Mothers’ Resolution of Their Children’s Diagnosis: 
Organized Patterns of Caregiving Representations

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ABSTRACT: In this paper we examine mothers’ representations of one form of trauma to the caregiving system: the experience of receiving a diagnosis of a chronic illness or disability in their child. An interview and classification system was used with 91 mothers of children ages 15–50 months with cerebral palsy or epilepsy. Mothers were classified as Resolved or Unresolved with respect to their child’s diagnosis and grouped into subcategories within these major groups. Roughly half of these mothers were classified as Unresolved with respect to their child’s diagnosis. Diagnosis type, severity of condition, developmental age, and time since receiving diagnosis were all unrelated to the distribution of Resolved/Unresolved classifications. Patterns of resolution in which cognitive strategies predominated were the most frequent form within the Resolved classification. Findings provide support for the organizational nature of caregiving representations as well as a number of implications for clinical practice.

RESUMEN: En este ensayo examinamos las representaciones que las madres tienen sobre una forma de trauma hacia el sistema de prestar cuidado: la experiencia de recibir un diagnóstico de una enfermedad crónica o de una incapacidad física o mental en sus niños. Se utilizó una entrevista y un sistema de clasificación con 91 madres cuyos niños, de edades entre 15 y 50 meses, tenían parálisis cerebral o epilepsia. Las madres fueron clasificadas como Resueltas o No Resueltas con respecto al diagnóstico sobre sus niños, y se agruparon en subcategorías dentro de estos dos grandes grupos. Casi la mitad de estas madres fueron clasificadas como No Resueltas con respecto al diagnóstico de sus niños. El tipo de diagnóstico, la gravedad de la condición, la edad de desarrollo, y el tiempo que había pasado desde que se supo el diagnóstico no estuvieron relacionados en la distribución de la clasificación Resueltas / No Resueltas. La forma más frecuente dentro de la clasificación de Resueltas fueron los patrones de resolución en los cuales predominaron estrategias cognitivas. Los hallazgos proveen apoyo para la naturaleza organizacional de las representaciones de prestar cuidado así como un número de implicaciones para la práctica clínica.

RÉSUMÉ: Dans cet article nous examinons les représentations que font les mères d’une forme de trauma au système de mode de soin: l’expérience du fait de recevoir un diagnostic d’une maladie chronique ou d’un handicap chez leur enfant. Un entretien et un système de classification ont été utilisés avec 91 mères d’enfants âgés de 15–50 mois atteints de paralysie cérébrale ou d’épilepsie. Les mères ont été classifiées en tant que résolues ou

This research was supported by grants from the National Institute of Child Health and Human Development (R01HD26911) and the National Institute of Disability and Rehabilitation Research (H133G20118) to the first two authors. We wish to express our sincere gratitude to the families who participated in this research. Address requests for reprints to either of the first two authors at Child-Parent Attachment Project, Kluge Children’s Rehabilitation Center, 2270 Ivy Road, Charlottesville, Virginia 22903.
Non Résolues pour ce qui concerne le diagnostic de leur enfant, et regroupées en sous-catégories au sein de ces principaux groupes. Environ la moitié de ces interets ont été classifiées comme Non Résolues en ce qui concerne le diagnostic de leur enfant. Le type de diagnostic, la sévérité de l'état, l'âge de développement, et la période écoulée depuis le moment où le diagnostic a été fait n'étaient pas liés à la distribution des classifications Résolues/Non Résolues. Les patrons de résolution dans lesquels les stratégies cognitives dominaient étaient la forme la plus fréquente au sein de la classification Résolue. Les résultats soutiennent la nature d'organisation des représentations de modes de soin et soutiennent également un nombre d'implications pour la pratique clinique.

In addition to the attachment system that utilizes child behaviors to maintain proximity to the parent in times of threat, Bowlby (1969) hypothesized a complementary system in the parent (George & Solomon, 1989, 1993, 1996) described as the "caregiving system." Both the attachment system in the child and the caregiving system in the parent evolved with the biological function of protecting the child from danger (Bowlby, 1969, 1980). Together, attachment and protective caregiving systems function as a self-regulating dyadic system to keep the child safe from harm.

The attachment and caregiving systems are represented in two subsystems: as patterns of behaviors, and as internal representations held by each of the partners in the relationship (Bowlby, 1969; Bretherton, Ridgeway, & Cassidy, 1990; Main, in press; Main, Kaplan & Cassidy, 1985). The representational system includes the inferences, attitudes, goals, plans, feelings, and defenses that organize and regulate the smooth functioning of the behavioral system(s). Recently, the caregiving system (and its representational and behavioral subsystems) and the processes regulating the attachment behavioral and representational subsystems have received increased attention in research on child–parent attachment. These are appropriate advances in attachment theory, as research moves toward a more comprehensive understanding of the way dyadic behavioral and representational processes function within child–parent relationships ( Fonagy, Steele, & Steele, 1991; George & Solomon, 1993, 1996; Lyons-Ruth, Block, & Parsons, 1993; Slade & Cohen, 1993).

