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COPING STRATEGIES OF MOTHERS WITH DEVELOPMENTALLY DELAYED CHILDREN WHO ATTEND A SUPPORT GROUP AND WHO DO NOT ATTEND A SUPPORT GROUP

by

DONNA SALVO FOSTER

A Thesis
Submitted in Partial Fulfillment of the Requirements
for the Degree of Master of Science in Nursing
in the Division of Nursing
Mississippi University for Women

COLUMBUS, MISSISSIPPI

August, 1997

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COPING STRATEGIES OF MOTHERS WITH DEVELOPMENTALLY DELAYED CHILDREN WHO ATTEND A SUPPORT GROUP AND WHO DO NOT ATTEND A SUPPORT GROUP

by

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Abstract

When faced with stress, behavioral and psychological reactions occur to decrease the person's perception of the stress. Rearing a child with developmental delay is one such stressful event. The purpose of this investigation was to explore coping strategies of mothers who are rearing a child with developmental delay. Two hypotheses were generated: There will be no statistically significant differences in perceived coping strategy scores used by mothers with developmentally delayed children in a support group and those not in a support group, and there will be no statistically significant differences in perceived effectiveness of coping strategy scores used by mothers with developmentally delayed children in a support group and those not in a support group. Lazarus' cognitive transactional theory of stress postulates that the perception of mental and physical health relates to the ways people evaluate and cope with the stresses of life and was used as a theoretical framework. Mothers were from Mississippi, between the ages of 16 and 40, and parenting a children with developmental delay secondary to cerebral palsy. Perceived use and perceived effectiveness scores were obtained using the Jalowiec Coping Scale and analyzed using t-test statistical analysis. There was no statistically significant difference in the use of total coping styles between the two groups of mothers (p = .573). However, when analyzing the coping styles separately, mothers in the support group used the confrontive, optimistic, supportant, and self reliant coping styles significantly more than mothers in the non-support group. Mothers in the nonsupport group used the evasive and fatalistic styles style more. There was a

significant difference in the total effectiveness of coping style scores between the two groups of mothers (p = .024). Mothers in the support group perceived the confrontive and supportant styles of coping to be more effective than did mothers in the non-support group. Themes identified by mothers who responded to the open ended question, "Is there anything else you you like to say about being a parent of a child with cerebral palsy?" were indicative of a more positive attitude by the mothers in the support group. Further research is needed to determine the effectiveness of support groups as an intervention for mothers of children with disabilities. Curricula in graduate schools of nursing should be evaluated to include a conceptual approach to family-centered nursing for the family with a developmental delayed child. Replication of this study with inclusion of hypotheses reflecting each of the eight subscales of the JCS is recommended.

Dedication

To My Sisters and Niece

Judy Carol Davis (October 28, 1948 - July 17, 1994)

Wanda Lynn Horton

Ashley Lynelle Horton (April 1, 1986 - January 16, 1989)

And All Other Children With Disabilities And Their Mothers

They that wait upon the Lord shall renew their strength;
they shall mount up with wings as eagles;
they shall run, and not be weary;
they shall walk and not faint.

Isiah 40:31

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The final words of gratitude go to God for keeping this author safe during the rainy drives to Columbus, and giving her the knowledge, preserverance, and innate caring for all disadvanged persons to make this research study possible.

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Chapter I

The Research Problem

Among developmentally disabled persons, those with cerebral palsy represent a combination of physical, mental, social, and vocational disabilities that pose special problems to their mothers. These mothers must adapt not only to the maternal role change, but also to an associated sense of loss over the perfect child they had imagined. Olshansky (1962) proposed that most parents who have a child with developmental delay suffer from a pervasive psychological reaction called chronic sorrow. This sorrow varies in intensity and is influenced by multiple factors which include social networks. Olshansky (1962) suggested that parents require an opportunity to ventilate and clarify feelings and need support to legitimize these feelings throughout the lifespan. Care of developmentally delayed children involves disruption of family systems with the majority of the care for the child resting with the mother (Clements, Copeland, & Loftus, 1990). Thus, the foci of this study were coping strategies of mothers with a developmentally delayed child and the impact of group support meetings on these coping strategies.

Establishment of the Problem

The initial parental reactions to learning their child will be developmentally delayed have been described as shock, disbelief, anger, denial, and guilt (Cameron, 1979; Childs, 1985; Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; Fraley, 1990; Howell, 1973; MacKeith, 1973; Quine & Pahl, 1987). These feelings have been

labeled as grief that is relative to the loss of the anticipated normal child.

Researchers have found that these grief feelings do not culminate in a final stage of acceptance, but rather a state of chronic sorrow (Wikler, Wascow, & Hatfield, 1981).

Chronic sorrow continues throughout the life of the child, although the intensity may change. All of these parents experience chronic sorrow to some degree as a reaction to the loss of the expectations they had for the child (Olshanky, 1962). Cameron, Snowdon, and Orr (1992) determined that chronic sorrow is charaterized by recurring stress and sadness over time and can intensify after years. Therefore, parental responses to their developmentally delayed children include periodicity, variability, and

Wikler, Wascow, and Hatfield (1981) studied the work begun by Olshansky and identified critical developmental times, during the lifespan of the child, that are predictors of chronic sorrow. The feeling of sorrow has been projected to be reactivated during periods of developmental crises at 12 months, at 6 years, at the onset of adolescence, and at 21 years (Burke, 1989; Wikler, 1986). At these times of stress, specific parental feelings emerge including sadness, depression, frustration, self-blame, and emptiness.

permanence of sadness.

The following remarks made by a parent of a developmentally delayed daughter, in her twenties, who had completed a state vocational program illustrate the attributes of chronic sorrow.

When she was born, the doctor said she was severely retarded, and the best thing to do was put her in an institution. We were devastated. We cried. Then we dried our tears, and practiced taking steps with her until she walked at three. When she was five, we tried to enroll her in kindergarten. The teacher said to take her

home because she would not learn 90% of what was taught. We went home and cried. The next day we returned with our daughter. We told the teacher to teach our daughter the 10% she could learn. When she finished special education classes at 18, they said she couldn't graduate. We cried. Then we took her out to dinner to celebrate her last day of school. Now she has finished five years here at the Center and brings a check home for her work in the bakery unit. We cry in our hearts because she will never be able to be totally on her own, but rejoice at how far she has come (Anonymous speaker at daughter's graduation from a State Vocational Program, 1988).

Learning that a child is developmentally delayed has the unique characteristic of promoting, if not demanding, changes in the family's established patterns of functioning. The adaptation of the family becomes the central concept in understanding the family's struggle to manage the stress created by the diagnosis of developmental disability. According to Lazarus (1966) stress is the disruption of meanings, and coping is what the person does about the stress. Coping strategies are learned responses which mothers of developmentally delayed children can use to adapt to stress. Types of stressors encountered by these mothers have been identified as: (1) intellectual (learning to care for child), (2) instrumental (getting what the child needs), (3) interpersonal (dealing with the family system), (4) emotional (respecting emotions of love, fear, anxiety, sadness, loneliness, and anger), and (5) existential (altering life goals) (Northington, 1996). When a baby is diagnosed with a defect, the mother encounters these stressors before she is able to work through the loss of the desired child and adapt to the demands of loving the handicapped child. Adaptive tasks of these mothers have been determined to include: (1) managing the day-to-day

care of the child, (2) meeting the needs of other family members, (3) establishing support systems, and (4) educating others about the child's needs (Northington, 1996). Adaptive tasks have been accomplished using coping strategies, a combination of conscious and unconscious defense mechanisms, to adjust to environmental demands without altering individual goals. Unsuccessful coping has resulted in lack of control and a feeling of helplessness.

Nurse practitioners preparing for the primary care of families with a developmentally delayed child need ways to measure how the individual family members are coping with stress. Other families with a developmentally delayed child can provide support and encourage the risk-reduction behavior. In fact, Schilling (1988, p. 6-7) described families as the hidden health care system. Schilling (1988) further described the social network intervention process as follows: "Forces of healing are set up within the living social fabric of people.... The energies and talents of people can be focused to provide the essential supports, satisfactions and controls for one another, and these potentials are presenting the social network of family, neighbors, and associates of the person or family in distress." Schilling (1988) found that the family network, when mobilized effectively, can improve communications among family members and reduce tensions. Further, a network can strengthen the family by providing support for the development of alternative options in solving a crisis.

Although all mothers experience grief and stress as a result of having a developmentally delayed child, maternal long-term coping strategies differ greatly (Beavers, Hampson, Hulgus, & Beavers, 1986). Variables such as past experiences, social roles, perceptions of social support, financial resources, and coping strategies can either enhance adaptation or intensify dysfunction (Allen & Afflect, 1985; Beavers et al., 1986; Schilling, 1988). This researcher explored

differences in coping strategies of mothers of developmentally delayed children who were in a parent support group and compared them to mothers who did not participate in group support.

Significance to Nursing

The fact that chronic sorrow is a phenomenon that occurs throughout the lifespan in mothers of children with developmental delay has implications for nursing practice. The nurse practitioner is in an ideal position to manage the family as a whole and, because of accessibility to families, is in a position to offer preventative, supportive, and therapeutic interventions. By combining knowledge of crises, understanding of families, and skill in nursing, the nurse practitioner can effectively influence the quality of the experience of parenting a developmentally delayed child.

