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Stress, Depression, and Support Group Participation in Mothers of Developmentally Delayed Children

Johanna Shapiro*

Fifty-six mothers of children with a variety of developmental delays are studied to better understand the relation of support group participation and meaning attribution to maternal levels of stress and depression. Results indicate that both support group participation and meaning attribution are associated with decreased levels of stress and depression as well as with specific coping strategies. Implications of these findings for intervention with mothers of developmentally delayed children are discussed.

That chronic health problems in children, including a variety of disabling conditions, have a psychological and functional impact not only on the affected child, but on the parents and entire family has been clearly established (Crnic, Friedrich, & Greenberg, 1983; Gardner & Eheart, 1984; Shapiro, 1983). Families of children with disabilities are confronted with an overwhelming range of emotional, interpersonal, and inter-social stresses (Darling, 1979; Shapiro, 1986a). They attempt to respond to, or cope with, these stressors in a variety of adaptive and maladaptive ways (Farber, 1960; McCubbin et al., 1983; Schilling, Gilchrist, & Schinke, 1984). Two parental "coping" responses which have received particular attention in the literature are the family's ability to share the burden of their child's condition, both emotionally and physically, and the nature of the family's idiosyncratic appraisal of the implications of their child's condition (Venters, 1981).

One way to understand aspects of parental response to disabling conditions in their children is by applying the double ABCX model (McCubbin & Patterson, 1983). This conceptual framework is based on Reuben Hill's (1958) classic model of response to crisis, in which A represents the stressor event which interacts with B, the family's crisis-meeting resources, in turn interacting with C, the definition of the event by the family, to produce X, the crisis. McCubbin and Patterson (1983) elaborate on this model by theorizing that: the Aa factor exists on a continuum from maladaptation to *bon* (or good) adaptation; both resources and concurrent stressors exist pre- and postcrisis; and the family's appraisal of the experience is an evolving and crucial part of the adaptation process (Koch, 1985). Other researchers have

also identified appraisal of the crisis as a critical mediating event (Lazarus, DeLongis, Folkman, & Gruen, 1985; Leahy & Wright, 1985).

This study focuses on the two aspects of parental response mentioned earlier, sharing the burden and appraisal of the crisis, and defines them in terms of the McCubbin model as follows: The stressor (A) is considered to be the presence of a handicapped child in the family. The family crisis-meeting resource that is examined is the parents' ability to share the burden of their child, both physically and emotionally, by participating in a parental support group. The C factor of appraisal is defined as the parent's ability to assign meaning to the stressful event. The degree to which a crisis (X) is considered to exist is defined by the respondent's emotional state, as measured by a psychometric test for depression, as well as a measure of perceived respondent stress.

A negative association is hypothesized between the parental behavioral and cognitive responses to their child's disability, in this study defined as their support group involvement and meaning attribution, and measures of psychological dysfunction, in this case stress and depression.

Method

Subjects

Subjects were 56 mothers of children suffering from a variety of developmental delays. Subjects were recruited by the primary investigator through a series of presentations at three community early intervention programs. Thirty-six of the identified patient-children in these families had been diagnosed with Down Syndrome. The remaining 20 carried a variety of diagnoses, including cerebral palsy,

William syndrome, spina bifida, and developmental delay, etiology unknown. The developmental age of the children ranged from 0-4.3 years with a mean of 18.8 months. The chronological age of the children ranged from 1-5 years with a mean of 2.5 years. Thirty-one of the children were male and 25 female. The ethnic identification of the families was 78.6% white, 8.9% Hispanic with the remainder Oriental (7.2%) and black (5.4%).

