

**Autism as a Factor Affecting Family Systems:
A Comparative Study of Stress, Self-Efficacy and Self-Perception**

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Submitted in partial fulfilment of the requirements of the Bachelor of Arts degree
(Psychology Specialisation) at DBS School of Arts, Dublin.

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March 2012

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ACKNOWLEDGMENTS

A strong and genuine debt of gratitude must be extended to the Principal and Parents of the five primary schools who embraced the aims of the study and volunteered to participate. The schools that participated have been acknowledged and thanked privately.

A very special thank you to Margaret Walsh who provided the supervision, support, direction and encouragement critical to ensuring a well realised research project.

Finally, to the lecturing staff of the Psychology Department, in the School of Arts, Dublin Business School; thank you.

ABSTRACT

Many factors combine to affect the interactive and interdependent nature of family systems, stress associated with long term care of children with autism has psychological and physiological consequences. The purpose of the study is to investigate differences in levels of stress, self-efficacy and self-perception. A convenience sample of 77 participants were administered a questionnaire. Parents (n=28) of children with autism reported higher levels of stress, and lower levels of self-efficacy and self-perception than parents (n=49) of children without autism. A statistically significant relationship existed between high levels of stress and levels of self-efficacy ($r=-.543$), global self-perception ($r=-.690$), job competence ($r=-.593$) and household management ($r=-.419$). The results of a regression indicated that five predictors of stress explained 55% of the variance.

INTRODUCTION

Autism

No single disability or chronic illness has a monopoly on the amount of care that a family needs to contend with. Considerable research has been carried out on long-term care of children with autism (Gray, 2006; Baxter, Cummins & Yiolitis, 2000). Autism is a “life-long neurological pervasive developmental disorder” often not diagnosed until the child is at least three years old (Pottie & Ingram, 2008, p.855). Although several studies differ in the prevalence rate of autism in the world population, the most accurate figure is 1:166 of the population being affected with the condition (WHO, 2004,). Autism is characterised by a “triad of impairments in communication, social isolation and lack of social reciprocity and stereotypical repetitive behaviours” (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010, p.449). Compared with parents of typical children, and parents of children with other disabilities, parents of children with autism experience significantly higher levels of parenting stress and psychological distress (Pottie & Ingram, 2008; Hartley et al, 2010). The challenges faced by parents raising a child with developmental disability vary depending on the nature of the disability (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy, 2004). Abbeduto et al set a precedent in comparing levels of psychological well-being and coping in parents of children with Down’s Syndrome, Fragile X Syndrome and Autistic Spectrum Disorder, and found that mothers of children with autism had lower levels of well-being compared to the other groups. It was also established that the most consistent predictor of these low levels was the behavioural symptoms of the child (2004).

Family system

The family dynamic was historically characterised as the linear relationship between the mother and her child (Seligman & Darling, 1997). However Minuchin (1974) captured the

concept of the interactive family; “the family, then, operates as an interactive unit and what affects one member affects all members” as cited by Seligman & Darling (1997, p.5), essentially the family began to be viewed as a dynamic system. The extension of this is that many factors and variables will interact with the family; a number of static and dynamic characteristics of the family structure have been identified. For instance (1) the membership characteristics of the family can vary from the extended family, to who lives in the home, geographical location, single parent families and families where there is unemployment or substance abuse (Seligman & Darling, 1997). A further characteristic is (2) cultural style which is considered the most static component; this will include cultural beliefs, ethnic, racial, religious beliefs and socio-economic status, often having an effect on the family ideology. Finally (3) the ideological style is based on family beliefs, values and culture which will influence the coping behaviour that will be employed, for instance, some families value academic achievement, whereas McGoldrick, Pearce and Giordano (1982) as cited by Seligman & Darling (1997) emphasise family closeness and affection.

The family can be divided into four sub-systems, these include (1) Marital: husband and wife interaction, (2) Parental: parent and child interaction, (3) Sibling: child and child interaction and (4) Extra familial: extended family, friend, and professional interactions (Seligman & Darling, 1997). The way family members interact is characterised by a balance between enmeshment and disengagement between the sub-systems. A product of this interaction is described by Turnbull & Turnbull (1990) as family function. Typical family function allows family member’s individual needs to be met successfully. These functions include economic functions such as ease of generating income, paying family bills, domestic and health care functions, such as, family weekly shopping, transportation and medical visits. Another function is recreation; which highlights aspects such as access to hobbies and social

outings, educational functions such as ability to access further education and career prospects, and finally self-identity and affection functions which look at how a family recognises strength and weaknesses, and addresses belonging, nurturing and intimacy needs (Turnbull & Turnbull, 1990). Mitchell (1983) highlighted how family function and structure has been successfully integrated into Bronfenbrenner's social ecology model in order to explain how the family system operates in families that may have additional burdens or issues. The Bronfenbrenner Social Ecology model consists of (1) a *microsystem*, which embodies the family inter- personal relationships within the immediate family. (2) The *mesosystem*, which is a range of settings which the family participates in, these may include, healthcare professionals, educational professionals, extended family, local community, work and recreational pursuits. (3) The *exosystem*, consist of settings that the family does not actively participate in, but may have an effect on attitudes, policy or supports, these may include, media, health services and social welfare. (4) The *macrosystem* which may influence the family values and social inclusiveness, these could include cultural, religious, economic and political attitudes and policies. Finally (5) the *chronosystem* simply is the time line which all of the other systems interact during the family's life span.

The purpose of this study is to compare levels of stress between parents of families who have a child with and without autism. In addition the study will also compare scores in parental self-efficacy and self-perception, and determine if a relationship exists between them, or if they can be highlighted as predictors of stress. The variable which is assumed to have a direct impact is the disability of a child. The challenge is in drawing firm conclusions about whether these variables have a direct effect on the family system of structure and function "the research in this area is beset by many methodological problems, which has resulted in mixed and contradictory results" (Crnic, Fredrich & Greenberg, 1983, p.126).

Structure, being identified as the parent/parent, parent/child, and child/child relationships and interactions and function which is identified, as the ability for the individual needs of the family being met successfully. Function, would include, family social gatherings, ability to generate income and pay bills, health and education access and career prospects. However one of the main challenges in managing disabled children is maintaining the requirements of everyday living (Raina, O' Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu, & Wood, 2005). Raina et al further state that "the provision of such care can prove detrimental to both the physical health and psychological well-being of parents of children with chronic disabilities and have an impact on family income, family functioning and sibling adjustment" (2005, p.627). "Disability can place a number of complex demands on family systems" in addition "disability has a personal impact on all family members" (ISPCC, 2005, P.7).

Policy makers and service providers often compartmentalise a provision or service to the individual who has a disability within the family. This may include therapists requiring the primary care giver to have exercises or homework completed before the next session, or expect a family to provide complex or specific time limited changes to documentation for a child with a disability in order to be enrolled into a school or service. Recently highlighted is the expectancy of parents of children with disability to take up the fight for Special Need Assistants (SNA) on behalf of schools. This is often inadvertently done without considering if it places more strain on the family. An additional aim of this study is to initiate a debate into developing a more effective partnership between service providers and policy makers in looking holistically at a family situation before perceived additional burdens are added.

Stress

Considerable research exists in respect of levels of stress that parents of children and adolescences with autism contend with. Stress and maternal depressive symptoms (Bristol, Gallagher, & Holt 1993; Barker, Hartley, Seltzer, Floyd, Greenberg & Orsmond, 2010) have highlighted the strain that mothers experience, predominantly as they are often the primary caregiver. Little in the way of specific paternal stress has been studied, however some studies (Konstantarcas, 1991; Gray, 2006; Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005; Mash & Johnston, 1983) note that fathers of children with autism experience less stress than their spouses. Most suggest that this is due to an avoidance coping mechanism employed by the fathers, characterised by the fact that fathers may spent more time in work and in work related activities, and as a consequence are often unavailable for visits to therapies, doctors, school and shopping errands, where the child with a disability has to be taken.

