

Stressors Experienced by Families
With Children on Peritoneal Dialysis

by

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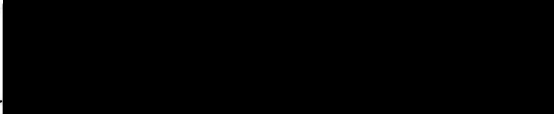
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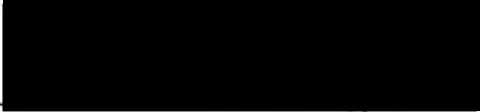
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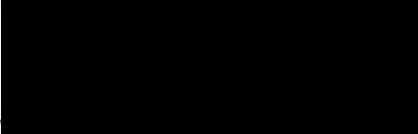
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TABLE OF CONTENTS

CHAPTER	PAGE
I. INTRODUCTION.....	1
Statement of the Problem.....	4
Purpose.....	4
II. REVIEW OF THE LITERATURE.....	6
Chronic Childhood Illness and the Family.....	6
Children with Chronic Illness and Family Functioning.....	9
Children with Chronic Renal Disease its Impact on the Family.....	14
Conceptual Framework.....	20
Research Questions.....	23
Operational Definitions.....	23
III. METHODS.....	25
Sample.....	26
Procedures.....	26
Instrument.....	29
Data Analysis.....	32
IV RESULTS.....	34
Sample.....	34
Demographic Characteristics.....	34

TABLE OF CONTENTS (Cont.)

CHAPTER	PAGE
IV. RESULTS (Cont.)	
Data Analysis.....	37
Question 1.....	55
Question 2.....	56
Question 3.....	57
V. DISCUSSION AND SUMMARY.....	59
Limitations.....	66
Implications for Nursing Practice.....	69
Recommendations for Further Research.....	69
Summary.....	70
REFERENCES.....	74
APPENDICES	
Appendix A	
Initial Letter and Consent Form.....	77
Appendix B	
Followup Letter for all Respondents.....	79
Appendix C	
Final Reminder Letter.....	80
Appendix D	
Demographic Questionnaire.....	81
Appendix E	
Questionnaire on Resources and Stress... ..	82

LIST OF TABLES

TABLE		PAGE
1	Conceptual Organization of the QRS.....	30
2	Comparison of Ages Between Groups: CAPD, CF, and Control.....	36
3	Mean Values, Standard Deviations, and F Scores for Each Group.....	38
4	Comparison Between CAPD and CF for Scales With Significant Results.....	41
5	Comparison Between CAPD and Control for Scales With Significant Results.....	42
6	Comparison Between CF and Control for Scales With Significant Results.....	43
7	Correlation Between Age and Scores on QRS for CAPD Group.....	50
8	Mean Values, Standard Deviations, and F Scores for CAPD Group When Divided into Preschool, School-age, and Adolescent Age Groups.....	51
9	Comparison Between Preschool and Schoolage CAPD Patients for Scales with Significant Results.....	52

LIST OF TABLES (CONT'D.)

10	Comparison Between Schoolage and Adolescent CAPD Patients for Scales with Significant Results.....	53
11	Comparison Between Preschool and Adolescent CAPD Patients for Scales with Significant Results.....	54

CHAPTER I

INTRODUCTION

Continuous ambulatory peritoneal dialysis (CAPD) is a relatively new form of treatment for end stage renal disease (ESRD), having been developed in the late 1970's as an outpatient alternative to hemodialysis. It now accounts for a good portion of the treatment for people in the United States with ESRD who are on dialysis. The remainder of the dialysis population is on hemodialysis.

The number of children who are diagnosed with end stage renal disease each year is relatively small when compared with some of the other more common chronic childhood illnesses. It has been estimated (Foreman & Chan, 1988) that the incidence of ESRD in children is between six and eight new cases per one million children per year.

The ultimate goal for every child with chronic renal failure is a successful kidney transplant. There is sometimes a prolonged wait for a kidney transplant, however, during which time dialysis is indicated. Occasionally for a variety of reasons, a successful match is never found. For children on dialysis, CAPD

is the preferred method of treatment at Oregon Health Sciences University (OHSU), as it is in a number of other institutions around the country (Zaontz, Cohn, Moel, Majkowski, & Firlit, 1987). It is preferred because it is a mode of therapy that can adapt more easily to the lifestyle of the family and the child's need for schooling. Also, when compared with hemodialysis, fluid intake and diet are less restricted. Therefore, CAPD often enables children to grow better and lead a less restricted lifestyle. Peritoneal dialysis is also technically a much less difficult type of dialysis to perform on people with relatively small blood volumes such as children.

After a training period of from one to two weeks, CAPD is done at home by the family, usually by one or both parents. The child is encouraged to participate in these procedures when it is developmentally appropriate. The procedure consists of instilling a prescribed amount of dialysis fluid into the peritoneal cavity via a surgically implanted catheter. This procedure takes place four to five times per day. Fluid then dwells in the abdomen for a specified amount of time, usually from four to six hours while it

absorbs much of the body's waste products and excess fluid. After this, the fluid is drained from the abdomen, and fresh fluid is then re-instilled. The techniques are simple. The complexity lies in the knowledge of and compliance with sterile technique and the parent's ability to problem-solve situations that may occur such as dehydration, fluid overload, or high blood pressure. In situations such as these, the dialysis solution and techniques must be varied somewhat to accommodate for these changes. In addition, parents are required to be able to identify and treat infections that may occur within the system. Finally, the presence of chronic renal failure brings with it numerous medications that must be taken every day in order to keep the body's mineral balance within relatively reasonable levels. The family is responsible for ensuring that these medications are taken properly and at the correct time.

It has long been assumed that the presence of a child with chronic illness places a great deal of stress upon a family. However, researchers are still in the process of systematically studying the effects of chronic illness on families. There continues to be

much to learn about the extent and the nature of the impact on the family when chronic illness strikes a child. In addition, the continuing impact that chronic childhood illness has on family functioning is also in need of further study.

Statement of the Problem

Since CAPD is such a new method of treatment for ESRD, information about it in the literature is primarily anecdotal. There are no studies that look at how the presence of a child on home peritoneal dialysis affects family functioning. No systematic inspection has been made of the impact on the family of this particular mode of therapy for chronic renal failure, even though it is rapidly becoming the preferred method of treatment of ESRD in children. The literature that is currently available has focused primarily on children who are on hemodialysis. Virtually no work has been published that specifically looks at the stresses placed on families with children who are on home peritoneal dialysis.

Purpose

The major purpose of this study is to more clearly understand how the presence of a child on CAPD affects

the functioning of the family. In addition, it is anticipated that family responses to this particular chronic childhood illnesses which may be similar or dissimilar to those of other chronic childhood illnesses, will be identified. In doing so, the opportunity is provided to bring attention to this uncommon but often devastating disease. As a result, perhaps nurses can learn to be more effective in interventions with these children and their families.

CHAPTER II
REVIEW OF THE LITERATURE

Introduction

The literature pertaining to chronic childhood illness and the family will be presented in this chapter. First, there will be a discussion of some of the literature that examines the subject of childhood chronic illness and the family. Next, the impact of specific chronic childhood illnesses on families will be discussed. Finally, the current state of knowledge about childhood renal disease and its impact on the family will be presented. The conceptual framework for the study will follow the literature review. The research questions and operational definitions for the study will conclude the chapter.

Chronic childhood illness and the family

When chronic illness strikes a child, the entire family is influenced. Families are often greatly affected by the stress of constant care, and the frequent restrictions of activity that can make the family increasingly socially isolated (Futcher, 1988). The decreased frequency of social contacts may not entirely be a choice made by the family. Often

families with chronically ill children become stigmatized (Kazak, 1989) and this can further lead to social isolation.

When caring for a child with a chronic illness, age and developmental level must be taken into account. "The meaning and demands of childhood chronic illness change with the child's development and with developmental changes within the family" (Kazak, 1989, p. 26). Also, changes within the family over time can affect family functioning as adaptation to the presence of a chronically ill child is not a one-time process. Finally, it is often believed that the range of functioning of a family with a chronically ill child can be very broad, and can vary from family to family. Some researchers believe that the emphasis should be upon an attempt to identify variables within specific chronic illness groups that contribute to an increase in stress within the family (Kazak, 1989).

A common theme in the literature on chronic childhood illness is the restrictions that it places on the family lifestyle (Vavasseur, 1987). No longer can a family simply take off for a weekend; considerable planning usually must be involved if the family can

leave at all. Often parents have no one to watch their child so they can leave for a few hours or spend an evening alone together. Restrictions can also be economic in nature. The expense of having a child who is chronically ill can be considerable and can greatly affect family lifestyle.

The effects of childhood chronic illness can be felt acutely by siblings of the affected child. A recent study examined the effects on children who have a sibling with a chronic illness. Tritt and Esses (1988) compared the siblings of 27 chronically ill children with the siblings of 27 well-matched healthy children in Winnipeg, Manitoba, Canada. Siblings of children with diabetes, juvenile arthritis, and gastrointestinal problems were the pool from which the sample was taken. These diseases were chosen to be included because they all are non life-threatening, require prescribed medications and treatments, and frequently require parental involvement in the care of the child involved. Excluded from the study was any child whose physical appearance was affected by the disease, or who had been hospitalized at any time prior to the diagnosis. These two exclusion criteria limit

the applicability of the results to other chronic illness populations including children on CAPD, as does the fact that the diseases chosen were considered not to be life-threatening. The authors found that the siblings of the chronically ill children were much more likely to be perceived by their parents as having more behavioral problems. The siblings themselves often experienced feelings of abandonment and loss, half of them saying they felt as if their ill brother or sister received special treatment. In addition however, the authors also report that some of the older siblings felt as if they had developed more patience, understanding, and sensitivity as a result of the experience.