The Individuals with Disabilities Education Act (IDEA) was reauthorized on June 4, 1997 (Tharp, 1997). IDEA mandates a free public education to meet the needs of children with disabilities. As quoted by Tharp (1997, p6), President Clinton stated during the signing ceremony, "To the 5.8 million children whose futures are in the balance, we are saying, we believe in you; we believe in your potential and we are going to do everything we can to help you develop it." This bill recognizes that the definition of disability includes infants and toddlers who are at-risk of developmental delay. This bill recognizes that if these children are to succeed in society, they need early intervention. Nurse practitioners must continue working with legislators to ensure that the needs of children with disabilities are met.

Children who present with abnormal neurological behavior in the newborn period need full assessment and careful followup. The nurse practitioner may be the first professional to discern the abnormal. Clinically, cerebral palsy is difficult to diagnose in the first six months of life. The nurse practitioner must be atune to the presentation of early signs. Feeding difficulties are common but may be managed

within the family with great difficulty for a prolonged time. The problems revolve around persistant primitive brain stem reflexes. A floppy infant should be a clue to the nurse practitioner as a symptom of cerebral palsy. The nurse practitioner should be aware of non-ambulatory patterns of movement which reflect the nature of underlying cerebral palsy. The parents will want the nurse practitioner to paint a picture of the child's future. Once parents are given the news that their child has cerebral palsy and will be developmentally delayed, a system of social and professional support needs to be devised with emphasis on how to manage everyday problems. Linking mothers who have developmentally delayed children can be beneficial since coping strategies can be shared (Fraley, 1986; Wikler, et al., 1981).

Leahey and Wright (1990) proposed cognitive, affective, and behavioral interventions. Cognitive interventions include giving information to the parents about the child's illness and information about community resources. Affective interventions can modify the emotions that accompany rearing a child with a developmental disability. The behavior interventions include encouraging parents to seek opportunities to share their experiences and seek respite. The nurse practitioner, as an advocate for the child, can make sure the child and the mother are receiving all the available services. The mother of a developmentally delayed child will be constantly adjusting to the needs of the child and often want to know her child's prognosis based on the age of attainment of motor skills and growth paramenters.

To cope with these situations the parents need information from health care practitioners. The developmentally delayed child needs a nurse practitioner for normal childhood illnesses plus problems created by the specific disease processes, such as disturbances in mental and emotional behavior, bowel and bladder problems, feeding problems, spasticity, excessive drooling, and assistive technology. The nurse

practitioner is in a position to assess the child's development and intervene appropriately.

Children with developmental disabilities can be supervised throughout life by a family nurse practitioner. The aim of the family nurse practitioner's involvement is to understand the causation of the problem and offer the family appropriate support and referrals. The nurse practitioner should review the disabled child in regular increments to prevent the development of secondary effects of handicaps.

Nurse practitioner programs need to include an overview of a conceptual approach to family-centered nursing for the family with a developmentally delayed child. The curriculum needs to include nursing strategies to be used at transition points in the child's development which may overwhelm family members and render ineffective their usual coping mechanisms. Learning more about families' experiences with a child with a developmental delay can help the nurse practitioner become more comfortable and effective when working with families experiencing this type of crises.

Theoretical Framework

The theoretical framework which guided this research was Lazarus' cognitive transactional theory of stress. Lazarus purported that perception of mental and physical health relates to the way people evaluate and cope with stresses of life. A person's coping srategies reflect appraisal of stress, the frequency of its occurrence and the perceived intensity of the stress (Kanner, Coyne, & Lazarus, 1981; Lazarus & Folkman, 1984; Lazarus & Launier, 1978).

The perception of mental and physical health relates to the ways people evaluate and cope with the stresses of life. Lazarus and Folkman (1984) proposed that the perception of stress is related to introspectiveness and coping responses, which mediate the relationship between stressful events and outcomes such as perceived coping strategies. The mediator of the coping is a psychologic response, and the

cognitive appraisal is essential to initiate the response. The perception of threat is the central characteristic of stress and, especially, a threat to a person's most important values and goals which occurs when the demands on the person exceed his resources. In this study, the most important goal for the mothers was assumed to be related to the expectation of parenting a child who would have appropriate development.

Lazarus (1974) emphasized that stress depends not only on the external conditions but also on the internal vulnerability of the person and the adequacy of his/her coping strategies. Lazarus draws attention to the person's appraisal of the situation, and to the role of conflict and threat in producing the stress. The threat is a form of harm which has occurred, which for the purpose of this study, was the diagnosis of cerebral palsy for the child. The conflict was letting go of the image of the perfect child and learning to love and accept the imperfect one.

When faced with a threat, a behavioral or psychological reaction is activated to eliminate, reduce, or change the perception of the threat. Coping strategies are the activities that intervene between the perceived threat and the behavioral reaction. Coping strategies involve the cognitive activity of appraisal of the conditions causing the threat. "Coping includes the most casual and realistic forms of problem-solving activities as well as the most highly motivated or pathological efforts to be extricated from real or imagined dangers" (Lazarus, Averill, & Opton, 1974, p. 56). Of particular importance to this study was the fact that when faced with the birth of a developmentally delayed child, the sources of stress for the mother change. These changes include a decrease in control over her life with regard to confidence, mental and physical powers, increased financial worries, family and other relationship problems, and emotional and psychological stress. Thus, coping must change to accommodate the new demands (Lazarus & Folkman, 1984).

Assumptions

The proposed study was based on the following assumptions:

- 1. Chronic sorrow is a phenomenon present to some degree in mothers who have a developmentally delayed child (Burke, 1989).
- 2. In Lazarus' Theory of Stress, coping strategies are processes that affect how mothers with chronic sorrow adapt to their roles (Folkman & Lazarus, 1985).
 - 3. Mothers with chronic sorrow are able to identify their coping strategies.

Statement of the Problem

Perception of a situation has been strongly linked to how the person responds to the situation. In parenting a child with developmental delay, the mother's view of the situation is important in aiding professionals to assess the need for interventions. No previous research has been found which compares coping strategies of mothers of developmentally children who attend support group meetings and those who do not attend support group meetings.

Purpose of the Study

The purpose of this study was to ascertain the differences and effectiveness in perceived coping strategies of mothers with chronic sorrow who are involved in a support group and those who are not.

Hypotheses

The null hypotheses which were tested included:

- 1. There will be no difference in total mean perceived coping strategy scores used by mothers with developmentally delayed children in a support group and those not in a support group.
- 2. There will be no difference in the total mean perceived effectiveness of coping strategy scores used by mothers with developmentally delayed children in a support group and those not in a support group.

Definition of Terms

The following terms are defined for the proposed study:

1. Coping Strategies: Theoretrical definition: Coping strategies are cognitive and behavioral reactions used for adjusting to stress (Lazarus, 1966). Coping strategies are actions directed toward managing internal and external demands that tax or exceed a person's resources (Lazarus & Folkman, 1984). Operational definition: The use and effectiveness of coping strategies will be measured using the Jalowiec Coping Scale.

2. Mothers of Developmentally Delayed Children: Theoretical definition: Mothers

- will be the biological and legal parent of a child they are rearing at home who has a medical diagnosis of developmental delay secondary to cerebral palsy.

 These mothers are experiencing pervasive sadness over their lifetimes as a result of parenting the child with developmental delay based on an assumption from review of the literature that chronic sorrow will exist from parenting a child with developmental delay. Operational definition: Mothers will be between the ages of 16 and 40 years old and have a child with a diagnosis of developmental delay secondary to cerebral palsy.
- 3. Developmentally Delayed Children: Theoretical definition: Developmentally delayed children have below normal intellectual and/or motor functions and may have impaired learning, social adjustment, motor skill, and/or maturation. Operational definition: Children between the ages of one and five years of age who have documentation in the medical chart of a diagnosis of developmental delay secondary to cerebral palsy will be used for the proposed study.
- 4. Support Group: Theoretical definition: Support group will be parents who meet for the purpose of sharing problems and concerns they have as parents of a child with developmental delay secondary to cerebral palsy. Support groups are

designed to share the benefits of experience and offer encouragement. Operational definition: For the purpose of this study, support group will be the Cerebral Palsy Support Group which meets once a month for the purpose of providing network support for parents of children with developmental delay secondary to cerebral palsy.

Chapter II

Review of the Literature

Review of the literature revealed that the concept of chronic sorrow was first coined by Olshansky (1962) in describing recurring sadness of parents he had observed in a clinic for mentally retarded children. The term gained use in the professional literature, but it was not until the 1980's that researchers established chronic sorrow as a phenomenon in parents of all children with developmentally delays. Studies by Wikler, et al. (1981) and Fraley (1981, 1984, 1986) established the phenomenon of chronic sorrow as a pervasive psychological reaction of parents who have developmentally delayed children. The work of Cameron, Snowdon, and Orr (1992) documented emotional experiences of parents throughout their lifespan as a result of parenting a developmentally delayed child. The study by Brandt (1983) further identified adaptive difficulties faced by parents of children with handicapping conditions and describes the social support and concurrent life events of mothers with developmentally delayed children. Finally, Damrosch and Perry (1989) found that mothers have a greater need to ventilate feelings since the burden of care falls upon them.