Stress has been conceived as “the balance between external environmental demands and the perceived internal ability to respond and may occur when the demands prevent the pursuit of other life objectives” (Raina et al, 2005, p.627). This view of stress could suggest that factors other than the behavioural aspects of the child’s disability “prevent” the pursuit of life objectives. Stress as a transactional model involves the parent evaluating or appraising the event, determining whether they have the internal resources (e.g. personality) or external resources (e.g. income) to address the situation (coping strategy) (Pottie & Ingram, 2008). In terms of parents meeting the family needs, could it be suggested that extraneous burdens placed on the family from the *mesosystem* (i.e. local community, health and education provision) of the social ecology model, have as much of an impact on the stress of the family as the behaviour of the child? Seligman & Darling suggest that professionals such as health

care staff pay particular attention to how a family may be able to integrate therapeutic interventions within the family system before sending “home work” back with the family to be completed before the next visit (1997, p.12). This could equally be applied to other areas that a child with autism has to access in the course of a daily routine, for instance schools insistence on parents fighting for SNA’s or their child’s placements in local schools. These questions have been and can be answered by qualitative means. The National Autistic Society in their meta analysis of research have found these extraneous issues to be in some way responsible in adding additional stress to families, particularly the “long and frustrating process of obtaining a diagnosis”, “parents charged with parental incompetence by health workers”, the association of “maternal depressive symptoms” as a precursor to the child’s autism, rather than as a possible result of the associated care needs” (NAS, 2007, para 1.).

Possible outcomes of stress on the family can result in effects such as higher divorce rates in families where there is a child with autism. Hartley et al found that United Kingdom divorce rates in these families run at 25.53% and continue to be high throughout childhood, adolescence and adulthood. In comparison families without a child with autism record a divorce rate of 13.81% with the likelihood of divorce reducing over time (2010). Empirically other aspects of the family system such as reduced earnings (Gray, 2003), lack of access to further education, reduced community involvement have not been quantitatively measured but have been suggested. Equally the stress of advocating for a child with autism can lead to negative views of the parent(s) which can have an effect on the family; one comment from a mother states that she must work a considerable distance from her home because she advocated for her son in her local area and as a result cannot secure work there Turnbull & Turnbull, (n.d.) as cited by Paul, Lavelly, Cranston-Gringras & Taylor (n.d., p. 89).

The “special demands” of the atypical child such as self injurious behaviours, hyperactivity, social and communication deficits, on other family members have produced a large number of stressors that have been identified as being beyond normative “daily hassles”, the consequences of which can lead to “reactive depression, physical illness and other psychopathological manifestations” (Konstantarcas, 1991, p.359). Availability of therapeutic services, particularly in rural areas, can drain families of financial resources when faced with having to travel or pay for them privately, lack of educational placements and supports for the disabled child, as well as the requirements for supplementary assessments and recommendations to support the child’s educational application, has also been identified as unnecessary stressors (ISPCC, 2005). Sibling responses to questionnaires identify family holidays and family outings as well as time for parents to bond with the son or daughter without a disability as having a significant impact on the family dynamic and system (ISPCC, 2005). A further significant contributor to levels of stress in the family is the gender of the disabled child, with parents of male children with autism experiencing greater marital disharmony and “more stressful experiences” than parents with a female child with autism (Konstantarcas, 1991, p.366).

The current study will attempt to illicit some of the stressors that the families are living with by answering three qualitative questions, based on identifying family stressors that happened in the previous month, what may be a current stressor and what activity may pose a stressful occasion in the next six months.

Stress has shown to be a well researched and reported variable in relation to the health and well-being of a family with a child with autism (Baxter et al, 2000; Grey, 2006; Hartley et al, 2010). The first of five hypotheses that this research project will investigate is levels of

stress in families where there is a child with autism are significantly different than a family with children who have no autism.

Self-Efficacy

With effects of stress physiologically and psychologically having been evaluated, a question that may be asked is whether stress has an impact on a parent(s) self-efficacy? Is it worth looking at a possible relationship? Self-efficacy is a variable that has been identified as a strong predictor in affecting outcomes in parents of children with autism (Hastings & Brown, 2002). A particular benefit of self-efficacy has been seen in mediating the effects of the child with autism's behavioural issues on the mother's anxiety and depression; however it has not been successful in showing a moderation of a father's anxiety (Hastings & Brown, 2002, p.222). Bandura (1977, 1986, 1989), as cited by Hastings & Brown (2002, p.222) defines self-efficacy in terms "of one's skills in a given domain". As self-efficacy is therefore domain specific, studies have focused on the particular dimension of the child's "behaviour problems" and how parents have addressed it. Bristol et al, studied the impact of "psycho-educational intervention" on the depressive symptoms of mothers of children with autism, and found that depressive symptoms decreased over time when the mothers were helped to understand their child's condition and how to manage the child's education, learning and behaviour problems (1993). These studies have highlighted specific areas where specific skills can be focused on, but once again with reference to the ecological model theory, the family as a whole needs to be focused on, particularly if the function of the family is to meet all its necessary needs. Advocating for a child with a disability is as important as advocating for a child without a disability. Rather than domain specific issues such as problem behaviour, can overall perceived stress have an effect on the family?

Self- efficacy has been applied in the parenting domain to test parenting behaviours and stress (Hastings & Brown, 2002). A cognition adaption theory developed by Taylor (1983) cited by Hastings & Brown (2002) suggests that people develop “coping strategies that serve to enhance feelings of efficacy and self-concept when faced with traumatic events” (p.223). These strategies are referred to as cognitive illusions, creating a positive “spin” has a positive impact on self-efficacy, and as a result positive/ adaptive outcomes are increased. Self-efficacy in specific domains have shown how problem-focused coping strategies are employed by parents to a greater extent when trained in differing techniques such as Applied Behaviour Analysis (Hastings et al, 2005), having availability of specific autism services (Gray, 2006), pro-social, communication skills and further education (Montes & Halterman, 2007; Pottie & Ingram, 2008; Abbeduto et al, 2004).

The ISPCC study highlights several specific headers including: (1) information provision for parents and families, on that disability, (2) parenting programmes, peer support groups and individual counselling from therapy providers, (3) child centred approaches from educational and health providers, and, (4) access to further education for parents (2005). Sivberg states that an important and beneficial aspect of self-efficacy is the ability to “confidently advocate for the child” (2002, p.49), and further suggest that management of services should increase their competencies in order to support parents to “reach an optimal level of functional capacities in family life” (2002, p.48). This, however, could be viewed negatively by these very services as highlighted by Turnbull & Turnbull (n.d.) as cited by Paul et.al (n.d., p. 89). In a number of references to parents who, having advocated for their child, suggest that they have “paid a high price” leading to stress on the family. Blanchard, Gurka and Blackman (2006) quote the American Academy of Paediatrics “families are the most central and enduring influence in children’s lives...the health and wellbeing of children

are inextricably linked to the physical, emotional, and social wellbeing of their parents” (p.1209). To this end they suggest that policy makers and healthcare professionals need to place greater emphasis on finding “creative solutions” in order to help families of children with developmental disorders (p.1209).

The second hypothesis this study posits is that the levels of self-efficacy in parents of children with autism may be significantly different than those with a typically developing child.

Self-efficacy is one’s ability to achieve in certain domains and consequently leads to a person’s heightened self-esteem, a further observation might question if self-efficacy is affected, how might this reflect on a person’s self-perception?

