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The impact on the family of the co-existing conditions of children with Autism Spectrum Disorder

Alexandra M. Petrou¹, Abigail Soul¹, Beena Koshy¹, Helen McConachie², Jeremy R. Parr¹

¹ Institute of Neuroscience, Newcastle University, Newcastle Upon Tyne, England, NE1 4LP

² Institute of Health and Society, Newcastle University, Newcastle Upon Tyne, England, NE1 4LP

Scientific abstract

We aimed to investigate whether the impact on families of children with Autism Spectrum Disorder (ASD) is associated with the number and/or type of emotional and behavioural co-existing conditions that parents/carers of children with ASD reported as occurring frequently. In addition, we examined whether there was a greater impact on families if their child was male, had lower levels of language, had more severe autism symptomatology, and whether impact was associated with the number and/or type of co-existing conditions. Families were recruited from large UK research databases. 420 parents/carers of children aged 3 years 2 months to 18 years 8 months completed the revised Impact on Family (IoF) Scale and reported on the frequency/rate of their child's co-existing conditions. Parents/carers reported higher mean IoF scores if their child: had a greater number of frequent co-existing conditions; had sleep problems; was only able to communicate physically; and had more severe autism symptomatology. The development and implementation of targeted treatment and management approaches are needed to reduce the impact of co-existing conditions on family life.

Key words: Impact on the family, co-existing conditions, sleep, autism, ASD

Lay abstract

Autism Spectrum Disorder (ASD) is commonly associated with emotional and/or behaviour conditions that affect family life. Parents/carers of children with ASD who: a) reported a greater number of frequent co-existing conditions, b) had sleep problems, c) were only able to communicate physically, and d) had more severe symptoms characteristic of autism, reported a greater burden/strain on the family. Treatment approaches to target co-existing conditions alongside characteristics of ASD are needed to reduce their impact on family life.

Autism Spectrum Disorder (ASD) is commonly associated with co-existing conditions that can be maladaptive, emotional, and/or behavioural (e.g., sleep disturbances, temper tantrums, feeding problems, atypical eating habits, and anxiety; Maskey et al., 2013). At least 50% of children with ASD may have four or more different co-existing conditions (Mattila et al., 2010; Maskey et al., 2013).

In keeping with chronic diseases, mental illness, and accidents and disability, ASD is a condition that families find stressful and burdensome (Martínez-Montilla et al., 2017). Caring for a child with ASD can affect several areas of family life, functioning, and wellbeing and heightens negative health and social outcomes for the family, irrespective of socio-demographic factors (Williams et al., 2006). The effect of having a child with ASD on the family has been assessed using various measures of overall wellbeing such as the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983) in families with a developmentally delayed child (Scott, Sexton, Thompson, & Wood, 1989) and children with ASD (Honey, Hastings, & McConachie, 2005). Using the QRS-F, Cassidy, McConkey, Truesdale-Kennedy, and Slevin (2008) found that the majority of families who had a child with ASD reported marked impacts on family life. Poorer health-related quality of life and overall quality of life have been found for families with children diagnosed with ASD compared to families of children with attention deficit hyperactivity disorder or neurotypical controls (Lee, Harrington, Louie, & Newschaffer, 2008; Khanna et al., 2011).

In addition to having an overall influence on family functioning and wellbeing, both caring for a child with ASD and the severity of a child's ASD symptoms have been found to affect specific family health and social outcomes such as depression, social isolation, and parental stress (Lecavalier et al., 2006; Epstein et al., 2008; Manning et al., 2011). For example, elevated stress and psychological distress levels have been found in parents of preschool and school aged children with ASD (Smith et al., 2001; Estes et al., 2009), and in particular, mothers (Hastings et al., 2005; Ekas, 2010). Measuring the impact of stress, parents of children with ASD were more likely to score in the high aggravation range than parents of children: with developmental problems, with special health care needs without developmental problems, and without special health care needs (Schieve et al., 2007). Parents of children with ASD have been found to experience mental health consequences such as anxiety and depression (Benson, 2006), as well as social consequences such as greater social isolation and financial demands (Schall, 2000; Epstein et al., 2008), lower family cohesion, relationship satisfaction, and wellbeing (Higgins, Bailey, & Pearce, 2005; Brobst et al., 2009), and higher levels of marital discord, conflict, and divorce (Benson & Kersh, 2011; Freedman

et al., 2012; Harper et al., 2013). For the purposes of this study, the various and overall health and social consequences in terms of family wellbeing of having a child with ASD, can be characterised as the level of ‘impact’ on the family as a global measure of the extent/level of pressure/burden/strain on the whole family.

