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## Development and Testing of the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP)

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Development and Testing of the Stress  
Adaptation Scale for Parents with  
Chronically Ill Children (SASP)

by

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B.S.N. May 1979, Medical College of Virginia

A Thesis Submitted to the Faculty of Old Dominion  
University in Partial Fulfillment of the  
Requirement for the Degree of

Master of Science

Old Dominion University  
May, 1988

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## ABSTRACT

### Development and Testing of the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP)

Carolyn M. Rutledge  
Old Dominion University, 1988  
Director: Dr. Helen Yura

This research study consisted of four phases used to develop and test the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP). The first phase dealt with developing the items on the SASP from a review of the literature and the researcher's professional experience. The SASP was then divided into the six categories of health care, social, personal, familial, financial, and spiritual. In phase II, content validity was evaluated by a panel of experts. In phase III, stability over time and face validity was demonstrated using 26 parents of chronically ill children. The SASP achieved a Pearson's  $r = .85$  with  $p < .000$ . In phase IV, the SASP was tested for internal consistency using scores from 110 parents of chronically ill children. The entire tool and each category obtained a Cronbach's alpha  $> .70$ . Based on the results of the study, the SASP appears to have potential as a valid and reliable instrument for use in research and clinical settings.

## ACKNOWLEDGEMENTS

I wish to thank my husband, Jim, for without his patience, support and understanding I would not have been able to undertake this study.

I wish to remember Joey for through his chronic illness and death I found a desire to help parents such as his.

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## Chapter 1

### Introduction

"Stress is the body's nonspecific response to any demand placed on it, whether that demand is pleasant or not" (Selye, 1978, p. 60). Human beings deal with some stress in order to maintain well-being. This positive stress is "eustress." When people are unable to adapt to stress, the stress is considered to be negative stress or distress (Selye, 1978).

Many times, parents are unable to adapt to the stress that accompanies the chronic illness of a child. This often results in the development of additional problems which in turn stress the family structure (Fife, 1980; Green, 1982). The presence of an ill child within a family may result in the lack of intimacy and companionship among family members, a change in roles, loneliness, withdrawal, guilt, fleeing, aggression, depression, anxiety, stifling of emotions, financial difficulties, overprotection of the child, denial, inability to problem-solve, fear, marital troubles, and difficulty in reintegrating the child into the family (Fife, 1985; Green, 1982; Gibbons & Boren, 1985; Hogan, 1983; Kaplan, 1977; Mattsson, 1977; Stein & Riessman, 1980; Tomlinson, 1986; McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983).



Difficulty in adapting to stress tends to be a significant problem for parents of chronically ill children and is an area where attention must be focused. Nurses, caring for chronically ill children, work closely with parents and are in a position to assist with the fulfillment of the human need to adapt to stress. In order for nurses to assist in minimizing stress, they must be able to identify signs that indicate a parent is either able or unable to adapt to the stress. The nurse may then assist parents in becoming aware of stressors and in fostering human need fulfillment by removing, changing, or controlling the stressor. The nurse's desire is to prevent or minimize parent's ineffective adaptation (Hogan, 1983). This in turn will allow parents to assist their children in fulfilling their human needs. In order for nurses to assess the effectiveness of parents in adapting to the stress created by a child's chronic illness, a reliable and valid instrument should be developed.

#### Purpose

A tool that would identify effective and ineffective adaptation to stress would enable health care providers to identify parents requiring assistance in dealing with the stress associated with the chronically ill child. The health care providers could also provide support and assistance to parents that are adapting in an effective manner. The purpose of this study was to develop and test a valid and reliable tool that could be used in clinical

settings and for research to identify whether parents with a chronically ill child are adapting to the stress.

### Problem Statement

Currently, there are no effective methods to measure whether the human need to adapt to stress is being met by the parents of a chronically ill child. There is a demand for a method of identifying the parents whose human need to adapt to stress is in the met or unmet state in order to minimize stress within the family (Fife, 1985; Hogan, 1983). Many of the tools that are currently being used require further reliability testing. The tools tend to deal with identifying selected coping behaviors, uncertainty, parental attitudes, or the impact of the illness. None of the tools in use deal with identifying areas of effective adaptation. What stressors commonly affect the parents of a chronically ill child and compromise their human need to adapt to stress? Are the adaptive behaviors used by parents of chronically ill children effective or ineffective?

### Theoretical Framework

Two theories, Nursing's Human Need Theory by Yura and Walsh (1988) and Stress Theory by Hans Selye (1978), were used as the theoretical frameworks for this research study. According to Nursing's Human Need Theory, a human need is that requirement necessary for a person to maintain a state of well-being or wholeness. In Nursing's Human Need Theory, persons are viewed as holistic beings who are motivated toward satisfying human needs. The fulfillment of the human

need may become altered when persons undergo experiences of a biologic, intellectual, spiritual, pathophysiologic, emotional, social, environmental, psychopathological, or economical affront. According to Yura and Walsh (1988), a human need will either be "met", "partially met", or "unmet". The parent's adaptive behavior will either meet the need or not meet the need at all. In order to reach human need fulfillment or meet the need, persons must learn to adjust to changes in life as they occur. When human needs are not fulfilled, the well-being of the person, the family and the society is threatened (Yura & Walsh, 1988).

