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The Coping ability of military parents of disabled children

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THE COPING ABILITY OF MILITARY PARENTS OF DISABLED CHILDREN

A Thesis
Presented to
The Faculty of the Department of Nursing
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In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
Leslie Jean Neal
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ABSTRACT

THE COPING ABILITY OF MILITARY PARENTS OF DISABLED CHILDREN

by Leslie Jean Neal

This thesis addresses the topic of the coping ability of military parents of disabled children who were assigned to an Army post in northern California. It examined the perceptions, beliefs, feelings, and concerns of parents whose children's disabilities ranged from epilepsy to Walker/Warburg Syndrome and whose ages ranged from 8 months to 17 years.

This study was descriptive and exploratory in design. A survey packet which included the Chronicity Impact and Coping Instrument, the Self-Reliance Index, and the Family Index of Coherence was mailed to subjects whose children met the eligibility criteria of the California Regional Centers.

Data indicated that the coping ability of the parents in the study was better, in general, than that of their civilian counterparts. Subjects had few concerns, considered themselves self-reliant despite frequent separations from their spouses, and perceived little effect of their military lifestyle on family coherence.

ACKNOWLEDGMENTS

To my husband and children
without whose love and support
I could not have accomplished
this dream
And to my mother
my nursing heroine

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Chapter 1

INTRODUCTION

Military parents in the Monterey area of California complain often about the distance of specialty medical resources and the stress of separations. The Monterey area is not unique in this respect, as these parents have experienced these same difficulties during other assignments both in the United States and abroad. Parents deal with many day-to-day stresses in their efforts to raise children. However, parents of disabled children deal with additional stress associated with their child's disability. Research is needed to determine whether or not the stresses of military life are affecting the ability of these parents to cope with the stresses of parenting a disabled child.

Problem

Parents of disabled children have many stressors. Military life adds certain unique stressors, such as: (a) frequent and often long separations from one's spouse, (b) separation from one's relatives and support system, (c) unusually long work hours, (d) social pressures, (e) the frequent lack of appropriate local medical resources, and (f) the constant threat of deployment of the active duty member to war. Dealing with these added stressors may affect parents enough to alter their coping ability, either by enhancing the skills necessary to increase their ability to cope or by burdening them to the point of inability to cope. It is possible, however, that the benefits of military life may help compensate for the stressors of military life. If so, then the coping ability of military parents of disabled children may be equivalent to that of their civilian counterparts. Some benefits of military life include: (a) financial security, (b) free medical care, and (c) free housing.

Research Questions

This study sought to answer the following questions:

1. Is the coping ability of military parents of disabled children affected by military life?
2. If so, what is the effect on the coping ability?

Purpose

The purpose of this study was to determine if military life has any effect on the coping ability of military parents of disabled children. The author of this study is a military family member and facilitates a support group at a military post in northern California for parents of disabled children. After working with these parents, the author questioned the effects of military life on the coping ability of these parents.

Extensive research has been done on the coping ability of families with disabled children. However, no distinction is made in the literature as to whether the families studied were of military or non-military background. A search of the literature reveals that research specific to the coping ability of military families with disabled children is scarce.

A program does exist in the military with objectives to coordinate resources for families with disabled children and influence the location of duty assignments to accommodate the special needs of these families. This program, however, has had questionable success with minimizing parental stress and increasing coping ability through its services.

The coping ability of military parents is crucial to the morale of the service member, since the satisfaction of the parents is likely to influence the decision of whether or not to stay in the service. "Clearly, the family system is but one of a host of interrelated environmental influences which can and does have a profound impact upon the military member and other family members" (McCubbin & Thompson, 1991, p. 315). Throughout everyday life, the coping ability of family members is bound to affect the mood and, consequently, the work performance of the service member.

The coping ability of military parents may also affect the care received by the disabled child and his/her siblings. If the parent is having difficulty coping with parenting the disabled child and that parent's needs are not being met by the military system, then the ensuing frustration and stress may influence the quality of the attention the parent then gives to the child(ren).

Additionally, the parent's marriage may suffer from this same frustration and stress. Parents may be left feeling exhausted and hopeless by the needs of their disabled child. These feelings may carry over into the marriage and weaken its ability to remain intact.

Thus, the coping ability of military parents of disabled children is a relevant and timely study. A study such as this may generate hypotheses for future research. Results of future studies may help to determine whether or not the existing program was effective and what interventions were effective to increase the coping ability in this population.

Definitions

For the purpose of this study, the following definitions apply:

1. Military parents are the active duty service member and his/her spouse.

2. Military is defined as "...of or relating to armed forces" (Woolf, 1975, pp. 729-30).

3. Parent is defined as "one that begets or brings forth offspring" (Woolf, 1975, p. 833). Adoptive parents are also included for the purpose of this study. Parents in this study were either single (including parents who were separated geographically for whatever reason from their

spouses) or married. Surveys were only addressed to the parents of eligible children, so if an unmarried parent was living with a partner during the study period, only the parent would have received a survey.

4. Disabled is used here interchangeably with the word handicapped and is defined by the Lanterman Disability Services Act (Assembly Bill 3635) as a disability "originating before a person's 18th birthday that is expected to continue indefinitely and constitutes a substantial handicap" (D. McCoy, personal communication, November 12, 1991).

5. Disabled Child refers to a child age 18 or younger who is mentally retarded, autistic, epileptic, has cerebral palsy, a seizure disorder or any of the conditions described above.

6. Coping Ability is defined as "efforts, both action-oriented and intrapsychic to manage environmental and internal demands and conflicts among them, which tax or exceed a person's resources" (Shapiro, 1983, p. 915). Coping ability, in this study, was measured by subjects' responses to questions evaluating their self-image, sense of emotional control, and emotional feelings, such as: anger, sadness, hopefulness, helplessness, guilt, and contentment. Coping ability was also measured by subjects' responses to questions regarding how they deal with stress and stressful situations.

Variables

Variables which were controlled in this study are the following:

1. Military status: All subjects were active duty military or their spouses. Although retirees do use the services of the hospital on this military post, they were not selected to be subjects for this research. Active duty status was indicated on the computer printouts used in data collection.

2. Child's diagnosis: All subjects had children who fit the Regional Center's eligibility criteria. At this post hospital, diagnoses are coded before they are entered into the computers in the respective clinics. Subjects were chosen based upon their child's coded diagnosis.

3. Residence: All subjects were residing in an area where the primary health provider is this military post hospital. This was evident by the address in the computer.

Variables which were not controlled are the following:

1. Age of parents: Subjects were of varying ages. This may have affected coping ability due to the effect of life experience.

