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## Comparison Of Family Needs Of Parents Of Chronically Ill Children Who Participate In A Parental Support Group Versus Those Who Do Not

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Comparison of Family Needs of Parents of Chronically Ill Children  
Who Participate in a Parental Support Group  
Versus Those Who Do Not

by

Kim Wilson Hardin

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

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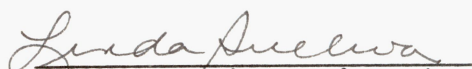
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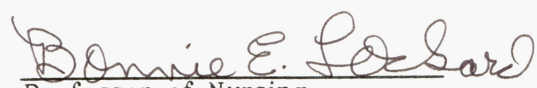


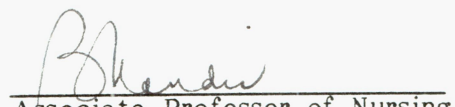
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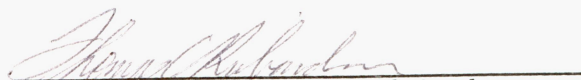
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### Abstract

The purpose of this retrospective study was to determine the dimensions of family needs of parents of chronically ill children in rural northeastern Mississippi who participate in a parental support group, and the dimensions of family needs of parents who do not participate.

The hypothesis of the study was: Parents of chronically ill children who participate in a parental support group will have significantly less unmet family needs than parents of chronically ill children who do not participate.

Data were collected from a convenience sample of 40 subjects who were parent/caregivers of chronically ill children in rural northeastern Mississippi, 20 of whom were support group participants, and 20 of whom were not support group participants. The data collection instrument employed was the Family Needs Assessment Tool (Rawlins and Horner 1988).

The dimensions of family needs were determined using descriptive statistics, and the hypothesis was tested using a one tailed t-test. Analysis of the data revealed that the support group participants identified none of the family needs as unmet ( $p < .05$ ), while the non-support group participants identified 13 areas of unmet needs as significant ( $p < .05$ ). Therefore the researcher retained the hypothesis.

The conclusions of this study can be used to improve the health care and services given to these families and their children. The agencies in rural northeastern Mississippi who offer services to chronically ill children will be made aware of the findings of this study concerning the 13 areas of needs which were identified. They can therefore tailor their programs and services to better meet these needs.

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## Chapter I

### The Research Problem

The prevalence of chronic disease in childhood has been well-documented in the literature. It is estimated that the number of children from birth to twenty years of age in the United States with some form of chronic condition is between ten to twenty percent of the total population (Gortmaker and Sappenfield, 1984).

The number of chronically ill children in Mississippi in 1989 receiving services from Children's Medical program (CMP) was approximately seven thousand (Gladys Johnson, RN, personal communication, February 28, 1990). CMP serves children with congenital heart defects, orthopedic defects, sickle cell disease, hemophilia, cleft lip/palate, neurological disorders, and spina bifida.

The prevalence of chronic childhood illness has remained constant over the past forty-five years, according to a retrospective study by Gortmaker and Sappenfield (1984). Although the birth rate and prevalence of chronic childhood disorders has not changed, the survival rates of these children have increased dramatically due to improvements in medical technology (Horner, Ralwins, and Giles 1987).

There has also been a trend in recent years to deinstitutionalize children with chronic health problems, and handicaps. This has resulted in many youngsters with varied physical and cognitive impairments

residing at home with their families. Thus, family members must assume the primary responsibility of caring for these children who require a broad range of services to meet their many physical and emotional needs (Strauss and Munton, 1985).

Rollins (1987) found that one of the most effective ways to meet the many needs of these families is through participation in a self-help group for parents. These parental self-help groups offer emotional support, impart information and advice, and help promote change for these families.

Rawlins, Rawlins, and Horner (1990), identified three areas of need among parents of chronically ill children. These family needs were in three dimensions: programs/services, information, and access to health care.

Mixed findings regarding the effectiveness of support groups in meeting needs of families with chronically ill children has been reported and suggests more research in this area is needed (Rawlins and Horner, 1988). Therefore the purpose of this study was to examine the dimensions of family needs of parents of chronically ill children in rural northeastern Mississippi and to assess the effectiveness of participation in a parental support group in meeting family needs of parents of chronically ill children.

#### Conceptual Framework

The conceptual framework for this study is King's Interacting Systems Framework. A factor of importance to consider in this study

is an accurate perception of the needs of parents caring for chronically ill children. King defines perception as a "process of organizing, interpreting, and transforming information from sense data and memory. Perception is a process of human transactions with the environment which gives meaning to one's behavior" (King, 1981, p. 24).

It is imperative that health-care professionals who are responsible for planning care and services for these children and their families have an accurate assessment of what these client's perceive as their needs (Rawlins, Rawlins, and Horner, 1990). The perceptions of the individual are influenced by his personal, interpersonal, and social systems. The health-care provider must also be aware of the client's perceptions concerning these systems so that they may "plan together to achieve their goals" (King, 1981, p. 26).

In King's Interacting Systems Framework, there are three systems which comprise the person, or individual: the personal system, the interpersonal system, and the social system. This systems classification lends itself well to the conceptualization of the current study.

King (1981) defines personal system as a "unified complex whole self who perceives, thinks, desires, imagines, decides, identifies goals, and selects means to achieve them" (King, 1981, p. 27). This personal system processes input from the environment and gives meaning to the incoming messages (Fawcett, 1989).



The parent/caregiver in this study is the personal system. This personal system is goal-directed, and wishes to learn and implement the best care possible for his/her child.

The interpersonal system is composed of the person (personal system) interacting with two or more individuals in a given situation (Fawcett, 1989). This process of interaction among individuals as in a support group involves verbal and non-verbal actions that are goal-directed (King, 1981). According to King (1981), the process which occurs during interaction is communication. Communication, when implemented in the interactive process, is used as a mean to mutually identify goals, and to agree on a means of achievement. The means of achievement are transactions, which King (1981) defines as "goal attainment" (King, 1981, p. 61).

Two other concepts related to the interpersonal system identified by King were role and stress. Role was defined as a "set of behaviors expected when occupying a position in a social system" (King, 1981, p. 93). The fulfillment of role expectations requires individuals to communicate effectively and to interact in purposeful ways to achieve their goals (King, 1981). In the situation under consideration in this study, the parenting role changes to one of caregiver with the advent of a chronically ill child in the family.

Stress is another factor in the interpersonal system which must be addressed. Stress is defined by King as "a dynamic state whereby a human being interacts with the environment to maintain a balance for

growth, development, and performance, which involves an exchange of energy between the person and environment for regulation and control of stressors (King, 1981, p. 98). King (1981) noted that all events in life cause stress to some degree.

In applying King's concept of the interpersonal system to this study, consider that the parent/caregiver of the chronically ill child, and the child himself comprise a portion of the interpersonal system. If the parent/caregiver has not previously interacted with a chronically ill child, he or she suddenly acquires a new role. The stress elicited by this new role becomes a motivator to acquire new skills. As a consequence of this role stress, the parent may seek out other individuals who have knowledge related to their particular problem, or those who have the common bond of having had the same experience.

Support groups for parents of chronically ill children can help parents acquire new skills. It is the responsibility of health care providers to support these parental groups in achieving their goals, which are to learn about the children's condition and how to properly care for them.

