

The Impact of Major Events on the Lives of Family Caregivers of Children with Disabilities

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ABSTRACT: *The authors examine the family caregiving experience among families with children with severe emotional disabilities from a perspective that recognizes the importance of the family's views and feelings. This viewpoint anticipates the occurrence of both positive and negative experiences and seeks to illuminate the caregiving process from the perspective of outcomes achieved. Family caregivers of 164 children with serious emotional disorders were asked to identify major pleasant and stressful events that had occurred in the past 12 months. The most frequently described pleasant events related to children's behavior, school activities, and interactions with professionals and friends. Frequently described problem areas included children's behavior, professionals/services, and difficulty with school. The impact of these pleasant and stressful events was examined with respect to caregivers' perceived well-being: (1) overall stress, (2) the ability to fulfill responsibilities, and (3) pleasure experienced in various life domains. Implications of the study findings for supporting family caregivers in their roles are discussed.*

FAMILIES PLAY AN IMPORTANT ROLE in the development of their children. No other social group relates to children more intimately or influences them more profoundly throughout their lives. Family caregivers play a critical role in facilitating the process of change as the family tries to accommodate the developmental needs of its members and adapt to the demands of major events and changed social circumstances (Carter & McGoldrick, 1980; Dohrenwend & Dohrenwend, 1974). In facilitating change and maintaining continuity, most adapt to various stressful events (Hill, 1949; McCubbin et al., 1980; McCubbin & Patterson, 1983; Minuchin, 1974; Olson et al., 1983).

Children with disabilities are more likely to be cared for by their families than any other social organization (Lourie, 1987). The challenges that family caregivers face in meeting the needs of their children increase dramatically when the child has a severe emotional or behavioral disorder (Friesen, 1989). Like all families, families

with a child with an emotional disorder must "provide a context that supports need attainment for all its members" (Terkelson, 1980, p. 25). They must provide an environment within which children can meet their developmental needs for socialization, self-definition, affection, guidance, education, vocational preparation, economic sustenance, health care, and rest and recuperation (Turnbull, Summers, & Brotherson, 1988). In addition, caregivers may have to

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contend with their child's special needs or deal with stressful events. Research shows that these families often face maternal depression, maternal distress, less parental bonding, substance abuse, and antisocial behavior on the part of fathers (Early & Poertner, 1993; Epstein, Cullinan, & Quinn, 1994). Furthermore, caregivers' perceptions indicate that these families have various special needs: provision of services, especially respite care; social education; parent support; and financial stress. Interaction with teachers, mental health professionals, and related social agencies often become a large part of the caregiver's life as he or she attempts to care for the child with a disability and meet the needs of the family as a whole (Bailey & Garralda, 1989; Collins & Collins, 1990).

Although studies indicate that these families often seek professional help and services, reports suggest that caregivers do not always perceive these experiences as positive. Major areas of concern for parents include the need for a stronger commitment from professionals to help families maintain their children at home and to stop what parents describe as their exclusionary and blaming attitudes (Early & Poertner, 1993; Petr & Barney, 1993).

Lack of conceptual clarity and diversity in theoretical perspectives and assumptions are limitations in the research on families of children with an emotional disorder. Until recently, research in this area was based on a conceptual model that focused on the child. A commonly used methodological approach has been the use of correlational data to suggest causality between a set of characteristics of the child and certain characteristics of the family (Early & Poertner, 1993; McDonald, Donner, Gregoire, Poertner, & Early, 1993). Although this research has contributed to our knowledge about strengths of families, the importance of life cycles, the coping strategies used, responses to stress, and the interactions of family members, it has contributed little to our understanding of how these forces interact. Furthermore, research tends to overemphasize negative outcomes or pathology, consistently blaming parents, primarily the mother, for causing their children's problems while focusing little or no attention on potential beneficial effects (Caplan & Hall-McCorquo-

dale, 1985; Early & Poertner, 1993; Knitzer, 1982; McDonald et al., 1993).

The present article is part of a larger study that sought to develop a conceptual model of family caregiving that looks more comprehensively at factors influencing caregiver well-being in families of children with emotional or behavioral disorders (McDonald et al., 1993). Findings presented here expand our current knowledge base and provide an enhanced understanding of (1) the major events that caregivers experience as pleasant or stressful while caring for their children with emotional or behavioral disorders and (2) the impact of these major events on the well-being of the adults with primary responsibility for the care of these children. Understanding the major events that family caregivers encounter in caring for their children with disabilities will allow us to develop interventions that empower and strengthen adults in their role as caregivers and to promote family-support initiatives that are directed at enhancing family empowerment.