As noted above, the regulation and smooth functioning of the caregiving system are related to psychological processes such as cognition and emotion, and behavioral processes involved in social interaction. Ontogenetically, attachment-related experiences with caregivers in infancy create behavioral and internal organizations that are carried into adulthood and become the organizational core of the caregiving system (Sroufe & Fleeson, 1986). Parents' beliefs, attributions, perceptions, and expectations for and about the child are cognitions that affect a parent's behavior toward the child (Bugenthal, Mantyla, & Lewis, 1989; Dix, Ruble, & Zamborano, 1989; Kochanska, 1990; Melson, Ladd, & Hsu,
1993). Emotional experience is also an important component of the caregiving system. Bowlby (1969) suggested that emotion was a state that served a signaling capacity, and as such, caregiver’s emotional states, such as depression, or anger, and their representations of emotional experience affect their behavior toward the child (Cohn, Campbell, Matias, & Hopkins, 1990; Field, 1989; Lyons-Ruth et al., 1993). Furthermore, social interaction processes such as sensitivity, synchrony, and reciprocity are qualities of caregiving behavioral interactions that play important roles in the functioning of the caregiving system (Ainsworth, Blehar, Waters, & Wall, 1978; Cohn & Tronick, 1989; Isabella, Belsky, & von Eye, 1989). Together, these psychological and social interaction processes operate as a package to regulate the caregiving system in relation to the child’s attachment behaviors. Critical to this theory is the notion that the caregiving system, and particularly its representational subsystem, is an organized system, in which represented elements affect one another and are regulated by internal processes (such as attention and working memory).

Because of its systemic nature, the smooth functioning of the caregiving system can be disrupted if any of these psychological or social interaction processes become disordered, distorted, or otherwise stressed beyond some specifiable limit (George & Solomon, 1996; Main, 1991; Main & Hesse, 1990). Main and colleagues suggest that parents’ unresolved early loss and trauma experiences disrupt the caregiving/attachment systems in part through alteration of the psychological processes involved in the regulation of caregiving behavior. When the child’s attachment behavior evokes memories that are dissociated from parents’ cognitive functions, this is thought to be frightening to the parent and to disrupt that parent’s caregiving system (Main, 1991; Main & Hesse, 1990). The frightened parent does not act to comfort and protect the child, and the child is confused by competing motivations to flee or approach the parent, thus lacking an organized behavioral strategy for such situations.

Learning that one’s child has a disability or chronic illness is another possible trauma to the caregiving system. It introduces information and experience about a child, and about parenting, that challenge existing beliefs, feelings, and expectations. Parents associate learning of their child’s diagnosis with a sense of loss or trauma, and report grief reactions similar to individuals who experience the loss of someone through death including phases of shock and denial; emotional disorganization featuring anger, guilt, and disillusionment; and adjustment or acceptance (Blacher, 1984; Bowlby, 1980; Burden & Thomas, 1986; Waisbren, 1980). Previously we reported preliminary information for a small sample on a method for assessing and classifying parent’s representations of their child’s diagnosis of cerebral palsy (Planta, 1993) and the very strong link between parents’ resolution of the diagnosis and the quality of their child’s attachment to them (Marvin & Planta, in press). Consistent with the view that caregiving representations are organized as a system, in the present investigation we extend this initial work to a larger and more diverse sample and describe elements of representations of the trauma of receiving a diagnosis, and the patterns into which these elements are organized, as Resolved and Unresolved states of mind with respect to the diagnosis (Main, 1991). We also examine the extent to which the patterns of mental strategies shown by parent’s differ according to the child’s diagnosis and the extent to which these patterns are independent of severity of the condition, and other measures of impairment.
ELEMENTS OF PARENTS’ REPRESENTATIONS OF LOSS OR TRAUMA DUE TO A DIAGNOSIS FOR THEIR CHILD

Using questions from the Adult Attachment Interview (AAI; George, Kaplan & Main, 1985), resolution of loss is characterized by coherent speech when discussing the loss/trauma, recognition of change since experiencing the event, and the absence of extremely unusual reactions to the experience in the past or during the interview itself (Main & Goldwyn, 1985–1994). Interview responses marked by these elements of resolution indicate that the experience is available to executive mental functions such as attention, working memory, problem solving, and logic/reasoning and is integrated with the individual’s internal representations of self and relationships (Main, in press). Incoherent speech, insistence on an inability to recall the event, excessive absorption in recalling or retelling the event, or odd forms of speech are consistent with a dissociative process through which the loss/trauma is not integrated with present experience.

We developed the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1992a) to examine resolution of loss/trauma associated with parents’ learning that their child has a disability or chronic illness. Parents report this to be a period of crisis: the family’s routines are disrupted, expectations for the child may be challenged, parents may feel guilty or may search for a reason/cause, and their sense of themselves as effective nurturers and protectors is challenged. This experience represents a specific threat to the biological function of the attachment-caregiving system because the parent cannot/could not protect the child from the diagnosis and related conditions. Thus the parent is faced with undertaking extraordinary caregiving tasks under circumstances that challenge very basic ideas of the function of a parent (e.g., protection from harm).

The RDI probes for episodic recall of events and experiences at the time of diagnosis, emotions associated with that experience, change in these emotions since the time of diagnosis, and the parents’ search for reasons for this experience. Parents’ responses to these questions reflect representations of themselves as caregivers, and their child, in relation to this specific trauma. These representations contain elements of resolution, and lack of resolution, that are hypothesized to be organized as Resolved and Unresolved patterns within systems of caregiving representations.

Elements of Resolution

Resolution is characterized by elements reflecting integration of the experience of the diagnosis into parents’ representations, which in turn allows for a reorientation and refocus of attention and problem solving on present reality. Specific elements of resolution include the following:

1. Recognition of change since the diagnosis. The difficulty of the diagnostic period is acknowledged, accompanied by an emphasis that feelings have changed. Some degree of mourning may continue, but the baseline emotion has changed. The parent attends to differences between the past and present.

