The efficacy of parent counseling and support groups on stress levels, self-esteem and degree of coping of parents of developmentally delayed or handicapped infants involved in an infant intervention program

Rebecca Marie LaFountain
College of William & Mary - School of Education

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The efficacy of parent counseling and support groups on stress levels, self-esteem and degree of coping of parents of developmentally delayed or handicapped infants involved in an infant intervention program

LaFountain, Rebecca Marie, Ed.D.

The College of William and Mary, 1987
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UMI
THE EFFICACY OF PARENT COUNSELING AND
SUPPORT GROUPS ON STRESS LEVELS, SELF-ESTEEM AND
DEGREE OF COPING OF PARENTS OF DEVELOPMENTALLY DELAYED OR
HANDICAPPED INFANTS INVOLVED IN AN
INFANT INTERVENTION PROGRAM

A Dissertation
Presented To
The Faculty Of The School Of Education
The College Of William And Mary In Virginia

In Partial Fulfillment
Of The Requirements For The Degree
Doctor Of Education

by
Rebecca Marie LaFountain
December 1987
THE EFFICACY OF PARENT COUNSELING AND
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by

Rebecca Marie LaFountain

Approved December 1987 by

Fred L. Adair, Ph.D.

Sally Al Franek, Ph.D.

Kevin E. Geo^Lroy, Ed.D.

Chairman of Doctoral Committee
Dedication

This report is dedicated to my family members, Terry, Michael and Elizabeth, who so often adjusted their schedules in order to accommodate my educational endeavors.
ACKNOWLEDGMENTS

Deep appreciation is extended to Dr. Fred Adair, Dr. Sally Franek and Dr. Kevin Geoffroy for serving on my committee. Dr. Kevin Geoffroy, the chairman of my committee, devoted much time and understanding during this project.

Warm thanks are offered to Dr. David Keenan, Dr. Roger Smith and Brenda Northern of the Chesapeake Community Services Board for guiding me in the development of a practical and worthwhile study. Dr. Keenan's supervision of the study is also much appreciated.

This study could not have been conducted without the support of Phyllis Jackson, Coordinator of the Virginia Beach Infant Stimulation Program, her staff members and program participants. Jeanne Burger was also invaluable in her counseling role. A special thanks is extended to all of them.

Finally, thanks and appreciation are offered to my parents who instilled in me the importance and joy of education.
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Chapter I
Introduction

Justification for Study

Parenting in general is a stressful situation with some of the common stressors being physical, psychological, and financial (Miller and Myers-Walls, 1983). Other stressful aspects of parenting that have been identified are loss of personal freedom (Burnside, 1978) and less time and companionship in marriage (Barnett and MacDonald, 1976). Having difficult children or children with handicaps appears to be an additional stressor in an already stressful situation (Drotar, 1967).

Parenting a child with a chronic condition is particularly stressful. According to Mattsson (1972), a chronic condition can be associated with a relatively normal life span despite impaired physical or mental functioning. Periods of acute exacerbations requiring intensive attention may occur.

According to Bailey and Bricker (1984), prior to the late 1960s, few programs existed for the generally delayed, retarded, or multiply handicapped infant or preschool child. The sole option available for severely handicapped children was a residential facility which was primarily custodial. With the advent of the Handicapped Children's Early Education Act of 1968 the number of programs available for the handicapped preschoolers increased substantially.
In the 1960's, programs were designed that reflected the equal educational opportunity goals of the War on Poverty. These programs were designed to help low income parents become better teachers of their young children in order to increase the children's probable success in school (Halpern, 1984). During the 1970's, programs expanded significantly and often emphasized strengthening the development of the relationship between infants and their parents. Since the mid 1970's, new program purposes and populations have been identified.

These programs recognize the family's role in managing the child with a chronic condition. Travis (1976) points out that the child's prognosis depends upon the family's ability to provide the care.

According to Wikler (1981), the chronic illness never goes away. The child may have periods of improvement but always remains less than a normal healthy child—a situation which produces recurrent grief for parents as the child moves through different developmental stages at a delayed level or restricted pace. The child's limitations impact the whole family, affecting such aspects as family relationships, family activities and goals, increased tasks and time commitments, finances, housing adaption, social isolation, medical and educational concerns, along with chronic sorrow.
In the research by McCubbin and Patterson (1983), it was found that while some families grow weaker in response to the crises of a chronically ill child, and in some cases, the family system is dissolved, other families appear to grow stronger and thrive. Their studies were based on the work of Hill (1958) who concluded that the level of vulnerability that families have to crisis depends on the interaction of the stressor with existing resources and with family perception.

In studies of families of children with cerebral palsy (McCubbin et al., 1981) or myelomeningocele, (Nevin et al., 1981), it was found that the pile-up of stressors, known as chronic strain, (such as increased financial burdens, increased caretaking tasks, and increased marital or sibling conflict) were judged by most families as the most problematic in their overall struggles of coping with the chronic condition. The health and well being of the child with the chronic condition can be affected by this chronic strain.

In studies of cystic fibrotic children, the accumulation of chronic stressors had an averse effect on the child's health as measured by a decline in the functioning of the child's respiratory system (Patterson & McCubbin, 1983.) The pile-up of unresolved strains also contributes to undesirable characteristics in the family environment. Studies of families with a myelomeningocele child (Nevin et al., 1981), who had an accumulation of family life strains,
were characterized by more conflict than families experiencing less stressors.

It was also found that when families have insufficient resources, the demands are not adequately met and this contributes to increased conflict in the family (McCubbin, 1981). In their studies of families of cerebral palsy children, less conflict was found in families who had the resources of (a) self-esteem; (b) open, effective communication; (c) mutual assistance and support; (d) problem solving abilities; (e) physical and emotional health; and (f) a sense of mastery over events they were experiencing.

Venters (1980) concluded that a family's effort to redefine a situation as a "challenge," as an "opportunity for growth," or to "endow the situation with meaning" appears to play a useful role in facilitating the family coping, and eventually adaption.

Much evidence of dysfunctional coping by parents of children with chronic conditions is found in the literature. Many parents overprotect their children (Spock & Stedman, 1966), or one parent overprotects and forms a coalition with the child which excludes the other parent (Travis, 1976). Some parents withdraw from social involvement (Meyer & Crothers, 1953) while other parents cope by denying the reality of the chronic illness and reject their child by withdrawing emotional support or ignoring his or her special needs (Patterson & McCubbin, 1983).
According to Dodge (1976), some parents display anger and resentment about the situation and toward the child and/or toward each other. Increased incidence of marital discord or divorce has been reported in cases where each parent blames the other.

Functional methods of coping have also been evidenced in the literature. Darling (1976) observed parental "activism" which involved efforts to "normalize" the child's life, to initiate services for the child, and in some instances, to bring about societal changes which would be more supportive of families with handicapped or chronically ill children.

Some parents found it helpful to rely on a broad philosophical or religious perspective to make the event of their child's illness understandable to them (Chodoff, Friedman and Hamburg, 1964).

Parental efforts to find sources of social support form the community for the child (Arnold, 1976) and in the whole family (Nevin, 1979) have been emphasized as important coping behavior for living with chronic illness. Medical staff, psychologists and social workers are some of the most important sources of support.

McCubbin and Patterson (1983) assessed the coping behaviors of parents employed to successfully manage family life when one of the children has a chronic illness. They used a self-reporting questionnaire--Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin &
Cauble, 1979)—with over 500 families who have a child with cystic fibrosis, cerebral palsy or myelomeningocele. Three coping patterns used to manage family life when a child has a chronic illness were identified:

1) Maintaining family integration, cooperation, and an optimistic definition of the situation.

2) Maintaining social support, self-esteem, and psychological stability.

3) Understanding the medical situation through communication with other parents and consultation with medical staff.

Researchers in the field (Compton & Gallaway, 1974; Hoff, 1978; Parad, 1966; Golan, 1978) recommend intervention programs designed to promote prevention of additional adverse effects of chronic illness and focus attention on current functioning and utilization of problem solving techniques. The parents need to understand the medical situations, to manage the disturbing changes in family relationships, and to develop a range of coping strategies.

According to Cobb (1976), one of the most useful forms of problem solving seems to be social support. One type of social support he advocates is that of a "helper" (either professional or nonprofessional) who offers the family encouragement and understanding as well as information which helps family members to feel understood, capable, and a sense of belonging to a larger group (network support).
The purpose of this study was to investigate the effects of parent support groups and group counseling on the stress levels, self-esteem, and degree of coping on parents of developmentally delayed or handicapped infants who were involved in an infant intervention program.

Statement of the Problem

Families of pre-school children who are handicapped, no matter what the particular condition is, all experience similar stressors. The family's perception of the condition along with available resources, seem to determine the family's level of coping.

In their studies, the researchers came up with similar conclusions as to what would facilitate functional coping for families with a child who has a chronic condition. Social support was prevalent throughout the literature (Darby, 1979). Social support is a preventive function, whose goal it is to alleviate or moderate present and future crises. Compton & Gallaway (1974), are supporters of preventive interventions with these families.

The research cited here clearly explains the needs of families with children who have chronic conditions and demonstrates the need for parents to have support systems available to them.

Although the literature does not specifically call for parent support groups or group counseling, it advocates interventions that will offer these parents support and
strategies to help them cope with the stresses availed to them due to having a child with special needs.

This study describes two types of parenting programs, specifically a support group model and a group counseling model, that offered parents affective intervention in order to help them cope with their children's needs and to better accept their children, or at least the services that their children need. In addition, this study investigated the impact that each of these models had on the stress levels, self-esteem and degree of coping of parents of developmentally delayed or handicapped infants who were involved in an infant intervention program.

Theoretical Rationale

The birth of a handicapped child into a family is usually an unexpected and traumatic experience. It is similarly devastating for parents to discover that their infant, who initially appeared to be normal, is actually developmentally delayed. The loss of the normal, healthy child and all of the accompanying dreams and expectations that the parents hoped for, evokes a multitude of emotions, often commencing with shock and disbelief and progressing in an uneven manner through fear, guilt, resentment and sorrow (Meyerson, 1983). This process closely parallels the five stage grieving model determined
by Kubler-Ross in her work with dying patients and their families.

According to Kubler-Ross (1969), the terminally ill patient moves through a series of stages in an attempt to cope with the catastrophic news.

**First Stage: Denial and Isolation**

Initially, patients experience denial when confronted with their terminal illness. Denial functions as a buffer and allows the patients time to collect themselves and eventually utilize their defenses.

**Second Stage: Anger**

When the denial and shock can no longer be maintained it is replaced by feelings of anger, rage, envy and resentment. The patient asks, "Why me?" The anger is displaced on people and the environment at random.

**Third Stage: Bargaining**

Those patients who have been unable to accept the unexpected news in the initial phase and have been angry at people in the second stage often decide to try an alternate approach. They make an agreement, which is often a bargain with God, in hopes that they may postpone their death.

**Fourth Stage: Depression**

When the dying patient can no longer deny the truth
about the illness, anger is replaced by depression. This depression is deepened by the impending losses such as people, one's career and material goods.

**Fifth Stage: Acceptance**

If a patient has been able to work through the first four stages, the patient will reach a point of feeling neither anger nor depression. The patient will have grieved the impending losses and the patient's interests wane. In this stage the patient finds peace and contemplates the coming end with quiet expectation.

Movement through these stages is rarely smooth; progression from one stage to the next is often followed by regression to an earlier stage. Fixation at a particular stage may also occur (Meyerson, 1983).

The importance of research in the stages of grief resolution for the dying person is in what we learn about the entire process of recovery for the family. Families experience similar phases prior or following the death of a family member (Figley, 1983).

Kubler-Ross (1969) states that at first family members cannot believe that the patient has a terminal illness and go from doctor to doctor seeking a less severe diagnosis. They may seek reassurance that this is not true from fortune tellers and faith healers. They may take expensive trips to famous clinics and physicians in search of the
answer to what they want to hear. Only gradually do they face up to the impending truth.

Just as the ill family member goes through a stage of anger, likewise, the family members will blame the physicians and other medical professionals. They may criticize the care that the patient is getting out of anger and out of envy for being unable to care for the family members themselves. The anger is often accompanied by guilt for being unable to make up for the past or unaccomplished activities.

When these feelings of anger, resentment and guilt are worked through, the family will then go through a period of preparatory grief. This phase is easier for the family members when they are able to express their grief. The more they are able to grieve before death, the less unbearable it becomes after the death.

At the time the patient has reached the stage of a acceptance, it is unusual for the family members to have accepted their loved one's impending death. This period can be the most heartbreaking for them because they do not understand that a dying person who has found peace and acceptance in dying must become detached from the world, thus, becoming isolated from family members.

The recovery-reorganization process varies according to families and individuals as well as the situations surrounding the family member's death and is typically cyclical rather than linear (Figley, 1983).
According to Meyerson, when viewing Kubler-Ross' work from a broader perspective, grieving is a universal phenomenon, something that everyone experiences as a result of the loss of something of importance.

Meyerson further extends the Kubler-Ross concept to include families of handicapped infants. The families of a handicapped infant experiences loss when discovering that the infant is disabled or developmentally delayed. At first, the family members may deny or reject the diagnosis and search for a less severe one, more commonly known as shopping behavior. Prolonged denial is more likely when the child's physical appearance is normal.

Denial often turns into anger as almost everyone and everything is attacked in the parent's world. Physicians, other medical professionals, friends, relatives and God are often blamed. Unconscious anger and resentment toward the handicapped child is often present. These emotions, because of their unacceptability, are replaced by guilt—a self-directed anger that if they had possibly done something differently, things would be all right. Depression sets in when parents realize that their bargaining tactics are not effective. Helplessness and hopelessness often accompany the depression. The depression, however, signals that the parents are finally confronting the fact that their child is disabled and the implications of their child's condition.
Eventually, Meyerson believes, most parents are able to accept the reality of their child and the impending limitations. Some parents see their child as special and their destiny as a special calling to contribute to the world. Most parents reconcile themselves to the situation and are able to seek out the necessary community resources that provide services to their child as they try to cope effectively with the situation.

