

COPING STRATEGIES AND PARENTAL ATTITUDES

A Comparison of Parents with Children with Autistic Spectrum Disorders and Parents with non-autistic Children

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ABSTRACT

This study focused on the coping strategies of parents' with children with autistic spectrum disorders (ASD) and the relation between these strategies and parenting styles. Coping strategies were measured using the Sense of Coherence Scale (SOC) and the Purpose in Life Test (PIL-R). Parental attitudes toward loving care, stress, worry, and guilt feelings were assessed using the Family Impact Questionnaire. Two groups of participants were included: parents with children with ASD (EG) (n = 66) and a matched control group (CG) (n = 66). Paired Samples t-Test and Pearson's r correlation were used as methods of analysis. Main results distinguished significant ($p < .001$ to $.003$) differences between the EG and CG for almost all variables included. The M level of coping strategy was much higher for the CG than for the EG. SOC showed a stress-reducing effect in both the EG and CG. PIL-R explained 50 % of the variance in SOC for the EG and 33 % for the CG. The only significant gender difference in the EG was on SOC indicating a higher sense of coherence among the fathers and probably an indicator of a stronger burnout effect of the mothers.

Keywords: Autism, Parental Attitudes, Families, Children

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Approaches to working with parents of autistic children have changed significantly during the past twenty years. Marcus, Kuncze, and Schopler (1) noted a parallel between this change and the recognition of autism as a developmental disorder rather than as an emotional disturbance. As part of this change, parents have become more directly involved in the treatment of their child (2-4). Parents are no longer viewed as the cause of their child's problem, but rather recognized as partners in the treatment of their child. Parents need functional coping strategies to succeed in this new role. However, the current situation for parents and families in Swedish society is far from ideal. Parents still struggle against the municipal authorities to gain their legal rights, and they have difficulty obtaining special programs directed by skilled and competent professionals for their children. This struggle has often been a challenge for parents, who need coping strategies in order to manage. Without functional and flexible coping strategies, parents risk burn out effects. When that happens, either extended family or society must deal with the child or adult with autism. One strategy to avoid these negative effects is for parents' to fight for their children, net working with other parents and lobbying communities and governments for services.

The better parents are able to cope with daily life situations, the more probable it is that they successfully can contribute to the care of their children. Further, good coping skills may facilitate parent's to have enough strength over to take part in the democratic process to change the rules and laws regulating how society cares for its individuals with difficult – to – serve disabilities.

FOCUS OF THE STUDY

The present study was a comparison between parents with a child with autism and parents with non-autistic children regarding two coping strategies assumed to be of importance for the parents' capability to manage the stress brought on by daily situations in family life. Coping strategies are looked upon as being cognitive structures of the emotional system influencing the individual's structure of emotions (5). The coping strategies for the study of parental stress were *Sense of Coherence* (SOC) (6) and *Purpose in Life* (PIL-R) (7), originally designed by Victor Frankl (8). SOC measures three dimensions of the sense of coherence, *comprehensibility* (the extent to which the world is perceived as sensible, ordered, and predictable), *manageability* (the degree to which personal resources are perceived as

adequate to meet demands), and *meaningfulness* (the degree to which the world is conceived to make emotional sense, that problems are worthy of commitment, and that challenges are accepted). PIL-R measures the level of an individual's experience of having clear and stable goals in life. SOC and PIL-R scores were assumed to be related to parental attitudes and feelings concerning the care, the worry, the stress, and the feelings of guilt for their children. There is probably a mutual influence between coping strategy and parents' attitudes and feelings. In the present study, the notion of attitude or feeling was understood in a cognitive sense (5), assuming that emotions arise as a result of certain kinds of cognition. The focus was on the explanation of how people's perceptions of the world – their construal – cause them to experience emotions. Ortony raises two questions: 1. "What is the cognitive structure of the emotional system as a whole?" and 2. "What is the cognitive structure of individual emotions?" (5, p.12). This study does not define the concept of emotion as it is done in psycho-dynamic psychology since it has appeared to be unfruitful in the field of autism.

