

Living with children with autistic spectrum condition: parental stress and the impact upon family functioning.

Kathleen Dickinson MA

Faculty of Health and Life Sciences
Northumbria University, Coach Lane Campus,
Newcastle Upon Tyne, NE7 7XA

Maurice Place MD

School of Health and Life Sciences,
Northumbria University, Coach Lane Campus,
Newcastle Upon Tyne, NE7 7XA

Summary

Introduction. Parenting a child with Autistic Spectrum Condition (ASC) is both practically and emotionally challenging. The condition brings difficulties in communication and social interaction, as well as abnormal behaviour patterns, all of which have an impact upon parents. **Method.** As part of a larger study, one hundred mothers of children with ASC were asked to complete several scales including the Family Adaptation and Cohesion Evaluation Scale (FACES IV), and The Parenting Stress Index-Short form (PSI-SF). **Results.** The Parenting Stress Index scores showed that the mothers of the primary aged children felt very high levels of parental stress, and distress, while the mothers of secondary age children reported lesser levels. The FACES IV scores indicated that the sense of flexibility was higher in the mothers of adolescents, and that the families of girls were less cohesive than that of boys. **Discussion.** The highest level of parental stress was reported by the mothers of younger children, with the parenting of teenage girls being the most stressful. **Conclusion.** A family pattern which tends to seek smaller changes could reduce the sense of family distress that parents of children with ASC experience. As the children move into adolescence the mothers tend to feel less stressed, but less so for the mothers of teenage girls.

Keywords: autism, family functioning, FACES IV, parenting stress index

ACKNOWLEDGEMENTS

Our grateful thanks to all of the schools, staff, children and their parents who took part in this study.

INTRODUCTION

Following Kanner's original case description [1] there emerged a view that significant issues within the functioning of the family, particularly "emotional coldness", could be a major factor in the causation of Autistic Spectrum Condition (ASC) [2, 3]. This supposition has been completely disproven, but the patterns of family functioning observed do emphasize the huge impact which parenting a child with ASC can have upon family life. The condition brings difficulties in communication and social interaction, as well as abnormal behaviour patterns, such as over sensitivity to external stimuli [4, 5], and such difficulties can make parenting a challenging and frustrating experience [6]. The challenge of dealing with these elements of functioning can, both individually and cumulatively, exert a huge influence on family

interaction, and demand carefully judged parenting to be successfully managed. It is therefore not surprising that most studies have highlighted the high degree of stress that parenting a child with ASC can engender [7-10]. It is the mothers who seem to suffer the greater impact from their children's disabilities [11, 12], with the most common explanation being that they focus upon their child's difficulties while putting their own needs aside [13-15].

As part of a wider study, the opportunity arose to explore the views of mothers of children with ASC in some detail, particularly asking about their family's functioning, and the stresses that they were experiencing. The data also permitted the differences between different age groups of children, and gender differences, to be examined.

METHOD

Having obtained ethical approval from academic bodies, educational gatekeepers and parents the families of the children attending three schools that offered specific educational provision for children with ASC in one geographical area were approached to participate in the study. The children all had Statements of Special Educational Need which specified they should be taught in a setting specifically designed for children with ASC. The children ranged in age from 5 to 15 years of age, with IQ's in the moderate to severe range, and no other major physical disorder or illness. Following a process of informed consent, all parents consented for themselves and their children to take part.

The demographic information and details of family makeup revealed that 33 of the children were eleven years or older, and 21 were girls. 75 of the children were living with both parents. 34 were the only children in the family, and in terms of parental employment 16 came from families where both parents were in employment, and 25 of the children lived in families where both parents were unemployed.

The mothers of the children were asked to complete four assessment scales.

The Family Adaptation and Cohesion Evaluation Scale (FACES IV) [16] is a self-report instrument designed to assess family functioning in terms of the Circumplex Model of Marital and Family Systems [17]. There are three key concepts which underpin the model. Cohesion is defined as the emotional bonding that family members have toward one another, and flexibility is the quality and expression of organization, rules and roles, and how negotiation of these elements are undertaken within the family. The third concept is communication, defined as the positive communication skills used by the family system, and is seen as a dimension which assists families to facilitate between different levels of cohesion and flexibility [18]. The Circumplex Model proposes that healthy family functioning requires a balance between these parameters, with extremes being associated with problematic family functioning. The FACES IV is the most recent version of the scale, and in addition to the core measures of Balanced Cohesion and Balanced Flexibility it provides four subscales which reflect the extremes of the core measures. These four subscales are Disengaged and Enmeshed for the Cohesion Dimension, and Rigid and Chaotic for the Flexibility Dimension. The combination of these six scales is said to provide a more comprehensive assessment of family functioning than previous versions [18]. The scores also permit the calculation of balanced/unbalanced ratio scores for the two core scales, with ratio scores above 1 reflecting a more balanced family system. Conversely the lower the ratio score below 1, the more unbalanced the system. These two ratio scores are claimed by the developers to summarise a family's relative strength and problem areas into two scores, reducing some of the complexities of the six scale score description [18].