2. Assertion of moving on in life. After a period of mourning and crisis there is a re-assertion of activity and action. “You have to do what you have to do” or “We had to get on with our lives” are statements reflecting this strategy. There is an assertion of coping with the situation and an orientation to the present and future.
3. **Suspending the search for a reason.** Despite the common admission of wanting to know why the child has a disability (functional reason) or why the parent has to raise a child with this disability (existential reason), there no longer is an active search for the answer to these questions. The parent consciously suspends the search in recognition that it distracts attention from present reality.

4. **Accurate representation of the child’s abilities.** The child’s abilities are described consistent with observations of the child, or general knowledge about the disability. High, but not unrealistic expectations can be present, but the uncertainty of the outcomes is acknowledged.

5. **Balanced statements regarding benefits of the experience to self.** Ambivalence is acknowledged in the experience of raising a child with special needs. Benefits can be mentioned ("I am a more patient [or accepting] parent") but are accompanied by report of difficulty associated with the growth, or that the child’s disability is not worth the benefit to the parent. The parent is able to attend to both the positive and negative aspects of the experience in relation to representations of self. Attention is flexible and balanced, without polarized perceptions.

**Elements of Lack of Resolution**

Lack of resolution is characterized by elements associated with grieving. These elements reflect an underlying strategy of attempting to change, or alter, the reality of the experience. Attention is focused on other than the cognitive and emotional realities of the diagnosis. The experience may not be accessed by working memory, and problem-solving functions do not operate fully, all of which marginalize the experience or exclude it from representations of self and relationships. These elements reflect the parents’ representational systems’ focus away from the reality of the child’s needs, feelings, and signals. Information from the child may be distorted, filtered, ignored, or amplified in such a way so as to prevent sensitive, balanced caregiving responses (Marvin & Planta, in press).

1. **Cognitive distortions.** These include unrealistic beliefs, denial, or pursuit of wished-for realities. Cognitive distortions can be operationalized as a search for a different diagnosis in the face of contradictory evidence, a belief the child will grow out of the disability, or unrealistic expectations in the face of strong evidence to the contrary. One mother of a child with cerebral palsy expected her child to be a brain surgeon and help other children who have cerebral palsy even though he was nonlocomotor and only minimally communicative at age 2.5.

2. **Active search for reasons.** This process involves engaging in an active search for the reasons the child has a disability. Attention to the reality of the child’s condition is displaced on the search, thus distracting the parent from attending to painful emotions. The search is active even when the parent has been told repeatedly that no reason will be found and when there is no evidence that knowing the reason for a child’s diagnosis would change prognosis.

3. **Stuck in the past.** Attention is focused on the past rather than the present in one of three ways: (1) Grieving is active and ongoing. Present tense is used when discussing the past, and the past is recalled with grief and pain, “just like it was yesterday.” (2) Preoccupying anger is the link between the present and the past. Anger regarding the diagnosis is thematic and in the present. (3) The view of the self is
transformed. There is a focus on the self as helpless, or as a survivor, and the parent's identity is defined by the trauma of the diagnosis. Common to all three of these strategies is parent behavior that attempts to obtain the interviewer's sympathy.

4. Cut off from the experience of the diagnosis. Emotion associated with the experience of the diagnosis is unavailable for report. There may be insistence on lack of memory for the experience. Incomplete versions are also present in which memory is adequate for events and details, but the emotions or emotional impact of the diagnosis is minimized ("It wasn't that bad, it didn't bother me"). This mental strategy uncouples emotions linking the self and the child's diagnosis, even though memory for events may be excellent.

5. Confusion and mental disorganization. Responses are reported with such incoherence and disorientation that it is difficult to understand the story. This process includes losing one's train of thought, having difficulty seizing on an answer (i.e., oscillating between one characterization and another), and contradicting oneself. These indicators signal a lack of an organized mental strategy for addressing the diagnosis and its impact.

In a small sample of mothers with children with cerebral palsy, these elements of resolution and lack of resolution appear organized as Resolved or Unresolved states and are related to the child's quality of attachment (Marvin & Pianta, in press; Pianta, 1993). However, these elements, and the larger organizational patterns, have not been examined with respect to differential effects of type of diagnosis, severity of the child's condition, and time since receiving the diagnosis. These issues are important for understanding the relations between the organization of caregiving representations and parents' experiences as caregivers.

In this paper we examine patterns of resolution to the diagnoses of cerebral palsy and epilepsy. Epilepsy, as a chronic illness condition, reflects many different features from cerebral palsy. Epilepsy is a more unstable condition. Seizure activity can be life-threatening, may stop as the child develops, medications can reduce or eliminate seizures, and seizures can be mild or have little disruptive effect. On the other hand, cerebral palsy is a static condition, is not life-threatening, and change is often very slow, requiring intensive interventions by parents and professionals. These differences affect parents' hopes, as well as their day-to-day interactions with the child. Thus epilepsy can be contrasted with cerebral palsy on dimensions expected to be related to resolution. On the other hand, factors other than the diagnosis per se may affect resolution. These may include the functional impairment level of the child, the severity of the condition (within diagnoses), or the time elapsed since receiving the diagnosis. Consideration of these factors is important to understanding the extent to which resolution is determined by characteristics of the child or the illness/disability condition.

In the present investigation we examine organizational aspects of caregiving representations with regard to the experience of raising a child with a chronic illness or disability. Specifically, we report on how elements of resolution and lack of resolution are organized within larger patterns reflecting Resolved and Unresolved states of mind with respect to this experience, and various subpatterns within these larger patterns. This effort is analogous to other efforts describing organized patterns of attachment behavior, states of mind with respect to attachment, loss/trauma, and caregiving. In this context, the present inves-
tigation adds to the already impressive body of literature relating to attachment (and caregiving) as organizational constructs (Sroufe & Waters, 1977).