Methodology

Procedure

Data were obtained from a study of caregivers of children with serious emotional disorders whose broad purpose was to gain a better understanding of the family caregiving process. Caregivers were identified through the public mental health system in North Carolina. Children meeting the state's definitions of "atypical development" for preschoolers and "serious emotional disorder" for children 6 to 12 years of age were included in the study.

Subjects were recruited from targeted areas of the state. The criteria used to determine which area programs would be invited to participate were (1) population diversity (primarily race and urban/rural), (2) community service diversity, (3) identification of children in the three- to five-year-old range, and (4) willingness to participate.

Approximately 1,800 solicitation packets distributed by the mental health agencies resulted in the return of approximately 450 agreement cards indicating willingness to participate in the study. Of these, 108 respondents were screened

out because of the age of the child. For the 14 families who returned two cards for different children in the family, a decision was made to complete only one questionnaire for each family. Ultimately, questionnaires were mailed to 335 families; 258 useable questionnaires were returned from the initial survey.

A second survey of these respondents was conducted 12 to 18 months after completion of the first survey. The purpose of the second survey was to obtain longitudinal data on the status of the family, primary caregiver, and child with an emotional disorder. The second survey also contained questions about the occurrence of major events in the past year that were not included in the first survey.

Major areas of concern for parents include the need for a stronger commitment from professionals to help families maintain their children at home and to stop what parents describe as their exclusionary and blaming attitudes.

At the end of the first survey, respondents were asked to indicate if they were willing to participate in a future study. Of the original 258 respondents, six indicated that they did not wish to participate in future studies; one other respondent was excluded from the follow-up study because she had contacted the researchers for assistance shortly before the follow-up survey was mailed and it seemed inappropriate to send another survey. Follow-up survey questionnaires were then mailed to 251 respondents of the first survey.

Reminder cards were mailed to those who did not return the survey within three weeks. A second reminder letter, a second mailing of surveys, and phone calls to nonrespondents were used to encourage participants to return the surveys. Many of the respondents to the first survey had moved in the 12- to 18-month intervening period, and slightly more than 10% of the initial sample could not be located. Follow-up surveys were ultimately completed by 164 respondents, for a response rate of 65% of the total sample or 73% of the delivered questionnaires.

Subjects

Almost all of the children (94%) were living at home at the time of the survey. In almost all cases (89%), the respondent to the survey was the mother of the designated child. The majority of the families had other children in addition to the study child. Approximately half of the families were headed by a married couple; one-third were divorced or separated single parents. Approximately half of the families reported that they lived in a small or large city (population 25,000 or more), and one-fourth lived in small towns (population 2,500 or fewer) or rural areas. The majority of respondents reported their racial or ethnic identification as White, and nearly one-third of respondents for the older group identified themselves as Black. More than 20% of the respondents had not graduated from high school. More than 40% were employed full time, and slightly more than half of the respondents' partners were employed full time. One-third of the respondents reported a gross household annual income of less than \$10,000.

The children represented in this study had severe problems as indicated by their responses to the Achenbach Child Behavior Checklist (CBCL) (Achenbach, 1991). The CBCL is a checklist consisting of more than 100 specific problem behaviors and competencies. The items can be grouped into syndrome scales. The problem-behavior syndrome scales of withdrawn, somatic complaints and anxious/depressed can be grouped into a broad internalizing scale, and the problem-syndrome scales designated as delinquent behavior and aggressive behavior can be grouped under an externalizing scale. These two broad problem scales, together with the total competency scale, which combines subscales measuring activities, social, and school competencies, were used in the analyses described in this article.

It is possible to compare the children in this study with groups reported by Achenbach (1991), because data broken down by gender are available for a normative sample of children as well as for a group referred for mental health services. In terms of total problems, the males in this study had an average total problem score of 76.0 and the females had an average total prob-

lem score of 65.0. This compares with an average total problem score for Achenbach's normative sample of 24.3 for males ($t = 28.84$, $df = 725$, $p > .001$) and 23.1 ($t = 17.94$, $df = 688$, $p < .001$) for females. Achenbach's referred sample averages were 54.5 for males ($t = 8.49$, $df = 716$, $p < .01$) and 52.1 for females ($t = 3.49$, $df = 699$, $p < .01$). The group of children requiring care in this study are more disturbed than the referred sample and are clearly very troubled children.

