Comparing parental stress of children with neurodevelopmental disorders: The case of Williams Syndrome, Down Syndrome and Autism Spectrum Disorders.

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Abstract

Background: Although parental stress is higher for children with neurodevelopmental disorders (NDs), it is unclear how this stress compares to more common NDs. The current study compared stress in parents of children with Williams Syndrome (WS), Down Syndrome (DS), and Autism Spectrum Disorders (ASD). The impact of individual and contextual factors was also explored. Method: Parents of children with WS (n = 107), DS (n = 79), and ASD (n = 79) completed a background questionnaire, a parental stress questionnaire, and a satisfaction with life questionnaire. Results: Although all groups displayed similar levels of parental stress, the factors that influenced this stress differed between the groups. There were also differences for life satisfaction and relationships between parental stress and individual and contextual factors. Conclusions: Although parents of children with NDs are not at an increased risk for parental stress, the results suggest that interventions should be syndrome specific.

Keywords: Stress, Parents, *Williams Syndrome*, *Down Syndrome, Autism Spectrum Disorder*

Extensive research has shown that parents of children with an intellectual disability (ID), including those with Autism Spectrum Disorders (ASD), Down Syndrome (DS), as well as rarer disorders such as Cri du Chat Syndrome (CdCS) and Prader-Willi Syndrome, can experience elevated levels of psychological stress and depression compared to parents of typically developing (TD) children (Griffith et al., 2011b; Hodapp, Wijma, & Masino, 1997; Olsson & Hwang, 2001; Woodman, Mawdsley & Hauser-Cram, 2015). Experiencing this stress can have a negative influence on parents' mental health and wellbeing. Schulz and Sherwood (2008) found that chronic stress was linked to poor psychological and physical health in caregivers and research has established that psychological distress is negatively related to satisfaction with life (Hamarat et al., 2001; Mahmoud, Staten, Hall & Lennie, 2012). Moreover, stress can have an extended negative influence on the family. Parental stress has been shown to have a damaging effect on relationships within the family (i.e., between parents and other children), and can also foster less effective parenting (Boles, Johnston & Joseph, 1997; Coldwell, Pike & Dunn, 2006).

It has been argued that parents of children with rare genetic disorders may be at a greater risk of experiencing stress and mental health problems than parents of children with more common disorders, due to rarity of the disorder impacting on finding expert support and advice and this lack of information may lead to increased worrying about the future of their child (Griffith et al. 2011a; 2011b). For example, Griffith et al. (2011b) investigated the levels of stress in parents of children with very rare disorders, including Angelman syndrome, Cornelia de Lange syndrome, and CdCS. Parents in all groups reported elevated levels of stress compared to a normative sample in relation to stressors such as education, health, and care provision. Additionally, all parents of children with rare disorders experienced stressors related

to the rarity of their child's syndrome. These findings offered further evidence that parents of children with ID experience elevated levels of stress, and also suggest that syndrome rarity may be a relevant factor for parental stress. However, there is wide variability in parental stress of children with IDs, suggesting that there may be a number of influential factors (such as level of family support) that affect parental stress (Halstead, Griffith & Hastings, 2017). Although some studies have examined how these factors impact stress levels of parents of children with ASD (e.g., Griffith et al., 2011b), it has not yet been examined how age and severity of the child's needs impacts on parental stress for parents of children with Williams Syndrome (WS). In addition, previous studies that have argued that parental stress is linked to the rarity of the disorder did not include comparisons to more common IDs and thus, it is not yet clear whether parental stress is linked to the rarity of the disorder per se or to other difficulties that are shared between the different IDs. Comparing parental stress levels across different neurodevelopmental disorders allows greater insight into the syndrome specific and general difficulties that can cause stress for parents of children with ID.

Williams syndrome, Down syndrome and Autism Spectrum disorders

Williams syndrome (WS) is a rare congenital disorder caused by the microdeletion of 28 genes on chromosome 7, affecting approximately one in 20, 000 live births (Martens, Wilson & Reutens, 2008). People with WS have significant and complex difficulties including general cognitive delay, health and sensory issues, fine and gross motor problems, and anxiety (Martens et al., 2008). However, despite the demanding education, health, and care needs of people with WS, to date there has been little research investigating the stress levels of parents with offspring with WS.

Some studies indirectly explored WS parental stress by partially investigating family life. For example, families of children with WS reported higher levels of pessimism and more family problems than families of children with DS (Fidler, Hodapp & Dykens, 2000). Out of 70 parents of WS adults, 25% said their offspring's needs caused family conflict (Udwin, Howlin, Davies & Mannion, 1998), and all parents (n = 79) reported at least one challenging aspect in relation to raising a child with WS (Reilly, Murtagh & Senior, 2015). This handful of studies suggests that having children with WS can have a significant and sometimes negative effect on family life. However, to our knowledge no research has directly explored stress in parents of children with WS or compared this to stress of parents of children with other neurodevelopmental disorders, nor examined what factors may influence parental stress levels.