METHODS

Sample

The sample consisted of 91 children ages 15–50 months, who had a diagnosis of cerebral palsy or epilepsy, and their primary caregivers. Children were recruited from clinics at university medical centers, community hospitals, and early intervention programs in Virginia, West Virginia, North Carolina, Maryland, and Washington DC. Sixty-eight of the children had a diagnosis of cerebral palsy, and 23 were diagnosed with epilepsy. Children varied with respect to the length of time between when they were diagnosed and when they participated in data collection (range = 2–50 months). Mean yearly family income for the sample was $29,603 (range = $6,000 to $120,000).

Cerebral palsy group. Thirty-nine of the children with cerebral palsy were functionally locomotor. This means they could, without assistance, follow their caregiver around the house, or crawl, scoot, roll, or walk easily enough to locomote across a room. These children could be considered, as a group, to be mild-moderately impaired. Twenty-nine of the children with cerebral palsy were classified as functionally non locomotor. These children could not locomote across a room without assistance and were unable to follow their caregiver around the house. As a group, these children were in the severe range of impairment and were considered to be more severely impaired than the locomotor group. The distinction between the locomotor and non locomotor group was used to reflect severity.

The diagnosis of cerebral palsy was made by physicians associated with the cases. Medical chart review showed a diagnosis of cerebral palsy in 100% of the cases; severity ranged from mild to severe. All children met a minimum criterion of an 8 to 10-month level of cognitive development as assessed by the Bayley Scales of Infant Development, the Vineland Adaptive Behavior Scales, and clinic staff and parent reports of functional levels. All children demonstrated minimal competencies in communicating with their mothers (verbal or nonverbal), object permanence, and distinguishing between strangers and familiar person. There were 17 males and 12 females in the non locomotor group and 27 males and 12 females in the locomotor group. Median age of the children in the non locomotor group was 31.5 months (range = 16–52 months), and 37 months (range = 18–53 months) in the locomotor group. Three children were African American, one Hispanic American, and the remainder were Caucasian. Mothers' mean age for the entire sample was 30.3 years.

Mothers were the primary caregivers for all children in the groups with cerebral palsy, except for three cases in which the primary caregiver was the grandmother. (The remainder of the paper refers to primary caregivers as "mothers.") Median level of mothers' education was 12.5 years (range = 8–16 years) in the non locomotor group and 12.7 (range = 10–18 years) for the locomotor group. Seventy percent of the mothers in the non locomotor group were married or had a live-in partner at the time of data collection; 80% of the mothers in the locomotor group were married or had a live-in partner. Median fathers' education was 12 years (range = 4–18 years) in the non locomotor group and 12.5 years (range = 8–19 years) in the locomotor group.
Epilepsy group. The 23 children with epilepsy had an average age of 30.6 months. None of the children in the epilepsy group had a motor impairment or cerebral palsy. The degree to which the children’s seizures were controlled varied. Only three were not receiving medication for seizures. In 17 cases, seizure control was described by parents as fair to good, indicating some breakthrough seizures or complete control. The other 12 cases reported poor or no control of seizures reflecting daily seizures or several seizures a week. Type of seizures varied, with absence, generalized, and partial complex seizures all represented in the sample. Parents of 12 of the children with epilepsy indicated that the child’s seizures were mild, suggesting that they were not disruptive of the child’s functioning, and the child could return to normal functioning soon after the occurrence of a seizure. On the whole, the sample of children with seizures represents a mild to moderate level of epilepsy severity. Seventy-eight percent of the mothers of children with epilepsy were married at the time of data collection, the average age of mothers was 30.6 years. The median number of years of education for the mothers was 14 (range = 10–20) and the median for fathers was 13 (range = 9–19). Twenty-one of the children were Caucasian, two were African American.

There were no differences across the groups in race of the child, marital status at the time of data collection, mothers’ age, mothers’ education, fathers’ education, length of time between diagnosis and data collection, or mean family income.

Measures and Procedures

Families were recruited through medical clinics and contacted in person or by mail by the principal investigators. Mothers and children (and usually fathers or live-in partners) traveled to the laboratory to participate in the study. All data were collected at the laboratory site. Parents and children participated in a variety of observational and interview procedures and standardized assessments. Parents were administered the Reaction to Diagnosis Interview (Plante & Marvin, 1992a) as part of an extended interview session.

Reaction to Diagnosis Interview. The Reaction to Diagnosis Interview (Plante & Marvin, 1992a) was designed specifically to assess parents’ resolution of loss/trauma associated with receiving a diagnosis of cerebral palsy for their child. The RDI is based on the Adult Attachment Interview (George et al., 1985), in which parents’ mental representations of relationships are assessed through probes for feelings and memories of certain relationship experiences. The questions are as follows:

1. When did you first realize that (child) had a medical problem (probe for details)?
2. What were your feelings at the time of this realization?
3. How have these feelings changed over time?
4. Tell me exactly what happened when you learned of your child’s diagnosis. Where were you, who else was there, what were you thinking and feeling at that moment? Have these feelings changed since then?
5. Parents sometimes wonder or have ideas about why they have a child with special needs. Do you have anything like that that you wonder about?