The principle psychometric properties of the FACES IV show an internal consistency of moderate to high Cronbach's alpha values (Enmeshed = .77, Disengaged = .87, Balanced Cohesion = .89, Chaotic = .86, Balanced Flexibility = .84, Rigid = .82) (Olson, 2011). Two additional scales have been developed to compliment and extend the results provided by the FACES IV.

The Family Communication Scale. Based on the 20 item scale developed by Barnes and Olson [19], this 10 item variation is rooted in the hypothesis that family communication will have a positive relationship to balanced family systems and, conversely, a negative relationship with unbalanced ones. It was produced by using the items which made up the first factor from a factor analysis of the originating 35 items used to develop the scale. The internal consistency of the scale is 0.90, and it has a test re-test of 0.86. In a large U.S. sample of 2,465 individuals the total mean score was found to be 36.2 (std. dev. 9.0) [20].

The Family Satisfaction Scale [21]. This 10 item scale was one of the first satisfaction scales to be developed, and is based on the theoretical assumption that families with high scores on balanced cohesion and balanced flexibility would have higher levels of family satisfaction. The scale has a reported internal consistency reliability of 0.92 and a test re-test of 0.85. In a large U.S. sample of 2,465 individuals the total mean score was found to be 37.9 (std. dev. 8.5) [21].

The Parenting Stress Index-Short form (PSI-SF) [22] is a 36 item questionnaire with responses being recorded on a 5 point likert scale, which gives three sub-scales: Parental Distress (PD), Difficult Child (DC), and Parent-Child Dysfunctional Interaction (P-CDI), as well as a Total Stress score. The PD sub-scale measures parents' perceptions of their own behaviour including perceived competence, marital conflict, views of social support, and life restrictions because of the parenting demands. The PCDI sub-scale measures the parents' view of expectations and interactions with their child, and the DC sub-scale measures the parents' perceptions of their child's temperament, demandingness, and compliance. The scale has been used in studies as diverse as exploring the impact of being child sex abuse survivors [23] to having a child with juvenile idiopathic arthritis [24].

It is frequently used to assess the effectiveness of parenting programmes [25], and in the context of this study, it has been used widely in studies assessing parental stress in families with children with ASC [26]. However, some individual items have been judged to perform less well in this population, and after a re-evaluation of the elements Dardas and Ahmad [27] have recommended a variation to the standard scoring be made to improve its validity. This involves deleting questions 19, 22, and 24 from the Parent-Child Dysfunctional Interaction subscale; deleting questions 31, 32, and 33 from the Difficult Child subscale, and moving the scores from questions 18 and 21 to the Difficult Child subscale. The overall effect of these changes leaves the Parental Distress and the Difficult Child subscales unchanged, but the cut-off for the Parent-Child Dysfunctional Interaction is reduced by 17, and that of the Total Score is reduced by 15. With this re-structuring the Cronbach alphas for the subscales are the same, or better than the original structure, namely 0.91 for parental distress, 0.86 for parent-child dysfunctional interaction, 0.87 for difficult child and 0.92 for the total score [27]. On the subscales, high scores represent higher levels of stress, with scores above the 90th percentile considered high and scores below the 15th percentile deemed low.

To explore if in the present study sample this variation showed a similarly improved pattern of cumulative variance, a principal components analysis with varimax rotation was performed. This compared the 36 items in the original PSI scale and with the modified 30 items, and

revealed that the loading of the 30 items on the three factors accounted for 46.4% of the cumulative variance, with the 36 item version returning a result of 39.6%. It was thus decided to report the results using the Dardas and Ahmad correction.

All statistical analyses were conducted with SPSS version 21.0 (SPSS for Windows Inc., Chicago, IL, USA), with results presented as means and standard deviations, and analysis undertaken using Student's t-test, two tailed. The numerical scores are analysed using chi-square test (χ^2), with correlations reported as Pearson's r score.