Kubler-Ross (1969) states that, "We cannot help the terminally ill patient in a really meaningful way if we do not include his family." She stresses the significant role that the family plays during the time of illness. Likewise, Meyerson (1983) says that while the birth of a handicapped child affects the feelings, attitudes and behavior, of all family members, the child's feelings, attitudes and behavior, including the child's self-concept, are influenced by the messages, both verbal and nonverbal, received by family members.

Counseling with the family members is not only beneficial to the patient but is also helpful and necessary for family members themselves. Kubler-Ross points out that the more we can help relatives express their emotions, the more comfortable they will be. If family members can share their feelings together it will facilitate an easier acceptance of the loved one's death.
Likewise, the optimal development and management of the disabled child depends upon a supportive, competent family structure. This supportive family structure is also necessary for the well-being of all of the family members. The movement toward treatment of the family is consistent with the increasing emphasis in counseling on a systems approach (Fogarty, 1976).

In this study, an objective paper and pencil instrument was used to assess a parent's stage at the conclusion of the treatment period. Unlike the Q-sort methodology used by Metzger (1980) which relied on retrospective perceptions of patients and their spouses, this instrument assessed the parent's current experience. Therefore, results obtained from this objective instrument, which was administered to groups of parents, were statistically treatable and serve as a piece of evidence in the analysis of Kubler-Ross' stage theory.

Definition of Terms

As an assurance against ambiguity, the terms for the purpose of this research are defined as follows:

Counseling Group

Counseling groups are groups that focus on promoting actualization of parents as individuals, with the expectation that this would enable them to relate to the child's handicap in healthier and more constructive ways (Heisler, 1974).
**Developmentally Delayed**

Children are considered to be developmentally delayed when they are not developing at the same rate as their peers in areas such as cognitive, language, motor, and psycho-social development.

**Early Intervention**

A multidisciplinary approach for promoting growth in the areas of cognitive, language, motor, and psycho-social development in children with preacademic deficits.

**Efficacy**

Efficacy has two connotations: The overall effectiveness of a program and the measure of progress of an individual child. (Reynolds, Egan, & Lerner, 1983)

**Infant Intervention/Infant Stimulation**

Infant Intervention/Stimulation Programs are Early Intervention programs specific to children from birth to two.

**Preacademic Deficit**

Preacademic deficit is used broadly to designate any deficit in the cognitive, language, motor or psycho-social development areas (Reynolds, Egan, Lerner, 1983).

**Social Support**

Social support is a preventive function, whose goal it is to alleviate or moderate present and future crises (Cobb, 1976).
STEP

STEP (Systematic Training for Effective Parenting) is a parenting program that is based on Adlerian concepts and provides parents with counseling skills they can use with children.

Support Group

A support group is a "self-help" group whose goal is to offer the participants support, advice and understanding.

Research Hypotheses

This study investigated the effect that parent support groups and group counseling have on the stress levels, self-esteem, and degree of coping of parents of developmentally delayed or handicapped infants that were enrolled in an infant intervention program. Data was obtained on the parents who participated in support groups; on parents who received group counseling; and on parents who were not involved in any treatment (the control group). The following hypotheses were made:

1. There will be no significant differences between the self-esteem scores of those parents involved in treatment groups and those parents in the control group as measured by the Coopersmith Self-Esteem Inventory.

2. There will be no significant differences between the stress index of those parents involved in treatment groups and those parents in the control group as measured by the
Parenting Stress Index.

3. There will be no significant differences between the coping scores of those parents involved in treatment groups and those parents in the control group as measured by the Coping with Loss Scale.

4. There will be no significant difference between the U and P subscale scores (Used to Feel and Presently Feel) on the Coping with Loss Scale of those parents participating in this study.

Sample Description and General Data Gathering Procedures

The sample consisted of parents of developmentally delayed or handicapped infants who were involved in an infant intervention program in Virginia Beach, Virginia. The parents were randomly assigned to either the support group, the counseling group or the control group. Following the two months of intervention, the participants were administered the three following instruments: The Parenting Stress Index, The Coopersmith Self-Esteem Inventory, and the researcher's self-constructed coping with loss scale. The data was given to the researcher for scoring and statistical analysis.

Limitations

A number of limitations to the quality and generalizability of the findings stem from the procedures of this research. The most salient limitations are reviewed below.
Although the Coopersmith Self-Esteem Inventories are said to be the best known and widely used self-esteem measures and seem to possess enough reliability and validity to recommend their use in research, much of the research on the inventories was done on the Student Form, rather than the Adult Form.

All three of the measurement instruments were of the paper-pencil self-report type and relied on the informant's accuracy and memory for valid completion. The researcher had to rely on the exactness of the informant's perceptions of level of stress, self-esteem and degree of coping.

Since the parents were primarily Caucasian, married and middle class, the subject population limits applicability of the results. Also, the subjects were drawn from an infant intervention program in a select region (Southeastern Virginia) which could also limit the applicability of the results, however, since some of the families were military families, they allowed the researcher to obtain data which reflects a geographical diversity.

Ethical Considerations

The ethical guidelines established by the American Psychological Association and the American Association for Counseling and Development were strictly followed. Confidentiality and appropriate informed consent were the responsibility of the researcher. All test scores were
kept confidential and results were shared only with those participants who requested to see them.

Once the initial data was gathered, the alternate group formats were offered to all those participants who did not receive them during the experimental phase.
Chapter II
Review of the Literature

Chapter II surveys the major literature which relates to the topic under investigation. This chapter is organized into three parts:

1. Review of Kubler-Ross' Loss Theory.
2. Summary of relevant research involving the intervention on family members of infants who are developmentally delayed or handicapped.
3. Summary of research on affective intervention.

Review of Kubler-Ross' Loss Theory

Historical and Theoretical Overview of Kubler-Ross' Loss Theory

Kubler-Ross' Theory is based on her work with hundreds of dying patients which she conducted in order to assist four theology students of the Chicago Theological Seminary in a research project on "crisis in human life" beginning in 1965. Since these students considered death as the greatest crisis people have to face, it was decided that they would observe critically ill patients, evaluate the reactions of the people around them, and interview the dying. Thus, Kubler-Ross interviewed over two hundred dying patients for the study. These interviews were conducted in a hospital setting. Trained as a psychiatrist, Kubler-Ross believes, as Freud stated, that we cannot, in our unconscious minds, conceive of ourselves dying, therefore, death becomes a "bad act."
Another of her beliefs is that a psychiatrist, as a result of training, is able to accurately interpret a person's thoughts and actions in such a way as to become aware of the person's unconscious mind and is able to define inner reality better than the patient.

From this perspective, Kubler-Ross interpreted the thoughts and actions of dying patients and proposed the five stages through which individuals pass as a result of their impending death. Although Kubler-Ross uses the term stages, her work makes it clear that the stages are not actually ordered, but may last for different periods of time and possibly co-exist.

Kubler-Ross found that initially, patients will defend themselves against the information of their impending deaths by denying it to be true. When they are no longer able to deny the reality of death, they become angry and project their anger on the environment. Bargaining then results as the patients attempt to delay death. Depression, however, sets in as the patients begin to acknowledge their impending loss. After working through their depression, the patients await their death with a certain degree of quiet expectation, which is considered to be acceptance. Throughout the process, hope is ever present, according to Kubler-Ross.

Since Kubler-Ross' five stage theory was published in the late 1960's, professionals have been analyzing and challenging her work. According to Stephenson (1985), Kubler-Ross' data gathering techniques are in question. Not only was the
material gathered by Kubler-Ross, herself, and her seminary students, but there was not an independent gathering of data. Kubler-Ross' underlying assumptions of her study have also been challenged. Neither the definition of the unconscious nor the role of the psychiatrist as Kubler-Ross describe them are accepted by scientists and researchers outside of the psychiatric community. Stephenson cites an example where a nun was referred to Kubler-Ross for psychiatric treatment because she was "acting out her anger" by bothering the nurses. Stephenson points out that it is possible that she was responding appropriately to the lack of care of patients. The underlying assumption in referrals such as this is that anyone who questions the organization must need psychiatric help.

Kubler-Ross interprets the actions and emotions of her patients throughout her work. Stephenson raises the point that all of these interpretations may in turn reinforce her theory and that over time her stages are no longer hypotheses but rather a self-fulfilling prophecy.

Also in question, (Stephenson, 1985), are the conditions under which the data was gathered. The terminally ill patients whom Kubler-Ross interviewed were in no position to debate the interpretations of a psychiatrist and possibly did not want to cut off the relationship that developed with her. Similar to victims of thought reform, the terminal patients may find it very difficult to reject the psychiatric interpretation of his or her behavior (Lifton, 1975).
Further doubts are raised about the stages as described by Kubler-Ross, according to Stephenson, due to a lack of observable behavior patterns. For example, how does one know that the stage of bargaining exists, when according to Kubler-Ross it is usually done secretively?

Charmaz (1980) argues that a great deal of Kubler-Ross' work deals with patient management. She explains that each stage can be redefined to describe rational, direct and purposeful responses to the hospital environment. She hypothesizes that denial occurs when patients have not yet put together the cues about their impending death; isolation is the result of realizing that things are not quite right; anger is when they find out that everyone else knew about it before them; depression is the realization that there is so much to do and so little time; and acceptance occurs when they realize that nothing more can be done.

Schulz and Aderman (1974), in a review of the literature of stage theory, found that Kubler-Ross' theory is contradicted by the work of Hinton, who is also a psychiatrist. In his study of seventy dying patients, where he used nondirected interviews similar to Kubler-Ross', he found that depression was present in half of the patients throughout the last two months of their lives. He also reported that depression and anxiety increased toward the end of life, although anxiety wasn't as prominent, while Kubler-Ross maintains a final stage of acceptance. Hinton points out the effects of medication on the patients as an important factor while Kubler-Ross does not
account for this variable. Schulz and Aderman raise the question that although both researchers used the same gathering techniques, how does one account for the differences in their results? Hinton states that only 20 percent of his patients knew they were dying and another 20 percent knew death was probable while Kubler-Ross stated that all of her patients knew of their impending deaths. Did 60 percent of Hinton’s patients die in denial?

In another study cited by Schulz and Aderman, Lieberman used assessment devices, including the Bender-Gestalt test, the Draw-a Person test, a timed reproduction task and a projective test, and concluded that dying individuals were socially withdrawn, as a result of their attempts to deal with their decline in interacting with the environment. That which Kubler-Ross had clinically observed as depression has been identified as social withdrawal by Lieberman.

Metzger (1980) also attempted to use an objective assessment—a Q sort methodological study to assess the correspondence between the stage changes hypothesized by Kubler-Ross and the perception of the course of illness by seriously ill patients and their spouses. The implications for the validity of the Kubler-Ross theory were ambiguous. Factors which emerged did not reveal evidence of stages although pervasive feelings of hope may have masked any evidence of stages and the recall method used may not have been accurate enough to reveal stages.
In addition, Schulz and Aderman reviewed the work of Weisman and Kastenbaum, who used a technique called psychological autopsy to review eighty cases of patients with terminal illnesses. They concluded that dying patients either adopt withdrawal or energetic living behavior which they maintain until death.

Daniel Cappon (1959), from a psychoanalytical approach, contends that people essentially die as they have lived and use denial, withdrawal or repression in face of the threat of death. He disputes the idea that hope is always present.

Churchill (1979) argues that Kubler-Ross' stage theory attempts to impose a "quasi-medical model of dying" upon the patient, and essentially depersonalizes the process of death into "rationally-ordered scientific data." Pattison (1977) calls this approach by physicians as "exaggerated detachment" which allows the medical profession to remain emotionally protected from the human aspect of a person's dying.

Finally, Edwin Schneidman (1973) challenges Kubler-Ross' five definite stages by stating that his experiences lead him to believe there is a constant coming and going. "The emotional stages seem to include a constant interplay between disbelief and hope and, against these as background, a waxing and waning of anguish, terror, acquiescence and surrender, rage and envy, disinterest and ennui, and even yearning for death—all these in the context of bewilderment and pain."

Kubler-Ross also applies her stage theory to the family members and loved ones of the terminally ill (Kubler-Ross, 1969).
Others have applied the stage theory to other human crisis situations such as divorce (Sprenkle and Cyrus, 1983) and the birth of a handicapped child (Meyerson, 1983).

The idea that parents experience several stages of adjustment in coping with the birth of a handicapped infant has appeared in professional literature since the mid-1950s (Blacher, 1984). Blacher reviewed 23 studies in which researchers investigated the stages that parents of handicapped infants go through, one being that of Huber's (1979) adaption of Kubler-Ross' stages. The methods used by researchers to document the existence of stages were either: (a) references to a body of earlier literature or to a specific study in the area; (b) interview techniques involving parental descriptions of their experiences and behaviors; (c) observations based on either the author's own experiences or involvement with other parents of handicapped children; and (d) no mention of methodology of how the stages were derived.

Huber's (1979) work was that of the first methodology mentioned above. He based his hypothesis that parents of handicapped children go through stages on the work of Kubler-Ross but he did not present the use of any objective quantitatively-based instrument.

Critique of Kubler-Ross' Loss Theory

Although critiques have attempted to present evidence that challenges Kubler-Ross' stage theory, they have not been successful in disproving her theory. Some of the very
techniques for which Kubler-Ross has been criticized have been used by others, such as Hinton, to discount her theory. For example, the data gathering methods used by Kubler-Ross are challenged. However, very similar techniques were used by Hinton (Schulz and Aderman, 1974) in his research, and his conclusions are used in an effort to determine that Kubler-Ross' findings are not supported by other research. Likewise, Weisman and Kastenbaum's conclusion (Schulz and Aderman, 1974) that dying patients adopt either a pattern of withdrawal or activity which they maintain until death was based on a post hoc technique of psychological autopsy which is viewed just as skeptically, or more so, than the method used by Kubler-Ross.

