Exploring Parental Stress And Sleep Deprivation In Parents Of Children With And Without Autism.

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ABSTRACT

The main aim of this study was to explore and assess parental stress and sleep deprivation in parents of children with (N=228) and without autism (N=111), and to investigate if factors such as the Childs language (verbal/non-verbal) and behaviour (challenging behaviour/no challenging behaviour) had an impact on parental stress and sleep within the population of parents of children with autism. Questionnaires were distrusted online which consisted of 3 scales, The Perceived Stress Scale (PSS) measuring stress levels, the Pittsburgh Sleep quality (PSQI), and the Epworth Sleepiness Scale (ESS) in order to measure sleep deprivation .Demographics questions on the child's language and behaviour were asked as a parental report measure.

Results from correlation analysis and independent t-tests found that parents of children with autism reported higher levels of stress, higher levels of daytime sleepiness, and poorer levels of sleep quality than parents of children without autism. Parental Stress and Sleep deprivation were associated with one another, Parents of children with autism who display challenging behaviours reported higher levels of stress than parents of children with no challenging behaviours, Parenting a child with autism who is verbal/nonverbal had no significant difference in parental stress, and lastly Parents of children who have autism that also have reported challenging behaviour had no significant impact on daytime sleepiness in parents.

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INTRODUCTION

Parental stress is a normal part of the parenting experience. Parenting/parental stress has been defined over the years as a difficulty parents may feel or experience while raring their children (Abidin, 1995, 1992; Reitman, Currier, & Stickle, 2002). According to Deater-Deckard (2004) at some stage in life all parents or individuals who have primary care responsibility for raising a child will experience a level of stress as they attempt to meet the needs and challenges of caring for their children. This includes parental employment, child social, cognitive and physical development and parental mental health. A more recent definition of parental stress stated by Pontoppidan, Nielsen & Kristensen (2018) consists of parental stress being a set or processes that may lead to unpleasant physiological and psychological reactions that arise from attempts to meet the demands of parenthood. Parenting stress in a key construct in family functioning and parent behaviour, this has been associated with children's behavioural adversity and child negativity (Piskernik, Supper & Ahnert, 2018).

Minor everyday stressors are increasingly affecting the psychological wellbeing and health of individuals (Bolger, DeLongis, Kessler & Schilling, 1989). High levels of parenting stress can be particularly concerning with its association to a number of undesired outcomes (Neece, 2013). These outcomes include martial conflict (Suárez, Baker & Suarez, 1997; Kersh et al., 2006) parental depression (Deater et al., 1998; Hastings et al., 2006), less effective parenting (Coldwell et al. 2006; Crnic et al. 2005) and, poorer physical health (Eisenhower, Baker & Blacher, 2009). Due to the severity of these outcomes parenting stress should be an important area of research.

Findings have confirmed that emotionally stressful daytime events have an impact on an individual's sleep quality and well-being. However, this is a two-way relationship not only does daytime events affect sleep, sleep quality and the amount of sleep an individual gets is an important factor in how they feel and cope with emotionally stressful events or challenged that arise of the next day. (Vandekerckhove & Cluydts, 2010). Poorer sleep quality has been found to not only contribute to the occurrence of stressors but also to reduce the ability to cope with them. (Doane & Thurston, 2014)

Sleep deprivation which is more commonly known as insufficient sleep refers to the condition of not getting enough sleep. The level of sleep deprivation can vary from acute to chronic. Sleep is a repetitive active and reversible behaviour which serves for several different functions such as growth and repair restorative processes and learning/memory consolidation, which all occur throughout both the body and the brain. Hence during sleep physiological, neuro-cognitive and behavioural processes occur and these are subjective to impairments by the loss of sleep (Curcio, Ferrara & Degennaro, 2006). Sleep loss has been in fact stated as being one of the most widely known problems in modern society (Kryger, Roth & Dement, 2000), with poor sleep quality being highly associated with parental stress (Gallagher, Phillips & Carroll, 2009). Parents sleep routine is scheduled around their infants sleep and majority of the time while their infant is sleeping throughout the day their attending to other activities, they may not of being able to juggle while their child is awake. Unfortunately sleep deprivation can have a very of consequences such as impairments in psychomotor and neurocognitive performance and sleepiness (Pilcher & Huffcutt, 1996). Overall Parenting or

primary caregivers are exposed to both stress and sleep loss when caring and meeting the demands of parenthood.

Autism

The Understanding and study of autism has greatly developed over recent years and to date has become an emerging area of research in numerous scientific fields. Modern day definitions define autism as a lifelong neuro development disorder that affects one's brain developments is specific areas such as communication and social interaction ("Autism.ie", 2018). Mechler, Hoffmann, Dittmann and Ries (2016) gave a more in-depth definition of autism stating that it is a disorder that is characterised by persistent deficits in interaction and social communication that is persistent across various contexts in combination with repetitive/ restricted patterns of behaviours and interests.

Autism is known as a spectrum disorder due to its wide variation in the severity and type of symptoms individuals experience. The core symptoms that usually begin in early childhood if recognized early are Restricted, repetitive behaviours which would include repetitive body movements such as running back and forth spinning or rocking, having an extreme or narrow interest in specific topics or things, ritualistic behaviour which includes lining up objects or setting order to objects with colours or numbers, and social communication challenges which include the misunderstanding or appropriate use of spoken language, this depends whether or not the induvial or child is verbal or nonverbal, Gestures, and eye contact. There is a checklist of criteria within these two categories that specialised health professions use to diagnose and asses the individual's symptom severity ("Autism Speaks", 2019) in addition to evaluating the two core domains the DSM-5 specifies whether

or not language deficits or intellectual impairments are present in the characterization of ASD (Ousley & Cermak, 2013).