Of the mothers, 34 were currently participating in one of 3 support groups. The remaining 22 mothers had never been a member of any type of support group associated with their child's condition nor had they received any formal psychotherapy associated with their child's handicap. All except 5 mothers had had some college education, and 61.8% had graduated from college and/or had some postgraduate training. Approximately 67% were full-time homemakers, with the remainder working in primarily professional-technical or managerial type jobs. All except one of their husbands were employed with the majority in professional-technical jobs. Over 79% of the mothers and 80% of the fathers were either Catholic or Protestant. The sample overall evaluated themselves as *somewhat* (3) to *fairly* (4) religious, with a mean of 3.3 ($SD = 1.2$). Over 60% of the families had gross incomes over \$35,000 with 10 families ranging between \$15,000 and \$34,999 and 4

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families between \$7,500 and \$12,000. Age of mothers ranged from 21–42 years with a mean of 31.4 years. Father's age ranged from 23–45 years with a mean of 34.2 years. All families had between one and four additional children living in the home with a mean number of 4.3 people per household.

A subjective assessment of the time allocation suggested that households tended to be traditional in terms of their time distribution. Regardless of their employment status, mothers estimated that they did most of the housework and household-related tasks. Both working and nonworking mothers reported themselves to be the primary caretakers, both in terms of estimated time meeting the handicapped child's needs and in simply playing with the child.

Assessment

Interview. Subjects agreed to an in-depth (1–2 hour) semistructured interview on various aspects of the impact of their developmentally delayed child on their personal lives. A large portion of this interview was devoted to their experience (if applicable) in a support group and their perception of the meaning of their child's condition.

Involvement with a support group seemed a particularly important area for investigation for both theoretical and pragmatic reasons. The overriding purpose of the support groups studied was to teach individual participants how to share the burden of their handicapped child, especially with parents in a similar situation. Thus it is a coping response likely to give participants specific means for achieving the end of "sharing the burden," although this objective could clearly be accomplished in other, less structured ways (e.g., through an informal extended family network). On a practical level, based on anecdotal observations of the investigator and parental reports, support groups are one of the most frequently recommended forms of intervention for parents of handicapped children by physicians, nurses, and other developmental specialists. There is already some anecdotal evidence that participation in a support group has a beneficial effect on parental attitudes toward having a handicapped child (Forstenzer & Curry, 1980; Fossen, 1983; Intagliata & Doyle, 1984; Reeves, 1979), although there is still only imprecise understanding of how this result is accomplished. Further, there is some evidence that coping directly related to the stressor (in this case, seeking out a group specifically

focused on dealing with a Down Syndrome or developmentally delayed child) may be more strongly related to positive outcome measures than are more general measures of coping (Kupst & Schulman, 1981).

The 34 mothers participating in support groups came from three different groups, two associated with early intervention programs in the community and one organized through the local Regional Center. All groups met approximately once a week, for 1–1½ hours, and were in all cases led by a licensed psychologist. All subjects designated as "participants" were currently enrolled in a group and had been participating in some sort of support group for between 2 months and 1 year. The groups varied slightly in their emphases, with two being more discussion oriented and the other more clearly psychotherapeutic.

Nevertheless, all three groups included time spent on the mourning or grieving process and helped participants understand some of the stages of responses to disability as functions of grief (Sullender, 1985). All three also spent some time clarifying misunderstandings and elaborating about factual information that mothers had received about their child's condition. The groups focused regularly on the impact of the handicapped child on family life with particular emphasis on siblings and the marital relationship. On a regular basis the groups gave parents concrete help with specific behavioral problems in their children. Further, the groups stressed problem-solving approaches to mothers' interface with the outside world including extended family, friends, neighbors, and strangers (cf. Kornblum, 1982). Finally, all groups made an active effort to promote networking among group participants, with the result that the mothers in these groups maintained regular contact with each other outside the group. Specifically, they were available to lend emotional and instrumental support to each other on a regular basis.

Numerous articles have cited the importance of the C factor, one's subjective definition of the stressor, in relation to positive adaptation. Although meaning or purposiveness is rarely mentioned in the research literature (Taylor, 1983; Wong & Weiner, 1981; see Reiss, 1980, for an opposite example), the anecdotal literature is replete with examples of the importance of meaning attribution in response to disease, especially from a re-

ligious perspective (Craig, 1979; Killilea, 1952; Massie & Massie, 1976).