2. Socioeconomic status: Subjects were of varying socioeconomic status due to the military rank structure.

3. Sex of the subjects: Subjects were both male and female.

4. Ages of children: The ages of subjects' children varied. Age and developmental differences may have affected the level of stress caused by caring for a disabled child.

5. Length of time in area: Subjects had been assigned to the area for varying lengths of time. This may have affected the subjects' knowledge of local resources.

6. Disabilities: The level of disability of subjects' children varied as did the types of disability.

In summary, there are several variables which may have affected the outcome of this research. Controlled variables included the military status of the parents, the child's diagnosis, and the parent's residence. Variables which were not controlled included the ages of the parents and their children, the sex of the subjects, their socioeconomic status, and the length of time the parents had been living in the local area. Additionally, the types and severity of the disabilities of the subjects' children varied. It is important to consider the conclusions and recommendations of this study in terms of the influence of these variables upon data collected.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

The conceptual framework for this study will be discussed in the first section of this chapter, followed by a discussion of the related literature and a chapter summary. The conceptual framework was chosen because of its appropriateness to the study of the research problem. The conceptual model describes the effects of demands upon one's perceptions. The related literature provides a base of knowledge from which to begin the study of military parents of disabled children. Previous research concerning the stress of parenting a disabled child as well as the stress of military life is reviewed.

Conceptual Framework

The Typology Model of Adjustment and Adaptation (McCubbin & McCubbin, 1987) is well suited to the topic under study. "The model assumes that families are seldom faced with one single stressor at a time but must manage an accumulation of demands from all areas of work and family life" (McCubbin, 1989, p.102). Family strengths, demands, resources, and coping behaviors are thought to influence adaptation of the family over time to both normal and situational stresses. Existing resources or the development of resources are used in the management of stress. The family's "appraisal" of its ability to handle the stressors is important to its adaptation to the stressors. "Coping is viewed as dynamic interaction between resources, perceptions, and behavioral responses" (McCubbin, 1989, p.103).

Military life adds frequent stressors to the lives of parents with disabled children. These parents deal with "an accumulation of demands from all areas of work and family life" (McCubbin, 1989, p.102). A major source of stress to military parents is whether resources are adequate to meet their needs at each location to which the family is assigned. Frequently, resources must be developed or done without for a period of time.

The Typology Model extends the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983b). Briefly, this model illustrates the effect of a crisis "x" upon "a" the patient, "b" family resources, and "c" the patient's perceptions. The patient attempts to cope with the original stressors in his/her life (Aa); plus the new hardships caused by the crisis (x); plus previous and new resources such as health care professionals (Bb); and his/her old perceptions and his perceptions of the crisis (Cc). Either the patient is successful and adapts in the post-crisis period or is unsuccessful and acquires maladaptive behaviors, such as overeating, smoking, and excessive crying.

This conceptual framework was used in this study to provide a foundation for understanding the stress experienced by military parents of disabled children. If the military parent is viewed as the patient described in the model, then his/her perceptions may be affected by previous perceptions and the availability of old and new resources following the introduction of a crisis. The crisis might be represented by the demands of caring for a disabled child, by the introduction to military life or by any setback related to either of these.

This study attempted to determine parents' perceptions and their ability to cope with these crises. The instruments used to gather this information included questions which addressed parents' perceptions and resources. A discussion of the findings and the resulting conclusions will relate this conceptual framework to the perceptions expressed by the study subjects in an attempt to formulate implications for future nursing research and practice.

Related Literature

The related literature will be discussed in two separate sections. The first section is devoted to a discussion of the current literature about the stress experienced by parents of disabled children. Included in the first section is a discussion of the incidence of maltreatment of children with disabilities. The second section is devoted to a discussion of the stress of military life.

Stress for Parents of Disabled Children

Parents of disabled children have increased stress. A review of the literature reveals that most of the major contributing researchers agree. Using similar methodologies (i.e., self-reports through the use of questionnaires, interviews, and standardized inventories), these researchers have concluded that parents of disabled children do indeed have increased stress (Crnic, Friedrich, & Greenberg, 1983; Friedrich & Friedrich, 1981; Gath, 1977; Kazak & Marvin, 1984; McCubbin & Patterson, 1983a; Schilling, Schinke, & Kirkham, 1985; Shapiro, 1983; Wikler, 1981). More recent studies have validated these conclusions with similar findings (Dyson & Fewell, 1986; Fisman & Wolf, 1991; Friedrich, Cohen, & Wilturner, 1987; McKinney & Peterson, 1987; White, Benedick, Wolff, & Kelley, 1987; Wilgosh, 1990).

Research has been conducted concluding that these parents go through stages of grief in their attempt to cope with their child's diagnosis (Eden-Piercy, Blacher, & Eyman, 1986). Other investigators call this process "chronic sorrow" (Copley & Bodensteiner, 1987). Still others have concluded that the level of the communication skills, not necessarily the degree of disability, of the child determines the stress level of the parents. For instance, the lower the ability to communicate, the higher the stress level of the parents (Frey, Greenberg, & Fewell, 1989).

Some researchers disagree that parents of disabled children have increased stress (Gowan, Johnson-Martin, Goldman, & Appelbaum, 1989; Harris & McHale, 1989; Salisbury, 1987). These studies, however, have certain methodological flaws which leave their findings open to question. Two studies used unequal groups for comparison (Gowan, Johnson-Martin, Goldman, & Appelbaum, 1989; Salisbury, 1987). The third study investigated parents of children with a wide variety of handicaps and ages (Harris & McHale, 1989). The results of the latter study may have been skewed by the effect of developmental differences on the behaviors of the children, thus possibly influencing the stress level of the parents.

Research on the stress experienced by military parents of disabled children or on their coping ability has been scarce since 1985. Beginning in fiscal year 1986, two 5 year studies were scheduled to begin and, as of this writing, the results have not been published. These studies were "The Effect of the Disabled Child on the Military Career" and "The Effect of Severe Childhood Illness on the Military Family" (Lewis, 1985).

It is logical to assume that the increased stress on parents of disabled children may correlate with an increased incidence of child maltreatment in these families. "The most frequent categories mentioned in the maltreatment literature are mental retardation, undefined disability, and congenital malformations....Although blindness, cerebral palsy, epilepsy, and other such conditions are also mentioned in the clinical maltreatment literature, little substantive information is available about the circumstances that may make a child with any of these conditions more vulnerable to maltreatment" (White et al., 1987, p.97).

Sameroff and Abbe (1978) studied the correlation between low birth weight and the incidence of maltreatment. They and other researchers theorized that the unrealistic expectations of the parents, early separation of the newborn from the parents, and the increased caretaking responsibilities contribute to maltreatment of the low birth weight or premature infant (White et al., 1987, p.96).

