7,20]) (Fig. 1)
- Regression modelling (Fig. 2-4) was undertaken to determine influence of child demographics, ASD symptoms and sleep scores against QoL domains.
- Initial univariate regressions conducted of child variables against each dependent QoL domains
- Variables demonstrating univariate association were entered into linear regression modelling, with model developed through manual backward elimination.

Results

Fig. 1 Child sleep - percentage above clinical cut-offs

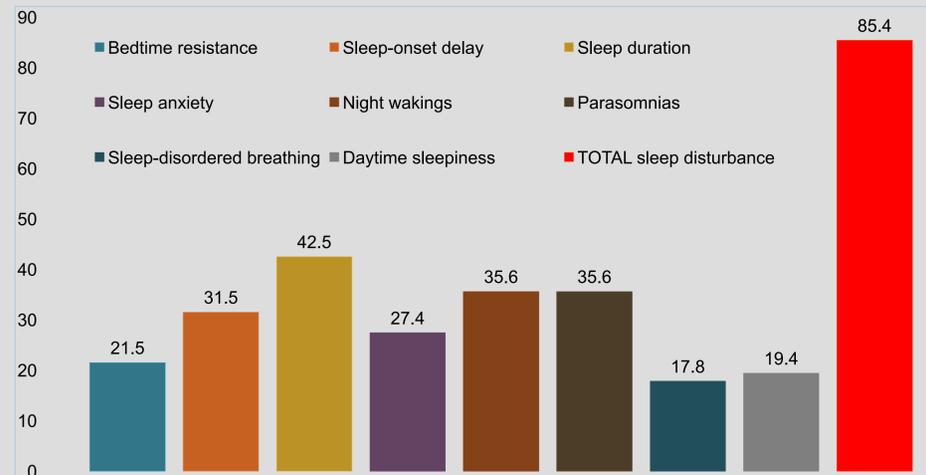
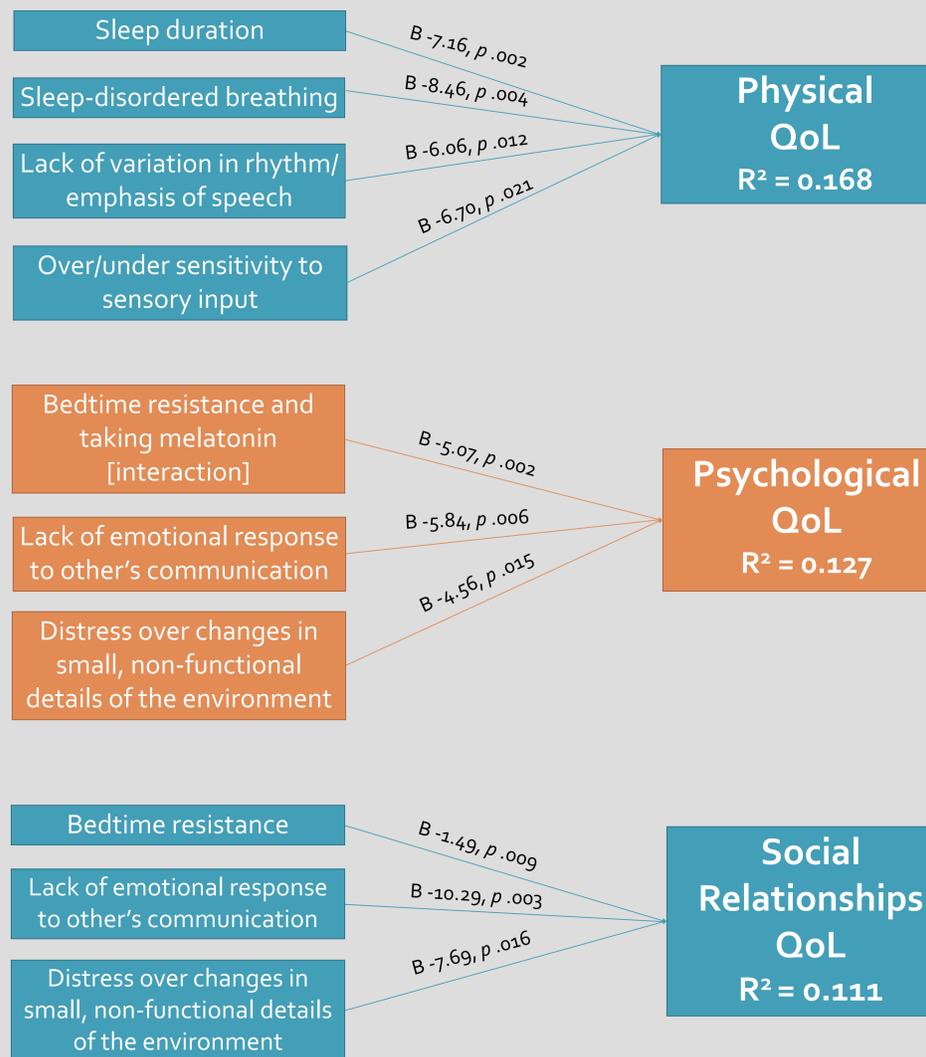


Fig. 2-4 Regression analyses of caregiver QoL



Conclusions

- Over eighty five per cent of Western Australian children with ASD were found to experience sleep problems, a similar rate to other international studies of children with ASD [23]
- Findings confirm the need for clinicians to screen for sleep issues when working with children and adolescents with ASD and intervene as required.
 - Sleep is a foundational need for all of us; need to consider the implications of how significant sleep problems may be impacting child's behaviour and ability to participate and engage in therapeutic interventions – for sleep and other skills
- Regression analyses suggest that different aspects of child sleep impact caregiver QoL
 - Child sleep behaviours relating to the amount and quality of sleep (duration, sleep-disordered breathing) contribute to poorer physical caregiver QoL
 - Impact on parental sleep well-established, consider other flow-on health effects
 - Behavioural bedtime resistance influences caregiver psychological and social relationships QoL
 - Having to 'fight' your child to get them to bed is a stressful experience, and is likely to impact a parent's relationships with that child, their other children and partner.
 - Also consider impact of child co-sleeping on partner intimacy
- These findings confirm the wider impact of child issues on family life
 - If parents of poorly sleeping children with ASD have poorer reported QoL, this highlights the need for interventions to fit not just the child, but the family as a unit.
 - Recommended interventions should therefore be considered not only in terms of effectiveness for the child, but also the feasibility for families to integrate methods into their lives without undue strain.

Key Points

- This study provides a profile of the sleep problems experienced by 204 children with ASD aged 2-18 years in Western Australia.
- 85% were reported to experience clinically significant sleep problems
- Problem areas for over one-third of children were sleep duration, night wakings, parasomnias and sleep-onset delay.
- Through regression analyses child sleep was found to be a significant predictor for three domains of caregiver QoL
 - Clinically-significant issues with sleep duration and sleep-disordered breathing contributed to negative physical caregiver quality of life
 - Child bedtime resistance contributed to poorer psychological and social relationships quality of life of their caregiver.
- Findings confirm the impact of child sleep on caregiver QoL and thus have implications for intervention recommendations needing to fit both child and family needs, particular in decision making balancing best-practice therapeutics with potential burden placed on the family.

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