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Family Adaptation, Coping and Resources: Parents Of Children With Developmental Disabilities and Behaviour Problems

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Abstract

The present study used a Double-ABCX model to explore parental stress in 48 British families with children with developmental disabilities and behaviour problems in relation to certain child characteristics, resources, parents' perceptions and coping styles. Results indicated that the strongest predictors of parental stress were family coping style and parental internal locus of control. Parents who believed their lives were not controlled by their child with a disability and who coped by focussing on family integration, co-operation, and were optimistic tended to show lower overall stress. This study also examined parents' qualitative responses to questions concerning the stress they experience in dealing with friends, family, and doctors or other professionals. The emerging themes and clinical implications of these findings, methodological issues, and suggestions for future research are discussed.

When a child is born with a disability, the unexpected and permanent nature of such an event generally increases a parent's vulnerability to stressors. There is considerable evidence to suggest that parents of children with developmental disabilities (DD) experience greater stress than parents of children without DD (Hastings, 2002; Konstantareas, 1991; Scorgie, Wilgosh & McDonald, 1998). Historically, research has assumed that outcomes for parents of children with DD who may experience additional stressors such as unmet service needs and financial problems would inevitably lead to pathology and maladaptation (Byrne & Cunningham, 1985, Dykens, 2000).

However, recent research has shown that although some families are at risk for having numerous difficulties many families positively cope and adapt to this stress (Konstantareas, 1991; Scorgie et al., 1998). The vast amount of research has shown that family outcomes can vary from healthy adaptation to maladaptation as a result of changing family responses over time (Donovan, 1988). Current literature has therefore moved away from the single cause and effect relationship between parental stress and pathology and has emphasized the successful adaptation and normality of families.

One model that has been used to understand parental stress is the ABC-X model (Hill, 1958). McCubbin (1979) recognized the need to expand the original model to assess post-crisis behaviour, and include coping strategies, external resources and the accumulation of various life stressors. Thus, McCubbin and Patterson (1983) developed the Double ABC-X model of stress and coping. In this model, a parent's ability to cope with a stressful situation is determined by the interaction of the stressor event and subsequent life stressors, family resources, parental perceptions and coping strategies. The outcome of this interaction is the level of family adaptation ranging from severe stress or crisis to successful adaptation. Several studies have used this model to examine the parental stress of having a child with DD (Bristol, 1987; Konstantareas, 1991; Minnes 1988a).

Multiple studies have found the nature and severity of a child's disability to be significantly related to parental stress, as well as a child's temperament, behaviour problems and demands placed upon the parent (Cunningham, Bremner & Secord-Gilbert, 1992; Kazak & Marvin, 1984; Minnes, 1988a). Variations in family environments have also been associated with successful family adaptation, and support networks beyond the immediate family have been identified as important mediators in parental stress (Barakat & Linney, 1992; Henggeler, Watson & Whelan, 1990; Park, Turnbull & Rutherford, 2002; Rimmerman, 1991). Families have been reported as one of the most frequent sources of support for parents (Scorgie et al., 1998). However, results have been inconclusive regarding the effects of professional support on parental stress. While some research has shown the benefit of professional intervention and services, negative effects and stressors experienced by parents in dealing with professionals have also been reported (Minnes & Nachshen, 1997; Todis & Singer, 1991).

In addition, parental perceptions or cognitive appraisals of the child's disability have been found to mediate such stress, although results have been contradictory (Grant & Whittell, 2000; Miller, Gordon & Daniele, 1992). Whether having a child with disabilities leads to stress or adaptation will depend upon the explanations made by the family, their understanding of why events occur and what existing coping strategies they may use to alleviate stress. Parental locus of control has also been recognized as an important component in influencing parental stress. Researchers have found that a family's perception of having internal control over outcomes is related to reduced stress and greater positive adjustment in families of children with DD (Dyson, 1991; Hastings & Brown, 2002; Miller, et al. 1992; Rimmerman, 1991).

The purpose of the present study was to explore the relative impact of the level of coping resources, strategies, and perceptions on the stress experienced by parents of children with DD and behaviour problems. The Double ABC-X model of family stress and coping was used as a framework. This investigation expands previous research by using a clinical subsample of children with DD. This study also provides an in-depth and individualized understanding of family resources and supports related to family adaptation through the use of a qualitative interview. It is hoped the results of the research will help professionals to understand the interaction of variables related to family adaptation, the nature of the stressors experienced, and the successful coping strategies used by families of children with DD.