The second important focus of the interview was to attempt to understand the mother's appraisal of the "meaning," if any, of her child's condition. This issue was approached in several ways. In an open-ended fashion, respondents were asked whether the fact that their child had a disability had any meaning to them. In addition, they were asked to respond to the question of "why this had happened in their lives?" (a question often asked by parents in similar situations). The interview also focused on how this sense of meaning had evolved over time from the point of birth or diagnosis to the present.

Inventories. The psychological inventories included in the questionnaire packet were as follows: (a) The Center for Epidemiological Studies Depression Scale, a 20-item symptom checklist used to assess situational depression (Roberts, 1980). (b) The Coping with Stress Inventory (Billings & Moos, 1981), a 33-item self-report checklist using a Likert-type rating scale. This inventory was selected for the purpose of identifying more detailed coping characteristics of respondents in the study. Three coping subscales (problem focused, emotion focused, and avoidance) were used in data analysis. (c) The Questionnaire on Resources and Stress (Holroyd, 1974), a well-validated and reliable measure developed specifically to assess stress in the family resulting from the presence of a handicapped member. While the questionnaire yields 11 nonoverlapping factors, only 2 were selected for inclusion in this data analysis, to reduce the number of *t* tests performed. The choice of these scales was based on a prestudy interview with five mothers which focused on the areas of greatest stress in their lives. It was concluded that the scale measuring degree of daily burden and the scale measuring family disharmony reflected most accurately the sources of greatest stress as reported by the interviewees. Research also suggests that daily burden is an accurate index of both maternal enmeshment with the index child and simultaneous alienation from the rest of the family (Faerstein, 1981), and the strongest predictor of maternal stress is daily caregiving demands (Foster & Berger, 1985). Similarly, several studies report disturbance of the family unit in association with the presence of a child with handicaps (Kazak & Marvin, 1984).

Sixty-one subjects volunteered to participate in the study, and 56 (91.8%)



Table 1.
The Relationship Between Maternal Participation in Parent Support Group and Respondent Depression, Stress and Coping

Scale		Maternal Participation		2-Tailed <i>t</i> Test
		\bar{X}	<i>SD</i>	
Depression	Yes (<i>N</i> = 34)	4.9	3.4	-2.7**
	No (<i>N</i> = 22)	9.4	7.8	
Stress Burden	Yes = 39	3.3	1.3	-1.9*
	No = 22	4.0	1.4	
Family disharmony	Yes = 34	0.2	0.5	0.6
	No = 22	0.3	0.7	
Coping Emotion focused	Yes = 34	30.1	5.6	-1.4
	No = 22	27.7	6.1	
Problem focused	Yes = 34	38.8	5.0	2.1*
	No = 22	35.4	6.6	
Avoidance	Yes = 34	11.7	2.9	-0.5
	No = 22	11.6	2.5	

**p* < .05.
 ***p* < .01.

completed both interview and questionnaire portions.

Results

Participation in a support group (Table 1). First, participants and non-participants were compared on the parameter of socioeconomic status, using Hollingshead's Two-Factor method (Hollingshead, 1957). Other control variable comparisons included: (a) family size, (b) number of parents within the household, (c) diagnosis of child and, (d) sex of child. All of these comparisons were made using *t* tests and resulted in nonsignificant differences between the two groups.

Those mothers (*N* = 34) who participated in a support group were less depressed than those mothers who did not (*p* < .01); perceived themselves as less burdened by their child than did nonparticipants (*p* = .05); and also tended to engage in more problem-solving coping strategies with their child than did nonparticipants (*p* = .04). There were no significant relationships between participation and other stress or coping scales.