A review of the literature (9) has shown that parents with ASD children are exposed to stress in the areas of obtaining a diagnosis for the child's condition, of family support, of information, of appropriate short-term services(10), and of finding group homes for their young adults (11). The chronic nature of ASD can affect parents negatively and there is a danger of becoming exhausted and pessimistic with a risk for burn out(12-15). There are factors in autism that facilitate life stress of such magnitude, intensity, duration, and unpredictability that these tend to constitute the most stressful situations (16). Parental disappointments and worries regarding the future cause stressful experiences (17). Morgan (18) has called attention to the necessity of approaching the family with an ASD child as a whole. Harris (19) has described how different subsystems in the family easily are established involving the parents, the siblings, and the ASD child. This despite the fact that the family's successful adaptation of the child was highly correlated with degree of cohesion, expressiveness, and active recreational orientation (12). Mothers of ASD children report significantly greater stress(20), greater depression(20,21), greater social isolation(23), and a lower level of marital intimacy when compared to mothers of normal children and mothers of Down's Syndrome children (16,24,25). Mothers who typically do far more parenting work (26,27) than fathers report that the more

they share the overall burden with fathers, the more satisfied they become. For fathers, the best predictor of satisfaction in the parenting role was the level of total parenting burden, not the balance with their wives(28).

AIM

The aim of the study was to compare and find out if there were any significant differences as follows:

- (1) between the parents' coping-strategies SOC and PIL – R,
- (2) between the parents' attitudes towards their children regarding Loving care, Worry, Stress and Guilt feelings,
- (3) regarding the association between the coping strategies SOC and PIL – R, and the parental attitudes of Loving care, Worry, Stress and Guilt-feelings,
- (4) between mothers and fathers on the coping strategies and the parental attitudes.

The following hypotheses were tested:

Coping-strategies:

H_0 There is no difference on SOC and PIL – R for the two groups of parents.

H_1 There is a significant difference between the ASD parents' and the CG' regarding the level of Sense of Coherence and Purpose in Life.

Parental attitudes:

H_0 There is no significant difference between the two groups of parents regarding the parental attitudes of Loving care, Worry, Stress, and Guilt-feelings.

H_2 There is a significant difference between the ASD parents' (EG) and the matched CG regarding the attitudes of Loving care, Worry, Stress, and Guilt-feelings.

Association between coping-strategies and parental attitudes:

H_0 There is no association between the coping-strategies of SOC and PIL – R and the parental attitudes of Loving care, Worry, Stress, and Guilt-feelings.

H_3 There is a significant relation between SOC and PIL-R and the attitudes of Loving caring, Worry, Stress, and Guilt feelings towards the children.

Gender differences:

- H₀ There is no gender difference on the coping-strategies SOC and PIL – R, or parental attitudes of Loving care, Worry, Stress, and Guilt-Feelings.
- H₄ There is significant gender difference on the coping-strategies SOC and PIL – R, and on the parental attitudes of Loving care, Worry, Stress, and Guilt-feelings.

METHOD

Procedure

In the spring of 1997 the known population in the county of Kronoberg in southern Sweden with a child with a diagnosis of autism (ASD) and in which the child was still living at home consisted of 70 families. They were asked (by the Center of Autism Kronoberg) if the researcher was allowed to contact the parents with a letter containing detailed information about the project. They were informed of their right to break off the co-operation at any time without giving a reason upon when they gave their written consent to take part in the project. The study was approved by the local committee of ethics. Thirty-nine families accepted to take part in the study and these formed the Experimental group (EG). However, two families left the study, one of diagnostic reasons and one due to a divorce. Likewise, a random sample of 300 families out of 6200 in the municipality of Växjö with children still living at home were asked if they wanted to take part in the study as Control group (CG). The families were informed about the aim of the study and briefly about the instruments and the distribution of these. From the families who accepted to take part, a paired (with EG) matched Control group (CG) was formed. The three instruments of investigation, *Sense of Coherence* (SOC) (6), *Purpose in Life* (PIL-R) (7), and the *Family Impact Questionnaire* (FIQ) (29) were distributed by mail. The FIQ Test has been translated into Swedish (1997), and Sivberg (30) has made a first validation of the PIL-R test in a Swedish cultural context.