The RDI was administered by one of the authors or a trained graduate student. Interviews were videotaped. All interviewers were trained to meet criteria for standardized administration of the RDI, including rapport-building, uses of probes, and remaining neutral. In-
Interviewers engaged in at least two practice interviews, viewed several interviews live and on tape, and tapes of their interviews were reviewed in supervision sessions. The RDI takes approximately 15 minutes to administer.

**Reaction to Diagnosis Classification System (RTDCS).** Subjects' responses to the RDI were coded using the Reaction to Diagnosis Classification System (Piana & Marvin, 1992b). The RTDCS consists of a list of elements of resolution and lack of resolution (described earlier), a set of two major categories (Resolved and Unresolved), and two sets of subcategories associated with each of the major categories.

Most interviews contain elements of Resolution and Lack of Resolution. The coder must determine the organizational pattern to which this configuration of elements best corresponds, much like the type of classification decisions made when coding the Strange Situation for child—parent attachment (Ainsworth et al., 1978) or the Adult Attachment Interview (Main & Goldwyn, 1985–1994). There is not a preset criterion for a particular number or percentage of elements that corresponds to a particular classification decision.

 Coders view the videotape of the interview at least twice, taking extensive notes each time. Coders list the elements of Resolution and Lack of Resolution (see following descriptions), and make a final classification of Resolved (R) or Unresolved (U). After the R/U classification is made, coders view the tape a final time and make a subcategory classification within the R/U major category.

**Resolved:** Major category and subcategories. The Resolved classification reflects an organization in which elements of resolution predominate. Prominent among them are a re-orientation to the present and future, a realistic view of their child's condition and skills, a balanced view of the impact on themselves, and a sense of coherence and autonomy during the interview. These individuals are focused on recounting their story and they do so with clarity and without enlisting the interviewer's sympathy. Their affect is balanced and the story is realistic with appropriate detail. Although these individuals share, to a greater or lesser degree, the elements of resolution noted earlier, they differ among themselves in the extent to which one of three forms of resolution is present. These forms, or subcategories, reflect the prominence of a particular strategy for integrating the individuals’ experience of the diagnosis with their representations of self and relationships. Table 1 presents brief descriptions of the subclassifications for the Resolved and Unresolved major classifications. Within the Resolved classification are included: Feeling Oriented, Action Oriented, and Thinking Oriented.

**Unresolved:** Major category and subcategories. The Unresolved classification reflects an organization in which the elements of lack of resolution are prominent. These can include cognitive distortions, an active search for reasons why the experience occurred, unbalanced perceptions of the impact on the self (denial or victimization), and selective attention on past experience to the neglect of present reality. Also included are individuals whose interviews are marked by confusion and mental disorganization with respect to their discussion of the diagnostic experience. As in the case of individuals classified Resolved, one or more of these elements may be evident in the interview. Extending Main's work in which Unresolved loss or trauma is considered within a single classification, we attend to specific subcategories within the Unresolved major category: Emotionally Overwhelmed, Angrily Preoccupied, Neutralizing, Depressed/Passively Resigned, Distorting, and Confused. See Table 1 for brief descriptions.
Table 1
Subclassifications of Resolved and Unresolved Regarding Child's Diagnosis

Subclassifications of Resolved

1. Feeling oriented
   • Feelings apparent in the interview
   • Access to and expression of feelings were essential to coping (with the diagnosis)
   • Do not seek sympathy or nurturance from the interviewer
   • Clarity of the interview is pronounced

2. Action oriented
   • Orientation toward action and caregiving of the child
   • Statements such as, "I realized you gotta do what you gotta do."
   • Resolution resulted from establishing routines of caregiving adapted to the child's disability.

3. Thinking oriented
   • Strong emphasis on cognitive processes and beliefs to, "get through the day."
   • Primary importance of information about their child and the disability.
   • Tendency to respond to "feeling" questions in terms of beliefs and thoughts.

Subclassifications of Unresolved

1. Emotionally overwhelmed
   • Strong expression of sadness and pain during the interview
   • "Enlisting" the interviewer's sympathy
   • Crisis continues to be experienced in the present

2. Angrily preoccupied
   • Active and thematic anger throughout the interview
   • "Enlisting" the interviewer's endorsement of own anger

3. Neutralizing
   • No perception or report of negative emotion associated with the interview and the diagnosis
   • May be recall of details of events, but no recall of emotion

4. Depressed/passively resigned
   • Appears sad, listless, and/or passive during the interview
   • Reports of events and feelings are minimal
   • Appear "stuck" in the sadness of the experience
   • Overwhelmed at the prospect of caring for the child
   • Little hope for the future expressed during the interview

5. Distorting
   • Clearly distorted expectations regarding the child's condition or future
   • Unbalanced perceptions, i.e., idealizing, regarding the benefits vs costs of the experience

6. Confused
   • Incoherence, contradiction and/or confusion in interview content or presentation
   • May ramble, lose train of thought, or need to be re-oriented by the interviewer
   • Often oscillate between polarized perceptions

With regard to reliability, all interviews were double-coded by at least two coders blind to the others' classification decision(s). Four coders participated in this process with reliability being estimated by the pairwise agreement of the coders. A total of 91 interviews were coded by at least one pair of coders; some interviews were coded by more than one pair of coders. For a small subset of interviews (n = 12), judgments about major category and subcategory were made independently by different coders; for the remaining interviews, coders made the classification decisions in sequence, first major category then subcategory. There was a somewhat higher rate of agreement on subcategories than on major categories for the 12 cases in which these were coded independently. The results for agreement in the entire sample, including these 12 cases, reflect this artifact.
At the major category level across all 91 cases, there were 132 opportunities for agreement (because several interviews were coded by more than one pair of coders), and 122 agreements for a rate of 92% agreement. Within the locomotor cerebral palsy group there were 55 opportunities for agreement, and 53 agreements, for a rate of 96% agreement. Within the nonlocomotor group there were 48 opportunities for agreement, and 42 agreements, for a rate of 88% agreement. Within the epilepsy group there were 29 opportunities for agreement and 27 agreements, a rate of 93% agreement. The rates of agreement did not differ across diagnostic group.