Specific chronic illnesses and family functioning

There is little information in the literature about families with children on CAPD. There is however, a great deal written about family adaptation to other specific chronic childhood illnesses.

Families of children with cystic fibrosis (CF) have been studied extensively. Walker, Ford, and Donald (1987) researched 64 mothers, half of these women had children with cystic fibrosis, half had

healthy children. These children were then matched for age and sex with control subjects. The purpose of this study was to examine the variables of age of the child and the severity of the illness, with respect to the stress reported by the mother. The study showed fewer differences in levels of stress between the mothers of children with cystic fibrosis and the mothers of the matched control subjects than was expected based on the author's review of the literature. However, the results identified a positive relationship between the mother's own assessment of the severity of her child's illness and her stress levels. That is, mothers who saw their child's illness as being more severe "reported financial strain, greater limits on the family's ability to engage in activities, feelings of personal burden in the caretaking role, worry about the child's future, and anticipation of the child's death" (p. 244). In addition, the mothers of preschool-age and adolescent children with CF reported significantly more depression than did mothers of healthy children in these age groups.

A different perspective of childhood chronic illness and the family was examined by Lewis and Khaw

(1982). Their study looked at the relationships between behavior problems in children and family adaptability and cohesion. One third of the 84 children included in the study had CF, one third had asthma, and one third were healthy controls. The three groups were matched for age, gender, and race. Olson's circumplex model of adaptability and cohesion was the conceptual framework used. However, the instrument that was used to measure adaptability and cohesion has yet to be validated. The study concluded that although caring for a chronically ill child can be inherently stressful, it does not have to lead to deficits in family functioning.

Families of children with leukemia have also been studied. Two studies (Fife, Norton, & Groom, 1987; and Kupst & Schulman, 1986) addressed the family variables that lead to healthy adaptation in families of children with leukemia. Unlike some of the studies reviewed above, family members in addition to the mother and the affected child were examined. Both of these studies found that families with stable relationships and adequate support within the family were able to do well over time. In addition, Kupst and Schulman (1986)

found that the quality of the parents' marriage and lack of other concurrent stresses, especially financial ones, resulted in positive adaptation.

Dr. Jean Holroyd is a well-published researcher in the field of chronic childhood disorders and their impact on the family. In a frequently cited study, Holroyd and Guthrie (1986) compared the stress experienced by parents of children with neuromuscular disease, cystic fibrosis, and renal disease with that experienced by parents of healthy children. The Questionnaire on Resources and Stress (QRS) (Holroyd, 1974) was the tool used on the 43 children that were included as subjects. This tool divides family functioning into 15 separate scales, and then measures the family functioning within each of these scales. In this way different sources of stress can be identified. Using a t test, the authors discovered that each of the three groups families with chronically ill children had increased levels of stress when compared with the control group. However, the number and types of stressors experienced were found to be different for each illness. The families of children with renal disease were found to have the lowest levels of stress

of the three groups. Financial problems and difficulties with the physical limitations of the child were the only stressors that were found to be higher in the families of children with renal problems than in the control group. One problem with applying this information to the family of the child on CAPD is that the children in the Holroyd study were not yet at the stage in their disease where dialysis was necessary. In fact, the authors noted this when they identified the fact that "[Renal disease] does not generally require as much family care as cystic fibrosis and Duchenne's dystrophy unless the patient is on home dialysis" (p. 553). The children with CF were found to differ significantly from the control group in the high degree of financial stress the families experienced, as well as a perceived lack of social support. In addition, parents felt burdened by the physical incapacitation of the child, were sensitive to the child's "different" appearance, and felt the threat that although the illness was eventually terminal, they anticipated a lifetime of care.

Children with renal disease and its impact on the family

There is much information in the literature about the impact of chronic childhood illness on the family. There is however as stated earlier, little information on the family consequences of childhood renal disease. No studies were found that specifically looked at children on peritoneal dialysis.

Vance, Fazan, Satterwhite, and Pless (1980) examined the effects that a child with nephrotic syndrome has on the family. Nephrotic syndrome is often a precursor to end-stage renal disease. Both the subjects and the matched control group were from two large cities in the Eastern United States. A total of 35 families completed the study. No report of reliability or validity of the measures that were used was given. Of particular interest was the fact that while parental adaptation to the illness was often good (denial being a frequently used coping mechanism), schoolage and adolescent siblings showed lower self-security and self-confidence, and poorer academic performance than the control group.

Although not a formalized study, LePontois, Moel, & Cohn (1987) provided an interesting anecdotal account of the family's adjustment to having a child on CAPD. The information came from the 39 children who had at that time entered the CAPD program at Children's Memorial Hospital in Chicago. In addition, the authors used a developmental approach, dividing the children into three groups: infants and toddlers, school-age children, and adolescents.

The authors found that the two times when there is the most stress on the family is when the child is an infant or toddler, and again during the child's adolescence. School-age children were found to successfully use coping skills such as sublimation, intellectualization, and mastery. The use of these age-appropriate defense mechanisms allowed the children to more effectively cope with their feelings of anger, anxiety and helplessness about the disease.

When the child on CAPD is very young, he or she is totally dependent on the parent(s) for all of his or her dialysis needs. It was felt that parents eventually begin to experience feelings of ambivalence about the child's need for continuous medical care.

The negative feelings can be threatening to parents who realize that their children's lives depend on their close following of medical procedures. These feelings therefore, tend to either get suppressed or displaced on to other family members, or on to the health care team.

As the child enters adolescence a greater awareness is developed of the differences between him or herself and the peer group. Differences in stature, delayed sexual maturation, the presence of a catheter in the abdomen, all now lead to feelings of rejection. The child responds to these feelings of rejection by his or her peer group with shame and isolation. Children who were previously very compliant with their medical regimen and procedures, during adolescence may become very non-compliant. Most parents during this time realize that their child needs to exert independence and self reliance by becoming more responsible for his or her own care, but are hesitant to trust the non-compliant teenager to perform the procedures correctly, if at all. The authors conclude that perhaps it is best to not expect equal and simultaneous success in all areas of the child's and

the families adaptation to this often cruel and difficult disease.

The psychiatric adjustment of children with chronic renal failure was examined and contrasted with that of children with less severe forms of renal failure, and healthy matched controls (Garralda, Jameson, Reynolds, & Postlethwaite, 1988). Twenty two children who were on hemodialysis were matched for age and sex with 22 children with chronic renal failure not yet on dialysis. It was assumed that all children not yet on dialysis, would eventually be candidates for dialysis and/or transplantation. The two groups of ill children were comparable in terms of age of onset and length of illness. Twenty two control children were then selected from schools in the area and were individually matched for age and sex with the dialysis patients. The healthy control sample was then increased in size to a total of 36 children in order to allow comparison with the larger combined sample of both dialysis and non-dialysis children. Psychiatric disorder was found to be present in one third of the children in the dialysis group, although what is meant by psychiatric disorder was not stated. Also, the

authors found a statistically significant correlation between psychiatric disturbance in the children on dialysis and high levels of family stress. It was felt that the increased stress in the family led to the psychiatric disturbances. Finally, problems with psychiatric adjustment were more numerous and more severe in the hemodialysis group than in the non-dialysis group of children with chronic renal failure. Although the results of this study cannot be applied directly to families and children on CAPD, the authors do suggest that attention to psychologic functioning be given routinely to all children with chronic renal failure. This would certainly apply to children on CAPD.

Using the same information from the study described above, the authors examined the data from the point of view of family functioning, rather than the functioning of the individual child (Reynolds, Garralda, Jameson, & Postlethwaite, 1988). As mentioned previously, peritoneal dialysis was not discussed. This analysis of the data showed greater and more frequent disruption of family life in the dialysis group when compared with the non-dialysis

group. Although more than twice as many parents with children on hemodialysis reported marriage problems, the area where parents of the dialysis group reported the most difficulty was with finances and in dealing with the other children at home. Disruption in family life caused by the child's illness was reported by 77% of the parents in the dialysis group, as compared to 31% of the parents in the non-dialysis group. Again, since children on CAPD were not included in the sample, no conclusions can be drawn, but it is clear that not only are children on dialysis frequently adversely affected by the ramifications of the disease, but equally affected is the family. It is also clear that much more information needs to be obtained about families with children who use CAPD as their treatment modality. CAPD as a treatment option for end stage renal disease is a viable and well-accepted method of treatment for chronic renal failure in children when dialysis is indicated.

In summary, the literature has often addressed the subject of chronic childhood illness and its impact on the family. More recently, the focus has been to look at specific chronic childhood conditions and how each

impacts the family in a slightly different manner. Many researchers feel that each and every chronic illness brings with it its own array of needs, problems, and consequences. In order to understand the impact on the family of a particular chronic childhood illness then, that illness needs to be examined separately from other illnesses.

One particular group of chronically ill children that has had virtually no systematic study are children with chronic renal failure who are on CAPD. CAPD is felt by many to be the treatment of choice for children with ESRD for a number reasons that have been previously described. It was felt therefore that a beginning investigation was needed of the stressors experienced by families with children on CAPD.

Conceptual Framework

The two concepts that will be examined in this research project are chronic disease and family stress. It is believed that the presence of chronic illness within the family unit will create or increase stress in the family. This relationship has been studied extensively in families with children who have cystic fibrosis. It is the intent of this project to

investigate whether a similar relationship between the presence of a child on CAPD, and an increase in stress in the family exists.