Self-Perception

Self-perception can be notoriously difficult to define, however within the context of this study it may be as simple as the “self of which one is aware” or put another way one’s “attitudes, beliefs and self-characterisations are to a considerable degree, determined by observation of one’s own behaviours” (Reber & Reber, 2001, p.662). The principle of self-perception is that we tend to judge the feelings of others by what we see them do; we tend to infer our own attitudes of ourselves. A number of studies have made some generalisations on parental self-perception in light of findings made in relation to the self perception of the disabled child in specific domains such as academic and social competence (Dyson, 2003) or in a parent’s perception of their own disabled child’s behaviour problems (Mash & Johnston, 1983). Little, in the area of specific quantitative study has been conducted on the parents own self perception, Dyson (2003) has highlighted this “unanswered question” along the lines of

“what family psychological factors are related to self perception in families with a child with learning disabilities?” (p. 3). Dyson continues by speculating that “parental stress may have a negative relationship with self-concept and social competence” and “positive family functioning may be related to positive developments in self-concept and social competence” (2003, p.3). Mash and Johnston (1983) go as far as saying that “mothers of problem children may be isolated from social support, such as contact with friends, and this insularity may be predictive of higher levels of maternal negativism” (p. 87). Perception of parenting ability has been highlighted with questions such as; “what kind of parent am I?” Or “am I a good enough parent?” (NAS, 2007, paragraph 5; ISPCC, 2005; Paul et.al, n.d.), all asked as a result of encounters with various different professions that they turn to for assistance.

The inclusion of family functioning and a disabled child’s development, as “reciprocal influences between children and their ecological environment” (Dyson, 2003, p. 3), into Bronfenbrenner’s ecological model (Seligman & Darling, 1997; Dyson, 2003; Paul et al, n.d), has had an important affect on studies of childhood disability on families. Dyson (2003) cites Margalit & Heiman (1988) indicating that “parents of children with LD (learning disability) were found to be more anxious and more concerned with family organisation” (p.3). Dyson (2003) continues by speculating that answers to the question of parental self-perception “would increase the understanding of the effect of disabilities” on the child and “would guide interventions” (p.3).

Mash and Johnston (1983) cite a number of studies supporting negative self image, low self esteem, depression, anxiety, fatigue, anger and isolation specifically in mothers of children that exhibit aggressive behaviours as a result of their disability (p.87). While difficult to extract specific examples of how parents rate their own perception of themselves,

anecdotal references to their views about themselves as social beings, as parents and as carers are liberally found in qualitative studies (NAS, 2007; ISPC, 2005). Sivberg (2002) suggests that the “question of causes” in respect of “good enough parenting” is more about creating a parent’s own meaning about themselves by comprehending the situation and learning more about the disability of autism (P.48). The three sub-scales; job competence, house-hold management and global self-perception were chosen as they give a broad reflection on aspects of a parent’s day to day family life.

Seligman and Darling (1997) highlight societies attitude to both disabled children and the parents of disabled children by quoting an extract between a customer (a journalist) of a restaurant who was appalled by the irresponsibility of a parent who took a disabled child into the premises, and the parent who felt ridiculed and ostracised by the article that resulted. They suggest that “the experience of difference felt by children with disabilities is also, by association, felt by other members of the family” including the extended family and in the “social or interactional context, these families feel devalued, which can result in a sense of shame and stigma” (Seligman & Darling, 1997, p.99). As a result they also suggest that “professionals must examine their own attitudes” towards the parents and family (p.100) in order to avoid this “stigmatisation”.

The third hypothesis suggests that the level of parental self-perception in the domains of the global context, job context and household context, of families with children with autism, may be significantly different from that of parents with children without autism.

The fourth hypothesis suggests that a possible relationship between stress, self-efficacy and the three domains of self-perception exists. Should there be a correlation

between these variables, it may provide a starting point for further investigation into a longitudinal model of measuring the impact of disability within a family.

A fifth hypothesis suggests variables such as global self-perception, job competence, house-hold management, self-efficacy and having a child with autism may be predictors of stress in parents.

The aim of the study is to highlight five variables that may relate to each other with respect to how they may impact on the family's ability to function and on the family's structure. Two areas have been highlighted with respect to this. Firstly, stress as a variable has been focused on in respect of increasing depressive symptoms in parents, and in how parents address it in various coping methods. What perhaps needs to be highlighted is that a difference exists between levels of stress in families where disability exists and families with typically developing children. It is also worth keeping in mind that stress may not necessarily be as a result of the child's disability, but perhaps may be the act of caring for the child, and being able to successfully address the needs of the family too. Secondly a great deal of research on stressors and how they affect persons within the family is anecdotal and supported by qualitative studies. In order to empirically support the effect of disability on the family, this study hopes that a discussion on identifying specific domains such as parental self-efficacy and self-perception or others may help educational and health service providers identify family needs when instituting care plans or education programs. "Families of children with persistent developmental problems are struggling in the areas of finances, employment, parent- child relationships and caregiver burden" (Blanchard et al, 2006, p.1210) The study also hopes to stimulate discussion into refining experimental methodological designs that can be used to predict what families with children with autism

need in order to meet the needs of the whole family, a new approach in the way these issues are addressed may have a potential to enhance the quality of life of the child and parents (Blanchard et al, 2006).

A greater focus on the reciprocal relationship of the ecological environment on the development of the disabled child should be considered when parents of these children are asked to accept additional burdens that families of typically developing children are not required to. For instance aspects of the *mesosystem* such as health services need to ensure that they are accessible, non judgmental and helpful; minimising the amount of “red tape” families are subjected to; or demands from schools for parents of disabled children to fight education cuts or Special Need Assistant reductions. The rationale behind the demographic and qualitative questions is to identify a general ecological system that each family operates in and what stressors they face on a daily basis.

The aim of this study is to compare the levels of stress on families with and without a child with autism. In addition it will also compare scores for each family in the areas of self-efficacy and self perception. Quality of life (Poston, Turnbull, Park, Mannan, Marquis & Wang, 2003) and emotional well being (Barker et al, 2010; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008), which appear central to the function of a family, are evaluated in respect of effects on parents physical and psychological health. Coping appears central to how parents of children with autism buffer or mediate themselves to reduce the strain. Self-efficacy is domain specific and as such evaluations of the parents ability to address their disabled child’s needs appear mediated by the level of information they have about autism and the level of instruction they have been given to address the “behavioural problems” of the child. These are very specific areas of a family’s daily routine, but little in the way of

quantitative information exists as to how other aspects of their day conform to a “typical daily routine”. Qualitative studies (ISPC, 2005, NAS, 2007) have highlighted the diminishment of career prospects, financial struggles, urban rural divides in service provisions, and how the levels of education of parents can affect how parents of children with autism cope with the care giving duties and the deficits of the child. The focus of this study is to examine if a relationship between the specific variables, could act as predictors for professionals to determine levels of intervention that may be required. While the argument has been well made on the effects of stress on the health of parents, critical variables such as self-efficacy across domains and self-perception based both on how parents view themselves and how they perceive society viewing them in different domains may show an effect on how parents meet the needs of all members of the family.

In order to address the questions and observations highlighted the study is a quantitative cross-sectional, between group survey. Parents of primary school going children in a mainstream setting and parents from an autism specific special schools are surveyed to determine their levels of stress and scores in self-efficacy and self-perception using existing psychometric questionnaires. Parent’s level of stress are measured using the fourteen item Perceived Stress Scale (PSS14) (Cohen, Kamarck & Mermelstein, 1983). Parental self-efficacy is measured using the ten item Generalised Self-Efficacy Scale (GSES) (Schwarzer, 1993). Parent self-perception, is measured using the six item Global Self-Perception, and the four item Job Competency and Household Self-Perception aspects of the Harter Self-Perception Questionnaire (Messer & Harter, 1986). There will be an opportunity for the parents to provide a brief opinion within a series of short qualitative questions. The central focus of the study is based on the reciprocal interactions of the family with the various systems of their immediate and extended environment. The five hypotheses being addressed

are (1) the levels of stress in parents with children with autism will differ significantly from the levels in parents with children without autism. (2) The level of self-efficacy in parents with children with autism will differ significantly than levels in parents with children without autism. (3) The level of self-perception in three specific domains will differ significantly in parents with children with autism compared to parents with children without autism. (4) To determine if a correlation exists between the variables, representing a relationship that may impact on family function. (5) To identify those variables that may predict levels of stress in parents.