The third system of consideration in King's Interacting Systems Framework is the social system. The social system King defined as "units of analysis in a society in which individuals form groups to carry on activities of daily living, to maintain life, health, and hopefully, happiness" (Fawcett, 1989, p. 107). King noted several

concepts that are related to social systems. Three of them are of particular relevance to this study.

Organization is an essential aspect of parental support groups. According to King (1981), an organization is composed of human beings with prescribed roles who use resources to accomplish personal and organizational goals. The parental support group members have the common bond of needing support for the many challenges of rearing a chronically ill child.

Power is also an important factor in social systems such as parental support groups. Power is defined as "the ability to control events and behaviors in specific situations" (King, 1981, p. 127). The information and emotional support which these parents receive on an on-going basis from the support groups empowers them with sufficient resources to cope with their chronically ill child.

Decision making is an essential element in all social systems. Decisions are the "judgements made that affect a course of action to be taken in situations" (King, 1981, p. 13).

In relating these aspects of social systems to this study, first consider King's definition of social systems from Fawcett (1989). King noted here that groups are formed to carry on the business of living, and being happy. The purpose of parental support groups is to provide participants with information and support to promote a happier, more secure life. Support groups are organized to promote dissemination of information to participants. Parents of chronically ill children who



participate in support groups are empowered when they gain information to support decision making regarding the care of their chronically ill child. This power increases their control over their life and increases their life satisfaction.

King's Interacting Systems Framework works toward goal attainment in social systems. King (1981) defined goals as events that one wants, desires, and values. Goal attainment is the positive outcome of the transactions within interpersonal systems (King, 1981).

Parental support groups promote the decision-making process and goal and goal attainment for parents of chronically ill children. This enables these parents to improve home care of their children and to experience satisfaction within the family unit.

#### Significance of the Study

This study is significant to nursing science in several ways. Data from this study will identify the dimensions of family needs of parents of chronically ill children in rural northeastern Mississippi. The findings which indicate the areas of greatest need will be made available to healthcare providers such as the Public Health Service, local pediatricians, and social workers so that programs and services may be altered to meet these needs.

The findings concerning areas of need will also be disseminated to the various support groups in the area so that they may modify their programs to meet these needs. The findings may also be used as

a guide to presenting parents of chronically ill children with the information which they need most crucially.

This study gives direction for further research in this area. Since findings of this study are not generalizable to other geographic locations, the study can be replicated in other parts of the country.

The findings of this study can also be used in the educational setting, to educate health care providers concerning the family needs of parents of chronically ill children. This will promote the dissemination of the most urgently needed information and services by health care providers.

From an administrative perspective, the findings of this study can be used by local Public Health agencies who provide services to these special children and their families. Agencies can adapt their programs and services to better meet the needs of families with chronically ill children.

#### Assumptions

The assumptions for this study were:

1. Parents who have chronically ill children have special family needs which parents of healthy children do not experience.
2. Parents with chronically ill children realize that they have special needs concerning his/her child and seek outside help in meeting these needs.
3. The dimensions of family needs of parents with chronically ill children can be measured.



### Statement of the Problem

This study addressed the question: Does participation in a parental support group significantly decrease the family needs of parents with chronically ill children?

### Research Questions and Hypothesis

Two study questions were answered by this research and one hypothesis was tested.

Question 1. What are the dimensions of the family needs of parents of chronically ill children who participate in a parental support group?

Question 2. What are the dimensions of the family needs of parents of chronically ill children who do not participate in a support group?

Research hypothesis: Parents of chronically ill children who participate in a support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a support group.

### Definition of Terms

For the purpose of this study, the following terms were defined:

1. Parent - the primary caregiver of the child, be it a natural or adoptive relationship, or appointed legal guardian of the child.
2. Chronically Ill Child - a child, between the ages zero to twenty-one, who resides in rural northeastern Mississippi and has an illness, physical or cognitive disability with a prolonged course, which requires special medication, treatments, intervention, and education,

and is progressive or fatal, and alters physical functioning to some degree.

3. Parental Support Group - a small voluntary organization composed of parents of chronically ill children in rural northeastern Mississippi who meet on a routine basis to share information, experiences, and emotional support with one another for common goals of improving the care of their children both at home and within the health-care system.

4. Family Needs - special needs of children/families with chronic illness which are in three domains:

a. service/program needs - needs regarding training about special therapy, educational programs, day care services, counseling services, parent support groups, etc.

b. information needs - needs regarding medication, surgery, child's diet, immunizations, sexuality/sex education of the child, child's activity level, etc.

c. access to health care - problems with obtaining appointments, waiting too long at appointments, questions not answered at visits, rudeness, impersonal treatment, no transportation, and others. These needs are operationalized by the Family Needs Assessment Tool (FNAT). See Appendix A.

## Chapter II

### Review of Literature

There is abundant literature regarding the concept of parental support groups and chronic illness. However, few empirical studies exist linking these variables. The review of literature will begin with a discussion of the self-perceptions of needs of parents of chronically ill children, and the remainder of the chapter will discuss social supports for parents of chronically ill children, and instrument development for assessing family needs of parents of chronically ill children.

#### Needs of Parents of Chronically Ill Children

Horner, Rawlins, and Giles (1987) conducted a study to determine the perception of needs among parents caring for chronically ill children. The purpose of the study was to alleviate the misconception of the professional's perception of the parent's needs, versus the parent's perception of his or her own needs.

A questionnaire was developed to identify the most pertinent needs of families of chronically ill children. The questionnaire was mailed to a convenience sample of 493 families in a large Mid-Western city. One hundred sixty-four questionnaires were returned and tabulated for analysis. The findings of the survey revealed three major areas of concern for these parents. The first category was service/programs needs. Noted problems were impersonal treatment and



rudeness by staff, not understanding or disagreeing with treatment, lack of transportation, and difficulty making appointments.

The second category of concern was health care. Those needs identified here were lack of funds for medical costs, recreation for the child, educational opportunities, recreational and emergency childcare, counseling for families, parent support groups, home-training, in-home nursing, and out-of-home placement.

The third category of concern was socioeconomic/informational needs. Here the parents identified needs such as financial strains, lack of funds for proper care, concerns about the future of the child, questions about behavior expectations of the child, and growth and development of the child. Parents confirmed their own need for information as at least 25% expressed a lack of knowledge concerning 12 of the 24 needs listed in this category.

Recommendations for further study included extending the study to a larger population, or to other geographical areas, comparing the needs of rural parents versus urban parents, and examining the needs of the young person as a direct health care consumer.

Strauss and Munton (1985) identified the health care needs of developmentally delayed children and their families. This study was conducted due to the recent movement of cognitively and physically handicapped children out of institutions and into homes. Thus many families were faced with caring for these children, and some were unprepared to do so.

This descriptive study was conducted using a convenience sample of sixteen families with infants in two infant stimulation programs. The study was composed of brief structured interviews with open-ended questions regarding parents concerns and support systems.

Content analysis of the responses to the questions revealed three major areas of concern for the parents. They were grieving and depression, difficulty in obtaining services for themselves and their children and fears about the future.

The grief and depression experienced by these parents of chronically ill children is common and well-documented. The parents revealed that the majority of the support and understanding came from association with parents of other special children. Ministers and religious faith were also noted as significant sources of support.

The second area of concern involved the health care needs and special services required by the children. The parents cited problems with referral, negative experiences with health care providers, and the need for early intervention programs as the areas in need of improvement.