The children in this study also scored significantly lower on Achenbach's Total Competence Scale than did his normative sample. The males in this study had an average competence score of 13.8 and the females had an average score of 15.8. This compares with an average of 18.6 for males and 18.7 for females in Achenbach's normative sample. Both of these differences are statistically significant ($t = 14.94$, $df = 602$, $p < .001$ for males; $t = 5.65$, $df = 557$, $p < .001$ for females). The children in this study are similar to Achenbach's sample of children referred for mental health services with mean competence scores of 14.5 for males and 14.6 for females. Neither of these differences is statistically significant.

Questionnaire

The outcome measure, caregiver well-being, was assessed by the Quick Stress Inventory (Press, 1989, 1993). On the basis of self-ratings on 13 different areas (job, home and family, marriage or primary relationship, other family relationships, child[ren], social life, way you feel about yourself, pleasurable activities, physical appearance, weight, time management, physical health, and life in general), this questionnaire yields overall scores on three scales: stress, ability to handle responsibilities, and pleasure or satisfaction. Press (1989) reported reliability coefficient alphas for this instrument ranging from .70 to .93, with a median value of .86. In Press's study, the scale demonstrated a reliability coefficient of .87. As evidence of validity of the scale, Press reported a correlation of .63 between his scale and Hudson's Index of Clinical Stress (Press, 1993).

Press derives norms for this scale from a large study of 3,960 respondents. The Press sample can be considered fairly representative of the

population and thus his results can be used for general comparisons. Press's item average of 3.3 was used as the norm for the scale, and a difference of .2 was necessary to show something other than measurement error (Press, 1993). Using these norms as a basis of comparison, the caregivers in the present study reported time management ($M = 2.91$), physical appearance ($M = 2.69$), physical health ($M = 2.77$), social life ($M = 2.32$), and fun activities ($M = 1.83$) as less stressful areas of their life. The life domains of marriage ($M = 3.47$), work ($M = 3.4$), family relationships ($M = 3.17$), weight ($M = 3.08$), and feelings about themselves ($M = 2.64$) were in the average range. The domains of mothers' lives that one would expect to be most stressful did reflect the highest averages. Caring for their home and family was the most stressful domain, with a stress average of 4.06. "Your child(ren)" was the next most stressful domain, with an average of 3.97. "Your life in general" was third, with an average of 3.64. Press (1993) suggests that the item reported in "your life in general" is a good indication of overall stress. Results of the present study suggest that caregivers are reporting somewhat higher stress than average. As anticipated, the other two items that relate to caregiving are considerably higher. Given that this collection of life domains with higher levels of reported stress relate directly to caregiving, one can conclude that these caregivers are reporting high levels of caregiving stress.

In addition to measuring the outcomes for the caregiver, the survey was designed to collect information on other aspects of caring for the child. This article focuses on a combination of an open-ended question, checklists, and Likert-scale questions used to obtain the caregiver's evaluation of whether the time between the surveys had been a relatively easy or difficult period in terms of caring for the child and presents information about both pleasant and stressful aspects of caring for the child.

Positive Caregiving Experiences

Respondents were asked to "think about the most pleasant event or situation involving caring for your child in the past year" and then to describe that event in response to an open-ended

question. Caring for a child with emotional and behavioral problems often is considered an overwhelmingly stressful and negative experience. However, most respondents (90%) to the follow-up survey described a positive aspect to caring for their child. However, a large majority (82%) of those describing a pleasant event indicated that the event was unusual in that such events happened infrequently (46%) or nothing like it had ever happened before (36%).

Although the survey item asked for a description of a specific event, many of the responses were very general. The general responses yielded themes, and the more specific responses provided glimpses into the richness of these caregivers' experiences. Themes identified by content analysis included improvements in the child's behavior, changes in family relationships, academic success, school situation improving, participation in normal activities, and benefiting from mental health or other services. Behind these content themes were overarching themes of child, family, and environment.

Respondents were also given a list and asked to circle applicable areas related to the pleasant event (see Table 1). Results were quite consistent with the general themes that emerged from the content analysis of the open-ended responses.