To include the family as the client when working with the chronically ill child is part of a logical process. The life expectancy of children with chronic illness has been greatly extended with recent advances in medical technology. In addition, the care of these children has shifted from the hospital to the home (Walker, Ford, & Donald, 1987). The home, therefore, and the family environment is the arena where most of the care of the child with chronic illness takes place. "In chronic illness, there is no expectation that the problem will disappear. The disease and the sick family member become part of a recast family" (Griffith & Griffith, 1987, p. 202). If the family is to be looked at from a systems perspective, where a change in one part of the system has an effect on all other parts (Clements & Roberts, 1983), then nursing needs to focus on the family when working with a chronically ill child.

Different chronic illnesses have various degrees of impact and of severity. Often the severity of the

illness can be a major factor in determining the impact of that illness on the family unit. In addition, different chronic illnesses will often impact the family in distinct ways (Holroyd & Guthrie, 1986). Of the chronic illnesses that have been extensively studied, cystic fibrosis appears to bear the most similarity to children with chronic renal failure who are on CAPD.

Cystic fibrosis is a chronic childhood illness that has been frequently examined from from a family systems perspective. The families of children with CF have a number of elements in common with families of children on CAPD. These elements will be described in further detail below. In addition, the effects of each of these diseases on the family can be compared for several reasons. First, both are chronic illnesses that affect children of all ages and have a great deal of variation in terms of severity. In both diseases the child often looks physically different from his or her peers, sometimes quite different. Also, certain procedures must be carefully and painstakingly followed every day in both CF and CAPD. Ignoring these procedures or omitting them can have tragic results.

In addition, in both cases the parents or caretakers often have no one else to care for the child. It can frequently be difficult to get away for any length of time at all. These two diseases are similar in that they are often seen as a series of acute hospitalizations followed by periods of relative health. Finally, the disease in both cases never goes away, and the child and family must deal with the ever-present possibility of death.

Research Questions

1. Will the types of stressors encountered by families of children with chronic renal failure who are on CAPD, be similar to those encountered by families of children with cystic fibrosis?

2. Will the amount of stress be similar in families with children on CAPD when compared with that of families of children with CF?

3. Will the amount and type of stress be similar in both CAPD and CF groups, when compared to families with healthy children?

Operational Definitions

The operational definitions for the concepts used in this proposal are as follows. 1) Pediatric patients

will be defined as children age 18 or younger, who are at least partially dependent upon a parent or another adult for assistance with peritoneal dialysis procedures. 2) Chronic renal failure on CAPD will be defined as any person who is on CAPD and is beyond the training period that it takes to learn to perform the procedures at home. 3) A family is any group of two or more persons who live in the same household and perceive themselves as a family unit.

CHAPTER III

METHODS

Introduction

The aim of this study was to identify the stressors experienced by families with children who are on CAPD. Data for the families of children with CAPD was collected specifically for this project using methods to be described in detail below. Information gathered from CAPD families was then compared to similar data obtained by Holroyd and Guthrie (1986). Their study looked at families of children with CF and families with healthy children using the same instrument as was used with the CAPD families in this project. As a result, it was possible to combine the data and have a study that examined three groups: families of children with chronic renal failure on CAPD, families of children with CF, and families with healthy children.

The format of this study is that of a descriptive survey. A survey design can be a useful tool when attempting to identify or describe the presence or incidence of a phenomenon (Woods & Catanzaro, 1988). Since identification and description of stress in

families with children on CAPD is one of the intents of this research project, this particular format was selected.

Sample

Prospective subjects for the CAPD sample included families with children up to and including age 18 years who were at that time on CAPD. The only other condition for participation in the study was that the child must have been on CAPD for at least one month, so that families still in training were not included. Sources for the study sample consisted of the pediatric CAPD population at Oregon Health Sciences University. At the time, this consisted of 20 children and their families. The pediatric CAPD clinic at OHSU is the largest peritoneal dialysis clinic in the Pacific Northwest that is geared specifically toward the care of children with renal failure who are on CAPD.

Procedures

Questionnaires were administered by mail primarily due to the fact that many of the families with children on CAPD live not only far from the hospital and city in which the clinic is located, but a number of families live in other states.

Prior to contacting families, the proposed research format was presented to and approved by the Human Subjects Committee at OHSU. After approval was obtained, questionnaires were sent to each family along with a cover letter which included the information needed to make an informed consent to participate in the study. Participation in the study was voluntary and care was taken that responses could be made anonymously. Assurances were made to families that if they chose not to participate, the care of their child would not be affected in any manner.

Respondents were asked to supply some demographic information with the returned questionnaires. Demographic information that was requested included whether the respondent was mother, father or another caretaker of the child; marital status of the respondent; age of the child on CAPD; length of time on CAPD; and number of siblings living with the child on CAPD. In addition, in order to encourage response, a MacDonald's gift certificate was included with the letter. A returned, completed questionnaire was assumed to indicate that the family had given consent to participate in the study. A total of three mailings

was sent to each family, the second and third letters being reminder letters. The format of the mailings followed the suggestions made by Dillman (1978) except that a total of only three letters were sent to each participant. (See Appendices A, B, and C for reproductions of the letters sent to each family.)

Incidentally, a note about the recommended format of the mailings. The first mailing according to Dillman (1978), usually brings a response rate of between 19% and 27%. He further states that the first follow-up mailing (the second contact) is often followed by a response that can equal, and sometimes surpass the response of the first mailing. Finally, it is expected that the response from the final contact (the certified letter) will result in another one third of the unanswered questionnaires. In this survey these predictions did not hold out. There were eight responses (57% of the total) obtained from the first mailing. The second mailing brought another five responses (36% of the total number of respondents). There was only one response (7%) that can be attributed to the fact that a third mailing, a certified letter, was sent. The fact that such a small response was

obtained with the final mailing makes it debatable if it is worth the time and expense of sending this mailing by certified mail.

Instrument

The Questionnaire on Resources and Stress (QRS) (Holroyd, 1974) is the instrument that was used in the study. The QRS is a 285 item true-false questionnaire that can be self administered. It takes approximately 30 minutes to one hour to complete the tool, and requires a minimum of a sixth grade reading level. (See Appendix E for a copy of the QRS.)

Conceptually, the QRS is comprised of 15 scales that encompass three domains: personal problems for the respondent, family problems, and problems for the chronically ill child. (See Table 1 for an outline of the organization of the tool.) Each individual scale of the instrument can be scored independently of the others. This organization enables the researcher to examine more clearly the types of stress that individual families and groups of families have when faced with the chronic illness of a child.

The QRS has been used extensively in the study of stress and coping in families of children with various

Table 1

Conceptual Organization of the QRS

Scale	Number of Items
Personal Problems Scales	
1. Poor health/mood	11
2. Excess time demands	14
3. Negative attitude toward index case	23
4. Overprotection/dependency	13
5. Lack of social support	10
6. Overcommitment/martyrdom	7
7. Pessimism	13
Family Problems Scales	
8. Lack of family integration	23
9. Limits on family opportunity	9
10. Financial problems	17
Problems of Index Case Scales	
11. Physical incapacitation	14
12. Lack of activities for index case	6
13. Occupational limitations for index case	7
14. Social obtrusiveness	7
15. Difficult personality characteristics	32

physical and/or mental disabilities, as well as families with healthy children. It has also been used to compare the stress encountered by families of children with a variety of types of chronic illnesses. In this way it has been used as a vehicle to assess the needs of families and compare how those needs differ with different illnesses.

The reported Kuder-Richardson-20 internal consistency reliability correlations for the QRS is .96 (Holroyd, 1987). Kuder-Richardson internal consistency reliability has also been measured on each of the 15 subscales. Median coefficients ranged from a low of .24 (scales 5 and 14) to a high of .88 (scale 15). Generally, the shorter the scale the lower the reliability estimate.

Content validity for the QRS was established by having a group of 12 experts in the field of chronic illness and families select the most appropriate items from a 556-item pool during the initial development of the tool. Items were selected on the basis of content, appropriateness, clarity, and lack of redundancy (Holroyd, 1987).

The correlation of QRS scores with external criterion scores in order to obtain a validity coefficient has reportedly not been feasible because of the lack of measures of criteria for the type of stress the tool is attempting to measure (Holroyd, 1987).

After its development, the QRS has itself however, been used as the external criterion for stress by several researchers (Holroyd, 1987).

Data Analysis

As QRS questionnaires began to be returned, data analysis was begun. Templates were used to score the returned questionnaires. The templates were supplied by and purchased from the publisher of the tool. The 15 templates divide the questionnaire into separate scales, making it possible to examine each scale independently of the others. In scoring the questionnaires, one point is given for each item that is answered in a direction indicating an increase in family stress. No points are given for answers that are made in the direction not indicating increased stress. Thus, the higher the score for each scale, the higher the stress.

In summary, the intent of this research project was to utilize the QRS to provide information from families of children on CAPD. The data from the CAPD families was then compared with similar data from families of children with CF and families with healthy children. Research done by Holroyd and Guthrie (1986) was the source of the data from the CF families and the healthy families.

When the three sets of data had been gathered, an ANOVA was calculated on each of the 15 scales of the QRS in order to identify significant differences among the three population samples. T-tests were then calculated on those scales that showed statistically significant differences. In this manner, an attempt was made to identify more clearly where the differences were between the two chronic illness groups, CAPD and CF, and the control group.

CHAPTER IV

RESULTS

Sample

Collection of the data from the CAPD families took place from January through March of 1990. Of the 20 families contacted, 14 of them returned questionnaires and were included in the study. This yields a 70% rate of return of questionnaires.

Demographic Characteristics

Demographic information was requested and obtained from each of the CAPD families. Family characteristics were identified using a series of questions that accompanied the packet initially sent to each family. (See Appendix D for a copy of the demographic questionnaire.)