RESULTS

The Parenting Stress Index scores (using the Dardas and Ahmad correction) are shown in Table 1. This shows that the number of mothers reporting very high levels of parental stress was highest among the families of primary aged children (63% for boys; 54% for girls), and the gender difference at this age group proved to be significant ($\chi^2 = 6.44$, $p < 0.01$). At the secondary age level the boys mothers reported less parental stress than the girls ($\chi^2 = 6.44$, $p < 0.01$), and less than the mothers of the younger boys ($\chi^2 = 5.01$, $p < 0.02$). This pattern was also evident when considering the Parental Distress score, with 80% of the primary boys mothers reporting significant distress, compared to 36% of the mothers of the secondary boys ($\chi^2 = 14.46$, $p < 0.0001$). The mothers of the girls showed a reversal of this trend, with all of the mothers of the senior girls reporting significant distress, compared to 69% of the primary girls mothers, but the small sample size prevented the difference reaching statistical significance. However the higher level of distress in the mothers of secondary aged girls was statistically significant when the genders were compared ($\chi^2 = 9.94$, $p < 0.002$).

The Parent Child Dysfunctional Interaction subscale again showed a relatively large number of parents in each of the groups reporting dysfunction in their interaction with their children. In the boys families this was markedly less in the older age group ($\chi^2 = 5.92$, $p < 0.014$), with the trend reversed in the reports by the girls mothers. When the scores for the mothers of the secondary aged children were compared this reversal proved noteworthy ($\chi^2 = 5.61$, $p < 0.017$).

Given the nature of children with ASC it would not be surprising to find that the Difficult Child subscale returned high scores. However the number of families in each group who did report marked difficulty was comparatively modest (18% for boys; 38% for girls), with the small number of teenage girls making a significant contribution to this latter result. The reduced frequency in older boys, when compared to the families of younger boys was statistically significant ($\chi^2 = 4.72$, $p < 0.02$).

The results from the dimensions of cohesion and flexibility of the FACES IV questionnaire are shown in table 2. This shows that there was little difference in the average scores between the mothers of primary aged and teenage boys on both the cohesion ($t(77) = 1.07$, NS), and flexibility scales ($t(77) = 0.6$, NS). The mothers of girls were fewer in number, but although the average of the cohesion scale shows no significant difference between the age groups ($t(19) = 0.7$, NS), the flexibility score was higher in the adolescent group ($t(19) = 2.2$, $p < 0.04$). Comparing the average scores by gender reveals no significant difference between the sexes on the cohesion scale at primary level ($t(65) = 0.93$, NS), but higher mean scores for the mothers of boys of secondary age ($t(31) = 2.87$, $p < 0.01$). The average scores on the flexibility scale show no significance between the mothers of the boys and the girls at either of the age points.

The basic hypothesis of the Circumplex Model is that “balanced” families will be more satisfied with their system than “unbalanced” families. The ratio scores were developed by the Minnesota team to measure the level of balance versus unbalance in the family system, with a score over 1 indicating a balanced or healthy system. Given the range of scores that were achieved on the core scales, these ratios also permit actual numbers who are showing difficulty to be identified. Using this ratio calculation (table 2), it is clear that most of the mothers are reporting a balanced (i.e. healthy) pattern to their family life, but a smaller percentage of the mothers of the primary aged boys reported reduced cohesion than the mothers of the primary aged girls, a trend that was not evident in the families of the senior pupils. In addition, there was an increase in the percentage of mothers of boys in the secondary age group reporting difficulties with cohesion over those of primary age. However the percentage of mothers of girls who reported having low family cohesion was not different between the age groups. In terms of flexibility, the unbalanced ratio for the families of the boys, both in primary and secondary, was very similar, and it was the mothers of the senior girls who reported the most difficulties with flexibility.

The results from the analysis of the satisfaction scale indicate that a large number of the families had low levels of satisfaction, with around 10% reporting the level to be very low. The mothers of the adolescent boys reported less concern with satisfaction than the parents of primary age boys, while the eight mothers of adolescent girls all reported dissatisfaction with family life, compared to 69% of the mothers of the primary aged girls. Comparing the reports by gender, the scores from the mothers of the primary aged children showed no significant difference ($t(65) = 1.77$, NS), but in the secondary age group the poorer average score from the mothers of the girls was significant ($t(31) = 2.4$, $p < 0.02$). When these results are compared to the instrument norms offered by Olson and Wilson [21] (table 3), the boys’ mothers scores show no significant variation from those norms ($t(2542) = 1.04$, NS), while the scores from the mothers’ of the girls indicate they were significantly less satisfied ($t(2484) = 4.71$, $p < 0.001$).