TABLE 1. Source of "most pleasant" events.

Categories	Percent responding yes (N = 148)
Child's behavior	69.6
Child's school	59.5
Dealing with professionals	43.9
Friends	23.6
Other children in the family	20.9
Other relatives	15.5
Spouse or partner	12.2
Obtaining other services	11.5
Child care	9.5
Out-of-home placement	8.1
Money	8.1
Health	6.1
Child custody	6.1
Transportation	4.7
Other	9.4

Child's Behavior

Most of the respondents reported pleasant events in regard to their child's behavior improving. Some respondents attributed changes in behavior to the child becoming more mature, as reflected in comments such as "B's behavior has improved dramatically over the past year. He has become more emotionally mature, which has made things a lot smoother all around." Other respondents attributed positive changes in the child's behavior to medication. "Since she started medication she has received a sticker for good behavior every day at school, and I've noticed her teacher more willing to do 'extra' with her." Behavior changes noted by other respondents resulted in improved social skills, getting along with other children better, making friends, and doing what is expected. For example,

C's behavior seemed to have improved at home. He had begun to simply follow some rules or give some indication that he had some understanding of what you expected of him. I was able to remain in the car while he went into the local store and made purchases appropriately.

Other respondents noted contributions to the family: "Didn't argue with his parents when asked to do his chores." These positive changes in the child's behavior seemed to be related to the child him- or herself. Even though actions of others may have influenced the changes (e.g., a child receives medication after the parent takes the child for mental health treatment or a parent makes expectations clear), the responses emphasize change at the level of the child. The caregiver also influenced the child's behavior, as reflected in several respondents' comments.

We became more able to deal with D's learning problem and his attention span. I learned ways to deal with him, and he learned ways to accept his problem.

Many respondents cited the child's participation in normal activities as the most pleasant event in caring for the child: "He and I were alone for a Saturday afternoon and I let him take me to a video arcade to teach me how to play. As you can imagine he was feeling pretty darn superior." "He learned how to fish by him-

self.” For several parents, normal activities included participation in church activities such as being baptized or taking the child to church and the child sitting through the service.

School

The majority of respondents also reported pleasant situations regarding improvements in the child’s school situation. Several related issues were identified: school placement, the teacher, and the child’s behavior or effort. The school-situation theme reflected the important influence of the environment on the child, particularly the type of school placement (e.g., special classroom) and the child’s primary teacher. Respondents described various placement issues that were pleasing. “A school situation did not work out, and a change to a new school made a 180-degree change in child and family.” “He has been placed in a regular fourth-grade class.” “Her grades in school improved slightly when she was put into the BEH [behavioral] program.”

The child’s teacher and how he or she deals with the child also made a difference in the child’s experience of school. “He is fortunate to have a patient, understanding special-ed teacher who is willing to work with him and me concerning his problems.” “F returned to previous BEH class, made tremendous progress as a result of teaching methods and teacher awareness. F gained confidence and self-esteem.” Both placement (school and class) and teacher constitute environmental-level effects.

Finally, some parents described pleasant situations resulting from the child’s effort and success in school.

It was a day when we got a note from his teacher stating that they had a wonderful day in school. There was no arguing about homework, chores; we all worked together and it was a good day.

The most pleasant event was seeing the happiness he displayed when he was recognized during a PTA meeting for improving in his grades for the first semester of school and for not missing any days of school. He was extremely proud of himself.

Professionals and Services

Nearly half (44%) of respondents cited the role of professionals and the services they pro-

vide as being related to their most pleasant event or situation. In some cases a specific incident involving a professional was cited:

Mental health advocates went with me to a school-based committee—raised issues and rights that led to testing and evaluation, whereby G is on Ritalin [a mild central nervous system stimulant used in the treatment of attention deficit disorder] and has had only one bad day in five months at school.

Other situations involved obtaining services that the caregiver perceived as needed for the child, including in some cases out-of-home placement:

Finally beginning to get some needed services. We are taking H to a psychologist at the mental health center and are currently evaluating her for attention deficit disorder.

Being able to get psychotherapy services from the same person we had originally worked with a few years ago.

Things started falling into place, behavior improving, got services that were needed, found a preschool day care willing to work with us instead of complaining. Receiving speech and language for a year now.

Better relationship with new case manager, a weekend of respite care.

Placement in group home with children like him . . . he seems to “fit in” better with these children.