Critiques, such as Schneidman (1973) have argued that rather than five definite stages, there is a wavering back and forth between the stages. Kubler-Ross also states that the stages are not necessarily sequential, which is found on page 138 of her book (Kubler-Ross, 1969), and therefore she is unfairly criticized. Unfortunately this statement does not appear more forcefully in an earlier part of her book (Groenwald and Bermansolo, 1979).

Supporters of Kubler-Ross contend that the criticisms of Kubler-Ross' work are not her fault, rather the problems are due to the ways in which others attempt to use what she has written (Stephenson, 1985). According to Groenwald and Bermansolo, there are those people who insist that all dying behavior must be seen as manifestations of the stage theory.
and it is cruel to dictate emotional hoops through which dying persons must jump.

Although the misuse of Kubler-Ross' findings can be criticized, along with the scientific rigor of her study, her work has contributed much to the awareness of death and dying and has offered a sympathetic approach to death and dying among the general public. It also appears that the American Public finds comfort in Kubler-Ross' prescription for successful dying which helps to lessen their fear (Stephenson, 1985).

While Kubler-Ross' studies can provide awareness and comfort to those facing death, or other crises, studies which are more scientifically designed need to be conducted in order to add more credibility to her work.

Methodological problems are also inherent in studies on stage development of parents of handicapped children according to Blacher (1984) upon reviewing 23 studies. Most of the research studies were based upon one family or small sample sizes. While some used observation, most used open-ended interviews. Blacher states that non-structured interviews may be relevant to the development of theoretical formulations, but at the same time they can be subjective and limit the generalization of the findings and the validity of the stages derived. A structured interview, on the other hand, would be less problematic.

Blacher continues that it would be useful to test some of the assumptions of stages of adjustments using some objective,
quantitatively-based instrument. This instrument would lend credibility to the stage theory as clinically and scientifically derived fact.

In this study, an objective paper and pencil instrument was used to assess a parent's stage at the conclusion of the treatment period. Unlike the Q-sort methodology used by Metzger (1980) which relied on retrospective perceptions of patients and their spouses, this instrument assessed the parents' present experience. According to Blacher (1984), a noted change in parental reaction indicates a movement from one stage to another. Therefore, results obtained from this objective instrument, which was administered to groups of parents, are statistically treatable and are analyzed in respect to Kubler-Ross' stage theory.

Summary of Relevant Research Involving the Intervention of Family Members of Infants who are Developmentally Delayed or Handicapped

Summary of Early Intervention Programs

According to Bailey and Bricker (1984), prior to the late 1960's, few programs existed for the generally delayed, retarded or multiply handicapped infant or pre-school child. The sole option available for severely handicapped children was a residential facility which was primarily custodial. With the advent of the Handicapped Children's Early Education Act of 1968 the number of programs available for the handicapped preschoolers increased substantially.
In the 1960's, programs were designed that reflected the equal educational opportunity goals of the War on Poverty. These programs were designed to help low income parents become better teachers of their young children in order to increase the children's probable success in school (Halpern, 1984). During the 1970's, programs expanded significantly and often emphasized strengthening the development of the relationship between infants and their parents. Since the mid-1970's, new program purposes and populations have been identified. Although there is great variation among these programs in their focus and approach, their goals are quite similar. All attempt to provide the infant with the best possible opportunity for optimal development.

The parent-as-teacher model is currently the most common one used with handicapped infants (Bromwich, 1981). The model defines the parent as the primary teacher of the infant. The parent is taught by a teacher how to teach sequentially ordered developmental skills to the infant. The infant's development is assessed by the program's staff by using a behavior checklist that is usually derived from standardized infant developmental test. Evaluation studies of intervention with handicapped infants have shown that programs that involve parents in the educational process are more effective than those that do not (Bromwich, 1981).

In an attempt to examine how different types of intervention programs affect measures such as parent-child interaction, family stress, social networks and social support,
Moran (1985) interviewed 85 families of developmentally disabled infants enrolled in 23 programs in Massachusetts. She found that no one program type was clearly superior in all ways. However, whether services for developmentally disabled infants are offered in the client's home or in a center does make a difference for families. It was found that mothers who participated in home-based programs had more positive attitudes toward their infants than mothers participating in nonhome-based programs. When the former mentioned group of mothers were asked to describe their child, they noted more positive personality traits and more of the child's accomplishments. Mothers in home-based programs were said to seek child care advice from a relatively larger number of sources. Mothers of children in home-based programs evaluated their marriages as less stressful than those in primarily center-based intervention programs. However, mothers of children in center-based programs reported decreased homemaking stress. Center-based intervention was associated with larger social networks for mothers.

Child-related variables, such as type of handicap, were not significantly related to mothers' attitudes toward the child. Significant variables noted were the presence of other children in the family, maternal education, and the most significant variable being the type of intervention.

Halpern (1984) examined a study of Simeonson, Cooper and Scheiner (1982) in which they reviewed 27 early intervention programs serving biologically handicapped
infants and children. Almost all of the programs focused on cognitive and/or motor stimulation of infants either directly, with, or through parents.

The assessment of effects of interventions varied in focus: Ten studies focused on "age equivalence"; Seven studies focused on Intelligence Quotient/Developmental Quotient; Four focused on program-specific criteria; Two focused on behavioral frequencies; and five were not specific. Research designs also varied with statistical procedures used in 59% of the studies and statistical support for effectiveness reported in 48% of the studies. Some 93% of the studies reported clinical, or anecdotal, evidence of positive program effects on participating events. The authors explain that given small sample sizes, effects may not have been large enough to reach statistical significance, or significant effects may have occurred in domains not measured by the dependent variables chosen. Simeonson, Cooper and Schenner imply that so far there is not an adequate model of the processes that early intervention programs set in motion in families lives, and therefore of the effects these programs may be having. Halpern notes that Fitzgerald et al. (1980) state that the specific process of training parents of handicapped infants as therapists seems to have important broader effects on their psychological adjustment to their child's disability and to the altered family situation.

Halpern concludes that a growing body of anecdotal evidence suggests that early intervention is providing
valuable child-rearing support, yet there are discrepancies in the statistical effects due to limitations in research design, specifically problems related to sampling, lack of adequate measurement tools, and procedures.

Reynolds, Egan and Lerner (1983) surveyed the literature in an attempt to analyze the efficacy of early intervention on handicapped children and preacademic deficits. Although they cited studies from 1939 - 1982, the only one that they discuss involving handicapped infants in an early intervention program was that of the Heber's Milwaukee Project (Heber & Garber, 1975). This study was conducted with mothers with low socio-economic status and low I.Q. and their babies, who were at-risk for mental retardation. Standardized tests, such as Wechsler Preschool and Primary Scale of Intelligence, and other discrimination measures were used to evaluate the effectiveness of the program. The performance data from the standardized tests showed that experimental subjects did not show the relative decline in test scores as seen in the control group. Substantial positive differences in language development, learning performance and behavior between the two groups was shown.

Reynolds, Egan and Lerner recommended that the quality of research studies on efficacy should be refined, and that a greater number of both longitudinal and short term studies are needed.

Bailey and Bricker (1984) made similar recommendations following a study of the efficacy of thirteen early
intervention programs for handicapped children under the age of six. Their study was based on studies published between the years of 1974 and 1983 that had the provision of objective outcome data on child change in terms of general program impact. Although thirteen programs differed in intervention approaches, models, and staffing patterns, the programs similarly focused on the acquisition of functional skills and behaviors across major areas of development (i.e., language, motor, cognition, self-care, social).

The role of parents varied in relation to the study of the program. In home-based models, parents were seen as primary interventionist, while in center-based programs parents'involvement varied. A variety of evaluation designs and analytical procedures were used. All programs reported positive outcomes as indexed by a variety of child change variables. Although a consistent pattern of child performance gains suggests the positive impact on the enrolled children, the authors point out that interpretation through aggregation of outcomes is not justified due to the variability of the programs and that methodological limitations reduce the reliability of the reported data.

Critique of the Early Intervention Studies

The early intervention program concept, although still in its infancy, has made great strides in the period since its conception, less than 20 years ago. In the last decade, both the number and quality of programs and services for young
handicapped children have greatly increased. Overall the programs' effectiveness have been positive, however, these results have been generally based on anecdotal evidence rather than statistical results. Although the quantity and quality of research in the efficacy of early intervention programs is improving, it needs to be further developed and refined. One weakness inherent in the studies presented here is the difficulty in comparing programs of varying designs and results from different means of measurement. A more valid and reliable study would be one where identical programs are evaluated using the same standardized instruments to measure identical variables. Both short-term and longitudinal studies are needed.

The ability to find or develop identical programs would be difficult since early intervention programs are inherently nonstandardized due to the population which they serve. In most programs, teachers attempt to respond to the immediate concerns of the children and parents. This flexibility and responsiveness are strengths of the programs, yet they are weaknesses when it comes to the area of research.

According to Halpern (1984), current early intervention programs are reaching only a small percentage of families who could benefit from the services. Until more evidence as to the strengths and weaknesses of the programs is available, it will be difficult to advocate these programs and compete successfully for the dwindling government funds. The groundwork for gathering this evidence should be laid now.
Development of statistical techniques to deal with small sample sizes and differential effects within treatment groups is needed along with the development of instruments that measure variables appropriate to this population.

This study used statistical techniques, rather than anecdotal support, to measure the effect on treatment groups which have small sample sizes. In addition, this study examined changes in the parents, rather than the impact that the intervention program has on the children, which has traditionally been the focus of research. Much has been done with parents from an instructional approach but little has been done in the affective realm. That which has been done in terms of affect has been primarily one on one and has been presented in the form of case studies which offer anecdotal evidence rather than statistical results. This study examined parental changes resulting from affective intervention in group settings which allowed for statistical measurement.

**Coping with Loss Scale**

At the present time there are no instruments being marketed that measure the degree of coping with loss that parents are experiencing in response to their child having a developmental delay or handicap. No such instrument exists in respect to other crises, such as death of a loved one, either. Such an instrument could be used to assess whether intervention strategies are effective in helping parents accept their child's handicap, or at least in acknowledging
that their child needs services in order to maximize the child's potential.

The researcher has devised such an instrument and used the five stages of grief that was developed by Kubler-Ross (1969) as the basis. Huber (1979) has adapted the five stage theory to predict the stages that parents of handicapped children experience and the researcher has developed statements that are descriptive of each of the stages. Fifty statements (ten from each of the five categories) are in random order on the inventory and the parents are to indicate which statements they identify with. They differentiate those statements that represent how they presently feel; how they have felt previously, but no longer do; and those feelings that they have not experienced. The overall score represents the stage with which they most identify: denial, anger, bargaining, depression, or acceptance.

Seventy-five items were originally developed (twelve for each of the five stages) and rated by six doctoral students in the Counseling program at the College of William and Mary as to their appropriateness for each stage. The inventory was revised with the twelve best items for each of the categories and it was sent to Elisabeth Kubler-Ross to rate in order to lend validity to the scale. Unfortunately, Dr. Kubler-Ross wrote back stating that due to her involved schedule, she was not able to assist any students in their research projects. The scale was then sent out to twelve professionals who have trained under Kubler-Ross throughout the United States and
who are members of the group, Friends of Kubler-Ross. The inventory was again revised to include the ten items from each of the five scales which best represented the stages according to the seven members of the Friends of Kubler-Ross group who responded.

The inventory is a pencil-paper test whose original form was administered to six parents involved with the Chesapeake Community Services Board's Infant Intervention Program during a pilot study held in March 1986. It took no more than fifteen minutes for the parents to complete the survey.

Research on Affective Intervention

Although the literature supports a need for affective intervention of the parents of handicapped infants, (Huber, 1979), the research reveals that most of the interventions have been one on one. Case studies reveal anecdotal evidence that a combination of infant stimulation and emotional support for the parents has had favorable results.

One such case is that described by Tynan, Asp, Serper and Emory (1985), and involves a couple and their infant with a genetic defect. It became apparent in the first few months after the child's birth that the family needed help in coping with a sitter and she reported loss of sleep, depression, and loss of appetite. The father expressed helplessness. College student volunteers intervened by
providing both stimulation for the baby and emotional support for the family for a period of 14 weeks. By the end of the intervention period, the child had achieved minimal gains. The mother, however, more frequently left the child with a sitter and began evaluating programs to enroll him in. Her mood had improved greatly, she was sleeping more regularly and had returned to work full time. The father saw improvements in the child's behavior. At the 39 month follow up there was little improvement in the child's condition, however, both parents had continued in their careers, their marriage was intact and stable, and neither reported major problems. The mother had given birth to a healthy baby girl who was 3 months old.

Other researchers, such as Mintzer, Als, Tronick and Brazelton, (1985), combine the results of individual case studies in order to make general conclusions about areas of study. Mintzer et al. (1985) followed five families with handicapped infants over a period of two years in order to understand how the parents handled their feelings, particularly their self-esteem. Although the purpose of their developmental research approach was not initially therapeutic, the research team developed a sequence of interventions which were both instructional and of a supportive, affective nature. These interventions were made in the home and in laboratory sessions and the kind of treatment used varied according to an awareness of the family systems.
Their findings suggest that parents of handicapped infants need empathy and help specific to their problems and to their level of self-esteem. In four of the five families, it was found that a form of balancing reciprocity for coping developed between the spouses. Contrary to the general belief that marriages break up with the birth of a child with a defect, the couples were brought closer together over time, although there were periods of marital disorganization when each parent was at a different stage of adapting. It was found that when both parents experienced their infant as a negative extension of themselves, they lacked the ego strengths of flexibility and adaptability. The parents' self esteems improved when they experienced their infants as separate persons rather than as negative extensions of themselves and when they began to identify positive qualities in their infants.

Although some noteworthy conclusions have been drawn from this study, the sample base was small and there were no controls. Moran's work (1985) represents a much larger sample of parents of handicapped infants. In her study of 85 families of disabled infants in early intervention programs in Massachusetts, she found that the mothers who participated in support groups evaluated the sources of their stress differently than those not active in support groups and evaluated their stress as less intense. The husbands of the women who were active in the support groups also reported their stress as less intensive than husbands of women who
did not participate in support groups, although neither group of husbands were personally involved in the support groups.