Co-existing conditions and child behaviour problems can have a significant impact on families of children with disabilities including ASD (Floyd & Gallagher, 1997; Hodapp et al., 1997; Baker et al., 2002; Hurtig et al., 2009; Rao & Beidel, 2009). The various ways in which these co-existing conditions can impact the family depend on their nature, severity, frequency, and number. For example, a child who has anxiety may avoid social situations and withdraw from opportunities for family activities. As a result, the family may suffer social isolation or need to pay for respite care, causing financial hardship. Similarly, a child who has attentional and/or hyperactive problems may display behaviours that are disruptive and that interfere with the family’s daily routine and activities. This may cause difficulties for the family in terms of coping with frustration alongside the need for additional patience and understanding. In turn, this may place strain on marital and parent-child relationships. An important factor to consider when assessing the association between a child’s behaviours and family functioning is that the relationship may be bi-directional. That is, a child’s challenging behaviour can exacerbate a mother’s poor wellbeing and in turn, a decline in a mother’s wellbeing can send a negative indication to a child that inadvertently encourages reactive challenging behaviour (Majnemer et al., 2012). In fact, co-existing conditions that are associated with the ASD phenotype can cause an equal or greater strain on family members of a child with ASD than the core symptoms of ASD themselves (Kasari & Sigman 1997; Manning et al., 2011), particularly hyperactivity (Graziano et al., 2011; Carlsson et al., 2013; McStay et al., 2014).

Co-existing conditions may be found in association with certain ASD characteristics. For example, children who have received a diagnosis of ‘classic’ or core autism are known to experience social withdrawal, depression, and atypical behaviour more often than children with another autism spectrum disorder diagnosis (Pearson et al., 2006). Boys present with hyperactivity more commonly than girls (Brown et al., 2002). Children with language impairment or whose speech is delayed, experience co-existing conditions such as sleep problems, toileting problems, eating problems, hyperactivity, self injury, and sensory difficulties more frequently (Maskey et al., 2013). The degree of burden on the family that may affect a parent’s coping resources have been found to increase as a function of a) the severity of impairment of the co-existing condition (Tobing & Glenwichk, 2002); and b)

the frequency or rate at which the child expresses their co-existing behaviours (Stephens et al., 2008). Less is known about whether the number and/or type of co-existing conditions also have an impact on the family.

This study used data from large representative UK databases and aimed to examine whether impact on the family:

1. increases with a greater number of co-existing conditions, and is associated with specific type(s) of co-existing conditions;
 2. increases as a function of male gender, lower levels of language, and increased ASD severity; and
 3. is associated with the number and/or type(s) of co-existing conditions, gender, language level, and ASD severity.
- These aims relate to the need for the development and implementation of targeted, specific treatment and management approaches to reduce the impact of children's co-existing conditions on family life.

Methods

Participants

Families were recruited from research databases of children with ASD: The Database of children with autism spectrum disorder living in the North East of England (Dasl^{ne}, <http://daslne.org>) and the Autism Spectrum Database – UK (ASD-UK, www.asd-uk.com). Dasl^{ne} covers six areas around Newcastle Upon Tyne, whilst the Autism Spectrum Database–UK (ASD-UK) covers the rest of the UK. By 2017, the databases held data from over 4000 families, including information on children's ASD and other medical diagnoses, behaviour problems, and language levels as reported by parents/carers and professionals.

Dasl^{ne} and ASD-UK share similar methodologies and type of data collected. Recruitment has been described previously (Warnell et al., 2015; Brett et al., 2016). Parents/carers are invited to join Dasl^{ne} shortly after their child (aged 2 to 18 years) receives an ASD diagnosis. The child's diagnostic status is validated by a questionnaire completed by their clinician. Validation of children's ASD diagnoses was examined previously with corroboration of diagnosis using standardised assessment or clinical notes (McConachie et al., 2009). For ASD-UK, parents/carers of children with a clinical diagnosis of ASD (aged 2 to 16 years) are invited to join through health teams or self-referral.

Measures

Following informed consent, parents/carers complete a paper or online questionnaire, and the Social Communication Questionnaire-Lifetime version (SCQ; Rutter et al., 2003; ASD-UK only, see below).

Socioeconomic status (SES) was measured using the Townsend Index of Deprivation (Townsend, 1988). A measure of deprivation is assigned to families based on their postcode (zipcode) that is calculated based on unemployment, non-car ownership, non-home ownership, and household overcrowding.

Published information about representativeness

By comparing the characteristics of children from families who consented to join Dasl^{ne} and ASD-UK with families who decided not to take part, Dasl^{ne} has been shown to be representative of children with ASD living in the North East of England in terms of gender and Townsend deprivation index (McConachie et al., 2009). ASD-UK has been shown to be representative of children with ASD for the rest of the UK in terms of gender, diagnosis type, median year of birth, and Townsend deprivation index (Wood et al., 2015; Warnell et al., 2015). Table 1 shows the demographic and some ethnic background information of included children.

Emotional and behavioural problems (co-existing conditions)

When families join ASD-UK/Dasl^{ne}, parents/carers report whether their child has the following ten common emotional and behavioural problems (Maskey et al., 2013): anxiety, aggression, feeding problems, hyperactivity, reluctance to separate from parent, self-injury, sensory reactions, sleep problems, temper tantrums, and toileting problems. This was indicated as ‘frequent’ (i.e., behaviour is apparent three or more times a week), ‘sometimes’ (i.e., behaviour occurs once or twice a week), ‘never or rare’, or ‘in the past only’. The analyses report only on co-existing conditions reported as ‘frequent’. ‘Co-existing conditions’ refer to emotional and/or problem behaviours that have been reported by a parent/carer that may or may not be formally diagnosed. Table 2 displays the number and percentage of co-existing conditions reported as ‘frequent’ by gender and ASD diagnosis type.