These aspects of accessing services reflected the effects of the service system environment on the child and family.

Family relationships. Respondents identified the child’s relationship with parents or the family as another area that was pleasant. Several respondents described attachment issues in this regard: “J is interacting with her younger sister, her dad, and me better. She’s more willing to accept love from us but still doesn’t trust we will be there for her and that we won’t abandon her.” Changes in the family situation such as an adoption becoming finalized, blending, and change in contact with a parent were described as increasing the child’s and family’s stability.

Our adoption of K was final in the past year. This makes everything easier—knowing her placement is permanent—being certain and definite. . . . She appears calmer now that she

does not have to see her natural father so often.

Since there have been some changes made with custody and visitation with his father, L has been happier, has tried to work harder in school and on his behavior. The day this was settled he was so glad and happy.

Regardless of the situation, matters being settled had positive effects on the child. Respondents' comments about these aspects of the child's relationship with the family reflected the family's influence on the child. The wider environment also affected these relationships, particularly through custody and adoption proceedings. Other improvements in the child's relationship with the parent or family were more directly attributed to the child him- or herself.

Her attitude toward me [mother] became a little better. We didn't argue or fuss as much.

The short period of time while he was on [Ritalin], day-to-day activities and interactions at home and school were mostly positive. I felt a connection with my son that had not previously occurred.

My relationship with him improved greatly. M admitted to crying himself to sleep over his new school. The sharing was touching and pleasant.

In summary, caregivers reported many different kinds of pleasant events in caring for their children with emotional disorders. Some of the events were specific to the child's problems (e.g., behavior improving, obtaining services) and some events would be pleasant for the parent of any child (e.g., relationship improving, child receiving awards). The effects of the environment on the child were evident in school situations, receiving appropriate services, and the stability of the family situation in cases dealing with custody and visitation issues. Aspects of the situation attributable to the child included positive changes in behavior, effort in school, academic success, and participation in activities. The effects of the family on the child were illustrated by caregivers' comments regarding family situation changing (e.g., contact with a parent, who is included in the family) and the caregiver becoming better able to deal with the child.

Stressful Caregiving Experiences

The next section of the survey directed the respondent to "think about the most stressful event or situation in caring for your child in the last year." By "stressful" we meant a situation that was difficult, upsetting, or took considerable effort to deal with. Respondents were asked to describe the stressful event or situation. Eight respondents wrote nothing in response to this question. Three of these respondents also did not respond to the question concerning positive caregiving experiences. One answer to this question was unintelligible. The following analysis is based on 157 responses.

More than half the respondents indicated that the stressful event they chose to describe was extremely stressful compared with other situations involving the child during the past year. Family caregivers responding to the follow-up survey described a range of stressful experiences in caring for their child. Content analysis of these responses revealed themes similar to those described for the pleasant events. More than half of the stressful situations described by caregivers seemed to be related directly to the child's behavior problems, including difficulties obtaining services for the child's problems.

TABLE 2. Source of "most stressful" events.

Categories	Percent responding yes (N = 157)
Child's behavior	62.4
Dealing with professionals	27.4
Child's school	26.8
Money	22.3
Other children in the family	20.9
Spouse or partner	18.5
Friends	14.6
Obtaining other services	11.5
Health	10.2
Child care	8.9
Other relatives	8.3
Child custody	6.4
Out-of-home placement	6.3
Transportation	5.7
Other	11.5

The caregivers' attribution of the cause of the stressful event is shown in Table 2. As occurred in the analysis of sources of pleasant events, the child's behavior was identified by approximately two-thirds of the respondents. Similarly, the other top two sources of stressful events were "the child's school" and "dealing with professionals." However, these were identified much less frequently as sources of stress than as sources of pleasure. Money, identified by less than 15% of respondents as a source of pleasant events, was identified by more than 20% as a contributor to stressful events.

Child's Behavior

Many parents described aggressive, destructive, and defiant behavior on the part of the child. Several respondents described seriously problematic behavior.

The most stressful thing that happened to me was when the police kept bringing him home for getting in trouble and being with the wrong crowds and fighting a girl. We have to meet in court for it.

N ran away from home and ended up stealing a car along with some other boys. He was gone three days before I found out he was out of state.

P recently took an overdose of over-the-counter medications and indicated she had thoughts of suicide one to two times weekly.