Method

Participants

A sample of 48 primary care-givers (i.e. parents, grandparents and foster parents) with 51 children with DD and behaviour problems was obtained from the current case-load and waiting list of a behaviour team supporting children with a learning disability (developmental disability) in the United Kingdom. Three sets of care-givers were excluded from the study due to the parents having DD themselves or being identified as in crisis.

The families were a combination of 16 one-parent and 32 two-parent families (biological and non-biological) with 16 girls and 35 boys. The mean age was 8.0 years (*SD*=2.9 years). There were three pairs of siblings with DD, one being a twin set. All the children presented with significant behaviour difficulties and met criteria for the WHO classification of DD (onset before 18, adaptive behaviour deficits and IQ < 70). These children may have had additional diagnoses of Autism, Down syndrome, ADHD or Cerebral Palsy. The prevalence of child diagnoses can be found in Table 1.

Table 1. Types of disability

Type	*Frequency*	*Percentage*
Learning disability/ developmental delay	20	39.2%
Autistic spectrum disorder	15	29.4%
Attention deficit hyperactivity disorder	5	9.8%
Cerebral palsy	3	5.9%
Down syndrome	3	5.9%
Genetic/ metabolic disorder	5	9.8%

Measures

Child and parent characteristics. Information concerning the child's characteristics such as gender, age and disability type was obtained from the team's initial assessment completed at the time of referral, including a 'behaviour difficulties' checklist. Parents were asked whether their child displayed any of 53 behaviours yielding a total score from 0 to 53.

Parental stress. Family adaptation was assessed by using the Questionnaire on Resources and Stress - Short Form (QRS-SF; Holroyd, 1974) that measures the level of distress of having a child with DD or a chronic illness in the family. Sixty-six true/false items on eleven sub-scales address parental responses to various stressors. Adequate levels of reliability and validity have been established for the scale (Holroyd, 1982).

Table 2. Questions of the Family Stress and Support Questionnaire

1. What challenges have you faced with this particular issue?
2. What successes have you had and how did you achieve them?
3. How stressful is this issue for you? - Rated on a scale from 0 (Not stressful) to 4 (Extremely stressful)
4. Who did you turn to for support? (e.g., self, parents, siblings, partner, friend, child, work colleague, professionals, other mothers).
5. What would you like to see change that would make this experience easier for you and for other children with special needs?

The Family Stress and Support Questionnaire (FSSQ; Minnes & Nachshen, 1997) was used to obtain data concerning issues parents encounter in raising a child with DD. Of the original 17 issues, the authors chose two items of particular interest. These issues asked about "dealing with friends, family, and neighbours on a day-to-day basis" and about "dealing with doctors and other professionals". The same five questions (see Table 2) were asked about both issues. Of these questions, the responses for 1, 2, and 5 were coded into thematic categories emerging from the data (see Procedure). The FSSQ has demonstrated adequate content validity, and is more effective as an interview (than as a questionnaire; Nashchen, Woodford, & Minnes, 2003) as was done in this study.

Family resources. The availability, type and helpfulness of family resources was measured using the Family Support Scale (FSS; Dunst, Jenkins & Trivette, 1984). Ratings were recorded using a five-point Likert-type scale, ranging from 'not helpful at all' (1) to 'extremely helpful' (5). Both dimensions of quantity and quality of social support (i.e. sources, helpfulness and satisfaction) were examined. The FSS has a reliability of .91 and acceptable levels of validity (Dunst, et al., 1984).

Coping Strategies. The Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, Patterson & Cauble, 1983) was used to assess parental coping styles and perceptions of the helpfulness of certain strategies. The scale uses a four-point Likert-type scale, ranging from 'not helpful' (0) to 'extremely helpful' (3). Forty-five items are divided into three sub-scales; family (maintaining family integration, co-operation and optimistic definition of the situation), support (maintaining social support, self-esteem and psychological stability), and medical (understanding the medical situation through communication with other parents and professionals). The authors report the internal consistency of all three sub-scales to be satisfactory.

Locus of control. The Parental Locus of Control Scale (PLOC; Campis, Lyman & Prentice-Dunn, 1986) was used to assess parental perceptions of a stressor by measuring internal or external locus of control. Across 47 items (making up five sub-scales; parental efficacy, parental responsibility, child control of parent's life, parental beliefs in fate/chance, and parental control of child's behaviour) higher scores indicate a greater external locus of control. The authors reported sufficient internal consistency for all subscales and adequate validity.

Procedure

After identification of potential participants, an initial contact letter was sent providing information about the project and asking permission to contact the family. Once consent was given, the researcher explained the nature of the project and answered any questions. Parents were assured that they would not be penalized for refusing to participate or withdrawing from the project. Each interview lasted 1-2 hours and was conducted in the participant's home.