While WS is a rare disorder, DS and ASD are more common neurodevelopmental disorders affecting approximately 1 in 700 and 1 in 100 people, respectively (Silverman, 2007; Baird et al., 2006). Individuals with WS and DS experience similar cognitive impairments and delays, and both have a low average IQ between 50 and 70 (Mervis et al., 2000). This is dissimilar to individuals with ASD for whom there is wide variability in cognitive ability and IQ (Charman et al., 2011). However, all three syndromes have specific cognitive strengths and weaknesses: those with WS have better verbal abilities in relation to their non-verbal abilities and gross motor skills, whilst those with DS show specific weaknesses in memory, fine motor, and language abilities. Individuals with ASD, in contrast, often show strengths in non-verbal abilities compared to their verbal abilities. In addition, although those with WS are very sociable and caring, individuals with WS and ASD have comparable behavioural and sensory profiles, both exhibiting repetitive behaviours and similar

sensory needs, eating difficulties, and anxieties, unlike people with DS. From a health point of view, most children with WS have complex medical needs, including cardiovascular, gastrointestinal, and feeding difficulties. Children with DS are also at an increased risk of medical problems, including heart disease, thyroid problems and blood disorders, whereas a diagnosis of ASD has not necessarily been linked to a higher incidence of health related difficulties. The varying overlapping strengths and difficulties in these disorders' phenotypes, including the cognitive, medical, and behavioural profiles, allow for useful cross-syndrome comparisons. This can provide more insight into the syndrome specific factors, such as syndrome rarity and behavioural profiles, that may influence parental stress. For example, if behavioural difficulties rather than cognitive difficulties cause parental anxiety then both parents of children with WS and ASD are expected to show higher levels of anxiety but not those with DS. However, if medical issues cause parental anxiety, then parents of those with WS and DS would show higher stress levels than those of children with ASD. Alternatively, by comparing ASD, DS, and WS, it is also possible to examine whether higher levels of parental stress are caused by contextual factors that are shared across the three neurodevelopmental disorders, such as family support.

Factors that influence parental stress

Instances of maladaptive behaviour have been shown to be relatively low in children with DS, compared to children with other developmental disorders (Dykens & Kasari, 1997; Stoneman, 2007). Hodapp, Ly, Fidler and Ricci (2001) suggested that parents of children with DS reported less parenting stress compared to parents of children with other IDs due to the more appropriate sociability of many people with DS. Conversely, parents of children with ASD are often reported as being significantly more stressed than parents of children with other IDs (Watson, Hayes &

Radford-Paz, 2011). Although there is wide variability, many individuals with ASD can have severe difficulties with communication, social interaction, and rigid patterns of behaviour, which may result in behaviours, such as anxiety and obsessive rituals that are difficult and stressful for parents to manage (Lai & Oei, 2014; Peters-Scheffer, Didden & Korzilius, 2012). While individuals with WS can present many sociable behaviours, other potential difficulties with high anxiety, fear, hypersociability, and health complications may also result in outcomes that may be more difficult for parents to manage (Scallan, Senior & Reilly, 2011). These findings suggest that the amount and type of challenging aspects presented by the phenotype of a neurodevelopmental disorder could influence parental stress levels (Estes et al., 2009).

In a similar vein, the age of the child has been found to influence parental stress levels. Parents of younger children with WS and DS were more pessimistic compared to those who had older children (Fidler et al., 2000). This could be due to the delayed developmental trajectory of infants with WS and DS as well as common feeding and sleeping difficulties (Martens et al., 2008; Silverman, 2007). There are a number of factors that could change how a child's age might impact on parental stress. Lounds, Seltzer, Greenberg and Shattuck (2007) found that parents of older children with ASD had higher levels of psychological wellbeing compared to those of younger children with ASD and argued this was due to the prevalence of ASD symptoms and behaviour problems decreasing over time. On the other hand, older age could increase parental stress due to concerns about the future as the child reaches adolescence and adulthood, and the differences in provision and support available as children grow older. There may also be group differences in how the child's age impacts parental stress. For example, Abbeduto et al., (2004) found that pessimism

about their child's future and depressive symptoms were lower in parents of adolescents and young adults with DS than those with ASD. These studies suggest that the child's age plays an influential role in parental stress, but also highlight the range of factors and explanations for the level for parental stress.

Finally, all children are unique and there is considerable variability within all three developmental disorders with regards to the severity of the cognitive, behavioural, and health difficulties that each child may display (Charman, 2015; Tsao & Kindelberger, 2009; Van Herwegen, Rundblad, Davelaer & Annaz, 2011), alongside the many different strengths and unique aptitudes of children with developmental disorders that also bring joy to their families (Hastings & Taunt, 2002; Skotko, Levine & Goldstein, 2011). Yet, very few studies have examined how severity of a child's difficulties or the number of challenging behaviours a child exhibits affect parental stress, especially for WS and DS.