The final area of concern was apprehension about the future. The parents had many questions regarding growth and development of their children, changes ten years in the future, possible plateaus for their children, and the child's ultimate cognitive outcome.

No recommendations for further study were noted. However, recommendations for health care providers caring for these clients

included giving appropriate information that is pertinent to the child's physical and cognitive level. Early referral to developmental programs was noted as critical, along with positive feedback and appropriate assessment of parents' coping skills and resources to determine their particular needs for intervention. Support and encouragement were also advocated for these parents.

#### Social Support for Parents of Chronically Ill Children

In a descriptive study by Rawlins and Horner (1988), the relationship between informational needs of parents of chronically ill children and parental participation in support groups was examined. The study question was: does membership in a support group alter needs of parents of chronically ill children? The purpose of the study was to determine the informational needs of parents of chronically ill children, and to assess the effect of participation in a support group on these needs.

This study was undertaken in a large Mid-Western city. It employed the use of the Family Needs Assessment Tool (FNAT), which was developed by the researcher, and whose content validity had been verified by two maternal-child nursing experts. It was also pretested on twelve families with chronically ill children for comprehension and appropriateness.

The FNAT was mailed to 461 families in the area with chronically ill children. Of the 159 which were completed and returned, 65 were members of a support group, and 94 were not. Of



the families who participated in a support group. Ninety-two percent felt that it was beneficial.

For data analysis, a two-tailed  $t$ -test was performed on each questionnaire item to test for significance between the groups. Results revealed that in general, parents who did not participate in a support group (59.7%) differed very little in the perception of their needs from the parents who did participate in a support group (40.3%).

Regardless of support group participation, both sets of parents had most of their general needs met. There were however, seven items that were identified by support group participants as significant. They were: help with child's medical bills ( $t = -2.719$ ,  $df = 156$ ,  $p = .01$ ), babysitting for emergencies ( $t = -2.269$ ,  $df = 154$ ,  $p = .05$ ), and information on sexuality/sex education ( $t = -2.247$ ,  $df = 156$ ,  $p = .05$ ). The non-participants needs identified as significant were: information on immunizations/routine childcare, ( $t = 2.718$ ,  $df = 157$ ,  $p = .01$ ), chance of having another child with same problem ( $t = 4.416$ ,  $df = 156$ , and  $p = .01$ ), training and information about the child's special therapy ( $t = 2.113$ ,  $df = 155$ , and  $p = .05$ ), and information on parent support groups ( $t = 8.735$ ,  $df = 154$ , and  $p = .01$ ).

In examining these statistically significant needs, it was apparent that the parents who did not participate in a support group were seeking information that would have been readily available to them had they participated in a support group. The support group

participants were seeking information on a higher level, as more of their basic needs were met through support group participation.

Recommendations for further study included: investigating services provided by support groups, the sources and accuracy of information provided by the groups, the quality of referrals provided by the groups, and why some groups are successful and others are not. A report by Rollins (1987) also examined self-help groups for parents, in order to properly define the concepts of self-help groups and delineate its' functions related to parent self-help. A self-help group was defined as a "small voluntary organization composed of individuals who share a similar problem in health, mental health, or daily living" (Rollins, 1987, p. 403). The functions of self-help groups for parents were also noted. They included giving social re-enforcement, promoting change, teaching self-control behaviors, modeling, demystification, imparting information and advice, giving alternate perceptions of problems and solutions, support for changes in attitude, reduction of isolation, and alternatives in social structure.

Rollins (1987) noted that a parental self-help group can be formal or informal in nature. She also noted that the value of such groups is irrefutable. They enable parents to cope with many problems the normally fall within the domain of mental health care professionals. These support groups enable parents to feel more positive about their role, and therefore increase their ability to cope with rearing their special child.



Rollins (1987) did note two disadvantages with parental support groups. The first was the failure of the group to recognize when more extensive therapy was needed. This failure often resulted in the appropriate referrals never being made. The second was failure to recognize the uniqueness of a child or family's particular situation. This could be detrimental to the development of the child, and the well-being of the family. The author did note that these have become less problematic in recent years due to increased parent and professional communication.

A study by Ferrari (1986) examined the perceptions of social support by parents of chronically ill children. The focus of the study was concerned with social support and its potential as a stress-controlling agent for families with a chronically ill child. The purpose of the study was to determine the perceived level of social support by parents of children with different chronic conditions, and determine if type and degree of disability affect the perceptions of social support.

The sample was composed of 148 adults (74 married couples) from three states in the northeastern United States that were selected through outpatient hospital programs and school groups. The parents were divided into three groups: those who had normal, healthy children, those who had children with juvenile diabetes mellitus, and those with children who suffered from infantile autism. The rationale for using two distinct groups of handicapped children was that they

represent two populations greatly distinct in nature and severity of illness, with the autism being considered more comprehensively disabling.

The parents were interviewed in their homes, where the Inventory of Socially Supportative Behaviors (ISSB) was administered to both parents. The ISSB is a 40-item questionnaire which uses Likert scales to assess an individual's perception of the type and amount of social support they receive. The ISSB has been reported to have a high internal consistency, and a high test-retest reliability (alpha coefficient  $r = .882$ ).

In analysis of data, Duncan's multiple range test was used to examine mean group differences. Results revealed that the parents of healthy children had significantly higher levels of perceived social support (healthy  $\underline{M} = 97.297$ ,  $\underline{p} = <.001$ ), than had either of the two groups (autistic  $\underline{M} = 89.134$ ,  $\underline{p} = <.001$ , diabetic  $\underline{M} = 83.130$ ,  $\underline{p} < .001$ ). The difference in the mean scores between the parents of autistic children and diabetic children was also statistically significant based on the Duncan test. This indicated that the parents of diabetic children perceived the lowest levels of social support. Sex of the parent was also found to be a significant factor in perception of social support. The mean score for mother's perceived support was 92.022, where the father's mean score was 88.18. Since the father's perceived even less social support than the mothers, interventions might be developed to support these fathers.

Recommendations for further study based on these findings were replication of the study, an exploration of parent-child attachment relationships in families with handicapped children, and an exploration of the phenomena of apparently less impaired children's parents perception of lower social support than parents with more profoundly impaired children.

#### Instrument Development

Rawlins, Rawlins, and Horner (1990) developed a family assessment instrument that can be employed with families of chronically ill children. The tool was developed in response to the increasing number of chronically ill children who are being cared for at home, and for whom the traditional approach to raising children is inadequate.

These children in the home setting present special challenges to the parents that are caring for them. This instrument was designed to assess the perceived needs of parents, so that appropriate education, planning, and referral could be implemented when necessary.

Based on past experiences and previous research, the researchers theorized that perceptions of the needs of parents of chronically ill children lie within three domains: program/service needs, information needs, and access to health care.

Development of the Family Needs Assessment Tool (FNAT) occurred in several stages. In stage one, the focus was content validity of the three needs dimensions: program/services (Q1),



information (Q2), and access to health care (Q3). Appropriate test items were written for the three dimensions. They were then evaluated by a criterion group of twelve families with chronically ill children, two doctorally prepared maternal-child nursing experts, and the chairperson of the Governor's Taskforce on Pre-school and Handicapped Children in Kansas. The next step was a pilot test on a small group of Kansas families ( $N = 164$ ) whose children had a variety of chronic conditions.