In terms of demographic characteristics, two out of fourteen, or a total of 14% of respondents, were fathers. The remaining 12 respondents, or 86% of the total, were mothers. Each of the responding fathers was married and living with his wife.

Eleven of the 14 CAPD families (80%) had parents who were married. One respondent was divorced, two

respondents reported their marital status as "other". There is no similar information in either the CF or control groups with which to compare these characteristics.

In the CAPD group (n=14), the mean age of the affected child was 8.75 years, with an age range of from 6 months to 17 years. In contrast, the CF group (n=16) had a mean age of 10.9 years, with a range of ages from 6 to 14.9 years. The child's mean age in the control group (n=14) was 9.9 years, with a range reportedly similar to that of the CF group but not specifically given (Holroyd & Guthrie, 1986). It was quickly realized that the three samples were not similar, particularly the CAPD group, in either mean age or age range. A discussion later in this chapter will speak to these differences, and what was done to allow for them. (See Table 2 for a depiction of the sex and age distribution of the children in the three groups.)

In the CAPD group seven children, or 50%, were boys, and seven children were girls. In the CF group, 11 of the children were boys (69%), with only 5 girls (31%).

Table 2

Comparison of Ages Between Groups: CAPD, CF, and Control

	CAPD (n=14)	Cystic Fibrosis (n=16)	Control (n=14)
Male	7	11	8
Female	7	5	6
Mean Age	8.75	10.9	9.9
Median Age	8	Not Available	Not Available
Range	.5-17 Years	6-14.9 Years	Not Available

In the control group (the families with healthy children) there were 12 boys (86%), while 2 were girls, which is 14% of the total sample.

Length of time on CAPD varied for the CAPD families from 4 months to 16 years, with a mean of 4.1 years, and a median age of 8 years. There are no similar data available from the CF children with which to compare these data. Mean number of siblings for the CAPD group is 1.7, no number is given for either CF or control groups in this category.

Data Analysis

After each returned questionnaire from the CAPD group was individually scored in the manner described in Chapter III, sample means and standard deviations were calculated for each of the 15 scales from the compiled scores. The information obtained from the families with children on CAPD was then compared with the data obtained by Holroyd and Guthrie (1986) on families of children with cystic fibrosis and families with healthy children. (See Table 3 for a display of the means, standard deviations, and F scores on each scale for the three groups.) Mean scores on each scale

Table 3

Mean Values, Standard Deviations, and F Scores
for Each Group

Scale	Group						F
	CAPD (n= 14)		CF (n= 16)		Control (n= 14)		
	Mean	S.D.	Mean	S.D.	Mean	S.D.	
**1	3.50	3.55	2.69	2.68	1.86	2.03	1.19
2	6.28	3.41	3.50	2.19	3.21	2.08	*6.03
3	5.79	3.26	4.69	2.15	4.79	2.64	0.73
4	3.71	2.46	2.13	2.31	3.21	2.12	1.87
5	3.29	1.44	3.81	1.60	2.5	1.51	2.78
6	2.86	1.66	2.25	1.29	2.29	1.38	0.80
7	2.07	1.54	3.63	2.39	2.64	1.15	2.88
8	3.43	2.47	2.88	1.36	2.79	2.04	0.43
9	2.50	2.93	0.56	0.81	0.36	0.74	*6.34
10	5.79	5.16	3.81	2.64	2.21	1.97	3.67
11	3.71	2.46	2.13	1.31	1.14	1.17	*7.92
12	0.79	0.98	0.38	0.72	0.57	0.94	0.80
13	2.00	1.57	1.88	0.72	1.21	1.37	1.64
14	1.36	0.84	1.06	0.85	0.43	0.65	5.04
15	7.43	5.64	2.75	1.95	3.71	2.92	*6.27

* $p < .01$

** See Table 1 for Scale Titles

for both the cystic fibrosis group and the control group were published by the authors in the study cited above. However, standard deviations for each scale were not published. These data were obtained directly from Dr. Holroyd (personal communication, March 1, 1990).

Both an analysis of variance (ANOVA) and t-tests were utilized in the analysis of the data for this project. The ANOVA is a statistical test that is used to look for differences between the means of three or more independent groups. A t-test measures differences between the means of two independent groups (Phillips, 1978; Polit & Hungler, 1987). An analysis of variance was calculated for each of the group scores on the 15 scales of the tool.

Examination of the results obtained using the ANOVA showed statistically significant differences in scores ($p < .01$) among the three groups, on four of the 15 scales. These were scales 2 (Excess time demands), 9 (Limits on family opportunity), 11 (Physical incapacitation), and 15 (Difficult personality). Next, the data was analyzed further to discover where among the three groups the differences in the results

occurred. For this, individual t-tests for independent groups with pooled variance were computed on each of the four scales that showed statistically significant differences. (See Tables 4, 5, and 6 for a depiction of this information.)

The reason that t-tests were used rather than the customary post hoc analysis was due to the manner in which the data analysis was performed. Because it was from a secondary source, there were no raw data from either the CF or the control groups available to put into the computer. Since means and standard deviations were the only data available, it was not possible to use the computer program that normally performs a post hoc analysis after calculating an ANOVA. Therefore the ANOVA was calculated by hand, as were the t-tests. The use of the t-test then, was simply because of the necessity to find a statistic that was feasible to calculate by hand. Because the use of a t-test in this circumstance is not ideal, it was decided to use a stricter p value. Therefore, throughout the study a level of $p < .01$ was used.

In scale 2 (Excess time demands) there were statistically significant differences found ($p < .01$) in

Table 4

Comparison Between CAPD and CF for
Scales with Significant Results

Scale	Group				
	CAPD (n=14)		CF (n=16)		T
	Mean	S.D.	Mean	S.D.	
2	6.28	3.41	3.50	2.19	*2.70
9	2.50	2.93	0.56	0.81	*2.55
11	3.71	2.46	2.13	1.31	2.24
15	7.43	5.64	2.75	1.95	*3.13

*p<.01

Table 5

Comparison Between CAPD and Control for Scales with Significant Results

Scale	Group				
	CAPD (n=14)		Control (n=14)		T
	Mean	S.D.	Mean	S.D.	
2	6.28	3.41	3.21	2.08	*2.89
9	2.50	2.93	0.36	0.74	*2.66
11	3.71	2.46	1.14	1.17	*3.54
15	7.43	5.64	3.71	2.92	2.20

*p<.01

Table 6

Comparison Between CF and Control for
Scales with Significant Results

Scale	Group				T
	CF (n=16)		Control (n=14)		
	Mean	S.D.	Mean	S.D.	
2	3.50	2.19	3.21	2.08	0.37
9	0.56	0.81	0.36	0.74	0.70
11	2.13	1.31	1.14	1.17	2.18
15	2.75	1.95	3.71	2.92	1.07

*p<.01

scores between both the CAPD group and the CF group, and between the CAPD group and the control group. The score for the CAPD families was significantly higher when compared to the other two sets of families. The CF group did not show a statistically significant difference in scores when compared with the control group.

In scale 9 (Limits on family opportunity) statistically significant ($p < .01$) differences in scores were found between the CAPD and the CF groups, and between the CAPD and the control group. The CAPD families had higher scores than either of the two sets of families with which it was compared. Again, there were no statistically significant differences found in the scores when the CF group and the control group were compared.

Analysis of scale 11 (Physical incapacitation) did not demonstrate statistically significant differences in scores between the CAPD group of families and the CF group of families. There were, however, significant differences ($p < .01$) seen when the CAPD group and the control groups were compared. Interestingly, no statistically significant difference

in scores was obtained when the CF families were compared to the control families. The most likely explanation for this finding is that the mean scores for the CF group fell in between those of the CAPD and the control groups, so that significant differences were found only when groups on each end were compared. There apparently was not enough difference in scores to have statistical significance when either end was compared against the middle.

Finally, scale 15 (Difficult personality) showed a statistically significant difference in scores between the CAPD and the CF group, but not between the CAPD and the control group. Neither were there significantly different scores between the CF group and the control group. Again, as stated previously when describing the results of scale 9, the most likely explanation for this finding is that the control group this time fell in the middle in terms of scores, while the CF and CAPD groups were on either end. Statistically significant results were found only when the ends were compared. Interestingly, the CF group had the lowest scores on this scale, lower than either the CAPD or the control group. This indicates that for this sample, families

of children with CF had less trouble with difficult personality in the affected child than did the families with healthy children.

Although statistically significant differences were found in only four of the 15 scales, it is noteworthy that in 9 of the remaining 11 scales, the CAPD group had higher mean raw scores than both the CF group and the control group. These scales were scale 1 (Poor health/mood), scale 3 (Negative attitudes), scale 4 (Overprotection/dependency), scale 6 (Overcommitment/martyrdom), scale 8 (Lack of family integration), scale 10 (Financial problems), scale 12 (Lack of activities), scale 13 (Occupational limitations), and scale 14 (Social obtrusiveness).

There were two scales in which the CF group had highest mean raw scores. In scale 5 (Lack of social support) and in scale 7 (Pessimism) the CF group had higher mean raw scores than either the CAPD group or the control group.

There were five scales in which the CF group had lower mean raw scores than either the CAPD or control groups. These were scale 3 (Negative attitudes), scale 4 (Overprotection/dependency), scale 6

(Overcommitment/ martyrdom), scale 12 (Lack of activities), and scale 15 (Difficult personality).

It is important to recognize that there were notable differences between the CAPD group and both the CF and control groups in terms of the mean age of the samples and the range of ages. Some important questions arose: Was there a relationship between the age diversity in the three samples, and the statistically significant differences that were found in four scales? Were the statistically significant results due to the fact that the CAPD group had both preschool age and adolescent subjects, while the CF and the control group did not? Because of these questions, an attempt was made to determine whether the inability to match the samples on age had an impact on the results that were obtained.