Other information about the child

Language level

Parents/carers reported children’s language level as one of seven categories: ‘uses sentences with reasonably good grammar’, ‘uses mostly simple phrases (2 words or more, with a verb/doing word)’, ‘uses mostly single spontaneous words’, ‘mostly echoes (repeats) other people’s words’, ‘no speech but tries to communicate spontaneously by gesture, sounds, picture cards etc’, and ‘no speech, but lets you know some of what he/she wants physically’. Parents/carers can also report ‘other’, and this was not included in analyses.

ASD diagnosis type

Parents/carers reported the child's diagnosis within six categories: autism, autism spectrum disorder (ASD), pervasive developmental disorder (PDD), atypical autism, and Asperger syndrome. Parents/carers can also report 'other', and this was not included in analyses.

Social Communication Questionnaire

Parents/carers from ASD-UK (not Daslⁿe) completed the SCQ (Rutter et al., 2003). The SCQ focuses on the child's entire developmental history and provides a total score that is interpreted in relation to specific ASD cut-off points. The SCQ can be used as a screening device; to select children who need a more thorough assessment for a possible ASD; to compare levels of ASD symptomatology across groups, and levels of change over time.

Impact on Family

Parents/carers completed the revised Impact on Family (IoF) Scale (Stein & Jessop, 2003) that assesses overall impact of paediatric illness on the family across the following domains: Familial-Social Impact, Financial Burden, Personal Strain, and Mastery. This measure has been used in other studies assessing family burden in children with ASD (e.g., Rodrigue et al., 1992; Rodrigue et al., 1992; Stuart & McGrew, 2009; Brown et al., 2011). The 15 items include 'We see family and friends less because of my child' and 'It is hard to find a reliable person to take care of my child'. The Likert scale has four possible answers: 'strongly agree', 'agree', 'disagree', and 'strongly disagree'. Item scores range from 1–4, therefore total IoF scores range from 15–60, with a higher score indicating a greater impact on the family. The IoF scale has been shown to have good validity and reliability and construct validity (Stein & Jessop, 2003; Williams et al., 2006). Cronbach alphas (internal consistency) for total impact were high (.84).

Procedure

Parents/carers who had a child with ASD (autism, Asperger syndrome, or 'ASD' diagnosis [grouped to include autism spectrum disorder, PDDm and atypical autism]), aged between 2 and 18 years old were contacted by post with a letter of invitation, information sheet, consent form, the Impact on Family questionnaire (and other questionnaires whose results are not reported here) and a return envelope ($n=1179$). Four-hundred and twenty parents/carers responded (35.6%) and were included in the analyses. There were no exclusion criteria for participation. Completion of the IoF

scale was at a different time point to reports about co-existing conditions (mean [SD] months later=9.3 [7.4], range=4-26 months]).

The study was approved by the local UK National Health Service Research Ethics Service Committee West Midlands-Black Country (reference number: 13/WM/0098). Additional permission to contact database families was sought from the ASD-UK/Dash's research committee, which includes parents/carers and clinicians.

Statistical analyses

All analyses used SPSS 22.0. Independent-samples t-tests were used to assess whether SES scores differed between parents/carers of children with ASD who reported at least one co-existing condition compared to parents/carers of children with ASD without co-existing conditions, and the association between IoF scores and gender. One-way ANOVAs were used to test whether IoF scores were influenced by the number and type of co-existing conditions, and language level with post-hoc Bonferroni comparisons. Pearson's Correlation Coefficient was used to test the relationship between IoF and SCQ scores. A stepwise multiple regression analysis was performed to determine whether gender, language level, SCQ scores, number and type of co-existing condition, and SES scores predicted IoF scores. Standardised regression coefficients are reported with beta values reporting the relative change between categories within factors in IoF scores. For dummy coded variables, this was the difference between each category and the reference category. All other statistical analyses were descriptive in nature. For all statistical analyses, alpha was set to .05. Effect sizes were reported and interpreted using partial eta squared and Cohen's *d* accordingly to describe the quantitative measure of the difference between groups (interpreted as .01 small, .06 medium, and .14 large for partial eta squared and .2 small, .5 medium, and .8 large for Cohen's *d*).

Results

To investigate responder bias on some core ASD characteristics, data from the 420 responders and 759 non-responders were compared (Table 3). There was no significant difference in the ratio of males to females, the language level, or the number of co-existing conditions of responders and non-responders. The mean age of children in the responder group was younger (8 years 6 months, SD=3.7) than those in the non-responder group (9 years 5 months, SD=4.5). Analyses were rerun with age as a covariate; no differences in results were found.

Overall, the characteristics of the children of responders and the children of non-responders were very similar. As the database cohorts are representative of children with ASD in the UK (Warnell et al., 2015), this suggests that the children of responders are representative.

There was no significant difference in SES (Townsend deprivation) scores (where a higher score denotes more deprivation) of children with co-existing conditions and children without co-existing conditions (M [SD]=.91 [3.72] vs M [SD]=.38, [3.80]; $t(380)=.94$, $p=.35$, $d=0.14$).