METHODOLOGY

Materials

The study relies on a self-administered questionnaire that the primary care giver in each family responds to. The questionnaire (appendix 1) has five individual parts comprising of (1) a demographic overview with seven questions, (2) the fourteen item Perceived Stress Scale (Cohen et al 1983), (3) the adult Harter Self-Perception profile (Messer & Harter, 1986) specific to Global Self-Worth, Job Competence and Household Management domains, (4) the ten item Generalised Self-Efficacy Scale (Schwarzer, 1993), and (5) three qualitative questions.

The qualitative questions, require the participants to, 1) identify a family stressor that had occurred in the last week, 2) an event or situation within the last week, that prevented the family participating in a “family event”, and 3) identify a possible stressful event that may occur in the next six months, which may impact on a typical family outing. Responses from the qualitative aspect of the questionnaire will be used to support the observations made under each hypothesis. The three psychometric scales were chosen based on their consistency, reliability and validity.

Perceived Stress Scale

The Perceived Stress Scale (PSS) (Cohen et al, 1983) was designed as a measure of which situations in one’s life are determined as stressful; it has the added benefit of addressing daily hassles and how one copes with them. The consistency of the scale, assessed by Cronbach’s alpha was in the range of 0.85; additionally short term reliability was high at 0.85 dropping to 0.55 after six weeks (Cohen et al, 1983). While the validity of the scale varied between low to

moderate (0.17-0.49) in respect to life events and their impact on the respondent, the PSS showed adequate reliability. Cohen et al noted that the PSS fourteen question scale was a better predictor of future physical symptoms with a validity of 0.52 to 0.76 (1983, p. 393). The Perceived Stress Scale is a Likert scale where items are scored from 0 to 4, with the numbers representing the following; 0= never, 1= almost never, 2= sometimes, 3= fairly often and 4= very often. Questions such as “in the last month, how often have you felt nervous or stressed”, would require the participant to place a value from the 0 to 4 score in the space provided, and it is recommended that this is done fairly quickly. For the purposes of analysis items 4, 5, 6, 7, 9, 10 and 13 are scored in the reverse direction (0= 4, 1= 3, 2= 2, 3= 1, and 4= 0) and summed with the other negatively worded items. Scores range from 0 to 56, with lower scores (less than 28) suggesting lower stress and higher scores (above 28) representing higher levels of stress.

Harter Self-Perception Scale

The Harter Self-Perception Profile (Messer & Harter, 1986) was presented focusing on three identified domains within the family system, Global Self-Worth, Job Competence and Household Management, studies support the findings that this scale has better reliability and convergent validity within specific domains (Wickstraum, 1995,) and perceptions of Global Self- Worth were stable over time (Granleese & Joseph, 1994). The Harter Self- Perception profile has 50 questions covering 12 sub-groups, this study focused on 3 of the sub- groups, Global Self- Worth, Job Competence and Household Management, with the former sub-group having 6 questions and the latter two having 4 questions each. The questions are presented in the centre of the page, with two spaces to the right of one statement and two to the left of the other statement. Participants are asked to pick one or the other statement from each question which best reflects their description of themselves; for example “some adults

like the way they are leading their lives” BUT “other adults don’t like the way they are leading their lives”. Two options are presented with each statement, “really true of me” and “sort of true of me”. A Likert scale scores the answers from 1 to 4. Should the participant choose the more negative statement, it will attract a score of 2 for the “sort of true of me” response and a 1 for the “really true of me” response. However should the participant feel that the more positive side of the statement reflects their perception of themselves, the “really true of me” response will attract a score of 4 and the “sort of true of me” response, a score of 3. The score of 4 will represent a high level of self- perception and a score of 1 will represent a low level of self- perception. The fourteen questions were presented randomly with a Global Self- Worth question being preceded or followed by either a Job Competence or Household Management question.

Generalised Self-Efficacy Scale

The Generalised Self- Efficacy Scale (Schwarzer, 1993) measures the strength of one’s ability to respond to “novel tasks” and how “to cope with adversity in a broad range of stressful and challenging encounters” (Luszczynska, Gutierrez- Dona, & Schwarzer, 2005, p. 80). The scales strengths in consistency, validity and reliability have been supported by a number of multi-cultural and international studies (Luszczynska, Scholz, & Schwarzer, 2005). The Generalised Self- Efficacy Scale has ten items in which a Likert scale scores 1 to 4 where; 1= not at all true, 2= hardly true, 3= moderately true, and 4= exactly true. Participants are asked to select a value that represents how much the statement applies to them and place it in the space provided, for example, the question “I can usually handle whatever comes my way” can attract a 1 for “not at all true” or a 4 for “exactly true”. The scores for each of the ten items are summed to give a total score; the range will be between

10 and 40. The score on the scale will reflect the participants belief in their self- efficacy, therefore the higher the score the greater the participants sense of self- efficacy.

This is a “pen and paper” survey, two hundred questionnaires were distributed, each questionnaire had an envelope and sealed cardboard boxes were supplied to the schools so that participants could place their returned questionnaires in.

Participants

In order to ensure that a group of parents of school going children who have autism was available, four schools for children with autism were identified in the commuter belt of a major Irish urban location. Children attending these schools have to have a primary diagnosis of autism made by a team of professionals including a Psychologist and supported by one or a number of assessments such as the Autism Diagnostic Interview-Revised (ADI-R), Vineland Adaptive Behaviour Scale and the Childhood Autism Rating Scale (CARS). A number of mainstream primary schools in the urban area have ASD (Autistic Spectrum Disorder) units attached, to this end a primary school without an ASD unit was identified and selected.

Parents of Irish primary school going children (age range 7-12 year old), half of the participants were selected from a mainstream school setting, and the other half from autism specific schools for children with autism and complex needs. In order to minimise any potential for family discord or disagreement, the introduction page indicated that the “primary care giver” should fill in the questionnaire. 38.5% (N=77) of the 200 questionnaires were responded to, 15.6% (n=12) males and 84.4% (n=65) females made up the gender demographic.

Design

The study is a quantitative, cross-sectional, between group survey design; correlational study. There is a three question qualitative aspect to the study also. The sample is a convenience sample.

Variables

The Predictor Variable (PV) in the first three hypotheses is the family with and without a child with autism; the Criterion Variables (CV) will be stress, self-efficacy and self-perception. In the correlation analysis the PV will be stress and the CV's will be self-efficacy and self-perception. Regression analysis will nominate stress as the dependent variable and utilise self-efficacy, self-perception and families of children with autism as predictor variables.

Procedure

Five primary schools were selected within a large urban commuter belt in order to select parents of 7-12 year old children. Letters of introduction were sent to the Principals of each school where permission was sought and subsequently granted. Two hundred questionnaires were distributed; half were delivered to a mainstream primary school, where the principal placed the questionnaires and envelopes in the schoolbags of children from 4th, 5th and 6th class in order to ensure that the age range identified was best observed. Half were distributed between four Special Schools for children with Autism and Complex needs. The Principals of these schools ensured that the parents of the children received the questionnaires and envelopes by placing them in the children's schoolbags. All participants received the same instructions in relation to completing the questionnaires. All ethical guidelines as prescribed by the Psychological Society of Ireland and the ethics committee of the third level institution

were adhered to. Each participant could withdraw from the study at any time and debriefing was afforded to each participant with the availability of helpline phone numbers attached to the questionnaire. A sealed box with a post box style “slot” was left at the reception of each school in order for the participants to deliver their sealed completed questionnaires. A deadline of one week was communicated to all participants via the instructions, in order to complete the questionnaires; late returns would not be included in the study.