Wikler, et al. (1981) studied the original proposal of chronic sorrow (Olshansky, 1962) as being a natural phenomenon in parents who have children with developmental delay and explored the pattern of chronic sorrow in these parents. Whether the process of chronic sorrow was time-bound or ongoing was the purpose for the descriptive, survey research study. The sample (n=64)

consisted of 32 parents and 32 social workers who were intervening with the families. The parents were selected from a clinic list, and the social workers were randomly selected. Data were analyzed using a Total-Distress Measure to quantify the degree of perception of happiness or sadness at ten crises points in the lives of the children. The researchers compared the scores from early developmental points with later ones and determined if the parents' adjustment was reflective of time-bound grief or ongoing chronic sorrow. Results were that the majority of the parents depicted a life of chronic sorrow. The results from the social workers confirmed the finding that the parents suffered from chronic sorrow throughout their lifespans. The social workers, however, misinterpreted the times in which parents experienced the most difficulty in coping. Parents reported more grief later in the child's life as compared with the grief at the time of diagnosis. Social workers felt the time of diagnosis was the most stressful for the parents.

Wikler, et al. (1981) found that chronic sorrow was a coping mechanism that allowed for grieving over the loss of the perfect child. Ten crisis points specific to times in the child's life when developmental milestones should be achieved were peaks in chronic sorrow for the parents. Five of the critical times were at ages 12 to 15 months, 24 to 30 months, 6 years, onset of adolescence, and 21 years. The crises occurred because the normal parenting expectations were not being fulfilled. The remaining critical periods were at time of diagnosis, when a younger child surpassed the child who was developmentally delayed, at times of professional intervention, and when confronted with guardianship issues.

Limitations of the study were a possible bias in the results due to the nonrandomization of the parent sample and the small sample size. Findings suggested that chronic sorrow is a coping mechanism that allows for grieving throughout the lifespan and, furthermore, utilization of support services should

continue throughout the life of the child. Thus, the findings of Wikler, et al.

(1981) gave impetus to this research study comparing coping strategies of mothers
who are in a support group with those who are not.

Based on the frameworks of Olshansky (1962) and Wikler, et al. (1981), Fraley (1981) studied the relationship between stressful events experienced by the disabled child and the parent's corresponding chronic sorrow. Seventy-one subjects from a random sample identified their feelings when their disabled child underwent events that were stressful using a questionnaire with checklists and forcedresponse answers. Mothers and fathers expressed similar feelings regarding their sorrow when their child had a stressful event. Parents responded to feelings regarding the events of re-evaluation, education, relocation, going to school, changing schools, discovery of a new problem, adolescence, and adulthood. The parents described feelings of helplessness, frustration, and depression more often than any other feeling. Findings were that parents felt a greater amount of helplessness, sadness, frustration, and fear for their child's future when their child should have experienced normal developmental milestones. The results of this study supported the hypothesis that these parents experienced grief, loss, and fear at the time of diagnosis. An expression of hope was a pervasive feeling experienced by the parents. The findings of the study suggested that the parents did not resolve the grief and fears and suffered from chronic sorrow. It was concluded that parents of delayed children reexperienced the emotions of grief and the fears associated with their child's present and future development when the child experienced a stressful event. It can also be concluded from the study that the mothers spent more direct time with the child and is, thus, germaine to this researcher's study comparing coping strategies of mothers.

Fraley replicated his study in 1984 and in 1986 to determine the relationship

between the premature child's experience of a stressful event and the experience of chronic sorrow by his parents. A volunteer sample of 43 parents were in the 1984 study and 36 in the 1986 study. The same stressful events as used in the original questionnaire were used, and parents were asked to identify their feelings when their child experienced the stressful events. Results of both studies were similar. Helplessness, frustration, depression, anger, and irritability were the most frequent responses of the parents when the child experienced the discovery of a medical problem, was surpassed developmentally by a younger child, and upon entering school. Parents often felt fear that the child would die when he/she became ill. The response of parents' to their child's behavioral problems were frustration, anger, irritability, and depression. The developmental stages of preschool, kindergarten, and elementary school evoked feelings of hope when the child first entered school and then helplessness when he was developmentally behind his classmates. Years after the birth of a premature child, many parents continued to express fear for the child's future and often blamed themselves for their child's premature birth. Data indicated that the subjects experienced feelings of loss/grief and fear when their child experienced stressor events, as well as when another child surpassed their child developmentally. These data may help nurse practitioners to become aware of emotional responses of parents and assist them in coping with their needs and concerns. Identifying the coping strategies will further enable nurse practitioners to assist parents and, for this reason, Fraley's study is relevant to this research study.

By the 1990's chronic sorrow was an expected response in mother's of children with developmental delay. There was, however, a lack of studies focusing on parents, using a retrospective approach, to explore their emotions over time.

Cameron, Snowdon, and Orr (1992) explored the emotions mothers of

children with developmental disabilities experience throughout the lifespan. The research questions were: What is the nature of the mothers' emotional experiences relative to caring for a child with a developmental disability and how do the emotions of the mothers experience change as the family grows and develops over time? Prior to this research, there had been no documentation of the emotional experiences of families with developmental disabilities throughout the lifespan. Previous research had proposed that the emotions of these parents would continue throughout the life of the child. Therefore, the problem for the research study was to examine the emotional experiences of these mothers throughout their lifespans. The sample consisted of mothers who were similar in the variables of age, marital status, and socioeconomic status and who had children ages 5 to 21 years with developmental delays due to Down syndrome, cerebral palsy, chromosomal abnormalities, and some unknown causes. Developmental delayed children ranged from being mildly to severely disabled. A convenience sample of mothers was used by contacting the school board where the children were enrolled (n=63). The mothers completed a battery of questionnaires at which time they were asked to be interviewed in their homes. Sixty-three mothers were interviewed. Mothers were asked questions, and the interview was tape recorded with the permission of the mother. The questions were open-ended and were designed to discern how the mothers felt when they learned of their child's diagnosis and how these emotions changed over time. The interviews were transcribed verbatim and data analyzed using grounded theory methods.

Cameron et al. (1992) noted common themes expressed by the mothers. The emotional experiences were then coded into categories. The mothers described emotional experiences of shock, disbelief, feeling isolated, sadness, feelings of loss, guilt, anger, and frustration. Mothers described how contact with other children

of the same age stimulated personal feelings. Upon first learning about their child's disability, mothers expressed feelings of shock and disbelief. Other feelings mothers described were loss of memory during the first weeks or even months after learning of the child's disability and feelings of isolation during the early weeks of the child's disability. The feelings of shock, memory loss, and isolation were not noted after the first few weeks or months. Grieving the loss of the "normal" child was another emotion described. Mothers felt the need to distance themselves from the child in order to grieve this loss. The inability of the child to achieve developmental milestones caused the feelings of sadness to resurface. Guilt was an emotion experienced throughout the lifespan. As the developmentally delayed child grew older the mothers reported feelings of anger and frustration. Mothers felt frustrated when the child did not achieve developmental milestones or when access to healthcare was difficult.

Cameron et al. (1992) concluded that although for some of these mothers it had been over a decade since they had received the diagnosis of developmental delay for their child, they were able to recall the nature of their emotions.

Mothers of developmental delayed children experienced shock, disbelief, and denial during the early period of learning of the diagnosis, and beyond the initial period the mothers experienced anger, guilt, and sadness. These feelings re-emerged with developmental milestones the child should have been reaching. These findings supported the concept of chronic sorrow characterized by recurring stress and sadness which require coping strategies to determine the quality and intensity of the emotional reactions of these mothers.

Brandt (1983) explored social support and its relationship to negative life events experienced by mothers of developmentally delayed children to determine the adaptive difficulties of the mothers. Ten research questions were generated:

(1) What are the patterns for choosing resources to help? (2) Is there a difference in the number of resources between groups of mothers? (3) Does the level of satisfaction with help differ with the type of problem situation experienced? (4) Is there a difference in perceived support between groups of mothers? (5) What resource category predicts perceived support? (6) How are the three estimates of social support related? (7) What types of negative life events are experienced by the mothers in this study? (8) Is there a difference in negative life events between the mothers? (9) Is social support related to the negative life events experienced? (10) Does the relationship between perceived support and negative life events persist if relationship loss events are controlled statistically?

Brandt (1983) reviewed the variables examined in earlier studies and directed her research toward social support and negative life events. The social support variable, number of resources, was obtained by the sum of resources indicated in seven problem situations: emergency, help needed for handicapped child care, interpersonal difficulty, loneliness, family concerns, upset with life conditions, and general problems. The support variable, satisfaction with help, was obtained for each problem situation identified by the respondent. The support variable, perceived support, was obtained by using a 7-point Likert scale to measure perceived support for: provision of intimacy nurturance, social integration, selfworth, and guidance. A score for negative life events was obtained by using the Life Experiences Survey (LES). The descriptive study had a sample of 91 mothers of children with developmental disabilities between the ages of six months to three years. Mothers were asked to volunteer if they were over age 18, had 8 years of formal education, and had a child attending a school for children with disabilities. Brandt (1983) used a mailed questionnaire which was completed and returned anonymously. The Personal Resources Questionnaire (PRQ) was used to measure

social support. The PRQ measured three variables of support including availability of number of resources, satisfaction with help during problem life situations, and perceived support. The Life Experiences Survey (LES) was used to measure the variable of negative life event.