Impact on Family and number and type of co-existing conditions

Figure 1 shows the number of co-existing conditions that parents/carers reported their child experienced as frequent and how these were associated with IoF scores. There was a significant main effect of the number of co-existing conditions on IoF scores ($F(10, 409)=16.00$, $p<.001$, $\eta^2p=.28$). There was no significant effect on IoF scores by parents/carers reporting 10 co-existing conditions compared to parents/carers reporting 5, 6, 7, 8, or 9 co-existing conditions ($p=.27$ to $p=1.00$). However, parents/carers of children who experienced 10 co-existing conditions reported significantly higher IoF scores than parents/carers of children who reported 0 to 4 co-existing conditions ($p<.001$ to $p=.02$). A similar trend was found for parents/carers of children who reported 8 and 9 co-existing conditions compared to 0 to 4 co-existing conditions ($p<.001$ to $p=.03$), 6 and 7 co-existing conditions compared to 0 to 3 co-existing conditions ($p<.001$ to $p=.01$), 5 compared to 2 ($p=.04$), 4 compared to 1 ($p=.01$), and 2 compared to 0 ($p=.01$). There was no significant difference in IoF scores between parents/carers of children who reported no co-existing conditions and 1 co-existing condition ($p=1.00$).

There was a significant main effect of the type of co-existing condition on IoF scores ($F(1, 409)=12.26$, $p<.001$, $\eta^2p=.23$). Parents/carers reported significantly higher IoF scores if they also reported that their child experienced: sleep difficulties vs no sleep difficulties (M [SD]=43.1 [9.0] vs M=36.5 [9.8], $p<.001$), hyperactivity vs no hyperactivity (M [SD]=43.4 [8.6] vs M=36.9 [10.1], $p=.02$), and temper problems vs no temper problems (M [SD]=43.1 [8.2] vs M=36.3 [10.4], $p=.004$). There were no significant differences on IoF scores between parents/carers who reported that their child experienced toilet problems ($p=.10$), aggression ($p=.48$), injury to self ($p=.11$), reluctant to separate from parent ($p=.60$), anxiety ($p=.43$), eating problems ($p=.50$), or sensory problems ($p=.17$).

Impact on Family and child characteristics

Parents/carers of girls with ASD reported significantly higher IoF scores than parents/carers of boys with ASD (M [SD]=42.5 [9.8] vs M =39.2 [9.8] (t (408)=2.26, p =.03, d =0.34). There was a significant main effect of language level on IoF scores (F (5, 393)=4.07, p <.001, $\eta^2 p$ =.05). Compared to children who had no speech but communicated physically, parents/carers reported significantly lower IoF scores for children who spoke in simple phrases (p =.004) and children who spoke in sentences (p =.001). There was a significant positive correlation between IoF scores and autism severity scores as measured by the SCQ (r =.31, p <.001, n =227).

Regression analyses

To explore the predictive utility of the factors associated with impact on the family, a stepwise multiple regression analysis was carried out with IoF scores as the dependent variable. Gender was included in Step 1. The dummy coded language level variables were entered in Step 2. This resulted in 5 dummy coded variables ('gestures', 'echoes', 'single words', 'simple phrases', 'sentences'). Children whose parents/carers reported 'no speech but lets us know physically' were the reference category. The SCQ score was entered in Step 3. The number of co-existing conditions and the type of co-existing condition were entered in Step 4. Only sleep problems, hyperactivity, and temper problems were included as previous analyses showed these were the only co-existing conditions that showed a significant difference on IoF scores between parents/carers of children who reported the co-existing condition and those children whose parents/carers did not. Finally, SES was entered in Step 5. Table 4 shows the results of this multiple regression (n =209).

Step 1 of the model, gender, was not significant (F (1, 208)=2.85, p =.10, R^2 =.013) explaining 1.4% of the variance. Parent reported IoF scores did not differ between boys and girls (β =-.116). Step 2 of the model, language level, was significant (F (6, 203)=2.56, p =.02, R^2 =.070) and explained a further 5.6% of the variance. Parents/carers of children who had no speech but communicated physically reported higher IoF scores compared to parents/carers of children who spoke in simple phrases (β =-.359) and children who spoke in sentences (β =-.423). No other language level explained any additional variance. Step 3 of the model, SCQ score, was significant (F (7, 202)=5.15, p <.001, R^2 =.151) and explained a further 8.1% of the variance (β =.291). Parents/carers who reported higher SCQ scores also reported higher IoF scores (r =.31, p <.001). Step 4 of the model, the number of co-existing conditions and the type of co-existing condition (sleep problems, hyperactivity, and temper problems), was significant (F (11, 198)=8.64, p <.001, R^2 =.324) and explained a further 17.3% of the variance (β =.224).

Parents/carers who reported an increasing number of co-existing conditions also reported higher IoF scores ($r=.53$, $p<.001$) and parents/carers who reported that their child had sleep difficulties reported higher IoF scores than parents/carers who reported that their child did not have sleep difficulties ($\beta=.171$). Hyperactivity or temper problems did not explain any significant additional variance. Although the final step of the model, SES, was significant ($F(12, 197)=7.88$, $p<.001$, $R^2=.324$), SES did not explain any significant additional variance ($\beta=-.007$).

The model overall explained 32.4% of the variance in IoF scores.

Discussion

This large study of children from representative research databases examined the association between impact on the family scores with the number and type of co-existing conditions, and whether male gender, children with lower levels of language, and increased autism severity had a greater impact on the family compared to female gender, children with higher levels of language, and less severe autism. Our large sample size allowed more robust subgroup analyses than those found in previous studies (Brown et al., 2002; Pearson et al., 2006).

