

Social Impact of ASD on Families and Alternative Treatments

**A major project submitted in partial fulfilment for the award of the degree Graduate
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ABSTRACT

Introduction: There is increasing interest about the involvement of diet in the etiology and treatment of Autistic Spectrum Disorder (ASD). However, minimal research has focused on parental beliefs and practices in the management of children with ASD, or the impact that a child with ASD potentially has on their family. The search for effective orthodox and unorthodox treatments for children with ASD can be difficult and exhausting for primary caregivers. Anxiety-related traits have been associated with the burden of caring for children with ASD, and may also contribute to the development of psychiatric problems in parents.

Objective: To examine the role of diet, parental beliefs and practices with regard to the management of children with ASD. Also, to explore levels and predictors of stress in primary caregivers of children with ASD compared to children without ASD.

Methods: Questionnaires were posted to primary caregivers of three groups, namely children diagnosed with ASD, those with milk intolerance and a control cohort. The questionnaires were designed to gather information about the children, including developmental history, and behavioural, sleep and food issues. The mental health status of parents and the impact of the child on the family were also examined. Focus groups were conducted with primary caregivers, which aimed to explore their experiences in the management of ASD.

Results: Data from 73 participants was analysed. Compared with children without ASD, primary caregivers of children with ASD experienced higher levels of depression, anxiety and stress. The impact of a child with ASD on their family was greater than for children without ASD, including those with food intolerance.

Some parents found their child's eating habits difficult to cope with, and many of these were not willing to consider dietary modification for this reason. Others however, found dietary modification effective and relatively easy to implement.

Discussion: The results highlighted that high levels of depression, stress and anxiety in primary caregivers are associated with difficulties in coping with children with ASD. Furthermore, parents need to have access to sufficient, suitable information, with respect to the treatment and dietary management of ASD.

INTRODUCTION

Autistic Spectrum Disorder (ASD) is a developmental disorder, which affects the manner in which children communicate and associate with those around them. Often, ASD is referred to as a triad of impairments as social communication, social interaction and imaginative understanding are affected (1,2). Further signs are obsessive repetitive behaviour, hyperactivity, self-injury and selective eating (2). ASD is generally related to other disorders that present symptomatic similarities, such as Asperger's Disorder and Coeliac disease (3). ASD is one of the five disorders that is categorized under the Pervasive Developmental Disorders (PDD), a category of neurological disorders that are characterized by severe and pervasive impairment in several areas of development, including social interaction and communication skills as specified by the diagnostic criteria DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) (1,4,5,6).

Symptoms typically become apparent around the age of two years, when there is a regression in behaviour, and children lose speech and the ability to interact with others (1). ASD is considered one of the most common of Pervasive Developmental Disorders, affecting approximately from 4 to almost 60 per 10 000 individuals (4,8,9,10,11). The pattern of prevalence is not influenced by maternal age, race/ethnicity, education or social boundaries, however it seems to be four times more prevalent in boys than girls (4,5,6,7).

An association between behavioural disorders and dietary intake was made as early as the mid sixties and has been associated with improvement in behaviour (2,15). Interaction with the brain and intestine is suggested to evolve as a result of abnormal intestinal permeability, which leads to the incomplete breakdown of food proteins and absorption of toxic peptides (3). As a result food intolerance and gastrointestinal problems such as diarrhoea evolve, resulting in the implementation of exclusion diets for therapeutic effects (3,12). Findings of immunoreactivity against casein and gluten, have implemented the exclusion of milk and wheat from the diet, as a result of an association between coeliac disease and ASD. Behavioural improvement has been linked to the exclusion of these proteins (2,15).

Recent research has demonstrated that gluten is broken down in the intestine, producing opioid peptides. Opioid peptides affect brain development, and their presence in high concentrations is suggested to limit development and function in the brain (12,13,14,15).

Hence, the multitude of behaviours in ASD is suggested to evolve from interaction with the brain and opioid system. A diet excluding casein and gluten is suggested to reduce the opioid effect (3,12,13,15)

Dietary intervention in the form of a gluten and casein free (GF/CF) diet used in the treatment and management of ASD is considered an alternative treatment to conventional therapy and often classed in the same category as naturopathy (12,16). Hence, dietary intervention is considered somewhat controversial, as it is deemed as a denial of the scientific basis of medicine (16).

Parents and in particular the primary caregiver of children with ASD seem to experience more stress and are more susceptible to negative outcomes than parents of children with non-disabilities (27). Anxiety related traits to ASD related conditions have been associated with the burden of caring for ASD children, and may also contribute to the development of psychiatric problems in parents (18).

Dietary intervention is not simple or cheap and thus may place more stress on an already demanding situation, due to the removal of foods that are doing more harm than good and replacing them with alternatives that repair the digestive and immune systems (3,12). Cost and difficulties encountered in the management of ASD may preclude parents from trying or continuing dietary treatment (3,12,13). Significant adverse factors in the management of diet modification in children with ASD are believed to include parental stress and depression, as a result of the limited coping resources, such as social support from formal sources (child care professionals) and informal sources (family and friends). (19).

Lifestyle changes and the perception that medical practitioners are not promoting dietary treatments add to the concern of parents. Medical professionals do not agree on the most appropriate balance in treatment (3,19). This limited support seems to lead parents to search for other avenues of treatment and source information from friends, support groups, media and internet, adding to the concern and stress of an already demanding situation (19).

Due to minimal research focused on problems in the management of dietary modification, the aim of this study was to examine parental beliefs and practices with regard to the management of children with ASD, aged 3-10 years.

Also, to explore problems involved with dietary modification and predictors of stress in primary caregivers of ASD children, in comparison to caregivers of children without ASD.

METHODS

Research Design

The research was conducted in three parts, and will be outlined in the following sections:

- Part 1: Questionnaire Booklet
- Part 2: Practitioner Interviews
- Part 3: Focus Group

Ethics Approval

Approval was sought and approved by the Ethics Review Committee of the Central Sydney Area Health Service (RPAH Zone).