Standardised assessment that were conducted on individuals with ASD found that one third or more of individuals with an ASD diagnosis also meet the criteria for a formal ADHD (Attention deficit hyperactivity disorder) diagnosis (van Steensel, Bögels & de Bruin, 2012). Researchers also found that a number of young children who had ASD present difficult to manage behaviour and these behaviours become more opposing and defiant as they grow into childhood and adolescents (Barnevik Olsson et al., 2017; Estes et al., 2013;). Anixety symptoms also co-occur in ASD and are a top treatment concern of clinicians and parents (Coury et al., 2012) as well as impairments in controlling incoming sensory input/information. (Tomchek & Dunn, 2007) Autism is still a major interest through numerous fields of research, and it has been stated as perhaps being the most prolifically studied of all child psychiatric conditions/disorders (Wolff, 2004).

Parental stress and autism

As previously discussed, parental stress in small dosages is normal within the parenting experience (Abidin, 1992, 1995; Reitman, Currier, & Stickle, 2002). However, when looking at the specific population of parents of children with autism different aspects such as the child's abilities are increasingly relevant to how much stress a parent may be exposed to as a result of trying to meet the extra demands and needs of the child. Factor, Swain and Scarpa (2017) state that caregivers of children with autism report greater levels of stress due to the unique requirements and parenting demands. This could be the case due to more complex teaching methods. For example, if the child is non-verbal, they may need to be thought

different ways of communication such as PEC cards. PECS (picture exchange communication system) are used in order to help the child convey their needs and thoughts.

Davis and Carter (2008) also found that other secure factors that are associated with parental stress in parents of children with autism are communication and cognitive functioning deficits. Another study conducted by Phetrasuwan and Shandow Miles (2009) found that a primary source of parental stress in mother of children on the autistic spectrum were behavioural symptoms. Child behavioural problems were also determined as a leading factor in parenting stress in a study done by Hastings (2002).

Exploring parental stress in parents of children with and without autism

A more recent and up to date study conducted by Keenan, Newman, Gray and Rinehart (2016) focused on how parents of children with ASD/ autism experience greater stress, psychological distress and attachment-related anxiety. They focused on this population by using a comparison control group of parents with 'Typically developing' children. It was concluded from this study that caregivers of children with autism did report higher levels of stress and attachment anxiety than parents of children without. Another Study conducted by Craig and colleagues (2016) assessed parental stress amongst different groups of parents with different neurodevelopmental disorder (ASD, Attention deficit hyperactivity and language disorders) and a control group in order to explore differences between all groups. Results of this studied found that parents of children with autism/autistic spectrum disorders and attention deficit hyperactivity disorder reported feeling the most stressed. Another study that was conducted around the same time by Hutchison and colleagues (2016) also concluded that

Parents of children with autism and Attention deficit hyperactivity disorder are exposed and experience more parental stress than parents of typically developing children.

Parental sleep deprivation and stress in parents of children with autism

In a report focused on parental sleep deprivation amongst parents of children with autism by Meltzer (2007) consisted of assessing 57 parents sleep using 7-day sleep diaries and an Actimetry sensor which was worn by parents for 1 week. Results were then compared to a control group of parents of children without autism. Results of this study showed very poor sleep and significant different in sleep patterns of parents of children with autism. In addition, this study also found that parents of children with autism have completely different sleep patterns, with a shorter total sleep time and an earlier wake time than parents of TD children. Reasons behind this vary, many studies however believe that children with Autism have disruptions in GABA and melatonin. Which both regulate sleep (Bonuck & Grant, 2012). Several studies highlight the abnormal melatonin regulation in autism spectrum disorders (Bruni et al., 2015; Nir et al., 1995; Tordjman et al., 2005). Therefore, sleep disturbances or problems sleeping that affect a child with autism will ultimately affect the parents/caregivers also due to parental requirements.

Language/communication in children with autism and how it affects parents

Understanding human communication is central to theory and clinical practice within the field of autism. Language and communication play significant roles in various points in understanding the development of someone with autism. Short and Schopler (1988) stated that for parents of children with autism first initial concerns that there might be delayed developmental factors would be when there are early delays in the development of speech.

Language fluency and flexibility of expressive language are important factors when it comes to underlying the dimensions distinguishing between 'high- functioning' and 'low-functioning' autism in children of school age (Tager-Flusberg, Paul & Lord, 2013). Nonverbal autism is a subset of individuals on the autistic spectrum who have little to no speech at all, some individuals/ children however do tend to communicate using gestures or facial expressions. Communication and language are subjected to developmental delays when an individual has autism. However, this doesn't necessarily mean they can cannot later in life develop a better grasp of language and speech.

Although it is evident that there is a lot of research that focuses on language deficits and communication aspects within the autistic spectrum, (Lord, Cook, Leventhal & Amaral, 2000; Luyster, Kadlec, Carter & Tager-Flusberg, 2008) there is a lack of how these factors affect parents and their parental stress. A study conducted by Bebko, Konstantareas and Springer (1987) concluded that language impairments are a significant and stressful factor for parenting a child with autism. This could be due to the different teaching and learning techniques such as PECS that parents may need to learn and learnt their children to use daily in order to try and understand their needs and wants. Stress may arise when the parents cannot pin point what the child needs or wants and both the child and parent can become flustered. A more recent study conducted by Estes et al (2009) mentions how deficits in language and communication may pose difficulties and stress for mothers.

Challenging behaviour in children with autism and how it affects parents

Children with autism tend to display high rates of challenging behaviours that can impair functioning (Stadnick, Chlebowski & Brookman-Frazee, 2017). Challenging behaviours include what could be considered physically aggressive behaviour but can also

include any other behaviours if they have a negative effect on both the person and their family, for example physically challenging behaviours could be anything from biting to spitting to hair pulling. Other challenging behaviour includes pica, or self-injury. There are numerous reasons for a child with autism to be displaying these behaviours, these include having difficulty in processing incoming information, over or under sensitivity to sensory stimuli or a change in routine. They could be also be a result of a physical reason like feeling sick, hungry or tired but being unable to communication properly or explain these symptoms can lead to anger and frustration for the child ending in an outburst of challenging behaviours ("Challenging behaviour - National Autistic Society", 2019). These behaviours can all affect parental stress and sleep deprivation as parents are trying to juggle and meet the demands of caring for their child alongside trying to handle and managing any outburst of challenging behaviours. It may also be stressful for a parent whose child is nonverbal as they cannot simply ask them what is wrong and ask them what they want or need.