Both the number and type of co-existing conditions in children with ASD had a significant impact on the family; however, effect sizes were small. Parents/carers of children with ASD who reported their child had a greater number of co-existing emotional and behaviour problems reported higher impact scores than parents/carers of children with ASD without co-existing conditions. These findings should be considered in the context of previous research showing that increasing numbers of co-existing conditions are associated with an increased likelihood of parental mental health conditions such as anxiety, depression, and psychological distress, that correlate negatively with maternal health-related quality of life (Bromley et al., 2004; Hastings et al., 2005). Although we found that parents/carers of children who reported their child as hyperactive and had temper problems had higher impact scores, it was only the presence of sleep problems that provided the additional variance in impact alongside the core symptoms of ASD in the regression analysis. Sleep disturbances occur in 50-80% of children with ASD compared with 11-37% in typically-developing children (Owens et al., 2000) and have been associated with poorer adaptive skill development and more internalising and externalising behaviour problems (Sikora et al., 2012). Sleep problems have been found to impact the family in terms of parental distress and the functioning of the family (Lecavalier et al., 2006; Manning et al., 2011). This may occur as a result of managing sleep

disturbances or the consequential behavioural challenges that come with sleep deprivation for both the family and child.

We found that parents/carers of girls with ASD reported higher impact on the family scores than boys with ASD; however, this small to medium effect disappeared when gender was included in the regression model suggesting gender does not independently predict impact on the family when other factors are taken into account. If the effect of gender on impact on the family is taken in isolation, it is possible that our finding that the greater impact on the family of girls with ASD could be due to similar behaviours presenting differently in girls compared to boys. For example, Holtmann et al., (2007) found that parents of females reported more social problems, attention problems, and thought problems than parents of males despite no differences on core ASD characteristics. In addition, it has been suggested that if children are selected for studies based on behaviour problems, any gender effect disappears (Rojahn & Helsel, 1991). This could explain the lack of variance explained by gender in the current study since children were included in the regression model if parents/carers had reported their child experienced frequent co-existing conditions.

Regarding language level, we found children who are unable to use spoken language but could let their parent/carer know what they want physically, had a greater impact on the family compared to children who spoke in simple phrases and sentences. This medium sized effect is supported by previous research that has shown that children with less complex speech are more frequently found to have some of the most common co-existing conditions such as toileting and sleeping problems (Maskey et al., 2013). The increase in impact on the family of children with lower levels of speech may be due to parents/carers requiring additional support to meet their child's needs and increasing the level and type of resources needed to cope with their child's different co-existing conditions. However, it is important to note some co-existing conditions such as temper tantrums, aggression, separation anxiety, fear and phobia occur in children of all language abilities (Maskey et al., 2013).

Impact on the family scores also increased, with a small to medium sized effect, as a function of autism severity (as measured by the SCQ), in keeping with previous research (Epstein et al., 2008; Maskey et al., 2013). The finding that higher impact on the family scores appear independently related to ASD diagnosis type and language level is unsurprising. Changes to the new diagnostic criteria (DSM-5; American Psychiatric Association, 2013) have been made to consider separately severity factors including language level in order to better distinguish

between ASD subtypes (Lord et al., 2012). Therefore, the impact that lower language levels have on the family found in this study should be regarded as a separate factor to the impact that the characteristics of ASD have on the family.

Overall, the number and type of co-existing conditions and child characteristics studied accounted for 32.4% of the variance in impact scores irrespective of socioeconomic status. The determinants of strain for individual families of children with ASD are complex. Further detailed research is needed to better understand other factors that might relate to families' 'risk' and 'resilience' and the relationship with prognostic outcomes. For example, this study could be replicated with the inclusion of measures of parental resilience to help identify whether resilience is related to lower impact scores.

Importantly, the relationship between parental strain and a child's co-existing conditions may be bi-directional in that strain/burden may exacerbate the frequency and severity of co-existing conditions and vice versa (Lecavalier et al., 2006). Parental strain/burden has been identified as a major negative factor for parents/carers who have a child with ASD and associated co-existing behavioural conditions. This is key, as it has been found that parental stress levels affect the success of early interventions for children with ASD in terms of education and behavioural functioning (Osborne et al., 2008). It therefore follows that, in order for interventions to work well, they have to be designed to address the level of day to day impact that the child is having on the family, and strain/burden caused, in the context that impact is proportionally related to the number of co-existing conditions. For example, interventions for children with ASD who have more co-existing conditions may need to occur sooner than for children who have fewer co-existing conditions in order for the intervention to have beneficial effects on outcomes for the child and the family.

The study has some limitations, as well as the strengths of representativeness and large numbers that allow subgroup analyses. First, all data were provided by parent report; the accuracy of which may vary between parents/carers, increase the level of agreement between reported behaviours, and level of impact. Second, it was not clear whether data were reported by the mother or father; this meant we were unable to investigate parental gender effects, or replicate the findings of higher maternal impact of co-existing conditions. Third, autism severity data as measured by the SCQ that were only available for ASD-UK participants resulting in the inclusion of approximately 50% of the sample, reducing the power of the analysis. However, despite this reduction in sample

size, considerable variance was explained by the regression model (32.4%). Fourth, parents/carers were asked to complete a number of questionnaires about their child's co-existing conditions. No measure of parent stress was included in the present study, though it might have been helpful to assess a specific type of impact on specific family members. Nonetheless, the parent committee considered that the use of more questionnaires would have adversely affected the response rate. Finally, the reports about co-existing conditions and the Impact on Family scale were completed at different time points, which might decrease the level of agreement observed. However, as the behaviour difficulties of children with ASD tend to persist (Lecavalier et al., 2006), it is suggested that the validity of the observed relationships stands.