A clearer understanding was needed of exactly where the differences in the scores occurred. In order to identify how the presence of preschool and the adolescent subjects affected the results from the CAPD families, further statistical analysis was done on the CAPD group itself.

First, linear correlations using Pearson's r were calculated for each of the four statistically significant scales (2, 9, 11, and 15). The ages of the CAPD children were plotted on the X coordinate, and compared to scores on the QRS which were plotted on the Y coordinate.

Presumably, if there was a tendency for families with either the youngest or the oldest children in the sample to have higher scores, then the linear correlation should be curvilinear. A curvilinear relationship would demonstrate that the preschooler and the adolescent families had higher scores than the school-age families. In fact however, there was a negative correlation between age and scores for each of the four scales. Therefore, while families with younger children did indeed have higher scores than those with school-age children, families with adolescents on the whole tended to have scores that were lower. Scale 2 (Excess time demands) had a correlation in this manner that was statistically significant at $p < .01$. Scale 11 (Physical incapacitation) had a correlation that was statistically significant at $p < .05$. Scales 9 (Limits

on family opportunity) and 15 (Difficult personality) while still having a negative correlation, had no statistical significance to their correlations. (See Table 7 for a display of the results.)

Next, the CAPD sample was divided into three groups: preschoolers (n=4), school-age children (n=6), and adolescent subjects (n=4). An analysis of variance was calculated on the data from the four scales after it was grouped in this manner, with both interesting and informative results. (See Table 8 for a depiction of these results.) Calculations on scale 2 show that there were statistically significant differences found when the three groups were compared ($p < .01$). T-tests were then run which showed some statistically significant differences between groups when each was individually compared to another. (See Tables 9, 10, and 11.) Again, it should be noted that the preschool children had the highest scores, the adolescent group had the lowest scores, with the schoolage children falling in the middle.

The same information for the other three scales was also obtained. On scales 9, 11, and 15 there were

Table 7

Correlations Between Age and Scores on
QRS for CAPD Group

Scale	Pearson's r	Significance
2	-0.7185	p<.0038
9	-0.4261	*n.s.
11	-0.6197	n.s.
15	-0.0407	n.s.

* Not Significant

Table 8

Mean Values, Standard Deviations, and F Scores
for the CAPD Sample, When Divided into Preschool,
School-Age, and Adolescent Age Groups

CAPD							
Scale	Preschool (n= 4)		School-Age (n= 6)		Adolescent (n= 4)		F
	Mean	S.D.	Mean	S.D	Mean	S.D.	
2	9.50	1.91	6.50	2.81	2.75	1.71	*8.50
9	3.75	3.30	2.83	3.37	0.75	0.96	1.14
11	6.50	2.08	2.50	1.87	2.75	1.26	6.80
15	12.75	5.68	3.50	1.52	8.00	5.72	5.52

*p<.01

Table 9

Comparison Between Preschool and
School-Age CAPD Patients for
Scales with Significant Results

Scale	Group				
	Preschool (n=4)		School-Age (n=6)		T
	Mean	S.D.	Mean	S.D.	
2	9.50	1.91	6.50	2.81	n.s.
9	3.75	3.30	2.83	3.37	n.s.
11	6.50	2.08	2.50	1.87	*0.005
15	12.50	5.68	3.50	1.52	*0.007

*p<.01

Table 10

Comparison Between School-Age and
Adolescent CAPD Patients for
Scales with Significant Results

Scale	School-Age (n=6)		Adolescent (n=4)		T
	Mean	S.D.	Mean	S.D.	
2	6.50	2.81	2.75	1.71	n.s.
9	2.83	3.37	0.75	0.96	n.s.
11	2.50	1.87	2.75	1.26	n.s.
15	3.50	1.52	8.00	5.72	n.s.

*p<.01

Table 11

Comparison Between Preschool and Adolescent CAPD Patients for Scales with Significant Results

Scale	Preschool (n=4)		Adolescent (n=4)		T
	Mean	S.D.	Mean	S.D.	
2	9.50	1.91	2.75	1.71	*.002
9	3.75	3.30	0.75	0.96	n.s.
11	6.50	2.08	2.75	1.26	n.s.
15	12.50	5.68	8.00	5.72	n.s.

*p<.01

no statistically significant ($p < .01$) differences found in the scores between the three age groups, based on results of the ANOVA.

Age of the children on CAPD did not appear to demonstrate a curvilinear relationship to their scores on the QRS. Therefore, it can be concluded that the presence of preschooler and adolescent families in the sample did not yield significantly different results than if the sample had been composed of only families with school-age children. In addition, for three of the four scales, there was no difference in results when the three age groups were compared using an ANOVA. It seems once again possible therefore, to look at the scores of all three groups, CAPD, CF, and the control and draw some conclusions.

Question I Results

Research question I asked if the types of stress would be similar between CAPD and CF, when compared to a group of healthy controls? The answer to this question was both interesting and surprising. Essentially, the CAPD group showed a statistically significant increase in stress on three scales when compared to the control group. The CF group showed no

statistically significant increase in stress at a level of $p < .01$ on any of the 15 scales when compared to the control group. However, on one scale the CF group showed significantly lower scores than either the CAPD group or the control.

Sources of stress for the CAPD group came from each of the three categories of the QRS instrument: parent problems, family functioning problems, and index case problems. The answer to question I is no, the CAPD families appeared in this project to have different types of stress, at least when measured using the QRS.

Question II Results

Question II asked whether the amount of stress would be similar between CAPD and CF groups when compared to a group of healthy controls? Again, the answer to the question was both surprising and interesting.

As described above, the CAPD group showed significantly increased stress in three scales when they were compared to the control group. The one scale where the CF group showed a statistically significant difference in results from the control group, their

score was actually lower. The answer to question II is no, the CAPD group showed a greater amount of stress when compared to the CF group in this study.

Question III Results

Question three asked whether the amount and type of stress would be similar in both CAPD and CF groups when compared to families with healthy children. When comparing families of children on CAPD, families of children with CF and families with healthy children, the most striking observation was how similar the CF group and the control group were in terms of their responses. In addition, on the one scale in which the CF group differed from the families with healthy children, it actually scored lower.

The CAPD group was statistically different from the control group on only three of the 15 scales of the questionnaire. This is not a great difference. It should be noted however, that the scales in which the groups differed encompassed all three of the domains of the QRS. These include personal problems for the respondent, family problems, and problems for the ill child. As a result, the two groups CAPD and CF, were not found to be similar in either amount or type of

stress when compared to the control group. Therefore, there were some significant differences found between the CAPD group and the CF group both when compared to each other, and when each was compared to a control group; but there were more similarities between the three groups than differences.

restrictions of activity that may result for the entire family. The CAPD group had significantly higher scores than did the other two groups on scale 2 which addresses increased time demands on the parent. According to Holroyd (1987), high scores on scale 2 relate to the primary caretaker, and his or her concerns about the inability to get out of the house as often as they may like. Scale 2 also includes things relating to the presence of outside activities such as a job, visiting friends, and having time for oneself. This is not particularly surprising, since the procedures required daily for CAPD are very time-consuming. What is surprising is that while the CAPD group had increased levels of stress in this scale, the CF group did not.

Social isolation was another theme discussed by Futcher. Even though a perception of lack of social support was not statistically different among the three groups of families, excess time demands can certainly decrease the amount of time available to families for social interaction. Although the higher scores on lack of social support for the CF families was not significantly different than either the CAPD or the

control group, the finding is certainly interesting. It is particularly surprising when the numbers of children with CF are compared to the numbers of children on CAPD. The prevalence of childhood cystic fibrosis is much greater than childhood chronic renal failure of any type.

The findings from this study are intriguing in light of the information provided by LePontois, Moel, and Cohn (1987). The authors felt that in their CAPD program, family stress was greatest both during the preschool years and the adolescent years. The results from this sample do not bear this out. While the families with preschool children in this study showed higher scores on QRS scales, adolescent families tended to show lower scores when compared to school-age families. One possible confounding variable in this situation might be the length of time that the child has been on CAPD. It seems reasonable and has been shown (Kazak, 1989) that family adaptation to childhood chronic illness changes over time. Certainly, adaptation would be expected to be most difficult during the initial stages of dealing with the disease. Perhaps length of time on CAPD should be taken into

effect when looking at adaptation. It seems likely that a group of preschoolers will have had chronic renal failure for a shorter period of time than a similar sized group of adolescents.

Vavasseur (1987) spoke of the restrictions that chronic childhood illness had on the lifestyle of the family. These restrictions include limitations on travel, childcare options, and finances. Although financial problems in the CAPD group were not significantly greater than the other two groups, scores on scale 9 which examines limits on family opportunity, was significantly higher in the CAPD group than the other two groups of families. Holroyd (1987) reports that items on this particular scale "pertain to family members' needing to forgo opportunities for jobs, education, social activities, and personal growth" (p. 19). Scale 9 is similar to scale 2 in that the presence of the child on CAPD not only handicaps the primary caretaker in terms of personal, social and sometimes financial fulfillment, but also seems to limit the entire family. Certainly the results from this study further demonstrate that chronic illness does have an impact on the entire family.