Morse, Sahler, and Friedman (1970) and Sangrund, Gaines, and Green (1974, p.329) found a higher incidence of maltreatment in mentally retarded children than in children with normal IQs. Other researchers have concluded that children with disabilities were more likely to suffer from neglect than maltreatment, (Glaser & Bentovim, 1979, p.573; Jaudes & Diamond, 1985, p. 343; White et al., 1987, pp.97-98).

It is likely that the relationships identified in the literature between disabilities and the incidence of child maltreatment or neglect in the general population is applicable to the military population as well. The combination of feelings experienced by the new parent of a disabled child and the stress added by military life has the potential to increase the incidence of child abuse in the military population.

Military Life Stress

Research has been done linking signs of stress in the wives of deployed active duty servicemen with separation from their spouses (Bermudes, 1973, 1977). Separation is a frequent occurrence at the installations serviced by the study hospital and one of several factors which may be especially stressful to parents of disabled children. Other factors may include: (a) separation from support systems, (b) long work hours for active duty service members, (c) social pressures, (d) the lack of local medical resources appropriate to the child's disability, and (e) the constant threat of the deployment of the active duty member to war.

In the geographical area under study separation between spouses is a particularly frequent occurrence. The military division assigned there deploys several times per year on training exercises and, as a rapid deployment force, is occasionally called upon to deploy to sites of violence, such as police actions, riots, and war. Separation from other support systems occurs to every family member whose relatives and friends reside outside the Monterey area. Long work hours are common for soldiers assigned to the division as the division is required to maintain high standards of training and expertise (P. Neal, personal communication, June 11, 1992).

The spouses of service members are often pressured to participate in social activities which are sponsored by the military unit to which the service member is assigned. The author's husband is a military service member serving in this division. The author has been praised in several of her husband's evaluations throughout his career, as well as publicly for her participation in unit social events. The military has traditionally looked upon the spouses of soldiers as active participants in the military way of life. Finally, specialized medical services and therapies for children are not provided at the study hospital, so parents must often travel long distances and/or spend their own income to at least partially pay for these services.

Summary

In summary, the conceptual model which was selected to be the framework for this research is appropriate to the topic under study. Military parents of disabled children are faced with the multiple demands of parenting a disabled child and the military lifestyle. Both the parent's previous and new perceptions of these demands, as well as the parents' access to resources are likely to affect the parents' adaptation to the stress imposed by those demands. The parents' adaptation or maladaptation will be reflected in the parents' ability to cope.

The review of the literature indicates that most researchers agree that parents of disabled children have increased stress. The increased incidence of maltreatment of disabled children also suggests that there is increased stress on parents of disabled children. Military life and its effects upon the coping ability of parents has not been specifically studied in recent years. Finally, military life itself is stressful due to certain unique aspects of the military lifestyle. The intent of this study was to gather information about the coping ability of military parents of disabled children in order to provide exploratory data regarding this population. This study may entice other interested researchers to do further research on this topic.

Chapter 3

THE METHOD

Research Design

This study was descriptive in design, since it attempted to describe the coping ability of military parents of disabled children. After data were collected, generalizations about the coping ability of parents of disabled children in the general population (as discussed in the literature) were compared with results from this study. The purpose of this study was to determine how military life affects coping ability and not to establish cause and effect. In that respect, this study was also exploratory since it investigated an area which has not been researched in recent years.

The Typology Model of Adjustment and Adaptation (McCubbin & McCubbin, 1987) and the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983b) were used to provide the conceptual framework for this research. Subjects were surveyed regarding their perceptions of their ability to cope with the demands of caring for a disabled child and life in the military. Survey questions also addressed the resources and coping strategies available to and utilized by the respondents. Subjects' feelings of self reliance and family coherence were also evaluated.

Human Subjects Approval

Human subjects approval was obtained through the San

Jose State University Institutional Review process. Approval to collect data using information and staff from the military hospital in northern California was obtained fron the Deputy Chief of Clinical Services and from the Department of Clinical Investigation at Madigan Army Medical Center in Tacoma, Washington.

Selection Criteria and Sample

The selection criteria for this research were based on the eligibility criteria of the California Regional Centers. The Lanterman Act was used to establish the eligibility criteria and as a guide to evaluate each child's case to determine whether or not the disability posed a "substantial handicap." The Regional Centers provide supportive services to the developmentally disabled and define developmental disability as mental retardation, autism, cerebral palsy, and epilepsy. Also considered for eligibility were people with conditions which were associated with mental retardation but were not physical or psychiatric in origin. Children with learning disabilities, alone, were excluded (D. McCoy, personal communication, November 12, 1991).

The Regional centers vary among themselves as to the strictness of their standards; however, all are required to use the Lanterman Act as a guide. In keeping with these broad guidelines, the definition of <u>disabled</u> for the purpose of this study was also fairly general.

For the purposes of this study, all cases of mental retardation, except those which clearly originated from psychiatric causes, were included for eligibility in this study as were all cases of cerebral palsy and autism. Children with epilepsy, according to the Regional Centers, were only considered if the epilepsy was debilitating, uncontrolled or has contributed to mental retardation. Children with seizures are considered by the Regional Centers only if the seizures are uncontrolled. Data collection for this research, however, depended heavily upon non-medical personnel who may have been ignorant of the distinctions among seizures and the types of epilepsy. All cases of epilepsy and seizure disorders were therefore considered for subject selection.

Children who were eligible for the Regional Center's "Early Intervention Program" were also included as eligible for the purposes of this study. Children who were under 3 years of age and had conditions which predispose for developmental disability were eligible for the early intervention services. These children receive services until age 3 and are then re-evaluated to determine continued eligibility. As with the regular Regional Center program (described earlier), each case was evaluated individually. Medical, genetic, and environmental conditions were considered for eligibility as were delays in development due to frequent or prolonged hospitalizations.

Prematurity of 32 weeks gestation or less, or birth weight of 1500 grams or less qualifies for Regional Center services. The following conditions qualify a child for Regional Center early intervention services: (a) severe respiratory distress syndrome requiring ventilation; (b) Apgar scores of 5 or less; (c) hyperbilirubinemia requiring an exchange transfusion; (d) neonatal seizures; (e) central nervous system lesions; (f) abnormalities, infection or damage as a result of abuse; (g) previous hospitalization in the intensive care unit; (h) congenital anomalies or disorders (if not purely physical); (i) a positive toxicology screen; (j) failure to thrive; and (k) persistent muscle tone abnormalities. Finally, if the child was born to a developmentally disabled parent, he or she also qualifies for services (J. Tremelling, personal communication, March 1, 1992).