Participant Recruitment

Participants were randomly selected for inclusion in the research from three groups:

1. **ASD Cohort** – consisted of patients existing or previously seen at the RPAH Allergy Unit, diagnosed with ASD; a group from the Illawarra School for Autistic Children, diagnosed with ASD; and a group from Sylvanvale Handicapped Children's Centre, New South Wales, diagnosed with ASD.
2. **Milk Intolerant Cohort (MI)** - patients existing or previously seen at the RPAH Allergy Unit with known non-atopic milk intolerance. This formed an age-matched non-ASD control group that was food intolerant but had no allergies.
3. **Control Cohort** - age matched control group without ASD or food intolerance or allergy, drawn from the general childcare centre and preschool community, within geographical convenience of the Central Sydney Area Health Service.

All groups were contacted by phone for interest in participation in the research. Those interested in participating were sent a study package (Appendix 1-2) containing:

- A patient information sheet outlining the aims and procedures of the study
- Expression of interest form, indicating parents to consent to study participation
- Coded questionnaire booklet (identifying cohort and study participation number) with a requested return date to the Allergy Unit
- A reply paid envelope for return of questionnaires and expression of interest form.

214 packages were posted to participants from the RPAH Allergy Unit Sydney (ASD and Milk Intolerant), and delivered to the Illawarra School for Autistic Children, Sylvanvale Handicapped Children's Centre New South Wales, and Childcare Centers during late August to mid September 2003. Questionnaires returned to the Allergy Unit by 17th October 2003 were included in the study results. Participants' initials and a study identification number were used to identify participants.

Inclusion Criteria

Inclusion criteria for the ASD diagnosed group included primary caregivers of children with ASD, diagnosed as per DSM IV criteria-American Psychiatric Association (1) and children aged between 3 to 10 years, male and female, and toilet trained. Inclusion criteria for the milk intolerant and control groups included primary caregivers of children aged between 3 to 10 years, male and female, and toilet trained.

Exclusion Criteria

Exclusion criteria for the ASD cohort included primary caregivers of children with any other metabolic disorders other than coeliac disease or asthma. Exclusion criteria for the milk intolerant and control groups included primary caregivers of children diagnosed with ASD, and/or metabolic disorders other than asthma and coeliac disease.

Exclusion criteria for all groups included the absence of daily interaction with the child, and a known existing mental issue of the primary caregiver. A controlled variable included any unknown mental issues that were quantified by the mental health assessment questionnaires.

Part 1: QUESTIONNAIRE BOOKLET DESIGN

Self-administered questionnaires were sourced from various studies. After close consideration it was determined that some questionnaires used in previous studies would not provide the range and detail of information that was being investigated. Therefore, questionnaires were altered in format but not content to allow for consistency, whilst other questionnaires were redeveloped from existing questionnaires, and some new questionnaires were developed. Permission was granted from authors where appropriate. The questionnaire booklet composed of nine questionnaires, six of which were used in this report of the study. (Questionnaires and questionnaire development are reproduced in Appendix 2). The questionnaires consisted of a mixed open and closed response format, and were designed to gather information about the children including; developmental and behavioural history, eating behaviour, sleep behaviour, food issues, impact of the child on the family, mental health status of the parent, and general questions regarding dietary modification and treatments pursued.

Part 2. PRACTITIONER INTERVIEWS

Two practitioners well recognised in the medical field for their work with ASD, namely Dr Antony Underwood (Consultant Paediatrician at Pymble Grove Health Care Centre) and MS Joanna Harnett (Naturopath and Nutritionist at Northern Beaches Care Centre) were consulted for their orthodox and unorthodox treatments in the management of ASD.

Part 3: FOCUS GROUPS

Focus Groups

Focus groups are group interviews that allow direct interaction with respondents, thus providing opportunity for probing of responses, clarification and follow up questions. Focus groups are a tool for discovery and exploration, by listening to people and learning from their experiences and beliefs. Focus groups create lines of communication, exploration, discovery and interpretation (20). They are a medium that encourages participants to investigate the ways that they are both similar and different to each other (20).

Primary caregivers who had consented to participation in the focus groups were contacted by telephone, to confirm their interest and participation in the groups. Parents were sent a letter confirming participation date and directions to the Allergy Clinic (Appendix 5).

Both focus groups ran for 1.0-1.5 hours, and participants were provided with refreshments prior to commencement of each group. Verbal permission for audio recording and note taking by two co-researchers was obtained. The facilitator (Dr Soutter) provided participants with a brief description of the study and explained how the information provided by the groups would be used. An information statement was read out (Appendix 5) to explain the process and reinforce that participation was voluntary, and to give assurance that the data would be kept confidential. Dr Soutter was the facilitator for each group.

Due to time constraints, a total of nine primary caregivers from the ASD group who had or had not included dietary intervention in their child's diet at some stage, participated in the two pilot focus groups. The focus groups were conducted at the RPAH Allergy Unit, as it was geographically convenient for all the participants

Participants

Primary caregivers were members of the ASD group, and had a child who had been diagnosed with ASD as per DSM IV criteria (1), aged 3-10 years of age.

DATA ANALYSIS

Part 1. Questionnaires

Identification coded data were entered into Access SQL Query Analyser 2000 (Microsoft Corp., USA). Participant files were checked to ensure data were accurate. When recording responses to questionnaires, only definite answers were included. Blank answers were treated as a null response, and were not included in data analysis.

Responses were analysed by Access SQL, to determine sub-scale scores. Data was further analysed to determine the variance within the three groups, for the various subscales, using One Way Anova and Post Hoc Scheffe analysis with SPSS (Statistical Package for the Social

Sciences) for Windows, version 10 (SPSS, Inc, Chicago, IL, USA). Bar graphs and tables were produced representing variations within groups, and were analysed using Microsoft Excel 2002 (Microsoft Corp., USA).

Part 2. Focus Groups

The tapes from the focus groups were transcribed, transcriptions edited against the tapes and a coding frame was developed (Appendix 5). The data was then coded manually and analysed using thematic and content analysis techniques.