Although siblings of the children on CAPD were not specifically included in the study, the fact that excess time demands, limits on family opportunity, and physical incapacitation of the ill child were statistically significant findings, it can be inferred that there is probably significant impact of this disease on siblings. This finding can be coupled with the findings of Vance, Fazan, Satterwhite and Pless (1980) in their study of children who were not yet ill enough to need dialysis. These authors found that siblings were more frequently adversely affected than parents. Parental adaptation was often seen as good by these authors, while schoolage and adolescent siblings showed a lowering of self-esteem and reduced academic performance when compared with a control group. It should therefore be reemphasized that siblings of these children cannot be ignored if health care providers expect to promote happy, healthy, and functional family units.

Scale 11 of the QRS looks at the physical incapacity of the chronically ill child. This relates to the child's ability to care for his or her own physical needs. Included in this scale are such things

as feeding, toileting, and ambulation. In addition, any special requirements such as a need for medicine are included in this category. Finally, the child's capacity to participate in normal sporting events or outings are included here. One of the reasons that CAPD is being hailed by many as the optimal treatment for ESRD in children (until renal transplant becomes an option for the child) is because of the reduction in physical disability that it provides. This is an important piece of information to keep in mind--these children even though they are not on hemodialysis, are still seen by their families as physically incapacitated.

According to Holroyd (1987), parents of children with emotional disorders score higher on scale 15 generally than do parents of physically incapacitated children. This scale looks at behavioral and personality problems in addition to cognitive deficit. Holroyd has also found that scores are influenced by the amount of social support that parents receive. Interestingly as reported earlier, the CF group had scores that were significantly different from the CAPD and the control group. However, the CF families had

scores that were actually lower than the other two groups. The CAPD group had statistically similar scores to the control group.

An intriguing finding in the literature (Walker, Ford, & Donald, 1987) is that mothers with chronically ill children showed fewer differences in stress levels than had been anticipated, when compared with mothers with healthy children. The difference in levels of stress was in the mother's assessment of the severity of her child's illness. Perhaps it is just as important to ask parents how they are doing, as to use fancy tools that enable us to measure stress.

Finally, it must be remembered that although the presence of a chronically ill child may inherently place an increase in stress on the family, it does not necessarily lead to family dysfunction (Lewis & Khaw, 1982). Families with chronically ill children come in all shapes and sizes, and just like families with healthy children, have various degrees of function and dysfunction. The CAPD families had more significant differences in scores than the CF group, when compared to the control group. However, it should be pointed out that for the CAPD families, there were only 3 of a

possible 15 scales in which there were scores that were significantly elevated. It may be just as difficult for the family when health care providers only seek out and identify cases of dysfunction, as it is when we fail to notice family problems at all.

Limitations

As mentioned in the discussion, the age range of the CAPD group was much more broad than the other two groups. This may make the three groups more difficult to scientifically compare. Because of the relatively small numbers of children with ESRD who are on CAPD, the sample size was limited, and the sample did not match the CF or the control samples in terms of demographic characteristics. Perhaps this study will be a starting point at which nursing can more thoroughly examine the pediatric CAPD population.

Scale 2 itself has some age specific limitations. Results from scale 2 show that there is a negative relationship between age of the child and level of scores. This data is consistent with the data gathered on families with healthy children (Holroyd, 1987). This may have accounted for some of the differences found between the two chronic illness groups in this study.

Further exploration of this would be helpful, as would a study that had better matched sample groups.

Because of the small sample size, the generalizability of the findings to other CAPD centers may be questionable. Also, other demographic information that might have been useful would be educational levels of the parents, as well as respondents' income levels. Because the CAPD program at OHSU serves virtually all of the children on CAPD in the states of Oregon, Alaska, Idaho, and parts of Montana, the sample can be assumed to be somewhat representative of the total population in question.

One major limitation of the study is that the feelings and attitudes of siblings of the affected child were not evaluated. Any conceptual framework that uses systems theory, should at least speak to siblings. In addition, there is much information in the literature that demonstrates the big impact that the presence a sibling with a chronic illness has on other children in the family (Vance, Fazan, Satterwhite, & Pless 1980). Hopefully, the information gathered here will encourage further study of siblings of children with chronic illness, specifically siblings

of children on CAPD. In addition, mention should be made to health care providers that siblings need special attention as well as the ill children.

Since these families are dependent upon the CAPD clinic for their child's care, it must at least be considered that a socially desirable response set bias may have occurred, as well as acquiescence. The presence of both or either of these phenomena can limit the internal and external validity of the study. Hopefully, anonymity helped to prevent either of these events from occurring.

A further question of internal validity is related to who the families were that chose not to respond, and why they chose to do so. Are things going so well that they found the tool ridiculous to complete? Or perhaps are they so stressed out by the demands of their child's illness that they cannot find the time it takes to answer and return the questionnaire? Either, both, or neither of these explanations may in fact be the case for families that did not respond to the study. Any of these possible explanations can further limit the findings from this study.

Implications for Nursing Practice

The results of this study provide both valuable and timely information regarding a relatively new method of treatment for end stage renal disease in children. In addition, the scope of the problems facing these families has at least been partially addressed.

The findings from this research project can perhaps be used as a starting point for looking more completely at the implications of chronic renal failure and CAPD in children. Nurses can only work toward meeting the needs of families of chronically ill children if there is a clear picture of what those needs are. If the stressors experienced by families with children who are on CAPD can be more clearly defined, nurses can more knowledgeably reach out and be effective in their interventions. By looking at the similarities and the differences of the impact of various chronic illnesses on the family, we gain a more clear understanding of this complex topic.

Recommendations for Future Research

An interesting follow up to this study might be one that compares a measure of family stress such as

the QRS, with an interview format that would be able to obtain more information about parent's feelings and perceptions of their child's illness. A format such as this may give more information that may enable health care providers to further understand the impact of chronic illness on families. Also, the use of a sibling assessment tool along with the QRS would be helpful in enabling health care providers to more fully understand chronic childhood illness from a family systems perspective.

Finally, there is a need to look further into the preschool, school-age and adolescent experience of chronic illness. Perhaps an examination of developmental stage and length of time on CAPD would be helpful in enabling nurses to realize that the impact can and does vary over time and developmental stage.

Summmary

In conclusion, the literature has frequently examined the impact of chronic illness in children, and its effect on the family. It has been shown that each chronic illness has its own unique problems, stresses, and needs. One population of chronically ill children that has had little systematic examination are children

with chronic renal failure who are on continuous ambulatory peritoneal dialysis (CAPD). This method of dialysis is rapidly becoming the preferred method of dialysis in children in many pediatric nephrology centers around the country. CAPD has however, never been studied, particularly in relationship to the impact of the disease and its treatment on the family.

This study was undertaken in order to get a beginning understanding of the impact of this particular chronic childhood illness on the family. In order to more clearly appreciate the information, families with a separate chronic childhood illness were used to provide a comparison to the CAPD families. Also, data on families with healthy children was included. Holroyd and Guthrie's data (1984) on families of children with cystic fibrosis and families with healthy children was used in this manner. The Questionnaire on Resources and Stress (Holroyd, 1974) was the tool used to measure the stressors in the three groups of families.

Questionnaires were sent to 20 families who at that time had children on CAPD. These families were followed by the pediatric CAPD clinic at Oregon Health

Sciences University. Fourteen families responded, yielding a 70 percent rate of return of questionnaires. Although the CAPD sample was very different from the CF and the control samples in terms of mean age and the age range, there were some very interesting results.

When the three groups were compared, statistically significant scores were obtained on four of the 15 scales of the QRS questionnaire. These were scales 2 (Excess time demands), 9 (Limits on family opportunity), 11 (Physical incapacitation), and 15 (Difficult personality). Of these, the CAPD families scored higher than the other two sets of families on three of the scales. These were scales 2, 9, and 11. For scale 15, it was the CF families that had statistically significant scores when compared to the control group. However, the CF families actually had lower scores on this scale.

This study supports the belief that chronic illness does have an impact on families, and also that different chronic illnesses have different impacts. In addition, in this research project, the CAPD group showed more difference from the control group than did the CF group. This will hopefully be the beginning of

a clearer understanding of the impact on the family when a child has chronic renal failure and is on CAPD. This study also contributes to the chronic illness literature in general, providing information on how two chronic illness populations compare both to each other and to families with healthy children.

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Appendix A

Initial Letter and Consent Form

Date

Name

Street Address

City, State, Zip Code

Dear _____,

A child that is in kidney failure and is on CAPD can often place a lot of stress on the family. It can be difficult to do all the tasks and procedures that need to be done with the child. Sometimes even the doctors and nurses that care for you and your child don't know of all the problems and concerns you might have.

There has never been a complete look taken at what it is really like to have a child on CAPD. As part of the work in completing my Master's degree, and under the supervision of Cathie Burns, RN, PhD, CPNP, I am researching how the family is affected when there is a child on CAPD. Your family is one of many families at Oregon Health Sciences University that we are asking to assist us in learning more about what CAPD is like. We are asking that you take some time to fill out the enclosed questionnaire. In order to get the most accurate picture of what CAPD is really like, it is important that each questionnaire be filled out completely and returned. Either the mother or father can fill out the questionnaire. It should take about 30 minutes to complete the form.

The results of these questionnaires will be kept strictly confidential. There is an identification number on the questionnaire so that we can check your name off the list when you return the questionnaire to us. We will never use your name when we compile the results. Your name or identity will not be used for publication or publicity purposes. Also, participation in this study is purely voluntary. By returning the completed questionnaire, you are giving us permission to include you in the study. If you choose not to participate, your care at the University will not be affected.

The results of this study will be shared with the CAPD centers all over the country. This will help us to know how to better help you and your family. While you may not personally benefit from participating in this study, by serving as a subject you may contribute new information which may benefit families like yours in the future.

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please call Dr. Michael Baird at (503) 279-8014.