In terms of communication, there was a degree of consistency among the mothers with around 25% of them reporting low levels of communication, and about 10% reporting the communication to be very low. Given this relative consistency, it is perhaps not surprising that none of the inter-comparisons reached statistical significance. When the results are compared to the instrument norms offered by Olson and Wilson [21] (table 3) it is clear that the mothers of the primary aged boys reported a greater level of communication than the published norms, and this difference was highly significant ($t(2517) = 4.63$, $p < 0.001$). The scores from the mothers of the primary aged girls show a similar tendency, but the small sample size and wide spread of scores prevented this from reaching statistical significance ($t(2476) = 1.75$, NS).

The subscales generated by the FACES IV questionnaire offer a more in-depth look at family functioning. The results (table 4) show that none of the families had high levels of disengagement, but some of the mothers reported low disengagement, predominantly the mothers of the boys. 39% of the primary aged boys’ mothers reporting they had very low disengagement, and when compared to the scores from the mothers of secondary aged boys this difference proved to be significant ($c2 = 4.14$, $p < 0.04$). Some of the mothers of the primary aged girls also reported very low levels of disengagement, but this was not present in the senior aged sample. However the small numbers involved meant this did not reach statistical significance. The enmeshed sub-scale is not measuring the reverse of the disengaged sub-scale, rather its focus tends to be towards the emotional links (e.g. “Family members are too dependent on each other”). Again none of the mothers reported having very high enmeshment, but the mothers of the primary aged children did tend to report very low levels

(boys = 41%, girls 31%). This level was significantly less than reported by the mothers of the adolescent boys ($\chi^2 = 4.74, p < 0.02$), and the zero from the mothers of the teenage girls, but there were only eight families in this group ($\chi^2 = 3.04, NS$).

The mothers of girls did not report very high levels of rigidity in their functioning, though a small number (8%) in the primary aged group did report very low levels. In the group with primary aged boys 17% reported very high rigidity, but there was none reported by the mothers in the teenage group, and this difference proved to be statistically significant ($\chi^2 = 4.70, p < 0.03$). Finally none of the mothers reported very high chaotic functioning, with nearly half (48%) of the mothers of the primary aged boys reporting very low chaotic functioning (i.e. highly organised, firm and clear family routine and structure), and this was significantly less evident in the scores from the mothers of the adolescent boys ($\chi^2 = 9.61, p < 0.002$). The mothers of the girls reported a similar, though less frequent, pattern (23% of primary and 13% of secondary reported very low chaotic function), but none of the comparisons reached statistical significance.

To explore the relationship between the questionnaire scores, Pearson's correlation calculations were undertaken using the data split by age and gender. No significant associations for the families of the primary aged boys or girls were found. The number of families of secondary aged girls was relatively small and therefore the lack of significant findings in this age group was not surprising. However carrying out a Pearson correlation on the questionnaire data provided by the mothers of the secondary aged boys did produce one statistically significant result, a negative association between the levels of parental distress and scores on the chaotic subscale ($r = -0.68, n = 25, p < 0.01$). When the calculations were repeated controlling for age, the data from the mothers of the girls also showed this significant negative correlation between the levels of parental distress and scores on the chaotic subscale ($r = -0.44, n = 21, p < 0.05$). This negative association indicates that families where there was a clear structured pattern to family life (i.e. markedly non-chaotic family functioning) tended to report higher levels of parental distress.

The results from the PSI had highlighted that in the families of teenage children the mothers of girls tended to report differing patterns from the mothers of boys. To try to gain a more general picture, a Pearson correlation was carried controlling for gender in the secondary-aged pupils (table 5). This showed significant negative associations between total stress on the PSI and the disengaged and chaotic subscales of the FACES IV. The P-CDI subscale also showed a negative association with the Chaotic scale. These findings tend to reinforce the view that families with highly organised, firm and clear family routine and structure (i.e. notably low scores on the chaotic subscale of the FACES IV) report higher levels of parental distress and concerns about interaction with their child.

DISCUSSION

It has long been recognised that mothers of children with ASC experience a high level of stress [28], and that this is probably at a greater level than that experienced by parents of children with other developmental difficulties [29, 30]. The results from this study point to the highest level of parental stress within this group being felt by the mothers of adolescent girls, though the sample size was small. By contrast, it was the mothers of younger boys who reported the greater level of stress when considering the families of the boys. This pattern was also evident in other measures. Parent-Child Dysfunctional Interaction, and viewing the child as difficult, were reported less by the mothers of teenage boys when compared to the scores from the

mothers of younger boys. However higher rates were reported by the mothers of teenage girls. This discrepancy with gender was also echoed in the results obtained from the FACES IV. The mothers of girls viewed their families as less cohesive than did the mothers of boys, and adolescent girls tended to be living in families where the mothers reported poorer flexibility in family functioning.