The average Number of Resources that the subjects reported for each of the seven life situations was three. Mothers reported their partners as one of their resources for each life situation. Partners were chosen more frequently to help during problems than other resources. To determine differences in the number of resources among groups of mothers, t tests were used. Data were analyzed for differences in number of resources among groups of mothers. Fewer resources were available to employed mothers, mothers ages 18 to 28 years and mothers without a partner. There were no significant differences determined by education, income, number of disabilities of the child, or number of hours the child was in school. Satisfaction with Help in emergency situations and child care was determined from the data by the researcher as situations where the subjects experienced more satisfaction with the help received. When the situation required emotional support with life conditions or interpersonal problems, fifty-eight percent of the mothers were dissatisfied with the help they received. Fifty-three percent of the mothers reported being lonely. A moderate level of the relational Provisions of Support as measured by PRQ was evident in most of the mothers. Mothers with incomes of \$20,000 and above perceived their support to be greater. There were no significant differences for the other groups of mothers.

The availability of a partner was the only significant predictor of a mother's perceived support ($p \le .01$). The three Estimates of Support were related in that the mothers with higher levels of perceived support had higher numbers of resources across life situations. Negative life events that impacted on the mothers during

the last year were: partner related problems, child related problems, and self related problems. The mothers of children with three or more disabilities reported higher scores on negative life events. Mothers with high negative life events were likely to feel less supported and less satisfied with the help obtained. Life stressors experienced by the respondents during the previous year were assessed by the Life Experiences Survey. Examples of negative life events were partner-related problems, child-related problems, and self-related problems. Mothers of children with three or more disabilities had higher scores on negative life events than mothers with one or two disabilities. There were no statistically significant differences on negative life event scores between younger and older mothers, employed and unemployed women, low and high income mothers, women with partners or without partners, and low and high education mothers. Social support was significantly related to the negative life events that were experienced. Pearson correlations obtained between negative life events and each support variable indicated that the negative events were associated with perceived support, r(91) = .51, p = .001. Mothers who had high negative life event scores were likely to feel less supported. Because life events can influence losses or gains in support relationships, partial correlations between negative life events and perceived support (r (91) = .45, p = .001) were obtained controlling for loss events experienced. By controlling for the losses, the shared variance between negative life events and perceived support decreased somewhat from the shared variance obtained with no control for losses (26% no control, 20% control).

Brandt's (1983) research contributes to the knowledge of social support by linking earlier research on children with developmental disabilities and their families to the concept of chronic sorrow. Further study of social support was facilitated

by this researcher's study using a measure of coping strategies used by mothers with developmentally delayed children and the effectiveness of strategies.

No previous research existed comparing differences in adjustment, chronic sorrow, and coping between mothers and fathers of children with Down syndrome until Damrosch and Perry (1989) compared patterns of adjustment, chronic sorrow, and coping between mothers and fathers of children who have Down syndrome. Another variable included in the study was the evaluation of the helpfulness of professional approaches as perceived by the mothers and fathers.

Damrosch and Perry (1989) used a mail survey with 25 families who had a child with Down Syndrome. These families were living in a northeastern state and had an affiliation with a parent support group. The respondents remained anonymous to the researchers. A representative of the parent support group had access to the names and addresses and was responsible for mailing the surveys. There were 18 fathers and 22 mothers who responded, and of these, 17 were husband-wife pairs. The mean number of children by family was two. Ages of the children with Down Syndrome were from infancy to adulthood with a mean age of 6.59 years. Mean ages were 37.7 and 39 of mothers and fathers respectively. Most of the parents were college educated.

To depict Overall Pattern of Adjustment, Damrosch and Perry (1989) had parents use a graph to depict his or her own experience. The bottom of the graph meant "awful" and the top meant "great". Graph 1 started out with "awful" at the time of diagnosis but improved through time. Graph 2 had peaks and valleys over time meaning the emotional experiences waxed and waned.

Parents were given a definition of chronic sorrow and asked to respond on a 0 to 4 Likert scale ranging from never (0) to most of the time (4). The Parental Coping Scale was designed by Damrosch and Perry to represent items from

Lazarus' Ways of Coping instrument and items recommended by an advisory pane of parents of children with Down Syndrome. Answers were given using a Likert scale ranging from (0) for never to (4) for most of the time. The authors composed a scale listing seven professional approaches which were evaluated by (1) not useful to (5) extremely useful scale. The approaches were: assuming cheerful attitude toward parents, encouraging parents not to dwell on the negative, encouraging expression of sadness, encouraging parents to be strong, allowing parents to be weak, giving parents a chance to temporarily escape the situation and giving parents positive feedback (Damrosch & Perry, 1989). Analyses of means were performed using t-tests for the entire sample and for the husband-wife pairs. There were differences in patterns of adjustment between the mothers and fathers. Over 83% of the fathers felt their adjustment to be a steady, gradual increase; 68% of the mothers felt their adjustment to be a chronic, periodic crisis. Almost everyone in the sample felt they experienced chronic sorrow. For the total sample, there were no statistically significant differences in the mean frequency for mothers and fathers. However, husband-wife pairs significantly differed (M = 2.00; SD = 0.79) compared to fathers (M = 1.47, SD = 0.72); \underline{t} = 2.50, \underline{p} = .024. Coping frequency means were higher on all subscales for the mothers. Mothers found six of the seven approaches by professionals to be somewhere above the mid-point of useful on the 1 to 5 scale. Fathers found five of the seven above the midpoint. Mothers evaluated encouragement of their expression of sadness, allowing parents to be weak, and giving parents positive feedback to be significantly higher than what the fathers indicated.

The findings of Damrosch and Perry (1989) indicate that mothers have a greater need to ventilate feelings since the greater burden of caring falls upon them and is, therefore, related to this researcer's study comparing the coping

strategies of mothers. Mothers and fathers reported their adjustment differently; fathers (83%) reported adjustment as being a gradual return to the level of adjustment prior to the diagnosis while mothers (68%) reported a pattern of periodic ongoing crises.

The review of the literature revealed that chronic sorrow is an ongoing phenomenon in parents of child with developmental delay. Wikler's (1981) study affirmed the original proposal of Olshansky (1962) that the grief felt from the loss of a perfect child was experienced later as well as at the time of diagnosis. There was found to be a relationship between stressful events experienced by the disabled child and the corresponding chronic sorrow of the parents.

The emotions that mothers experienced throughout the lifespan and how these emotions changed over time were explored by Cameron, Snowdon, and Orr (1992). The mothers expressed common themes of shock and disbelief upon learning of the child's disability, and later sadness, loss, and guilt would continually resurface during what would have been the child's school-age years. Adaptive difficulties of the mothers were explored by Brandt (1983). The study revealed that caregiving demands and resources to help with child care were contributors to stress. Employed mothers reported difficulties in finding childcare.

Coping between mothers and fathers was compared by Damrosch and Perry (1989). Findings indicated that mothers have a greater need to ventilate feelings since the greater burden of caring falls upon them. An underlying theme throughout the literature is that mothers of developmentally delayed children will require lifelong support and connection with community resources. The ability to function for these mothers depends on the perception and effectiveness of their support systems and the ability to mobilize these systems during a crisis.

CHAPTER III

Methodology

Statement of the Purpose

The purpose of this study was to ascertain if there were differences in the coping strategies and effectiveness of coping strategies used by mothers of developmentally delayed children who attend a parent support group and those who do not attend a support group.

Design of the Study

For this study, a comparative descriptive design was used to determine what differences, if any, existed in coping strategies of mothers with chronic sorrow who were in a support group and those who were not. A comparative descriptive design was chosen since the coping strategies were being described, rather than explained, and then compared between mothers in a support group and those not in a support group. The dependent variable was perceived coping strategies and perceived effectiveness of these coping strategies as measured by the Jalowiec Coping Scale. The independent variable was the mothers with chronic sorrow who were either involved in a parent support group or not involved in a parent support group. The control variable was the phenomenon of chronic sorrow experienced by mothers who were parenting a child with developmental delay secondary to a diagnosis of cerebral palsy.

Setting

A Pediatric Clinic in north Mississippi that serves children from the entire state who have been diagnosed with cerebral palsy and a meeting site of the Cerebral Palsy Support Group in north Mississippi provided the sites where data collection took

place. Private, quiet rooms were loaned to the researcher for data collection to ensure confidentiality.

Population

Mothers between the ages of 16 to 40 years old who were the biological and legal parent of a child they are rearing at home were the subjects of the study. All of the children were between the ages of one and five and had a medical diagnosis of developmental delay secondary to cerebral palsy. These mothers were experiencing chronic sorrow over their lifetimes based on an assumption from review of the literature that chronic sorrow exists in mothers of developmentally delayed children. The subjects included two groups, mothers involved in a support group (n=25) and those not involved in a support group (n=25). The total sample was obtained by convenience using mothers who met the criteria and were willing to participate in the study.

Instrumentation

Two instruments were used in this study: a Demographic Data Questionnaire form and the Jalowiec Coping Scale. Data collected on the descriptive data form included the subject's age, race, marital status, religion, educational background, income and/or sources of income, living arrangements, health problems, transportation, and employment status (See Appendix A). One open ended question was asked wherein the subjects could identify any specific feelings and thoughts they had associated with parenting their developmentally delayed child.