In addition to the individual factors that influence parental stress, there are a number of contextual factors that can impact on parental stress. Family cohesion has been shown to be an important predictor of quality of life for parents of children with ASD, which included parents engaging in activities with their other children as well as their child with ASD (Higgins, Bailey & Pearce, 2005). Therefore, if a child has siblings, this could allow for more opportunities to engage in enjoyable and beneficial joint activities which increase parental life satisfaction and thus, decrease stress. In addition, siblings may act as a buffer against stress for parents of children with a neurodevelopmental disorder in that they may be able to take on some caregiving duties for their sibling with a disorder (Hastings, 2003; Lai & Oei, 2014), decreasing the demands on parents and parental stress. However, this may not be the case for all disorders; due to the inherited genetic element of ASD, parents of children with ASD

may also have to manage raising multiple children with special needs (Abbeduto et al., 2004). Therefore, for families of children with ASD, siblings may not act as a buffer but may exacerbate parental stress if this child is on the spectrum as well.

Finally, feeling valued and cared for as a result of receiving social support from others could also serve as an important variable for parental stress. Social support from partners, family members, and/or extended support groups has consistently been found to be related to lower stress levels in parents of children with ASD and other IDs (Hall & Graff, 2011; Hassall, Rose & MacDonald, 2005; Telleen, Herzog & Kilbane, 1989). This evidence suggests that social and family support could be a protective factor for parental stress.

The current study

In sum, although there have been a few studies to suggest that the rarity of the disorder can cause augmented parental stress, previous studies have not yet directly examined parental stress in WS or directly compared stress in parents of children with rare disorders (such as WS) to those of children with more common disorders (such as DS and ASD). The current study examined parental stress and life satisfaction in a large group of parents of children with WS, compared with those parents of children with DS and ASD. Including parents of children across a large age range in all three groups allowed for the first time to examine how different individual (e.g., age and the number of challenges the child displays) and contextual factors (e.g., family composition) impact on parental stress and life satisfaction. Obtaining a better understanding about the parental stress levels for children with rarer disorders compared to more common ones, in addition to the individual and contextual aspects that may contribute to increased or reduced parental stress, allows valuable

information for the development and implementation of intervention studies and practical resources that may help parents manage this stress.

Based on previous research (Griffith et al., 2011a; 2011b) four hypotheses were made. It was hypothesised that 1) parents of children with a rare neurodevelopmental disorder such as WS would be more stressed and have worse life satisfaction compared to parents of children with more common developmental disorders, despite the fact that the disorders share a similar behavioural (ASD) or cognitive (DS) profiles, and 2) that across the different groups stress levels would correlate negatively with satisfaction of life. To explore any further group differences, the current study examined the relationship between individual factors, such as age and severity of the disorder, as well as contextual familial factors, such as family support and number of siblings and parental stress. 3) For individual factors, it was hypothesised that with increasing age parents of children with WS and DS would have less stress but that stress levels might increase in parents of children with ASD. 4) For contextual factors, it was hypothesised across the three groups that severity of the disorder would relate to augmented parental stress but that number of siblings and family support would have a beneficial impact on parental stress and thus correlate negatively with parental stress.

Method

Participants

In total, 265 parents of children and young people aged 4 – 25 with either WS (n = 107), DS (n = 79) or ASD (n = 79) were recruited via social media and parental support groups. All responders were mothers (100%). Further demographic information for each group, such as the age and gender of the children for whom

parents completed the questionnaires, can be found in Table 1. As ASD is more prevalent in boys, the current study included more parents of boys with ASD compared to the other two groups. All parents confirmed their child had a formal diagnosis established by a clinical psychologist or genetic test.

The majority of the mothers had been educated to degree level or above: graduate degree (WS: 28%, DS: 32%, ASD: 38%), post-graduate degree (WS: 22%, DS: 31%, ASD: 24%), or above (WS: 5%, DS: 6%, ASD: 0%), whilst others had completed a vocational degree (WS: 19%, DS: 12% and ASD: 21%). A quarter of the mothers in the sample had little or no formal schooling and had either no formal qualifications (WS: 1%, DS: 4%, ASD: 1%), were only educated to GCSE level or equivalent (WS: 22%, DS: 12%, ASD: 15%) or to A-levels of equivalents (WS: 3%, DS: 3%, ASD: 1%). A non-parametric chi-square analysis did not reveal any differences between the three groups for parental level of education; $\chi^2(12)= 13.833$, $p = .312$, and thus parental education levels were not included as a factor to explore any group differences for parental stress levels.