One parent described her own out-of-control reaction to her child's behavior:

It was a bad day even before 7:00 A.M. Q was being very difficult to deal with. The other kids weren't helping the situation any. R was screaming and talking back and telling me what she was and wasn't going to do. I was trying to get the kids ready for school. I had slapped her and left her with a black eye. Then I went and cried for two hours.

Professionals and services

Several respondents described an out-of-home placement of their child as their most stressful experience in caring for the child during the past year. Specific placements mentioned included group home, mental health facility, hospital, and training school. One parent commented, "The out-of-home placement almost destroyed me. I had a really hard time dealing with it."

For other respondents, obtaining information about their child's problems was the most stressful experience, as typified by the following responses:

Waiting for the school to evaluate her behavior prior to the doctor's visit to see if she was ADD [attention deficit disorder] or LD [learning disorder].

When I first found out that S had a behavior problem, when he was in Head Start, I took him to the preschool, at the guidance clinic, and I kept taking him there for help and no one could tell me anything about his problem.

Other respondents described difficulties obtaining services for their child

We are having trouble getting services for her. We've tried the Social Security office, we've tried the schools, but no one seems to understand or care.

Obtaining services at mental health for counselors. Social worker was unavailable for several weeks. Definitely felt at one point that I was not receiving any assistance with two very serious problems.

Several respondents described difficulties with service providers not listening to them.

Teacher and school administration who say they understand attention deficit disorder; however, their actions and responses show they do not. They are unwilling to listen to us.

Not being understood by his current therapist. We've lost our old therapist and the new one tends to feel that T has a learning disability rather than a behavioral. Being the parent of another with disabilities, this just doesn't justify the behavioral problems we've experienced in the past.

Several respondents described therapy or other actions designed to help the child as stressful. One parent stated that dealing with the child's problems was sometimes emotionally difficult:

When the therapist told us that we would have to tell V that he could call only one parent once a day for no longer than five minutes, that was a hurting moment for us as parents, because you don't want to feel that you are not concerned for him when he's upset. But now we know it was for the best because he stopped the calling in about two weeks and hasn't needed to call us.

School

Some stressful situations involving school or other services are more directly attributable to the child than to the professionals involved. Typically, stressful situations with school involve the child refusing to go to school, refusing to do schoolwork at school and/or at home, and the child's behavior at school in general. As one parent stated,

W refused to do what the teacher asked of him. He lay on the classroom floor and refused to get up. Peed on classmate in bathroom. [Principal] said things have got to change or W might have to be put in a special class [for behaviors].

Another respondent said the most stressful experience was the child's "aggression toward other children and especially the teacher if he were angry enough."

Family relationships. Respondents described stressful situations involving family relations that affected the child's problems or were affected by the child's problems.

We are currently fighting a custody battle involving Y. This has not only caused me stress, it has also greatly affected the improvements she had made.

My daughter and son and I moved in with my fiancée in August. Things went smoothly at first, but we had our rocky times. A couple of months ago we almost split up over the children [mainly because of Z's recurring behavior problems].

Several respondents stated that their work schedules prevented them from spending enough time with their child: "My work hours increased and caused us to spend less time together. I'm a single parent, and this tends to cause additional stress."

Major Events and Caregiver Well-Being

Correlations among the three well-being scales (stress, responsibility, and pleasure) ranged from a low of .483 (stress/pleasure) to a high of .794 (pleasure/responsibility). MANOVA was used to test the relationships between the different sources of pleasant and

stressful events and the overall caregiver well-being as measured by these three scales. Each of the sources listed in Tables 1 and 2 was used as a group variable (was a source or was not), and mean scores on the three dependent variables were compared between the two groups. The analysis was repeated for each of the listed sources.

Only pleasant events associated with two relatively infrequent sources had any relationship with the caregivers' overall well-being. Caregivers who described a pleasant event related to the child's out-of-home placement had significantly higher stress scores, lower ability to fulfill responsibilities, and lower pleasure scores ($F = 3.02$, $df = 3,156$, $p = .031$). Caregivers who described a pleasant event related to the resolution of the child's custody reported lower stress levels ($F = 5.25$, $df = 1,159$, $p = .02$). While the multivariate F test for all three dependent variables was also significant for this analysis, only the stress scale was significant for the univariate tests.