Conclusions

Frequent co-existing emotional and behavioural conditions, sleep problems, and more severe autism symptomatology, have an impact on the family of their own, as well as in conjunction with symptoms of ASD. Of note is that in comparison to these other factors, language level had the largest effect on impact scores. The impact of co-existing conditions emphasises the need for health care, social care, educational, voluntary organisations, and other professionals to have an active discussion with parents/carers about these conditions throughout their child's early and teenage years, and to coordinate support and guide families toward appropriate interventions (Nicholas et al., 2015). However, inequalities in the availability of services and the coordination of care amongst health care professionals have been found and this is likely to affect what support can be provided (Parr et al., 2013; Gray et al., 2015).

It has been recognised that families of disabled children often have unmet needs and children with ASD or behavioural problems are often most affected (Smidt & van der Windt, 2006). In the future, provision of the appropriate range of services and effective interventions are needed to reduce the symptoms of co-existing conditions in children and assist the family with ongoing and new challenges. Support is needed for parents/carers to lessen the impact of co-existing conditions on family life (Manning et al., 2011), including other family members who share the same environment such as siblings of children with ASD who are known to experience feelings of anxiety, resentment, neglect, and being treated unfairly compared to siblings of typically-developing children (Dillenburger et al., 2010). Future research is required to investigate how best to provide services and implement new approaches to treatment and management, the impact on the family on other family members, as

well as whether co-existing conditions in children with ASD affect specific types of impact on the family (e.g., financial, social, or personal impact).

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Table 1. Demographic, ethnic, and baseline characteristics of children with and without frequent co-existing conditions

	With co-existing conditions^a	Without co-existing conditions^a
	N (%)	N (%)
Gender		
Male	302 (82.1)	45 (86.3)
Female	66 (17.9)	7 (13.7)
Age (years:months)		
Mean	9:8	11:5
Standard deviation	3.6	4.5
Ethnicity (ASD-UK only)		
White	165 (44.8)	19 (36.5)
Mixed	8 (2.2)	1 (1.9)
Asian	1 (0.3)	1 (1.9)
Black	0 (0.0)	1 (1.9)
Other	2 (0.5)	0 (0.0)
Missing	192 (52.2)	30 (57.7)
ASD diagnosis		
Autism	73 (19.8)	7 (13.5)
Autism Spectrum Disorder	221 (60.1)	30 (57.7)
Pervasive Developmental Disorder	0 (0.0)	0 (0.0)
Atypical Autism	2 (0.5)	1 (1.9)
Asperger Syndrome	62 (16.8)	10 (19.2)
Other	6 (1.6)	1 (1.9)
Missing	4 (1.1)	3 (5.8)
Language ability		
Uses sentences with reasonably good grammar	192 (52.2)	36 (69.2)
Uses mostly simple phrases	77 (20.9)	6 (11.5)

Uses mostly single spontaneous words	18 (4.9)	1 (1.9)
Mostly echoes (repeats) other people's words	19 (5.2)	0 (0.0)
No speech but tries to communicate spontaneously by gesture, sounds, etc	27 (7.3)	3 (5.8)
No speech but lets you know some of what he/she wants physically	19 (5.2)	1 (1.9)
Other	10 (2.7)	1 (1.9)
Missing	6 (1.6)	4 (7.8)
Total	368 (87.6)	52 (12.4)

N.B: "frequent" = occurring 3 or more times per week.

Table 2. Number and percentage of co-existing conditions reported as frequent by gender and ASD diagnosis type

Male Co-existing condition ^a	ASD diagnosis, N (%)					Total frequent	Total number of responses
	Autism	ASD	Atypical Autism	Asperger Syndrome	Other		
Sleep problems (including settling and night waking)	29 (8.6)	96 (28.6)	1 (0.3)	30 (8.9)	5 (1.5)	161 (47.9)	336
Toileting problems (including constipation, retaining faeces, smearing faeces, diarrhoea, wetting self after it is usual for his/her age group)	24 (7.2)	73 (21.9)	1 (0.3)	13 (3.9)	3 (0.9)	114 (34.2)	334
'Hyper' periods, very restless and irritable	34 (10.2)	94 (28.2)	1 (0.3)	24 (7.2)	2 (0.6)	155 (46.5)	333
Temper tantrums when not able to do what s/he wants	38 (11.2)	100 (30.0)	1 (0.3)	32 (9.5)	4 (1.2)	175 (51.8)	338
Aggression to other people	14 (4.1)	46 (13.5)	1 (0.3)	10 (2.9)	1 (0.3)	72 (21.2)	340
Injury to self (such as head-banging, biting hand)	11 (3.2)	27 (7.9)	0 (0.0)	6 (1.8)	2 (0.6)	46 (13.5)	340
Reluctant to separate from one parent	12 (3.6)	37 (11.0)	0 (0.0)	7 (2.1)	0 (0.0)	56 (16.7)	335
Anxiety, fears or phobias	26 (7.8)	84 (25.1)	2 (0.6)	31 (9.3)	4 (1.2)	147 (44.0)	334
Selective about eating	39 (11.5)	106 (31.2)	1 (0.3)	30 (8.8)	2 (0.6)	178 (52.4)	340
Sensory reactions (such as great distress at noises, hair cutting, dentist; or unusual sensory interests)	49 (14.4)	117 (34.1)	2 (0.6)	35 (10.3)	4 (1.2)	207 (60.9)	340
Other: (<i>please describe</i>)	11 (21.6)	22 (43.1)	2 (3.9)	9 (17.6)	1 (2.0)	45 (88.2)	51

