

**ADAPTATION IN FAMILIES OF CHILDREN WITH
DEVELOPMENTAL DISABILITIES FROM THE
PARENTS' PERSPECTIVE:
A QUALITATIVE/QUANTITATIVE
METHODOLOGICAL APPROACH**

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ABSTRACT

Introduction. This research used a combined qualitative/quantitative approach to explore constructs that parents considered essential to successful coping with a child with developmental disabilities. **Method.** 58 parents (29 couples) participated in open-ended interviewing to describe their adaptation process, and also completed quantitative assessments of stress and depression. **Analysis.** Employing a grounded theory methodology, researchers coded interview transcripts and identified four main elements, **coping, communication, support, and disruption** that emerged as important contributors to the broad theoretical category of daily **survival skills**. These constructs were then transformed into quantitative global scores, which were statistically analyzed to determine their relationships to the standardized measures. **Results.** General linear modeling equations that predicted 24% of the variance for depression and 47% of the variance for stress implicated qualitatively derived variables of coping, communication, and disruption. **Conclusion.** A combined qualitative-quantitative methodological approach provides the possibility of richer, more particularistic interpretation of quantitative findings.

When considering parental adaptation to the presence of a child with disabilities in the family, researchers currently and historically have explored domains such as stress and emotional wellbeing (Hoare, Harris, Jackson et al, 1998; Frey, Greenberg, & Fewell, 1989). In fact, various dimensions of stress (Krauss, 1993; Heaman, 1995; Dyson, 1997) and depression (Miller et al, 1992; Glidden & Floyd, 1997) are two of the more commonly measured parental outcomes in disability-related research. Still, understanding of adaptation remains an elusive, and to some degree necessarily a subjective concept. The transactional model of family stress, which emphasizes individual appraisal of stressful situations (McCubbin et al, 1993; Grant et al, 1998), suggests that parental subjective perceptions of their own adaptive processes deserve more study.

Voicing a related concern, Helff and Glidden (1998) make the point that family adjustment research over the past 20-year period reflects a distinct negativity bias, and that this is in part a result of instrumentation that itself emphasizes maladaptation and dysfunction. In a provocative article, Glidden (1993) suggests that our understanding of families raising children with development delays is limited by the kinds of questions we have asked and the ways in which we have measured parental responses. Glidden and colleagues also note that what such quantitative measures actually assess is less clear than we would like (Clayton, Glidden, & Kiphart, 1994).

One solution to such dilemmas is to explore the *meaning* behind differential performance on quantitative measures. To accomplish this, qualitative methodologies are particularly useful. They are designed not to determine generalizability, but to provide

new insight into the perceptions of specific individuals and families (Morningstar, Turnbull, Rutherford, 1996). Qualitative approaches are often used when investigators wish to learn more about the *why* of a particular phenomenon.

Purpose of the study. In this study, we first wanted to determine which factors parents of young children with developmental disabilities regarded as essential to positive personal adaptation. In other words, instead of the researchers choosing and defining the important constructs (i.e., social support), we wanted such choices and definitions to emerge from the study participants. We then wanted to discover, using quantitative methods, whether we could identify relationships between these parent-identified components of successful adaptation and standardized measures of depression and stress.

METHOD

Subjects and setting. Subjects were recruited at an informational meeting for parents at a local Regional Center. Approximately 50 people were in attendance at this meeting. Parents volunteered to participate in the study by signing a contact sheet. Since research has shown differences on a number of psychological dimensions between single-parent and two-parent families, subjects were restricted to two parent families in which both parents were present and agreed to participate. We obtained a total of 37 signatures from individuals interested in participating. In follow-up telephone contact, two of these subjects were eliminated because they did not have a significant other participating in the raising of their child. Four other subjects were eliminated because their spouses refused to participate due to lack of interest or unavailability. The nature of the study was explained to all subjects, and written consent obtained.