Rationale

When reviewing previous literature conducted on autism and parental stress and sleep deprivation, it is evident that although there is a lot of research into the understanding of autism and the autistic spectrum ("Autism.ie", 2018; Frith, 2003; Hobson, 1993; Mechler et al., 2016), as well as parental stress (Abidin, 1995, 1992; Deater-Deckard, 2004; Reitman, Currier, & Stickle, 2002). there is however little research focused on parental sleep deprivation. As previous stated according to Vandekerckhove and Cluydts (2010) the amount of sleep an individual gets will impact how they cope or deal with stress that arises the next day. Having a good sleep and being a good sleeper may affect the way the individuals deal and cope with stress and stressful events that arise in the next day as opposed to poor sleepers

(Doane & Thurston, 2014). There is also very limited research on how a child's language can affect a parent's exposure to stress and how challenging behaviours (e.g. Head banging, hair pulling, throwing items, spitting, biting, kicking to themselves or others) displayed by the child can affect a parents' sleep and stress. Another gap in the literature is that there hasn't been any focus on the relationship between parental stress and sleep deprivation in parents of children with autism. Interest should be focused on these topics/factors as measuring and monitoring the amount of stress and levels of sleep quality parents of children with autism are subjected to could initially raise more awareness on the area and in turn make way for more in dept research and studies to be conducted , to better understand the underlying factors of parental stress and sleep deprivation within this population of people.

Research aim's and Hypotheses

The main aims of this research are to asses parental sleep deprivation and parental stress in parents of children with autism. This includes investigating whether or not factors such as the child's language and behaviour coincide to parental stress and sleep deprivation. In order to explore sleep deprivation, daytime sleepiness and sleep quality will be assessed. In order to carry out this study three questions were formulated;

Q1- are parents of children with autism exposed to higher levels of stress and sleep deprivation than parents of children without autism. In regards to this question 3 hypothesis were generated, [H1]-parents of children with autism report higher levels of stress than parents of children without autism , [H2]-parents of children with autism report higher levels of daytime sleepiness than parents of children without autism, and lastly [H3]-parents of

children with autism report poorer levels of sleep quality than parents of children without autism.

Q2- is there a significant correlation between parental stress and parental sleep deprivation. To asses this question two hypotheses were generated, [H4]- parents who report high levels of stress also report high levels of daytime sleepiness, and [H5]- parents who report high levels of stress also report low levels of sleep quality.

Q3-Does the behaviour and language of a child who has autism impact parenting stress and sleep. In order to asses this question three more hypotheses were generated, [H6]- parents of non-verbal children with autism report higher levels of stress than parents of verbal children with autism, [H7]- parents of children with reported challenging behaviours display higher levels of stress than parents that did not report any challenging behaviours(behaviours listed above), and lastly [H8]- Parents of children with reported challenging behaviours report higher levels of daytime sleepiness than those who do not report any challenging behaviours. These questions will be addressed by using a control group of parents of children without autism.

METHODS

Participants

This current study targeted two groups of parents with children under the age of 18. A data collection from 350 participants was analysed and 11 of these participants were excluded, ten of which were due to their children not meeting the age criteria and 1 due to medical reasons. The total number of participants included in data analysis was 339. The first group of participants being the parents of children with autism (N=228) and the second being parents of children without autism (N=111). Participants were recruited online through social media and invited to voluntarily complete a questionnaire. There was no payment for completion. Out of the total 339 participants 89.1% of them were female (N=302) and only 10.9% of were male (N=37). Convenient and snowball sampling was used in order to recruit participants so there were no biases. This gender difference is just a result of more females voluntarily participating in this study by completing the online questionnaire distributed online. This was done by posting the link to an online survey online and into suitable parenting group pages online. The parents were asked to complete a survey which also consisted of them answering questions on their child's characteristics.

Design

This current research design is a cross-sectional, between groups quantitative study. This study is a comparative study between two groups of individuals the first group being parents of children with autism and the second being a control group of parents of children without autism. This was done to enable sufficient examination of the relationship between variables. These variables consist of parental stress, sleep quality, daytime sleepiness, language and behaviour. To examine these different variables and their relationship between each other a quantitate study was necessary as this study involves correlating and testing

variables against each other. The survey opens with demographic questions which consist of asking them their gender and if their child has autism. Whether they clicked yes, or no separate questions were made available in order to screen for any implications within the control group.

When assessing and testing the eight generated hypotheses the main Independent Variables were, whether or not the child has Autism, Language, and Challenging behaviours and the main Dependent variables were, Stress, Sleep quality, and Daytime Sleepiness

Materials

In order to conduct this study 3 scales and 6 demographic questions where used to generate the completed. Demographic Questions included: Gender of the participant, the child's age, whether or not the child had autism, and a parental report on the language and behaviour of the child. The first scale that was used was the 'Perceived Stress Scale' (PSS) which was published by Cohen, Kamarck, and Mermelstein, (1983) and has been stated as being one of the most popularly used instruments is psychology for measuring general perceived stress (Lee, 2012). The PSS is used to measure perceived stress of individuals in different situations. The re-test reliability and validity of the PSS has been universally studied to be significant in numerous studies (Chiu et al., 2016; Cohen, Kamarck & Mermelstein, 1983; Ivarsson, Lindström, Malm & Norlander, 2011; Lee & Jeong, 2019; Lee, 2012; Sun, Gao, Kan & Shi, 2018). Total PSS scores were attained by adding up all items. Items 4,5,7, and 8 required reverse coding. The higher the total score the higher perceived stress. The PSS was then broken down into three level scores from 0-10 indicating low stress, 11-21 indicating moderate stress, and 22-32 indicating high stress. Analysis on the internal validity of this scale yielded a Cronbach Alpha of (α=0.43).