The FSSQ was then completed as an interview and the questionnaires were administered. The interviewer recorded answers as each item was completed and the interview was audio taped. In addition, time was given at the beginning and end of the interview to discuss any issues.

Both authors examined the transcripts of the interview responses for each item and generated a list of themes that represented the core ideas expressed by the respondents. The authors then generated a final list of themes for each question through discussion. The authors independently coded all the responses into thematic categories, and inter-rater reliability was assessed. For question 3 parents responded with a rating of their stress and for question 4 a list of support persons was requested, therefore coding was not needed for these items. Reliabilities were adequate for all categories with kappa's ranging from 0.80-0.95.

Results

Means and standard deviations of the total and subscale scores of the QRS-SF can be found in Table 3. Step-wise multiple regressions were used to explore the associations between predictor variables and the QRS-SF. Kinnear and Gray (1995) comment on the need to under-interpret the magnitude of beta weights due to multicollinearity, and recommend that residual diagnostics be carried out to remove any outliers and identify abnormalities in the data. The investigator completed this process and examination of the adjusted data revealed that the assumptions of normality, linearity and homogeneity of variance were met.

A total of 6 out of 12 predictor variables were significantly related to parental stress and were therefore entered into the regression analyses: total helpfulness of support score from the FSS, the two coping scales and the three locus of control scales. Bi-variate relationships were examined using Pearson's product moment correlations and can be found in Table 4. Other variables were excluded due to non-significant associations with parental stress.

Results of the stepwise multiple regressions revealed two significant predictors ($F = 20.94$, $p < .001$). Both family coping style ($t = -3.7$, $p < .001$) and parental locus of control relating to 'control by child' ($t = 3.7$, $p < .001$) were the most significant predictors of total parental stress, explaining 15% and 32% of the variance in parental stress, respectively (see Table 5). All other variables were non-significant.

Table 3. Means and standard deviations of the QRS-SF.

Subscale	*M*	*SD*
Dependency and management	4.2	1.5
Cognitive impairment	4.0	1.4
Limits on family opportunities	4.1	1.7
Life span care	5.6	0.7
Family disharmony	1.3	1.4
Lack of parental reward	1.3	1.6
Child's physical limitations	0.7	1.5
Financial stress	3.7	1.5
Terminal illness	2.8	1.3
Preference for institutional care	1.0	1.0
Personal burden	4.5	1.0
QRS Total	33.1	6.9

Table 4. Bivariate correlations of predictors with QRS-SF total

Predictor	*r*
PLOC parental efficacy	.270*
PLOC parental responsibility	-.040
PLOC child's control of parent's life	.567***
PLOC parental beliefs in fate/chance	-.059
PLOC parental control of child's behaviour	.373**
CHIP family coping style	-.567***
CHIP support coping style	-.319*
CHIP medical coping style	-.172
Number of challenging behaviours	-.046
FSS sources of total support	-.175
FSS perceived helpfulness of support	-.242*
FSS perceived satisfaction of support	-.154

* $p < .05$, **$p < .01$, ***$p < .001$

Table 5: Stepwise Multiple Regression for total Parental Stress

Variable	*R*	*R2*	*ß*	*t*	*p*
Control by child	.567	.322	.416	3.65	.001
Family coping style	.686	.471	-.415	-3.65	.001

Further stepwise multiple regression analyses were conducted to determine which variables were most associated with the parental stress sub-scales (see Table 6). Individual regressions identified predictors of parental stress as family and support coping styles, parental internal locus of control (control by child) and perceived helpfulness of social support.

Table 6: Summary of Beta Weights for Significant Predictors of Parental Stress Sub-Scales (QRS-SF) From Stepwise Multiple Regressions

QRS-SF Subscales	*Social Support*	*Family*	*Support*	*Medical*	*Parental Efficacy*	*Control by Child*	*Belief in Chance*	*Control by Parent*	*R2*
Dependency & Management	-.279*					.340*			.261
Cognitive Impairment									nsp
Limits on family Opportunities						.541*			.293
Life Span Care						.307*			.094
Family Disharmony		-.362**							.131
Lack of Parental Reward		-.333**	-.501**						.482
Terminal Illness Stress						.319*			.102
Child's Physical Limitations									nsp
Financial Stress	-.385**								.148
Preference for Institutional Care		-.317*							.101
Personal Burden									nsp

*Note: nsp = no significant predictors; * $p < 0.05$; ** $p < 0.01$*

When asked about experienced stress, parents generally felt that the issues presented were indeed stressful. Most parents (66.7%) found dealing with friends, family and neighbours on a day-to-day basis "extremely stressful", with the mean stress rating being 3.02 (*SD*=1.57) out of 4. Parents reported dealing with doctors and other professionals as being slightly more stressful with 82.4% reporting it as "extremely stressful", and a mean stress score of 3.49 (*SD*=1.24).