In stage two, test items were revised to improve clarity, and reduce redundancy, based on the recommendations of those mentioned above. The revised FNAT was administered to twenty families at two-week intervals, establishing a test-retest reliability of 0.77 (range = -0.07 to 1.00). The FNAT was then mailed to 4,236 families with chronically ill children in the state of Kansas, and 1,494 useable questionnaires were returned.

Factor analysis using Bartlett's chi-square Chattell's Scree test, and the Kaiser-Guttman root determined tool reliability and construct validity. Bartlett's chi-square for the significance of the variance in the correlation matrix of the service/program needs (Q1) and information needs (Q2) was 27766.14 with 861 degrees of freedom ( $\underline{z} = 131.02$ ,  $\underline{p} < .0001$ ). Bartlett's chi-square indicated a factorable correlation matrix of the access to health care needs (Q3):  $\chi^2(66) = 4790.994$ ,  $\underline{z} = 55.60$ ,  $\underline{p} < .0001$ .

Although designed as a tool to assess large numbers of subjects, it is possible to adapt the FNAT to an ambulatory clinical setting, as would be useful to the Family Nurse Clinician. Currently there are investigations in eighteen states around the country employing the use of the FNAT. The developers are encouraging the use of the FNAT as they seek to normalize it to the entire nation. Therefore, recommendations for further study noted by the developers included use of the FNAT with other populations and in other settings.

#### Summary

In conclusion, the researcher has reviewed several studies related to self-perception of needs of parents of chronically ill children, the functions of social support in meeting these needs, and instrument development for analysis of these family needs.

Review of the literature revealed a consensus of opinion on the perception of the need for information, services and program needs, and obstacles to health care (Horner, Rawlins, and Giles, 1987, and Rawlins and Horner, 1988). There was also a consensus that family needs could be met through adequate social support (Rollins, 1987, Rawlins and Horner, 1988, Ferrari, 1986, and Strauss and Munton, 1985).

The purpose of the study was to answer two research questions and test one hypothesis. That is, what are the dimensions of family needs of parents of chronically ill children who participate in a support group, and the dimensions of family needs parents of

chronically ill children who do not participate in a support group? The research hypothesis was that parents of chronically ill children who participate in a support group will have significantly less unmet family needs than those who do not participate. Much evidence was noted in the review of literature to support this hypothesis. However, the conflicting findings that were noted as part of the study by Rawlins and Horner, (1988), which indicated that there were only seven areas of statistical significance in support group participants versus non-support group participants, provided the basis for this study.



## Chapter III

### The Design

The research design utilized in this study was a non-experimental, retrospective one. A retrospective study is defined as an "ex-post facto investigation in which some phenomenon existing in the present is linked to other phenomena occurring in the past" (Polit and Hungler, 1987, p. 145).

In this study, data were collected from parent/caregivers of chronically ill children using the Family Needs Assessment Tool (FNAT) (Rawlins and Horner, 1988). Data were then analyzed using descriptive statistics and content analysis to determine if participation in a parental support group significantly altered the dimensions and level of the family needs of the parent/caregivers of these children.

#### Variables

The dependent variable was the dimensions and of the family needs of parent/caregivers of chronically ill children as determined by scores on the FNAT. The independent variable was participation in parental support groups. Controlled variables in the study included the places of residence, and being primary caregiver of a chronically ill child. The intervening variables were the participants' educational level, marital status, physical and mental state at the time of testing, and truthfulness when answering the questionnaire.

### Research Questions and Hypothesis

The following questions were answered in this study:

Question 1. What are the dimensions of the family needs of parents of chronically ill children who participate in a support group?

Question 2. What are the dimensions of family needs of parents of chronically ill children who do not participate in a support group?

Hypothesis (Hr) : Parents of chronically ill children who participate in a parental support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group.

### Limitations

1. The sample size of this study was small, therefore results may not be generalizable to the population at large.
2. This study will be limited to the sample in rural northeastern Mississippi, therefore the results are not generalizable to other geographic areas.

### Setting, Population, and Sample

The setting for this study included three northeastern Mississippi counties within a thirty mile radius of one large industrialized city. This region is largely agricultural although the industrialized city was included.

In county number one, the 1988 average annual income was \$17,336. According to the 1988 update of the 1980 censuses, the population of county one was 64,580, with 54,940 Caucasian and



13,120 Black. There were 2,565 live births in county one in 1988 (Mississippi Statistical Abstract, 1989).

In county number two, the average income for 1988 was \$14,807. The county reported a population of 22,850 with 19,230 Caucasian, and 3,570 Black, according to the 1988 update of the 1980 census. There were 10 live births in county number two reported in 1988 (Mississippi Statistical Abstract, 1989).

In county number three, the third county's average annual income was \$11,045. County three recorded a population of 25,110, with 22,350 Caucasian, and 2,700 Black, in the 1988 update of the 1980 census. There were no live births in county number three in 1988. This was due to the lack of a physician in the county who would deliver babies (Mississippi Statistical Abstract, 1989).

According to the Director of Children's Medical Program (CMP) for District II, which encompasses the three counties described above, there were over 7000 children in Mississippi who receive services from CMP. In 1989 there were approximately 525 applicants or renewals for CMP in District II (G. Johnson, R. N., personal communication, May 15, 1990).

Data were collected from a convenience sample of parent/caregiver of chronically ill children who receive services from various agencies in the counties including Public Health Departments, the regional medical center, a school for cognitively and physically

disabled children, and also from parents who were members of various support groups in the area.

The sample consisted of 40 subjects, in two groups, one being those who were support group participants, and the other being those who were not participants. Those who did not participate in a parental support group became the control group, and those who did participate in a parental support group became the treatment group.

The population for this study consisted of all parent/caregivers of chronically ill children in rural northeastern Mississippi. All subjects which met the criteria for inclusion and were willing to participate in the study comprized the sample, which included 40 subjects.

#### Methods of Data Collection

##### Instrumentation

The instrument used to collect data was the Family Needs Assessment Tool (FNAT), a self-administered questionnaire, developed by Rawlins and Horner (1988). (See Appendix A). The FNAT consists of 58 multiple choice and fill-in-the-blank questions, with three open-ended questions added to the questionnaire. The questions were divided into six sections. Sections Q1-Q3 were the dimensions of family needs: service/program needs (Q1), information needs (Q2), and access to health care (Q3). Section Q4 were the support group participation questions, and section Q5 was the demographic section.

The questionnaire concluded with three open-ended questions concerning the support groups, and elicited other sources of

information and family needs for those who did not participate in a support group.

### Validity and Reliability

Establishing the validity and reliability of the FNAT has been an on-going process by the developers as related by Rawlins, Rawlins, and Horner (1990). The content validity of the tool has been estimated by several means. The developers, who were Master's prepared maternal child nursing experts, used clinical literature, and their combined thirty-five years of personal and professional experience as the starting point.

The tool was then reviewed by several authorities on care of chronically ill children, and a criterion group of 20 families with chronically ill children. The tool was pilot-tested on several families with chronically ill children. ( $N = 164$ ). The tool was then revised to eliminate redundancy, based on recommendations of the reviews and the pilot study. The revised FNAT's test-retest reliability was confirmed with an administration of the FNAT to 20 parents of chronically ill children in Wichita, Kansas area at two-week intervals. The average coefficient of stability of the individual items were 0.77 (range = -0.07 to 1.00) (Rawlins, Rawlins, and Horner, 1990).