The sample size in this study was determined according to the concept of theoretical sampling described by Glaser and Strauss (1967). In this approach, participants are selected based on the idea that emerging data categories dictate the direction and need for further data. Therefore, we continued to interview subjects to address gaps and questions in the emerging theory until participant responses became redundant. This is what is referred to as theoretical saturation of categories, and was achieved in the opinion of the research team after interviewing 29 couples.

The total number of subjects included in the qualitative analysis was 58 (29 couples); in the quantitative analysis, 55. This latter number represents 26 couples, and 3 mothers whose husbands participated in the interview process, but did not complete our questionnaires. Demographic statistics were calculated only for those subjects in the quantitative analysis.

Approximately eighty-five percent of the sample ($N = 55$) was Caucasian, with 2 Hispanic and Asian subjects each, 1 African American, and 3 who declined to state their race or ethnicity. The mean age of mothers was 32.5 years ($s.d.=5.3$), and the mean age of fathers was 34.7 years ($s.d.=5.8$). The sample was well-educated, with 23.6% having had some college and 30.9% each having completed college or graduate work. The mean age of the children was 20.8 months, with a range of 1.5-44 months. There were 19 male and 10 female children included in the sample. The most common child diagnosis (as reported by parents) was Down Syndrome ($n=17$). Other diagnoses included cerebral palsy, spina bifida, chromosomal abnormality, mental retardation, and developmental delay of unknown origin.

Approximately 41% of families reported financial stress associated with their child's medical condition (N = 42). Approximately one-third of the sample (31.3%) had no other children, 34.5% had one other child, and 34.2% had two or more other children in the family. Approximately one-third of the sample (all mothers) reported themselves as homemakers, while 41.8% described themselves as employed in professional/technical occupations. Subjects were primarily Protestant (25), and Catholic (18), with 2 Jewish, and 5 each reporting no or other religion.

Measures. Our approach to measures combined qualitative and quantitative techniques. Respondents participated in an unstructured interview lasting approximately 1-2 hours, addressing how the respondent had adapted to the presence in the family unit of a child with a disability. These interviews were audiotaped and designed to be in-depth conversations to evoke the subject's worldview and perspective. Mothers and fathers were interviewed separately. The interview started with a general question: "Please tell me what it has been like for you since the birth of [child with disability]." This was followed by other general questions about social and family environment. Then participants were asked the first key question: "**How are you adapting to your child's having a disability?**" Participants next responded to the following key questions: "**What has helped you adapt?**" and "**What has gotten in the way of your adapting?**" Probes were used to stimulate recollections or to clarify points. Field notes, in the form of memos, were also kept. These noted interviewer perceptions, observations, and insights about the interview, and were made at a time temporally close to the interview. Participants later were mailed a written summary of our qualitative findings, with an

invitation to make suggestions and modifications as to its accuracy. Twelve mothers returned this material, with only minor comments.

We allowed the constructs of parental adaptation to emerge from these qualitative data. Through open-ended interviewing, the respondents themselves identified whatever factors they perceived as essential to adaptation. Based on qualitative analysis of these interviews, we identified a general adaptational theme, **survival skills**, comprised of four dimensions: **personal coping; familial/spousal and professional communication; social and professional support; and daily stability or lack of disruption**. Then students who had participated in the qualitative analysis rated subject audiotapes with a single global score for each of the above dimensions using criteria based on the qualitative analysis. Coping, communication, and support were scored by raters on a 5 point scale, with 1 = poor, and 5 = excellent. Disruption was coded using a scoring of 1 = low, 5 = high.

Rater reliability was calculated as $\text{actual agreement} / (\text{agreement} + \text{disagreement})$. Initial reliability for these ratings based on cross-coding of 6 tapes was less than 50%. However, through team discussion and review of problematic tape excerpts, final rater agreement (calculated for 15 tapes, or 25.9% of the sample) ranged from .68 (personal coping) to .72 (communication), .77 (social support), and .85 (disruption).