The Jalowiec Coping Scale is composed of 60 coping strategies in Likert-type format with 0 to 3 rating for each strategy from never used (0) to used often (3). Effectiveness of strategy usage can be rated on the scale by having the person complete the effectiveness rating scale, a rating scale ranging from not helpful (0) to very helpful (3). The 60 coping items are classified into eight coping styles:

confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant. The Jalowiec Coping Scale uses this multi-dimensional approach to characterize the diversity of coping behavior.

Summary of homogeneity reliability for the Jalowiec Coping Scale (x Cronbach alphas based on results of 24 studies) were as follows: total use = .86; total effectiveness = .91; use subscales ranged from .48-.81 (x for all 8 use subscales = .62); effectiveness subscales ranged from .48-.82 (x for all 8 effectiveness subscales = .65). Stability reliability (based on significant correlations from Jalowiec NIH heart transplant study, using retest intervals of 3, 6, 9, 12 months) were as follows: stability of total use scores ranged from .57-.69 (x for all retest intervals = .61); stability of total effectiveness scores ranged from .43-.63 (x for all retest intervals = .52). Stability of use subscales ranged from .37-.70 (x for all retest intervals = .55). Stability of effectiveness subscales ranged from .22-.65 (x for all retest intervals = .47). Therefore, use of coping styles showed greater stability over both short and long time periods than the effectiveness of the coping styles. Using three judges, content validity for 8 subscales = .85; therefore, support was shown for relevance of items for each subscale (Jalowiec, 1981).

Content validity of the JCS is supported by the broad literature base from which the items are drawn, the large number of items used and the diversity of the types of coping behavior. Empirical construct validity of the JCS was supported by a panel of 25 nurse researchers from the Midwest Nursing Research Society who were familiar with the stress and coping literature (Jalowiec, 1981).

Data Collection

After the proposal was approved by the thesis committee, an application for permission to conduct the study was submitted to the Committee on Human Subjects in Experimentation at Mississipi University for Women and approved as

submitted with the researcher cautioned to make a distinction between cerebral palsy and developmental delay to indicate they are two separate medical problems; however, the diagnosis of cerebral palsy imparts with it the diagnosis of developmental delay (See Appendix B).

Verbal permission to approach potential subjects was obtained from the Director of Pediatrics at a major clinic in north Mississippi that serves children with cerebral palsy throughout the state. Sample selection was accomplished by the researcher's review of charts and collaboration with professional staff. Permission was obtained from the President of the Cerebral Palsy Support Group in North Mississippi to approach members at monthly meetings. Written permission to use the Jalowiec Coping Scale was obtained from Anne Jalowiec (See Appendix C).

Participation was on a voluntary basis. The potential subjects were given a verbal explanation of the study as well as a written information and consent form (See Appendix D). Each subject was assured that participation was voluntary and that refusal to participate would in no way affect the quality of care their child received. Subjects were told that they can withdraw from the study at any time up to data analysis. Each participant was assured of confidentiality. Each participant was informed that the time required would be approximately 30 minutes.

Data collection was done in the Clinic setting or meeting site. During the session, the Demographic Data Form and the Jalowiec Coping Scale were completed by the subject. The forms were coded with (1) for mothers in a support group and (2) for mothers not in a support group. The researcher remained in the Clinic or meeting site and was available to answer any questions.

Statistical Analysis

Age, marital status, employment status, education, income, religion, number of children in family, sex and age of the child, birth status of the child, whether

or not the child attended daycare, number of times the child visit the doctor or had been hospitalized, number of people living in the household, health of the child, physical and mental health of the mother, and who they turn to for help were nominal level data. These variables were described using frequencies and percentages. Cronback's coefficient alpha was calculated for the Jalowiec Coping Scale using the total sample for both use and effectiveness scales. For the study both a total perceived coping use and total perceived coping effectiveness was obtained. Perceived use and perceived effectiveness scores were obtained for each of the eight coping styles for mothers in a support group and those not in a support group. Comparison of differences in perceived coping strategy use and effectiveness by the two troups of mothers were calculated using an independent test statistic. The level of significant was set at p<.05.

The answers to the open ended question were analyzed using content analysis. Similar themes between the groups of mothers were identified.

Limitations

Limitations to this study included a small, convenience sample which does not assure confidence that the results of the study can be inferred to the population from which the sample was taken. The eight subscale scores and overall JCS scores were not intercorrelated to determine if each of the subscales and the overall JCS were independently or dependently related.

CHAPTER IV

The Findings

The purpose of this study was to examine the coping strategies of mothers with developmentally delayed children. A descriptive comparison design was used to evaluate coping styles and their effectiveness identified by mothers in support and non-support groups. This chapter includes the empiricalization of the study and the results of the data analysis.

Description of the Sample

The convenience sample (N = 50) consisted of two groups, one comprised of those who attended a support group (n = 25) and one comprised of those who did not attend a support group (n = 25). The ages of mothers in the support group ranged between 27 and 40 years. The ages of mothers in the non-support group ranged between 16 and 40 years. Mothers in both groups were single, married, or divorced. The majority (48%) of mothers in the support group were married and the majority (52%) of mothers in the non-support group were single. Mothers in both groups reported that they were employed full time, part time, or unemployed. The highest percentage of mothers in the support group and non-support groups worked full time, 44% and 52% respectively (see Table 1).

Table 1

Demographic Variables of Sample by Group Using Frequencies and Percentages

Variables	Support group		Non-support group	
	f	<u>%</u>	f	<u>%</u>
Age			· · · · · · · · · · · · · · · · · · ·	
16 - 20			5	20
21 - 26	8	32	8	32
27 - 33	7	28	6	24
34 - 40	10	40	6	24
Marital status				
Single	9	36	13	52
Married	12	48	9	36
Divorced	4	16	3	12
Employment status				
Full time	11	44	13	52
Part time	7	28	5	20
Unemployed	7	28	7	28

Subjects in each group reported varying types of occupations. A higher percentage of mothers in the support group worked in professional types of occupation than did mothers in non-support groups (see Appendix E). Four (16%) of the 25 mothers

in the support group and seven (28%) of the mothers in the non-support group did not respond to this question.

The highest grade levels of mothers in the support group (n = 24) and mothers in the non-support group (n = 24) ranged from junior high school to college. Three (12%) of the mothers in the non-support group and one (4%) of mothers in the support groups reported that their highest grade level was junior high school. The majority of mothers in the support (n = 13, 54%) and non-support group (n = 17, 71%) reported that they were high school graduates. It was noted that substantially more mothers in the support group (n = 10, 42%) had attended college than those in the non-support group (n = 4, 17%).

The mothers in both groups reported that their religion was Protestant,

Catholic, Episcopalian or other. The highest percentage (n = 10, 42%) of mothers in
the support group and (n = 18, 72%) of mothers in the non-support group stated
that they were Protestant. Nine (38%) of those in the support Group and (n = 1,
4%) of those in the non-support group stated that they were Catholic. One (4%) of
mothers in the support group indicated that she was Episcopalian. Four (16%) of
mothers in the support group and six (25%) of mothers in the non-support group
reported their religious denomination as "other."

The majority of mothers (n = 20, 80%) in the support group and non-support groups (n = 18, 72%) reported that their physical health was good. It was noted that six (25%) of mothers in the non-support group stated that their physical health was fair compared to two (8%) of mothers in the support group. Three (12%) of the mothers in the support group perceived their physical health to be excellent compared to one (4%) of the 25 members in the non-support group.

The majority of mothers in the support group (n = 20, 80%) and non-support group (n = 14, 56%) stipulated that their mental health was good. However, it was

noted that more mothers in the non-support group (n = 8, 32%) rated their mental health as fair when compared to mothers in the support group (n = 4, 16%). Three (12%) of mothers in the non-support group and one (4%) of mothers in the support group indicated that their mental health was excellent.

The number of people in the household for both groups ranged from 1 to 5 or more. The highest percentage (n = 6, 24%) of people in household of the 25 mothers in the support groups was three, while the highest percentage (n = 7, 28%) of people in the households of the 25 mothers in the non-support group was five or more. Four (16%) of mothers in the support group and two (8%) of mothers in the non-support group reported that there was one person in their household. Five (20%) of mothers in the support group and 16% of mothers in the non-support group stated that there were two persons in their household. Five (20%) of mothers in the support group and six (24%) of mothers in the non-support group stipulated that there were four persons in the household.

Assistance in emergency situations which involved the child included family member, church member, health care provider, family and church member, family and health care provider, and family, church, and health care providers. The majority mothers in the support group reported that they received assistance from family church, and health care providers. The majority of mothers in the non-support group received such assistance from family and church members (see Table 2).

Table 2

Assistance in Emergency Situations with Child

Who assists in emergencies with child	Support group		Non-support group	
	fx	%	<u>fx</u>	<u>%</u>
Family member	1	04	1	04
Church member			1	04
Health care provider (HCP)	1	04	6	24
Family & church member	4	16	11	44
Family & HCP	9	36	5	20
Family, church & HCP	10	40	1	04

Internal Consistency Reliability of the Use and Helpfulness of Subscales and Total JCS

Internal consistency reliability (ICR) of the use and helpfulness of the eight subscales and the total JCS was tested using alpha. The ICR of the use of the fatalistic, palliative, and supportive coping styles were determined to be below the accepted ICR level. The remaining subscales and overall JCS depicting use and helpfulness meet the requirements expected for internal consistency reliability (see Table 3). Jalowiec (1981) did not report the ICR for each subscale separately, only in ranges. The only ICR reported was significant to the total use and effectiveness of the JCS.