RESULTS

Response Rate

Of the 214 questionnaires delivered or posted, 73 (34.11%) were returned. Forty questionnaires (18.69%) were returned incomplete, 2 were misplaced (0.93%) and 99 (46.26%) were not returned by 17th October 2003. Completed questionnaires received after the 17th October, 2003 were not included in the current research and are to be used in further analyses of the study. Incomplete responses in the questionnaires were excluded from analysis and only definite answers were included.

Gender and Age of Participants

The ASD group comprised 100% males, in comparison to the milk intolerant (MI) and control groups, which comprised of 52.38% and 73.08% males respectively.

Table 2. Age, Gender and Sample size of Total Respondents

Gender and Age	ASD Group	Milk Intolerant (MI)	Control
Male (n)	26 (100%)	11 (52.38%)	19 (73.08%)
Female (n)	0 (0%)	10 (47.62%)	7 (26.92%)
Total n	26	21	26
Mean Age (years)	6.32	5.54	5.41
SD for Age (years)	2.23	2.06	1.76
Age Range (years)	3.42-11.00	3.17-9.00	3.67-10.83

The mean age for participants ranged from 5.41 to 6.32 years, with the ASD group slightly older than the MI and control groups. There was no significant difference in age between the three groups.

Conners' Parent Rating Scales (CPRS-48)

All children participating in the study had their behaviour assessed using the Conners' Parent Rating Scales. This scale comprised of six subscales and was scored using T-scores

(Appendix 3). A T-score of 45-55 is the average for the population and should not raise concern (17).

Table 3. Conners' Parent Behaviour Rating Scales Mean T-Scores

Subscale	ASD	MI	Control
	Mean T-score ± SD	Mean T-score ± SD	Mean T-score ± SD
Opposition	48.73 ± 17.02	54.80 ± 17.72	47.27 ± 6.86
Learning Difficulties	74.96 ± 21.32	52.45 ± 14.18*	47.12 ± 11.72*
Psychosomatic	51.96 ± 21.43	75.90 ± 19.96**	60.96 ± 20.44
Impulsive-Hyperactive	59.04 ± 17.96	54.35 ± 15.01	47.88 ± 17.96***
Anxiety	49.80 ± 16.89	55.35 ± 13.58	46.54 ± 7.91
Hyperactivity Index	64.76 ± 17.44	51.65 ± 17.08 ∞	45.92 ± 9.43*

Mean difference is significant at: *p = 0.000, **p = 0.001, ∞ p = 0.017, ***p = 0.025

Learning difficulties were significantly higher in the ASD group than the MI and control groups (p = 0.000). The mean T-score of the ASD group for learning difficulties was 74.96, which is more than two standard deviations above the mean (50) for the standard population, and thus positions this group above the 97th percentile.

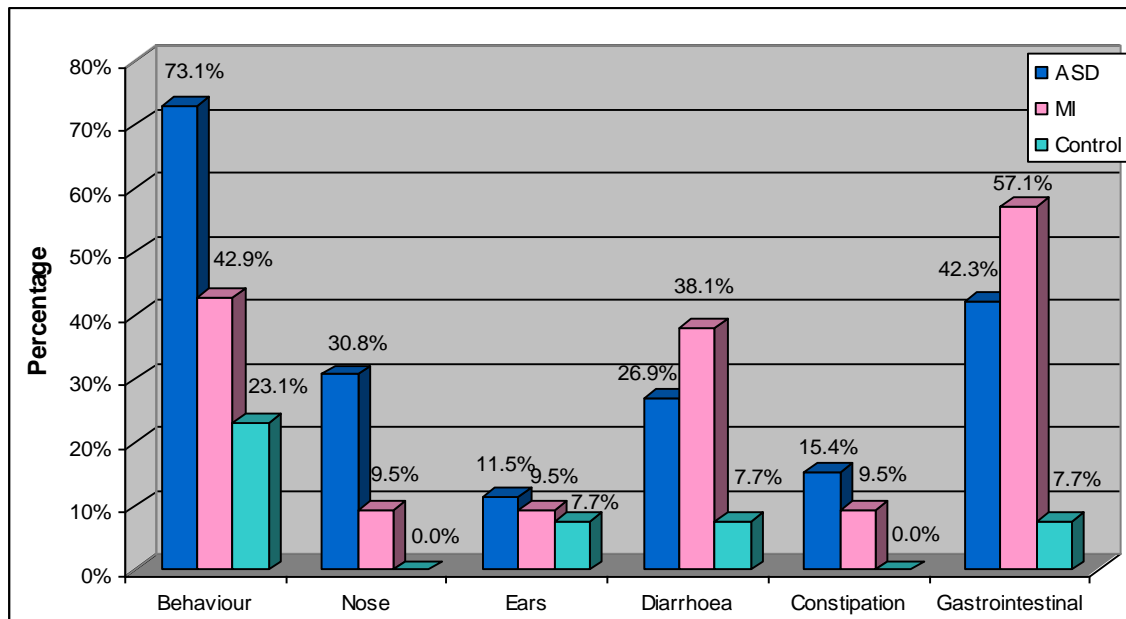
The mean T-score for impulsiveness/hyperactivity for the ASD group was 59.04, almost one standard deviation above the mean. The ASD group was significantly higher than the control group (p = 0.025) but similar to the MI group. There was no significant difference in mean score amongst the three groups for anxiety or opposition. The ASD group was significantly higher in hyperactivity index than the MI (p = 0.017) and control (p = 0.000) groups, and more than one standard deviation above the mean for the standard population.

Current Symptoms Experienced in Relation to Behaviour, General Health and Diet

Current Symptoms were investigated from the General Behaviour Checklist concerning; behaviour, gastrointestinal symptoms, food reactions, blocked nose, ear problems and general dietary related issues. Data were analysed by grouping symptoms together in similar groups and calculating the percentage of participants affected (scores of 2 or 3 on the questionnaire) by each symptom in each group.