At the subcategory level across all three groups there were 102 opportunities for agreement (because of several interviews being coded by more than one pair of coders) and 95 agreements, for a rate of 93% agreement. Within the locomotor cerebral palsy group there were 38 opportunities for agreement and 32 agreements, for a rate of 84% agreement. Within the nonlocomotor cerebral palsy group there were 35 opportunities for agreement and 34 agreements, for a rate of 97% agreement. Within the epilepsy group there were 29 opportunities for agreement at the subcategory level and 27 agreements, a rate of 93% agreement. The rates of agreement did not differ across diagnostic group at the subcategory level. All levels of agreement were tested against chance agreement using a chi-square test and exceeded levels of agreement expected by chance at the $p < .05$ level.

With respect to validity, mothers' resolution of a diagnosis of cerebral palsy was strongly related to their child's attachment classification. The relation between the Resolved/Unresolved classification and the classification of children as Secure or Insecure in the Strange Situation was very high. The hit rate reported in Marvin and Pianta (submitted) is 81%. With regard to discriminant validity, Resolved and Unresolved groups did not differ on years of maternal education ($F = .02, df = 1, p = .97$), or median yearly family income ($F = 2.54, df = 1, p = .11$). There was a significant difference on age of the child at the time of data collection ($F = 4.45, df = 1, p = .04$) with children of mothers classified as Resolved being younger (mean = 30.12 mos.) than children of mothers classified as Unresolved (mean = 35.78 months).

Time since diagnosis. For each child, the length of time (in months) elapsed between age at which the diagnosis was reportedly received by parents and the date of data collection was calculated.

Standardized developmental assessments. Each child was administered either the Bayley Scales of Infant Development—Mental Index (Bayley, 1965) or the Peabody Picture Vocabulary Test—Revised (Dunn & Dunn, 1981) depending on child age and impairment(s). Children's raw scores were converted to the common-metric of age equivalents. Age equivalents were obtained from normative tables for each test using raw scores. In this way each child had an age-equivalent score from a standardized administration of an "ability" test. These scores roughly correspond to an index of the child's performance on a standardized measure of cognitive ability.

Seizure severity scale. Each mother in the epilepsy group completed a self-report measure of her perception of the severity of her child's condition. Two Likert-type items from this scale, one measuring mother's rating of the degree to which her child's seizures were controlled (good, fair, poor) and the other measuring her rating of the overall impact of the child's condition on daily life (very mild, mild, moderate, severe) were used as separate indices of epilepsy severity.
Table 2
Frequency of Resolution Classification Categories by Diagnosis

<table>
<thead>
<tr>
<th>Classification</th>
<th>Nonlocomotor CP</th>
<th>Locomotor CP</th>
<th>Epilepsy</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>RESOLVED</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling</td>
<td>2 (7)</td>
<td>4 (10)</td>
<td>3 (15)</td>
<td>9 (10)</td>
</tr>
<tr>
<td>Action</td>
<td>5 (17)</td>
<td>4 (10)</td>
<td>4 (17)</td>
<td>13 (14)</td>
</tr>
<tr>
<td>Thinking</td>
<td>8 (23)</td>
<td>8 (21)</td>
<td>6 (26)</td>
<td>22 (23)</td>
</tr>
<tr>
<td>UNRESOLVED</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overwhelmed</td>
<td>2 (7)</td>
<td>4 (10)</td>
<td>2 (9)</td>
<td>8 (9)</td>
</tr>
<tr>
<td>Angry/presoccupied</td>
<td>4 (14)</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Neutralizing</td>
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<td>4 (10)</td>
<td>2 (9)</td>
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</tr>
<tr>
<td>Depressed</td>
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<td>0 (0)</td>
<td>6 (7)</td>
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<tr>
<td>Distorting</td>
<td>3 (10)</td>
<td>2 (5)</td>
<td>2 (9)</td>
<td>7 (8)</td>
</tr>
<tr>
<td>Confused</td>
<td>1 (3)</td>
<td>7 (18)</td>
<td>3 (13)</td>
<td>11 (12)</td>
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<tr>
<td>TOTAL</td>
<td>9</td>
<td>39</td>
<td>25</td>
<td>91</td>
</tr>
</tbody>
</table>

Note: Column percentages in parentheses.

RESULTS

The results of classification at the major category and subcategory levels are presented in Table 2. Frequencies and within-diagnostic group percentages are presented.

Results for Major Classifications

At the major category level, by diagnostic group, 52% of the mothers of nonlocomotor cerebral palsy children were classified as Resolved. 41% of the mothers of locomotor children were classified as Resolved, and 56% of the mothers of children with epilepsy were classified as Resolved. Comparing rates of Resolved/Unresolved across the three groups, the differences were not significant. chi square = 1.59 (2 df), p = .45.

In order to examine differences associated with diagnosis per se, the two groups of children with cerebral palsy were collapsed, resulting in 46% Resolved, 54% Unresolved in the combined cerebral palsy group compared with 56% Resolved, 43% Unresolved in the epilepsy group, a difference that is not significant. chi square = .82 (1 df), p = .36. Thus relative frequencies of Resolved/Unresolved classifications were unrelated to diagnosis type.