The second scale used was the 'Pittsburgh Sleep Quality Index Scale' (PSQI) which was developed by Buysse and colleagues in 1988 to create a standardised measure to collect information about individual's quality and patterns of sleep using a self-rated question (Buysse, Reynolds, Monk, Berman & Kupfer, 1989). This scale includes 19 self-rated questions which are then generated into seven components scores which: Subjective sleep quality, sleep duration, habitual sleep efficiency, sleep disturbances, sleep latency, daytime dysfunction, and use of sleep medication. Component scores ranging from (0-3) were then added to provide a global sleep quality score. Global scores ranged from (0-21) with scores greater than 5 indicating poor sleep quality (Fontes et al., 2017; Zhong, Gelaye, Sánchez & Williams, 2015). The re-test reliability of the PSQI was represented in a study conducted by Backhaus, Junghanns, Broocks, Riemann and Hohagen, (2002) where they tested insomnia patients against a control group of healthy participants twice and got an overall global PSQI score correlation coefficient for test-retest reliability of (.87). This study proves high re-test reliability of the PSQI. Analysis on the internal validity of this scale produced a desired Cronbach alpha of (α= .70).

The final scale used within this study was the Epworth Sleepiness Scale (ESS) which was developed in 1991 by Johns Murray (Johns, 1991). The ESS is a self- reported 8 question scale that's measures participants daytime sleepiness. Participants were asked to score their chances of falling asleep or dozing off on a 4-point scale ranging from (0-3) 0 being 'no chance of dozing' to 3 being 'high chance of dozing' while engaged in 8 different situations. All 8 item scores were added together to produce a total ESS score which ranged from (0-24) The higher the total score was the higher that person average daytime sleepiness or Sleep Propensity was in daily life. Numerous Studies have rated the re-test reliability of the ESS as Sufficient and rate it as moderate- good (Nguyen et al., 2006; Kendzerska, Smith,

Brignardello-Petersen, Leung & Tomlinson, 2014). This current study produced a strong internal validity score of (α=.82).

Procedure

This study was developed with the Psychological Society Of Ireland ‘s code of ethics in mind throughout and then received ethical approval from the NCI board of ethics before conduction. A questionnaire was then generated which consisted of demographic question which screened for variables such as language and behaviour in both children with and without autism. These questions that involved the children were self-reported by parents for ethical reasoning. There were also three scales present within the questionnaire to collected data on the sleep quality and stress levels of the parents, these were the ‘Perceived stress scale, the Perceived sleep quality index scale and the Epworth sleepiness scale’.

After generating the questionnaire on google docs, it was then distributed online into different social networks and online group pages for parents of both children with and without autism. The option to share the link and questionnaire was made available and the link included the title of the study and that is was completely voluntarily based. If participants choose to engage in this study they clicked onto the link where they were presented with an information sheet which included all aspects of this study, the purpose behind it, instructions in how to take part, the confidentiality of this study, how their data will be kept safe and they were once again informed it was completely voluntarily based. To continue they had to give consent to participate by clicked a box presented to them which stated “I have read the terms and conditions of this study and I agree to take part” after this the rest of the questions and questionnaire was made available for them to answer.

After submission they were presented with a debriefing sheet which included online support groups for both groups of parents to find support or seek help if needed or if they felt in anyway distressed after taking part in this study. contact information was also made available for them if they wished to seek future information about this study. Coming up to the end of data collection the link was shared once again letting people know that it will no longer be accessible in a weeks' time and if they wished to take part to do so before closing date, to ensure everyone who wished to participate got the chance. After the questionnaire was no longer made available, all the data was analysed, and all suitable responses were organised and prepared to undergo statistical testing and analysis.

Data Analysis

In order to test the 8 generated hypotheses different forms of analysis will be used. Hypotheses [1, 2, 3, 6, 7, & 8] will be tested using Independent T-tests to determine where or not there is a statistically significant difference between the two groups. Due to the nature of this study and the two different groups an independent t test is fit to use as it compares mean score between two groups of people. Hypotheses [4 & 5] will be tested using correlation analysis. to determine the direction and strength of the relationship between the variables. A correlation coefficient will also be calculated to express the nature of the relationship.

RESULTS

Descriptive Statistics

Frequency analysis conducted across all categorical variables highlighted that nearly 90% of the participants were female, majority of the population had a child with autism with a little over half the percentage being verbal, and over half of the population reported that their child engaged in challenging behaviour. A large majority of parents of a child without autism reported no language impairments. Refer to (Table 1) below for detailed analysis.

Table 1 - Frequencies for the current sample of Parents of children with and without autism on each demographic variable (N=339)

Variable	Frequency	Valid Percentage
Gender		
Male	37	10.9
Female	302	89.1
Autism		
Autism	228	67.3
No Autism	111	32.7
Language		
Verbal	136	59.6
Non-Verbal	92	40.4
Impairments	23	20.7

No Impairments	88	79.3
Behaviour		
Challenging Behaviour	177	52.2
No Challenging Behaviour	162	47.8

Frequency analysis on sleep quality displayed that the data consisted heavily of bad sleepers. See (Table 2) below for a detailed representation of data.

Table 2- Frequency of good and bad sleepers (N=313)

Groups	Frequency	Valid Percentage
Good Sleepers	34	10.9
Bad Sleepers	279	89.1

Descriptive analysis conducted on all 339 participants across all continuous variables provided the following information. As can be seen in (Table 3), out of the whole population the average age of the child reported by the parent was 7 years old, Parents reported average moderately high means with regard to the range of stress levels, similarly parents reported moderately high poor levels of sleep quality, and the average score in regard to levels of daytime sleepiness the parents felt were low in regards to the range.