RESULTS

The aim of this study was to determine if significant differences existed between two groups of parents of primary school going aged children, in the areas of stress, self-efficacy and three domains of self-perception. One group of parents will have children with autism and the other group of parents will have children who do not have autism. Two additional aims will determine if a relationship exists between stress, self-efficacy and self-perception and can a number of variables predict stress. Three qualitative questions were asked in order to identify possible family stressors and to see if these could be linked positively or negatively to the function of all the family's needs being successfully met.

Two hundred questionnaires were distributed, 79 (39.5%) were returned, two questionnaires were rejected due to being left substantially un-answered. 77 (38.5%) were deemed valid, a small number of missing values were detected, but these were deemed insignificant. An overall analysis of the responses to the demographic questions (table 1) offers an insight to the general characteristics of the participants. The participants ranged in age between 29 and 53 (m= 40.68 years).

Table 1

Descriptive statistical results of responses received from the demographic questions, highlighting factors affecting the family system.

Descriptive Statistics/ Demographic Questions	N	%
<u>Gender</u>		
Male	12	15.6
Female	65	84.4
<u>Families with children with autism</u>		
Families with a child with autism	28	36.4
Families with a child without autism	49	63.6
<u>Number of Children in family with autism</u>		
No children with autism	49	63.6
One child with autism	23	29.9
Two children with autism	3	3.9
Three children with autism	1	1.3
Four children with autism	1	1.3
<u>Location where the family lives</u>		
Urban	17	21.1
Suburban	49	63.6
Rural	8	10.4
<u>Parents level of education</u>		
Primary School	14	18.2
Secondary School	29	37.7
3 rd Level	33	42.9

Between group analysis of difference

Table 2

Mean, standard deviations and scoring range of perceived stress, generalised self-efficacy and the three sub-scales of self-perception.

Statistics/ Variables	Mean m	Standard Deviation s.d	Score Range
Perceived Stress	23.85	9.26	0-56
Generalised Self-Efficacy	30.03	5.17	10-40
Global Self-Perception	2.87	0.65	1-4
Job Competency	2.97	0.55	1-4
Household Management	2.96	0.56	1-4

Although the sample size might be considered small, it must be understood within the context of the study that a very specific group of participants with a specific quality (a family with a child with autism), was being studied along with families with children who do not have autism. It was decided that the sample size was of a sufficient size to consider parametric analysis. In order to determine what the levels of stress, self-efficacy and self-perception each group of parents had identified as experiencing, table 2 illustrates the mean score. Values above the mean indicate higher levels of stress, self-efficacy and self-perception, with values below the mean indicating low levels of each variable. The Q-Q Plots of the variables for stress, self-efficacy and self-perception were consistently linear. In light of the fact that parametric tests are sufficiently robust, independent samples t-tests were used to investigate differences between groups (table 3).

Table 3

An Independent Samples t-test analysis of the differences between both groups of families, with respect to stress, self-efficacy and three domains of self-perception.

Statistics/ Variables	t	p	mean	SD
<u>Perceived Stress</u>				
Families with children with autism	4.07	p=.001	28.96	10.08
Families with children without autism			20.89	7.08
<u>Self-Efficacy</u>				
Families with children with autism	-3.05	p=.003	27.79	5.70
Families with children without autism			31.25	4.19
<u>Global Self-Perception</u>				
Families with children with autism	-2.51	p=.014	2.64	0.75
Families with children without autism			3.01	0.54
<u>Job Competence S-P</u>				
Families with children with autism	-2.82	p=.006	2.77	0.56
Families with children without autism			3.13	0.52
<u>House Hold S-P</u>				
Families with children with autism	-1.98	p=.051*	2.82	0.54
Families with children without autism			3.08	0.56

Note 1: * p was approaching statistical significance.

Perceived Stress

An independent samples t-test found that there was a statistically significant difference between stress levels in families with children with autism and families who have children with no autism ($t(73) = 4.07, p = .001, 2\text{-tailed}$). Families with children with autism

(mean=28.96, SD=10.08) were found to have higher levels of stress than families with children without autism (mean=20.89, SD=7.08).

Self-Efficacy

An independent samples t-test found that there was a statistically significant difference between self-efficacy in families with children with autism and families who have children without autism ($t(73)=-3.05$, $p=.003$, 2-tailed). Families with children with autism (mean=27.79, SD=5.69) were found to have lower levels of self-efficacy than families who have children without autism (mean=31.25, SD=4.19).

Global Self-Perception

An independent samples t-test found that there was a statistically significant difference between levels of Global Self-Perception in families with children with autism and families who have children without autism ($t(74)=-2.51$, $p=.014$, 2-tailed). Families with children with autism (mean=2.64, SD=0.75) were found to have lower Global Self-Perception than families who have children without autism (mean=3.01, SD=0.54).

Job Competence Self-Perception

An independent samples t-test found that there was a statistically significant difference between levels of Job Competence Self-Perception in families with children with autism and families who have children without autism ($t(73)=-2.82$, $p=.006$, 2-tailed). Families with children with autism (mean=2.77, SD=0.53) were found to have lower Job Competence Self-Perception than families who have children without autism (mean=3.13, SD=0.52).

House Hold Self-Perception

An independent samples t-test approached statistical significance between levels of House Hold Self-Perception in families with children with autism and families who have children without autism ($t(75)=-1.98$, $p=.051$, 2-tailed). Families with children with autism (mean=2.82, SD=0.53) were found to have lower House Hold Self-Perception than families who have children without autism (mean=3.08, SD=0.56).

Correlation

Table 4

A Pearson correlation co-efficient; highlighting the relationship between stress and self-efficacy, global self-perception, job competence and house hold self-perception.

Statistics/ Variables	Pearson's (r)	Sig (2-tailed)
Self-Efficacy	-0.543	0.000
Global S-P	-0.690	0.000
Job Competence S-P	-0.593	0.000
House Hold S-P	-0.419	0.000

The fourth hypothesis asked if a relationship existed between levels of stress and levels of self-efficacy and the three sub groups of self-perception in both groups of families. The scatter plot analysis of the sample of participants and responses to the three psychometric levels suggested that parametric testing was robust enough to determine a correlation between the criterion variable. A Pearson's correlational analysis was carried out to investigate if a relationship existed between levels of stress (now identified as a Predictor Variable) and Self-Efficacy, and the three sub groups of Self-Perception (table 4).

A Pearson's correlation coefficient found that there was a strong negative significant relationship between stress and self-efficacy ($r = -0.543$, $p < .001$, 2-tailed), in addition a strong negative significant relationship also existed between Perceived Stress and Global Self-Perception ($r = -0.690$, $p < .001$, 2-tailed) and a strong negative significant relationship exists between Stress and Job Competence ($r = -0.593$, $p < .001$, 2-tailed), with a moderate negative significant relationship existing between Stress and House Hold Self-Perception ($r = -0.419$, $p < .001$, 2-tailed). This suggests that higher levels of stress correlate with low levels of Self-Efficacy, Global Self-Perception, Job Competence and House Hold Self-Perception.

Analysis of Variance

Table 5

An analysis of variance values of a multiple regression where families with children with autism, self-efficacy, and three domains of self-perception were selected as predictors of stress.