To compare qualitative and quantitative methods of assessing adaptation, we also administered to participants validated, reliable quantitative instruments measuring stress and depression. **Stress** was assessed with the 52-item short-form of The Questionnaire on Resources and Stress (Friedrich et al, 1983; Holyroyd, 1974), a well-validated and reliable measure sensitive to child level of disability that can be used to score overall

stress in parents associated with having a disabled child. For analytic purposes, a single cumulative score was calculated. **Depression** was measured using The Center for Epidemiological Studies Depression Scale, a 20-item symptom checklist used to assess situational depression (Radloff, 1977).

The above measures were administered immediately following the open-ended interview, along with a questionnaire containing demographic information. In total, this packet took approximately 30 minutes to complete.

Data analysis: Qualitative. Grounded theory was used as the basis for analyzing the respondent interviews. The purpose of this method is to discover categories of a phenomenon (eg., adaptation) evident in respondent reports that will begin to generate a theory to explain the phenomenon. All tape recordings were transcribed. Line by line coding was used in analysis to identify emergent categories and compare them with other categories that addressed how respondents were adapting to their child's medical condition. Major themes were noted and used to generate "theoretical notes," which in turn were reviewed to interpret or attribute meaning (Strauss & Corbin, 1990).

This study used the constant comparative method in which simultaneous coding and data analysis occur. In this process, the data collection influences the results and the emerging results influence the way in which data are collected. Investigator triangulation was used by giving transcripts to all members of the research team to simultaneously categorize certain sections of the data set and reach convergence. Data triangulation occurred through the comparison of qualitative concepts with qualitative measures. As previously mentioned, membership checking was used to verify researchers' conclusions.

Quantitative. Data were analyzed with the Statistical Package for Social Science-X (SPSS, 1990). A correlation matrix showed initial relationships between qualitatively derived and quantitative variables. Variables were then bifurcated using a split-mean procedure. Chi-square analyses were performed to determine bivariate relationships between variables derived from the qualitative assessment and standardized measures. Two general linear model analyses (Proc GLM) were performed using depression and stress as the dependent variables and coping, communication, support, and disruption as the independent variables.

RESULTS

Qualitative. The 20 conceptual categories (see Table 1) initially identified by the research team were eventually integrated and combined through the ongoing comparison and interpretation of data items, until four main categories were formulated: **personal coping, familial/spousal and professional communication, social and professional support, and daily stability**. These were then further combined into a single encompassing conceptual category, **survival skills**. At this point theoretical saturation of the data was achieved, as researchers did not identify new categories or significant variations on existing categories.

The overarching concern of respondents could be described under the primary theme of Survival Skills: Managing Day by Day. Several aspects of this theme were important. First, respondents emphasized that their adaptational goal, for themselves and their families, was characterized in real, rather than ideal, terms. They were not interested in creating perfect lives for themselves, but in lives that “worked.” This word

was used by several respondents to describe their aspirations, and seemed to consist of qualities of coherence, competence, and satisfaction.

The term “survival” was chosen because it connotes an aspect of grittiness, courage, and determination, qualities that emerged repeatedly in our interviews. Respondents perceived themselves as needing a certain “backbone” or “guts” to adapt successfully. As one mother expressed it, “I can’t afford to break down. My family needs my strength right now.”

Finally, the “dailyness” of the challenge that parents perceived themselves to be facing deserves emphasis. Respondents seemed to feel that successful adaptation was not an abstract, theoretical task, (for example developing a coherent life philosophy or finding an overriding meaning in their child’s disability), but rather consisted of having certain personal and interpersonal qualities and resources on which they could rely on a daily basis.