These eligibility criteria are intentionally broad as the Regional Centers prefer to evaluate each child individually before determining whether or not to provide services (D. McCoy, personal communication, November 12, 1991). This researcher was unable to conduct this same individual evaluation on each child whose parents could be potential subjects for this research. Therefore, for the purpose of this study, the eligibility criteria were broadened.

The research sample (N = 23) consisted of 10 males and 12 females (one subject did not identify sex) between the ages of 19 and 49 years, who had children between the ages of 3 months and 17 years 1 month. The sample was selected by computer printouts at a specific military hospital in northern California. Some subjects were selected based on computer lists of eligible diagnoses and others were selected based on previous hospitalizations of their children. The addresses and phone numbers of the eligible children were retrieved from the hospital clinic computers and authorized staff members at the hospital mailed the surveys to the parents of these children.

In order to select the subjects for this research, computer printouts were retrieved from three areas of the hospital: the Pediatric Clinic, the Family Practice Clinic, and the Community Health Nursing Department (CHN). Under the supervision of the Head Nurse, clerks at the Pediatric Clinic addressed the survey envelopes and made the follow up phone calls. The secretary at the CHN Department addressed the CHN surveys, as well as the Family Practice Clinic surveys, and made the follow up phone calls for both areas. Since it was mandated by the Deputy Clinical Director at this hospital that only authorized hospital staff members have access to the names of the subjects, the researcher was required to rely on others to assist in the selection of subjects. The Pediatric Head Nurse and the CHN secretary were, however, given the same guidelines for selection as those described in the section of this study which defined <u>disability</u> (p. 5). The list of Pediatric Clinic subjects was obtained by the Head Nurse by locating the names of the children who had been in the Pediatric Clinic and had also been hospitalized here in the last year. The diagnosis for which each child had been hospitalized registered on the computer printout. The parents of the children with eligible diagnoses were then sent surveys.

The CHN list of subjects was obtained from a book of referrals which listed all of the patients referred to the CHN Department between January 1991 and February 1992. The researcher was able to hide the names of the patients while marking the accompanying diagnoses she wished the secretary to use. The secretary then mailed surveys to the parents whose children had those diagnoses.

Finally, the list of Family Practice Clinic subjects was obtained through the Information Management Coordinator at the hospital who entered the eligible diagnoses into the computer and retrieved a list of children, age 18 or younger, who had been seen in the Family Practice Clinic since 1987. This list included the most recent date the patient was seen in the clinic, enabling the CHN secretary to send out surveys to the parents of the children seen within the last year. The Information Management Coordinator sent his list to the CHN secretary via the hospital distribution system.

Additionally, 6 subjects were selected through the support group which the researcher facilitates. Members whose children met the eligibility criteria were asked to take the surveys home for themselves and their spouses to complete. All surveys mailed were addressed to either "the parent of..." or to Mr. or Mrs. (last name of the child).

Setting

Surveys were presumably completed in the subject's homes. Surveys were mailed to most of the subjects and given to a few subjects at a support group meeting. The latter subjects did not complete their surveys during the support group meeting and presumably took them home to complete there.

Data Collection Tools

Three tools were used to collect data for this research. These tools were:

1. The Chronicity Impact and Coping Instrument: Parent Questionnaire by Hymovich (1979, 1987) is designed to measure parent perceptions about caring for a disabled child (Appendix C). This instrument "has been used with families with children with a variety of conditions....The additional studies and applications support the validity and reliability

of the instrument" (D. P. Hymovich, personal communication, November 15, 1991). The PPI was retyped for legibility.

2. The Self-Reliance Index (Appendix D) "...a 9 item inventory, was developed as a reliable (Alpha = .88) and valid...index of the degree to which a family member felt capable of managing children, finances, decisions, and hardships in the absence of a military member" (McCubbin & Thompson, 1991, p. 321).

3. The Family Index of Coherence (Appendix E) is "...a 17 item inventory, [which] was developed as a reliable (Alpha = .85) and valid...index of the degree to which the family members feel" that they are committed to and have control over the military way of life and "can count on the military to help in time of need" (McCubbin & Thompson, 1991, p. 321).

Data Collection Procedure

Data were collected via three questionnaires which were coded and stapled into a packet and mailed to the subjects. Subjects who were selected from the support group were handed the survey packets at a group meeting. Each packet also contained a cover letter (Appendix A), a special instruction sheet (Appendix B), and a stamped envelope addressed to the researcher.

Data collection was initiated during the first week of February 1992. Surveys were mailed out from the Pediatric clinic, then the CHN Department, and finally, the Family Practice Clinic. The mailing was completed by the last week of February 1992. The selected subjects were mailed the packets and asked to return them within 7 days of receipt to the investigator in the enclosed envelope. Authorized staff members at the hospital each kept a record of the names of the subjects and the corresponding code numbers. The investigator then notified the staff members when the coded surveys had been received. The staff members made one follow-up phone call to each subject whose questionnaire had not been returned within the 7 day period and asked that the questionnaire be returned within the subsequent 7 days. Questionnaires received after this 14 day period were included in the study.

Data Analysis

Descriptive statistics were used to analyze the data. Percentages were used to describe the demographic data. Means, medians, and standard deviations were calculated for the Parent Perception Inventory (PPI), the Self-Reliance Index, and the Family Index of Coherence.

Chapter 4

FINDINGS AND INTERPRETATION

Analysis procedures

One hundred surveys (for the purpose of this study, a "survey" refers to the entire survey packet which includes three questionnaires) were mailed to eligible subjects. Thirty-six percent of the surveys were mailed to Family Practice Clinic clients, 26% to Pediatric Clinic clients, 26% to Community Health Nursing clients, and 6% were mailed to members of the support group.

Thirteen surveys were returned to the researcher marked "no forwarding address." Sixty-two surveys were not returned and 25 completed surveys were returned to the researcher. However, 2 of these 25 surveys were unusable. One was unusable because the child's diagnosis did not meet the eligibility criteria of the study, and the other because no diagnosis was listed with which to determine eligibility. Twenty-three surveys (92%) were accepted for data analysis because the listed diagnoses met the eligibility criteria of this study.