After administering the FNAT to another large convenience sample in Kansas ( $N = 1494$ ), analysis of data revealed the construct validity of Sections Q1 (program/service needs), and Q2 (information needs) using Bartlett's chi-square for the significance of the variance



of the correlation matrix. It was found to be 27766.04 with 861 degrees of freedom ( $\underline{z} = 131.02$ ,  $\underline{p} < .0001$ ). Bartlett's chi-square also indicated a factorable correlation matrix of Q3 (access to health-care) as  $\chi^2(66) = 4790.944$  ( $\underline{z} = 55.60$ ,  $\underline{p} < .0001$ ) (Rawlins et al., 1990).

#### Administration and Scoring

The questionnaire was self-administered, and required approximately 20 minutes of the participant's time to complete. The questions in sections Q1-Q3 were multiple choice, and the participant was instructed to circle the appropriate response, which indicated the direction of need. The multiple choices were then assigned a number value from 1-3 in sections Q1-Q3 for the purpose of scoring the instrument. The assigned values were as follows:

##### Q1 Service/Program Needs

1=need (parent/child has this need but adequate services are not available)

2=none (this is not a need for parent/child)

3=needs met (parent/child had this need but it has been met by community services)

##### Q2 Information Needs

1=yes (parents needs this information)

2=no (parent doesn't want/need this information)

3=already have (parent has already been given this information)

##### Q3 Access to Health Care

Frequencies of Difficulties Experienced

1=rarely

2=sometimes

3=frequently

Section Q4 was also multiple choice, and was merely assigned the number value (e.g. 1-4) of the chosen response for scoring. For the purpose of data analysis, scoring was done by obtaining a cumulative score of the frequency of which a response was chosen for each question.

The demographics in section Q5 were also scored using the number value of the chosen multiple choice response, and the fill-in-the-blank questions were scored with the number value of the given response. Again, for scoring, a cumulative total of the frequency of each chosen response for each question was totaled. As content analysis was employed with the open-ended questions, no scoring mechanism was required.

#### Procedures

Initially, the researcher contacted one of the developers of the FNAT to gain permission to use the instrument. Permission was granted (see Appendix B). The researcher then contacted the administrators of the agencies and support groups in the three counties where the data were collected to explain the study and obtain their consent to utilize their facilities (see Appendix D). During these contacts, the researcher obtained dates of clinics and meetings which could be used in the data collection process.

The researcher then attended these clinics and meetings to personally invite individuals who met criteria for inclusion in the study to participate. The nature and purpose of the research was then explained to the participants, and an informed consent was signed by each participant (see Appendix E).

At the support group meetings, the researcher invited the members to participate collectively, and participants completed the questionnaires during the scheduled meeting. At the walk-in clinics, subjects were approached individually, and invited to participate, then participants completed the questionnaire on his/her own.

Data collection occurred from April through June, 1990. The anticipated sample size was 40: 20 subjects who were parental support group members, and 20 who were not. When this number was reached, the data collected was completed.

#### Pilot Study

A small pilot study was conducted with five participants. The pilot study was conducted to determine ease of understanding and comprehension of the FNAT. The participants averaged about twenty minutes in answering the questionnaire, and two of the participants experienced minor difficulty understanding the directions to section Q1. Therefore, the researcher gave verbal directions twice to all participants when conducting the study. No changes were made in the FNAT, and the data from the pilot study were included with the rest of the study.



### Consideration of Human Subjects

This study was approved by the Institutional Review Board for Use of Human Subjects in Experimentation of Mississippi University for Women (see Appendix C). This review ensures protection of human subjects in research.

The administrator/director of each agency involved in the data collection process signed an Agency Consent Form (see Appendix D), which served to protect the rights of participants as human subjects. Each participant also signed an informed consent (see Appendix E) prior to voluntary participation which ensured his/her privacy, anonymity, and freedom from harm.

### Methods of Data Analysis

Two research questions were answered and one research hypothesis was tested by this study. Question 1. What are the dimensions of family needs of parents of chronically ill children who participate in a support group? This question was answered by using descriptive statistics to determine the dimensions of family needs, based on the three subscales of the FNAT.

Question 2. What are the dimensions of family needs of parents of chronically ill children who do not participate in a support group? This questions was also answered using descriptive statistics to determine the dimensions of family needs, based on the three subscales of the FNAT. Descriptive statistics were also employed to analyze the demographic data.

The research hypothesis: Parents of chronically ill children who participate in a support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a support group. The research hypothesis was tested using a one-tailed t-test on the test items to determine if significant differences existed between parents who participate in a parental support group, and parents who do not participate in a parental support group.

## Chapter IV

### The Findings

The purpose of this study was to answer two research questions and test one hypothesis. Question 1: What are the dimensions of family needs of parents of chronically ill children who participate in a parental support group? Question 2: What are the dimensions of family needs of parents of chronically ill children who do not participate in a parental support group? Research hypothesis: Parents of chronically ill children who participate in a parental support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group.

Data were collected from parents of chronically ill children in rural northeastern Mississippi, 20 of whom were parental support group participants, 20 of whom were not support group participants. The participants were administered the Family Needs Assessment Tool (FNAT) (Rawlins and Horner, 1988) for data collection purposes.

#### Sample

Of the 40 participants included in the data collection process, 20 had female children, and 20 had male children. The age range of the children was 1 to 11 years, with the mean age being 5.050 years.

There were no (0%) children reported as having arthritis, and 4 children (10%) were autistic. Four children (10%) had cerebral palsy, 7



(17.5%) children had cleft/lip palate, and none (0%) of the children had cystic fibrosis. One child (2.5%) was reported as having diabetes, and 4 (10%) children had Down's syndrome. There were 5 (12.5%) children with hearing loss, and 5 (12.5%) reported as having congenital heart defects. There were 3 children with seizures (7.5%), 5 (12.5%) with sickle cell disease, 4 (10%) with spina bifida, and 8, or 20% who reported children with other problems. Those other problems reported included hydrocephalus, speech defects, and Cornelia deLange Syndrome.

Thirty-five of the study participants (87.5%) were mothers of the children. The remaining respondents (12.5%) were fathers of the children. Examination of marital status of the participants revealed that 5 were never married, 26 were married, 2 were separated, and 7 were divorced.

There were 13 Black, and 27 White participants. The number of family members in the households represented ranged from 2 to 8, with the mean being 3.850. Analysis of income level revealed that 75% or 30 of the participants had yearly incomes of \$25,000 or less, while 25% had yearly incomes of more than \$25,000.

### Results of Data Analysis

#### Research Questions

Data to answer the research questions, which were to determine the dimensions of family needs of parents of chronically ill children who participate in a parental support group, and those family needs of

parents of chronically ill children who do not participate in a support group are shown in Appendix F.

Upon analysis of the data, it was noted that the support group participants identified only three areas in the service/program section (Q1) as categories of need ( $> 40\%$ ). There were seven areas which the participants identified as having their needs met ( $> 50\%$ ) (see Table 1).

In analysis of information needs (Q2), the support group participants identified seven areas of need which were unmet ( $> 40\%$ ) (see Appendix F). The support group participants identified 10 areas of need which were already met ( $> 50\%$ ) (see Appendix F).

Regarding the access to health care needs (Q3), the support group participants noted that they rarely experienced difficulty ( $> 40\%$ ) in eight areas. The participants reported that they frequently experienced difficulties ( $> 40\%$ ) in none of the areas (see Appendix F).