Assignment of meaning. For these analyses, audiotapes of interviews with mothers were scored by two independent raters, who achieved a rater reliability of .82. Respondents were assigned a score based on the perceived sense of meaning regarding their child's condition, and this was in turn combined with their own self-reported degree of active religious conviction. Mothers (*N* = 56) who were rated as high in meaning were correlated with decreased depression scores (*r* = -.48; *p* < .01); and decreased perceived stress in

terms of the daily aspects of care for their handicapped child (*r* = -.31; *p* = .01). Sense of meaning was also correlated with increased emotion-focused coping (*r* = .33; *p* = .01) and increased problem-focused coping (*r* = .37; *p* = < .01).

Anecdotal Results

Mothers who were participating in support groups seemed to interviewers to be more open and less anxious than those mothers who were not. These women had also often established other informal support systems for themselves and their families as well. They appeared to derive some benefit from discussing their problems with others and also enjoyed helping to solve other people's problems. They tended as a group to be assertive and expressive, and fairly confident that their actions could make a difference in their child's life.

Mothers who did not participate in support groups cited as reasons (in descending order of endorsement): distance from the group, family responsibilities, work responsibilities, lack of interest, pessimism that such a group could be useful, and opposition from their spouses. Descriptively, as a group these women appeared depressed, confused, isolated, and overwhelmed. Several seemed suspicious that a support group would try to "change their feelings," or make them feel even more "down and blue."

Mothers who tended to assign meaning to their child's condition also tended to rate themselves high on intensity of religious conviction, although this was not uniformly the case. Some mothers in this category

reported a feeling that they had been "chosen by God" to receive this child and that raising this child was part of the special meaning of their lives. Other respondents who were rated high in this category tended to be less traditional religiously, but reported a strong sense of the purposiveness of the world. Therefore, while they did not feel themselves able to speculate on precisely what the meaning of their child's disability was, they felt convinced that such a meaning did exist. Other examples of assignment of meaning included the following: "This child brings a special happiness into our lives"; "From this child, our other children have learned compassion and thoughtfulness toward others"; "This child has helped me to understand the meaning of courage."

These parents had experienced normal reactions of shock, disbelief, anger, depression, but appeared to have moved more quickly and less ambiguously toward an attitude of acceptance and challenge about their child. Descriptively, it appeared that mothers who tended to assign meaning also adopted the coping mode of seeing their child's health condition as a challenge, even if only a challenge to discover hidden significance in this unexpected and unwanted situation. In this sample, the assignment of negative meanings ("God is punishing me") was not encountered, although this has been reported in the literature, particularly with populations from other cultures (Shapiro, 1986b). By contrast, mothers who scored low in the area of meaning tended to have fixated on the "Why me?" phase, categorized the condition of their child as a random event or a genetic accident, and tended to deny any sense of meaning or comprehensibility associated with their child's condition.

Discussion

A strong association (*p* = .01) is found between mothers who participated in support groups and mothers who received the highest scores in the area of assignment of meaning. Do support groups cause the development of meaning attribution or vice-versa? At this point, it is impossible to determine whether mothers who sought out group participation came to those groups with an already established sense of meaning or developed a sense of meaning partially as a result of experiences within the groups. Interview data in this regard could not identify any clear patterns, with the majority of respondents describing an interactive



effect. According to these reconstructions, participation in a support group often resulted from an ongoing search for meaning, which was simultaneously nourished and supported by that participation.

Further, because of the cross-sectional nature of the study, data analysis is restricted to statistical methods which cannot predict causality between the variables of support group participation, meaning attribution, and the outcomes of depression, stress, and coping. Thus, chicken-and-egg interpretations abound, but no firm conclusions can be drawn. Not only is it impossible to disentangle the various contributions of group participation and meaning attribution, but it is further impossible to assume a causal relationship between these two and the measures of psychological dysfunction employed.