Table 3 – Descriptive statistics for all continuous variables

	Mean (95% Confidence Intervals)	Std. Error Mean	Median	SD	Range
AGE	7.53	.22	7.00	4.10	1- 18
PSS	15.85	.23	17.00	4.24	0-24
PSQI	10.78	.22	11.00	3.84	2-19
ESS	8.67	.29	8.00	5.36	0-22

Descriptive analysis conducted on all continuous variables within the group of parents of children with autism provided the following information; the average age of the child was 7, parents scored high average levels of stress and poor levels of sleep quality, and a moderate average level of daytime sleepiness in regard to the ranges. (see table 4)

Table 4 -Descriptive statistic for all continuous variables within the population of parents of children with autism (N=228)

	Mean (95% Confidence Intervals)	Std. Error Mean	Median	SD	Range
AGE	7.52	.27	7.00	4.09	2-18
PSS	16.94	.22	17.00	3.28	5-24
PSQI	11.70	.24	12.00	3.51	2-19

ESS	9.39	.36	10.00	5.49	0-22

Descriptive analysis conducted on all continuous variables within the group of parents of children without autism provided the following information; the average age of the child was 7, parents scored moderate levels of stress with a high standard deviation, Parents average sleep quality was poor, and they scored a low average level of daytime sleepiness in regard to the ranges. (See table 5)

Table 5- Descriptive statistics for all continuous variable within the control group of parents of children without autism (N=111)

	Mean (95% Confidence Intervals)	Std. Error Mean	Median	SD	Range
AGE	7.56	.39	7.00	4.13	2-17
PSS	13.59	.48	14.00	5.05	0-22
PSQI	8.85	.38	8.00	3.80	2-17
ESS	7.18	.45	6.00	4.76	0-20

In order to determine whether or not data for all continuous variables were parametric or non-parametric a test of normality was conducted which produced p values of <.05 Indicating non- normally distributed data across all variables. Non-normative data required the employment of non-parametric measures of testing. The non-parametric measure for Correlation was Spearman Rho and the non-parametric measure for Independent T-tests was Mann- Whitney U- test.

Inferential statistics

The relationship between Stress and Sleep quality was investigated using Spearman Rho correlation. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a moderate, positive correlation between the two variables (r = .33, n = 313', p < .01). This indicates that the two variables share approximately 11% of variance in common. Results indicate that higher levels of stress are associated with poorer levels of sleep quality.

The Second relationship that was investigate using Spearman Rho correlation was Stress and Daytime sleepiness. Preliminary analyses were once again performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There was a moderate positive correlation present between the two variables (r = .22, n = 339', p <.01). This indicates that the two variables share approximately 5% variance in common. Results indicate that higher levels of stress are associated with higher Daytime sleepiness. See Table 6

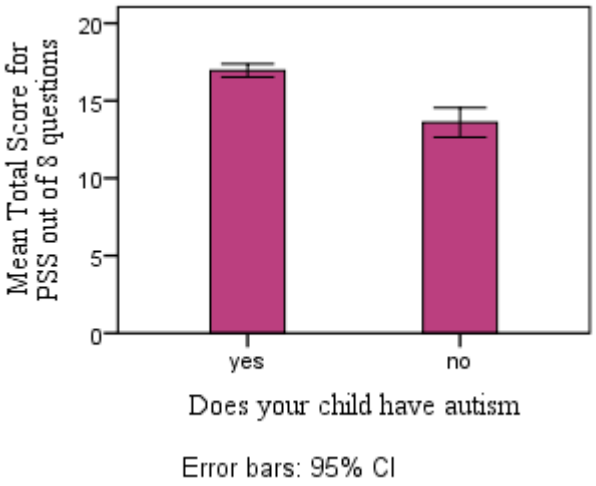
Table 6 – Correlation between continuous scale variables

Variables	1	2	3
1. Stress	1		
2. Sleep quality	.33**	1	
3. Daytime sleepiness	.22**	.24**	1

Note. Statistical significance: *p < .05; **p < .01; ***p < .001

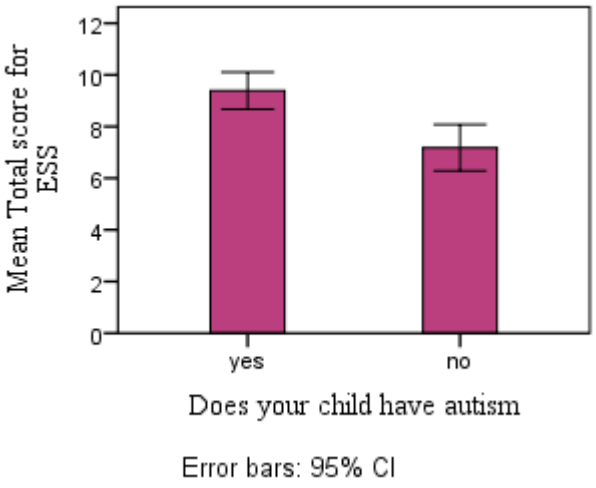
A Mann- Whitney U-test was conducted to compare levels of stress between parents of children with and without autism. As can be seen in (figure 1A), there was a significant difference in scores U= 7762, p <.05) with parents of children with autism (M = 16.94, SD = 3.28) scoring higher than parents of children without autism (M = 13.59, SD = 5.05). The magnitude of the differences in the means (mean difference =3.35) was medium (Cohen's d = .79).

Figure 1A- Bar chart displaying the significant difference in stress levels of parents of children with and without autism.