Figure 1, shows the affect of these symptoms in comparison to the ASD group. A substantially greater percentage of subjects in the ASD group (73.10%) than subjects in the other two groups.

Figure 1. Current Symptoms - Percentage of Each Group Affected by Behavioural, Gastrointestinal and General Health Problems

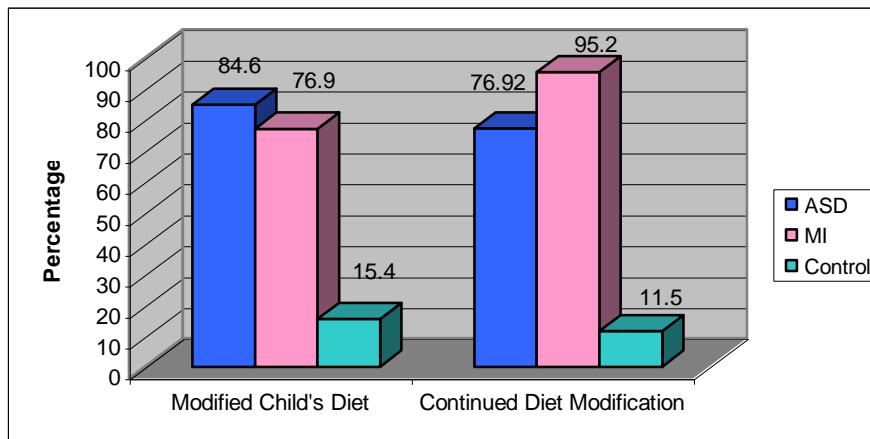


Considerably more ASD subjects suffered from a blocked nose (30.80%) than the MI (9.50%) and control subjects (0.00%). A slightly higher number of ASD subjects (11.50%) suffered from ear infections than MI (9.50%) and control (7.70%) subjects. The percentage of ASD subjects (15.40%) who suffered from constipation was greater than the MI subjects (9.50%), and far greater than the control subjects (0.00%). Although MI subjects experienced higher gastrointestinal problems (57.10%) than the ASD group (42.30%), the ASD group experienced far greater gastrointestinal problems than the control group (7.70%).

Dietary Modification for Improvement in behavioural and General Health Issues

Primary caregivers were asked if they had modified their child's diet for improvement in behavioural problems or learning difficulties. As shown in figure 2, the majority of primary caregivers in the ASD group (84.6%) have modified their child's diet and 6.92% were continuing diet modification.

Figure 2. Incidence of Dietary Modification and Continued Dietary Modification



Consultation of a Naturopath

Respondents were asked if they had consulted a naturopath about their child's diet. Consultation of a naturopath was most common in the MI group with 47.62% consulting, in comparison to 30.76% in the ASD and 7.69% in the control groups.

Sources of Recommendation Changes in Dietary Modification

Primary caregivers were asked about their sources of dietary information. As shown in table 4, parents of children with ASD obtained most of their dietary advice from medical professionals, friends and parents, reading, television, media and internet. The MI group received dietary modification advice from the medical profession, followed by friends and parents, but also consulted alternative practitioners.

Table 4. Sources of Recommendation for Dietary Modification

Source	ASD (%) n = 26	Milk Intolerant (%) n = 21	Control (%) n = 26
Medical/Paediatrician/Dietician	73.08	95.24	19.23
Friends/Parents	19.23	14.29	7.69
Reading	15.38	4.76	7.69
TV/Media	11.54	0.00	3.85
Internet	11.54	0.00	0.00
Alternative	3.85	9.52	3.85

Alternative medicine was the least sourced form for dietary advice with 3.85% in the ASD group.

Supplement Usage in Dietary Modification

Primary caregivers were consulted for their use of supplements in their child’s diet (Table 5).

Table 5. Supplements Pursued By Parents

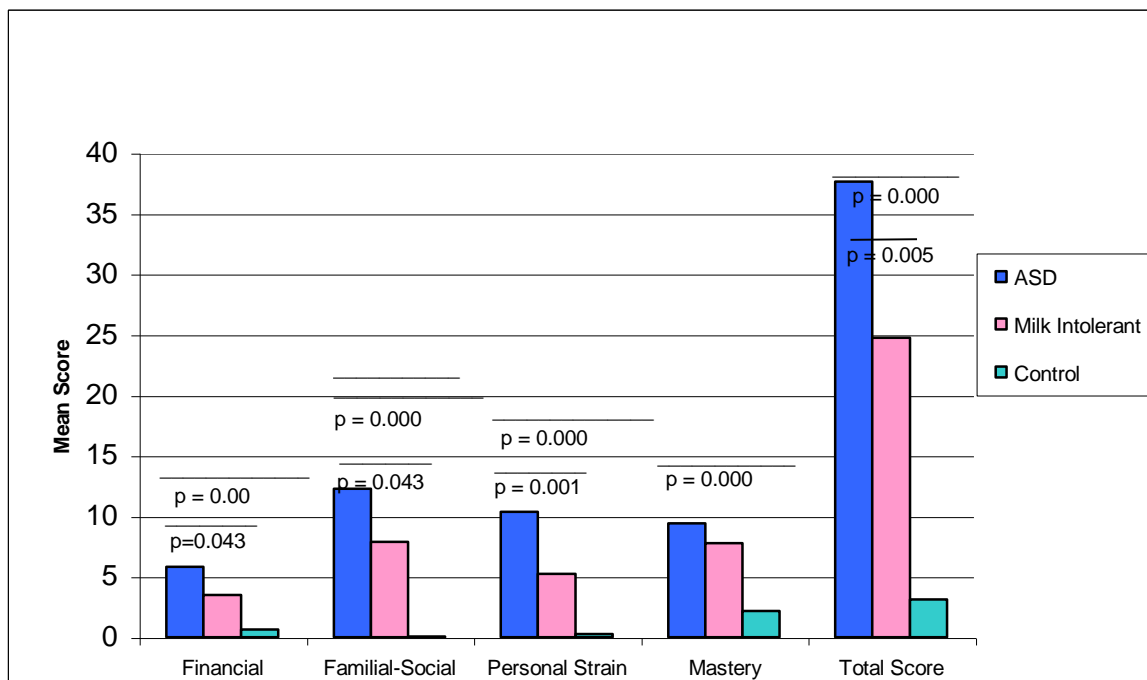
Supplement	ASD (%) n = 26	MI (%) n = 21	Control (%) n = 26
High Dose Minerals	50.00	28.57	7.69
Probiotic	30.77	19.05	0
High Dose Vitamins	26.92	28.57	15.38
Fish Oils	19.23	0	0
Digestive Enzyme	11.54	0	0
Special Formula/Powder	11.54	4.76	11.54
Regular Vitamins	7.69	0	7.69
Evening Primrose oil	7.69	4.76	0
Melatonin	3.85	0	0
Ginko	3.85	0	0
Homeopathic	3.85	4.76	0
Echinacea	0	4.76	3.85
Flaxseed oil	0	4.76	0