Subjects' responses to selected tables and questions from Hymovich's Parent Perception Inventory (PPI) were analyzed. Percentages were used to describe demographic data. Means, medians, and standard deviations were used to describe responses to the sections of the PPI entitled "Beliefs," "Feelings," "Concerns," and "Coping." Questions 8 and 9 of the PPI in the section entitled "Child Care Needs" and Question 6 of the PPI entitled "Coping" were not included for data analysis because they pertain to individual requests for help and information from a health care team. In the cover letter enclosed in each survey packet, subjects were informed that the researcher had access to information which could help them should they need and request it. However, it was made clear in the cover letter that no "health care team" was available to specifically respond to the health care needs described by subjects in their survey responses. McCubbin and Patterson's Self-reliance Index and Family Index of Coherence were both analyzed for means, medians, and standard deviations (Williams, 1992).

The midpoints of the theoretical ranges can be used as arbitrary numbers with which to compare the means and to make assumptions about the results of this study (D. P. Hymovich, personal communication, November 15, 1991). These comparisons provided a basis on which to form generalizations about the population studied. As this study was intended to be descriptive and exploratory in design, these generalizations, and not the statistics themselves, were used to compare the coping ability and the perceptions of the population of military parents of disabled children with the general population of parents of disabled children.

The assumption made for the purposes of data analysis was that a neutral respondent would give a neutral response which would be represented by the mid-point of the theoretical range. In other words, if the mean of a response equaled the mid-point, then one might assume that subjects did not feel strongly negative or strongly positive about a particular question. The data analyses were intended to provide indications and to describe tendencies about this population of military parents of disabled children.

All 23 surveys were used in the data analysis. Some surveys lacked responses to every question. Rather than reduce the sample, these surveys were retained. The means of the responses were compared to each other and to the midpoints of the theoretical ranges in order to prevent any skewing effect these surveys might otherwise have upon the results. In cases of demographic questions which lacked all 23 responses, the researcher has identified the number of responses upon which the descriptive percentages have been based. The reader may assume that the total number of respondents to all other demographic questions was 23.

Demographic Data

The results of the analysis of the demographic data are summarized below. They are divided into (a) general family characteristics, (b) the characteristics of the disabled child, and (c) spirituality and employment patterns of the subjects.

General Family Characteristics

Approximately an equal number of mothers and fathers responded to the survey (Table 1). The most frequent age range was between 35 and 39 years old. All of the 22 who responded to this question were married. Forty-one percent had been married over 12 years, 32% for 2 - 5 years, and 27% for 6 - 12 years. Only one respondent of 21 respondents was married more than once.

Most subjects graduated from high school and had some college. The most frequent income range was between $20,000 and $29,999. Children's ages ranged between 6 and 12 years of age. Seventy percent of the respondents described themselves as white.

Characteristics of the Disabled Child

The ages of the disabled children ranged from approximately 8 months to 17 years (Table 2). Most of the children had "moderately severe" conditions, and a slight majority have been admitted to the hospital 5 - 7 times. The latest hospital visit most often occurred "less than 1 month ago." Most of the children were diagnosed before the age of 6 months and about half were in "very good" condition at the time the survey was completed.

Diagnoses reported by respondents included the following: Down Syndrome, epilepsy, hydrocephalus, mental retardation, seizures, cerebral palsy, Walker/Warburg Syndrome, porencephalic cyst, congenital heart disease,

Table 1

Characteristics of General Family Characteristics by Frequency and Percent (N=23)

Characteristics	Frequency	%
Subjects[a]		
Fathers	10	45%
Mothers	12	54%
Children under 5 years old		
None	12	52%
1 Child	3	13%
2 Children	6	26%
3 Children	2	8%
Children between 6-12 years old		
None	9	39%
1 Child	3	13%
2 Children	9	39%
3 Children	2	8%
Children 13 years and older		
None	13	56%
1 Child	5	21%
2 Children	1	4%
3 Children	4	17%

Table 1 (continued)

Characteristics of General Family Characteristics by Frequency and Percent (N=23)

Characteristics	Frequency	%
Age of Parent		
Between 19-24	4	17%
Between 25-29	6	26%
Between 30-34	2	8%
Between 35-39	8	34%
Between 40-44	1	4%
Between 45-49	2	8%
Education		
High School Graduate	6	26%
Some College	8	34%
Community College Graduate	2	8%
College Graduate	5	21%
Masters/Doctoral	2	8%
Family Income[a]		
$10,000-$19,999	4	18%
$20,000-$29,999	13	59%
$30,000-$39,999	3	13%
$40,000 or More	2	9%

Note. Percentages may not equal 100% due to rounding.

[a] One subject did not answer this question.

Table 2

Characteristics of Subjects' Disabled Children by Frequency and Percent (N = 23)

Characteristics of Disabled Child	Frequency	%
Sex[a]		
Male	11	50%
Female	11	50%
Physical/mental Condition		
Not Severe	5	21%
Moderately Severe	11	47%
Very Severe	7	30%
Times Admitted to Hospital		
Never	4	17%
1 Time	3	13%
2-4 Times	5	21%
5-7 Times	6	26%
8 or More Times	5	21%
Last Hospital Visit[b]		
< 1 Month Ago	9	42%
1- 5 Months Ago	2	9%
6-12 Months Ago	3	14%
Over 1 Year Ago	7	33%
Age at Diagnosis of Disability		
< 6 Months	10	43%
6- 11 Months	6	26%
12- 47 Months	3	13%
48- 71 Months	3	13%
72-144 Months	1	4%

Table 2 (continued)

Characteristics of Subjects' Disabled Children by Frequencies and Percentages (N = 23)

Characteristics of Disabled Child	Frequency	%
Another Family Member With Same Disability		
Yes	4	17%
No	19	82%
Health Condition of Disabled Child Within Last 3 Months		
Poor/Fair	3	14%
Good	2	9%
Very Good	10	47%
Excellent	6	28%

Note. Percentages may not equal 100% due to rounding. [a] One subject did not answer this question. [b] Two subjects did not answer this question.

cranio-facial reconstruction, and monoparesis of the extremities.

Seventy-four percent of the respondents did not belong to a parents' association related to their child's disability. Of those that did belong, the majority attended meetings fairly frequently ("sometimes" or "often"). Fifty percent of those who belonged found the meetings "somewhat" helpful. Equal numbers, of 17% found them "not at all" or "not very" helpful. Another 17% found them "very" helpful.

Spirituality and Employment Patterns of Subjects

Half of the respondents described themselves as Protestant. Most respondents "never" attend religious services (Table 3).

A majority of the subjects were employed full time, and were satisfied with their work. A majority reported spending "less than 1 hour per day" caring for their disabled child's health needs.

Sixty-five percent of the subjects had emergency back-up plans for child care for the disabled child if it was needed for a 1 day period and 48% had plans for a week long period if needed. Fifty-two percent, however, had no emergency child care plans should they be needed for a week long period. Forty-three percent did not have a regular babysitter; 14% did have a regular babysitter; and 43% did not need a regular babysitter.