None of the other sources of pleasant events was found to be related to any of three measures of caregiver well-being. In addition, the caregiver's rating of how unusual the pleasant event was had no relationship to the measures of well-being.

Problems described by caregivers were somewhat more likely than were pleasant events to be related to the caregivers' well-being. Again, caregivers who described stressful events involving the out-of-home placement of a child reported lower levels of well-being on all three measures ($F = 2.69$, $df = 3,157$, $p = .048$). Although other multivariate F tests were not significant, several univariate tests were significant. Caregivers who described their most stressful event as involving problems with friends reported significantly higher stress levels ($F = 5.57$, $df = 1,159$, $p = .019$) and less pleasure in life ($F = 3.55$, $df = 1,159$, $p = .061$). Those who described stressful events related to their spouse or partner also felt less able to fulfill their responsibilities ($F = 4.90$, $df = 1,159$, $p = .028$) and less pleasure ($F = 6.00$, $df = 1,159$, $p = .015$).

The majority of caregivers described stressful events related to their child's behavior; this source was related to two measures of caregiver well-being. These caregivers reported signifi-

cantly lower ability to fulfill responsibilities ($F = 5.14$, $df = 1,159$, $p = .025$) and lower pleasure levels ($F = 5.06$, $df = 1,159$, $p = .026$). Stress levels for this group were also higher, but the difference was not statistically significant.

Summary and Conclusions

The intent of this article was to examine the family caregiving experience for families with children with severe emotional disabilities from a perspective that recognizes the importance of the family's views and feelings, expects both positive and negative experiences to occur, and seeks to illuminate the caregiving process from the point of view of outcomes achieved.

Our first goal was to understand major events in the lives of families from the perspective of the caregiver with primary responsibility for the care of a child with an emotional disorder. Almost all the caregivers surveyed were able to identify positive as well as negative experiences involving caring for their child over the previous 12-month period. Caregivers' responses ranked the child's behavior, the school, professionals/services, and family relations as the most frequent sources of pleasant events experienced in caring for their child. Interestingly, the child's behavior, professionals/services, and the school were also ranked as the most frequent sources of stressful events.

Pleasant experiences in caring for the child were often related to improvement in the child's behavior. The fact that most caregivers described experiences involving improvement in their child's behavior indicates that behavior problems are not static or immutable. Improvement in the child's behavior was characterized as the child becoming more responsible and reliable, capable of following rules at home and school, and doing house chores and school work. Improvement in the child's behavior also included the child becoming more responsive and social, capable of expressing emotions such as love and anger appropriately, making friends, and getting along with others at home and school. Caregivers attributed their child's behavior improvement to factors related to the child, the family, and the environment. Caregivers reported that the child becoming more

mature and the improvement or resolution of family problems and treatment, including medication, had a positive effect on the child's behavior. Not surprisingly, the child's behavior was also seen as the major source of stressful events. Negative experiences were described as serious problematic behaviors that were considered a danger to the child and others.

Caregivers ranked the child's behavior, the school, professionals/services, and family relations as the most frequent sources of pleasant events. Interestingly, the child's behavior, professionals/services, and the school were also ranked as the most frequent sources of stressful events.

Respondents also viewed the child's school as contributing to both positive and negative experiences. Pleasant experiences were reported when the type of school placement and the child's primary teacher were perceived as responsive to the child's needs and when they were believed to have a positive effect on the child's academic or behavioral status. Caregivers reported that some stressful situations involving the school were more directly attributable to the child's behavior, whereas others related their experience of stress to teachers' and administrators' lack of understanding of how to deal with their child.

Approximately 50% of the respondents reported professionals and services as important sources of pleasant events. Caregivers indicated that professionals who were responsive and supportive and who helped advocate for needed services (school programs, treatment/medication, out-of-home placement) contributed to positive experiences. Not surprisingly, several families that experienced the out-of-home placement of a child considered this experience as the most stressful event with which the family had dealt. When the placement was viewed as the only resource, for example, to protect the child from life-threatening situations, respondents perceived it as a positive experience.

Although some respondents considered professional and services to be a source of pleas-

ant events, others viewed them as a source of stress. Accessing services was often described as a negative experience by caregivers. In most cases, the stress was caused by services and professionals who were not considered responsive. Length of time and the process involved in obtaining services were described as a source of frustration.