Statistics Variables	Unstandardised Coefficients		Standardised Coefficients		t	p
	B	Std Error	Beta β			
Child with Autism	-4.197	1.622	-.220		-2.588	.012*
Self-Efficacy	-.026	.217	-.015		-.121	.904
Global Self-Perception	-6.990	1.625	-.493		-4.301	<.001*
Job Competence	-1.730	2.253	-.102		-.768	.445
House Hold Management	-2.919	1.532	-.177		-1.905	.061

Note: * p significant at .05 level
 Dependent Variable: Perceived Stress
 $R^2 = .582$, R^2 Adjusted = .550; $F = 18.632$

A multiple regression was undertaken to test whether self-efficacy, having a child with autism and three domains of self-perception were predictors of perceived stress (table 5). The results of the regression indicated that the five predictors explained 55% of the variance ($R^2=.55$, $F(5, 67)= 18.632$, $p<.001$). It was found that having a child with autism significantly predicted stress ($\beta= -.220$, $p=.012$, $95\%CI=-7.434- -.960$) as did global self-perception ($\beta=-.493$, $p<.001$, $95\%CI= -10.233- -3.746$).

Qualitative Overview

Three questions were asked, participants could respond to all three or to those which they deemed appropriate to themselves. Question one asked about a specific stressful event in the last week, whereas questions two and three requested information about a stressor, based on a whole family event, within the last week and in the next six months. 50 responses to the qualitative questions were received 12 (24%) from the parents with children with autism and 38 (76%) from parents with children without autism. 3 of 7 male primary care givers from the parent group with children with autism responded to the qualitative questions, and 2 of 5 male primary care givers from the parent group with children without autism completed the qualitative questions, the remaining 45 responses were from female primary care givers.

Four broad categories were chosen, reflecting the ecological model which families exist in; (1) Family, featuring responses centring on children or spouse; (2) Social, events centring on family outings in the community are recorded; (3) Economic, issues regarding employment are highlighted and (4) Wider community, features matters relating to health, education or governmental systems (table 6).

Table 6

Qualitative parental responses categorised within their ecological environment.

Categories/ Parental Groups	Family	Social	Economic	Wider Community
Families with children with autism	12	12	1	1
Families with children without autism	38	0	27	0

Responses by families with children with autism within the “Family” category saw 4 identify their child’s self injurious behaviours as stressful, with 6 citing “behaviours” by their child with autism as stressful, 1 response each, on strangers “ignorance” of their child’s special needs and an unsupportive spouse were identified as stressful. Whereas responses from families with children without autism centred on “new babies” in 2 cases, “deaths” in extended elderly family in 2 cases, spousal “rows” in 5 cases, child care arrangements during the holiday season accounting for 6 cases and children “not doing what they are told” in 23 cases were deemed stressful.

No incidences of issues within the “Social” category were highlighted as stressful by families with children without autism, however the special needs of a child with autism was identified in all cases for families with children with autism. 4 families cannot attend a family event, as an entire family in the next six months, due to their child’s needs. One is a wedding which only one parent could attend, one is a communion, and two are confirmations where only one parent can attend, so the other caregiver can “mind” their child with autism. Family visits to the zoo by one family and to a restaurant by two families are no longer options as

they are deemed too stressful and family holidays in 5 cases cannot be taken together, and cause stress each time they are mentioned.

Long term therapy funding for one family with a child with autism was highlighted as stressful, whereas, job security was identified in 21 cases in families with children without autism, debt in 5 cases and 1 case of a spouse working “away from home” were also highlighted as stressful.

The “Wider Community” was identified by one family with a child with autism as stressful, this involved “unnecessary bureaucracy” by an educational establishment surrounding their special need’s child. This category did not rank as stressful for families with a child without autism.

Additional Findings

Although not identified within the hypotheses, analysis of other variables identified two statistically significant differences between groups and levels of stress. An independent samples t-test found that there was a statistically significant difference between suburban and rural dwellers in levels of stress ($t(53)=-3.22$, $p=.002$, 2-tailed). Rural dwellers (mean=33.12, SD=7.12), were found to have higher stress than suburban dwellers (mean=22.96, SD=8.41).

Differences between male and females in their levels of stress was also identified, an independence samples t-test found that there was a statistically significant difference between males and females in their levels of stress ($t(23.79)= 2.82$, $p=.043$, 2-tailed). Males (mean=28.75, SD=5.79) were found to have higher levels of stress than females (mean=22.98, SD=9.40).

Aspects such as levels of education or location of where families lived did not highlight any statistical differences in self-efficacy, or the three sub groups of self-perception, levels of stress were shown not to differ significantly in respect of the caregiver's level of education.

DISCUSSION

The two aims of this study were; (1) to determine if there are significant differences in and a relationship between, levels of stress, self-efficacy and self-perception in families who have children with autism and families who have children without autism. (2) To stimulate discussion about whether additional tasks that Therapist and Service Providers give to parents of children with autism may have an effect on how well each member of the family fulfils the overall need of the family. In order to address these, five hypotheses were offered; (1) Do significant differences in levels of stress exist between parents of families with children with autism and families who have children without autism? (2) Do significant differences in levels of self-efficacy exist between both groups of parents? (3) Do significant differences in levels of self-perception in three different domains exist between families who have children with and without autism? (4) Is there a correlation between levels of stress, self-efficacy and self-perception? (5) If so, can any or all of the identified variables predict high levels of stress in families?

Three simple qualitative questions were asked in order to identify stressors that happened within the family in the last month. The questions also asked to identify a family setting that may be affected by the identified stressors. These stressors will not be able suggest a cause and effect of being responsible for upsetting a particular family function but it may provide an insight into differences that may exist between families with children with autism and families with children without autism.

In order to ensure that a group of parents of children with autism was recruited, Principals of four Department of Education and Science designated schools for children with

autism were approached. In light of the fact that children who attend these schools all have to have a primary diagnosis of autism, it was not necessary to re assess each of the children. These schools provided an unexpected benefit, (1) the children attending these schools would have been a number of years post diagnosis and (2) the schools catered for children with moderate to severe deficits in the autistic spectrum. This would have the advantage of assessing their parent's levels of stress, self-efficacy and self-perception from the point of view of several years of caring for their child with autism. These schools were previously Applied Behavioural Analysis (ABA) schools, which meant that the children were benefiting from direct intervention addressing a range of issues such as challenging behaviours to learning independence for future living. Therefore the parents would not be answering questionnaires based on their changed circumstances due to a very recent diagnosis but instead based on their current established family life.

Hypothesis 1: Stress

The study has found that the parents who have children with autism had significantly higher levels of stress than parents of children without autism when responding to the Perceived Stress Scale (PSS14). This had been identified in previous studies (Pottie & Ingram, 2008, Abbeduto et al, 2004). What is of interest is that the families of children with autism were several years post diagnosis, and stress levels were still significantly higher than in parents of children without autism. Ten of the twelve responses by families with a child with autism highlighted their child's "behaviours" as being stressful, with four of the respondents identifying their child's "self injurious" behaviours as being very stressful. Hastings & Brown (2002) and Hartley et al (2010) highlighted "behaviours" of children with autism as being directly linked to higher levels of stress in families with children with autism. Although Bristol et al (1993) had identified differences in levels of stress in parents of children with

autism after undergoing psycho-educational instruction in TEACCH (Treatment and Education of Autistic and related Communication-Handicapped Children) to assist them in addressing their child's behaviour. It is interesting to note that parents in this study still identified their child's "behaviours" as stressful despite the benefit of Applied Behavioural Analysis intervention. The question arises as to whether other factors, perhaps extraneous are a possible reason for the increased levels of stress. Some insight to this might be evident in the fact that parents identified family meals in restaurants, trips to the zoo or family holidays that are often cancelled, due to the behaviours of their child with autism, or perhaps due to "others ignorance" (participant 11).