Daily “survival” for these subjects seemed to depend on four elements: personal coping ability; communication, both with family, particularly one’s spouse, and with key professionals; social support, both formal and informal; and daily stability, or the absence or diminishing of chaos, disruption, and unpredictability in respondents’ lives. There was widespread agreement among respondents regarding the importance of these four components, whether or not the respondent felt them to be operating in his or her own life. Thus, Mrs. AT commented, “Without the help of my family and friends, I don’t know what I’d do;” while Mrs. SN. made the remark, “It’s very hard for me, because I’m very isolated, I don’t have family in the area, or really friends.”

Personal Coping. Coping was seen as a personal quality, something comprised of both skills (“I’m pretty good at expressing my emotions”) and inner qualities (“I’ve always been a can-do person”). Respondents frequently gave examples of their coping skills (“Prayer...getting close to the Lord...keeps me going”; “I try to learn as much as I can...I never stop asking questions”) or would comment on the self-perceived inadequacy of their coping (“I know I should read those books [about Down Syndrome that the grandmother bought], but somehow I still can’t face it. Reading those books would make it [child’s diagnosis] too real”). However, what respondents seemed to emphasize most was a core resiliency. As Mrs. AT expressed it, “I know I can count on myself to get through this because what’s the alternative?”

Family/Spousal and Professional Communications. This factor could be conceptualized either as a coping skill or as social support, but because it emerged as such a distinct category in the interviews, the research team concluded it merited recognition separate from these other two categories. Being able to talk openly about feelings, particularly to one’s spouse, as well as being able to sit down and problem-solve difficult situations together appeared central to the overall theme of daily survival. Mrs. CB: “My husband is a good doer, but when it comes to talking about his feelings – or listening to me talk about mine! – forget it!” Mr. AH: “Melissa (wife) and I are able to sit down and logically work our way through something – maybe a new medication for Emily (child), something like that – but we can also just hold each other and cry. It’s a good combination.” Subjects who were happy with their communication frequently made statements such as “We talk all the time” and “I can talk to my [spouse] about anything,” whereas subjects with poor communication commented on both their isolation

and how improved communication would help them. Mrs. BT: “I feel very alone most of the time. I want to be able to reach out to David [husband] but I don’t know how. It’s like there’s a wall between us, and if we could just break through, we’d both feel a lot better.”

Only slightly less important was being able to communicate with and being understood by a key professional. Often this was the child’s pediatrician, but sometimes a Regional Center staffer or an early intervention teacher was identified in this regard. Similar to communications with spouse, participants appeared to value both the opportunity to express their emotions and to obtain important information or identify useful resources. Mrs. AH stated, “I like Dr. S because he never makes me feel rushed and always listens respectfully to me. I can tell him anything, not just about (child’s) problems, but how I’m coping with those problems.” Interestingly, in general parents who felt they had good communicative relationships with their spouses tended to report similarly good communication with their pediatrician or other professionals.

Social and Professional Support. All respondents mentioned the value of support from others, in addition to the critical support of their spouse. Actual support ranged from almost none to primary reliance on formal structures (physicians, Regional Center, support groups, psychotherapists), primary reliance on informal structures (family and friends), or a mixture of both. Most respondents seemed to define support as being part of a larger whole, or community. “When I feel like I just can’t go on another minute, I know I can call my mom.” “Our church is like one big extended family for Stephen (child). They love him like he was their own.” When respondents had concerns about their level of support, they tended to make blame attributions: “[Child’s] doctor doesn’t

seem to care – not really.” “My family pretty much ignores the fact that Pete has Down Syndrome.” Occasionally, a respondent attributed lack of support to personal preference: Mr. CS: “My parents would probably like to help out more than they do, but I’m a self-reliant kind of guy, and I like to keep my family life private.”

Daily stability. Just as the above three categories supported and enhanced daily survival, chaos and disruption were its antithesis. Some respondents talked at great length about aspects of their lives that seemed disturbed, disorganized, and confused on an almost daily basis: Mrs. CG: “Since [R’] birth, life just hasn’t ever got back to normal. Nothing works right anymore... I keep trying to make plans, but with R, it’s so hard. I get up in the morning, and after doctor visits and therapy and errands, the day’s over, and I feel like I’m back where I started.” Another parent, Mr. RT stated, “I still feel like my world is upside-down.” And yet another parent: “I’m living in a completely alien world, and I don’t know if I’ll ever get used to it.” Parents who described a high level of disruption in their personal lives seemed to feel that their daily reality had been significantly altered since the birth of their child with developmental disabilities, and they still found it confusing and difficult to make sense of.