NB: ASD = Autism Spectrum Disorder. No parent/carer reported that their child had a diagnosis of Pervasive Developmental Disorder. Percentage calculated from total number of responses. ^a'frequent' = occurring 3 or more times per week.

Female Co-existing condition ^a	ASD diagnosis, N (%)				Total number of responses
	Autism	ASD	Asperger Syndrome	Total frequent	
Sleep problems (including settling and night waking)	11 (15.5)	26 (36.6)	5 (7.0)	42 (59.2)	71
Toileting problems (including constipation, retaining faeces, smearing faeces, diarrhoea, wetting self after it is usual for his/her age group)	7 (10.4)	26 (38.8)	2 (3.0)	35 (52.2)	67
'Hyper' periods, very restless and irritable	3 (4.3)	20 (28.6)	4 (5.7)	27 (38.6)	70
Temper tantrums when not able to do what s/he wants	6 (8.5)	26 (36.7)	4 (5.6)	36 (50.7)	71
Aggression to other people	0 (0.0)	11 (15.5)	1 (1.4)	12 (16.9)	71
Injury to self (such as head-banging, biting hand)	2 (2.8)	7 (9.9)	1 (1.4)	10 (14.1)	71
Reluctant to separate from one parent	1 (1.4)	9 (13.0)	1 (1.4)	11 (15.9)	69
Anxiety, fears or phobias	3 (4.2)	21 (29.6)	2 (2.8)	26 (36.6)	71
Selective about eating	7 (10.0)	24 (34.3)	6 (8.6)	37 (52.9)	70
Sensory reactions (such as great distress at noises, hair cutting, dentist; or unusual sensory interests)	11 (15.5)	21 (29.6)	7 (9.9)	39 (54.9)	71
Other: (<i>please describe</i>)	0	2 (40.0)	0	2 (40.0)	5

NB: ASD = Autism Spectrum Disorder. No parent/carer reported that their child had a diagnosis of Pervasive Developmental Disorder, Atypical Autism, or Other.

Percentage calculated from total number of responses. ^a'frequent' = occurring 3 or more times per week.

Table 3. Demographic characteristics for children of responders and non-responders

	Responders N (%)	Non-responders N (%)
Gender		
Male	347 (82.6)	632 (83.3)
Female	73 (17.4)	127 (16.7)
Age (years:months)		
Mean	8:6	9:5
Standard deviation	3.8	4.5
Under 7 years	130 (31.0)	284 (37.4)
7-11 years	165 (39.3)	242 (31.9)
12 years and over	125 (29.8)	230 (30.3)
ASD diagnosis		
Autism	82 (19.5)	169 (22.3)
Asperger Syndrome	76 (18.1)	145 (19.1)
Other/ASD	262 (62.4)	445 (58.6)
Language ability		
Speaks in sentences	238 (56.7)	438 (57.7)
Lower levels of language	182 (43.3)	312 (41.1)
Number of co-existing conditions		
Mean	3.7	4.1
Standard deviation	2.6	2.6
0	52 (12.4)	81 (10.7)
1-3	152 (36.2)	238 (31.3)
4 or more	216 (51.4)	440 (58.0)
Total	420 (35.6)	759 (64.4)

NB: Age was unknown for 3 non-responders (0.4% non-responders, 0.3% of total population). Language ability was unknown for 9 non-responders (1.2%).

Table 4. Results of the regression analysis for Impact on Family scores ($n = 209$)

Total variance explained = 32.4%		R ²	B	Std. Error	Beta	t	p
Step 1	(Constant)	.014	41.411	1.623		25.510	<.001
	Gender		-3.012	1.783	-.116	-1.689	=.093
Step 2	(Constant)	.070	48.850	2.850		17.139	<.001
	Gender		-3.175	1.770	-.123	-1.794	=.074
	No speech (reference) vs gesture		-6.097	3.449	-.161	-1.768	=.079
	No speech (reference) vs echoes		-5.323	3.750	-.122	-1.420	=.157
	No speech (reference) vs single words		-5.375	4.144	-.105	-1.297	=.196
	No speech (reference) vs phrases		-8.610	2.803	-.359	-3.072	=.002
	No speech (reference) vs sentences		-8.292	2.553	-.423	-3.249	<.001
Step 3	(Constant)	.151	38.390	3.623		10.595	<.001
	Gender		-3.733	1.700	-.144	-2.196	=.029
	No speech (reference) vs gesture		-4.648	3.320	-.123	-1.400	=.163
	No speech (reference) vs echoes		-5.261	3.592	-.120	-1.465	=.145
	No speech (reference) vs single words		-3.413	3.995	-.067	-.854	=.394
	No speech (reference) vs phrases		-6.971	2.710	-.291	-2.572	=.011
	No speech (reference) vs sentences		-6.569	2.476	-.335	-2.653	=.009
	SCQ total		.413	.094	.291	4.391	<.001
Step 4	(Constant)	.324	35.812	3.309		10.823	<.001
	Gender		-2.937	1.547	-.113	-1.899	=.059
	No speech (reference) vs gesture		-3.749	3.006	-.099	-1.247	=.214
	No speech (reference) vs echoes		-3.130	3.267	-.071	-.958	=.339
	No speech (reference) vs single words		-3.573	3.625	-.070	-.986	=.326
	No speech (reference) vs phrases		-6.571	2.444	-.274	-2.688	=.008
	No speech (reference) vs sentences		-5.244	2.242	-.267	-2.340	=.020
	SCQ total		.176	.093	.124	1.905	=.058
	Number of co-existing conditions		.859	.407	.224	2.112	=.036
	Sleep problems		3.335	1.482	.171	2.251	=.025