In a more controlled study, Furuno, O'Reilly and Ahern (1985) examined the transdisciplinary teamwork with parents of premature infants. Three study groups were formed to test three intervention models in a regional perinatal center. Family interventions consisted of direct intervention with infants while parents were taught activities appropriate to the babies' needs. Parent intervention involved educational intervention with the parents to promote interaction, attachment and caregiving skills, along with emotional support. The control group involved all the medical and nursing expertise available in a perinatal unit.

Results suggest that infants in treatment groups have done much better than those in the control group. Mother-infant interaction scores as measured at 3 months on the Nursing Child Assessment Feeding Scales were done only for the two intervention groups. In total scores and mother's sensitivity to cues, the parent intervention group did significantly better than the family intervention group. At nine months, all three groups were tested and both intervention groups surpassed the control group on all items except cognitive growth fostering. Significance was achieved in overall interactions (p=.03), response to distress (p=.02), and clarity of cues (p=.02), with sensitivity to cues approaching significance (p=.06).
While research is limited in the area of controlled studies of parent counseling groups for parents of infants who are disabled, there have been studies that researched the efficacy of parent counseling groups of parents of handicapped elementary school children. A study by Giannotti and Doyle (1982) researched the efficacy of Parent Effectiveness Training of parents of learning disabled children in fourth, fifth and sixth grades, and they used a pretest-posttest experimental design. The treatment model was the Parent Effectiveness Training program (Gordon, 1970). Significant differences at the .01 level were found between the treatment and control groups on all five attitudes measured by the Parent Attitude Survey (Hereford, 1963). Parents in the experimental group reported more confidence in themselves as parents, greater awareness of the effects of their behavior on children, a greater feeling of acceptance of their children, a greater understanding of their needs and a greater willingness to trust their children than did the parents in the control group. Similar results were obtained on the Children's Report of Parental Behavior Inventory (CRPBI) (Schaefer & Bell, 1965) where statistically significant differences were obtained on all four scales. The children whose parents were in the experimental group perceived their parents' behaviors as more accepting to them as individuals, less critical and rejecting of them, less neglectful of their needs and more willing to spend time with them, and more
understanding of them than did children of parents in the control group.

The results of the Piers-Harris Children's Self-concept Scale (1969) also showed a statistically significant difference at the .01 level. The children whose parents were in the experimental group showed a significantly greater increase in self-assessed self-concept than the children of those in the control group.

Similar positive results were achieved in studies that used the Systematic Training for Effective Parenting (STEP) program on parents of learning disabled elementary school children. In one study, Hammett (1981) examined the effect of 50 parents' participation in a STEP group on their child rearing attitudes and on the self-concepts of their learning disabled children. Treatment consisted of parent group sessions, which included didactic presentation, group discussions and homework assignments, designed to increase parents' democratic child rearing attitudes and understanding of their children. The study was an experimental design which used a pretest-posttest. The measurement used was the Parent Attitude Survey (PAS) (Hereford, 1963). On the posttest measures, multivariate analysis of variance yielded significant differences between the experimental and control group parents and their children. Parents in the STEP group scored higher in acceptance and trust subscales and their children scored higher on personal-self and social-self subscales.
Williams, Omizo and Abrams (1984) also yielded similar results in their study of the effects of STEP on parental attitudes and locus of control on their learning disabled children. The participants consisted of 38 volunteer parents of children classified as learning disabled. The PAS was also used in this study to examine the parents' attitudes about child rearing. The Locus of Control Inventory for Three Achievement Domains (LOCITAD) (Bradley, Stuck, Coop, & White, 1977) was used to measure locus of control orientation. It measures perceived acceptance of responsibility for both success and failure in the domains of intellectual activities, physical activities, and social activities. Each parent was randomly assigned to either the experimental groups or control groups. All parents were given the PAS one week prior to treatment and one week after treatment. The children were given the LOCITAD at approximately the same time. The STEP program which is based on the theory that behavior is purposeful and goal directed, with the primary goal for the child being to achieve a sense of belonging, was the treatment model.

Multivariate analysis of variance (MANOVA) indicate that experimental group parents were significantly different from control group parents; they were more accepting and trusting after participation in the STEP program. They also perceived their own behavior as more of a causative factor in their children's behavior. The findings suggest that the treatment group parents' attitudes had changed, implying that
the environment provided by the parents can be more positive. The MANOVA results indicated significant differences between the experimental and control group children on the LOCITAD. The results revealed that the experimental group learning disabled children were more internal in the Success Social Domain and Success Physical Domain at the .05 level and more internal at the .01 level for the Failure Intellectual Domain and Failure Physical Domain. The authors conclude that if future studies replicate their findings, it would mean that the learned helplessness pattern of many learning disabled children can be averted and remediated.

Critique of Research on Affective Intervention

Tynan, Asp, Serper and Emory (1985) and other such case studies support the need for a combination of infant stimulation and parental counseling. The evidence, however, has been largely anecdotal and based on small sample sizes. The treatment interventions have been primarily individualized to the families' needs, such as in the study by Mintzer et al. (1985), thus, offering few controls.

Those controlled studies such as Furuno, O'Reilly and Ahern (1985) provide evidence for the need of a combination of interventions which will treat both the infants and parents and have an affective component as part of the parental intervention. Since there have been so few controlled studies of systematic parent groups with an affective approach for parents of handicapped infants, it is necessary to look at
parental programs that have been successful with parents of handicapped or disabled elementary school children. Both the Parent Effectiveness Training Model (Giannotti and Doyle, 1982) and the Systematic Training for Effective Parenting Model (Hammett, 1981) appear to hold promise for assisting both parents and their LD children. In those studies, parental attitudes had been changed. This is consistent with the conclusion of Carlson and Russell's study (1982) that one of the strengths of Systematic Training for Effective Parenting is the ability of parents to register changes in their own attitudes. Since these studies have reported an increase in parental acceptance, the effectiveness of STEP classes for parents of learning disabled children is similar to that of the parent therapy groups run by Heisler (1974). He sees parent therapy groups as focusing on promoting actualization of parents as individuals, with the expectation that this would enable them to relate to the child's handicap in healthier and more constructive ways. Williams, Omizo and Abrams (1984) state that being in the group was an important factor in addition to participating in the STEP program and recommend that future studies be designed that have the control group parents participate in groups other than the STEP intervention. Further they recommend: the investigation of the long-term efficacy of the STEP program; the use of other affective and cognitive variables; and using STEP programs with parents of other special children.
This study took the work of Williams, Omizo and Abrams (1984) one step further by testing out some of the additional components that they have recommended. One of their recommendations was the use of the STEP program with parents of other special children. Their particular study dealt with special children in their elementary school years. This study applied the STEP model to parents of infants who were enrolled in an infant intervention program. A review of the literature fails to reveal research on the STEP program with parents of infants. In a comprehensive review of a number of STEP groups, (Dembo, 1985), the parents had children at least three years of age. Although the STEP manual does not indicate specifically for what age the program is written, it is strongly implied that the child is able to communicate verbally since parents are given directives that assume that the child can speak (Dinkmeyer and McKay, 1976).

In this study, the STEP model was adapted to include parent-infant interaction material from the works of Brazelton (1974) in order to meet the needs of parents of infants. Also, in line with the recommendations of Williams, Omizo and Abrams that other affective variables be used with the program, this study incorporated additional affective exercises into the STEP program. (The adapted version is outlined in the appendix.)

Use of the adapted version of STEP provided an affective intervention approach with the parents which helped them to
develop acceptance and trust of their infants while the infants continued to participate in the stimulation program. The group setting allowed for statistical measurement, rather than anecdotal report alone.
Population and Sample

Parents that have infants who are developmentally delayed or handicapped and enrolled in the infant intervention program located in Virginia Beach, Virginia participated in the study. At that time, there were about fifty infants enrolled in the program. The majority of the parents were caucasian and of middle class status. About 75% of the parents were married, their mean age was approximately 26, and about 33% of the parents had children other than the one enrolled in the early intervention program.

Upon signing up for the program in June of 1987, the parents were informed that during the regular school months (Sept. - May) they would be expected to participate in a parent support group while their children were receiving their therapy. They were notified that in addition to the regular support group procedure, a counseling group format would also be used. The parents were informed that the counseling groups were being added this year in order to try out a variety of parenting group approaches and were being done in conjunction with a dissertation study. The researcher's name, university affiliation and adviser's name was given. Consent was received from the parents to be assigned to a group, to participate in the study, and to complete three questionnaires at the close of the
study. The participants were informed that if they chose not to attend the sessions or participate in the questionnaires (all or in part), that it would in no way affect the services provided to their children. The parents were told that when the project was completed they would be offered the alternative treatment and that it would also be available to each participant's spouse.

Treatment Procedures

Intervention and treatment groups, including the support groups and counseling groups, are described as well as the control group.

Support Groups

Sixteen of the parents were randomly assigned to participate in support groups which met once a week over a period of eight weeks. These groups were led by the Infant Intervention Parent Coordinator. The primary goal of these groups was to offer emotional support to the parents in a nonthreatening atmosphere. The support groups were structured as self-help groups where individuals could feel free to bring up concerns and the group members would offer advice and support to that person. The topic for each group meeting depended on the concerns and needs of the group members at that time.

Counseling Groups

Sixteen of the parents were randomly assigned to participate in group counseling once a week for eight weeks.
They were led by a professional counselor who has had experience in group counseling. The primary objective of the groups was to offer parents a safe, warm environment where they could discuss feelings and concerns regarding themselves in their parenting role. Secondarily, the groups offered a place where the parents could learn new skills in regard to parenting in general and in respect to parenting a child who is handicapped or developmentally delayed.

Although the groups were based on the Systematic Training for Effective Parenting (STEP) model, which has a didactic component, the model was adapted to include parent-infant interaction concepts (Brazelton, 1974) and also included a therapy component that focused on promoting actualization of parents as individuals, with the expectation that this would enable them to relate to their child's handicap in healthier and more constructive ways (Heisler, 1974). (The group outline can be found in the appendix.)

Control Group

The sixteen parents who were assigned to the control group received no treatment although their children were involved in the infant intervention program as were the infants of the parents in the treatment groups. Measurements on the control group were gathered at the end of the summer session since routinely the parent component is not offered in the summer. This was done so that parent
intervention would not be withheld from any parent during the regular academic calendar.

Ethical Safeguards and Considerations

The study was conducted in accordance with the ethical standards established by the American Psychological Association and the American Association for Counseling and Development. Procedures as outlined by the Human Subjects Research Committee of the College of William and Mary were also adhered to. Confidentiality and appropriate informed consent was the responsibility of the researcher. Written consent forms are on file for all subjects. All test scores will remain confidential and the results shared only with the individual participant if requested. After the initial data was gathered, the alternate group formats were offered to those who did not experience them in the fall.

Instrumentation

The following three instruments were used in this study:
The Coopersmith Self-Esteem Inventory, The Parenting Stress Index and the researcher's self-constructed Coping With Loss Scale.

The Coopersmith Self-Esteem Inventory (Adult Form)

The Coopersmith Self-Esteem Inventories were constructed by Stanley Coopersmith (1981) and intend to measure "the evaluation a person makes and customarily maintains with regard to himself or herself." The questionnaires present statements for the respondent to indicate whether the item...
is "like me" or "unlike me". They are said to be among the best known and widely used self-esteem measures (Johnson, Redfield, Miller and Simpson, 1983). They are brief, easily scored, reliable, stable and have an impressive amount of information bearing on construct validity.

Research has shown that the Coopersmith questionnaires converge with other self-report measures on self-esteem. The Adult Form was adapted from the School Short Form for use with persons over fifteen years of age. The language and situations were modified to make them more meaningful to adults. The total score correlation of the School Form with the Adult Form exceeds .80 for three samples of high school and college students. Well over 100 studies on reliability and validity have been conducted, most of which have been conducted on school aged children. In a study by Spatz and Johnson (1973) Kuder-Richardson reliability estimates obtained coefficients of .81 for grade 5, .86 for grade 9, and .80 for grade 12. Data are insufficient for the short form, but in one study of college students, Bedeian, Geagied and Zmud (1977) reported KR20s of .74 for males and .71 for females. They also computed test-retest reliability estimates and reported coefficients of .80 for males and .82 for females. Again, substantial research has been done on the validity of the scale but primarily on the student population.

Taylor and Reitz (1968) reported a correlation of .45 between the Coopersmith Self-Esteem Inventory and the California Psychological Inventory Self-Acceptance Scale. Divergent
validity was examined by correlating Coopersmith Self-Esteem Inventory scores with scores on the Edwards and Marlowe-Croune social desirability scales and obtained coefficients of .75 and .44 respectively.

The Coopersmith Self-Esteem measures do possess enough reliability and validity to recommend their use in research (Patterson, 1985). This questionnaire shares problems in common with measures of self-esteem and there are cautions when used clinically: the subscales' differential validity needs to be established; guidelines for using the Lie Scale needs to be provided; and the cutoff values need to be justified. Sewell (1985) states that the Coopersmith Self-Esteem Inventory's applicability for research purposes seem virtually limitless, and the scale can be highly recommended for this specific purpose.

The Parenting Stress Index

The Parenting Stress Index is a screening and diagnostic assessment technique designed to yield a measure of the relative magnitude of stress in the parent-child system. Concurrent validity is demonstrated since test scores are positively correlated with alternate measures of the same construct such as with the State-Trait Anxiety Scale (Jenkins, 1982) where a significant (p<.001) correlation (.84) was found with Trait Anxiety and (.71) State Anxiety.