INSTRUMENTS

Antonovsky looked upon the origin of health as a totality seen as relative on a continuum between total health and total disease. The individual moves in a salutogenetic direction towards total health and in a pathogenetic direction towards total disease. What makes a

person move in a salutogenetic direction? Antonovsky stated that an individual is always exposed to stress. That is a part of the human environment. An individual's *general resistance resources* (material and non-material) give our existence consequence and make us able to gain control of our lives because we have them at our disposal and they make sense of our existence. The test *Sense of Coherence* is probably a measure of this dimension of an individual's coping capability as well as SOC assesses a more general personality structure.

Antonovsky has operationalized his facet theory into the SOC test with 29 items. O'Connor and Chamberlain's study (31) of people's accounts of their experiences of life meaning is congruent with Antonovsky's three dimensions in SOC. They revealed cognitive, motivational, and affective components in people's constructs of meaning in life. According to Antonovsky the emotional (meaning) component is the most profound. The meaningfulness component is probably overlapping the meaning dimension of PIL-R. Cronbach's α for the full-scale (29 items) ranges from 0.84 to 0.93, with test-retest reliability reported as 0.63 (6). SOC can be described as 'a global orientation that expresses the extent to which people believe their life is predictable and that things will work out as well as can be expected' (32, p 162). From the SOC-Test the total score of the Sense of Coherence was used. Scores from 29 to 87 are considered as low, from 88 to 145 as fairly moderate and scores from 146 to 203 as high. Parents in earlier Swedish studies have M around 150 on SOC.

The split-half reliability of the PIL-R Test was determined by Crumbaugh & Maholich (7) as .82 (Pearson r , $n = 225$). Crumbaugh (33) predicted from the standpoint of construct validity the order of scores on PIL-R in four 'normal' populations. The four groups were successful business and professional personnel ($n = 230$), active and leading Protestant parishioners ($n = 142$), college undergraduates ($n = 417$), and indigent non-psychiatric hospital patients ($n = 16$). They scored 118.9, 114.3, 108.5 and 106.4 in average, respectively. The total score of the PIL-R was also used. Scores < 111 are considered as not yet having found a clear meaning in life and scores > 112 as having found a clear meaning according to the manual of the test (34).

Donenberg and Baker (29) developed the Family Impact Questionnaire (FIQ) in a study of externalizing children diagnosed with hyperactivity or attention deficit hyperactivity disorder (ADHD). Families with these externalizing children were compared to families with normally developing children and a clinical control group of

parents with children with autism. The FIQ questionnaire has four sections with a total of 50 items. In the present study, Section 1 (attitudes towards child – 14 items) was used for the assessment of parents' perceptions of child impact on their families. The assessment was relative to the impact 'most children his/her age have on their parents/family' (e.g. "I feel loved by my child more" or "I am more embarrassed by his/her behaviour in public"). The FIQ is of Likert-type fashion on a 4-point scale from (0) *not at all* to (3) *very much*. The FIQ scale reliabilities range from $r = .83$ to $.92$. Four groups of parental attitudes and feelings (reliable factors from a principal component factor analysis with Cronbach's $\alpha > .74$) from the FIQ-questionnaire were used.

The first attitude, *Loving care*, and consisted of questions 2, 4, 6, 8, 10, and 12:

- 2. I enjoy the time I spend with my child more. (High load)
- 4. My child brings out feelings of happiness and pride more. (High load)
- 6. It is easier for me to play and have fun with my child. (High load)
- 8. My child makes me feel more loved. (High load)
- 10. My child makes me feel more energetic. (High load)
- 12. My child makes me feel more confident as a parent. (High load)

The second parental attitude, *Worry*, consisted of the items 7, 12, and 13 in the FIQ.