With such perceptions, it is not surprising that the mothers tended to report relatively low levels of satisfaction with family life, with average scores which were significantly below the published norms, and again the highest scores were from the mothers of the older girls. The numbers in this group was small, but this is a statistically significant finding, and it is tempting to speculate why this should be. Many studies have demonstrated that a child's disabilities have a greater impact upon the mother than the father (e.g. Hastings and Brown [11], Herring and colleagues [12]), and there is a longstanding body of evidence reporting on the positive and influential nature of the mother – daughter relationship [31, 32]. Could the lack of satisfaction in this particular group of mothers be driven by their struggle in coming to terms with not having the relationship with their teenage daughter for which they had perhaps hoped? A more in depth exploration would be necessary to explore this thread more fully, but the possibility is intriguing.

The relatively large number of mothers of the younger boys who reported low chaotic and low disengagement patterns tends to emphasise that these families strived for structure and routine. Meanwhile the pattern of low enmeshment points to these elements of family life being delivered in a muted emotional environment. Overall the trends described seem to mirror somewhat the characteristics of a child with ASC. It has been suggested that young children with developmental disabilities may experience simple tasks and activities, and even typical parental expectations, as aversive [33]. However, children with ASC have also been shown to respond to wider family functioning [34], and it may well be that an iterative pattern of modelling is taking place in these families. Perhaps reflection by the family of a modified pattern of the child's behaviour is then imitated by the child, prompting a small positive shift in functioning. If this were a continuous process this would explain the improvements in adaptability that are evident from the reports of the mothers of the senior aged children in this study, and be consistent with the improving family function that is said to emerge in most families over time [35], although this does to some degree depend upon the child's daily living skill functioning level [36].

To function well within a family good communication is important, and it might well be considered to be even more important if the family is parenting a child with ASC. On average, in this study, the families of the younger boys reported better levels of communication than those indicated by the published norms, though some families were clearly struggling. Overall, these results add to a growing picture of how families of children with ASC tend to cope with the tribulations of parenting their children, a picture which seems relatively independent of culture. For instance in a community sample in the United States, the mothers of children with ASC reported being highly stressed and tended to have relatively poor mental health [9]. In Taiwan the mothers of children with ASC reported experiencing a significantly lower level of family cohesion and adaptation than they expected, as well as reporting a greater dissatisfaction with family life in general than reported by controls [37].

To our knowledge this is the first study in a western population using the variation of the Parenting Stress Index recommended for families of children with ASC [27]. The PSI short form has been seen as having reasonable validity [38], but this has been questioned [39], especially

in families with children with ASC [27, 40], in part because the P-CDI and DC sub-scores are considered to have different qualities in these families [41]. The revision undertaken by Dardas and Ahmad [27] produced a scale with 6 fewer items, and yet in this study sample the three factors of the scale showed better cumulative variance than the original version. This suggests the new scoring format may give a more accurate reflection of the issues faced by parents of children with ASC than the original one.

There are a variety of caveats that need to be highlighted when considering the results from this study. The sample was drawn from a small geographical area, and although the schools were in different local authorities, there could be a heterogeneity to the parental functioning that would not be found elsewhere. It is also important to view with some caution results obtained using a variation of the PSI. This is reported to have a better validity in an ASC population than the original structure, but being established in an Arab population means it may not have the same superiority in a western population. However, although not a full validation study, the results here from a western community population do show similar improvement in cumulative variance when using this scoring correction.

It has been found previously [39] that aggregating results from different age groups can distort findings, and to avoid this the data has been considered separately by age and gender. This has led to a relatively small sample of mothers of girls, and therefore the interesting results that this gender splitting has produced need to be viewed with caution. Finally the information presented was obtained from mothers, and it has been emphasized that differences in family patterns do occur depending upon which member of the family is completing the instrument [42].

CONCLUSION

The results from this study echo the findings from previous work in several countries that parents of children with ASC experience significant stress. The present study suggests that the level of stress may ease somewhat as boys mature, and perhaps increase as girls move into adolescence. Despite these variations with age, the levels of stress remain at higher levels than those seen in parents of typically developing children. Children with ASC crave predictability and routine, but the findings of this study suggest that those families who respond to their child's ASC by being highly organised, with firm and clear family routines and structure, tend to experience the higher levels of parental distress. They also report more concern about their interaction with their child. Such variations are important to understand when trying to support families who are parenting a child with ASC.