Family relations were also considered a source of pleasure. Often the pleasure was related to family members getting along, to the appropriate expression of emotions (love, anger), to improved communication, and to the resolution of custody and visitation issues. The child was seen by caregivers as affected by or affecting family relations. Family relations affected by the child were testimonials to the challenges these families face in caring for their child. Challenges included time demands, financial demands, and parenting demands. Conversely, family issues described as affecting the child's behavior included unresolved issues around custody, the challenges most single parents face, and blended families. The picture that emerged from caregivers' responses is that in caring for children with severe emotional problems, major events such as the child's behavior, the child's school, contact with professionals and services, and family relations serve as sources of both pleasure and stress. Other factors related to the specific needs of the child and resources of the parents and environment determine whether the event is experienced as pleasant or stressful.

Analysis of the relationship between various sources of both positive and negative major events and caregiver well-being provides a very different perspective on caregiver's lives. Although the child's behavior problems and competencies are viewed as major events, caregivers seem to have adjusted to these events in that these sources were not found to be significantly related to measures of overall well-being. Rather, the occurrence of relatively infrequent events, such as the child's placement outside the home or resolution of custody issues, are most strongly related to overall caregiver well-being.

Families benefit from formal and informal supports such as family, friends, peer groups, and so forth (Caplan, 1974; Cobb, 1976). However,

caregivers' responses suggest that in certain situations these supports can become a source of stress. Stressful events involving friends were prevalent among caregivers with high stress levels and among those experiencing less pleasure. Stress associated with problems with a spouse or partner were reported by caregivers who felt less able to fulfill their responsibilities and experienced less stress. This finding suggests that it is a mistake to assume that friends or family are always a source of support, which in turn lends support to the notion that not only is the availability of social supports important, but the degree to which one derives satisfaction from them is also important (Gottlieb, 1981).

Implications for Practice

This research was guided by the notion that the family is the constant in the child's life, whereas service systems and providers within those systems fluctuate. Children, regardless of their problems, belong with families and need enduring relationships with adults. Therefore, when states or agencies become involved with families, permanency planning should be a priority.

These findings emphasize the need to provide necessary supports so that caregivers can care for their children at home. Furthermore, caregivers, not states and agencies, are in the best position to determine their own needs. Professionals who help caregivers continue to care for their children at home will benefit from studies that incorporate caregivers' experiences. The information shared by caregivers in this study identifies major events that are perceived as stressful and as pleasant. Understanding factors that contribute to these experiences can provide professionals with the information they need to facilitate more positive experiences and to prevent crises. Knowledge of major events that are perceived as stressful can be used to develop prevention plans for families. Information indicating that children's behavioral problems often exhaust caregivers' resources can be used to develop support services that assist parents in their roles as caregivers. Access to mental health services for therapy, medication, or hospitalization may be necessary and should be

used in crisis prevention. Coordination of services is essential. Teachers and counselors are viewed positively by caregivers and can contribute to the effectiveness of services.

Caregivers, for the most part, would rather raise their children at home than resort to out-of-home placement. Therapy and medication can help caregivers avoid placement of their child, and professionals must consider these as initial measures. Likewise, school initiatives to increase contact with parents and relevant service providers contribute to the development of programs that are sensitive to the child's needs as well as provide teachers with information they can use to work more effectively in the classroom. Because family relations both affect and are affected by the child with emotional disorder, support services are needed to increase caregivers' ability to cope with the challenges they face in caring for their child.

Caregivers' responses point out the need for a family-centered approach determined by the specific needs of caregivers and their children. Such services would meet the family's need for mental health service (treatment/medication), case management, special education, respite care, and education (child development and

parenting a child with emotional/behavioral disorders). Such services should build on the experiences and perspective of caregivers, emphasizing the importance of caregiver-professional collaboration.

A family-centered approach to working with families of a child with an emotional disorder has implications for social policy development and implementation, requiring a shift in the way human services programs and agencies are organized and how professionals view their roles. Professionals may need to reexamine their traditional roles and practices and develop new ways to work with families, placing special emphasis on practice that promotes mutual respect and partnership. Services should seek to enhance the family's ability to cope, rather than provide a system on which families become dependent. Family strengths, individuality, and unique methods of coping should be recognized and respected. Services should be flexible, accessible, and responsive to the family-identified needs. Ultimately, services should enable families to build and mobilize resources responsive to their needs so that they can continue to help themselves and their children with emotional disorders.

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