The most popular type of supplement used was high dose mineral, probiotics and high dose vitamins. Fish oils were used as a form of supplementation in the ASD group, whereas they were not used at all in the other groups. Homeopathic, Echinacea and flaxseed oil supplements were more popular in the MI group.

The Impact that a Child Has on the Family

The impact that chronic childhood illness has on the family was assessed in the three different groups by the Impact on Family Scale (IFS-24). Measurement of dimensions is detailed in Appendix 2. As shown in figure 3, the mean score for financial strain was significantly higher in the ASD group for primary caregivers than the control ($p = 0.000$) and MI ($p = 0.043$) groups.

Figure 3. The Impact on Family Scale (IFS)



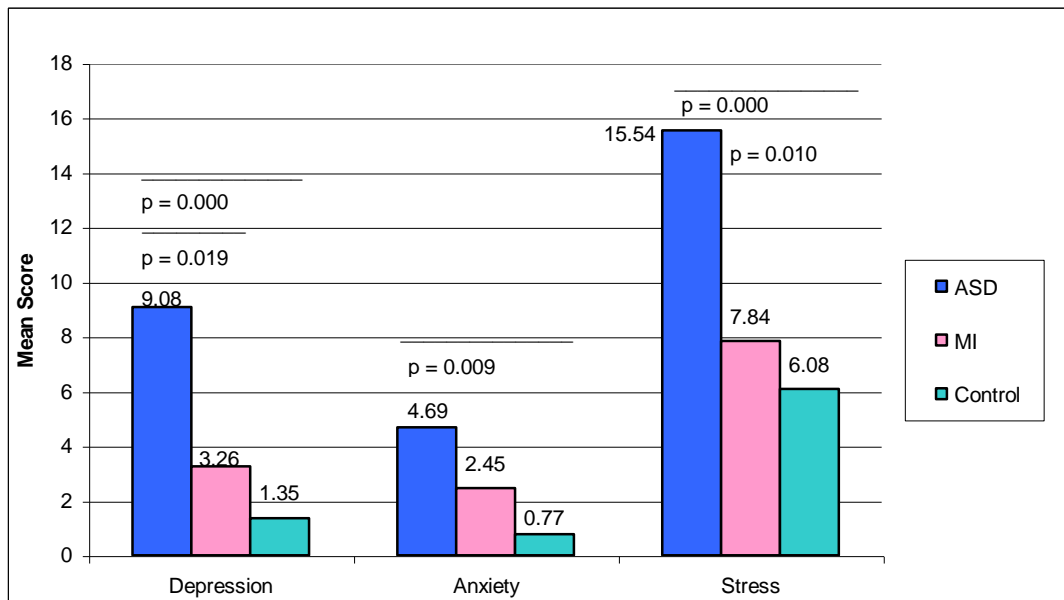
Key: Lines above each bar graph indicate levels of significance (p value) in comparison with the ASD group.

The mean score for familial and social strain in the ASD group was higher and significantly different from the MI group (p = 0.043) and the control group (p = 0.000). The mean score for personal strain on the primary caregiver was greater and significantly different in the ASD group in comparison to the MI (p = 0.001) and the control (p = 0.000) groups. The mean score for mastery required by primary caregivers in the ASD group was higher and significantly different to the control group, but not the MI group. Overall, the total mean score for all dimensions of impact on family resulted in higher scores for the ASD group, with significant difference in comparison to the MI (p = 0.005) and the control (p = 0.000) groups.

The Impact that a Child has on the Mental Health Status of the Primary Caregiver

The effect that chronic childhood illness has on the mental health status of the primary caregiver was assessed with the Depression and Anxiety Stress Scales (DASS42). Figure 4, displays the emotional states of depression, anxiety and stress of the ASD group in comparison to the MI and control groups. The primary caregivers in the ASD group experienced the highest level of depression and were significantly different to the levels of depression in the milk intolerant (p = 0.019) and the control (p = 0.000) groups.

Figure 4. The Depression and Anxiety Stress Scales (DASS42)



Anxiety levels were highest in the ASD group, and were significantly less than levels of anxiety in the control group but not the MI group. Stress was significantly higher in primary caregivers in the ASD group compared to primary caregivers in the MI ($p = 0.010$) and the control ($p = 0.000$) groups.

Assessment of the maximum scores achieved for each emotional state for primary caregivers in the ASD group, indicated z-score levels of extreme severity labels in depression, anxiety and stress (Appendix 3). A z score of 4.0 for depression indicated states of extreme severity for primary caregivers in the ASD group and positioned them in the 99.5 percentile. The maximum scores obtained for anxiety and stress, had z-scores of 4.0. This positioned states of extreme severity in anxiety and stress for primary caregivers in the ASD group in the 99.5 percentile.