Procedure and Materials

The current study was part of a larger study that examined education, health, and care provision for children and young adults with WS, DS, and ASD and obtained favourable opinion from the Faculty Research Ethics Committee Meeting at Kingston University. As part of this larger study, responders completed two standardised questionnaires used by Griffith et al. (2011a; 2011b) on stress and life satisfaction. They also completed a general questionnaire about demographic and socioeconomic information such as their child's age, the child's siblings, and the parents' highest level of education. Severity of the child's disorder was assessed by the total number

of items parents selected from a list of 20 potentially challenging cognitive, medical, and behavioural aspects, including language, motor, and attention difficulties as well as anxiety issues, social difficulties or sensory issues amongst others (for a complete list see Table 3). Although this was an unvalidated measure, this scale was put together to allow us to directly assess the similarities and differences, in terms of medical behavioural and cognitive strengths and difficulties, between the three neurodevelopmental disorders. For family support, we asked parents to select whether other adults were involved in their child's upbringing, including partners or spouses, grandparents, other family members, au pairs or nannies or any other adults. All questionnaires were completed online using Qualtrics software so that respondents could access the questionnaire via their computer, tablet, or phone.

Measure of parental stress

The Genetic Syndromes Stressors Scale (GSSS; Griffith et al. 2011b) measured parental stressors relating to rare genetic disorders. Participants were asked to rate 14 items on a Likert scale ranging from 0 *(Not at all stressful)* to 3 *(Extremely stressful)*, such as 'Not having access to professionals who have knowledge about my child's condition', with scores ranging from 0 to 42. Excellent internal reliability (α = .83 and α = .87) had been established previously (Griffith et al. 2011b) and in the current study (α = .89). The GSSS has also been reported to have good face validity and concurrent validity (see Griffith et al., 2011b for further details).

Measure of life satisfaction

The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen & Griffin, 1985) measured participants' global life satisfaction. Participants were asked to rate their agreement with five statements on a Likert scale ranging from 1 *(strongly disagree)* to 7 *(strongly agree)*, such as 'In most ways my life is close to my ideal'.

The cut-off scores for levels of life satisfaction are as follows: 31 - 35 *(Extremely satisfied)*, 26 - 30 *(Satisfied)*, 21 - 25 *(Slightly satisfied)*, 20 *(Neutral,)* 15 - 19 *(Slightly dissatisfied)*, 10 - 14 *(Dissatisfied)*, 5-9 *(Extremely dissatisfied)*. This scale had excellent internal reliability for the current study ($\alpha = .89$). For further details about the reliability and validity of this scale see Pavot and Diener (1993).

Results

One-way ANOVAs were used to compare any group differences and Bonferroni post-hoc analyses explored any significant differences between the groups. Welsh statistic was reported for those analyses where the assumption of homogeneity of variance was violated. Non-parametric Chi-square analyses were used to analyse any differences in number of participants who had selected a yes-no option and unstandardized residuals were used to explore group differences. To examine the relationships between the individual (age of the child and number of challenging aspects) and contextual factors (number of siblings and family support) with stress and life satisfaction outcomes Pearson correlation analyses were run.

Group differences for parental stress

A one-way between-subjects ANOVA showed there was no significant group effect for parental stress; $F(2, 262) = .278$, $p = .757$, $\eta_p^2 = .002$, suggesting that parents of children with WS, DS, and ASD had similar stress levels (see Table 1)[1]. However, the measures of central tendency for the GSSS total scores, such as standard deviations, revealed wide variability in parental stress levels in each group.

Table 1 about here

[1] Examination of parental stress levels for only the male participants did not show a significant effect for group; $F(2,153) = .855$, $p = .429$, $\eta_p^2 = .019$.

All GSSS items loaded onto one factor and there was good internal reliability for the scale ($\alpha = .89$). As this showed that each item contributed in a similar way to the overall general construct of parental stress, a mixed ANOVA with group as between factor and item as within factor was used to explore any group differences for each particular item. Using the Greenhouse Geisser correction, there was a significant interaction effect between the GSSS items and group; $F(20.48, 2304.88) = 3.20$, $p < .001$, $\eta_p^2 = .028$. These results revealed that there were group differences for what parents found particularly stressful (see Table 2). Parents of children with ASD found not having access to professionals (item 1) significantly more stressful than parents of children with WS ($p = .023$) and DS ($p = .024$). However, parents of children with WS found seeing professionals with limited knowledge of the disorder (item 6) more stressful than parents of children with ASD ($p = .027$). Parents of both children with WS ($p < .001$) and DS ($p = .001$) found the fact that their children were not reaching developmental milestones (item 4) significantly more stressful than parents of children with ASD. Parents of children with WS found accessing a suitable educational placement (item 8) significantly less stressful than parents of children with ASD ($p = .037$).