In order to encourage you to answer and return the questionnaires, I have enclosed McDonald's gift certificates to be used by you and your family. This is a small "thank you" in advance for your efforts. I will be happy to answer any questions you might have. Please write or call. My telephone number is (503) 452-9413. My address is on the return envelope that is enclosed with your packet.

Thank you very much for your time and help.

Sincerely,

Katie Thomas, R.N.

Appendix B

Follow-up Letter for all Respondents

Date

Name

Street Address

City, State, Zip Code

Dear _____,

Last week a questionnaire was mailed to you asking you to help us learn more about what it is like to have a child on CAPD.

If you have already completed and returned the questionnaire, thank you very much for your time and effort. If you haven't, please fill it out and return it today. In order to accurately know what it is like to have a child on CAPD, we need your answers.

If by some chance you did not receive the questionnaire, or have misplaced it, please call collect at (503) 452-9413. Another one will be sent to you right away.

Sincerely,

Katie Thomas, R.N.

Appendix C

Final Reminder Letter

Date

Name

Street Address

City, State, Zip Code

Dear _____,

We are writing to you about the questionnaire on the problems you may face with a child on CAPD. If you have already returned the completed questionnaire, thank you very much. If you have not done so, please complete it and return it today.

As we said before, it is very important that we learn more about what it is like to have a child on CAPD. If we know more about what it is like, your health care providers should be able to meet your needs more effectively.

Each questionnaire is very important in giving us the best and most accurate picture of what your problems are. Without all the questionnaires, we may not be able to be sure that our results are accurate.

It is for these reasons that we are sending this letter by certified mail. We need to be sure that you have received this letter. Please fill it out and return it as quickly as possible.

Thank you very much for your help in completing this study.

Sincerely,

Katie Thomas, R.N.

Appendix D
Demographic Questionnaire

In order to help us compile our information,
please answer the following questions:

1. Person filling out questionnaire

mother

father

other (please specify) _____

2. My child's age is _____

3. My child is a

boy

girl

4. My child has been on CAPD for

_____ months

_____ years

5. I have other children at home

6. I am

single

married

divorced

other (please specify) _____

Again, thank you very much for your time and
energy.

Katie Thomas

Appendix E

The Questionnaire on Resources and Stress

QUESTIONNAIRE ON RESOURCES AND STRESS (QRS) Test Booklet

Jean Holroyd

Neuropsychiatric Institute
Department of Psychiatry and Biobehavioral Sciences
University of California, Los Angeles

INSTRUCTIONS

The questionnaire deals with your feelings about a member of your family. There are many blanks on the questionnaire. Imagine the family member's name filled in on each blank. Give your honest feelings and opinions.

Please answer all of the questions even if they do not seem to apply. If it is difficult to decide if an item on the questionnaire is True or False, answer in terms of what you or your family feel or do most of the time.

The questions sometimes refer to an older or younger person, or someone who has problems that your family member does not have. Nevertheless, these questions still can be answered True or False.

Example: "We get special funds because of _____'s problem." If you are responding about a family member who does not have any problem, the answer would be False. There is no problem for which you would get special funds.

**DO NOT WRITE ON THE QUESTIONNAIRE.
SIMPLY IMAGINE YOUR RELATIVE'S NAME IS IN THE BLANKS PROVIDED.**

Now, fill in Name, Date, etc. on the answer sheet and begin.

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1. _____ demands that others do things for him/her more than is necessary.
2. _____ understands the idea of time.
3. Because _____ is the kind of person he/she is, he/she can handle his/her situation better than another person could.
4. _____ is cared for equally by all members of our family.
5. It will take us three years or more to pay off our debt.
6. A member of my family has had to give up education (or a job) because of _____.
7. One of the things I appreciate in _____ is he/she is independent.
8. Members of the family share in the care of _____.
9. _____ would not resent being left at home while the family went on vacation.
10. Members of our family praise each other's accomplishments.
11. _____ has a pleasing personality.
12. I do not attend very many meetings (PTA, church, etc.).
13. I know _____'s condition will improve.
14. _____ does not have problems with seeing or hearing.
15. Even if people don't look at _____, I am always wondering what they might think.
16. I take on responsibility for _____ because I know how to deal with him/her.
17. _____ has some unusual habits which draw attention.
18. In our house the whole family eats dinner together.
19. The doctor sees _____ at least once a month.
20. I usually do not have to take _____ with me when I go out.
21. There is more than one wage earner in our family.
22. _____ is a very capable, well-functioning person despite his/her other problems.
23. I always watch to make sure _____ does not do physical harm to himself/herself or others.
24. The special opportunities needed by _____ are available in our community.
25. Our house is comfortably arranged to meet _____'s needs without making it difficult for other members of the family.
26. Money from the government or an organization pays for part of our medical costs.
27. _____ would be in danger if he/she could get out of the house or yard.
28. I feel that our family situation will get better.
29. Medicine does not have to be given to _____ at a set time.
30. _____ doesn't communicate with others of his/her age group.
31. People who don't have the problems we have don't have the rewards we have either.
32. Other members of the family have to do without things because of _____.
33. _____'s problems or illness do not stand in the way of our family progress.
34. When others are around _____ I cannot relax; I am always on guard.
35. If _____ were more pleasant to be with it would be easier to care for him/her.
36. Thinking about the future makes me sad.
37. Much of the time I think about _____ dying.
38. If I knew when _____ would die I wouldn't worry so much.
39. I don't worry too much about _____'s health.
40. Our family agrees on important matters.
41. Professionals (nurses, etc.) in an institution would understand _____ better than I do.
42. When _____ is not well, I can't go out.

43. I am afraid that by limiting _____'s activities he/she will not develop on his/her own.
44. Our family's income has dropped over the past 5 years.
45. The constant demands for care for _____ limit growth and development of someone else in our family.
46. _____ feels that I am the only one who understands him/her.
47. In his/her own way _____ brings as much pleasure to our family as the other members.
48. I worry about what will happen to _____ when I can no longer take care of him/her.
49. I think in the future _____ will take up more and more of my time.
50. I am able to leave _____ alone in the house for an hour or more.
51. I fear the day when other members of the family leave home and I am left alone with _____.
52. It would be better for _____ if our house could be remodeled.
53. A counselor or a teacher sees _____ at least once a month.
54. I get out of the house to do something interesting at least once a week.
55. I am very careful about asking _____ to do things which might be too hard for him/her.
56. The attitude of our family makes it impossible for _____ to live with us any longer.
57. I would rather be caring for _____ than doing some other kind of work.
58. _____ is limited in the kind of work he/she can do to make a living.
59. I have accepted the fact that _____ might have to live out his/her life in some special setting (i.e., hospital, institution, foster home).
60. I have given up things I have really wanted to do in order to care for _____.
61. My family argues about how to care for _____.
62. _____ is able to fit into the family social group.
63. Some members of my family don't like the way I do things.
64. I would not want the family to go on vacation and leave _____ at home.
65. At times I fear _____ will not be able to function in society if he/she is out of our house.
66. It is difficult for me to stand back and watch _____'s condition get worse.
67. In the future our family's social life will suffer because of increased responsibilities and financial pressure.
68. It doesn't make any difference to _____ if he/she is at home or in a hospital.
69. _____ knows the difference between strangers and friends.
70. I am afraid that other members of the family will be hurt because they are related to _____.
71. There is no way we can possibly keep _____ in our house.
72. People should take care of their own.
73. One of us has had to pass up a chance for a job because _____ could not be removed from a clinic or a special school, etc.
74. I would rather help _____ do something than have him/her fail and feel badly.
75. _____ has always lived with our family.
76. I cannot manage _____.
77. Sometimes I avoid taking _____ out in public.
78. _____ is on a special diet.
79. Many people simply don't understand what it is like to live with _____.
80. Every member of our family has had to do without things because of money spent on _____.
81. _____ can feed himself/herself.
82. I tend to do things for _____ that he/she can do himself/herself.
83. When we go on vacation, I'm not afraid to leave _____ for any length of time.
84. As the time passes I think it will take more and more to care for _____.

85. I belong to organizations which help with problems I have with _____.
86. There have been serious emotional problems for someone in our family.
87. Our relatives have been very helpful.
88. We have discussed what will happen when _____ dies.
89. It is easier for me to do something for _____ than to let him/her do it himself/herself and make a mess.
90. _____ is easy to manage most of the time.
91. I don't think that _____ depends too much on me or other members of the family.
92. It is not necessary for _____ to go up or down steps in our house.
93. I feel that I must protect _____ from the remarks of children.
94. We can afford to pay for the care _____ needs.
95. Just talking about problems with close friends makes life easier.
96. I can never leave the house because of _____.
97. I am happy when I watch the development and achievements of _____.
98. It bothers me that _____ will always be this way.
99. No one in our family drinks alcohol too much.
100. The community is used to people like _____.
101. _____ uses special equipment because of his/her handicap.
102. _____ has a handicap which prevents him/her from improving.
103. _____ is sometimes too sexual.
104. _____ has a lot of pain.
105. I feel tense whenever I take _____ out in public.
106. _____ is easy to live with.
107. The doctor sees _____ at least once a year.
108. _____ eats his/her meals with other members of the family.
109. Wheelchairs or walkers have been used in our house.
110. An electricity failure would endanger _____'s life or health.
111. Caring for _____ has been a financial burden for our family.
112. _____ made a good income at one time.
113. Some friends are very helpful when it comes to _____.
114. I worry that _____ may sense that he/she does not have long to live.
115. _____ will not do something for himself/herself if he/she knows someone will do it for him/her.
116. I can go visit with friends whenever I want.
117. Members of the family show no interest in what happens to _____.
118. We enjoy _____ more and more as a person.
119. We have changed our house because of _____.
120. Taking _____ on a vacation spoils pleasure for the whole family.
121. The family does as many things together now as we ever did.
122. _____ knows his/her own address.
123. _____ gets along very well with others.
124. _____ is aware of who he/she is (for example, male 14 years old).
125. _____ prevents any communication within our family.
126. Someone in our family turns against _____ when his/her friends are around.
127. Sometimes I need to get away from the house.