Assignment of meaning, for example, appears to have a beneficial association with subjects' well-being in that it is related to decreased depression and decreased respondent concern about burden of daily care issues, and it is associated with respondent coping patterns which tend both to deal with the situation on a feeling level and to use strategies of acceptance and understanding as well as problem solving. Similarly, maternal participation in a support group also is associated with beneficial outcomes in the mother, both in terms of diminished stress and lower depression. Both mothers who participate in support groups and mothers who are high in meaning are also associated with increased active-behavioral coping. Data from interviews suggest that these parents have learned to feel more competent and effective in dealing with the stressors and issues raised by their child. They also appear able to ask for help from others and to communicate with others in greater detail about their child's condition.

However, in all these relationships it is premature to infer directionality. What is important is that significant relationships exist which merit further exploration. It is plausible, based on interview data with mothers, that in fact they perceive both group participation and a sense of purposiveness to have a positive impact on their feelings of despair and exhaustion. On the other hand, it is equally likely, based on the data alone, that women participate in support groups more frequently and are more likely to assign meaning to

their child's condition when they are less depressed and stressed, rather than vice-versa.

Interestingly, conflict within the family (Family Disharmony) does not appear to be associated with either support group participation or assignment of meaning. In fact, one concern about support group participation might be that while such involvement may tend to have a beneficial impact on the mother, overall family functioning may not be positively affected by participation of the mother alone. Intervention at a more systematic, family-oriented level may sometimes be needed to address more profound disturbances in the marital relationship and the family system (Foster, Berger, & McLean, 1981).

Implications for Therapy

Although none of the statistical associations in this study are particularly strong, taken together they indicate a general trend and point the way toward some important implications for psychotherapists working in the field of developmental disabilities. First, it behooves us all to remember that the bottom line of clinical assessment of coping remains the patient's, family's, and therapist's evaluation of function and adjustment, rather than coping strategies per se. While it is true that some studies have been able to identify coping strategies positively associated with subject adjustment, in general these associations have not been strong. Certain studies show no relationship at all (Barbarin & Chesler, 1984). Thus, it is premature for therapists to seek to improve family adjustment to disability in a child by injunctions to "join a support group" or "try to develop a sense of meaning." It is probably true that these behaviors and cognitions may be helpful, but in what manner, at what time, and under what circumstances very much still need to be determined.

Two areas of coping which have been consistently highlighted as related to positive parental outcome, sharing the burden of the stressor and attribution of meaning to the stressful event (Venters, 1981), are here shown to be negatively associated with the outcomes of stress and depression. Further studies, using more sophisticated designs, are necessary to determine a more precise relationship among these variables. At this point, while it is premature for therapists to conclude that support groups provide the easy answer for all mothers of developmentally delayed children, the

findings are highly suggestive of a role for support groups in the treatment of these patients. Certain forms of support and counsel can come best from similar others (Fossen, 1983). In fact, parents often disclosed that statements which they had rejected from a physician or therapist they were able to accept when voiced by other parents. However, there will always be a significant segment of the population who, for one or more of the reasons identified in this investigation, will be unable or unwilling to participate in a support group. Attention must be paid to their psychological adjustment needs as well.

In terms of meaning attribution, even if one could identify a clear relationship between this variable and positive outcome measures, there remains the question of whether psychotherapy can, in fact, endow a patient's experience with meaning. More inquiry is needed in this area as well. Should this concept become important in the future study of parental coping resources, it will require more precise definition and replication as well as a better understanding of how it can be developed. In the meantime, therapists, in their desire to provide clients with tangible coping "techniques" (Masters, Cerreto, & Mendlowitz, 1983) should not neglect this dimension of the integrative process by which parents come to an understanding and acceptance of their child's disabling condition.

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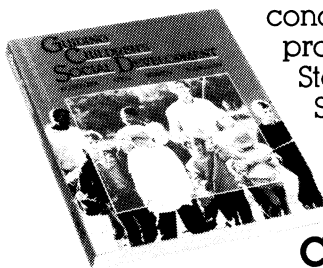
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