Quantitative. Global ratings of respondent audiotapes yielded the following results. In terms of **personal coping**, 40.9% of the sample was evaluated as having poor to adequate coping, while the remainder was evaluated as having good to excellent coping. Of this sample, 32.6% of the families were rated as having poor to adequate **family/professional communication**, while the remainder was considered to have good to excellent communication skills. The **social/professional support** of 14.4% of the sample was judged poor to adequate, with the remainder having good to excellent

support. Finally, 58.8% of subjects was judged to have a low to moderate level of **daily disruption**, while the remainder had a high frequency of disruption.

Bivariate analyses. Significant relationships among dependent and independent variables are shown in Table 2. Depression was negatively correlated with communication ($r = -.42$) and support ($r = -.30$). Stress was significantly negatively correlated with coping ($r = -.47$). Correlations between depression and coping, and between stress and communication and support were in expected directions but did not achieve significance.

Chi-square analyses based on bifurcated variables showed that parents who were rated as having good communication, coping, and social support were less likely to score high on depression, while parents rated as having high daily disruption were more likely to score high on depression. Parents who were rated as having high daily disruption also scored high on global stress, whereas parents who were rated as having good coping skills scored low on this measure (Table 3).

Multivariate analyses. Two multivariate analyses using general linear modeling were performed, using respectively depression and stress as the dependent variables. The first (depression) yielded a two variable model in which personal coping and communication explained 24% of the total variance (Table 4). The second (stress) yielded a three variable model in which coping, disruption, and communication explained 47% of the variance (Table 5).

DISCUSSION

In this sample, parents described domains of functioning that they perceived as critical to their adaptation, or “daily survival.” These included their personal coping,

their ability to communicate openly within the family, especially with their spouse, and with key professionals, the usefulness of support received from various sources, and the amount of stability or lack of disruption experienced in their daily lives. Based on these descriptions, dimensions of parental adaptation as judged by independent raters were associated with standardized measures of stress and depression. In general, parents who were evaluated by raters as having successful adaptational skills reported less stress and less depression.

These findings in themselves are not new. For example, previous quantitative research has identified a connection between coping and decreased stress and depression; Affleck & Tennen, 1993; Glidden, Kiphart, Willoughby et al, 1993; Krauss & Seltzer, 1993; Hayden and Heller, 1997). Similarly, much empirical evidence exists for the positive effect social support exerts on parental outcomes such as stress (Beckman, 1991; Beckman & Pokorni, 1988) and depression (Gowen et al, 1989; Hanson & Hanline, 1990; Hayden & Heller, 1997).

However, interesting nuances emerged from integrating a qualitative approach in our research design. For example, in terms of coping, our respondents rarely distinguished among categories of coping favored by researchers (ie., internal locus of control, hardiness, positive appraisal), with the exception of differentiating between emotion-focused and problem-focused coping. Generally, they interpreted coping more as a global ability to manage their lives and deal with difficulties as they arose. Support was also important to these parents, but they tended to interweave rather than distinguish between informal and formal sources of support; those rated as having the best support reported satisfaction in both these domains.

While quantitative research has shown marital relationships and family functioning to be related to parental stress and depression (Krauss, 1993; Sloper et al, 1991; Harris & McHale, 1989), our respondents specifically singled out communication as a key element in adaptation. Yet in the professional literature, most studies of communication tend to focus on the acquisition and development of language skills in the target child (Keogh, Garnier, Bernheimer et al, 2000; Rustin, 1995) or on physician-parent communication (Hasnat & Graves, 2000; Briskin & Liptak, 1995). Further, while the empirical measure of the construct known as daily hassles (DeLongis, Coyne, Dakof, Folkman & Lazarus, 1982) is associated in quantitative studies with increased global stress (Harris & McHale, 1989), our subjects seemed more concerned with the subjective experience of chaos and instability than with hassles per se.