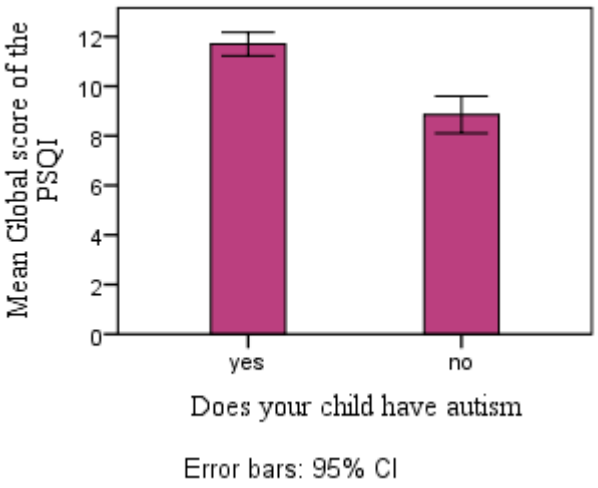
A Mann- Whitney U-test was conducted to compare levels of Daytime Sleepiness between parents of children with and without autism. As can be seen from (figure 1B), there was a significant difference in scores U= 9656, p <.05) with parents of children with autism (M = 9.39, SD = 5.49) scoring higher levels of daytime sleepiness than parents of children without autism (M = 7.18, SD = 4.76). The magnitude of the differences in the means (mean difference =2.21) was small (Cohen's d = .43).

Figure 1B – Bar chart displaying the significant difference in levels of daytime sleepiness in parents of children with and without autism.



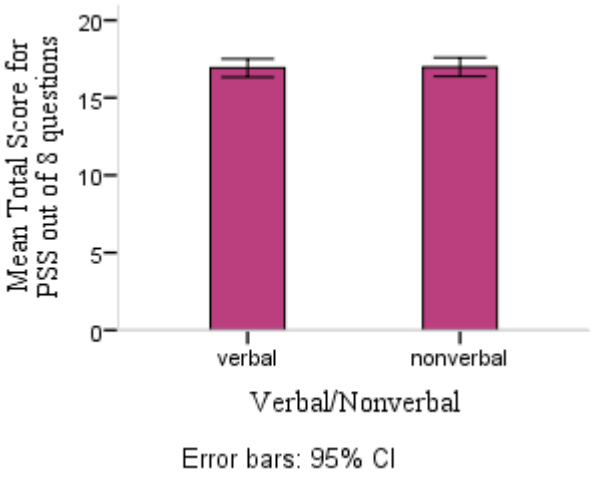
A Mann- Whitney U-test was conducted to compare levels of Sleep quality between parents of children with and without autism. As can be seen in (Figure 1C) there was a significant difference in scores U= 6242, p <.05) with parents of children with autism (M = 11.70, SD = 3.51) scoring poorer levels of sleep quality than parents of children without autism (M = 8.85, SD = 3.80). The magnitude of the differences in the means (mean difference =2.85) was medium (Cohen's d = .79)

Figure 1C- bar chart displaying the Significant difference in levels of sleep quality in parents of children with and without autism. Higher scores on the PSQI indicate Poorer levels of sleep quality.



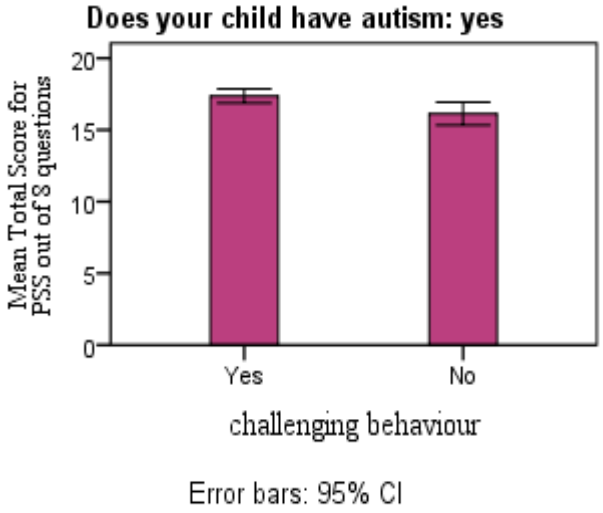
A Mann- Whitney U-test was conducted to compare levels of Stress between parents of children with Autism who are Non- verbal and verbal. As can be seen from (figure 1D) there was no significant difference in scores U=6086, p >.05) with parents of children with autism who are verbal (M = 16.92, SD = 3.51) scoring similar stress levels to parents of children with autism who are Non-Verbal (M = 16.98, SD = 2.92). The magnitude of the differences in the means (mean difference =0.06) was extremely small (Cohen's d = .02).

Figure 1D- Bar chart displaying that there is no significant difference in stress levels when comparing parents of children with autism who are verbal and non-verbal



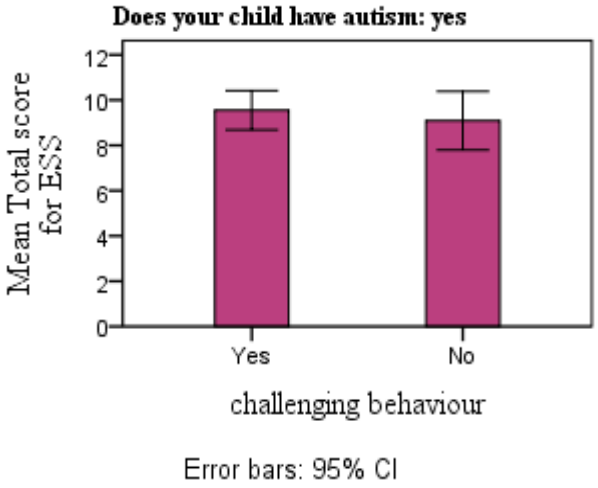
A Mann- Whitney U-test was conducted to compare levels of Stress amongst parents of children with autism who have reported challenging behaviours, and parents of children with autism who have no reported challenging behaviours. As can be seen from (figure 1A) There was a significant difference in scores U=4675, p <.05) with parents of children with reported challenging behaviours (M = 17.37, SD = 3.05) scoring higher stress levels than parents of children with no reported challenging behaviours (M = 16.13, SD = 3.56). The magnitude of the differences in the means (mean difference =1.24) was small (Cohen's d = .37).

Figure 1E – bar chart displaying the difference in stress levels in parents of children with autism who have and do not have challenging behaviour.