Table 3

Characteristics of Subjects' Spirituality and Employment Patterns by Frequency and Percent (N=23)

Spirituality & Employment Patterns	Frequency	%
Religious Background[a]		
Protestant	11	50%
Catholic	5	22%
Jewish	1	4%
Other	4	18%
No Religion	1	4%
Religious Attendance		
Never Attend	10	43%
Rarely	4	17%
Sometimes	4	17%
Often	5	21%
Employment[a]		
Employed	14	63%
Not Employed	8	36%
Type Employment[b]		
Full Time	13	92%
Part Time	1	7%
Work Satisfaction[c]		
Satisfied	16	84%
Not Satisfied	3	15%
Child Caring		
≤ 1 Hour Per Day	12	52%
1-2 Hours Per Day	4	17%
3-5 Hours Per Day	2	8%
6-8 Hours Per Day	2	8%
> 8 Hours Per Day	3	13%

Note. Percentages may not equal 100% due to rounding.
[a] One subject did not answer this question. [b] Nine subjects did not answer this question. [c] Four subjects did not answer this question.

Analysis of the Results from the Self-Reliance Index and the Family Index of Coherence

The results for each tool (the Parent Perception Inventory [PPI], the Self-reliance Index, and the Family Index of Coherence) will be discussed separately. Then the results will be discussed as related to the research questions.

Results of the PPI

The PPI is divided into 4 sections. These sections include: (a) beliefs, (b) feelings, (c) concerns, and (d) coping. The coping section is further divided into "how often" and "how helpful." The results of each section are discussed separately.

Beliefs (PPI)

"Beliefs drive coping strategies" (D.P. Hymovich, personal communication, April 6, 1992). Each question in this section is listed in Table 4 with the corresponding number and percentage of those who responded that they agreed, disagreed or were not sure with reference to the stated belief.

Most parents disagreed that they "usually need to take care of their own needs before they can help their children," although most responded that parents do need to "get out of the house to relieve the strain of child care." Most agreed that "it is usually better to talk about one's feelings" and disagreed that "trying to forget something makes it easier to

Table 4

Subjects' Beliefs by Frequency and Percent (N=23)

Beliefs	Agree Freq.	Agree %	Not Sure Freq.	Not Sure %	Disagree Freq.	Disagree %
Parents usually need...	4	17%	0	0%	19	83%
Sometimes parents need...	23	100%	0	0%	0	0%
It is usually better...	20	87%	1	4%	2	9%
Sometimes just trying...	3	13%	5	22%	15	65%
Taking one day...	15	65%	1	4%	7	31%
Sometimes getting away...	14	61%	5	22%	4	17%
I usually have...	14	61%	4	17%	5	22%
It is lucky...[a]	14	64%	4	18%	4	18%
There isn't much...	9	39%	1	4%	13	57%
Sometimes I think...	5	22%	1	4%	17	74%
Parents need[a] someone...	18	81%	3	14%	1	5%
People should try...	3	13%	5	22%	15	65%

Note. Please refer to page 66 of the Parent Perception Inventory (Appendix C) to read each "Belief" in its entirety.

[a] One subject did not answer this question.

handle." The majority of respondents felt that "taking one day at a time...usually [works] better than [does] making long term plans" and that getting away makes the situation easier to handle. Most responded that they usually feel in control over things that happen to themselves or their families and disagree that there is not much that they can do about their child's condition. While most responded that "it is lucky that this is [their] child's only condition," they disagreed that their "child's condition is a nuisance." The majority did respond that they think parents do "need someone to talk with about raising children" and disagreed that "people should try to handle their problems themselves."

Feelings (PPI)

The theoretical range of responses on this tool in this section is 0 - 63 with a mid-range point of 31.5. The mean of the responses in this study was 22.87 with a standard deviation of 8.75. If one is to assume that the mid-range point would indicate that the respondents have no strongly positive or strongly negative feelings about parenting their disabled child, then a comparison of the mid-range point and the mean indicates that most of the respondents have had good feelings frequently over the past 3 months. That is, a mean to the left of the mid-range point indicates good feelings as opposed to a mean to the right of the mid-range point which would indicate bad feelings.

Concerns (PPI)

The theoretical range of responses in this section was 0 - 136 and the mid-range point was 81.5. The results for this study were a mean of 63.09, a median of 63, and a standard deviation of 19.84. If one is to assume that the mid-range point would be an indicator that parents are neither unconcerned nor very concerned about any of the items listed in this section, then the mean which falls to the left of the mid-range point indicates that the respondents are not very concerned. The results indicate that the respondents were not "very concerned" about these items.

Coping (PPI)

"The feeling now is that it's the number of coping strategies not how often they are used that really measures coping. If one has several coping strategies, then they are coping better" (D. P. Hymovich, personal communication, April 8, 1992). This section is divided into two sections for the purpose of data analysis: "How Often" and "How Helpful."

How often. The theoretical range of this section was 0 - 87. The mid-range point according to Hymovich's design of this section was 43.5; the mean, 37.96; the median, 41; and the standard deviation, 16.15. A mean to the right of the mid-range point would indicate that the respondents are coping well (D. P. Hymovich, personal communication, April 8, 1992). Conversely, a mean to the left would indicate poor coping. The mean for this study of 37.96 falls to the left of the mid-range point, indicating that the respondents may not yet have developed several types of coping strategies. One respondent marked "do not do this" next to all of the listed coping strategies.

How helpful. The theoretical range was 0 - 3 and the mid-range point 1.5. The results for this study were a mean of 1.33, a median of 1.28, and a standard deviation of 0.56. The tabulated totals of the "How Helpful" section of each returned survey can be divided by the number of coping strategies used by the respondent (D. P. Hymovich, personal communication, November 15, 1991). These scores were then used to calculate the mean, median, and standard deviation. The high end of the theoretical range was then considered to indicate that the coping strategies were helpful and the low end of the range was considered to indicate that these strategies were not helpful. The mean for this study of 1.33 falls to the left of the mid-range, point indicating that the coping strategies have not been very helpful to this population of subjects.

Results of The Self-Reliance Index

The Self-Reliance Index tool (McCubbin & Patterson, 1982) measures "the degree to which a family member [feels] capable of managing children, finances, decisions, and hardships in the absence of a military member" (McCubbin & Thompson, 1991, p. 321). It is assumed that only the spouses of the military servicemembers completed this questionnaire. The theoretical range was 9 - 36 and the mid-range point 22.5. The mean in this study was 11.94; the median, 11.5; and the standard deviation, 2.14. A low score would indicate strong feelings of self-reliance and a high score would indicate feelings of poor self-reliance. Since the mean falls to the left of the mid-range point, the data indicate that the respondents have a tendency to be very self-reliant.