DISCUSSION

Part 1. Questionnaires

Behavioural (73.1%) and numerous gastrointestinal symptoms (42.3%) were prevalent in the ASD group compared to the milk intolerant and control groups. Behavioural symptoms such as learning difficulties (74.96%), impulsiveness and hyperactivity (59.04%) were significantly greater in the ASD group compared to the milk intolerant and control group. Gastrointestinal (GI) symptoms including diarrhoea, abdominal pain, gaseousness/bloating and unexplained irritability have been associated with intestinal permeability in various studies and have been linked to ASD (21,22,23,24,26). Studies by Horvath (21,22) found that 40-60% of ASD participants were noted to have chronic diarrhoea or constipation. There are conflicting views as to whether intestinal permeability is the cause of GI symptoms in ASD (21,22,24,28,29) and this is an area where further study is warranted. Studies demonstrate that children with ASD have a high prevalence of various GI symptoms (21,22,30). Despite their cause, symptoms may contribute to behaviour and learning problems that were found to be significantly greater in the ASD group.

Gastrointestinal symptoms, behaviour and learning difficulties pose considerable challenges for parents in the management of ASD. It is well established that families of children with developmental disabilities experience chronic stress (31,32,33), however minimal studies have looked at parental stress and the impact on family with ASD children.

Children with ASD had a significantly greater impact on their family in areas of financial strain, familial or social strain, personal strain and mastery. As a result ASD parents were significantly more depressed, stressed and anxious than the other study parents, similar to findings of other studies (31, 32). Problems in children's behaviour, difficulties in learning and an array of conventional and alternative therapies available for the treatment of ASD, may be associated with the significantly high results for mental health status of the ASD primary caregivers. As assessed by the DASS-42 and IFS assessment tools, emotional states for primary caregivers in the ASD group, indicated levels of extreme severity labels in depression, anxiety and stress, positioning them in the 99.5 percentile (Appendix 3).

As there is no etiology for ASD, parents try conventional and non-conventional therapies for the best possible outcome for their child. It has been postulated that ASD can be assisted by exclusion diets such as casein free and gluten free diets (28,34,35). While some orthodox practitioners are sceptical about dietary intervention there are complementary practitioners who practice in this area (Interviews with Practitioners detailed in Appendix 4).

In this study the main source of dietary advice came from medical practitioners (73.08%) in the ASD group, which is different to study findings by Cornish (3), with the initial source of information from media (television, newspapers, magazines) being 42% and medical practitioners ranging from 8-33%.

In the present study 84.6% of ASD parents had modified their child's diet and 76.92% were continuing modification. Findings by Cornish (3) indicated that 11% of families had used a gluten and/or casein diet in the past, and 21% were currently modifying their child's diet. Although dietary modification has received scrutiny for its effectiveness in the management of ASD and is considered difficult to implement (3), the majority of parents in our study were continuing dietary modification. A study by Bowers (37) indicated that families found improvement in social behaviour and level of concentration following a gluten free regime. Alternative therapies are based on a variety of beliefs and usually have not been subjected to clinical research. Most are supported by anecdotal evidence, but some alternative therapies have proven effectiveness (35). Hence, dietary modification may be a beneficial treatment for individuals, and the benefits outweigh the difficulties involved in dietary intervention.

Part 2. Practitioner Interviews

With available access to scientific and anecdotal information in print and electronic media, parents often seek alternative treatments that are not among the conventional treatments recommended by medical practitioners (35). Often parents trial alternative therapy if the orthodox approach has not met their needs. Whether it be that parents are attracted to a simple explanation of causality or by an approach considered more natural, various alternative treatments are put to trial, particularly if the approach is not considered harmful (35, 36). Interviews of practitioners that were consulted in order to establish treatments offered to patients are produced in Appendix 4.

PART 3. Focus Groups

Two pilot focus groups were conducted to obtain a better understanding of the issues that contribute to the impact of managing a child with ASD. Although primary caregivers had unique experiences, many common factors emerged that highlighted important issues surrounding the management of these children. Factors where minimal research has previously focused.

Main Findings and Discussion

The data from the focus groups has been organised into five broad areas:

1. The Impact on Family of an ASD Child
2. Who is Affected
3. Food Issues
4. Impact of Diet Modification
5. Own Experience and Future Direction

Within each of these areas, various themes emerged and these are discussed and illustrated with quotes from participants. The focus groups offered an opportunity to gain insight into some of the main issues and concerns surrounding the management of a child with ASD, possibly identifying where the parental depression, anxiety and stress is originating.

1. The Impact on family of an ASD Child

One of the main aims of conducting focus groups was to explore the problems and concerns parents were experiencing in relation to the management of a child with ASD. The impact on family referred to the perceived burden the family experienced, with respect to having a child with ASD (38). When participants were asked what the impact of an ASD child was on the family, from various comments made in the discussion, four main factors emerged that contributed to the problems primary caregivers were experiencing:

Behavioural Impact

Financial Implications

Emotional Impact

Practical (day to day) implications

1.1. Behavioural Impact: All primary caregivers agreed with issues that arose with respect to the impact of the child's behaviour on the family. Communication with children was perceived as difficult, and simple things such as explaining a different culture or language was not possible as would be with a normal child. Siblings of ASD children were treated differently, as the rules appropriate for a normal child are not applicable to a child with ASD. Hence, laws of parenting were perceived as different for children with ASD, rules were black and white with no grey area.

“ My son is the boss, it has to run his way, because he is not going to change. With my other child I am the adult, but my son has changed my role from being a parent to being an educator and yet he rules the roost.”
(Primary caregiver #4, Focus group 1)

Behavioural changes in ASD children were found to change from day to day. Where there seemed to be a strategy one day, it changed the next day. There seemed to be no pattern with behaviour:

“One of the frustrating things about autism, is that the code changes regularly, you never know when and you never know why. So you can't crack the code, you simply can't.”
(Primary caregiver #2, Focus group #1)

1.2. Financial Implications: The cost of raising an ASD child is something that parents felt was generally overlooked by society. Raising such a child took up a lot of one's time and adjustments had to be made. Raising an ASD child is a full time job, and eight of the nine primary caregivers who took part in the focus groups were not employed. One household income and larger expenses contributed to a financial strain on the family. Special schooling was required; early intervention, behaviour programmes and speech pathology. Pre-school costing was twice as much in comparison to a non-ASD child. With schooling there were also transport issues that contributed to financial strain. In particular for parents with two siblings, one with ASD and one not, children went to different schools and had different transportation requirements.