128. I get upset with the way my life is going.
129. Sometimes I feel very embarrassed because of _____.
130. Having to care for _____ has enriched our family life.
131. Neighbors want us to move because of _____.
132. I respect _____'s judgment about what he/she can do.
133. _____ doesn't do as much as he/she should be able to do.
134. Our family has been on welfare.
135. We have discussed what will happen if _____ lives longer than we do.
136. _____ is truly accepted by the family.
137. A bed that raises and lowers has made things easier.
138. We take _____ along when we go out.
139. It makes me feel good to know I can take care of _____.
140. Others do for _____ what he/she could do for himself/herself.
141. Because of _____ our family has never enjoyed a meal.
142. I hate to see _____ try to do something and fail.
143. _____ is accepted by other members of the family.
144. I fear _____ might get hurt while playing games or sports.
145. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her.
146. _____ spends time at a special day center or in special classes at school.
147. _____ is very anxious most of the time.
148. _____'s health is not getting worse.
149. There is no special government program to help _____.
150. I have no time to give the other members of the family.
151. Our family is quite religious.
152. In our family _____ takes an active part in family affairs.
153. There are many places where we can enjoy ourselves as a family when _____ comes along.
154. It is hard to think of enough things to keep _____ busy.
155. _____ is overprotected.
156. Our family income is more than average.
157. Some of our family do not bring friends into the home because of _____.
158. I try to get _____ to take care of himself/herself.
159. Caring for _____ gives one a feeling of worth.
160. We have discussed his/her death with _____.
161. _____ is able to take part in games or sports.
162. One of us has had to pass up a chance for a job because _____ could not be left without someone to watch him/her.
163. We think _____ will live longer in an institution.
164. _____ has too much time on his/her hands.
165. There is an organization for families who share our problems.
166. I am disappointed that _____ does not lead a normal life.
167. We spend up to 25 percent of our income on medical care (or care for _____).
168. Time drags for _____, especially free time.

169. I worry about how our family will adjust after _____ is no longer with us.
170. The part that worries me most about _____ going on his/her own is his/her ability to make a living.
171. _____ resents being treated as a handicapped person.
172. _____ can't pay attention very long.
173. I worry about what will be done with _____ when he/she gets older.
174. If _____ were healthier it would be easier to go away for a holiday.
175. Compared to others, we spend a lot of money on medical costs.
176. I get almost too tired to enjoy myself.
177. _____ has things to entertain him/her (TV, radio) in his/her room.
178. We owe a great deal of money.
179. _____ is depressed most of the time.
180. If I were healthier, it would be easier to care for _____.
181. Most persons in public places indicate they don't want _____ around.
182. _____ can get around the neighborhood quite easily.
183. _____ wants more freedom than he/she has.
184. One of the things I appreciate about _____ is his/her confidence.
185. I don't mind when people look at _____.
186. Whenever I leave the house I am worried about what's going on at home.
187. In our family _____ plays as important a role as other members.
188. _____ will never be any brighter than now.
189. One of the things I appreciate about _____ is his/her ability to recognize his/her own limits.
190. I believe _____ should go places as often as others in the family.
191. I am not embarrassed when others question me about _____'s condition.
192. There is a lot of anger and resentment in our family.
193. If _____ could get around better we would do more as a family.
194. Our family has managed to save money or make investments.
195. We own or are buying our own home.
196. Information and encouragement is available to those who seek it.
197. We get special funds because of _____'s problem.
198. One of the things I enjoy about _____ is his/her sense of humor.
199. We can have no luxuries.
200. I have enough time to myself.
201. _____ is able to go to the bathroom alone.
202. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.
203. I have too much responsibility.
204. No member of the family pities _____ too much.
205. _____ cannot remember what he/she says from one moment to the next.
206. _____ is better off in our home than somewhere else.
207. _____ can describe himself/herself as a person.
208. Others in the family should help care for _____.
209. A nurse sometimes works in our home.
210. Relatives have done more harm than good when it comes to _____.

211. I am afraid that as _____ gets older it will be harder to manage him/her.
212. It is easy to keep _____ entertained.
213. It makes me feel worthwhile to help _____.
214. _____ wants to do things for himself/herself.
215. In the future _____ will be more able to help himself/herself.
216. _____ needs a walker or a wheelchair.
217. I have become more understanding in my relationships with people as a result of _____.
218. The constant demands to care for _____ limit my growth and development.
219. _____ cannot get any better.
220. _____ is very tense in strange surroundings.
221. It is easy to communicate with _____.
222. I feel sad when I think of _____.
223. Our family should do more together.
224. I have had to give up a chance for a job because of _____.
225. _____ accepts himself/herself as a person.
226. Outside activities would be easier without _____.
227. Our relatives give us much help.
228. I enjoy church.
229. Caring for _____ puts a strain on me.
230. I often worry about what will happen to _____ when I no longer can take care of him/her.
231. _____ can use the bus to go wherever he/she wants.
232. People can't understand what _____ tries to say.
233. If it were not for _____ things would be better.
234. I feel that _____ would prefer a professional (nurse, day care helper, etc.) to care for him/her rather than a member of our family.
235. Some members of the family resent _____.
236. Members of our family get to do the same kinds of things other families do.
237. _____ embarrasses others in our family.
238. My happiness goes up and down with _____'s behavior.
239. _____ uses the phone frequently.
240. _____ has many things to keep him/her busy.
241. Sometimes the demands _____ makes drive me out of my mind.
242. I had high hopes for _____'s future.
243. _____ could do more for himself/herself.
244. My family understands the problems I have.
245. It is easy to do too much for _____.
246. _____ appreciates the interest others show in him/her.
247. It is easier for our family to do things with people we know than with strangers.
248. I am pleased when others see my care of _____ is important.
249. We can hardly make ends meet.
250. _____ rarely has nightmares.
251. I don't try to shelter _____ from life's difficulties.
252. Members of my family are able to discuss personal problems.

253. I often have the desire to protect _____.
254. I am as healthy as I ever was.
255. _____ does not dress right.
256. Most of _____'s care falls on me.
257. No one can ever understand what I go through.
258. We have household help (cleaning woman, nurse, etc.).
259. It is fortunate how _____ has adjusted to life.
260. _____ accepts his/her handicap.
261. _____ has his/her own room.
262. _____ is very irritable.
263. We have lost most of our friends because of _____.
264. _____ has an attractive, clean appearance.
265. _____ can ride a bus.
266. _____ will always be a problem to us.
267. _____ is able to express his/her feelings to others.
268. It is easy for me to relax.
269. _____ has to use a bedpan or a diaper.
270. I rarely feel blue.
271. We have good laundry facilities at home.
272. _____ can walk without help.
273. _____ needs help in the bathroom.
274. I have chances to carry on interests outside the home.
275. It bothers me to see _____ in pain.
276. Every cloud has a silver lining.
277. I like myself as a person.
278. I am worried much of the time.
279. _____ has a strongly defiant personality.
280. Because _____ uses special equipment and facilities, it is difficult to take him/her out.
281. One of the things I appreciate about _____ is his/her sensitivity to others.
282. Others have offered to share the load in caring for _____.
283. _____ likes to follow the same schedule all the time.
284. _____'s needs come first.
285. _____ attracts attention.

ABSTRACT

Title: Stressors Experienced by Families with Children On C.A.P.D.

Author: Catherine Thomas, R.N.

Type of study: Descriptive survey

Continuous ambulatory peritoneal dialysis (CAPD) is considered to be the optimal method of treatment for end stage renal disease (ESRD) in children at Oregon Health Sciences University (OHSU). Although this form of dialysis is used in many pediatric dialysis centers around the country, no systematic examination has been made of how this method of treatment impacts the child and the family. This study has been an attempt to identify the specific stressors experienced by the families of these children.

The prospective sample was composed of the current CAPD patients at OHSU, approximately 20 at the time. A total of 14 patients responded to the survey and were included in the study. Many of the patients served by the clinic live outside of the Portland area, some as far away as Alaska and Montana.

The instrument used was the Questionnaire on Resources and Stress (Holroyd, 1974). All contacts to families were made by mail. The questionnaire takes about 30 minutes to complete and is composed of 285 true/false questions. The QRS is divided into 15 separate scales, covering 3 domains: Personal problems, Family problems, and Problems of index case. A maximum of three contacts was made to all families, with second and third reminder letters sent to all non-respondents.

Statistical analysis was done using an ANOVA and t-test. Results from the CAPD families were compared with the results obtained by Holroyd and Guthrie (1986) on families of children with cystic fibrosis, and families with healthy children. The families with healthy children were used as a control group. Statistically significant differences were found between the three groups on 4 of the 15 scales of the QRS. These were scales 2 (Excess time demands), 9 (Limits on family opportunity), 11 (Physical incapacitation), and 15 (Difficult personality). The

families with children on CAPD had scores significantly higher than both the CF and the control group on scales 2, 9, and 11. The CF group had one scale (scale 15) that showed significant differences from the CAPD and control group. On this scale the CF group actually had lower scores than did the other two groups.

Generalizability of the findings was limited due to the convenience sampling, small sample size, and the fact that there was a great deal of difference in the age range between sample groups.

By identifying specific stressors experienced by the families of these children, nursing and other health care providers might be better able to provide thorough care and more effective interventions when dealing with this chronic illness population.

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Advisor