Implications of elevated long term levels of stress could spill over into the realm of chronic stress which has a consequence, of affecting the brain, behaviour, cognition and overall health of the Caregivers (Lupien, McEwen, Gunnar & Heim, 2009). An insight into how the stress of "behaviours" of a child with autism was evident in the comments made by parents with respect to future family outings or events being affected. It was clear from the qualitative responses of parents of families with children with autism that "not going" on holiday, to the zoo, or restaurant, or "only one of us" going to a family wedding, communion or confirmation suggests that typical family events are affected by having a child with autism. What cannot be determined is whether it is other people's perceptions of the children's behaviours that preclude parents from attending normal family events or whether parents rather avoid a situation than be placed in an awkward position. As stress is a transaction (Pottie & Ingram, 2004) between a person's perception of a stressful event and that person's ability to address the event utilising both their internal and external abilities, it is interesting to note how some of the participants addressed the stressor. In four of the responses to the qualitative questionnaire, an "unsupportive partner" was highlighted as a long term stressor,

participant 22 highlighted that “not being able to live a normal life anymore” was their partners serious concern, the difficulty was the partner was spending more time “working away from home” as a result.

In contrast, stressors identified by parents of children who do not have autism cited “unruly behaviour” of their children as stressors, these were children not doing their “chores” (participant 73), teenagers “not listening” (participant 51). Deaths in the extended family, the arrival of a new baby, or a child’s illness were also highlighted, participant 55 found a “four hour wait in A&E” stressful. “Rows with a partner” were identified as stressors (participants 31, 42, 45, and 77), however at no stage did any of the parents who have children without autism indicate that this had or will have an effect on a family event or outing. Financial stressors were also identified within this group with mortgage arrears and debt as stressors; this was to be expected within the current economic climate.

A number of factors potentially affecting stress, such as level of education showed no significant effect on either group, however rural dwellers (N=8) had higher levels of stress than their urban and suburban peers. Males (N=12) showed higher levels of stress than females, although no analysis was conducted within groups, this result was in contrast to studies (Baxter et al, 2000) that showed otherwise. A possible explanation could be due to traditional gender roles being reversed in the current economic climate with the male taking on the role of primary caregiver.

Hypothesis 2: Self-Efficacy

Significant differences were observed between both groups of parents in their responses to the Generalised Self-Efficacy Scale. Parents of children with autism had lower levels of general self-efficacy than parents of children without autism. Bandura (1997) as cited by Pervin & Cervone (2010) identified three concepts in self-efficacy, (a) competencies; or the cognitive capacity to cope with challenges, (b) expectancies; or one's beliefs directed towards the future, and (c) goals; or the ability to set specific goals for the future. Family function is the ability to have individual needs of the family being met successfully (Raina et al, 2005). To achieve this, parents should have high self-esteem and self-efficacy.

From the onset, it is critical to note that while parents of children with autism experience higher levels of stress than parents of children without autism, the lower levels of general self-efficacy identified, does not reflect parenting ability (Hassall, Rose & McDonald, 2005). Generalised Self-Efficacy takes an overall look at how parents address unexpected events or deal with an accumulation of everyday issues, studies which have identified parental satisfaction rates utilise the Parental Locus of Control Scale or Parenting Stress Scale (Hassall et al, 2005). While parents of children without autism identified a range of stressors related to their children, it was interesting to note that not one of these stressors, directly impacted on family life, function or structure. In contrast, the significant child centred stressor identified by parents of children with autism was "behaviours", it was clear that families would not be able to attend family functions such as weddings, communions, or confirmations as an entire family. Participants (13, 21, 25 and 28) indicated that "only one of us will go with the rest of the family, while the other looks after our child".

While no question arises in relation to parenting skills, clearly there appears to be either a lack of confidence, or ability to manage, or there exists an issue about others perceptions of the child with autism. Interestingly Hassall et al (2005) noted that the range of supports, alone, available to parents of children with autism has little or no correlation with levels of self-efficacy or stress, however the perceived helpfulness of such supports were a greater factor in reducing stress and increasing self-efficacy, with the highest effect resulting from partner/spouse support and formal and informal kinship support from immediate and extended family. Parents of children with autism felt less confident in addressing the unexpected or being involved in community activity. Participant 27 highlighted “school issues” and “overt bureaucracy” by a school as stressful. Clearly this parent was advocating for their child with autism and was finding it difficult; however it was not clear if it was the parent’s confidence in their ability that was a factor or the inflexibility of the situation. The question that remains is whether it is parental perception of their own ability or others perception of parents that affects levels of self-efficacy? Perhaps assessing parent’s self-perception will shed light on this.

Hypothesis 3: Self-Perception

Three sub-sections of the Harter Self-Perception scale were chosen to assess both groups of parents. Clear differences were found in levels of Global Self-Perception and Job Competence between families. Parents of children without autism were found to have higher self-perception in both these sub-scales than parents with children with autism. A difference within the house-hold sub-scale was approaching statistical significance between both groups with higher levels of self-perception in this sub-scale being attributed to parents of children without autism.

The three sub-scales were identified based (1) on the general aspect of self-perception and (2) on two domains that may show a relationship between family function and the parent's perception of them. A significant difference in Global Self-Perception was identified between both parent groups. Each sub-scale showed higher levels of self-perception in parents of children without autism.

Does society in general see parents of children with autism in a different light than parents with children without autism? Blanchard et al (2005) highlight diminished family function due to the chronic needs of a child with autism, with a family being less likely to be involved in sport and community activities, as well as having significantly more difficulty in childcare, and parental employment. It is difficult to establish a causation as to whether it is the parent whose perception is one thing or whether it is society's perception that is the other.

Job Competency addresses a person's perception of themselves in their job, whether career or as a caregiver. What is surprising is that there is a significant difference between both groups. Although the assessment was not carried out within a job situation where there would be a likelihood of placing a favourable bias on responses, it appears from the data that parents of children with autism view their competence in a work situation at a lower level than parents of children without autism. Although loss of work was identified by parents of children without autism as a stressor, their perception of their competence was higher than the other group of parents. The effect on a family system, if a parent loses a job or is not promoted, or feels that they are not doing a good job at home will be significant. Long term financial struggles are one of the highlighted effects on the family in the care of a child with autism (NAS, 2007).

The Household sub-scale was approaching statistical significance, again with parents of children with autism scoring lower in their self-perception than the other group. This sub-scale could have been open to a positive bias as all parents strive to ensure that they are as house proud as everyone else, however it showed that, long term care of a special needs child was potentially having an effect on a parent's perception. Could this have an effect on a family system? This is difficult to determine, none of the responses obtained in the qualitative aspect of the questionnaire made reference to household issues being of concern or stress.

Blanchard et al (2005), suggest that a combination of issues affect the family of a child with autism. Parents stress, self-esteem and self perception can affect the quality of life of the individual and the family as a whole. Is there possibly, a relationship, between these variables, and could they be associated with reduced family structure and function?

Hypothesis 4: Relationship between variables

Having identified that there are differences in levels of stress, self-efficacy and self-perception between both groups of parents; with parents of children with autism registering higher levels of stress and lower levels of self-efficacy and self-perception than parents who have children without autism. The next step was to determine if there was a relationship between the variables. A correlation analysis found that a strong relationship existed, higher levels of perceived stress correlated significantly with lower levels of self-efficacy and self-perception. The alternative was also true, lower levels of stress correlated strongly with higher levels of self-efficacy and self-perception.