In examining the dimensions of the family needs of non-participants, there were seven of the service/program needs (Q1) ( $> 40\%$ ) which were identified as a need (see Table 2). There was only one area ( $> 50\%$ ) identified as "needs met" for the non-participants (see Table 2).

Concerning information needs (Q2), there were 15 of the 24 areas ( $> 40\%$ ) identified as areas of need for the non-participants.

Table 1

Percentages of Service/Program Needs Identified by Parental Support  
Group Participants

Identified Need	% Need	%Need Met
Help with child's medical bills	50%	40%
Training/Information Child's Condition	35%	60%
Training/Information Child's Therapy	35%	60%
Appropriate educational opportunities	35%	50%
Daycare services	20%	60%
Babysitting for emergencies	45%	40%
Babysitting for recreation	25%	60%
Counseling services for family	35%	50%
Recreational/entertainment activities	45%	40%
Parent support group	10%	80%
In-home nursing help	15%	10%
Out-of-home placement	10%	0%

n=20



Table 2

Percentages of Service/Program Needs Identified by Non-Support  
Group Participation

Identified Need	% need	%needs met
Help with child's medical bills	80%	15%
Training/information child's condition	65%	20%
Training/information child's therapy	30%	25%
Appropriate educational opportunities	45%	30%
Daycare services	30%	60%
Babysitting for emergencies	15%	25%
Babysitting for recreation	40%	35%
Counseling services for family	55%	10%
Recreational/entertainment activities	50%	20%
Parent support group	75%	0%
In-home nursing help	0%	10%
Out-of-home placement	0%	0%

n=20

There were no areas (> 50%) of information needs identified as "already met" (see Appendix F).

The non-participants reported that they rarely experienced difficulty (> 40%) in 7 of the 11 access to health care needs (see Appendix F). They also reported frequent difficulty (> 50%) in only 1 of the 11 areas of the need in this dimensions (see Appendix F).

#### Research Hypothesis

The research hypothesis for this study was as follows. Parents of chronically ill children who participate in a parental support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group. The research hypothesis was tested using a one-tailed t-test to analyze the data for significant differences. The findings revealed that 13 of 47 areas of need in sections Q1 - Q3 were significantly different ( $p < 0.05$ ) for the non-support group participants (see Table 3). Therefore the research hypothesis was retained.

#### Additional Findings

Content analysis was employed to analyze the open-ended questions in the FNAT. One hundred percent of the support group participants responded when asked what had been most helpful in being a support group participant. The responses varied. The themes which emerged were: talking with others about their shared problems, meeting new people, a sense of helping others, information, a feeling

Table 3

Identified Needs of Statistical Significance Among Non-Support Group  
Participants

Identified Need	<u>t</u>	<u>df</u>	<u>p</u>
Help with medical bills	-2.01	38	.026
Training/Information about condition	-2.46	38	.009
Counseling Services for family	-2.32	38	.013
Parent Support Groups	-8.18	38	<.001
Immunizations/Regular Child care	-3.14	38	.001
Child's need for sleep and rest	-2.10	38	.021
Child's play and activity	-2.86	38	.004
How illness effect child's physical/ emotional growth	-1.73	38	.046
Helping child know what to expect when admitted to hospital	-1.86	38	.036
How child gets along with other family members	-2.21	38	.016
How child does in school	-1.73	38	.046
Reading materials about child's condition	-2.70	38	.005

n=20



of well-being, help in handling feelings, and receiving ideas from other parents.

The recommendations noted by 40% of the participants for improvement of services by support groups were: involving more people, giving more information, having professional speakers at meetings, outreach programs in hospitals for new parents of special children, and meeting more often.

Several sources of information regarding their special child were noted by the 92% of the non-parental support group participants who responded. These included: doctors, books, national foundations and organizations, and the special schools which their children attend.

There were also a minimal number of items which were analyzed using the one-tailed t-test which were marginally significant for the non-support group participants. They were: information on medications/treatments (t = -1.67, df = 38, p = .052), and information about child's diet (t = -1.67, df = 38, p = .051).

Also of importance to note were the results of the analysis of section Q4. This section was applicable only to the support group participants. When questioned concerning the extent to which he/she attended the support group meetings, the replies noted were: 5% seldom, 25% occasionally, and 70% frequently. When asked how helpful the participants found the support group to be, 80% of the respondents noted that participation in a support group was very helpful, while 20% noted that participation was somewhat helpful.

## Chapter V

### The Outcomes

This retrospective study was conducted to answer two research questions, and test one hypothesis. The research questions were: Question 1: What are the dimensions of family needs of parents of chronically ill children who participate in a parental support group? Question 2: What are the dimensions of family needs of parents of chronically ill children who do not participate in a parental support group? The research hypothesis was: Parents of chronically ill children who participate in a support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group. The Family Needs Assessment Tool was administered to 40 subjects in rural northeastern Mississippi, 20 of whom were parents of chronically ill children who participated in parental support groups, and 20 parents of chronically ill children who did not participate in a support group.

The research questions (i.e. dimensions of family needs) were answered by the percentages of needs identified (see Table 1, 2, and Appendix F). The research hypothesis, which stated that parents of chronically ill children who participate in a parental support group will have significantly less unmet family needs than parents of chronically ill children who do not participate in a support group, was tested using

a one-tailed t-test to determine significant differences between the groups. There were no items identified as unmet needs by the support group participants which were significantly different at 0.05 level, where as thirteen items were found to be significantly different at the .05 level for the non-parental support group participants, which retained the research hypothesis (see Table 3).

### Discussion

Based on findings noted in review of literature (Strauss and Munton, 1985, Rollins, 1987, and Ferrari, 1986) the researcher theorized that parental support groups aid significantly in meeting the special family needs of parents of chronically ill children. Thus the hypothesis was put forth that parents of chronically ill children who participate in a parental support group would have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group.

Upon analysis of data, there was evidence to support this hypothesis (see Table 3). There were trends noted in sections Q1 (service/program needs), and Q2 (information needs) that showed clearly that parents who participated in a parental support group had many more of the identified needs already met than did the non-support group participants. However, only 13 of these items were statistically significant ( $\underline{p} < .05$ ).

The findings of this study concerning the role of social support, and parental support groups were similar to the findings of Rollins



(1987), Strauss and Munton (1985), and Ferrari (1986), in that the importance of these groups and their social support were identified by the support group participants in the current study as very important to their well-being. The findings of this study differed somewhat from Rawlins-Horner (1988), in that 13 items were found to be significantly different for the non-support group participants, whereas Rawlins et al., (1988) noted only 4 items of significance for the non-participants. They were: immunizations/routine child care, chance of having another child with the same problem, training/information regarding child's therapy, and information regarding support groups.

The findings of this study also correlate well with King's Interacting Systems Framework. The personal system in this study was the parent/caregiver of the chronically ill child. The parent/caregiver was the person responsible for the child, therefore eliciting his/her perceived needs regarding the child was an accurate method of family assessment.

The interpersonal system, composed of the parent, interacting with two or more people in a given situation (Fawcett, 1989), is a process which involves communication. That is, as in a parental support group. The two other components noted by King as components of the interpersonal system, role and stress are also dealt with by participation in a parental support group. The emotional and psychological support that parents of chronically ill children receive from participating in these groups enable them to cope with the role

changes associated with raising a chronically ill child, and the accompanying stress.