- 7. My child's behavior bothers me more. (High load)
- 12. My child makes me feel more confident as a parent. (Low load)
- 13. I feel like I should have better control over his/her behavior. (High load)

The third parental feeling, *Stress*, consisted of the items 1, 3, 5, and 14 in the FIQ.

- 1. My child is more stressful. (High load)
- 3. My child brings out feelings of frustration and anger more. (High load)
- 5. When I am with my child, I feel less effective and competent as a parent. (High load)
- 14. My child does what I tell him/her to do most of the time. (Low load)

The fourth parental attitude, *Guilt feelings*, consisted of the items 9 and 11 in the FIQ.

9. I feel like I am working alone in trying to deal with my child's behavior. (High load)

11. I feel like I could be a better parent with my child. (High load)

PARTICIPANTS

The participants of the study consisted of two groups of parents. The Experimental group (EG, n = 66) consisted of parents with a child with autism still living at home. The Control group (CG, n = 66) was a matched group, matched regarding number of children living at home and their age and sex (see Table I), and the parents' sex, age, education, and occupation (see Table II). The number of families with four or more siblings in the CG was somewhat higher than in the EG, but five of these young adults in the CG families did not any longer live at home (see Table I). All types of occupations were represented: blue collar workers, farmers, various white collar workers, and different professionals. The M age in the EG and the CG was 43 and 39 years, respectively. The range of age was 25 to 62 years. The relative number of females was the same in both the EG and CG, 56%. The CG was matched according to the demographic pattern showed in Table I and Table II with only few minor deviations.

STATISTICAL ANALYSIS

The statistical analyses used to test the hypotheses of the study were Paired Samples t-Test for estimation of differences (since the two

Table I. Demographic presentation (age, sex and children per family) of the ASD in family system children and their siblings and the number of children in the matched group of families (percentage is given within parenthesis).

Age	ASD children			ASD siblings			EGControl group, CG			
	Male	Female	Total	Male	Female	Total	Total	Male	Female	Total
1 – 10 years	9	7	16	16	8	24	40	25	15	40
11 – 15 years	7	4	11	7	6	13	24	17	16	33
16 – 26 years	5	5	10	8	10	18	28	17	6	23
Total	21	16	37	31	24	55	92	59	37	96
	(53 %)	(47 %)	(39 %)	(56 %)	(44 %)	(61 %)	(100 %)	(61 %)	(39 %)	(100 %)

Note. Number of families with one child was 4 (4), two children 18 (12), three children 11 (12) and four to five 4 (9), respectively

Table II. Demographic presentation of the parents in EG (n = 66) and CG (n = 66). Data of CG is given within paranthesis.

Mothers (n)	Fathers (n)	M age mothers	M age fathers	Mothers (n) education	Fathers (n) education	Mothers (n) main occupation	Fathers (n) main occupation
37 (37) (56 %)	29 (29) (44 %)	42 (40)	45 (41)	8 (11) academic education 11 (14) white color 13 (7) workers 1 (0) self-employed 1 (2) farmer 0 (3) students 3 (0) at home	11 (13) academic education 8 (8) white color 6 (3) workers 3 (3) self-employed 1 (2) farmer 0 (3) as different kinds of students 16 (19) unspecified	11 (5) in the care-giving area 4 (2) as teachers 2 (0) as self-employed 4 (0) worked at home 0 (3) university students 0 (8) as different kinds of professionals 16 (19) unspecified	10 (10) as different kinds of professionals 5 (2) as workers 5 (5) as self-employed 9 (12) mainly white color
<p>Note. Five (4) mothers were single parents and three (4) were married but their husbands did not take part in the study. Totally 37 (37) families were included.</p>							

groups were dependent on each other due to the fact that they were matched), an Independent Samples t-Test for gender differences, and a bivariate correlation estimate of Pearson r.