There was also an overall effect for item; $F(10.24, 2304.88) = 38.156$, $p < .001$, $\eta_p^2 = .145$, suggesting that parents felt similarly about particular stressors. On two items, the mean GSSS scores were notably more extreme at each end of the 0 – 3 scale range. All parents rated worrying about their child's future because of the lack of specialist services in adulthood (item 14) as particularly stressful ($M = 2.39$, $SE = .06$). On the other hand, all parents rated a genetic diagnosis causing tension in the family (item 10) as relatively less stressful ($M = .74$, $SE = .07$).

Table 2 about here

Group differences for parental life satisfaction

A one-way between-subjects ANOVA revealed a significant group effect on life satisfaction; $F(2, 260) = 10.894$, $p < .001$, $\eta_p^2 = .078$. Although this effect size is small, the power was good (.988), showing that the real impact of this difference may be small. Post-hoc pairwise comparisons using the Bonferroni correction showed that parents of children with WS and those of children with DS had a significantly higher SWLS score than parents of children with ASD (see Table 1). There was no difference in SWLS score for parents of children with WS and DS ($p = .217$). According to Diener et al.'s (1985) cut-off scores for level of life satisfaction, parents of children with WS and DS were 'slightly satisfied' with life, and parents of children with ASD were 'slightly dissatisfied' with life.

Group differences for individual and contextual factors

As the assumption of homogeneity of variance was violated for a number of analyses, Welsh statistic was used to compare the group differences. There were no significant group differences for child's age; $F(2, 168.071) = 2.660$, $p = .073$, number of siblings; $F(2,159l420) = 1.602$, $p = .552$ or family support; $F(2,148.212) = .552$, $p = .597$. However, there was a significant group difference for the number of challenging aspects; $F(2,165.408) = 16.251$, $p < .001$, $\omega^2 = .11$, with those with WS reporting significantly more challenges (see Table 1 for descriptive statistics and post-hoc analyses). Table 3 provides an overview of what challenges each of the groups

identified for their child. The analyses show that the three groups had different strengths and difficulties, in line with the general descriptions of these populations.

Table 3 about here

Relationships between stress, satisfaction with life, and individual and familial factors

Pearson correlation analyses were run to explore the relationships between parental stress, satisfaction with life, individual factors (age and number of challenging aspects), as well as contextual familial factors (number of siblings and family support) within each group (see Table 4). A number of small to medium significant correlations were found. The GSSS score correlated negatively with SWLS score in all groups, suggesting that higher stress levels relate to lower life satisfaction for parents of children with WS, DS, and ASD. For parents of children with WS and DS, there was a significant positive correlation between GSSS score and the number of challenging aspects listed. For parents of children with WS, there was also a significant positive correlation between SWLS score and number of siblings, but this relationship was not significant for parents of children with DS and ASD. However, for parents of children with DS, number of siblings correlated negatively with stress as well as the number of challenging aspects listed. This pattern of results suggests that the number of siblings a child has may influence parental stress levels and life satisfaction for parents of children with WS and DS. For parents of children with ASD, stress and satisfaction with life were not related to any of the remaining variables. Despite the large age range of the participant, the child's age was not related to stress or satisfaction with life in any of the groups and neither was family support a significant factor.

Table 4 about here

Discussion

The current study examined for the first-time parental stress and life satisfaction in parents of children with WS, a rare neurodevelopmental disorder, in contrast to parents of children with more common neurodevelopmental disorders such as DS and ASD. The current study also examined what individual factors and contextual factors would influence parental stress and life satisfaction in these groups. Comparison of these three neurodevelopmental disorders allowed examination of whether the rarity of the disorder relates to parental stress or whether other individual or contextual factors are shared causes for parental stress across the different groups.

Parental stress levels and life satisfaction for rare versus more common neurodevelopmental disorders

Overall, the stress levels of parents of children with WS did not differ from those who had children with DS or ASD. These findings are in contrast to those reported in previous studies which suggested that parents of children with the rare disorders Angelman syndrome, Cornelia de Lange syndrome, and CdCS are at a higher risk for parental stress (Griffith et al., 2011a; 2011b). However, detailed analyses of what parents found stressful revealed some interesting group differences: whilst parents of children with ASD found it more stressful to access a professional, presumably due to the very long waiting lists to see professionals in the UK for children with ASD (Crane, Chester, Goddard, Henry & Hill, 2016), parents of children with WS found the lack of knowledge about their child's condition when meeting professionals more stressful. Again, it is not surprising that parents find that very few professionals have

an in-depth knowledge of WS, seeing the rarity of WS. Yet, parents of children with WS found accessing a suitable educational placement significantly less stressful than parents of children with ASD. This finding is rather surprising seeing that there are currently a number of schools that provide specialist education for those with ASD. In addition, many mainstream schools often have support staff with special education needs (SEN) training for children with ASD. In contrast, there are no specialist schools for children with WS and even SEN staff and schools have little understanding of WS (Van Herwegen, Ashworth & Palikara, 2018). However, it is possible that parents of children with ASD find choosing the right school (specialist or mainstream) or specific aspects of education provision particular stressful (see McNerney, Hill & Pellicano, 2015 for a discussion). It should be pointed though that the effect of school provision on educational experience of children and families with WS has not been explored yet in any detail (See Palikara, Ashworth & Van Herwegen, 2018 for discussion). Therefore, further studies are required to examine the impact of school provision on stress levels for parents of children with ASD and WS further. Finally, parents in all three groups worried about their child's future which is an important aspect that should be addressed in parental interventions programmes aimed to cope with stress.