A Mann- Whitney U-test was conducted to compare levels of Daytime Sleepiness amongst parents of children with autism who have reported challenging behaviours, and parents of children with autism who have no reported challenging behaviours. As can be seen from (Figure 1F), there was no significant difference in scores U=5556, p >.05) with parents of children with reported challenging behaviours (M = 9.55, SD = 5.38) scoring similar daytime sleepiness to parents of children with no reported challenging behaviours (M = 9.09, SD = 5.72). The magnitude of the differences in the means (mean difference =1.24) was extremely small (Cohen's d = .09).

Figure 1F – Bar chart displaying that parents of children with autism who have and do not have reported challenging behaviours have no significant difference in scores of daytime sleepiness.



DISCUSSION

The first research question which was previously stated within the introduction aimed to investigate the stress and sleep deprivation levels in both parents of children with and without autism was addressed by testing three hypotheses,

As predicted, results produced from statistical data analysis found that there was a significant difference in stress levels between parents of children with and without autism. Parents of children with autism reported higher levels of stress in comparison to the parents of children without autism. The present research found similar results produced by other comparison studies on parental stress between these two groups (Hutchison, 2016; Baker, Blacher, Crnic & Edelbrock, 2002; Baker-Ericzén, Brookman-Frazee & Stahmer, 2005; Keenan et al., 2016) Similarly results found a significant difference in levels of daytime sleepiness between the two groups with parents of children with autism scoring higher levels of daytime sleepiness than parents of children without autism.

Lastly analysis of the third hypotheses which investigated sleep quality between the two groups also produced a significant difference. Parents of children with autism scored high scoring on the PSQI which indicated that they have poorer sleep quality than parents of children without autism. A comparison study of sleep deprivation between these two groups conducted by Meltzer, (2007) also found that parents of children with autism were more sleep deprived that parents of children without autism.

Overall in regard to this first research question and all three generated hypotheses it was found that parental stress and sleep deprivation were higher within the parents of children with autism group. All hypotheses were accepted with the null Hypotheses being rejected.

The second research question stated within the introduction aimed to investigate if there was a significant correlation between parental stress and parental sleep. This was addressed by analysing two hypotheses which found that there was a significant relationship between stress and daytime sleepiness/sleep quality.

As hypothesised, there was a moderate positive correlation of parents who reported high levels of stress also reporting high levels of daytime sleepiness and poorer levels of sleep quality. Results from a study conducted by Gallagher, Phillips and Carroll, (2009) also found that Parental stress and poor sleep quality were highly associated with one another. Another study conducted by Vanderkerckhove and Cluydts, (2010) highlights that there is a two-way relationship being stress and sleep quality. Surprisingly, the literature itself is limited on the association of daytime sleepiness and parental stress. Although it should be noted that daytime sleepiness has been reported as one of the most common consequence of poor sleep quality (Dewald, Meijer, Oort, Kerkhof & Bögels, 2010; Fallone, Owens & Deane, 2002; Moore & Meltzer, 2008; Roehrs & Roth, 2015) and could thereby be assumed that it could be associated with stress.

Overall Stress and sleep deprivation were found to have a moderately positive correlation with one another. Therefore, both generated hypotheses were accepted with the null being rejected.

The last research question which was also stated previous within the introduction, aimed to investigate solely the population of parents of children with autism and to investigate whether factors such as the child language and behaviour has a Significant impact on

parenting stress and sleep. This question was addressed using three hypotheses which found mixed results.

As predicted Parents who reported their child to engage in challenging behaviour scoring higher levels of stress in comparison to parents of children with no reported challenging behaviours. A medium significant difference was present. A similar study conducted by (Hastings, 2002) also found that behavioural problems were a significant factor when investigate the parental stress. However, when investigating the second hypothesis which looked at the relationship between parents of children with and without reported challenging behaviours and levels of daytime sleepiness there was no significant difference between groups. When reviewing previous literature on parental sleep in parents of children with autism there was limited research that looked at and tested the difference within this group. Studies tended to compare parents of children with and without autism while looking at factors such as the child's behaviour.

Results from the analysis of the last hypothesis within this research question produced interesting results. It was predicted that Parents of children with autism who are non-verbal would report higher levels of stress than parents of children with autism who are verbal, however results rejected this hypothesis. Results produced a non-significant difference with only a very small mean difference (mean difference =0.06) between two groups of nonverbal and verbal children with autism on stress levels. T=indicating that whether or not a child who has autism is verbal or non-verbal had little impact on the parental stress levels. Although these findings reject the stated hypothesis, similar findings that state that there is no significant difference in the language of a child with autism on parental stress levels have been conducted and present within the literature (Davis & Carter, 2008; Sergen & Fernandes, 2016).

Overall as hypothesised Parents of children with autism with reported challenging behaviours displayed higher levels of stress in comparison to parents of children with autism with no reported challenging behaviours. The hypothesis is accepted. However, we reject our hypotheses for the remaining two hypotheses within this research question and accept the null. There was no significant difference found between parents of non-verbal/verbal children and stress and no significant difference found between parents of children with autism who have reported challenging behaviours and no reported challenging behaviours on parental daytime sleepiness.

Limitations

When conducting this current study limitations arose some that could not be avoided and some due to errors. The first limitation that arose became apparent when analysing the data retrieved from the questionnaire from the responding participants. 11 Participants had to be excluded ten dues to their child not meeting the age criteria for the study and 1 due to medical reasons. There was also a lot of missing values within the data as a result of participants answering short answer questions incorrectly or in a way that could not be interpreted into value form. An error within the questionnaire arose when analyses of the PSS scale found that the scale was missing two questions. The PSS should consist of 10 items(questions) that when summed can give a range of up to 40 with higher score indication higher stress. However, in order to conduct analysis on this scale 8 items were summed to give a possible range of up to 32. Fortunately, the two questions were generally related to others that had been asked however it should be noted that this could affect the validity of the scale somewhat. This resulted in the low Cronbach score stated in the materials. Analysis of the full scale in relationship to this research would be sufficient for future studies.