RESULTS

Group differences in coping strategies and parental attitudes

The study of differences between the EG and CG on the coping-strategies SOC and PIL – R and the parental attitudes of Loving care, Worry, Stress, and Guilt-feelings was performed by a Paired Samples t-Test. Data was paired in the same order as the matching process of the CG from the demo-graphical properties of the EG. Due to the matching, the CG was dependent on the EG when the number of children, siblings, and their age and sex were matched. The same was true for parents' sex, age, education, and occupation. The result of the Paired Samples t-Test showed significant differences in the cop-

ing-strategies of SOC $t(66) = -4.22, p < .001$, and PIL – R $t(66) = -2.43, p < .01$. Further, it found significant differences in the parental attitudes of Loving care $t(66) = -3.96, p < .001$, Worry $t(66) = 5.63, p < .001$, Stress $t(66) = 7.24, p < .001$, and for Guilt-feelings $t(66) = 3.46, p < .001$ (see Table III). Descriptive statistics for the variables included in the study are presented in Table III.

A consistent pattern of lower mean scores on both coping strategies and parental attitudes were found in the EG compared to the CG (see Table III).

Table III. Statistics for EG and CG on SOC, PIL – R, Loving care, Worry, Stress and Gilt-feelings.

Variabel	EG				t	CG			
	M	SD	Min	Max		M	SD	Min	Max
SOC	138.6	23.9	66	178	-4.22 ***	152.6	19.0	92	181
PIL – R	106.7	14.8	63	132	-2.43 **	113.3	14.2	63	133
Loving care	6.47	3.1	0	14	-3.96 **	9.14	4.4	0	17
Worry	3.78	1.5	0	7	5.63 ***	2.19	1.6	0	7
Stress	5.31	2.0	1	10	7.24 ***	2.89	1.6	0	7
Guilt-feelings	2.12	1.3	0	6	3.46 ***	1.44	1.3	0	6

Note. ** Significant at $p < .01$; *** Significant at $p < .001$

RELATIONS BETWEEN COPING STRATEGIES AND PARENTAL ATTITUDES

In the EG, there was significant negative correlation between SOC and Stress (Pearson $r = -.343^{**}$), (see Table IV). The correlation between Stress and Loving care and Stress and Worry were also significant ($r = .252^*, .335^{**}$, respectively). The correlation between Stress and Loving care was significant ($r = .252^*$) in the EG (not in the CG), indicating the most stressing parental experience of loving an ASD child. Finally, the correlation between Guilt feelings and Worry was significant in the EG ($r = .320^{**}$).

In the CG, the correlation between SOC and Stress, Stress and Worry, Guilt feelings and Worry, and Guilt feelings and Stress was significant ($r = -.309^*, .691^{**}, .377^{**}, .321^{**}$), (See Table IV).

The correlation pattern (significant negative correlation between Stress and SOC, significant positive correlation between Stress and

Table IV. Correlation Matrix (Pearson) between the coping-strategies of Sense of Coherence and Purpose in Life, and the parental attitudes of Loving care, Worry, Stress and Guilt feelings (EG above diagonal; CG below diagonal).

Variable	SOC	PIL-R	Loving care	Worry	Stress	Guilt-feelings
SOC		.715**	-.036	-.120	-.343**	-.183
PIL – R	.575**		-.106	.093	-.094	-.198
Loving care	-.116	.179		.114	.252*	.130
Worry	-.139	.045	.131		.335**	.320**
Stress	-.309*	-.132	.130	.691**		
Guilt –feelings	-.112	.056	.008	.377**	.321**	

Note. * Significant at $p < .05$. **Significant at $p < .01$

Worry, and Guilt feelings and Worry) was present in both of the groups. The correlation was stronger (positive or negative) in the CG (see Table IV) except for the relation between SOC and Stress, which was stronger in the EG. The CG differed from the EG with a much stronger correlation between Stress and Worry ($r = .691$). The M for Loving care was much higher in the CG than in the EG and Worry can be looked upon as an intervening variable for Loving care. Loving care does presuppose a reasonable level of Worry before the Loving care takes place. If the parental worry does not result in an increased level of loving care, the level of stress will probably increase as a negative result of frustrated worry. Probably, the number of children, especially a child with autism, demands the parents' purpose in life as well as their sense of coherence.