Mash's studies (1983) used behavioral observations which provided strong concurrent validity data for the Parenting
Stress Index in relation to parents and hyperactive children. In a supervised-task situation, negative behaviors in the hyperactive sibling dyad were highly correlated (.60) with the Child Domain Stress score of the Parenting Stress Index. Zakreski (1983) examined the relationship between Parenting Stress Index scores, marital status, full-term births and infant development as measured by the Bayley Infant Development Scales at 3 and 6 months. The Parenting Stress Index scores for the Child Domain, Mother Domain and Total Scores were all significantly correlated (p<.001) with the Bayley at both 3 and 6 months postpartum. Zakreski also examined infant development (Bayley scores) in relation to a division of her sample into high, medium and low stress groups. An analysis of variance indicated a significant difference (p<.01) among the groups, with an orderly decrease in mean Bayley scores from the low stress to high stress group.

Discriminant validity was demonstrated in numerous studies such as the following: Lafiosca (1981) found that the Parenting Stress Index was able to correctly identify 100% of the parents of normal children in her study and 60% of the parents of children seen at a child development clinic when the ninetieth percentile of the Parenting Stress Index Total Stress Score was used as a cutoff. Briston (1982) studied the effects of perinatal coaching on mother-infant interactions, using the Parenting Stress Index as one dependent variable. Significant group and the control group of mothers (at the p<.01 level) in the Total Stress scores and the three Domain scores. Kazak
(1983) utilized the Parenting Stress Index in a study that examined family stress and social support in families of children with Spina Bifida versus matched comparison families and reported significantly higher scores for the Spina Bifida group on the Depression, Competence, and Situational Stress. Total maternal stress for the combined samples was found to be positively correlated (.41) (p<.001) with a general measure of mental health, the Langner Symptom Checklist.

Alpha reliability coefficients were determined for each subscale, each domain, and the total score. The reliability coefficients range in magnitude from .62 to .70 for the subscales of the Child Domain and from .55 to .80 for the subscales of the Parent Domain. The reliability coefficients for the two domains are .89 and .93 respectively and .95 for the Total Stress Score. Numerous studies support these reliability figures such as the following:

Burke (1978) administered the scale to 15 parents visiting a pediatrics clinic and obtained a Spearman rank-order coefficient of .817 and .706 for the Child and Parent Domains, respectively, indicating a significant (p<.01) relationship over a three week interval. Abidin (1982) sampled 30 parents in a pediatrics practice and obtained Pearson correlations of .63 for the Child Domain, .91 for the Mother Domain, and .96 for the Total Stress score over a three month period. Similar results were found by Zakreski (1983) over three months in a study of 54 parents in the relationship between parent stress, marital stress, and infant development.
Coping with Loss Scale

The initial item pool consisted of 75 items that were developed by the researcher. The items were then rated as to their relevance to each stage of the grief process by six Friends of Kubler-Ross, professionals who have been trained by Kubler-Ross in the loss model and who serve as consultants and support group leaders in the area of grief and loss. The ratings and suggestions made by them were used to make revisions and derive the fifty items that make up the scale. Each of the five stages is represented by ten items.

The original scale was field tested with six parents of children enrolled in the infant intervention program in Chesapeake, Va. in a pilot study held March - May 1986. The parents' mean score prior to the treatment was 3.34 on a scale of 1-5, which represents the bargaining stage. The parents' group mean score following the treatment was 3.54 which represents a positive progression toward stage four—the depression stage. The level of significance was not established. The respondents found the instrument easy to use.

Research Design

This study used a Posttest-Only Control Group Design. According to Campbell and Stanley (1966), this is an experimental design where the participants are assigned to treatment groups randomly in some systematic, predetermined way. Measurements are taken only at the conclusion of the treatment.
This design controls for: History, Maturation, Testing, Instrumentation, Regression, Selection, Mortality, Selection-Maturation Interaction, and Interaction Effect of Testing. It may not control for Interaction of Selection & Treatment and Reactive Effects of Experimental Arrangements.

This design is depicted in this way:

\[
\begin{align*}
R & \times 01 \\
R & \times 02 \\
R & \times 03 \\
R &= \text{Randomization} \\
X &= \text{Treatment} \\
O &= \text{Testing}
\end{align*}
\]

Specific Null Hypotheses

The present study investigated the effect that parent support groups and group counseling have on the stress levels, self esteem, and degree of coping of parents of developmentally delayed or handicapped infants that are enrolled in an infant intervention program. The following hypotheses, stated in the null form, were made:

1. There will be no significant differences between the self esteem scores of those parents involved in treatment groups and those parents in the control group as measured by the Coopersmith Self-Esteem Inventory.

2. There will be no significant differences between the stress index of those parents involved in treatment groups and those parents in the control group as measured by the Parenting Stress Index.
3. There will be no significant differences between the coping scores of those parents involved in treatment groups and those parents in the control group as measured by the Coping with Loss Scale.

4. There will be no significant difference between the U and P subscale scores (Used to feel and Presently feel) on the Coping with Loss Scale of those parents participating in this study.

**Statistical Analysis**

In this study, the independent variable was the type of treatment that the parents received while the dependent variables were: the level of stress of the parents, the self-esteem of the parents, and the degree of coping with loss of the parents.

Since the \( n \) in each of the cells was 16, a non-parametrical analysis was used to determine whether the various groups differed on one or more of the dependent variables. Specifically, the Mann-Whitney U test was used since it can be used to determine whether the distribution of scores of two independent samples differ significantly from one another. If U is statistically significant, it means that the "bulk" of scores in one population is higher than that in the other population. It does not require assumptions about the shape of the underlying distributions. Confidence levels were prescribed at the \( p < .05 \) level of significance.
Summary of Methodology

This study was conducted to determine the effect that parent support groups and group counseling have on the stress levels, self-esteem, and degree of coping of parents of developmentally delayed or handicapped infants that are enrolled in an infant intervention program. This was achieved by analyzing stress indexes, self-esteem scores, and levels of coping to determine whether the various groups differed on any of the variables. These scores were attained by standardized measures of parental stress, self-esteem and degree of coping with loss. Also, the two subscales on the Coping with Loss Scale were analyzed to determine whether any movement between stages of coping were indicated. The sample consisted of 48 randomly selected parents who had children involved in the Infant Intervention program in Virginia Beach, Virginia. The program's parent coordinator conducted the support groups while an experienced counselor facilitated the counseling groups. The hypotheses were statistically analyzed through the employment of the Mann-Whitney U Test.
Chapter IV

Results

The statistical findings of this study are presented in this chapter. All of the raw data can be found in Appendix D. This study investigated the effect that parent support groups and group counseling have on the self-esteem, stress levels and degree of coping of parents of developmentally delayed or handicapped infants that are enrolled in an infant intervention program. The findings are the result of data obtained from the following scales:

1) The Coopersmith Self-Esteem Inventory (Adult Form),
2) The Parenting Stress Index,
3) and The Coping with Loss Scale.

The results are presented and interpreted for each hypothesis.

Evaluation of Hypotheses

In order to assess statistically significant differences between the three groups due to the training of the experimental groups, post-treatment scores from each of the treatment groups (support and counseling) were compared with post-treatment scores from the control group using the Mann-Whitney U Test (which is also known as The Wilcoxon Rank Sum W Test.) The Mann-Whitney U Test was used since it tests the hypothesis that two independent samples come from populations having the same distribution. It does not
require assumptions about the shape of the underlying distributions, thus, the population does not need to be normally distributed.

Procedure

Mann–Whitney U Tests were run on the various combinations of groups in order to test for similar sample distributions of rank. It is the assumption of the Mann–Whitney U Tests that if the groups' distributions are the same, their sample distributions of rank should be similar. If one of the groups has more than its share of large or small ranks, there is reason to suspect that the two underlying distributions are different. 

Assumption: The groups all have similar distributions.

Level of Significance: The 5 percent significance level was chosen.

Presentation of Data

For each combination of groups, the mean ranks and number of cases are given. (The mean rank is the sum of the ranks divided by the number of cases.)

The entry printed under W is the sum of the ranks for the group with the smaller number of observations, and in the cases where there are the same number of observations, W is the rank sum for the group named first in the NPAR TESTS (Non-parametric) command.
The number that is identified as U is the number of times a value in one group precedes a value in the other group when the observations from the two samples are first combined and ranked from smallest to largest. U is the smaller of these two numbers.

The significance levels associated with U and W are the same. They are obtained by transforming the score to a standard normal deviate (Z) and the exact probability level based on the distribution of the score is also given.

**Null Hypothesis I**

There will be no significant differences between the self-esteem scores of those parents involved in treatment groups and those parents in the control group as measured by the Coopersmith Self-Esteem Inventory.

**Null Hypothesis I-1:** There will be no significant difference between the self-esteem scores of those parents in the control group and those parents in the support group.

**Results:** **SELF-ESTEEM: CONTROL GROUP BY SUPPORT GROUP**

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10.00</td>
<td>11</td>
<td>Control Group</td>
</tr>
<tr>
<td>13.00</td>
<td>11</td>
<td>Support Group</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>Total</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact 2-Tailed P</th>
<th>Corrected for Ties Z</th>
<th>2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>44.0</td>
<td>110.0</td>
<td>0.3000</td>
<td>-1.0903</td>
<td>0.2756</td>
</tr>
</tbody>
</table>
Conclusion: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis 1-2: There will be no significant difference between the self-esteem scores of those parents in the control group and those parents in the counseling group.

Results: SELF-ESTEEM: CONTROL GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13.73</td>
<td>11</td>
<td>Control Group</td>
<td></td>
</tr>
<tr>
<td>11.46</td>
<td>13</td>
<td>Counseling Group</td>
<td></td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact 2-Tailed P</th>
<th>Corrected for Ties Z</th>
<th>2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>58.0</td>
<td>151.0</td>
<td>0.4585</td>
<td>-0.7845</td>
<td>0.4327</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis 1-3: There will be no significant difference between the self-esteem scores of those parents in the support group and those parents in the counseling group.
Results: SELF-ESTEEM: SUPPORT GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.05</td>
<td>11</td>
</tr>
<tr>
<td>9.50</td>
<td>13</td>
</tr>
<tr>
<td>24</td>
<td>Total</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact 2-Tailed P</th>
<th>Corrected for Ties 2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>32.5</td>
<td>176.5</td>
<td>0.0218</td>
<td>-2.2654</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is rejected since the observed level of significance is smaller than the established .05 level of significance. There appears to be a significant difference between the self-esteem scores of those parents in the support group and those parents in the counseling group. The mean ranks of 16.05 for the support group and 9.50 for the counseling group are given. This suggests that when the scores from both groups were combined and ranked from smallest to largest and then the ranks summed and divided by the number of cases, that self-esteem scores for the support group were ranked higher more often on the average than the self-esteem scores of the counseling group. It appears that self-esteem scores were significantly higher in the support group than in the counseling group.
Null Hypothesis II

There will be no significant differences between the stress index of those parents involved in treatment groups and those parents in the control group as measured by the Parenting Stress Index.

Null Hypothesis II-1: There will be no significant difference between the stress index of those parents in the control group and those parents in the support group.

Results: STRESS: CONTROL GROUP BY SUPPORT GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.00</td>
<td>11</td>
</tr>
<tr>
<td>11.00</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact 2-Tailed P</th>
<th>Corrected for Ties 2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>55.0</td>
<td>132.0</td>
<td>0.7477</td>
<td>-0.3612</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis II-2: There will be no significant difference between the stress index of those parents in the control group and those parents in the counseling group.
Results: STRESS: CONTROL GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.73</td>
<td>11 Control Group</td>
</tr>
<tr>
<td>14.85</td>
<td>13 Counseling Group</td>
</tr>
<tr>
<td>24</td>
<td>Total</td>
</tr>
</tbody>
</table>

Exact Corrected for Ties

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>2-Tailed P</th>
<th>Z</th>
<th>2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>41.0</td>
<td>107.0</td>
<td>0.0821</td>
<td>-1.7671</td>
<td>0.0772</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis II-3: There will be no significant difference between the stress index of those parents in the support group and those parents in the counseling group.

Results: STRESS: SUPPORT GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.91</td>
<td>11 Support Group</td>
</tr>
<tr>
<td>15.54</td>
<td>13 Counseling Group</td>
</tr>
<tr>
<td>24</td>
<td>Total</td>
</tr>
</tbody>
</table>

Exact Corrected for Ties

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>2-Tailed P</th>
<th>Z</th>
<th>2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>32.0</td>
<td>98.0</td>
<td>0.0218</td>
<td>-2.2895</td>
<td>0.0221</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is rejected since the observed level of significance is smaller than the established .05 level of significance. There appears to be a significant difference between the stress index of
those parents in the support group and those parents in the counseling group. The mean ranks of 8.91 for the support group and 15.54 for the counseling group are given. This suggests that when the scores from both groups were combined and ranked from smallest to largest and then the ranks summed and divided by the number of cases, that stress indexes for the support group were ranked lower more often on the average than the stress indexes of the counseling group. It appears that stress indexes were significantly lower in the support group than in the counseling group.

**Null Hypothesis III**

There will be no significant differences between the coping scores of those parents involved in treatment groups and those parents involved in the control group as measured by the Coping with Loss Scale.

**Null Hypothesis III-1:** There will be no significant difference between the coping scores of those parents in the control group and those parents in the support group.

**Results:**

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th>Exact 2-Tailed P</th>
<th>Corrected for Ties 2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.55</td>
<td>11</td>
<td>1.0000</td>
<td>-0.0328</td>
</tr>
<tr>
<td>11.45</td>
<td>11</td>
<td></td>
<td>0.9738</td>
</tr>
</tbody>
</table>

Total cases: 22
Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis III-2: There will be no significant difference between the coping scores of those parents in the control group and those parents in the counseling group.

Results: COPING: CONTROL GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13.64</td>
<td>11</td>
<td>Control Group</td>
</tr>
<tr>
<td>11.54</td>
<td>13</td>
<td>Counseling Group</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Total</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact</th>
<th>Corrected for Ties</th>
</tr>
</thead>
<tbody>
<tr>
<td>59.0</td>
<td>150.0</td>
<td>0.4940</td>
<td>-0.7247</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

Null Hypothesis III-3: There will be no significant difference between the coping scores of those parents in the support group and those parents in the counseling group.