Table 3

Internal Consistency Reliability of Use and Helpfulness Subscales and Total JCS

	Use Alpha coefficient		Helpfulness Alpha coefficient		
Subscales & Total JCS					
	Achieved	Expected	Achieved	Expected	
Confrontive coping style	0.73		0.85		
Evasive coping style	0.67		0.85		
Optimistic coping style	0.76	0.83			
Fatalistic coping style	0.07	0.79			
Emotive coping style	0.78		0.67		
Palliative coping style	0.51		0.66		
Supportive coping style	0.22	0.62			
Self-reliant coping style	0.77	0.77			
Total JCS	0.85	0.86	0.93	0.91	

Results of Data Analysis

Data relevant to the use and effectiveness of coping strategies in caring for developmentally delayed children were used to address the problem, do mothers who are in a support group differ in their use and perception of the effectiveness of coping strategies from that of mothers who are not in a support group? The score for each of the

subscales was obtained by summing the responses and dividing the result by the number of items pertaining to each of the subscales. The scores for the overall JCS were obtained by summing the responses for the entire scale and dividing the result by 60 (the total number of items in the scale). Two null hypotheses were tested in this study. The independent t-test was used to test the null hypotheses at p<.05.

Ho1: There will be no significant difference in the use of coping strategies by mothers with developmentally delayed children in a support group and those not in a support group.

Ho2: There will be no significant difference in the effectiveness of coping strategies by mothers with developmentally delayed children in a support group and those not in a support group.

Results of analysis of Ho1: There was no statistically significant difference in the use of the total coping styles between the two groups of mothers (t (48) = -.57, p = .573); therefore, the null hypothesis failed to be rejected. Coping strategies identified in the Jalowiec Coping Scale (JCS) comprised eight dimensions of coping styles: confrontive, evasive, optimistic, fatalistic, palliative, supportive, and self reliant, as well as the total JCS. In six of the eight coping styles there were significant differences between the groups (See Table 4).

Results of Analysis Ho2: There was a significant difference in the total effectiveness of coping style scores between 25 mothers in the support group and 23 mothers in the non-support group (\underline{t} (46) = 2.36, \underline{p} = .024). The null hypothesis was rejected. For effectiveness of the eight dimensions of coping styles, only one emerged as significant. The findings are presented in Table 5.

Table 4

Coping Strategies Use Scores on the Jalowiec Scale for Mothers in a Support Group (1)

and Mothers not in a Support Group (2)

Strategy Use	<u>N</u>	<u>M</u>	<u>\$D</u>	ţ	p
Confrontive					
Group 1	25	1.96	.445	2.71	.009*
Croup 2	23	1.56	.583		
Evasive					
Group 1	25	0.88	.440	-3.10	.003*
Croup 2	23	1.32	.583		
Optimistic					
Group 1	25	2.00	0.50	1.99	.050*
Croup 2	23	1.68	.627		
Fatalistic					
Group 1	25	0.92	.493	-1.99	.050*
Croup 2	23	1.24	.723		
Emotive					
Group 1	25	1.16	1.24	0.57	.573
Croup 2	23	0.37	0.59		
Palliative					
Group 1	25	1.20	1.12	1.20	.652
Croup 2	23	0.50	0.73		
Supportive					
Group 1	25	2.16	.374	2.00	0.05*
Croup 2	23	1.40	.707		
Self-Reliant					
Group I	25	1.32	.557	2.71	.009*
Croup 2	23	1.54	.578		

Table 5

Coping Strategies Effectiveness Scores on the Jalowiec Scale for Mothers in a Support

Group (1) and Mothers not in a Support Group (2)

Strategy Use	<u>N</u>	<u>M</u>	<u>SD</u>	1	р
Confrontive					
Group 1	25	1.96	.539	1.99	.019*
Croup 2	23	1.76	.879		
Evasive					
Group 1	25	1.45	.664	1.020	.316
Croup 2	23	1.52	.730		
Optimistic					
Group 1	25	1.764	.583	0.210	.836
Croup 2	23	1.60	.764		
Fatalistic					
Group 1	25	1.84	1.106	0.430	.157
Croup 2	23	1.60	.1.190		
Emotive					
Group 1	25	1.20	.707	-0.720	.475
Croup 2	23	1.56	1.003		
Palliative					
Group 1	25	2.12	.833	-0.720	.475
Croup 2	23	2.24	1.052		
Supportive					
Group 1	25	2.64	.569	2.00	0.05*
Croup 2	23	2.48	.770		
Self-Reliant					
Group 1	25	1.64	.810	1.32	.193
Croup 2	23	1.48	.770		

Additional Findings

An examination of the children's demographic characteristics revealed that the ages of children in both groups ranged between 1 and 5 years. Two (8%) of the children of mothers in the support group and three (12%) in the non-support group were 1 year old. Seven (28%) of the children in the support group and nine (36%) of those in the non-support group were 2 years of age. Five (20%) in the support group and five (20%) in the non-support group were 3 years old. Three (12%) in the support group and two (8%) in the non-support group were 4 years of age. Eight (32%) in the support group and four (16%) in the non-support group were 5 years old.

Eleven (44%) of the children in the support group and 14 (56%) of the children in the non-support group were male. Fourteen (56%) of the children in the support group and 11 (44%) of the children in the non-support group were female.

One (4%) of the children in the support group and 10 (40%) of the children in the non-support group did not attend day school. Twenty-four (96%) of the children in the support group and 15 (60%) of the children in the non-support group attended day school.

The number of times the children of mothers in the support groups visited the physician annually ranged from none to 20 times while the numbers of times children of mothers in the non-support group visited the physician ranged from one to over 20 times. One child in the non-support group was not seen by a physician. Seven (28%) of the children in the support group and eleven (44%) visited the physician between 1 and 5 times. Seven (28%) of the children in the support group and eleven (44%) visited the physician between 1 and 5 times. Eleven (44%) of the children in the support group and seven (28%) of the children in the non-support group visited their physician between 6 and 10 times. Seven (28%) of the children in

the support group and two (8%) of the children in the non-support group visited the physician between 11 and 20 times.

The number of times children of mothers in the support group were hospitalized annually ranged from none to 10, while the number of times children of mothers in the non-support group were hospitalized ranged from 1 to over 20 times. One (4%) child of a mother in the support group had never been hospitalized. Fourteen (56%) of the children in the support group and 20 (80%) of the children in the non-support group had been hospitalized. Ten (40%) of the children in the support group and four (16%) of the children in the non-support group were hospitalized between 6 and 10 times. One child (4%) in the non-support group had been hospitalized over 20 times.

Mothers in both groups rated their children's health from poor to excellent. One child in each group (4%) was rated as being in poor health. Eleven (44) of the children in the support group and eight (32%) of the children in the non-support group were rated as being in fair health. Ten (40%) in the support group and thirteen (52%) in the non-support group were rated as being in good health. Three (12%) in both groups were rated as being in excellent health.

Sixteen (64%) of the mothers in the support group and eight (32%) of the mothers in the non-support group responded to the open ended question, "Is there anything else you would like to say about your experience as parent of a child with cerebral palsy?" Responses were categorized into common themes. Seven common themes were obtained for both support and non-support groups. Four separate themes were identified for each of the two groups. The six common themes included: (a) denial/disbelief, (b) denial replaced with pain/anxiety, (c) sadness, (d) guilt, (e) optimism, and (f) chronic sorrow. The four separate themes identified from responses of mothers in the support group included: (a) pleasure in daily care

of the child, (b) increased financial support, (c) increased social support, and (d) supportive relationship with the father. The four separate themes identified for mothers in the non-support group included: (a) interactive difficulties with the child, (b) problems in relationship with the father, (c) lack of financial support, and (d) overprotectiveness/controlling. Most of the 16 mothers in the support group (n = 12, 75%) and the 8 mothers in the non-support group (n = 7, 87%) expressed feelings of disbelief and made comments similar to the mothers who stated, "I know she still can't walk, but she's just going to be a little slow the doctor said." Four of the mothers in both groups whose children were between the ages of 4 and 5 expressed initial feelings of denial which had been replaced with intense pain and anxiety. One mother commented, "I get a lot of tension in my neck when I think about how much he missed because I wouldn't believe the doctor and refused the physical therapy."

The mothers in the non-support group described interactive difficulties between themselves and their child such as hypoactivity, hyperactivity, and inattention. Four (50%) of the mothers in the non-support group with older children described parental behaviors that were overprotective and controlling. The following comment was made by one of these mothers, "I don't want him to go to school or away from me because I know other kids make fun of him, and besides that, he falls down a lot and will get hurt without me." As the children grew older, and did not achieve developmental milestones, mothers who were not in the support groups felt sadness because the disability became more apparent. One mother said, "She was so cute as a baby, but now people state at her because she looks an acts different and is doing less than she should be doing." Relationship problems with the father of the child as well as a lack of financial and social support were other response from this group of mothers. One mother states, "He's just never been there for us."