Gender differences

Gender differences in the EG and CG was investigated by Independent Samples t-Test for SOC, PIL-R, Loving care, Worry, Stress, and Guilt feelings. Significant differences were very few on the whole. The only significant difference between males and females in the EG was on SOC ($t(66) = 2.0, p < .05$), which indicated a higher Sense of Coherence for the males. There were no significant differences in the CG.

Test of Hypotheses 1 to 4

H_1 stating a significant difference on Sense of Coherence and Purpose in Life between the EG and CG was supported by data (SOC, $p < .001$; PIL-R, $p < .01$).

The result of the t-Test did not support H_0 hypothesis proposing there was no difference between the two groups regarding parental attitudes of Loving care, Worry, Stress, and Guilt feelings. On the contrary, significant differences were found for all of the attitudes and H_2 hypothesis stating significant differences between the EG and CG for Loving care, Worry, Stress and, Guilt feelings ($p < .001$) was supported (See Table III) by data. H_1 and H_2 were not falsified by the t-Test.

H_3 was supported by the findings. The EG and CG showed one main correlation pattern and some differences between the groups. In both groups there was a negative significant correlation between Sense of Coherence and Stress ($p < .01$ in the EG, but weaker $p < .05$ in the CG), Stress and Worry ($p < .01$; especially high in CG, $r = .691$), and Guilt feelings and Worry ($p < .01$).

H_4 got weak support in the t-Test analysis of gender differences on Loving care, Worry, Stress, Guilt feelings, SOC, and PIL-R. The significant difference on SOC in favor of males is probably explained by the deeper involvement of females in the care of the ASD child.

DISCUSSION

The main finding of this study was that sense of coherence had a strong stress-reducing effect regardless if one has an easy (the CG parents' $r = .309$) or a severe (the EG parents' $r = .343$) life situation as a parent (see Table IV). This finding raised the question of the significance of the individual's ideology or interpretation of life (life-view). The situation of life was, of course, of great importance for the parents. Among the ASD parents (EG) PIL-R explained 50 % of the variance in SOC, while 33 % was explained among the CG parents. The difference between the EG and CG in the variance of PIL-R in SOC was an indication of that the need for searching an individual meaning in life was greater the more severe the life-situation was. The interpretation of life or personal ideology had a therapeutic significance for parents.

The mean difference on the Sense of Coherence Scale between the EG and CG was a substantial difference which separated the EG parents from the CG parents and from the national M for parents in Sweden on SOC. It is quite clear that parents of ASD children have a lower sense of coherence than Swedish parents in general. How can this fact be explained? Sense of Coherence consists of three dimen-

sions: Meaning, Comprehensibility, and Capability. It is reasonable to link the fact of having an ASD child to questions of meaning in life. The questions of causes, responsibility, good enough parenting, and finally the personal meaning of life are raised. The crucial point is not to find the meaning but to create a meaning for your life. At the same time you have to comprehend the situation and increase your knowledge about the phenomena of autism if you are to manage the upbringing of an ASD child. The dimension of comprehensibility of SOC has the lowest average among Swedish parents (30) and it is probably even harder for ASD parents to grasp the complex situation of life in postmodern society. There is a wide range of resources demanded of parents in respect of manageability of daily life. This is also true for ASD parents, but they are focused on even more difficult and persistent problems in their parenting situation. They face a real challenge in their life situation. These circumstances together can explain the lower level for SOC in the EG, but on the other hand, a higher level of SOC would probably help the parents to cope better with their daily tasks in parenting the child. Also, it is worthy to note that for the CG, the higher the SOC the lower the stress.