Social systems, King's third component of the Interacting Systems Framework, were also of special importance to parents of chronically ill children who participate in parental support groups. Social systems have three important aspects: organization, power, and decision-making. The organization factor is important because these parents come together with a common bond, and with common goals. The parents derive power from support group participation, because of the information and emotional support they receive. This support, in turn, enables them to make appropriate decisions concerning the care of his/her child.

### Conclusions

The researcher concluded from the data analysis that parents of chronically ill children who participate in a parental support group have significantly less unmet family needs than parents of chronically ill children who do not participate in a parental support group. The dimensions of family needs of parents of chronically ill children who participated in a parental support group were determined using the FNAT (see Appendix F). As were the dimensions of family needs of parents of chronically ill children who do not participate in a parent support group (see Appendix F).

### Implications

There are several implications for nursing to be noted from this study. Health care providers will be made aware of the thirteen needs categories which were identified as significantly different for the non-support group participants (see Table 3). They can therefore tailor their programs and services to better meet these needs. The findings will also be used by area support groups to tailor their services to better meet the needs of their members. Family Nurse Clinicians working in this field can also use this information to begin new support groups, and to guide them in effectively meeting the needs of it's members.

The findings of this study also have implications for nursing education. Health care providers can be educated regarding the parents' own perception of his/her needs based, on the findings of this study. Administrators of the agencies which provide services to these children and their families can also use the findings of this study to appropriate funds, and adapt programs and services to better serve these clients.

### Recommendations

Based on the findings of this study, the researcher offer the following recommendations should be noted:

1. Replication of a similar study utilizing a larger sample.
2. Replication of a similar study in other geographic areas.



3. Conduction of a longitudinal study over 2 to 3 years to assess the value of continued participation in a parental support group.
4. Conduction of a study to assess the effects on the child of parental participation or nonparticipation in a parental support group.
5. Development of a more expeditious assessment tool for assessing the family needs of parents of chronically ill children.

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Appendix A

FAMILY NEEDS ASSESSMENT TOOL

Instructions: PLEASE COMPLETE THIS QUESTIONNAIRE AND RETURN IT BY \_\_\_\_\_ IT IS NOT NECESSARY TO SIGN YOUR NAME.

Q-1 The following services/programs are frequently needed by families of children with chronic illnesses. Please circle the answer that mostly clearly indicates your need for these services.

NONE means this is not a need for you/your child  
 NEED means you/your child have this need but adequate services are not available  
 NEEDS MET means you/your child had this need but it has been met by adequate services in the community

1.	Help with child's medical bills	NONE	NEED	NEEDS MET
2.	Training/information about child's condition	NONE	NEED	NEEDS MET
3.	Training/information about child's special therapy (i.e., OT, PT, speech)	NONE	NEED	NEEDS MET
4.	Appropriate educational oppportunities for child	NONE	NEED	NEEDS MET
5.	Day care services while working	NONE	NEED	NEEDS MET
6.	Babysitting for emergency	NONE	NEED	NEEDS MET
7.	Babysitting for recreation	NONE	NEED	NEEDS MET
8.	Counseling services for the family	NONE	NEED	NEEDS MET
9.	Recreational/entertainment activities for your child	NONE	NEED	NEEDS MET
10.	Parent support group	NONE	NEED	NEEDS MET
11.	In-Home nursing help	NONE	NEED	NEEDS MET
12.	Out of home placement	NONE	NEED	NEEDS MET

Q-2 Another important purpose of this study is to learn what kind of information would help you or your child. Please circle the answer that most clearly indicates your need for information on these topics.

YES means I need this information  
 NO means I don't want/need this information  
 ALREADY HAVE means I have already been given this information

1.	Medications/treatments	YES	NO	ALREADY HAVE
2.	Chance of having another child with the same problem	YES	NO	ALREADY HAVE
3.	My child's surgery	YES	NO	ALREADY HAVE

4.	Child's diet	YES NO	ALREADY HAVE
5.	Child's skin problems	YES NO	ALREADY HAVE
6.	How to improve communication among all the people who provide care for my child	YES NO	ALREADY HAVE
7.	Understanding of special treatments (i.e., OT, PT, speech)	YES NO	ALREADY HAVE
8.	Child's urinary or bowel elimination	YES NO	ALREADY HAVE
9.	Immunizations or other regular child care	YES NO	ALREADY HAVE
10.	Child's hygiene and grooming	YES NO	ALREADY HAVE
11.	Sexuality or sex education	YES NO	ALREADY HAVE
12.	My child's need for sleep and rest	YES NO	ALREADY HAVE
13.	My child's play and activity	YES NO	ALREADY HAVE
14.	How the illness affects my child's physical and emotional growth	YES NO	ALREADY HAVE
15.	Helping my child to know what to expect when he/she is admitted to the hospital	YES NO	ALREADY HAVE
16.	Behavior management	YES NO	ALREADY HAVE
17.	How to plan for my child's future	YES NO	ALREADY HAVE
18.	How my child could get along with other children	YES NO	ALREADY HAVE
19.	How to provide for my child's emotional, social, and intellectual needs	YES NO	ALREADY HAVE
20.	How to help family members get along	YES NO	ALREADY HAVE
21.	How my child could get along with other family members	YES NO	ALREADY HAVE
22.	How my child does in school	YES NO	ALREADY HAVE
23.	Community resources	YES NO	ALREADY HAVE
24.	Reading material about my child's condition	YES NO	ALREADY HAVE



Q-3 Parents of children with chronic illnesses frequently have concerns about obtaining health care. How often have you experienced any of these concerns? (Please circle appropriate answer) 51

1. Difficulty obtaining appointments	RARELY	SOMETIMES	FREQUENTLY
2. Waiting too long at appointments	RARELY	SOMETIMES	FREQUENTLY
3. Questions not answered at office visit	RARELY	SOMETIMES	FREQUENTLY
4. Questions between visits	RARELY	SOMETIMES	FREQUENTLY
5. Impersonal treatment	RARELY	SOMETIMES	FREQUENTLY
6. Rudeness	RARELY	SOMETIMES	FREQUENTLY
7. Costs too much	RARELY	SOMETIMES	FREQUENTLY
8. Don't understand the need for prescribed care	RARELY	SOMETIMES	FREQUENTLY
9. Don't agree with care	RARELY	SOMETIMES	FREQUENTLY
10. No transportation	RARELY	SOMETIMES	FREQUENTLY
11. Appointments conflict with job, school or family obligations	RARELY	SOMETIMES	FREQUENTLY

Others:

Q-4 Are you currently part of an organized parent group related to your child's disability? (Please circle)

1. No
2. Yes

1. b. To what extent do you attend?
  1. NEVER
  2. SELDOM
  3. OCCASIONALLY
  4. OFTEN
2. b. How helpful have they been?
  1. VERY HELPFUL
  2. SOMEWHAT HELPFUL
  3. NOT HELPFUL AT ALL
  4. DO NOT ATTEND







Kim,

Enclosed are the surveys. The first one (w/ date Aug. '85 in cover letter) involves the support group questions. We found this format confusing to the respondents. This is the survey that was reported in Red Asng. and included parents from Wichita / Sedgwick County. The second tool, revised from first, was sent to parents all over the state. The development of the tool (FNAT: Family Needs Assessment Tool) will be reported in the Western Journal of Nursing Research (they've accepted but not given us a date). If you need more info. about this, please call (316) 264-3894 home (316) 692-6822 work or write 945 Perry, Wichita, KS 67203.