Hypothesis 5: Predictors

In light of findings in the previous four hypotheses, a final question required resolution, could specific variables predict stress? An analysis of variance selected perceived stress as a dependent variable, with having a child with autism, self-efficacy and the three sub-scales of self-perception as predictor variables. All five predictor variables accounted for 55% of the difference of the variance, indicating that they were strong predictors of family stress.

Strengths of the study

While all five hypotheses have found support in previous studies, one of the strengths of the study is that short generalised psychometric tests can give a reasonably strong indication of family stress. Previous studies (Pottie & Ingram, 2008, Baxter et al, 2000, Hassall et al, 2005) highlight specific stressors whether they be the behaviour of a child with autism or social, economic or depressive symptoms, as being critical to the overall effect on family function (Hassall et al, 2005). This short questionnaire focused on perceived stress, general self-efficacy and the three identified sub-scales of self-perception which may perhaps highlight the potential for long term family functioning issues.

A second strength of the study was the two groups of parents, both groups required to have children between the age of 7 and 12 years old, this ensured that unexpected variables such as stress associated with new parenthood or with recent diagnosis of autism would not skew the data. Both groups were well established in both family function and structure. In addition the families with children with autism would have been a number of years post diagnosis of their child giving a more accurate reflection of their particular family circumstance.

Limitations

The participants were recruited using a convenience sample, although four schools for children with autism participated only one mainstream primary school was involved for the group of parents who had children without autism. Therefore the findings could not be generalised realistically to reflect the situation of all parents of children with autism within the Irish context. The study also relied on a subjective response to what constituted stressors within the family, it would not be possible to identify with accuracy those aspects of family life that caused stress, other studies have used specific scales such as the Family Support Scale, the Parenting Sense of Competence Scale, the Parent Locus of Control Scale and the Parenting Stress Index (Hassall et al, 2005).

Implications and Applications

Families with children with autism appear to suffer from long-term stress, this has consequences psychologically and physiologically (Lupein et al, 2009). Coping strategies were not measured in the study; it is clear that elevated levels of stress continue over time. There are implications for education, health, community, and society in general to take account of additional burdens that families of children with autism have, even if they do not appear to be obvious. It is clear from some of the qualitative feed-back that families are prepared to split its functioning in order to ensure that other members such as partners or siblings can engage with community and social activity. Expectations of healthcare, education and service provider staff, on parents of children with autism to “find time” for daily Occupational Therapy, Physiotherapy, Speech and Language Therapy or to fight cuts in Special Needs Assistants, in addition to the greater family needs being met may need to be identified as a part of care-packages or service plans.

Debate perhaps could start on how to apply a more holistic approach for families with children with specific needs. Further study on developing a short generalised set of psychometric tests and concise accurate qualitative identification of family stressors could be initiated that can give clear indications of potential family issues. This may assist policy makers and service providers in tailoring care and service plans specifically to those families.

Conclusion

Families with children with autism clearly need to be confident that they can advocate successfully for their child as well as their families. They also need to feel valued in society both as active participants socially and domestically. A change in focus emphasising the child's activity and participation rather than their impairment and disability (WHO, 2004) may greatly benefit service providers and policy makers. Education, community health, the social community and extended family perhaps need to work together to ensure that parents with children with autism have the self-efficacy and self-perception that they need to fully satisfy work, community and family commitments. A short psychometric assessment on parents at the time of evaluating a child with a potential pervasive developmental disorder may assist in a tailored and holistic approach to keeping the family system functioning at its optimum.

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APPENDIX 1**(Questionnaire Pack distributed to participants)**

Appendix 1 Questionnaire pack

Dear Participant,

Thank you for taking the time to read this introduction. As a part of the final year of my degree I am required to carry out a quantitative research project. I propose to look at how particular factors affect the family dynamic, more specifically how families with a child or children with and without disability may differ in how extraneous burdens (example, financial, work/family life balance etc) may have an impact on them.

The questionnaire aspect should take no more than 15-20 minutes to complete, with the qualitative questions taking as long or as short as you want.

The primary care giver is asked to respond.

There is no identifying information requested, there is no right or wrong answers and you are free to drop out at any stage. However I would be obliged if you have taken the time to complete the questionnaire, to seal it in the envelope provided and return it to the school Principal, where it will be placed in a sealed box to be returned to me.

All information is confidential and answers will be recorded as statistical information only.

Should you have any questions please direct them to your principal who can make contact with myself or my supervisor.

I would be grateful if you could **return** the completed questionnaire by **Monday January 23rd 2012** at the latest.

Regards

Padraic O hEadhra.

Demographic Questions

Circle the appropriate answer.

- (1) Gender of respondent: Male/female**
- (2) Do you have a child with a disability (other than ASD) in your family? Y/N**
- (3) Do you have a child with ASD in the family? Y/N**
- (4) How many children with ASD are in your family? 1, 2, 3, 4, more.**
- (5) Location of where you live: Urban/ Suburban/Rural.**
- (6) Standard of Education: Primary/ Secondary/ College or University**
- (7) Age of Respondent: (please write age in the space provided.)**

Instructions:

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems a reasonable estimate.

For each question choose from the following alternatives and place your choice on the dotted line before each question.

0= never

1= almost never

2= sometimes

3= fairly often

4= very often

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and stressed?
4. In the last month, how often have you successfully dealt with irritating life hassles?
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
6. In the last month, how often have you felt confident about your ability to handle your personal problems?
7. In the last month, how often have you felt that things were going your way?
8. In the last month, how often have you found you could not cope with all the things you had to do?
9. In the last month, how often have you been able to control irritations in your life?
10. In the last month, how often have you felt that you were on top of things?
11. In the last month, how often have you been angered because of things that happened that were outside your control?
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?

A reminder of the alternatives:

0= never

1= almost never

2= sometimes

3= fairly often

4= very often

13. In the last month how often have you been able to control the way you spend your time?

14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Harter Adult Self-Perception

Fourteen questions representing three sub-scales of the Harter Adult Self-Perception Scale, Global Self-Perception, Job Competence and House Hold Self-Perception, appeared here. Copyright restrictions apply.

Instructions: Please read the sentences below and select an answer for each statement which indicates how much the statement applies to you. Please place your chosen number on the dotted line before each question.

- 1= not at all true**
2= hardly true
3= moderately true
4= exactly true

- 1 I can always manage to solve difficult problems if I try hard enough.
- 2 If someone opposes me, I can find the means and ways to get what I want.
- 3 It is easy for me to stick to my aims and accomplish my goals.
- 4 I am confident that I could deal efficiently with unexpected events.
- 5 Thanks to my resourcefulness, I know how to handle unforeseen situations.
- 6 I can solve most problems if I invest the necessary effort.
- 7 I can remain calm when facing difficulties because I can rely on my coping abilities.
- 8 When confronted with a problem, I can usually find several solutions.
- 9 If I am in trouble, I can usually think of a solution.
- 10 I can usually handle whatever comes my way.

Qualitative Questions

Instructions: Feel free to elaborate on your answer in the space provided, or, you need not respond to any of the following questions.

- (1) In the last week, what, in your opinion constituted a stressful event in your family situation?

- (2) In the last week did anything outside your control result in preventing your family as a whole from participating in a typical family event? If so what: (A family event might include going to the park, cinema, or family restaurant).

- (3) In the next six months, what in your opinion might constitute a possible stressful event(s) that you feel would have an effect on a typical family outing or event? (A family event or outing may include going to the park, cinema, or family restaurant).

Dear participant, thank you for completing the questionnaire, should any of the questions asked caused you to think about aspects of your own or others family life at present, and you feel the need to talk to someone about it, please note the following numbers below.

Feel free to detach this page should you wish.

Aspire Ireland
Asperger Syndrome Association of Ireland

www.aspireireland.ie
01 8780027

Aware

www.aware.ie
Lowcall 1890303302

Irish Autism Action

www.autismireland.ie
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