	Hyperactivity	1.688	1.475	.086	1.144	=.254
	Temper problems	1.654	1.529	.085	1.082	=.281
Step 5	(Constant)	.324	35.858	3.340	10.736	<.001
	Gender	-2.960	1.562	-.114	-1.894	=.060
	No speech (reference) vs gesture	-3.742	3.014	-.099	-1.241	=.216
	No speech (reference) vs echoes	-3.146	3.278	-.072	-.960	=.338
	No speech (reference) vs single words	-3.610	3.648	-.071	-.990	=.324
	No speech (reference) vs phrases	-6.589	2.456	-.275	-2.683	=.008
	No speech (reference) vs sentences	-5.282	2.270	-.269	-2.327	=.021
	SCQ total	.176	.093	.124	1.897	=.059
	Number of co-existing conditions	.858	.408	.224	2.104	=.037
	Sleep problems	3.335	1.486	.171	2.245	=.026
	Hyperactivity	1.702	1.484	.086	1.147	=.253
	Temper problems	1.668	1.538	.085	1.085	=.279
	Townsend Index	-.019	.166	-.007	-.117	=.907

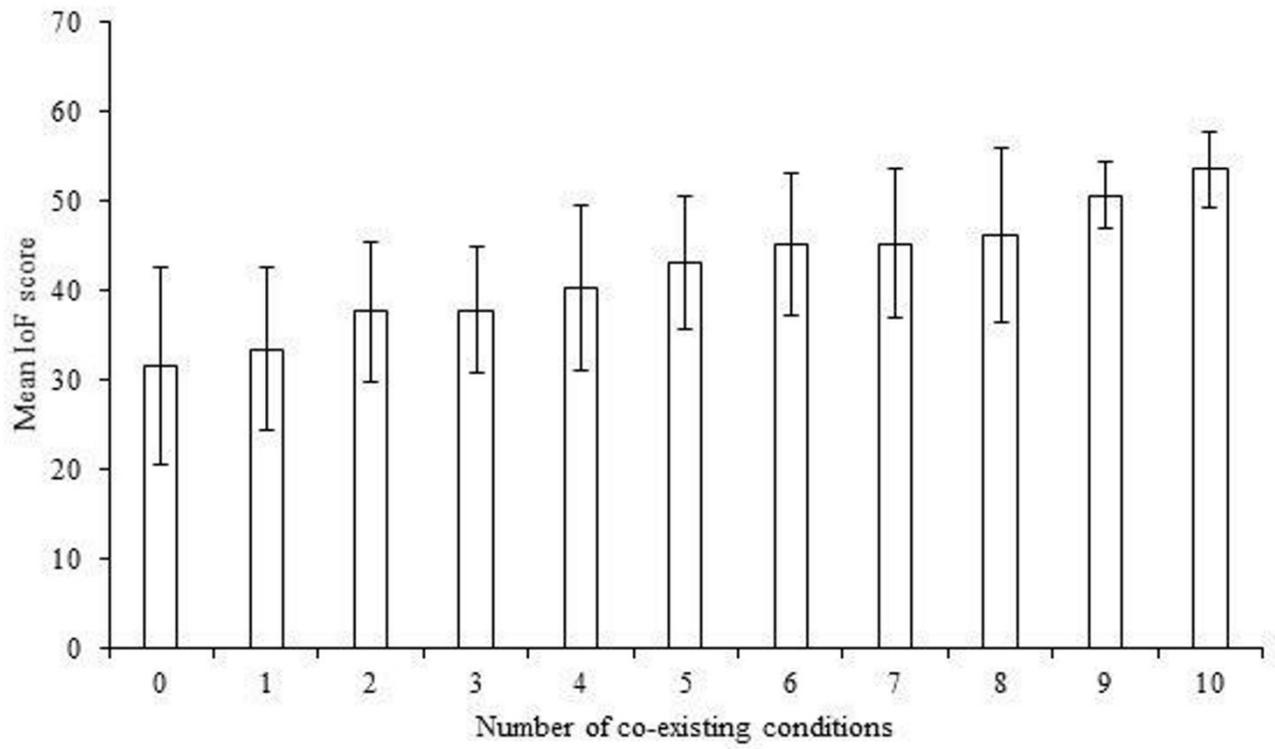


Figure 1. Impact on Family scores for children with ASD by number of co-existing conditions. Error bars are standard deviations.