Results: COPING: SUPPORT GROUP BY COUNSELING GROUP

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13.32</td>
<td>11</td>
<td>Support Group</td>
</tr>
<tr>
<td>11.81</td>
<td>13</td>
<td>Counseling Group</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Total</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>Exact</th>
<th>Corrected for Ties</th>
</tr>
</thead>
<tbody>
<tr>
<td>62.5</td>
<td>146.5</td>
<td>0.6085</td>
<td>-0.5215</td>
</tr>
</tbody>
</table>
Conclusions: The null hypothesis is not rejected since the observed level of significance is larger than the established .05 level of significance.

**Null Hypothesis IV**

There will be no significant difference between the U and P subscales (Used to Feel and Presently Feel) of the Coping with Loss Scale.

**Results:** COPING: USED TO FEEL SCALE BY PRESENTLY FEEL SCALE

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20.24</td>
<td>35</td>
<td>Used to Feel Subscale</td>
</tr>
<tr>
<td>50.76</td>
<td>35</td>
<td>Presently Feel Subscale</td>
</tr>
<tr>
<td></td>
<td>70</td>
<td>Total</td>
</tr>
</tbody>
</table>

Corrected for Ties

<table>
<thead>
<tr>
<th>U</th>
<th>W</th>
<th>2-Tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>78.5</td>
<td>708.5</td>
<td>-6.2758</td>
</tr>
</tbody>
</table>

Conclusions: The null hypothesis is rejected since the observed level of significance is smaller than the established .05 level of significance. There appears to be a significant difference between the two coping subscales. The mean ranks of 20.24 for the Used to Feel scale and 50.76 for the Presently Feel scale are given. This suggests that when the scores from both scales were combined and ranked from smallest to largest and then the ranks summed and divided by the number of cases, that coping scores on the Presently Feeling scale were ranked higher more often on the average than the coping scores...
on the Used to Feel scale. It appears that Present Feeling scores were significantly higher for the group than the Used to Feel scores.

Summary

Statistical analysis of post-test scores from the experimental groups and control group using the Mann-Whitney U Test indicate that:

1) No statistically significant difference was found in the self-esteem scores between those parents in the control group and those parents in the support group, nor between those parents in the control group and those parents in the counseling group. However, a statistically significant difference was found between the self-esteem scores of those parents in the support group and those parents in the counseling group. It appears that self-esteem scores were significantly higher in the support group.

2) No statistically significant difference was found in the stress indexes between those parents in the control group and those parents in the support group, nor between those parents in the control group and those parents in the counseling group. However, a statistically significant difference was found between the stress indexes of those parents in the support group and those parents in the counseling group. It appears that stress indexes were significantly lower in the support group.
3) No statistically significant difference was found in the coping scores between those parents in the control group and those parents in the support group; between those parents in the control group and those parents in the counseling group; nor between those parents in the support group and those parents in the counseling group.

4) A statistically significant difference was found between the Used to Feel subscale and the Presently Feel Subscale on the Coping with Loss Scale.
Chapter V
Summary, Conclusions, Discussion, and Recommendations

This chapter presents a summary of the research. Conclusions based upon the analysis of data are presented as well as a discussion of the implications of these conclusions. Recommendations for future research are suggested.

Summary

The literature indicates that families of preschool children who are handicapped, no matter what the condition is, all experience similar stressors. The loss of the normal, healthy child and all of the accompanying dreams and expectations that the parents hoped for, evokes a multitude of emotion, often commencing with shock and disbelief and progressing in an uneven manner through fear, guilt, resentment and sorrow. This process closely parallels the five stage grieving model determined by Kubler-Ross in her work with dying patients and their families. This study was based on this theory of loss and recognized that the parents may be in the process of grieving at various stages. One of the measurements in the study was used to attempt to assess movement of the parents among the loss stages. It was designed to produce statistically treatable results that could serve as a piece of evidence in the analysis of Kubler-Ross' Stage Theory and to discern at which of the following stages a parent is grieving.
At first, the parents may deny the child's diagnosis and search for a less severe one. Denial often turns into anger which is often directed at medical professionals, other family members, relatives, friends and God. Unconscious anger and resentment toward the handicapped child is often present. This anger is often replaced by guilt—a self-directed anger. Family members may attempt bargaining tactics but depression sets in when it is realized that these tactics are useless. Helplessness and hopelessness often accompany depression. The depression, however, signals that the parents are finally confronting the fact that their child is disabled and the implications of their child's condition. Eventually, most parents are able to accept the reality of their child's impending limitations and they are able to seek out the necessary community resources that can provide services to their child as they try to cope effectively with the situation. The family's perception of the condition, along with available resources, seem to determine the family's level of coping.

Research demonstrates the need for parents of young handicapped children to have support systems available to them. It advocates interventions that will offer parents support and strategies to help them cope with the stresses availed to them due to having a child with special needs.

One such model is the Infant Intervention Program which had its conception in the 1970's. Although there is great variation among the programs in their focus and
approach, they all attempt to provide the infant with the best possible opportunity for optimal development. This is often promoted through the use of the parent as the primary teacher of the infant. The parent is taught by a teacher how to teach sequentially ordered developmental skills to the infant.

While most programs offer parents cognitive skills to help their children, not all programs offer an affective component to help the parents cope with their children. The literature supports a need for affective intervention for the parents but the research indicates that most of these interventions have been one on one. Case studies reveal anecdotal evidence that a combination of infant stimulation and emotional support for the parents has had favorable results. Similar results were found in studies that researched the efficacy of parent counseling groups of handicapped elementary school children although research is limited in the area of controlled studies of parent counseling groups for parents of handicapped or developmentally delayed infants.

This study used statistical techniques, rather than anecdotal support, to measure the effect that different parenting group interventions had on the self-esteem, stress levels, and degree of coping of parents of developmentally delayed or handicapped infants who were involved in an infant intervention program. The two types of parenting
interventions investigated included a support group format and a counseling group model.

The support groups met once a week over a period of eight weeks. These groups were led by the Infant Intervention Program's Parent Coordinator. These groups were structured as self-help groups and the primary goal was to offer emotional support to the parents in an atmosphere that was nonthreatening. The counseling groups also met once a week for eight weeks. They were led by an experienced counselor. The primary objective of the groups was to offer parents a safe, warm environment where they could discuss feelings and concerns regarding themselves in their parenting role. Secondarily, the groups offered the parents new skills in regard to parenting in general and specifically in respect to parenting a special needs child. The groups were based on an adaption of the Systematic Training for Effective Parenting (STEP) model.

The research design for this study was posttest-only control group design. The samples consisted of parents whose children were enrolled in an Infant Intervention program. Sixteen subjects were assigned randomly to each of the independent variables (the two treatment groups and the control group.) The dependent variables were self-esteem, stress, and coping and were assessed through three self-report instruments: The Coopersmith Self-Esteem Inventory (Adult Form), The Parenting Stress Index, and The Coping with Loss Scale.
Data were gathered at the close of the treatment period. The data were interval in nature and were analyzed using Mann-Whitney U Tests. A significance level of .05 was chosen for rejection of the null hypothesis.

The results of the research revealed that a significant difference was noted between the self-esteem scores of those parents in the support group and those parents in the counseling group and it appeared that self-esteem scores were significantly higher in the support group. Similarly, a significant difference was found between the stress indexes of those parents in the support group and those in the counseling group and it appeared that stress indexes were significantly lower in the support group. A significant difference was found between the two subscales on the Coping with Loss Scale among all the parents as a group and it appeared that the Present Feeling scores were significantly higher than the Used to Feel scores.

No significant impact was measured in self-esteem scores between those parents in the control group and those parents in the support group, nor between those parents in the control group and those parents in the counseling group. Similarly, no significant difference was found in stress indexes between those parents in the control group and those parents in the support group, nor between those parents in the control group and those parents in the counseling group. No significant difference was found between any of the groups in the coping scores.
Conclusions

There were no statistically significant differences between the treatment groups and the control group on the self-esteem, stress, and coping variables; however, the support group treatment appears to have helped parents in increasing their self-esteem and in decreasing their stress more so than the counseling group intervention. It does appear, also, that movement within the loss stages can be noted through the use of the Coping with Loss Scale.

Discussion

Research, particularly experimental studies, in the efficacy of infant intervention programs is very limited. Research efforts are often hampered by the inherent problems of comparing programs of varying designs, dealing with small samples, and overcoming the particular problems that this population presents. Thus, this study on the efficacy of parent counseling and parent support groups of parents of children in an infant intervention program represents a much needed effort in this developing field.

Although the parent support group and counseling interventions did not have a statistically significant impact on the self-esteem, stress and coping of the parents involved in the program, this study serves as a beginning point from which others can follow. The support group
model did appear to be superior to the counseling group format on the self-esteem and stress variables, and possible reasons for this are discussed below. A highly statistically significant difference was found on the Coping with Loss Scale which may offer some credibility to Kubler-Ross' Stage Theory.

The literature documents the difficulty of doing research with infant intervention programs due to the fact that they are not standardized. The programs' uniqueness and flexibility are strengths of the programs, yet they are weaknesses when it comes to the area of research. The diversity of the three infant programs in the local area served as a deterrent to setting up an inter-program research study. While one program was a home-based model, the other two were center-based but had very different philosophies, formats, and served different socio-economic levels. An intra-program study was conducted with the largest of the area infant intervention programs, yet small sample sizes remained a problem. This was further complicated by numerous absenteeisms which are an inherent problem with this particular population due to the diverse medical problems of the infants. Medical appointments, scheduled and emergency surgery, and isolation at home become routine for many of these infants. Transportation is sometimes a problem also.

Although both treatment groups and the control group initially had sixteen subjects, data was collected and
analyzed on only those parents who participated in at least seventy-five percent (six out of the eight) sessions. Only eleven subjects in the control group, eleven subjects in the support group, and thirteen subjects in the counseling group met this criteria. Since the \( n \) in each of the groups was so small, it was unlikely that each sample represented a normal distribution, therefore, a nonparametric test, specifically the Mann-Whitney U Test was used to analyze the data. Distribution tests, such as the Mann-Whitney U, are generally less powerful than their parametric counterparts and may not always detect true differences between two populations. This is because substitution of ranks for actual values loses potentially useful information. Therefore, a more sensitive test may have detected more significant differences.

Absenteeism not only hinders the collection of data, but it also prevents the formation of group cohesiveness. When various people are missing from the group each week, (especially if it is different ones each week), it is difficult for the group members to establish themselves in the group and for the group to function at an intimate, working stage. According to Yalom (1985), cohesiveness is one of the critical ingredients of counseling groups. It is not a surprise then, that the support group model had a more significant impact on two of the variables than the counseling group. Support groups, on the other hand, usually follow a self-help format and are structured more
openly to allow for a change in membership. Possibly a lack of consistency in attendance is not as crucial in the support group process.

In addition to the lack of cohesiveness caused when members miss a group session, the length of treatment is also reduced. Although the length of time required for treatment to be effective is variable and an individual matter, eight weeks of treatment (and for most subjects, six weeks of treatment) is very minimal. A longer intervention period is probably necessary in order to indicate significant differences.

Another variable that needs to be addressed is the group leader. The support groups were led by the Infant Intervention Program's Parent Educator with whom the parents have contact on a continual basis. The counseling groups were led by an experienced counselor who is employed as a counselor at another agency and who came into the program only to run these groups. Although the parents commented very highly about the counselor, (a few counseling group members even requested that their spouse sit in on the sessions), it is a possibility that the leader variable had more impact than expected.

One measurement that did have a lot of impact was the difference between the two subscales (Used to Feel and Presently Feel) on the Coping with Loss Scale. When the parents' two subscales were compared as a group, the difference was statistically significant and a probability
of .0000 was given, indicating that there was no possibility that the difference was due to chance. The U scores and P scores on the Coping with Loss Scale each represent the stage of coping according to Kubler-Ross at which the parent is. The raw data is presented in Appendix E. A score of 1 represents the denial stage; 2 represents the anger stage; 3 represents the bargaining stage; 4 represents the depression stage; and 5 represents the acceptance stage. In 31 of the 35 cases, a progression was made to a higher stage on the coping scale. In the four cases that did not show forward movement, their regression was minimal (all within .39 of a point on the five point scale.) Although critiques have attempted to present evidence that challenges Kubler-Ross' stage theory, they have not been successful in disproving it. Blacher, as well as others, has contended that it would be useful to test some of the assumptions of stages of adjustment using some objective, quantitatively-based instrument in order to lend credibility to the stage theory as clinically and scientifically derived fact. The Coping with Loss Scale might serve as a basis for developing such an instrument.

In summary, this research study appears to have been beneficial in that its results suggest that support groups are more helpful to parents of infants enrolled in infant intervention programs than counseling groups, particularly if the treatment is going to be time limited, and consistency in attendance is a problem. The Coping with Loss
Scale appears to be a viable protocol in the development of an objective, quantitatively-based instrument in order to lend credibility to Kubler-Ross' stage theory.

Recommendations for Future Research

Several suggestions for further research are recommended. First, since sample size was a factor that seemed to largely impact this study, a replication of this study with a larger sample would answer many of the questions that surfaced as a result of this research. A larger sample would better represent a normal distribution and would allow for the use of a more sensitive test such as MANOVA.

Second, the problem of absenteeism needs to be addressed. Although absenteeism probably cannot be eliminated altogether, possibly it could be minimized by:
1) offering the groups in the evening so as not to conflict with medical appointments;
2) having volunteers serve as respite workers in the event that the infant is sick;
3) providing transportation to those who need it. Measures such as these could aid in the building of cohesiveness among group members.

Third, the length of treatment should be extended longer than a period of eight weeks in order to produce a greater impact on the subjects.

Forth, through the use of different leaders, the leader variable was introduced. The leaders' abilities and personalities were difficult to account for in the dependent
variables. A research design to overcome this limitation would be to repeat the experiment with a leader who would facilitate both groups.

Fifth, the study could be replicated with parents whose children are enrolled in other infant intervention programs to check for generalizability of results with other groups. Since these subjects were predominantly white, middle class females, it would be interesting to investigate any differences among other groups based on race, socio-economic status and sex.