There are medical expenses involved, supplements, taking children to various specialists conventional and non- conventional, whereby costs are not covered by the medical system.

“It makes me very angry as a parent that with a child with such strong disabilities, we have to pay so much more than everybody else, we have to travel so much further than everybody else.”

(Primary caregiver #4, Focus group #1)

1.3. Emotional Impact: Emotional impact plays a vital role in relation to the mental health status of the primary caregiver. Existing data suggests that stress and depression feelings, are associated with the care giving demands of children with ASD, due to the pressure of responsibility that they face (19).

Primary caregivers found that their life took a new direction and there was no time for them. Parents had to continuously adjust their lives, as it became tougher with increased complications as the children got older. “Frustration”, “fear” and “strain” were words used by primary caregivers to describe the emotional impact of having a child with ASD.

“For me my life is not my own anymore, it is driven by my son.”

(Primary caregiver #4, Focus group #1)

“I must admit I thought about suicide with my little boy in the first year, because our lives were too hard and no one understood that. I had to be the expert and with what information?” (Primary caregiver #4, Focus group #1)

“You have lots of plans and dreams and you hope that things go in a particular direction but, then you have to take different roads.”

(Primary caregiver #3, Focus group #1)

1.4. Practical (day to day) implications: Parents found that there was a large amount of learning and adaptation required with an ASD child. Decisions were difficult, as there are constraints in doing things as a family. Whether it was to go somewhere or do something, nothing seemed to go to plan. Parents did not consider it possible to go overseas without great planning and in most cases, could not go at all with the ASD child. A baby sitter is continuously required in order to allow some form of independence for parents. These issues were similar to findings in a study by Jarbrink and colleagues (31).

2. Who is Affected

2.1. Family

2.2. Other people in the community

2.1. Family: The impact of a child with ASD affects not only the immediate family but also has social consequences. Non-ASD siblings are often embarrassed about the ASD child's behaviour in public. This may create tension and hence contribute to the strain on the primary caregiver.

*“My other children say mummy I'm embarrassed, people are looking at us”
(Primary caregiver #2, Focus Group #1)*

The whole family has to be educated with respect to ASD behavioural traits. Parents are often in denial, at least initially, and this seems to cause great strain to the marital relationship. Most parents hid problems in relation to the child from their partner and relatives, including grandparents.

“It took twelve months for my parents to stop being frightened of my son, and he was three. I constantly have to pull up the grandparents and say you are the adults he is the child, get over it because he cannot. And they still do not understand that.” (Primary caregiver #4, Focus group #1)

“No one at home knows, my parents and relatives do not know he has ASD. It causes problems with my partner as he does not understand the issues. So I feed my son before my husband gets home. Sometimes I say a little white lie, to avoid the fuss.” (Primary caregiver #2, Focus group #1)

“ My husband was in denial. I'm not only hiding from the general public, we are hiding from our parents and our husbands. We are hiding our children and their issues. I hide my son's eating issues from my in laws, because I am sick of being told that no one can live with a diet that limited even though he is.” (Primary caregiver #4, Focus group #1)

2.2. Other People in the Community: Mothers found that they were constantly defensive as they were continuously criticised for being a bad mother. It was considered embarrassing that their child behaved badly, as behaviour was something that they could not hide. The feeding and eating issues that their child had could be hidden and dealt with at home. If their child did not eat in public no one would know the difference, whereas if their child behaved badly it was obvious. Parents expressed a constant fear of others, who would judge the behaviour of their child. There was a fear of a stigma by society.

“One of the most embarrassing things about my child, is that his behaviour goes with me. When my child throws a tantrum in a department store I am told he just needs a good smack”

(Primary caregiver #4, Focus group #1)

“If he runs around the food court, he looks like other badly behaving kids, but if he does not eat, no one knows, no one cares.”

(Primary caregiver #2, Focus group #1)

3. Food Issues

There were conflicting opinions between the two focus groups in respect to food management of an ASD child. Various themes emerged that were also similar:

- 3.1. Food Behaviour
- 3.2. Food Variety
- 3.3. Food Texture and Colour
- 3.4. Food Rituals

3.1-3.2. Food Behaviour and Food Variety: Some parents found that their children consumed a very limited diet, and hence the children were force-fed. This problematic eating behaviour was found to increase with age. Food variety tended to decrease and food would be turned away. Their children did not eat at pre-school or in public places, but would consume food in the car on the way home. There was the fear of trying something new.

Other primary caregivers however, had a different experience. Their children had a diet with a large variety. Their children tended to crave food every half hour to the point where some

would steal food. Some children would try new things when asked to, whereas others would not.

3.3-3.4. Food Texture, Colour and Food Rituals: Food texture and colour were also different in both groups. Some children ate a range of textures whereas others did not, and would only consume foods if they were mashed. There was a liking for colours but not all colours, and some children would continue to consume the same food even when the packaging had altered, whereas other children did not. Although there was no consistency in food issues between both groups, the presence of food issues was common in children with ASD, another factor that seems to contribute to difficulties in the management of these children.

4. Impact of Diet Modification

The impact of diet modification was a topic of conflicting views amongst the two groups. Five main areas in diet modification emerged in the group discussions:

- 4.1. Ease of Implementation
- 4.2. Affect of Diet on Behaviour
- 4.3. Affect on Health
- 4.4. Parental Beliefs
- 4.5. Supplements

4.1. Ease of Implementation: Parents found that the elimination diet through the RPAH Allergy Unit was difficult to implement but did indeed work. Eighteen months later some children were still on a GF/CF diet. Some children were on a 95% gluten free diet, which the primary caregiver managed quite well. Others however, did not try any form of dietary modification, due to difficulty in implementation. Some children had wide dietary variety and thus parents perceived difficulty in narrowing their dietary consumption.