Factors that relate to parental stress within the different groups

In line with previous studies (Halstead et al., 2017), our findings revealed that parental stress levels varied considerably. In order to explore this variability, we examined the relationship between parental stress and some individual as well as contextual factors and how these relationships differed between the different groups.

The child's age did not influence parental stress in any of the groups. This is in contrast to previous studies that have found that parents of younger children with neurodevelopmental disorders may be more stressed compared to those with older children (Fidler et al., 2000; Louds et al., 2007). The current study is the first to include children from a wide age range in all three disorder groups. Yet, the causes and reasons for parental stress may change over development. Therefore, it is possible that parents of young children and those of older ones are equally stressed, but for different reasons. Future studies should investigate this possibility further.

There was also no relationship between parental stress and family support in contrast to previous studies (Hall & Graff, 2010; Hassall et al., 2005; Telleen et al., 1989). As shown in the standard deviations of family support, this could have been caused by the fact that there was limited variability within this measure and all parents had family support which limits the finding of significant correlations.

The current study used the number of challenging aspects identified by the parents as a proxy measure of severity of the disorder. In the WS and DS group there were significant correlations between the number of challenges identified by the parents and parental stress. In contrast to previous studies in ASD (Abbeduto et al., 2004; Estes et al., 2009), parental stress in the current ASD sample did not relate to the number of challenges identified by the parents. However, previous studies in ASD have used a more direct approach of measuring disorder severity, including the use of cognitive standardised testing batteries. Thus, the different ways in which syndrome severity has been measured could potentially explain the different results between the current and previous studies. Nonetheless, seeing the fact that some children with ASD and WS have been argued to show similar behaviour difficulties, including resistance to change, repetitive behaviours, limited social abilities and sensory needs

(Rodgers, Riby, Janes, Connolly & McConachie, 2012), it would have been expected that similar relationships between parental stress and number of challenges as a proxy for syndrome severity would have been found, if behavioural difficulties alone were a driving factor for parental stress. Still, the finding that severity of the disorder related to parental stress in the DS and WS groups can be clinically informative in that it may highlight which parents are more likely to benefit from professional treatment to reduce parental stress.

For both children with DS and WS, decreased parental stress or higher satisfaction with life was related to the number of siblings. This confirms previous studies that have suggested that siblings may act as a buffer for parental stress (Lai & Oei, 2014) but that this may not be the case for ASD, due to the inherited genetic element of ASD and that parents of children with ASD may have to manage raising multiple children with special needs (Abbeduto et al., 2004).

In sum, overall none of the individual or contextual factors that were measured in the current study related to parental stress in all three groups, suggesting again that the causes of parental stress are syndrome specific. Still, the number of challenging aspects related to parental stress for both the WS and DS group, which indicates that instead of the rarity of the disorder, the severity of the disorder might be a better explanation for parental stress.

Limitations

There are a number of limitations of this study that should be highlighted. Although there were group differences for life satisfaction scores, the effect size of this analysis was very small, suggesting that further research is required to better

understand why parents of children with ASD may have lower life satisfaction levels. However, similar to previous studies (e.g., Schulz & Sherwood, 2008), higher parental stress correlated with lower life satisfaction in all groups.

Although age did not relate to parental stress levels in either of the groups, it is likely that parents experience more stress during particular times of their child's development, such as the child's transition from primary to secondary school or due to medical related problems arising. While there have been a few studies that have examined parental stress during these transition periods for children and young adults with ASD (Dillon & Underwood, 2012; Makin, Hill & Pellicano, 2017), there is a lack of information about these transition periods and the effects on parental stress in WS and DS. In addition, the current results should be replicated in future studies as stress levels may be time sensitive and influenced by one-off events. Therefore, further studies are required to provide a better understanding of when parents of children with developmental disorders perceive elevated stress levels.

One of the strengths of the current study was that it mainly included mothers who were educated to degree level or above, which reduced the possibility that our findings were influenced by differences in socioeconomic status (SES) in the groups, further research should be done with parents with lower education levels in order to see if the current findings replicate with different SES groups.