Possible Correlates of Resolution

Severity of child's condition. Several tests were conducted to examine whether differences in relative frequencies of resolution were associated with severity of the child's condition. First, within-diagnosis comparisons were made on indices of severity available for that particular diagnosis. Then comparisons were made across the entire sample on the age-equivalent scores from the Bayley and PPVT-R.

When the two cerebral palsy groups were compared in relation to frequencies of resolution, the distributions were not different in the locomotor and nonlocomotor groups. chi square = .77 (1 df), p = .38. Then we examined the association between severity of
epilepsy and resolution using mothers' reports of the seizure severity and seizure control items. These are fairly indirect indices of epilepsy severity, and because they are mother reported, they may be confounded with resolution. Nonetheless, among the 23 mothers of children in the epilepsy group, 12 indicated that the child's seizures were "very mild," meaning that the seizures had little or no effect on the day-to-day functioning of the child. The other 11 mothers gave responses of "severe," "moderate," or "mild." Among the mothers of children with epilepsy who rated their children's seizures as "very mild," 75% (n = 9) were classified as Resolved. Among mothers who rated their child's seizures as "severe," "moderate," or "mild" only 36% (n = 4) were classified as Resolved. This difference in proportions was not significant at the .05 level, chi square = 3.49 (1 df), p = .06. The maternal ratings of seizure control may be somewhat more independent of resolution than the overall "effect of epilepsy" rating. For the seizure control item, the frequencies of Resolved/Unresolved mothers' reports of the degree of seizure control ("good" vs. "fair" or "poor") did not differ, chi square = 1.35 (df = 1), p = .25.

Using standardized test performance as an index of severity, the Resolved and Unresolved groups did not differ with respect to the child's developmental age. Comparisons of the Resolved and Unresolved groups on the age equivalent scores of the children showed no differences between the groups, F = .98 (df = 1), p = .33.

Time since diagnosis. A final comparison examined differences in time since diagnosis between the Resolved and Unresolved groups. Across the entire sample, groups classified as Resolved and Unresolved did not differ on time since receiving the diagnosis, F = 2.09, (df = 1), .89, p = .15. Resolution of diagnosis was unrelated to time since receiving the diagnosis for children in the cerebral palsy subsample, F = 0.04, (df = 1), .66, p = .98, or the epilepsy subsample, F = 2.06, (df = 1), .21, p = .17.

Distribution of Subclassifications

Table 2 also presents descriptive results at the subcategory level. The numbers of subjects within cells were too small to conduct comparisons using the entire group-by-subcategory matrix, or to conduct tests related to the relative percentages of subcategory membership within diagnostic groups. However, sample size was sufficient to examine differences in the relative frequencies of the subcategories within the major categories across all diagnostic groups. Across all groups, in the right-hand column of Table 2, the relative percentages of the subcategories within the major categories were compared using a one-way chi-square test of significance. Within the Resolved category, Thinking-Oriented was the most prevalent subcategory, chi square = 6.05, (2 df), p < .05. The one-way chi square comparing the relative frequencies of the subcategories within the Unresolved major category was not significant, indicating that no single subcategory was the most prevalent among the mothers classified as Unresolved.

DISCUSSION

The results describe major patterns and subpatterns of caregiving representations related to parents' experience of receiving a diagnosis of a chronic illness or disability in their child. The major patterns of Resolved and Unresolved are organizations of elements of both resolution and lack of resolution. They appear to be descriptive of parents' states of mind regardless of (a) diagnosis type, (b) the length of time parents have known about the
diagnosis, (c) the child's performance on a test of cognitive ability, and (d) indices reflecting severity of the child's impairment. To the extent that severity of impairment was related to lack of resolution, there was a trend for this finding within the group of children with epilepsy using parent ratings of the effect of epilepsy on daily life (but not for seizure control). Finally, the most frequent subclassification within the Resolved group was one in which cognitive elements predominated.

Overall the findings suggest that caregiving representations with respect to child diagnosis are organized into two distinct major patterns, with several subpatterns reliably detected. It is important to note that major patterns were detected in caregiving representations not by applying an algorithm to the elements of resolution and lack of resolution present, but by examining the organization of these elements at a higher level. At this higher level of organization, the Unresolved and Resolved patterns were independent of diagnosis, severity of condition, or child ability. Together with separate results relating the Unresolved and Resolved patterns to security of attachment (Marvin & Pianta, submitted), these results suggest that caregiving representations (as operationalized in this study) are organized at the level of a system, not in terms of discrete elements or parts. To the extent that this is true, these findings are consistent with other work demonstrating that representations of attachment are organized (Main & Goldwyn, 1985–1994). Our findings provide preliminary evidence that the same organizational principles applied to attachment representations (and behaviors) may apply to caregiving representations (Sroufe & Waters, 1977).

We have not addressed questions related to the link between caregiving representations and the caregiving behavioral system, or whether caregiving representations are subsumed within attachment representations or somewhat independent. In work currently underway, we plan to examine responses to the Reaction to Diagnosis Interview in relation to specific caregiving behaviors such as feeding (Welch, in preparation) and exploratory/teaching behaviors, as well other assessments of caregiving representations (Pianta, O'Connor, & Marvin, 1993).