4.2. Affect of Diet on Behaviour: Most parents who had attempted diet modification saw huge changes in their child's behaviour 1-3 days into the GF/CF diet or RPAH elimination diet. There was improved concentration, increased confidence and overall happiness in their child. Removal of dairy from the diet resulted in health improvement with respect to no more diarrhoea and better sleep.

“After one and a half days on a GF/CF diet, there was an amazing change in my child like a fog lifting off him.”

(Primary caregiver #3, Focus group #2)

4.3. Affect on Health: When going cold turkey on the GF/CF diet, some children experienced chronic diarrhoea, however this stabilised and parents found that their child’s behaviour and health had improved greatly.

Those parents who did not modify their child’s diet were not familiar with the area of diet modification. Some parents had experimented with some form of dietary modification and had seen some improved change, whether it was the removal of wheat, or the removal of dairy from the diet.

Parents, who were not willing to modify their children’s diet, feared the possibility of regression in their child’s behaviour. Their children were at the stage where they were settled in behaviour and health (no diarrhoea) or able to communicate (eye contact etc.,).

“I’m scared that if I include milk in his diet, he could get back to just sitting in front of the television. It might take me years to get back what I’ve got now.” (Primary caregiver #2, Focus Group #1)

4.4. Parental Beliefs: Parents who had experimented with dietary modification believed that the removal of dairy or wheat made a huge improvement in speech and behaviour. There was the belief that there is some relationship with diet and the gut, and their children had not been harmed or malnourished by being on a GF/CF diet, which some see as a limited diet. Other parents did not know if dietary intervention did indeed make a difference, as behavioural intervention coincided with dietary modification.

4.5. Supplements: Eight out of nine parents had used supplements or were continuing to use them to complement their child’s dietary intake. Reasons for supplementation included complimenting the child’s diet particularly on days when intake was limited, or because it assisted with health and behaviour.

Some improvement was seen with supplementation whereas no improvement was seen in other children. Experimentation with naturopathic and homeopathic supplementation was a terrifying experience for some, whereas others believed it helped. With alternative treatments

such as chelation, most parents agreed that they would prefer to see the results on someone else, before exposing their child to such treatments.

5. Own Experience and Future Direction

The role of reading as an information medium and parents experiences were discussed. Key issues were highlighted for the direction of future research.

5.1. Reading

5.2. Experience and Future Direction

5.1. Reading: Is a medium that helped only from the point of informing parents that they were not the only ones experiencing these problems. They were not dreadful parents, and it is acceptable for their child to eat certain foods and behave certain ways. Reading was not helpful from the point of getting their child to do certain things. The battles parents faced were huge and others were also facing them. Reading did not provide solutions that can be adapted to management of an ASD child. Reading did not assist with respect to diet. It merely reassured parents, but did not provide a solution to the problem.

Experiences and Future Direction: Parents were asked where they would like to see future research addressed in ASD, if they had a wish list. The issues that were highlighted were that parents wanted practitioners to listen to their problems. They sought solutions for their children's feeding problems. Parents have been hiding their child's dietary problems from the general public, because of the ease in hiding such an issue. Hence, this problem has been overlooked and dropped to the bottom of the list of issues to be addressed.

Dietary issues have been hard and embarrassing, thus have not been brought into the open by parents. Parents did not want to add to the list of problems that already existed in managing a child with ASD. Because their children do not look malnourished it is something that has been overlooked by parents and practitioners.

Parents seek education with respect to diet. They do not seek a miracle cure but the knowledge that will allow their child the ability to function better. They seek a cause an effect relationship despite the conventional and non-conventional opinions that exist. Primary caregivers would like one centre where all analyses and diagnoses can be conducted. They

seek a centre in Australia where they are provided with a comprehensive picture and presented with follow up, in a form that parents can understand. Possibly, be provided with a facility whereby a professional may come to the home environment and monitor the child.

Future Research-Limitations

Although the data provides preliminary support for the hypotheses of heightened stress and anxiety in ASD parents and the effectiveness of dietary modification and alternative treatments, the study has areas that require further research.

Although the sample size is larger than studies in the area of ASD, with 26 subjects in the ASD group, the sample size is small for solid conclusions to be made. With a larger group of participants statistical analysis could determine any relationship of ASD, to age or gender within the groups.

Variations in parental interpretation of questionnaires, resulted in null responses, and were not included in data the analysis, contributing to decreased sample size.

Further focus groups need to be conducted to establish similarities and differences in a representative sample of the ASD population. Pilot focus groups however, provided an introduction into the experiences of primary caregivers of ASD children, which have been modestly addressed in previous studies.

The majority of ASD participants in the study were patients of the RPAH Allergy Unit. Future recruitment needs to be from the general ASD population in order to determine differences or similarities in experiences, amongst a large group.

Data was retrospective and entirely derived from parent reports, which may be subjective to bias. However, it has been demonstrated that parental information is an effective method for the detection of behavioural and developmental problems (39). As the study continues, additional assessment may be the validation of parental reports, by inclusion of teacher reports of behavioural assessment.

Both Conventional and non-conventional therapies remain controversial matters, as success is based on anecdotal reports that remain clinically unproven. A larger ASD population would show further valid results with respect to dietary intervention in the treatment of ASD.

CONCLUSION

This study has provided an introduction to the issues and concerns primary caregivers have in the management of children with ASD. Children with ASD had significantly greater impact on their family. Parents hid their problems and in particular children's food behaviour from society, including friends and family. As a result of these issues, ASD parents were significantly more depressed, anxious and stressed than "normal" parents.

Although dietary intervention is viewed as difficult to implement and is still considered by some as alternative treatment for ASD, parents had experimented with dietary intervention primarily GF/CF. The majority of ASD parents were continuing dietary modification. There were mixed views as to whether dietary modification made any difference, as some parents had seen improvements in speech and behaviour, whereas others were not certain, due to coinciding behavioural intervention. Future research needs to focus on the role of diet in ASD, with improved education for parents with respect to dietary modification.

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