The difference between the EG and CG on the PIL-R was great enough to divide the parents, according to the manual, into those who have not yet found a clear meaning in life and those who had. The question did not concern finding 'the normative meaning', but rather finding a specific personal meaning for themselves in life. The CG parents had usually done that. Having a clear goal in life and experiencing a meaning in one's own life probably strengthens a person's ability to cope with and manage daily problems in the upbringing of children.

Efforts to help the parents increase coping and general resistance resources should be directed towards all three dimensions of SOC. The dimension of comprehensibility is linked to cognition and could be applied for many different training programs for parents with special issues with the purpose to increase the knowledge of autism. Manageability could be increased by the development of societal services, personnel, and their competencies in the direction of being a more adjusted to support parents in their efforts to reach an optimal level of functional capacities in family life. This dimension also has a direct connection to behavioral questions in autism and specifically

how to learn to manage these deviating behaviours. Furthermore, it is very important not to forget the existential and ethical questions raised by the situation of having an ASD child. Every parent needs to be confirmed and respected as a person searching for a personal meaning or belief-system anchored in enhanced ideas and values helping them to find what they appraise to be the best treatment for their child.

CONCLUSIONS

Beyond every doubt, families with a child with an autism spectrum disorder do not get the support for their daily life situation needed. On the contrary, they need much more functional support focused on the whole. A variety of services are needed from social habilitation units in the municipalities, better adjustment of special pedagogy on all levels of school training, and an adapted social policy for autism as a communication disability legalized by the government. This study also supports the conclusion that parents also need to get better possibilities to deal with and to construct existential solutions for the interpretation of their lives.

REFERENCES

1. Marcus, L.M., Kuncze, L.J. & Schopler, E. Working with families. In D.J. Cohen & F.R. Volkmar (Eds.) *Handbook of autism and pervasive developmental disorders*. New York: John Wiley & Sons 1997; 631 – 649.
2. Harris, S.L. Treatment of family problems in autism. In E. Schopler & G.B. Mesibov (Eds.). *Behavioral Issues in Autism*. New York: Plenum 1994; 161 – 175.
3. Howlin, P. Help for the family. In C. Gillberg (Ed.), *Diagnosis and treatment of autism*. New York: Plenum 1989; 185 – 202.
4. Marcus, L.M. & Schopler, E. Parents as co-therapists with autistic children. In C.E. Schaefer & J.M. Briesmeister (Eds.), *Handbook of parent training: Parents as co-therapists for children's behavior problems*. New York: John Wiley & Sons 1989; 337 - 360.
5. Ortony, A. The cognitive structure of emotions. Cambridge: Cambridge University Press 1988.
6. Antonovsky, A. *Health, Stress and Coping*. San Francisco: Jossey-Bas 1987.
7. Crumbaugh, J.C. & Maholick, L.T. An experimental study in existentialism: The psychometric approach to Frankl's concept of noogenic neurosis. *J Clin Psychol* 1964; 20: 200-207.
8. Frankl, V. E. The will to meaning. *J Past Care* 1958; 12: 82 -88.
9. Sivberg, B. Literature review of autism, families and coping. Unpublished manuscript.
10. Freeman, N.L., Perry, A., & Factor, D.C. Child behaviors as stressors: Replicating and extending the use of the CARS as a measure of stress: A research note. *J Child Psychiatry* 1991; 32: 1025 -1030.