Results of The Family Index of Coherence

The Family Index of Coherence tool (McCubbin & Patterson, 1982) measures "the degree to which the family members feel they can predict the immediate future of work and family schedules, the degree of commitment the family has to the military mission and lifestyle, the degree of control the family feels it has in shaping its future, and the degree to which the family feels it can count on the military to help in time of need" (McCubbin & Thompson, 1991, p. 321). The theoretical range was 0 - 51 and the mid-range point, 25.5. The mean was 25.89; the median, 25; and the standard deviation, 5.45. The closeness of the mean and the mid-range point indicate that this population of subjects has neutral feelings about family coherence. The respondents as a group neither agree nor disagree with the questionnaire items.

Summary of Findings

This study sought to determine whether the coping ability of military parents of disabled children is affected by military life, and if so, what is the effect? According to the results of this study, military life does appear to affect the coping ability of military parents of disabled children stationed in this northern California military post. The effect appears to be a strengthening of coping ability, perhaps due to experience gained in coping with the additional stressors of military life. The following results indicate that this population of parents is coping adequately, if not well:

1. Most of the respondents expressed that they had "good feelings" frequently over the previous three months.
2. The military parents seem to be "not very concerned" about the demands and worries of parenting a disabled child.
3. The military parents expressed generally positive perceptions of military life.
4. The spouses of the service members expressed strong feelings of self-reliance.
5. The service members and their spouses expressed neutral feelings about the effects of military life on family coherence.

It is interesting to note that the military parents studied did not employ several different coping strategies nor did they find them particularly helpful. Whether this lack of concern and generally positive attitude relates to a coping ability strengthened by years of dealing with military life or other stressors is a question unanswered by this research study.

Chapter 5

DISCUSSION

Summary of Study

Military parents of disabled children who are assigned to a military post in northern California were studied to describe their coping ability and to explore the impact of military life upon their ability to cope with the increased stress of parenting a disabled child. McCubbin and McCubbin's Typology Model (1987) and McCubbin and Patterson's (1983b) Double ABCX Model of Family Adaptation provided the conceptual framework upon which this study was based.

Three questionnaires (Hymovich's Parent Perception Inventory, McCubbin and Patterson's Self-Reliance Index, and their Family Index of Coherence) were mailed in a survey packet to 100 parents of children who met the eligibility criteria of the California Regional Centers. Subjects were obtained through the Family Practice Clinic, Pediatric Clinic, and Community Health Nursing Department of a military hospital in northern California. Twenty-five surveys were returned to the researcher, of which 23 were usable for data analysis.

The results described tendencies in this population of military parents of disabled children. This population appeared to have good feelings and few concerns regarding the parenting of their disabled children. The spouses of the active duty service members seemed to feel very self-reliant when their military spouse is away from them. Both the service members and their spouses reported neither strongly negative nor strongly positive feelings about the impact of military life upon family coherence.

Most of the parents studied did not belong to a support group nor did they use several different methods of coping. They indicated that support groups or common coping strategies were not helpful. The majority of the subjects studied rarely or never attended religious services.

Despite these factors and the distance of specialty medical resources, it appeared that military parents assigned to this northern California military post were handling the increased stress of parenting their disabled children better than the general population of parents of disabled children described in the literature. This may be attributable to any or all of three major factors. One factor may be that 22 out of the 23 parents studied were married. Another factor may be that most of the respondents spent less than 2 hours per day caring for their child's health needs. A final factor, and perhaps the most significant in this research, may be that the military parents were self reliant therefore felt capable of handling the increased stress of caring for a disabled child.

Conclusions

The results of this research may be explained using the conceptual framework described earlier. According to The Typology Model of Adjustment and Adaptation by McCubbin and McCubbin, "families are seldom faced with one single stressor at a time but must manage an accumulation of demands from all areas of work and family life" (McCubbin, 1989, p. 102). Military families living in northern California certainly contend with several stressors at one time. These stressors include forced separation from spouses and among family members, long work hours for service members, social pressures, a lack of specialty medical resources locally, and the constant threat of deployment to violent situations.

One assumption which might be made as a result of this study is that the additional stressors imposed upon family members by the military lifestyle may also serve to strengthen the coping ability of the family members. This study did not attempt to differentiate among military parents who had been exposed to the military lifestyle for varying lengths of time, a factor which could strongly influence the ability of the parents to cope with the stresses of military life.

The Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983b) attempts to describe the effect of a crisis "x" upon "a" the patient, "b" family resources, and "c" the patient's perceptions. In this study, "a" represents the military parent, "b" represents family resources such as the supportive services provided by the military (Army Community Service, Army Emergency Relief, the American Red Cross, unit family support groups, the Exceptional Family Member Program), and "c" represents the perceptions that the military parents have about their life in general.

If the crisis "x" is represented by the increased stress imposed upon these parents by the needs of their disabled children, then the military parents in this study appear to have adapted to the changes incurred by the crisis in a positive way. According to the Double ABCX Model, the patient (i.e., the parent) attempts to cope with the original stressors in his/her life (the stresses of military life) plus the new hardships imposed by the crisis (the introduction of a child with a disability into the family). The parent attempts to cope by using his/her previous resources (military supportive services) and new resources (health care professionals and specialty resources for the disabled). The parent revises his/her old perceptions into new perceptions and he/she either adapts to the changes brought on by the crisis or begins to exhibit behaviors which are manifestations of maladaption.

This research did not attempt to determine whether the subjects had given birth to or adopted their disabled children prior to or following their entrance into military life. A parent who began his/her life in the military after the birth or adoption of the disabled child might perceive military life as the crisis to which they must adapt. In this case, the original stressors would have been derived from the child's disability and the new stressors would be imposed by the military lifestyle. Resources previous to the onset of the crisis (entrance into military life) might have included services related to the disabled child's special needs and new resources might include military supportive services.

This researcher expected subjects to respond negatively regarding their ability to cope with parenting a disabled child while living the military lifestyle. The reason for this expectation was based upon the researcher's experience with military parents of disabled children assigned to this military post in northern California, many of whom may have been study subjects.

The researcher created a support group for these parents over a year prior to the conclusion of this study. There had been no semblance of a support group for this population for as long as anyone could recall, despite the existence of the government sponsored Exceptional Family Member Program.