Sixth, a six-month follow up testing might reveal changes that are not so immediately evident and could yield information regarding consistency.

Seventh, a more prestigious design than the Posttest-Only Control Group Design used in this study, such as the Random Four-Group Design, (Solomon Squares) could be used since it overcomes some of the limitations of this current design.

Eighth, since the results are all based on data collected on self-report instruments, it is limited. It would be helpful to acquire behavioral data or changes acquired with unobtrusive techniques.

Ninth, the Coping with Loss Scale could be more widely field tested for reliability and validity. Some parents remarked that some of the questions provoked comments and possibly a format to include those could be added.
APPENDIX A

PARENTAL PERMISSION CONSENT FORM
PARENTAL PARTICIPATION CONSENT FORM

I,_____________________, understand that one component of the Virginia Beach Infant Stimulation Program is parental participation in a parenting group. I have been informed that this year, in addition to the regular parent support group, a parent counseling group based on the STEP (Systematic Training for Effective Parenting) model will be offered in conjunction with a dissertation study entitled, The Efficacy of Parenting Groups, conducted by Rebecca LaFountain. I have been told that she is a doctoral student at the College of William and Mary and that her advisor, Dr. Kevin Geoffroy is overseeing the study. I agree to be assigned to one of the parenting groups and and realize that if for any reason I choose not to continue to participate in the groups that this will no way affect the services provided to my child. I will also have the opportunity to participate in the alternate treatment at the close of the study.

I realize that at the end of the eight week sessions I will be requested to fill out three short questionnaires which I have the right to decline to do all or in part. I understand that the results will be kept anonymous and confidential and that my results will be interpreted to me on an individual basis if so requested. I understand that if I have any questions or concerns about my participation, I can contact Rebecca LaFountain at 494-0500 during the day or 485-4151 evenings and weekends; her clinical supervisor, Dr. David Keenan, Licensed Clinical Psychologist at 494-0500; or Dr. Kevin Geoffroy at 253-4434. I realize that the Infant Program's Coordinator, Phyllis Jackson is also available to me and can be reached at 496-0927.

______________________________  
signature

______________________________  
date
APPENDIX B

COPING WITH LOSS SCALE
Coping with Loss Scale

Below are lists of feelings and behaviors commonly experienced by parents of infants and young children who are developmentally delayed or handicapped. Please read each item and circle the one letter that show show you experience the feeling:

U = I used to feel this way, but I no longer do.  
P = I presently feel this way.  
N = I never have felt this way.

U P N I don't agree with the diagnosis that my child has received.

U P N If I work really hard with my child, my child will be normal.

U P N It appears that I have a long road ahead of me. Life is just so hard. Sometimes I wonder if it is worth it.

U P N I want to know why this is happening to me!

U P N If God will only pull us through this, my faith will be restored.

U P N When I look at my child, I am reminded of his or her problems and it's sometimes hard for me to see his or her good points.

U P N My baby was premature but will be fine when he or she catches up.

U P N I promise never to do anything harmful to my body again, if only my child will get better.

U P N I will do almost anything as long as my child will be all right.

U P N I enjoy my child very much.

U P N Some of these doctors don't know what they are talking about.

U P N I resent those people who didn't even take any precautions when they were pregnant and then didn't experience any problems.

U P N My child does many cute things.

U P N I promise that if my child is okay, I will be a better person.

U P N Some parents complain about trivial things such as their child's room being a mess. They don't know what it's like to have problems!

U P N I feel that dealing with my child has given me meaning in my life.

U P N I'm sure that I will be able to find a professional who will be able to give me the answers that I want to hear.

U P N My child is perfect. There's no doubt about it!

U P N People will find out that there is nothing wrong with my child.

U P N My child is just a little slow and will catch up in no time.

U P N I don't deserve this pain. I won't take this pain!

U P N If my child was okay, I would volunteer for a good cause.
UPN I feel very sad about my child's condition.

UPN If they can send a man to the moon, they can surely help my child.

UPN I am sorry that there are somethings my child may not be able to do but I will try my best to give my child opportunities in life.

UPN I get depressed when I try to figure out how I can help my child.

UPN My child requires a lot of extra care, but it is satisfying.

UPN I get so tired of people trying to tell me what to do and how to feel. They don't know what I am going through!

UPN Some days I wonder if I have the energy to meet my child's needs.

UPN I stay away from people who say something is wrong with my child.

UPN I found several people or organizations that will help my child.

UPN I am ready now to make the necessary arrangements for care for my child and to get involved again in things I used to enjoy.

UPN The family made a lot of adjustments. Our child is important.

UPN If I have faith, God will reward me and make my child better.

UPN If my child gets better, I'd volunteer to help parents like me.

UPN Sometimes when I think about my child, I just want to cry.

UPN My family has always been healthy. There can't be anything wrong!

UPN It's going to be tough dealing with our child. I don't know if our family can work through this. Do we have the energy?

UPN What kind of God would let this happen?

UPN I get angry at my child for his or her condition.

UPN Although I have many demands on me, I am content with my situation.

UPN My friends and family are accepting of my child.

UPN Even though I'm very tired, I must do what's needed for my child.

UPN I feel that things were kept from me by either my family or doctor.

UPN My child's difficulties are my spouse's fault.

UPN There can't be anything wrong with my child!

UPN If everything turns out okay, I'll make sure things are different.

UPN I feel depressed and feel I need some help coping with things.

UPN The truth hurts so badly. Will we be able to manage?

UPN I'll donate 10% of my salary to charity if everything is okay.
The Elisabeth Kubler-Ross Center
South Route 616
Head Waters, Va. 24442

Dear Dr. Kubler-Ross,

I am a doctoral student at the College of William and Mary and was so happy to learn that your practice is located in Virginia!

In my work with Chesapeake Mental Health, I consult with the Infant Intervention program and work with parents who are struggling with their infants who are either handicapped or developmentally delayed. It appears to me that they also go through stages of grief as they mourn the loss of the perfect child that they hoped for.

In my research, I discovered that although parents of handicapped infants are instructed in ways to deal with their infants, little is being done in a systematical approach to help parents deal with their emotions and concerns. For my dissertation, I plan to research group counseling for these parents. I also like to assess at what level the parents are at prior to and following this intervention. For this purpose, I designed a 50 point checklist for parents to indicate how they are feeling. The items are based on your five stage theory. In an effort to add validity to the checklist, I would like to ask if you would kindly read quickly through the items and number them depending on which stage you feel that the item represents (1-denial, 2-anger, 3-bargaining, 4-depression, 5-acceptance.)

I realize that you are a very busy person and I appreciate your time and consideration. I am also enclosing a small contribution to your fine organization.

Many Thanks,

Becky LaFountain

P.S. Please advise me of any other objective type scale that has been designed based on your theory.
The Elisabeth Kubler-Ross Center

Becky LaFountain
Chesapeake Mental Health Services
4715 Bainbridge Boulevard
Chesapeake, VA 23320

Dear Becky:

Thank you for your letter of August 25th which has arrived while Elisabeth is on a workshop and lecture tour in Europe and will not return until October. Therefore, she will not be able to fill out your checklist at this time.

I will enclose a newsletter and brochures so that you can bring yourself up to date with the happenings here.

Thank you for your interest and support.

Sincerely,

Page Lowry
Personal Secretary
to: Elisabeth K. Ross, M.D.

Enc.: Newsletter
Brochures

SOUTH ROUTE 616 • HEAD WATERS, VIRGINIA 24442 • (703) 396-3441
December 12, 1986

The Elisabeth Kubler-Ross Center
South Route 616
Head Waters, Va. 24442

Dear Dr. Kubler-Ross,

On August 25, 1986 I wrote to you asking you to review a checklist that I had developed to use with parents of children who are handicapped or developmentally delayed. On August 29, 1986, your personal secretary, Page Lowry, wrote me and informed me that you were out of the country at this time. I have enclosed our previous correspondences and have included a copy of the questionnaire that I ask you to kindly review. This will be of great help in my work with grieving parents of handicapped children which I do in my daily work and also toward my dissertation for my doctoral work at the College of William and Mary.

Also, could you kindly inform me if there are any objective type scales that have been developed based on your stages of grieving.

I know you are a very busy person and I appreciate your time and interest.

Sincerely,

Becky LaFountain

Becky LaFountain
Becky LaFountain
Chesapeake Mental Health Services
4715 Bainbridge Boulevard
Chesapeake, VA 23320

Dear Becky:

Thank you for your letter and for the questionnaire of December 12th.

I have learned all my stages of dying from the parents of handicapped or developmentally delayed children, although at that time nobody did a dissertation on it.

I have so much mail in my house that I could wallpaper every building on the farm with unanswered and requested material, so it will be impossible for me to fill out any questionnaires. Although I have promised to myself to answer 100 letters a day, I'm not able to help people with their research projects as my dying patients and parents of murdered children have my priority.

I wish you good luck however in your undertaking and a blessed and wonderful 1987.

Cordially,

Elisabeth

SOUTH ROUTE 616 • HEAD WATERS, VIRGINIA 24442 • (703) 396-3441
2901 Bara Way
Chesapeake, Va. 23323
March 30, 1987

Donna Santee-Oden
2604 Soapstone Dr.
Reston, Va. 22091

Dear Ms. Santee-Oden,

As a fellow friend of Elisabeth Kubler-Ross, I am eliciting your expertise and help in a research project I am conducting in the adjustment of parents of handicapped children toward their children's condition. A review of the literature suggests that these parents mourn the loss of the perfect child that they dreamed of and that they go through stages of grief, similar to those established by Elisabeth Kubler-Ross (Huber, Meyers, Wortis, etc.).

As a Mental Health Clinician who works with these parents, I have found that through counseling, these parents can more readily work through the stages of denial, anger, bargaining and depression, and finally they can begin to accept their child for who he or she is.

Unfortunately, many of the Infant Intervention programs that serve these families focus on the child, and few offer systematic counseling programs for the parents.

In the study that I am conducting for my doctoral dissertation in Counseling at the College of William and Mary, Williamsburg, Va., I will compare the levels of stress, self esteem, and acceptance of parents of handicapped infants who will be divided into three groups: a control group; a support group; and a counseling group.

Since I have been unable to locate an instrument that measures parents' level of acceptance of their children, nor was Elisabeth Kubler-Ross when I wrote to her, I am in the process of developing my own to use with parents of handicapped infants. I am turning to you experts in the field to help rate the items on the scale according to Elisabeth's stages of grief. Those items which are most similarly rated will be those that I will include in the checklist.

I am sure that you are familiar with the stages of grief and I am enclosing an article by Huber which adapts the stages to the parents of handicapped infants. Will you kindly look over the items and rate them as directed at the top of the instrument? I ask that you please return them to me by April 15, 1987 in the envelope provided. You may fill it out anonymously if desired.

Your help will be greatly appreciated by not only myself, but by those in the growing field of Infant Intervention. Also, if movement in stages is detected by this instrument, it will be another piece of evidence lending credibility to the stage theory.

Thank you for your time and effort. Sincerely,

Rebecca LaFountain, Ed.S.
COPING WITH LOSS SCALE — Preliminary Form

Below are lists of feelings and behaviors commonly experienced by parents of infants and young children who are developmentally delayed or handicapped. Please read each item and circle the letter that represents the stage of Kuhler-Ross' theory in which it most closely corresponds. DN=Denial AN=Anger B=Bargaining DP=Depression AC=Acceptance

DN AN B DP AC I don't agree with the diagnosis that my child has received.

DN AN B DP AC If I work really hard with my child, he or she will be normal.

DN AN B DP AC It appears that I have a long road ahead of me in terms of dealing with my child's condition. Life is just so hard.

DN AN B DP AC People ask me how I am doing. I don't understand what they are getting at.

DN AN B DP AC I want to know why this is happening to me!

DN AN B DP AC If God will only pull us through this, my faith in him will become restored.

DN AN B DP AC When I look at my child I am reminded of his or her problems and it's sometimes hard for me to see his or her good points.

DN AN B DP AC Although I don't understand why, I believe that God has chosen me to be one of those special parents to deal with a child with special needs.

DN AN B DP AC My baby was premature, but as soon as she or he catches up, my child will be just fine.

DN AN B DP AC I promise never to do anything harmful to my body again, if only my child will get better.

DN AN B DP AC I will do almost anything if only my child will be alright.

DN AN B DP AC I enjoy my child very much.

DN AN B DP AC Some of these doctors don't know what they are talking about.

DN AN B DP AC I resent those people who didn't even take any precautions when they were pregnant and then didn't experience any problems.

DN AN B DP AC My child does many cute things.

DN AN B DP AC If I am strong then all will be well.

DN AN B DP AC If my child comes through this okay I will be a better person.

DN AN B DP AC Some parents complain about trivial things such as their child's room being a mess. They don't know what it is like to have problems!

DN AN B DP AC I feel that dealing with my child has given me meaning in my life.

DN AN B DP AC I'm sure that I will be able to find a professional who will be able to give me the answers I want to hear.

DN AN B DP AC My child is perfect. There's no doubt about it.

DN AN B DP AC People will find out soon enough that there is nothing wrong with my child.
I get so angry at my child for his/her condition.

If I work with my child day and night, I'm sure he/she will develop normally.

Sometimes I get so angry, I wish terrible things about my child. But then I realize that it is just because I feel so helpless.

Although I have more demands on me now, I am content about the amount of time I have for friends and family.

Compliance with the Infant Intervention program will assure me that my child will be okay.

My friends and family are accepting of my child.

I feel numb in regard to my child's condition.

All that I want to do is sleep, but I know that I must begin to do what needs to be done for my child.

I feel that things were kept from me by either my doctor or my family.

My child's difficulties are my spouse's fault.

There can't be anything wrong with my child!

I've told myself that if everything turns out okay with my child, things will be different.

I need some help to cope with all that's been happening.

I am very depressed to know the truth about my child, but at least I can now begin to try to find out what I need to do.

The truth hurts so badly. Will we be able to manage?