11. Smith, B., Chung, Ch. Vostanis, P. The Path to Care in Autism: Is it better now? *J Autism Dev Disord* 1994; 24: 551 - 562.
12. Bristol, M.M. Family Resources and Successful Adaptation to Autistic Children. In Schopler, E. & Mesibov, G.B. (Eds.), *The effects of autism on the family*. New York: Plenum 1984; 293 - 306.
13. Bristol, M.M. & Schopler, E. Stress and coping in families of autistic adolescents. In Schopler, E. & Mesibov, G.B. (Eds.), *Autism in adolescents and adults*. New York: Plenum 1983; 251 - 278.
14. DeMyer, M.K. & Goldberg, P. Family needs of the autistic adolescent. In Schopler, E. & Mesibov, G.B. (Eds.) *Autism in adolescents and adults*. New York: Plenum 1983; 225 - 250.
15. DeMyer, M.K. *Parents and children in autism*. Washington D.C.: Winston 1979.
16. Wolf, L.C., Noh, S., Fisman, S.N., & Speechley, M. Brief Report: Psychological Effects of Parenting Stress on Parents of Autistic Children. *J Autism Dev Disord* 1989;19: 157 - 166.
17. Wing, L. (1988). The continuum of autistic Characteristics. In Schopler, E. & Mesibov, G.B. (Eds.), *Diagnosis and assessment in autism*. New York: Plenum 1988; 91 - 110.
18. Morgan, S.B. The Autistic Child and Family Functioning: A developmental-family system perspective. *J Autism Dev Disord* 1988; 18: 263 - 280.
19. Harris, S.L. A family system approach to behavioral training with parents of autistic children. *Child Family Behav Ther* 1982; 4: 21 - 35.
20. Breen, M.J. & Barkely, R.A. Child psychopathology and parenting stress in girls and boys having attention deficit disorder with hyperactivity. *J Pediatr Psychol* 1988; 13: 265 -280.
21. Forehand, R., Brody, G., & Smith, K. Contributions of child behavior and maritaldissatisfaction to maternal perceptions of child adjustments. *Behav Res Ther* 1986; 24: 43 - 48.
22. Morrison, J.R. Adult psychiatric disorders in parents of hyperactive children. *Am J Psychol* 1980; 137: 825 - 827.
23. Wahler, R.G. & Fox, J.J. (1980). Solitary toy play and time out: a family treatment package for children with aggressive and oppositional behavior. *J Appl Behav Anal* 1980; 13: 23 - 39.
24. Fisman, S.N., Wolf, L.C., & Noh, S. Marital Intimacy in Parents of Exceptional Children. *Can J Psychiatry* 1989; 34: 519 - 525.
25. Befera, M.S. & Barkely, R.A. Hyperactive and normal girls and boys: Mother - child interaction, parent psychiatric status and child psychopatology. *J Child Psychol Psychiatry* 1985; 26, 439 - 452.
26. Cantwell, D.P. & Baker, L. Research concerning families of children with autism. In Schopler, E. & Mesibov (Eds.), *The effects of autism on the family*. New York: Plenum 1984; 41 - 63.
27. Mash, E.J. & Johnston, C. A comparison of the mother-child interactions of younger and older hyperactive and normal children. *Child Dev*; 1982; 53: 1371 - 1381.
28. Holmes, N. & Carr, J. The Pattern of Care in Families of Adults with a Mental Handicap: A Comparison between Families of Autistic Adults and Down Syndrome Adults. *J Autism Dev Disord* 1991; 159 - 202.
29. Donenberg, G. & Baker, B.L. The Impact of young children with externalizing behaviors on their families. *J Abnorm Child Psychol* 1993; 21: 179 - 198.
30. Sivberg, B. A Validation Study of the Swedish version of Purpose in Life Test - Revised version. Submitted 2000.
31. O'Connor, K. & Chamberlain, K. Dimensions of life meaning. A qualitative investigation at mid-life. *Br J Psychol* 1996; 84: 461 - 477.
32. Zika, Sh. & Chamberlain, K. On the relation between meaning in life and psychological well-being. *Br J Psychol* 1992; 83: 133 - 145.
33. Crumbaugh, J.C. Cross-validation of Purpose in Life Test based on Frankl's concepts. *J Individ Psychol* 1968; 24: 74 - 81.
34. Crumbaugh, J.C. & Henrion, R. *The PIL Test: Administration, Interpretation, Uses Theory and Critique*. The International Forum for Logotherapy 1988; 11: 76 - 88.

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