The tool has been replicated so please give credit if used. Also, we would like to normalize the tool and are plotting results when it is used. Good luck.

Patricia Rawlins





MISSISSIPPI  
UNIVERSITY  
FOR WOMEN

Columbus, MS 39701

Office of the Provost  
P.O. Box W-1603  
(601) 329-7142

April 24, 1990

Ms. Kim Wilson Hardin  
Division of Nursing  
Campus

Dear Ms. Hardin:

The Committee for Use of Human Subjects in Experimentation has recommended approval of your research proposal "Comparison of the Informative Needs of Chronically Ill Children Belonging To A Support Group Versus Those Who Do Not Belong To A Support Group," and I am happy to approve their recommendation.

Sincerely,

*Dorothy Burdeshaw*

Dorothy Burdeshaw  
Interim Vice President  
for Academic Affairs

DB:wr

cc: Mrs. Mary Pat Curtis

## Agency Consent Form

Kim Wilson Hardin, RNC, BSN  
Route 3, Box 145  
Pontotoc, MS 38863  
601-489-5669

Mr./Ms. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Dear Mr./Ms. \_\_\_\_\_

I am a graduate student in nursing at Mississippi University for Women in Columbus, MS. My area of research for my Master's Thesis concerns the family needs of parents of chronically ill children. The purpose of my study is to determine the level and dimensions of family needs of parents of chronically ill children in rural northeast Mississippi.

I would like your permission to collect data from parents of chronically ill children that receive services from your agency or organization. The data collection instrument is the Family Needs Assessment Tool (FNAT) developed by Rawlins and Horner (1988). The FNAT is a five page questionnaire that will require approximately 20 minutes of the participants time to complete. There are no identified risks related to participation in this study.

The participants in this study will be included strictly on a volunteer basis, and will sign an informed consent prior to participation which ensures them anonymity, confidentiality, and freedom from harm. This study has been approved by the University's Human Subject Review Board. The subjects will be advised that while there are no immediate benefits, the study results will be used to improve the quality of care and services available to chronically ill children and their families.

The results of the study will be made available to you and your agency if you so desire. If you have questions, please feel free to contact me. Thank you for your time and consideration.

Sincerely,

Kim Wilson Hardin, RNC, BSN

Please sign here and return to me  
in the enclosed envelope if your  
permission is granted.

\_\_\_\_\_

## Consent Form

Dear Parent:

My name is Kim Wilson Hardin. I am a Registered Nurse, and I am also a graduate student in nursing at Mississippi University for Women. I am conducting a study through the University as part of the requirements of my Master's Degree. The study concerns the family needs of parents of chronically ill children in northeastern Mississippi. You are being asked to participate in this study on a volunteer basis because you are the parent or guardian of a special child.

The purpose of my study is to determine the level of family needs of parents such as yourself, and to determine if participation in a support group helps meet these family needs. All you have to do to take part in this study is to answer a questionnaire which will take about 20 minutes of your time to complete.

There are no risks identified in taking part in this study. There will be no immediate benefit to you or your child if you choose to participate, but the results of the study can help to improve the quality of care and services available to you and your child in the future.

As the research is being conducted with approval of Mississippi University for Women, you may be certain that all information received from you will be strictly confidential. You do not sign the questionnaire, so your answers will be anonymous. I will in no way be able to link your answers with your name. This consent form will be destroyed when the study is finished.

You have the right to refuse to participate, or to withdraw from participation in the study any time prior to data analysis, without consequence. Your refusal or withdrawal will in no way effect the care or services given to your child.

I will be available to answer any questions you have, and if you would like to receive the results of the study, please leave me your address on this form. Thank you for your time and cooperation.

Sincerely,

Kim Wilson Hardin, RNC, BSN

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Witness: \_\_\_\_\_



## Appendix F

Raw Data Percentages for the Family Needs Assessment Tool

Q1 Services/Program Needs	%Participants			%Nonparticipants		
	None	Need	Needs met	None	Need	Needs met
Help/medical bills	10%	50%	40%	5%	80%	15%
Training/Info. Child's Condition	5%	35%	60%	15%	65%	20%
Training/Info. Child's Therapy	5%	35%	60%	45%	30%	25%
Appropriate ed. opportunities	15%	35%	50%	25%	45%	30%
Daycare services	20%	20%	60%	10%	30%	60%
Babysitting for emergencies	15%	45%	40%	60%	15%	25%
Babysitting for recreation	15%	25%	60%	25%	40%	35%
Counseling services	15%	35%	50%	35%	55%	10%
Recreational/Entertainment Act.	15%	45%	40%	30%	50%	20%
Parent support group	10%	10%	80%	25%	75%	0%
In-home nursing help	75%	15%	10%	90%	0%	10%
Out-of-home placement	90%	10%	0%	100%	0%	0%

Q2 Information Need			already				already have
	yes	no	have	yes	no	have	
Medications/treatments	20%	20%	60%	40%	25%	35%	
Chance of having another child	35%	25%	40%	35%	35%	30%	
Child's surgery	30%	30%	40%	15%	70%	15%	
Child's diet	15%	70%	15%	5%	60%	35%	
Child's skin problems	20%	60%	20%	15%	80%	5%	
Improve communications—caretaker	60%	15%	25%	65%	25%	10%	
Understanding of special treat.	40%	10%	15%	50%	35%	15%	
Urinary/bowel elimination	15%	65%	20%	0%	95%	5%	
Immunizations/routine childcare	10%	30%	60%	60%	15%	25%	
Child's hygiene and grooming	15%	55%	30%	15%	60%	25%	
Sexuality/Sex education	20%	65%	15%	30%	70%	0%	
Sleep and rest needs	20%	30%	50%	50%	25%	25%	
Child's play and activity	10%	35%	55%	50%	25%	75%	
Effects of Illness on Growth	50%	20%	30%	80%	5%	15%	
Expect on admission to hospital	30%	15%	55%	45%	35%	20%	
Behavior management	35%	25%	40%	25%	60%	15%	
How to plan for child's future	70%	5%	25%	80%	10%	10%	
Get along with other children	20%	30%	50%	55%	30%	15%	
Child's emotional, social, intellectual needs	60%	10%	30%	65%	25%	10%	
How to help family members get along	25%	25%	50%	15%	45%	40%	
Child get along with other family members	10%	40%	50%	20%	65%	15%	
How child does in school	35%	25%	40%	55%	30%	15%	
Community Resources	65%	10%	25%	80%	15%	5%	
Reading materials about condition	40%	5%	55%	75%	10%	15%	

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Q3 Access to Health Care	Rare	Smts	Freq	Rare	Smts	Freq
Difficulty obtaining appointments	65%	15%	20%	50%	45%	5%
Waiting too long	30%	50%	20%	30%	45%	25%
Questions unanswered at visit	50%	50%	0%	40%	55%	5%
Questions between visits	25%	65%	10%	35%	55%	10%
Impersonal treatment	50%	40%	10%	85%	15%	0%
Rudeness	75%	20%	5%	75%	25%	0%
Costs too much	20%	60%	20%	25%	15%	60%
Don't understand need for prescribed care	80%	10%	10%	60%	40%	0%
Don't agree with care	70%	20%	10%	75%	25%	0%
No transportation	85%	5%	10%	85%	15%	0%
Appointments conflict	40%	45%	15%	35%	45%	20%

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Rare=Rarely  
 Smts=Sometimes  
 Freq=Frequently

n=20