As sources of support in dealing with family, friends and neighbours, parents rated their partner (55.6% of respondents), themselves (26.7%) and their parents (20.0%) as being the persons they turned to for support. In dealing with doctors and other professionals parents rated their partner (37.8%), other professionals (28.9%), themselves and their parents (both 26.7%) as being the persons they turned to for support. Other mothers of children with DD were listed by 8.9% of parents.

Prevalence of themes generated from the parent responses to each question are listed in Tables 7 and 8. In dealing with friends, family, and neighbours, experiencing a lack of understanding by others and negative social attitudes such as 'the way strangers look at her' were the most common challenges. Parents reported differing opinions of care by others and parental social isolation as significant concerns reflected in statements of 'everybody wants to give advice' and 'I feel like a social outcast'. In dealing with doctors and other professionals, over half of parents reported that lack of support from professionals and difficulty obtaining a diagnosis were sources of stress in this area. Further, parents felt that not being listened to and not being understood by professionals were concerns with statements including 'not listening that something is wrong' and 'talking above my head'. Five parents felt that obtaining agreement between professionals about interventions was a significant challenge.

In dealing with family, friends and neighbours, the majority of parents reported explaining their child's condition or disability to others as a successful strategy. Other parents felt ignoring or avoiding the situation was helpful. Five parents reported that planning for outings in the community was beneficial such as 'avoiding certain places' or 'not taking him with me'. In dealing with professionals, over half the parents reported that active/external strategies such as seeking other sources of information or support and continuing to 'do things yourself' and 'perseverance' were successful strategies. While some parents reported passive/internal strategies such as 'just accept things as they are' and 'expect the worse' as helpful, three parents felt that taking legal action was beneficial. Several parents reported getting a second opinion as a strategy and one parent reported that 'luck' was necessary.

Table 7. Frequency of themes for questions concerning family, friends, and neighbours

Category	*Frequency of response*	*% Responders*
Question 1: Challenges *(N = 43)*		
Lack of understanding	22	51.2
Social attitudes	13	30.2
Differing opinions of care	8	18.6
Social isolation	7	16.3
Management in the community	5	11.6
No problem	5	10.4
Question 2: Strategies *(N = 42)*		
Explain situation	24	57.1
Ignore situation	18	42.9
Avoid situation	10	23.8
Strategies in the community	5	11.9
Question 5: Changes to make things easier *(N = 42)*		
Accept situation	13	31.0
Persevere	12	28.6
Unique situation	11	26.2
Seek support from others	9	21.4
Explain needs	6	14.3
Ignore situation	5	11.9

Note: Frequencies of themes presented by less than 10% of respondents were not included.

Table 8. Frequency of themes for questions concerning doctors and other professionals

Category	*Frequency of response*	*% Responders*
Question 1: Challenges *(N = 44)*		
Lack of support	24	54.5
Diagnosis/ Information	15	34.1
Listening/ being ignored	13	29.5
Lack of understanding	11	25.0
Waiting for help	8	18.2
Agreement between professionals	5	11.4
Question 2: Strategies *(N = 43)*		
Active/external	23	53.5
Second opinion	17	39.5
Passive/ internal	11	25.6
Boycott/ legal action	5	11.6
Question 5: Changes to make things easier *(N = 44)*		
Persevere	29	65.9
Seek support from others	22	50.0

Note: Frequencies of themes presented by less than 10% of respondents were not included.

In interactions with family, friends and neighbours, most parents suggested strategies of either acceptance of the situation as difficult or continuing to persevere. Several respondents also indicated that every parent with a child with disabilities is in a unique situation, offering statements such as 'You need to do whatever works for you' and 'only you know your child the best'. In dealing with doctors and professionals, perseverance was suggested as a strategy by the majority of parents with statements including 'keep fighting for your child' and 'make your case clear'. Half the parents suggested seeking advice and support from others while three parents suggesting advocating for changes to services such as educational supports. Although no parents suggested ignoring problems with professionals, surprisingly only one parent suggested explaining your needs to professionals.

Discussion

The results of this study highlight the importance of coping strategies and perceptions in influencing the stress of having a child with DD and behaviour problems. Social support emerged as a predictor of financial stress, whereas coping strategies and locus of control were associated with differential types of stress. Although, the results indicate that coping styles and locus of control together significantly predict the stress associated with dependency and management, individually they accounted for multiple areas of stress.