Finally, the fact that the number of challenges identified by the parents, an unvalidated list put together for this study, was used as a proxy for syndrome severity may have restricted the scope for strong findings. For example, it is likely that the severity of the child's emotional and behavioural difficulties, rather than whether or not parents found this aspect of their child's disorder challenging, relates to parental stress above and beyond the child's diagnosis (Griffith et al., 2011b). This may be

especially true for the ASD group as no relationship between the number of challenges and stress levels were found for this group in contrast to the WS and DS group.

Conclusions

In sum, the current study included a large sample of children with a rare disorder and showed that, in contrast to previous studies, parents of children with a rare neurodevelopmental disorder, WS, are not more stressed than those with more common disorders, such as DS and ASD. However, further examination of parental stress showed significant group differences concerning the factors that may relate to increased or reduced parental stress, suggesting that the cause of parental stress in neurodevelopmental disorders is syndrome specific. These findings allow for a more complex theoretical model of factors that impact on parental stress to be developed.

However, further longitudinal research is required to clarify the causal relationship between individual and external factors and parental stress. In addition, longitudinal research can also provide further insight into the developmental changes that occur in the relationship between child characteristics, contextual factors, and parental stress.

Still, the current results suggest that clinical services and practical solutions aiming to support parents of children with neurodevelopmental disorders should be specific to the developmental disorder. Evidence based interventions could provide directed and efficient support for parents in response to the concerns specific to their child's neurodevelopmental disorder. For example, drawing from the current findings, parents of children with WS could be provided with information packs to give to professionals working with their children to help reduce stress about professionals' lack of knowledge about WS, whilst providing parents of children with ASD with

information about how they can access professional support may help reduce parental stress. In addition, the results offer further insight for SEN policy and support in that all parents worry about their child's future and would benefit from improved adult specialist services.

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Table 1.

Demographic information (child's age and gender) and mean scores (and standard deviations) for parental stress (GSSS), life satisfaction (SWLS), number of siblings (Siblings), Parental support (Support), and number of challenging aspects (Challenges) reported by syndrome group.

	Williams syndrome	Down syndrome	Autism Spectrum Disorders	Group difference
	Mean (SD) [Range]			
Child's age (years;months)	11;9 (5;9) [0;11-25;9]	10;10 (4;11) [2;6-23;5]	12;7 (4;2) [4;9-23;3]	*F(2, 168.071) = 2.660, p = .073*
Child's gender	53% female	46% female	21% female	χ^2 (2, 225) = 14.21, *p* = .001 WS = DS > ASD
GSSS score	21.40 (10.06)	20.37 (9.55)	21.28 (9.93)	N/A
SWLS score	22.24 (7.75)	20.25 (6.80)	17.08 (7.53)	*F*(2, 260) = 10.894, *p* < .001, η_p^2 = .078 WS > ASD ** DS > ASD*
Siblings	1.50 (1.25)	1.58 (1.29)	1.30 (.81)	N/A
Support	2.69 (.68)	2.54 (1.05)	2.67 (.76)	N/A
Challenges	10.11 (4.34)	8.04 (3.50)	6.87 (3.22)	*F*(2,165.408) = 16.251, *p* < .001, ω^2 = .11 WS > ASD ** WS > DS **

Table 2.

Mean scores (and standard deviations) for all 14 GSSS items on the parental stress questionnaire by syndrome group; Williams syndrome (WS), Down syndrome (DS), and Autism Spectrum Disorders (ASD).

GSSS Item	WS	DS	ASD	Item*Group
1. Not having access to professionals who have knowledge about my child's condition	1.55 (1.15)	1.55 (1.06)	1.94 (1.14)	ASD > WS*, DS*
2. People staring when I go out in public with my child	1.21 (1.04)	1.19 (1.00)	1.34 (1.02)	-
3. Getting my child's complex needs met through social services	1.52 (1.30)	1.42 (1.23)	1.39 (1.36)	-
4. The large amount of effort required to help my child reach developmental milestones (e.g., sitting up, self-feeding)	1.84 (1.00)	1.82 (0.89)	1.19 (1.10)	ASD < WS***, DS***
5. Having to be constantly vigilant about my child's state of health in case of a sudden change	1.57 (1.09)	1.40 (1.20)	1.51 (1.28)	-
6. Going to see professionals who are not knowledgeable about my	1.80 (1.09)	1.48 (1.12)	1.39 (1.28)	WS > ASD*