I promise I will donate 10% of my salary to a charitable cause if my child comes through this okay.

Name (optional)

Comments:
APPENDIX C

DESCRIPTION OF TREATMENT SESSIONS
PARENT COUNSELING GROUP

Objectives:

1. The primary objective of the group is to offer parents a safe, warm environment where they can discuss feelings and concerns regarding themselves in their parenting role.

2. Secondarily, the group is a place where parents can learn new skills in regard to parenting in general and in respect to parenting a child who is handicapped or developmentally delayed.

Guidelines for the Group Leader:

1. It is suggested that the group is run as a process group, rather than an educational one, and that the first objective above, takes precedence over the second one.

2. The leader is asked that in the event that a parent brings up a concern that should be brought to the attention of the staff of the program, that the parent be encouraged to do so.

3. Suggested format for group:
   
   A. Leader asks parents how their week has been and processes any feelings or discussion that may result from the parent initiated content.

   B. Suggested weekly topic is discussed along with any feelings and concerns that emerge.

   C. Group leader recaps the session and gives out any homework for the following week.
Group Counseling Sessions

<table>
<thead>
<tr>
<th>Session</th>
<th>STEP Concepts</th>
<th>Supplementary Information</th>
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<td>1.</td>
<td>Introduction to STEP</td>
<td>Sharing of Parents' Concerns</td>
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<td></td>
<td>Purpose of Parenting Groups</td>
<td></td>
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<td>2.</td>
<td>Understanding Goals of Behaviors</td>
<td>Feelings about Parenting in general and specifically a child</td>
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<td>Understanding more about Your Child and You as a</td>
<td>with special needs</td>
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<td>Parent</td>
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<td></td>
<td>Feelings of Worth</td>
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<tr>
<td>4.</td>
<td>Communication: How to Listen to Your Child</td>
<td>Attending to Your Infant: Cues and Nonverbal Communication</td>
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<td>5.</td>
<td>Communication: Expressing Your Ideas and Feelings</td>
<td>Managing Stress</td>
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<td></td>
<td>Discipline that Develops Responsibility</td>
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<td>7.</td>
<td>Natural and Logical Consequences (Cont.)</td>
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<td></td>
<td>Developing Confidence and Using Your Potential</td>
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<td>8.</td>
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<td></td>
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<td>Lists of Resources</td>
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SESSION I

<table>
<thead>
<tr>
<th>STEP Concepts</th>
<th>Supplementary Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction to STEP</td>
<td>Sharing of Parents' Concerns</td>
</tr>
<tr>
<td>Purpose of Parenting Groups</td>
<td></td>
</tr>
</tbody>
</table>

1. Group leader will introduce self and explain the purpose and objectives of the group. The parents will be informed that the researcher is investigating different modes of parental intervention and that at the eighth session, the parents will be asked to fill out three short questionnaires.

2. Consent forms will be signed and any questions answered.

3. The group will discuss group rules, in particular confidentiality will be discussed.

4. The group leader will introduce the STEP Model and explain to the parents that the STEP philosophy of parenting will be used throughout the sessions but that supplementary information will be used to better meet their needs.

5. The STEP books will be handed out.

6. Parents will be asked to share a little about themselves, their children, how they got involved in the infant stimulation program and any concerns they have.

7. The leader will introduce the concept that parents often parent the way that they have been raised and that parents need to make the conscious choice if they want to use the same methods with their children. The parents will be asked to share how they were raised and feelings about that.

8. Recap. Homework: To read chapter one of the STEP Parent Handbook.
SESSION II

STEP Concepts

Understanding Goals of Behavior
Understanding more about Your Child and You as a Parent

Supplementary Information

Feelings about Parenting in general and specifically parenting a child with special needs

1. The members will be asked to share any concerns they may have.

2. Goals of misbehavior will be discussed (using chart on page 14 of STEP Parent Handbook.) Parents will be asked to give examples that illustrate these concepts and to share their accompanying reactions.

3. Feelings about parenting in general and specifically parenting a child with special needs will be elicited.

4. Recap. Homework: To read chapter two of STEP Parent Handbook and to pay attention to examples of their children's misbehavior and how it affects them (the parents.)
SESSION III

STEP Concepts

Encouragement: Building Your Child's Confidence and Feelings of Worth

Supplementary Information

Parent's Self-Esteem: Building Your Self-Concept

1. The members will be asked to share any concerns they might have.

2. The members will be asked to share any goals of misbehavior they recognized in their children and to identify how the behavior affected them. Ways they cope will be discussed.

3. Encouragement, a tool to build children's confidence and self worth, will be introduced by using the illustrations on pages 38 and 39 of the STEP Parent Manual.

4. Parents will be asked how the parenting of their children has affected their self esteem. What has helped to build their esteem and what they feel would help them to feel better about themselves will be shared.

5. Recap. Homework: To read chapter three of the STEP Parent Handbook and to try using encouragement with their children when appropriate.
SESSION IV

STEP Concepts Supplementary Information

Communication: How to Listen Attending to Your
   to Your Child Infant: Cues and
   Nonverbal Communication

1. The members will be asked to share any concerns they may have.

2. The members will be asked to share any experiences that they had using encouragement with their children.

3. The members will be asked to share any incidents that may have made them feel good about themselves.

4. The members will be introduced to the effective listening by looking at the charts on page 52 of the STEP Parent Handbook.

5. Since many of the infants in the program are too young to speak or incapable of it, parents will be directed to be aware of nonverbal cues that the child gives them. This can help parents enjoy some of the rewards of parenting because often the parents are not aware of the small nonverbal cues that their infants give them. Parents will be asked to share examples of these cues. Some examples are:
   - The child turning toward the parent as the parent walks away or out of the room.
   - The child attempts to imitate what parent is doing.
   - The child smiles.

6. Recap. Homework: To read chapter four of the STEP Parent Handbook and to try out effective listening and/or be aware of nonverbal communication with their children.
SESSION V

STEP Concepts Supplementary Information

Communication: Expressing Managing Stress
Your Ideas and Feelings

1. The members will be asked to share any concerns they may have.

2. The members will be asked to share their experiences of effective listening that they had with their children.

3. Parents will be encouraged to express their their feelings with their children and others through the use of I-Messages. I-Messages are explained on page 60 of the STEP Parent Manual.

4. It will be explained to parents that I-Messages are an effective way to relieve stress. Parents will be encouraged to relieve stress in other productive ways also such as through exercise, going out on a regular basis, etc. Parents will be asked to share ways in which they relieve or manage stress.

SESSION VI

<table>
<thead>
<tr>
<th>STEP Concepts</th>
<th>Supplementary Information</th>
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<tbody>
<tr>
<td>Natural and Logical Consequences: A Method of</td>
<td>Alternate Methods of</td>
</tr>
<tr>
<td>Discipline that Develops</td>
<td>Discipline</td>
</tr>
</tbody>
</table>

1. The members will be asked to share any concerns they may have.

2. The members will be asked to share their experiences with I-Messages and stress management.

3. Members will be introduced to Natural and Logical Consequences which are explained on pages 77-78 of the STEP Parenting Handbook.

4. Alternate methods to spanking will be discussed. (See handout.)

5. Some parents (especially those with very young children) find positive reinforcement to be very helpful. This concept will be discussed with parents. (See handout.)

6. Recap. Homework: To read chapters six and seven in the STEP Parent Handbook and to try out natural and logical consequences along with the other methods of discipline discussed.
SESSION VII

STEP Concepts
Natural and Logical Consequences (Cont.)
Developing Confidence and Using Your Potential

Supplementary Information
Confidence Exercises

1. The members will be asked to share any concerns they may have.

2. The members will share their experiences with the use of natural and logical consequences and alternate means of discipline. In situations where parents could not think of natural or logical consequences, the other group members will help them brainstorm some.

3. The members will be asked to share what challenges they feel that they continue to be faced with. Positive approaches to dealing with these challenges will be discussed and parents will be encouraged to use the new skills they have learned and to build on their assets.

SESSION VIII

<table>
<thead>
<tr>
<th>STEP Concepts</th>
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<tbody>
<tr>
<td>Summary of STEP Concepts</td>
<td>Posttests</td>
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<tr>
<td></td>
<td>Resources</td>
</tr>
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</table>

1. The members will be administered three post-tests.
2. Recap of the STEP concepts will be given.
3. A list of community resources will be handed out.
SUPPORT GROUP

Objective:

The primary objective of the group is to offer emotional support to the parents in a nonthreatening atmosphere.

Guidelines for the Group Leader:

It is suggested that the group be run as a self-help group where parents feel free to bring up any topic that they choose. The parents are encouraged to share their own experiences with each other and to offer advice to one another. The group leader acts as a facilitator.

No prescribed group sessions are provided since the group creates their own agenda.
APPENDIX D
RAW DATA
## RAW DATA
### CONTROL GROUP

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### RAW DATA
#### COUNSELING GROUP

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VITA OF
REBECCA LAFOUNTAIN

Educational Experience

Grand Valley State Colleges, Allendale, Michigan
1975 B.A. Degree

Iowa State University, Ames, Iowa
1977 M.S. Degree

College of William and Mary, Williamsburg, Virginia
1986 Ed.S. Degree

Work Experience

Mental Health Clinician, Chesapeake Mental Health, Chesapeake, Virginia
Aug. 1985-present

Counselor, I.C. Norcom High School, Portsmouth, Va.
1984 - 1985

Teacher of French/Talented and Gifted, Chincoteague, Va.
1983 - 1984

Director of Social Services, Heritage Hall, Nassawadox, Va.
Mar. - Sept. 1984

Elementary Counselor, Lake Linden-Hubbell Schools, Lake Linden, Mi.
1979 - 1983

Instructor of Psychology, Michigan Technological University Houghton, Mi. (Part-time)
1979 - 1981

Resident Counselor, Michigan Technological University Houghton, Mi.
1977 - 1979

Psychology Teacher, Calumet High School, Calumet, Mi.
Adult Education Psychology Classes
1981 - 1983

Hall Advisor, Iowa State University, Ames, Iowa 1975 - 1977

Professional Memberships

Member of the Virginia Counselors Association
Editorial Board, The Virginia Counselors Journal
Member of the Hampton Roads Counselors Association
Member of International Assoc. for Infant Mental Health
Member of Virginia Association for Infant Mental Health
Member of Phi Kappa Phi Honor Society
Professional Presentations and Publications

Presentation at the following National Elementary and Middle School Counselors' Conferences:

West LaFayette, Indiana, 1982; *Guidance Activities for the Home.*


Ames, Iowa, 1980; *Assertiveness Training for Children.*

Publications:


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Abstract

THE EFFICACY OF PARENT COUNSELING AND SUPPORT GROUPS ON STRESS LEVELS, SELF-ESTEEM AND DEGREE OF COPING OF PARENTS OF DEVELOPMENTALLY DELAYED OR HANDICAPPED INFANTS INVOLVED IN AN INFANT INTERVENTION PROGRAM.

Rebecca Marie LaFountain, Ed.D.

The College of William and Mary in Virginia, December 1987

Chairman: Dr. Kevin E. Geoffroy

The purpose of this study was to assess the impact of parental intervention on the self-esteem, degree of coping, and stress levels of parents of developmentally delayed or handicapped infants involved in an infant intervention program.

The literature indicates that parents of special needs children experience the grief stages that Kubler-Ross proposed in her work with the dying. Although affective intervention is recommended to help parents resolve these stages, few infant programs offer systematic approaches in offering emotional support to the parents. In addition, the research reveals that no objective instruments exist to assess the various coping stages. This study provided three types of parental interventions and the effect that each one had. In addition, an instrument was developed to measure the movement among stages.

The research design for this study was a posttest-only control group design. The samples consisted of 48 parents who had infants enrolled in an infant intervention program. Sixteen subjects were assigned to each of the following treatment groups: Support, Counseling, and Control; each lasting for eight weeks.

The support groups were structured as self-help groups and were led by the Infant Intervention Parent Coordinator. They offered parents emotional support. The counseling groups which were led by an experienced counselor had a therapeutic element that focused on promoting actualization of parents as individuals. They also had a didactic component, which was based on the Systematic Training for Effective Parenting (STEP) model. The parents in the control group received no treatment.

Three self-report instruments: The Coopersmith Self-Esteem Inventory, The Parenting Stress Index, and the Coping with Loss Scale were used to assess changes in the dependent variables (self-esteem, stress, and degree of coping.)
It was hypothesized that:

1) There would be no significant differences between the self-esteem scores of those parents involved in treatment groups and those parents in the control group as measured by the Coopersmith Self-Esteem Inventory.

2) There would be no significant differences between the stress indexes of those parents involved in treatment groups and those parents in the control group as measured by the Parenting Stress Index.

3) There would be no significant differences between the degree of coping of those parents involved in treatment groups and those parents in the control group as measured by the Coping with Loss Scale.

4) There would be no significant differences between the Used to Feel and Presently Feel subscales of the Coping with Loss Scale.

The results of the research revealed that there were significant differences noted between the self-esteem scores of the support group parents and the counseling group parents, with self-esteem scores higher in the support group. Similarly, a significant difference was found between the stress indexes of support group parents and counseling group parents with the support group parents experiencing less stress. No significant difference was noted between any of the groups in respect to the degree of coping, nor were any significant differences noted between treatment groups and the control group on any of the variables. The subscales on the Coping with Loss Scale proved to significantly discriminate between each other.

Several suggestions for future research are recommended. Replication of this study with a larger sample would better represent a normal distribution and would allow for the use of a more sensitive test such as MANOVA. Measures to eliminate absenteeism were offered. Extending the length of treatment was suggested. The differential effects of the group leaders' abilities and personalities were noted as limitations along with the recommendation to repeat the experiment with one leader who would facilitate both groups. Replication of the study to check for generalizability among other groups based on race, socio-economic status and sex was recommended. It was noted that a follow up study would reveal changes over time and a more prestigious design would overcome some of the limitations of this one. Instrumentation other than self-report was suggested. Finally, further research on the Coping with Loss Scale was suggested.