References

1. Kanner, L., Autistic disturbances of affective contact. . *Nervous Child*, 1943. 2: p. 217 - 250.
2. Kanner, L. and L. Eisenberg, Early infantile autism, 1943-1955. *Psychiatric Research Reports*, 1957(7): p. 55-65.
3. Bettelheim, B., *The Empty Fortress: Infantile Autism and the Birth of the Self*. 1967, New York: Free Press.
4. Le Couteur, A., et al., Diagnosing autism spectrum disorders in preschool children using two standardised assessment instruments: The ADI-R and the ADOS. . *Journal of Autism and Developmental Disorders*, 2007. 38: p. 362 - 372.
5. Chandler, S., et al., Emotional and behavioural problems in young children with autism spectrum disorder. *Developmental Medicine and Child Neurology*, 2015. June 16.
6. Woodgate, R.L., C. Ateah, and L. Secco, Living in a world of our own: The experience of parents who have a child with autism. . *Qualitative Health Research*, 2008. 18: p. 1075 - 1083.

7. Karst, J.S. and A.V. Van Hecke, Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review* 2012. 15: p. 247 - 277.
8. Davis, N.O. and A.S. Carter, Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism & Developmental Disorders*, 2008. 38: p. 1278 - 1291.
9. Montes, G. and J.S. Halterman, Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, 2007. 119: p. e1040-e1046.
10. Valicenti-McDermott, M., et al., Parental Stress in Families of Children With Autism and Other Developmental Disabilities. *Journal of Child Neurology*, 2015.
11. Hastings, R.P. and T. Brown, Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation*, 2002. 107: p. 222 - 232.
12. Herring, S., et al., Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual and Disability Research*, 2006. 50: p. 874 - 882.
13. Hoogsteen, L. and R.L. Woodgate, Centering Autism Within the Family: A Qualitative Approach to Autism and the Family. *Journal of Pediatric Nursing*, 2013. 28: p. 135 - 140.
14. MacDonald, H. and P. Callery, Parenting children requiring complex care: A journey through time. *Child: Care, Health and Development*, 2008. 34: p. 207 - 213.
15. Reichman, N.E., H. Corman, and K. Noonan, Impact of child disability on the family. *Maternal and Child Health Journal* 2008. 12: p. 679 - 683.
16. Olson, D.H., Administration Manual; FACES IV Package 2009, Minneapolis, Minnesota.: Life Innovations, Inc.
17. Olson, D.H. and D.M. Gorall, Circumplex model of marital and family systems., in *Normal Family Processes.*, F. Walsh, Editor 2003, Guilford: New York. p. 514 - 547.
18. Olson, D.H., FACES IV and the Circumplex Model: Validation Study. *Journal of Marital and Family Therapy*, 2011. 3: p. 64 - 80.
19. Barnes, H.L. and D.H. Olson, Parent-adolescent communication and the Circumplex Model. Special Issue: Family development. *Child Development*, 1985. 56: p. 438 - 447.
20. Olson, D.H. and H.L. Barnes, Family Communication. FACES IV Package 2009, Minneapolis, MN.: Life Innovations, inc.
21. Olson, D.H. and M. Wilson, Family Satisfaction., in *Families: What Makes Them Work.*, D.H.a.c. Olson, Editor 1989, Sage Publishing: Newbury Park, CA.
22. Abidin, R.R., Parenting Stress Index Short Form: Test Manual. 1990, Charlottesville, VA.: Pediatric Psychology Press.
23. Allbaugh, L.J., M.O. Wright, and L.A. Seltmann, An Exploratory Study of Domains of Parenting Concern among Mothers who Are Childhood Sexual Abuse Survivors. *Journal of Child Sexual Abuse*, 2014. 23: p. 885.
24. Cox, A., et al., Maternal stress associated with juvenile idiopathic arthritis. *International Journal of Rheumatic Diseases*, 2014. 17: p. 541 - 547.
25. Barlow, J., et al., Group-based parent training programmes for improving parental psychosocial health. *Cochrane Database of Systematic Reviews* 2014. May 17;5:CD002020.
26. Zaidman-Zait, A., et al., Factor analysis of the Parenting Stress Index-Short Form with parents of young children with autism spectrum disorders. *Autism Research*, 2011. 4(5): p. 336-46.
27. Dardas, L.A. and M.M. Ahmad, Psychometric properties of the Parenting Stress Index with parents of children with autistic disorder. *Journal of Intellectual Disability Research*, 2014. 58(6): p. 560-71.
28. Koegel, R.L., et al., Consistent stress profiles in mothers of children with autism. *J Autism Dev Disord*, 1992. 22(2): p. 205-16.