Conclusion. Using a combined qualitative/quantitative methodology allowed us to combine an inductive approach to the parental adaptational process with standardized outcome measures of psychological health and well-being. This approach led to the conclusion that parents are most concerned with “good-enough” survival on a day-by-day basis, and recognize the value of coping, communication and support in facilitating adaptation, as well as the deleterious effects of daily disruption. What is especially noteworthy is that once respondents were able to identify constructs that they considered essential for positive adaptation, raters were able to reliably score them globally on these dimensions, and the dimensions were then shown to have significant relationships with frequently utilized quantitative parental outcome measures.

Of course, it is reasonable to ask what is the value of qualitative analysis if it serves only as a step toward a reductive analytic approach. We believe such criticism

misses the primary purpose of this study, which was to establish that qualitative constructs can also have demonstrable relationships to quantitative measures. The value of the qualitative data obtained in this study lies in its richness, particularity and specificity. For example, when a relationship between coping, stress, and depression is established, it deepens our understanding of this phenomenon to be able to refer back to respondents' own insights about the *nature* and *meaning* of this coping. Further research should continue to explore the utility of qualitatively derived measures in assessing parental adaptation in families with developmentally delayed children.

TABLE 1
INITIAL QUALITATIVE CODING CATEGORIES

Coping	Communication	Support	Stability
Emotional	Spousal-affective	Familial	Relational
Instrumental	Spousal-instrumental	Social	Medical/health
Inner qualities	Familial-affective	Spiritual	Daily routines
Spiritual	Familial-instrumental	Professional	Work
	Professional-affective		Financial
	Professional-instrumental		Social

TABLE 2
**CORRELATION MATRIX OF QUALITATIVELY DERIVED
AND QUANTITATIVE VARIABLES**

	DEPRESSION	STRESS
COPING (N=40)	-.27*	-.47***
COMMUNICATION (N=39)	-.42**	-.29*
SUPPORT (N=40)	-.30**	-.28*
DISRUPTION (N=41)	.12	.002

* P < .10 ** P < .05 *** P < .01

TABLE 3
CHI-SQUARE ANALYSES OF DICHOTOMIZED QUALITATIVELY DERIVED AND QUANTATIVE VARIABLES

	DEPRESSION			STRESS		
	X2	df	p	X2	df	p
COPING (N=40)	6.00	1	.01	13.98	1	.0002
COMMUNIC (N=39)	3.92	1	.05	2.37	1	NS
SUPPORT (N=41)	5.26	1	.02	0.70	1	NS
DISRUPT (N=41)	4.98	1	.03	4.98	1	.03

TABLE 4
FULL GLM MODEL SHOWING RELATIONSHIP OF COPING, COMMUNICATION, SUPPORT, AND DISRUPTION TO DEPRESSION

Source	df	Mean Square	F value	pr > F
Coping	1	177.0	5.23	.03
Communic	1	135.4	4.00	.05
Support	1	15.6	0.46	ns
Disrupt	1	24.7	0.73	ns
R2 = .24	df = 4	F=2.60	p = .05	N = 39

TABLE 5

**FULL GLM MODEL SHOWING RELATIONSHIP OF COPING,
COMMUNICATION, SUPPORT, AND DISRUPTION TO STRESS**

Source	df	Mean Square	F value	Pr > F
Coping	1	166.4	12.80	.001
Communic	1	59.3	4.57	.04
Support	1	40.1	3.09	.09
Disrupt	1	109.09	8.39	.007
R2 = .47	df = 5	F = 5.79	p = .0007	.N = 37

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