child's genetic syndrome				
7. Arranging care (e.g., babysitting, respite) that is suitable for my child	1.74 (1.17)	2.00 (1.09)	2.03 (1.14)	-
8. An educational placement that does not meet all of my child's needs	1.19 (1.25)	1.24 (1.24)	1.58 (1.34)	WS < ASD*
9. Sleep deprivation, due to my child's sleeping patterns	1.40 (1.11)	1.81 (1.13)	1.57 (1.15)	-
10. A genetic diagnosis causing tension within the immediate and extended family	0.88 (1.11)	0.73 (1.08)	0.64 (1.01)	-
11. Not being able to fully relax at home, as I need to attend to my child 24 hours a day	1.50 (1.14)	1.81 (1.09)	1.55 (1.06)	-
12. Having to explain my child's condition to new people I meet	1.43 (0.97)	1.22 (1.00)	1.49 (1.04)	-
13. Having to make extensive preparations for my child before leaving the house	1.41 (1.06)	1.52 (1.06)	1.52 (1.09)	-
14. Worrying about the future for my child because of the lack of specialist services once they reach adulthood	2.41 (0.81)	2.37 (0.85)	2.40 (0.92)	-

Note. *$p < .05$, **$p < .01$, ***$p < .001$

Table 3.

List of challenges and number of parents who identified this challenge for either child per group.

		Group			
		WS	DS	ASD	
Challenge		%	%	%	Group difference
Anxiety	No	25	52	47	χ^2 (2, 254) = 16.109, p < .001
	Yes	75	48	53	WS > DS =ASD
Attention	No	14	39	47	χ^2 (2, 254) = 25.420, p < .001
	Yes	86	61	53	WS > DS =ASD
Balance	No	48	78	91	χ^2 (2, 254) = 41.976, p < .001
	Yes	52	22	9	WS > DS = ASD
Coordination	No	45	68	83	χ^2 (2, 254) = 28.323, p < .001
	Yes	55	32	17	WS > DS = ASD
Eating	No	57	74	80	χ^2 (2, 254) = 11.794, p = .003
	Yes	43	26	20	WS > DS = ASD
General Learning difficulties	No	17	26	68	χ^2 (2, 254) = 54.697, p < .001
	Yes	83	74	32	WS = DS > ASD
Fine motor skills	No	20	38	58	χ^2 (2, 254) = 27.167, p < .001
	Yes	80	62	42	DS > WS > ASD
Gross motor skills	No	60	79	91	χ^2 (2, 254) = 24.328, p < .001
	Yes	40	21	9	WS > DS = ASD
Health	No	71	79	92	χ^2 (2, 254) = 11.746, p = .003
	Yes	29	21	8	WS = DS > ASD
Hearing difficulties	No	80	78	96	χ^2 (2, 254) = 11.553, p = .003
	Yes	20	22	4	WS = DS > ASD
Mental health	No	80	88	74	χ^2 (2, 254) = 5.284, p = .071
	Yes	20	12	26	
Communication	No	51	18	46	χ^2 (2, 254) = 22.022, p < .001
	Yes	49	82	54	DS > ASD > WS
Language comprehension	No	43	38	63	χ^2 (2, 254) = 11.443, p = .003
	Yes	57	62	37	WS = DS > ASD
Personal hygiene	No	50	66	74	χ^2 (2, 254) = 10.682, p = .005
	Yes	50	34	26	WS > DS =ASD
Reading difficulties	No	44	66	80	χ^2 (2, 254) = 25.730, p < .001
	Yes	56	34	20	WS > DS > ASD
Sensory issues	No	54	53	47	χ^2 (2, 254) = .945, p = .623
	Yes	46	47	53	

Social abilities	No	47	49	47	χ^2 (2, 254) = .142, p = .931
	Yes	53	51	53	
Visual difficulties	No	82	78	92	χ^2 (2, 254) = 6.034, p = .049
	Yes	18	22	8	WS = DS > ASD
Writing difficulties	No	22	44	61	χ^2 (2, 254) = 27.824, p < .001
	Yes	78	56	39	WS > DS > ASD
Other	No	96	94	100	χ^2 (2, 254) = 4.804, p = .091
	Yes	4	6	0	

Table 4.

Correlation matrix of stress and satisfaction with individual and contextual factors for WS, DS and ASD.

	1			2			3			4			5			6		
Variables	WS	DS	ASD	WS	DS	ASD	WS	DS	ASD	WS	DS	ASD	WS	DS	ASD	WS	DS	ASD
1. GSSS	-	-	-															
2. SWLS	-.28**	- .33**	- .35**	-	-	-												
3. Age of child (months)	-.02	-.19	-.15	-.07	-.03	-.01	-	-	-									
4. No of challenging aspects	.38***	.32**	-.08	-.07	-.06	.10	.15	.05	.02	-	-	-						
5. No. of siblings	-.02	-.25*	.05	.26**	-.02	-.01	-.04	.06	.07	-.00	-.23*	-.11	-	-	-			
6. Support	.04	.02	.08	.01	-.04	.07	.06	-.02	-.07	-.01	.05	.15	-.13	-.02	-.12	-	-	-

Note. n= 109 (WS), n= 80 (DS), n= 79 (ASD), *p < .05, **p < .01, ***p < .001