During group meetings, members expressed sorrow, anger, and frustration when discussing the care of their children and the military system. Therefore, these study results seem incongruous with the attitudes expressed through the support group. One reason for this could be that the subjects may have responded the way they thought the researcher would want them to respond. Another reason could be that while a support group provides an atmosphere for the ventilation of honest feelings, a questionnaire to be filled out in privacy may discourage one's honest and emotional evaluation of feelings.

Potential research questions include determination of why the parents studied did not belong to a support group and whether membership in a support group is necessary to an increased ability to cope. It would be interesting to study what coping strategies parents did use if not those suggested in the PPI. Other research questions could explore the difference in coping ability between parents who belong to a support group and those who do not and the difference in coping ability between parents who spend a lot of time caring for their disabled child and those who do not.

Perhaps a larger, more in-depth study could discover the reasons for this incongruity and whether or not military parents of disabled children do indeed have needs that have not been identified or addressed by the military or the health care system.

Scope and Limitations

This research was confined to the study of a small select population of military parents stationed at a military post in northern California. All of the subjects received services from the post military hospital which was lacking in specialty pediatric medical services and therapies. An unknown number of subjects were assigned to the division whose home is this military post and whose rigorous training schedule and demands on family time are well-known in the military.

Additionally, the subjects were of varying socioeconomic status. Financial concerns, especially since at least partial payment for specialized medical services may be necessary, might weigh heavily in one's estimation of coping ability.

The marital status and the ages of the subjects may also have affected subjects' responses. It was assumed that married subjects have a spouse with whom to share parenting responsibilities and older subjects are more likely than younger subjects to have acquired the emotional resources needed to cope with parenting a disabled child.

The age of the child, as well as the type of disability, may have influenced the coping ability of the parents. Older children are most likely in a school program and may have developed some self-care skills, while younger children require more home care. Frequency of doctor visits, therapy sessions, and hospitalizations are all factors of the severity of the disability and may increase the stress experienced by the parents.

A final, but significant limitation of this study was the necessary reliance upon non-medical personnel for subject selection. The possibility exists that eligible subjects were missed and ineligible subjects were mailed surveys. Fortunately, subjects were questioned in the survey regarding their child's diagnosis, eliminating the possibility that ineligible subjects were included in the final data analysis.

Recommendations

The results of this study have implications for nursing research and practice. The population of military parents of disabled children has been largely unstudied. However, the military is a select population of individuals with unique concerns and needs.

Nurses need to be aware of the unique needs and characteristics of their military clients. Specifically, in dealing with clients who are disabled family members or the parents of disabled children, nurses must be careful to avoid making assumptions about coping ability. It is important when working with these clients that nurses take the time to assess coping strategies and the clients' past experience with handling stressful situations before attempting interventions which may or may not be necessary or effective. This concept may carry over into the health management of non-military clients whose previous life experiences may have provided them with the tools that help them cope and adapt to new situations or crises.

Nurses caring for military clients also need to be cognizant of the types of resources available to the military and what resources may be lacking. Nurses who care for these clients in a non-military setting may encounter high levels of frustration and stress due to the expense and distance of specialty medical resources endured by their clients. It is important that nurses be aware of the source of these feelings and include in their nursing care good listening skills and a knowledge of resources which could be of help, such as: temporary living arrangements for family members near the hospital and financial aid.

Future nursing research might explore comparisons between military populations in different branches of service or in different geographical locations. The distance from specialty pediatric medical resources and the length of time the parents have resided in the area may influence their ability to cope. These variables are worthy of future study. A comparison study of military parents of disabled children who are members of a support group with those who do not belong to a support group would help further understanding of what enables military parents of disabled children to cope. Future nursing research may help to formulate theories about why the military parents in this study did not feel that support groups were helpful and yet seemed to be coping adequately if not well.

It would be worthwhile to explore the effects of adaptation to military life upon the individual's future encounters with stressful situations. It would be helpful to gain an understanding of the ways in which the adaptation to previous stress affects the ability to cope with future stress. Perhaps the most important implication for nursing research is the study of what strategies these military parents do use that enable them to cope with parenting a disabled child while living the military way of life and what assistance these parents do need to reduce the stress they encounter.

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APPENDIX A

Cover Letter

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I am a registered nurse and military wife who is studying the coping ability of military parents of disabled children for my Masters' thesis at San Jose State University. Your participation in the study is requested because your child meets the eligibility criteria for disability as defined by the California Regional Centers.

If you decide to participate, you will be asked to complete the enclosed questionnaires and return them to me promptly. Completion of the questionnaires should take approximately fifteen minutes of your time. Your information will help those that read this research to better understand the needs of parents like yourself. It is my hope that the outcome will be better care and more attention paid to your needs by the military and health care professionals.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. A list will be kept of the names of participants (to avoid duplication) either by me or by personnel at Silas B. Hayes Army Hospital who are authorized to have patient information. The list will be kept on my person or in a locked metal box in my home at all times, if it is not controlled by staff members authorized by Dr. Tuer (hospital clinical administrator) to handle patient information. Only such an authorized staff member, myself or my professor Joan Edelstein Dr. PH RN will have access to the list of names. Your address and child's diagnosis will also remain confidential. Following data collection, this personal information will be burned.

Your decision whether or not to participate will not prejudice your future relations with Silas B. Hays Army Hospital or San Jose State University. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice. If you have any questions, please contact me, Leslie Neal BSN, RN at 384-2457. I will be happy to answer them.

For questions or complaints about research subjects write, or in the event of research related injury, contact Serena Stanford Associate Academic Vice President for Graduate Studies and Research at (408) 924-2480.

YOUR COMPLETION OF THE QUESTIONNAIRES IS YOUR CONSENT TO PARTICIPATE.

Date: 1/23/92

Signature of investigator:

Leslie Neal

APPENDIX B

Additional Information about Completing the Parent Perception Inventory

Appendix B

Additional Information About Completing the Parent Perception Inventory

You will note in the survey directions and also in question number 8 of the section entitled "Concerns" that help and assistance will be offered to you based upon the concerns you express through your answers. Please understand that this questionnaire has been used in a variety of settings and in some cases, assistance from a health care team was readily available. As a student investigator, I do not have the ability to offer you the assistance of a health care team, however, I am available by phone to direct you to resources which may be helpful to you. Support Our Special...Kids (SOS...Kids) is a support group which meets weekly on Ft. Ord. I do facilitate this group, and that, among other resources I am aware of may prove helpful to you.

Thank you for your
participation,

Leslie Neal BSN, RN
(408) 384-2457

APPENDIX C

Chronicity Impact and Coping Instrument: Parent Perception Inventory

APPENDIX D

Self-Reliance Index

APPENDIX E

Family Index of Coherence