29. Dabrowska, A. and E. Pisula, Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 2010. 54: p. 266 - 280.
30. Estes, A., et al., Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 2009. 13: p. 375 - 387.
31. Boyd, C.J., Mothers and daughters: a discussion theory and research. . *Journal of Marriage and the Family*, 1989. 51: p. 291 - 301.
32. Barber, J.G., F. Bolitho, and L. Bertrand, Parent-child synchrony and adolescent adjustment. . *Child and Adolescent Social Work Journal* 2001.
33. Lucyshyn, J.M., et al., Transforming Parent-Child Interaction in Family Routines: Longitudinal Analysis with Families of Children with Developmental Disabilities. *J Child Fam Stud*, 2015. 24(12): p. 3526-3541.
34. Di Nuovo, S. and G. Azzara, Families with autistic children. . *Rivista di Studi Familiari*, 2011. 2: p. 25 - 38.
35. Baker, J.K., M.M. Seltzer, and J.S. Greenberg, Longitudinal Effects of Adaptability on Behavior Problems and Maternal Depression in Families of Adolescents With Autism. . *Journal of Family Psychology*, 2011. 25: p. 601 - 609. .
36. Gardiner, E. and G. Iarocci, Family quality of life and ASD: the role of child adaptive functioning and behavior problems. *Autism Research*, 2015. 8(2): p. 199-213.
37. Gau, S.S.-F., et al., Parental adjustment, marital relationship, and family function in families of children with autism. . *Research in Autism Spectrum Disorders*, 2012. 6: p. 263 - 270.
38. Haskett, M.E., et al., Factor Structure and validity of the Parenting Stress Index – Short Form. *Journal of Clinical Child and Adolescent Psychology*, 2006. 35: p. 302 - 312.
39. Farmer, A. and N. Peterson, Psychometric Properties of the Parental Distress Subscale. . *Child and Family Studies*, 2012. 21: p. 747 - 753.
40. Silva, L.M. and M. Schalock, Autism Parenting Stress Index: initial psychometric evidence. *Journal of Autism and Developmental Disorders*, 2012. 42(4): p. 566-74.
41. Zaidman-Zait, A., et al., An item response theory analysis of the Parenting Stress Index-Short Form with parents of children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 2010. 51(11): p. 1269-77.
42. Phillips-Salimi, C.R., et al., Perceptions of communication, family adaptability and cohesion: a comparison of adolescents newly diagnosed with cancer and their parents. . *International Journal of Adolescent Medicine and Health*, 2014. 26: p. 19 - 26.

Table 1 - The scores from the Parenting Stress Index using the Dardas & Ahmad correction

	Defensive Responding		Parental Distress (PD)			Parent-Child Dysfunctional Interaction			Difficult Child (DC)			Total Score		
	Mean	Std. Dev.	Mean	Std. Dev.	Percentage above cut-off of 40	Mean	Std. Dev.	Percentage above cut-off of 28	Mean	Std. Dev.	Percentage above cut-off of 40	Mean	Std. Dev.	Percentage above cut-off of 99
Boys (n=54)	20.61	5.39	37.15	9.22	33%	19.98	6.61	78%	27.13	6.77	21%	84.27	20.73	43%

	Seco dary (n=25)	22. 35	5. 40	39. 92	9. 77	16%	20. 42	5. 99	28%	26. 92	3. 83	4%	87. 28	17. 46	16%
	Total (n=79)	20. 92	5. 40	37. 64	9. 32	28%	20. 06	6. 47	62%	27. 10	6. 33	15%	84. 81	20. 12	34%
Gi rls	Prima ry (n=13)	22. 16	5. 68	40. 00	9. 86	38%	21. 00	6. 31	62%	27. 83	6. 42	23%	88. 83	18. 79	46%
	Seco ndary (n=8)	24. 66	5. 63	44. 11	9. 66	63%	23. 66	6. 89	88%	33. 00	8. 44	50%	100. .77	23. 92	83%
	Total (n=21)	23. 23	5. 66	41. 76	9. 75	48%	22. 14	6. 53	71%	30. 04	7. 61	33%	93. 95	21. 44	57%

Table 2 - The scores of cohesion and flexibility from the FACES IV and the Satisfaction and Communication scales