Analysis of several cases within the cerebral palsy sample suggest that resolution is related to parents' history of resolved or unresolved loss/trauma earlier in developmental time (Marvin & Pianta, 1992). Currently, we are investigating this more systematically by classifying mothers' and fathers' Adult Attachment Interviews and examining the degree to which there is an association between Unresolved Loss or Trauma on the AAI, and resolution of the child's diagnosis (Morog, in preparation). Developmentally oriented hypotheses suggest that previous experiences of loss or trauma, and the extent to which these experiences have been resolved or not by the parent, will both have an effect on resolution of the diagnosis.

Finally, a family systems approach to attachment and relationships (Marvin & Stewart, 1990) suggests that other relationships, including marital/partner, friend, professional, and support network relationships, play a role in creating the context in which integrative mental strategies can work toward resolution of the experience. Again, case studies suggest that spousal relationships are a critical factor; when the mother's spouse or partner strongly denies the impact of the diagnosis, or distorts the experience in some other form, it is increasingly difficult for the mother to maintain attention on the experience in an integrative fashion (Nicholas, in preparation).
Consistent with recent advances in attachment and relationship-systems theories, we hope to map representational systems related to attachment and caregiving, examine relations with behavioral counterparts, and identify specific aspects of representational and behavioral systems related to raising a child with a disability/illness that places specific stresses on attachment/caregiving systems. In this context, the present study is a "work in progress" in that it lays the foundation for subsequent studies.

From a more clinical perspective, the data clearly support the view that learning of a child’s diagnosis is traumatic for a parent (Blacher, 1984; Burden & Thomas, 1986). The fact that there was roughly a 50-50 chance of being classified as Resolved or Unresolved for mothers across all three groups indicates the powerful nature of this experience. All mothers in these groups were directly involved in their child’s medical care and intervention, and thus were exposed to realistic information on their child’s development and medical status. Many received considerable emotional and instrumental support from family members (nearly 80% were married), friends, and professionals (Button, 1994; Dimmock, 1994). Thus despite support and generally high quality medical care and intervention that provided mothers with feedback about their child, half of these mothers showed signs that this experience had not yet been integrated within their views of themselves and their relationships. As such, how this experience is organized and represented may pose a considerable threat to the larger representational system of caregiving and, in turn, the caregiving behavioral system.

The fact that diagnosis type and severity of condition were unrelated to prevalence of resolution suggest that the “mental work” involved in resolution may not be different across disability conditions. To the contrary, it appears that despite the differences in the nature of the condition, mothers still face very similar mental challenges with respect to integrating this experience. Common to both diagnoses and, we suspect, a range of other child diagnoses, the parents must eventually focus attention on the present and future, maintain an accurate, undistorted view of the child’s skills and abilities, hold a balanced view of the impact of this experience on themselves, and regulate their affective experience. Thus we suspect that the elements of resolution and lack of resolution, and the major patterns and subpatterns into which they are organized, operate across diagnostic conditions. Clearly the findings argue against a “child effects” position with regard to the correlates of resolution.

A major finding from the present investigation is the prevalence of the “Thinking-Oriented” strategy among the women classified as Resolved. This finding originally surprised us, because many theories describing coping processes posit that successful coping involves some form of emotional discharge or display, or catharsis (Trout, 1983). Our findings suggest that mental strategies that reflect the active work of cognitive processes are most frequent among mothers classified as Resolved. These findings are very consistent with Main’s position on the importance of working memory and executive mental functions in integrating loss of traumatic experience (Main, 1991). At the core of the Thinking-Oriented subclassification was the active working of executive function. These mothers indicated their awareness of the ways that their beliefs enabled them to focus on their child or to put grieving in the past. Many recalled episodes in which they used their beliefs in order to regulate their emotions during “bad days” (e.g., the mother who prayed when she felt depressed, or the mother who reported saying to herself, “I need to take this
one day at a time." during similar periods). One mother reported another cognitive-oriented strategy: "I think about the severity of (her child's) medical problems, and compare him with other children who are so much worse off, and realize that we can handle this and help him." It is interesting to note that these strategies are also present, although not as prominent, in Resolved mothers from the Action- and Feeling-Oriented subcategories. This form of executive function may be a core mechanism for integration and resolution and may suggest an avenue for clinical intervention.

Finally, a number of implications for practice are suggested by the results and by mothers' responses to the interview questions. Anecdotally, responses to the interviews offer insight into the extent to which the process by which the health care system delivers diagnosis and feedback information to parents can be a factor that, at best, does not facilitate resolution and in some cases mitigates against it. Frequently in our sample of families, situations are described in which parents learned of their child's diagnosis through means other than hearing it from their health care provider. These means include, for example, reading a letter from one physician to another that was not intended for them to read. These experiences trigger anger and resentment that can be preoccupying to vulnerable parents. Other parents describe circumstances in which they were given information in highly technical terms, were not told what they could expect to happen, or where to turn for help. These parents clearly state the need for sensitive delivery of accurate information using terms they can understand. In many cases parents seem to feel that some health care professionals are afraid to be the bearers of bad news and underestimate parents' coping skills. In addition, it is our impression that the diagnostic process, often prolonged over many months and many visits to many professionals, is itself traumatizing to caregivers and the caregiving system. We are just beginning to understand the effects of this trauma for parents, and for their relationship with their children. To the extent that the health care delivery system can provide accurate information, in understandable terms, and the opportunity to integrate the difficult emotions and changing perceptions of self and child that are a part of this period, it will enhance the process of resolution.

REFERENCES


Buiton, S. (1994). The role of fathers as social supports in families with a child with a disability. University of Virginia, Charlottesville, VA.