When Reviewing the literature, it was evident that there was little research that focus on parental sleep deprivation in parents of children with autism, the research manly focused on the child's sleep quality and pattern. There was also very limited research on how a child language (verbal and non-verbal) can affect parental stress in parents of children with autism. Surprisingly another topic that deemed difficult to find literature on was the focus between parental stress and parental sleep deprivation in parents of children with autism.

Overall, although there have been numerous comparisons studied future research should focus interest on the factors that relate to stress and sleep loss in parents of children with autism solely. It would be beneficial to focus on the population of parents of children with autism on its own to give a better understanding and insights into factors that affect parental stress and sleep levels within this population.

In conclusion this study focused on parental stress and sleep deprivation amongst parents of children with and without autism. Sufficient statically analysis was conducted on all variables to test all generated hypothesis and overall found that parental stress and sleep deprivation were associated with one another , the population of parents of children with autism were more stressed and sleep deprived, Challenging behaviours displayed by the child impacted the levels of stress in parents ,Language did not impact parental stress levels and reported challenging behaviours displayed by the child did not impact the levels of daytime sleepiness felt by parents. The growing diagnosis of autism sheds light on the need for more research in this area. This current study although not perfect did find sufficient results as well as highlighting the fact that parents of children with autism are at risk of high levels of stress and sleep deprivation, so in turn should be used as a foundation to build more in dept research on.

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APPENDICES

Appendix 1- Information sheet

Hi, my name is Leah O' Reilly and I am currently an undergraduate Psychology student, studying in the National College of Ireland. I would like to invite you to take part in my research study by completing attached questionnaire. Any participation will be greatly appreciated.

*Please note that participation is completely voluntary, and you do not have to part participate if you do not wish.

The overall aim of this study is to focus on the parents of children with and without autism and investigate the factors that coincide with parental stress and sleep deprivation. The benefits of this research are to better understand the effects autism has on caregivers and in targeting certain factors and predictions. This gives way for more in dept research to be conducted, which in turn helps highlights any need for more interventions and resources to be used and developed to help the parent/parents deal with these affects.

*General notes on this study
• Please note that this Questionnaire is completely anonymous and private, you will not be asked to supply any information such as (your name, age or location).

• After Submission there is no way to withdraw your questionnaire after it has been submitted.

• All Questions must be answered.

Appendix 2 -Consent form

• I confirm that I have read and understand the Participant Information Sheet

• I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified

• I agree that data gathered in this study may be stored anonymously and securely, and may be used for future research

• I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.

• I agree to take part in this study

*Required

Please check the box if you give consent to participate in this study and wish to continue *

Agree 

Appendix 3-PSQI

The Pittsburgh Sleep Quality Index

Name_____ Date_____

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

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

usual bed time_____

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

number of minutes_____

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

usual getting up time_____

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

hours of sleep per night_____

For each of the remaining questions, check the one best response. Please answer *all* questions.

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

(a) Cannot get to sleep within 30 minutes

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(b) Wake up in the middle of the night or early morning

Not during the past month____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____

(c) Have to get up to use the bathroom

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(d) Cannot breathe comfortably

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(e) Cough or snore loudly

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(f) Feel too cold

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(g) Feel too hot

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(h) Had bad dreams

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(i) Have pain

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

(j) Other reason(s), please describe_____
_____
_____

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

Not during the past month____ Less than once a week_____ Once or twice a week_____ three or more times a week_____

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

   Very good_____
   Fairly good_____
   Fairly bad_____
   Very bad_____

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

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

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

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

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

   No problem at all_____
   Only a very slight problem___
   Somewhat of a problem_____
   A very big problem_____

10. Do you have a bed partner or roommate?

    No bed partner or roommate _____
    Partner/roommate in other room _____
    Partner in same room, but not same bed____
    Partner in same bed _____

11. How often do you feel tired during the following times during the day?

Morning:

0	1	2	3
most days	often	occasionally	never

Afternoon:

0	1	2	3
most days	often	occasionally	never

Evening:

0	1	2	3
most days	often	occasionally	never

Appendix 4- ESS

The Epworth Sleepiness Scale

Initials: _____
Date: _____
Date of Birth: _____
Gender: Male/ Female (delete as appropriate)

How likely are you to doze off or fall asleep in the following situations, in contrast to just feeling tired? This refers to your usual way of life in recent times. Even if you have not done some of these things recently, try to work out how they would have affected you.

Use the following Scale to choose the most appropriate number for each situation:

0 - would never doze
1 - slight chance of dozing
2 - moderate chance of dozing
3 - high chance of dozing

Situation Chance of Dozing

Sitting and reading _____
Watching TV _____
Sitting, inactive in a public place (e.g. Cinema)_____
As a passenger in a car for an hour with out a break _____
Lying down to rest in the afternoon when given a chance _____
Sitting and talking to someone _____
Sitting quietly after lunch with out alcohol _____
In a car, while stopped for a few minutes in traffic _____

Office Use Only: Score _____
Please write down all medicines or tablets you are taking at present.
Appendix 5 -PSS

PERCEIVED STRESS SCALE (1983) **Sheldon Cohen**

0 = Never 1 = Almost Never 2 = Sometimes 3 = Often 4 = Very Often#

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?

0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

0 1 2 3 4

Appendix 6- Debriefing sheet

First and foremost, thank you for your participation in this study which is greatly appreciated.

This particular research study focuses on parents as a target population. It looks at how certain factors can affect the stress and sleep of a parent.

Benefits of this research will be to better understand the effects autism has on caregivers and in targeting certain factors affecting parental stress and sleep deprivation in both groups. This gives way for more in dept research to be conducted and in turn helps highlight any need for more interventions and resources to be used and developed to help the parent/parents deal with these affects.

Below are links for anyone who would Link to understand more about support groups, chats and resources available for parents

http://www.autismsupportnetwork.com/resources

https://turn2me.org/group-supports?gclid=Cj0KCQiA7IDiBRCLARIsABIPohglhekLmcmxY-MyxKHptEhLTGK6j39g1MXQauYo8gOzZIwuH9b12YQaAvlREALw_wcB

http://www.parentingsupport.ie/links/