		Balanced Scales						Satisfaction			Communication		
		Cohesion			Flexibility								
		Me an	Std. Dev.	percen tage with unbala nced ratio < 1	Me an	Std. Dev.	percen tage with unbala nced ratio < 1	Me an	Std. Dev.	No. below cut- off (low/v ery low)	Me an	Std. Dev.	No. belo w cut- off (low/ very low)
Bo ys	Prima ry (n=54)	59. 92	12.3 4	5%	51. 55	11.6 7	27%	36. 00	17.8 7	72%/1 1%	46. 55	17.4 1	24%/ 9%
	Seco ndary (n=25)	63. 45	11.8 4	12%	49. 9	9.52	28%	35. 27	18.4 8	40%/0 %	42. 63	23.7 7	23%/ 12%
	Total (n=79)	60. 41	12.2 5	7%	51. 32	11.3 6	28%	35. 89	17.8 4	62%/8 %	46. 01	18.3	24%/ 10%

Girls	Primary (n=13)	55.75	15.27	15%	52.66	7.61	23%	28.41	13.02	69%/15%	43.08	21.74	30%/15%
	Secondary (n=8)	51.77	9.54	13%	43.77	9.70	50%	24.11	8.35	100%/12%	38.66	13.08	25%/12%
	Total (n=21)	54.04	12.99	14%	48.85	9.48	33%	26.57	11.22	81%/14%	41.19	18.26	28%/14%

Table 3 - Comparison of the Satisfaction and Communication scales scores with the published norms (Olson & Wilson 1989)

	Satisfaction					Communication					
	study population		published norms (N= 2465)		t-test	study population		published norms (N= 2465)		t-test	
	Mean	Std. Dev.	Mean	Std. Dev.		Mean	Std. Dev.	Mean	Std. Dev.		
Boys	Primary (n=54)	36.00	17.87	} 37.9	8.5	} 0.71	46.55	17.41	} 36.2	9.0	} 1.34
	Secondary (n=25)	35.27	18.48				42.63	23.77			
	Total (n=79)	35.89	17.84				46.01	18.3			
Girls	Primary (n=13)	28.41	13.02	} 37.9	8.5	} 4.66***	43.08	21.74	} 36.2	9.0	} 0.53
	Secondary (n=8)	24.11	8.35				38.66	13.08			
	Total (n=21)	26.57	11.22				41.19	18.26			

* = p < 0.05, ** = p < 0.01, *** = p < 0.001

Table 4 - Analysis of the four unbalanced subscales of the FACES IV

		Disengaged			Enmeshed			Rigid			Chaotic		
		Me	Std	percen	Me	Std	percen	Me	Std	percen	Me	Std	percen
		an	De	tage	an	De	tage	an	De	tage	an	De	tage
			v.	over		v.	over		v.	over		v.	over
				cut-			cut-			cut-			cut-
				offs			offs			offs			offs
				(very			(very			(very			(very
				high/			high/			high/			high/
				very			very			very			very
				low)			low)			low)			low)
Boys	Primary (n=54)	37.04	14.98	0%/39%	32.17	13.09	0%/41%	49.27	19.52	17%/6%	33.50	17.09	0%/48%
	Secondary (n=25)	33.00	21.03	0%/16%	28.09	13.54	0%/16%	52.18	16.74	0%/0%	36.18	22.09	0%/12%
	Total (n=79)	36.48	15.85	0%/31%	31.72	13.11	0%/33%	49.68	19.08	11%/4%	33.87	18.50	0%/37%
Girls	Primary (n=13)	41.08	12.85	0%/15%	36.75	16.05	0%/31%	47.91	17.68	0%/8%	38.83	17.07	0%/23%
	Secondary (n=8)	48.33	11.96	0%/0%	38.44	9.18	0%/0%	48.55	14.65	0%/0%	42.44	22.02	0%/13%
	Total (n=21)	44.19	12.71	0%/9%	37.47	13.27	0%/19%	48.19	16.06	0%/5%	40.38	19.03	0%/19%

N.B. - <80% is "very high" and <26% is "very low"

Table 5 - Pearson correlation of the PSI results for the teenage children, controlling for gender

	Balanced Cohesion % Score	Balanced Flexibility % Score	Disengaged % Score	Enmeshed % Score	Rigid % Score	Chaotic % Score	Family Communication % Score	Family Satisfaction % Score
PD	0.33	0.08	-0.55*	-0.48	-0.13	-0.54*	0.14	0.27
P-CDI	0.03	-0.25	-0.48	-0.47	-0.19	-0.59*	-0.04	0.07
DC	0.07	-0.20	-0.37	-0.25	0.22	-0.48	-0.33	-0.16
Total Stress	0.17	-0.12	-0.56*	-0.45	-0.05	-0.59*	-0.06	0.08