The 16 mothers in the suport group had a more optimistic outlook and focused on finding pleasure in daily care of their child. These mothers reported more social and financial support and a more supportive relationship with the father of the child. These mothers were either married to the father of the child or received child support, and the father had visitation rights. The majority of mothers in this group also expressed feelings of hope and other attributes of chronic sorrow (See Table 6).

Both groups of mothers expressed recurrent guilt because they felt they did something that caused their child to be developmentally delayed. One mother felt because she had painted the child's room she had caused the development of cerebral palsy. All of the mothers in both groups acknowledged feelings of chronic sorrow, but none gave a more descriptive summary than the one who sent the following piece, originally published by Emily Perl Kingsley (1987).

I am often asked to describe the experience of raising a child with a disability to try to help people who have not shared that unique experience to understand and imagine how it would feel. It's like this. When you are going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make wonderful plans. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. When the plane lands, the stewardness says, "Welcome to Holland!" You say, "What do you mean Holland, I signed up for Italy. All my life I've dreamed and planned on Italy." But, there has been a change and you have landed in Holland and there you must

stay. The important thing is you aren't in a disgusting place, just a different place.

So you go out and buy new guidebooks and learn a whole new language. You meet a whole new group of people you never would have met. It is a different place. It is slower paced than Italy, less flashy than Italy. But after you've been there for a while and catch your breath, you look around and begin to notice the windmills and other wonderful things about Holland. Everyone you know is busy coming and going from Italy, and they are bragging about what a wonderful time they are having there.

And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special and lovely things about Holland.

Table 6
Themes Extracted From Open Ended Question

Theme	Support group		Non-Support group	
	f	<u>%</u>	f	<u>%</u>
Denial/disbelief	12	75	7	87
Denial replaced with pain/anxiety	4	25	4	50
Sadness	15	93	5	62
Guilt	12	75	6	75
Optimism	10	66	1	12
Chronic sorrow	16	100	8	100
Pleasure in daily care of child	9	56		
Increased financial support	9	56		
Increased social support	14	87		
Supportive relationship with father	12	75		
Interactive difficulties with child			5	62
Problems in relationship with father			6	75
Lack of financial support			7	87
Overprotectiveness/Controlling			4	50

Note: (Support group: n = 16)(Non-support group: n - 8).

Chapter V

The Outcomes

The purpose of this study was to explore the coping strategies and effectiveness of the strategies of mothers with developmentally delayed children who were involved in a support group and mothers who were not in a support group. Mothers from northeastern Mississippi between the ages of 16 and 40 and parenting a child between one and five years of age with developmental delay secondary to cerebral palsy were subjects in this study. Lazarus' cognitive transactional theory of stress was the theoretical framework which guided this research. A demographic form and the Jalowiec Coping Scale were the instruments used to collect the data. These instruments were administered to the subjects. Total scores for use and effectiveness to overall coping style and each of the eight coping styles were examined. The eight coping styles were as follows: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self reliant.

Summary of the Findings

The samples' median age range was 27 to 33 years for the support group (n = 25) and 21 to 26 for the non-support group (n = 25). More mothers in the non-support group were younger (52% vs. 32%), single (53% vs. 36%), and had less college education (17% vs. 42%) than mothers in the support group. Although the highest percentage of mothers in both groups were Protestant, more mothers in the support group were Catholic when compared to mothers in the non-support group (38% and 4% respectively). The majority of mothers in both groups were employed

full time (n = 11, 44% and n = 13, 52% respectively). Substantially more mothers in the non-support group reported that their mental health was fair (32% vs. 16%). A higher percentage of mothers in the non-support group reported a greater number of people in the household (four or more) than did mothers in the support group (52% vs. 40% respectively).

More mothers in the support group indicated that they sought assistance in emergency situations involving their child from (1) family members, church members, and health care professionals (40% vs. 4% respectively), and (2) family members and health professionals (36% vs. 20% respectively). Conversely, more mothers in the non-support group stipulated that they requested assistance from family and church members than did mothers in the support group (44% vs. 16% respectively).

Children (48%) of mothers in the non-support group were younger (1 to 2 years of age) than those in the support group (36%). More children (28%) of mothers in the support group were older (4 to 5 years of age) than those in the non-support group (24%). The non-support group had more male children compared to the support group (56% vs. 44%). More mothers in the support group reported that their children were in day school (96% vs. 60% respectively). A higher percentage of mothers in the support group reported that their children visited the physician between 6 and 10 times annually, while a higher percentage of mothers in the non-support group reported that their children were seen between 1 and 5 times annually. Children of mothers in the support group were hospitalized between 6 and 10 times annually, whereas children of mothers in the non-support group were hospitalized between 1 and 5 times annually. Thus, these mothers in the non-support group rated their children's health as good.

The internal consistency reliability (ICR) of the eight subscales and total Jalowiec Coping Scale was compared to that reported by Jalowiec (1981). The findings of the overall ICR in this study for both use and helpfulness of the coping styles was similar to that reported by Jalowiec (1981) (for use, alpha = .85 and .89 respectively; for effectiveness, alpha = .93 and .91 respectively). The use of fatalistic and supportant coping styles in this study were below the acceptable range for internal consistency reliability.

The first null hypothesis stated that there will be no significant difference in the use of coping strategies by mothers with developmentally delayed children in a support group and those not in a support group. This hypothesis was tested using the independent t-test. There was no statistically significant difference in total use of coping strategy scores (p>.05). The null hypothesis failed to be rejected. However, more mothers in the support group used the confrontive, optimistic, supportant, and self reliant styles of coping in caring for their developmentally delayed children ($p\le.05$). Significantly more mothers in the non-support group used the evasive and fatalistic coping style in caring for their developmentally delayed children ($p\le.05$).

The second hypothesis stated that there will be no significant differences in perceived helpfulness of overall coping strategies by mothers with developmentally delayed children in a support group and those not in a support group. There was a significant difference in total effectiveness of coping style scores between 25 mothers in the support group and 23 mothers in the non-support group (p<.05). The null hypothesis was rejected. Additionally, more mothers in the support group perceived the confrontive and supportant styles of coping as being more helpful. No significant difference was found in the remaining six styles (evasive, optimistic, fatalistic, emotive, palliative, and self reliant) between the two groups (p>.05).

Themes identified in response to the open ended question, "Is there anything else you would like to say about being a parent of a child with cerebral palsy?" by 16 mothers in the support group were indicative of a more positive attitude. The majority of the 8 mothers in the non-support group who responded to this question had less positive attitudes.

Discussion

The first hypothesis, there will be no difference in the total coping strategy scores, was accepted; however, although there were no differences in total coping strategy scores, the eight subscales of coping styles were used differently. Mothers in the support group used confrontive, optimistic, supportant, and self reliant styles of coping significantly more than did mothers in the non support group reflecting the value gained from peer discussions in the support group meetings. The rejection of the second hypothesis, there will be no difference in effectiveness of coping strategy scores of the mothers, was rejected. In addition, more mothers in the support group perceived the confrontive and supportant styles of coping as being more helpful. Peer group interactions may stimulate active participation in problem solving for stressors associated with living and caring for a child with a disability. These mothers have shown active participation in the problem solving of living with the child's disability, as evidenced by their styles of coping, and the fact that the mothers in the support group perceived the confrontive and supportant styles to be more effective. The researcher postulates that support group interaction contributes positively to the effectiveness of coping strategies.

The possibility of methodologic bias must be considered when interpreting the results of this study. The sample was limited to mothers of children with developmental delay secondary to cerebral palsy. Mothering issues related to children with cerebral palsy and their developmental delay may be quite different

than mothering children with other diagnoses such as mental retardation, spina bifida, and developmental delay from other causes. Since all mothers of developmentally delayed children experience chronic sorrow, perhaps coping strategies are the same.

Additionally, the sample either attended support group meetings in northeastern Mississipi or were in a clinic which serves children from the entire state. The non-randomized settings may have skewed the results, since these mothers may have cultural or demographic characteristics which influence their choice of coping mechanisms. For instance, the mothers in the support groups had higher incomes, higher level of education, and greater social and relationship supports.

The researcher made the assumption that chronic sorrow is an expected finding in all parents of children with developmental delay. Themes identified by the researcher of those parents who answered the open ended question identified critical developmental times during early childhood which are predictors of chronic sorrow and were similar to those critical times identified by Wikler (1981). Mothers in both groups related that these feelings were reactivated when the child should have been walking, talking, toilet training, or attending preschool. At these times, mothers in both groups expressed frustration, sadness, and self-blame. However, mothers in the support group had a more optimistic approach, perhaps because support groups facilitate a focus on the positive aspects of raising a child with developmental delay and allow opportunity to physically and verbally express feelings and perceptions. This type of sharing would account for the concentration on positive aspects of mothering these children.

The findings in this study supported Lazarus' cognitive transactional theory of stress in that a person's coping strategies reflect appraisal of stress. These coping strategies reflect the ability to better cope with stress related to caring for the

developmentally delayed child. The use of the evasive coping style by mothers in the non-support group may have the potential for feelings of guilt and increase in stress. Confrontive, supportant, and overall coping strategies were significantly more helpful to mothers in the support group and may enable the mothers to better cope with stress.