These findings support those of other studies that have emphasized the importance of active coping strategies in reducing stress for parents of children with DD (Donavon, 1988; Jarvis & Creasey, 1991; Quine & Pahl, 1991; Grant & Whittell, 2000). This study revealed that coping strategies involving the maintenance of family integration, co-operation and optimism were strongly associated with reduced stress relating to overall family cohesiveness, the parent's perceptions of reward or satisfaction in caring for their child, and their concerns regarding future care of their child and the possibility of institutionalization. Trute and Hauch (1988) found a strong correlation between family cohesion and coping strategies such that parents reporting active coping skills could discuss and debate alternative choices while maintaining a high commitment and responsibility to one another.

Previous studies have found locus of control to be highly correlated with parental stress (Friedrich, Wilturner & Cohen, 1985; Demaso, Campis & Wypij, 1991; Hastings & Brown, 2002). These findings are congruent with the results of the current study, as parents who felt effective in their parenting role and in control of their child's behaviour tended to have lower levels of stress.

In this study family resources were associated with parental stress; parents who valued social support had lower stress relating to finances, and both support services and family support were associated with lower stress related to lack of parental reward. These results are supported by numerous studies reporting social support to be highly important in the reduction of parental stress (Bristol, 1987; Barakat & Linney, 1992; Trivette & Dunst, 1992; Park & Turnbull, 2002).

Contrary to the hypotheses, problem behaviour did not emerge as a significant predictor of adaptation. This finding is divergent from previous literature and should be interpreted with caution. This result may be the function of the measure used, as the frequency and range of behaviour problems rather than their perceived severity was assessed. The severity of behaviour problems would more likely influence levels and type of parental stress. Perhaps using a different and more direct measure of problem behaviour (instead of parent ratings) would yield different results.

The majority of parents found dealing with friends and family on a daily basis was extremely stressful. The significant challenges faced were consistently related to a lack of knowledge and understanding by others. Most parents felt explaining their child's disability and specific difficulties to others as the most beneficial. In general, parents reported both active and passive strategies to alleviate stress, as has been found in previous research on parental cognitive appraisals of stressors (Minnes, 1988b).

Parents reported difficulties in obtaining diagnosis or gaining accessible and understandable information about their child's disability by doctors. Further, once help was received parents reported challenges in obtaining consensus from professionals about future services and appropriate supports. The majority of parents reported the need for perseverance and determination when acquiring supports for their children as well as getting second opinions and further information to support their decisions for their children. Parents also recommended that they advocate within the wider system and government for awareness of their concerns. More importantly, parents emphasized that although professionals are knowledgeable and essential in providing support, a parent knows more about their child's needs than anyone else.

The main limitation of this study is the small number of participants. With the number of analyses conducted there is a risk of type I error. Future research with larger, less selective samples and longitudinal designs may provide a clearer picture of the multiple factors associated with parental stress. This would allow for possible changes in family adaptation and levels of stress to be examined across different points in the family's life cycle (Baxter & Cummins, 2000). Researchers have postulated that parental stress is renegotiated at different periods of development in the child's life, but the duration and timings of these periods have yet to be thoroughly investigated. Future research could also explore the specific nature of help received from professionals that was helpful (or not helpful) so as to educate professionals as to how best to deliver services and supports without increasing parent stress.

The results of this study highlight the complexities of the stress associated with parenting a child with DD and behaviour problems. It emphasizes the need to adopt a multi-dimensional and inclusive approach to research and practice with such families. Thus, clinical assessments and interventions aimed at reducing parental stress need to include recognition the importance of parental perceptions and be aware of the potential for professionals to be a cause of increased stress. Support groups and advocates should be promoted to enable friends and the family network to improve their understanding and insight into children with developmental disabilities. Community agencies and government should be educating the general public about disabilities and raising awareness of the difficulties for parents of children with DD so that the general public is more compassionate and less critical.

These findings suggest that it is not enough for current services to provide professional support and consultation for such parents. For parents to become competent and effective in their parenting services must assist them to feel a greater sense of personal control over their child through teaching, training and further information. Various parenting approaches and coping strategies need to be recommended and taught to parents, including opportunities to promote family cohesiveness and co-operation, through parental support groups and respite for parents. In addition, parent training programs focussing on positive behavioural support strategies that enable parents to gain control over behavioural difficulties should be investigated to determine whether they have a significant impact on the perceptions of parent stress, control and coping. These recommendations can be applied for all parents of children with DD, as early after their child's diagnosis as possible, therefore potentially reducing the fluctuation of parental stress across the life span or even preventing the development of behaviour problems.

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