Although there was a lack of research studies pertaining to the use and effectiveness of coping styles by mothers in support groups and non-support groups, the findings in the study support the themes depicted in the review of literature. The themes depicted that the ability of the mothers of these children to function daily depends on the perception and effectiveness of their support systems and the ability to mobilize these systems during a crisis. Furthermore, mothers in the support group also reported the confrontive, supportant, and overall coping strategies to be significantly more effective than did mothers who were not in a support group.

The review of the literature studies dealt mainly with feelings and emotions. Brandt (1983) studied the relationship between satisfactions with number of support resources, satisfaction with help received from support resources, and perceived support. She concluded that mothers with high negative life events were likely to feel less support and less satisfied with assistance from support resources. Although the findings in this study did not directly examine these variables, mothers in the support group found use of confrontive and supportive coping styles to be more effective than did mothers in the non-support group. Brandt (1983) also explored adaptive difficulties experienced by mothers of developmental delayed children. Perhaps mothers in the support groups utilized more adaptive behaviors and, therefore, used more effective coping styles than did mothers who did not have support from others.

The findings in this study that mothers in the non-support group had substantially more younger children than mothers in the support group may be related to conclusions espoused by Wikler (1981) that there were critical points in a child's life in which developmental milestones should be achieved between the ages of 1 to 2 years and were peaks in chronic sorrow for parents which may have reflected the significant differences in the perceived helpfulness of confrontive, supportant and overall coping strategies. The fact that the mothers in a support groups used the confrontive, optimistic, supportant, and self reliant coping styles significantly more than did mothers in the non-support groups, while mothers in the non-support group used evasive and fatalistic coping styles more frequently, may be related to the findings by Damrosch and Perry (1989). These latter researchers stipulated that mothers have a greater need to ventilate feelings and share their feelings with others who have similar experiences. Therefore, mothers who share their feelings have increased effectiveness of coping strategies which allows them to cope more effectively with the stressors involving in caring for a developmentally delayed child.

Conclusions

Since no significant differences emerged, the researcher concluded that overall use of coping styles are used by mothers in support and non-support groups. However, mothers in the support groups used confrontive, optimistic, supportant, and self reliant coping styles significantly more than did mothers in non-support groups. Mothers in the non-support groups used evasive and fatalistic coping styles more frequently than did mothers in the support group.

Since there was a difference in the effectiveness of coping styles used by these groups, the researcher concluded that support group attendance impacts mothers with developmental delayed children. Specifically, mothers who attend support

groups feel the confrontive and supportant styles of coping with stress to be more effective. Perhaps with the support of the group meetings, the mothers learn to confront stressors, thus the findings that the supportant and confrontive styles are used more effectively. This researcher also purports that mothers with chronic sorrow use various coping styles to adapt to the stressors of raising a child with a disability.

Mothers revealed areas of stressors related to the care of a child with developmental delay. When answering the open ended question, mothers in both groups expressed worry about the future of their child, personal demands, relationship strain with the husband and others, and financial and medical demands. Implications for Nursing

The results of the study indicated the need for increased development of support groups for mothers of children who are developmentally delayed. Family nurse practitioners are in an ideal position to develop such programs in their community. Preventative, supportive, and therapeutic intervention are necessary to enable this population to adopt positive coping styles in caring for their child. Further research by family nurse practitioners in this arena is imperative in order to determine the effectiveness of such intervention. Furthermore, the nurse practitioner is in a position to evaluate a child's development and intervene by referring parents to appropriate health care agencies for early intervention and to special education facilities.

Curricula in graduate schools of nursing with nurse practitioners programs should include a conceptual approach to family-centered nursing for the family with a developmentally delayed child. Nursing strategies need to be incorporated into the curricula in order to provide assistance at specific critical transition points in the child's development. Greater emphasis should be placed on support groups in the

patient education programs relative to coping strategies in health care institutions, especially in pediatrics. Nurse practitioners can become more educated on how coping with a child with a developmental delay impacts not only the mother and child, but also the entire family. These findings can be used to establish programs to better serve these children and their families.

Recommendations for Future Research

The following recommendations for future research are offered by the researcher:

- 1. Replication of the study using a stronger research design to include probability sampling and a larger sample.
- 2. Inclusion of hypotheses (use and effectiveness) reflecting each of the eight subscales of the JCS.
 - 3. Replication of a similar study in other geographic locations.
- 4. Replication of a similar study with fathers, or fathers and mothers, of developmentally delayed children.
- 5. Implementation of evaluative research to determine nursing strategies used in caring for developmentally delayed children.
- 6. Implementation in nursing curricula of a family centered approach to giving care to the child with developmental delay and his/her family.
- 7. Indentification of and referral to support groups for mothers of children with developmental delay.

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Appendix A Demographic Data Questionnaire

1.	What is your present age? 16-20 21-26 27-33 34-40
2.	What is your marital status Single Married DivorcedWidowed
3.	What is your employment status? Full-time Part-time Not employed
4.	What is your present job occupation?
5.	Indicate the highest grade in school you have completed Grammar School
	Jr. High High School College
6.	What is your family's yearly income? Under \$10,000 \$10,000-\$20,000
7.	What is your religion? Protestant Catholic Episcopal Other
8.	How many children are in the family including this child? one two three More than three
9.	What is the sex of this child? Male Female
10.	What is the age of this child? One Two Three Four Five
11.	Is this child the oldest, youngest, or in the middle?YoungestOldestMiddleThis is only child in family
12.	Does this child attend daycare or school? Yes No
13.	How many times does this child visit the doctor per year? 1-5 6-10 More than 20
14.	How many times has this child been in the hospital since birth? 1-5 6-10 More than 20
15.	What people live in the household with this child? One Two Three Four Five or More than Five
16.	Overall, how would you rate the health of this child? Poor Fair Good Excellent
17.	Overall, how would you rate your physical health? Poor Fair Good Excellent
18.	Overall, how would you rate your mental health? Poor Fair Good Excellent
19.	When you experience an emergency situation with your child, who do you turn to for help? Family Member(s) Church Member(s) Health Care Provider(s)
20.	Is there anything else you would like to say about your experience as a parent of a child with cerebral palsy? Please use back of this form.

Appendix B

Letter from Committee on Human Subjects in Experimentation



Office of the Vice President for Academic Affairs
Eudora Wetty Hall
P.O. Box W-1603
(601) 329-7142

Columbus, MS 39701

February 28, 1997

Ms. Donna Salvo-Foster c/o Graduate Program in Nursing Campus

Dear Ms. Salvo-Foster:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research provided the following condition is met.

You are cautioned to make a clear distinction in your definitions of cerebral palsy and developmentally delayed to indicate that they are two different medical problems.

I wish you much success in your research.

Sincerely,

Susan Kupisch, Ph.D.

Vice President

for Academic Affairs

SK:wr

cc: Mr. Jim Davidson

Dr. Mary Pat Curtis

Dr. Rent

Appendix C

Permission to Use Jalowiec Coping Scale

PERMISSION IS HEREBY GRANTED TO

Donna Salvo Foster

TO USE THE JALOWIEC COPING SCALE IN A STUDY OR PROJECT

Anne Jaloure

ANNE JALOWIEC, RN, PHD
LOYOLA UNIVERSITY OF CHICAGO

DATE: 7/2/96

Appendix D Informed Consent

Informed Consent

Investigator: Donna Salvo Foster, R.N., B.S.N., CCRN

Graduate Nursing Student, Mississippi University for Women

The purpose of this study is to investigate the coping strategies of mothers of children who are developmentally delayed. This study will involve completing a Demographic Data Questionnaire and the Jalowiec Coping Scale, which will take about 30 minutes. Participation in this study is voluntary; you are not required to participate in it. Should you choose to participate in this study, the investigator will answer any of your questions about the study. The following information should be reviewed before you agree to participate in this study:

- *All information that you give will be kept confidential. Your name will not be used; you will only be identified by a number.
- *You have the right to refuse to continue with the study, or remove yourself from the study at any time, up to data analysis.
- *Your participation or nonparticipation in this study will not affect your child's care.
- *Your information will be collected on the Demographic Data Questionnaire and the Jalowiec Coping Scale and kept in a locked cabinet in the researcher's home. *The results of this study will be reported as a group in a graduate student thesis and may be published in a journal article or be presented at a professional meeting.

Permission to conduct this study has been granted by the Institutional Review Board (IRB), the agency committed to protecting the health, welfare, and privacy of research subjects at the University of Mississippi and Mississippi University for Women.

I have read and understand the above information. I agree to participate in this study.

Signature of Participant	Date
Witness	Date
Witness	Date

Appendix E Occupation by Type of Group

Occupation by Type of Group

	Support Group (n = 21)		Non-Support Group $(n = 18)$			
Occupation						
	fx	%	fx	%		
Family Nurse Practictioner	1	05				
Registered Nurse	2	09	1	06		
Teacher	2	09				
Social Worker	1	05				
Lab Technician	1	05				
Data Entry Programmer	1	05				
Licensed Practical Nurse		-4-	1	06		
Hair Stylist	1	05				
Secretary	2	09	3	17		
Bank Teller	1	05				
Nursing Assistant			3	17		
Sales	2	09				
Teachers Assistant	1	05				
Receptionist	1	05	2	10		
Waitress	1	05	1	06		
Cashier			2	10		
Cafeteria/Deli Worker	1	05	1	06		
Factory Worker			1	06		
Chicken Plant			1	06		
Housewife	3	14				
Housekeeper			2	10		