When alterations in human need fulfillment occur, the societal unit, which includes nursing, must assist persons in fulfilling the human need. The nurse is often responsible for supporting, fostering, facilitating, and intervening with both the well and the ill client in order to fulfill the human need. The nurse's goal is to assist the client in maintaining or achieving a state of well-being or wholeness. The nurse assists the client by first assessing the client's level of human need fulfillment. The nurse can then establish a plan of action and implement it. Once implementation has occurred, the nurse and client can once again evaluate the extent of human need fulfillment in order to determine the changes which must be made to achieve a state of well-being (Yura & Walsh, 1988).

According to Yura and Walsh (1988), there are thirty-five human needs which must be fulfilled in order for the

person, family, and community to maintain well-being. The human need to adapt to stress is one of the thirty-five human needs identified. The human needs are divided into three categories: freedom, survival, and closeness. The need to adapt to stress is in the survival category. A survival need must be satisfied if the person (parent) or group (family) is to survive (Yura and Walsh, 1988). Yura and Walsh (1988) define the human need for adaptation to stress as "the harmonious accommodation of the person with changed demands in his or her internal and/or external environment resulting in a balanced relationship with these environments" (p. 88). When the human need to adapt to stress is not fulfilled, the client is unable to maintain well-being.

According to Stress Theory by Hans Selye (1978), stress is the body's response to a demand placed on it, either pleasant or unpleasant. Pleasant stress is "eustress" and unpleasant stress is "distress". Causes of stress are known as stressors. When persons experience stress, their pulse increases, their breathing quickens, and they increase their body movements (Selye, 1978). The body responds to stress in three stages known as the General Adaptation Syndrome (GAS). The General Adaptation Syndrome consists of: (1) alarm reaction during which the body becomes aware of a stressor and prepares for fight or flight, (2) resistance during which the body adjusts to stress, and (3) exhaustion during which the body breaks down (Clements, 1983).

With parents of a chronically ill child, there are many stressors present which produce the General Adaptation Syndrome. Each stressor must be dealt with in order to minimize the progression towards the stage of exhaustion. The method for adapting to stress results from the individual's life experiences, environment, perception of the stress, genetic composition, personality, culture, and interpersonal relationships (Hogan, 1983; Auger, 1976).

In order to decrease the stress, it is important to identify areas of stress in parents with chronically ill children (Green, 1982). The tool developed in this study could enable the health care provider to assess these areas of stress and then assist the parent with adapting to the stress. This can be done by assisting the parent in setting goals and in using individual coping strategies to minimize or remove the stressors resulting from having a chronically ill child (Tomlinson, 1986). Stress, caused by physical or mental stressors, can be managed by intervention which is directed towards: (1) managing the stressor by avoiding, decreasing or changing it, (2) altering the perception of the stress fostering a healthier view of the situation, (3) increasing the choices on how to react to the stressor as far as health-enhancing reactions, and (4) managing the symptoms such as by physical fitness and relaxation (Green, 1982). Once the stressor has been identified, the nurse and client can begin to plan how to deal with the stressor such as by removing, minimizing, or manipulating it.

The tool developed in this study measures the human need for adapting to stress as being met, partially met, or unmet based on the scores obtained. With this tool, health care providers may be able to identify when the parent or family's well-being is threatened by the inability to meet the human need to adapt to stress. This will enable the health care provider to aid the parent in handling the stages of the General Adaptation Syndrome. Once inability to adapt to stress has been identified, the health care provider should be able to assist the parents in dealing with the stress and thus support the child experiencing a chronic illness.

#### Definition of Terms

1. Human need to adapt to stress - one of the 35 human needs according to Nursing's Human Need Theory. Yura and Walsh (1988) define it as "the harmonious accommodation of the person with changed demands in his or her internal and/or external environment resulting in a balanced relationship with these environments" (p. 88). In this study, the chronic illness of a child results in stressors that produce stress.
  - a. Human Need - according to Yura and Walsh (1988), it is "an internal tension that results from an alteration in some state of the system." "A basic human need is one that must be satisfied if the person or group is to survive" (p. 70). This

requirement is either "met", "partially met" or "unmet" by the parent or family. The extent to which it is met determines the parent's or family's level of well-being.

b. Adaptation - a method of coping with stress in order for the parent or family to maintain well-being. Some methods of coping will be effective, others ineffective.

c. Stress - the pressure or strain imposed upon the parent or family as a result of a child's chronic illness. Stress will be assessed under categories of social, financial, familial, spiritual, health care, and personal as measured by the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP).

2. Chronically ill child - unmarried person who continues to live with parents and rely on them for assistance with psychological or physical care related to a chronic illness. The child has a disease which continues indefinitely, may have periods of remission but will likely recur. Terminal illnesses are considered to be chronic in this study.
3. Parents - the natural, the adoptive, or the foster mother or father of a child with a chronic illness.
4. Stressor - a demand resulting from a child's chronic illness which causes stress on the family or parent and may be categorized as personal, health care,

familial, social, spiritual, or financial.

### Assumptions

The assumptions of this study were:

1. That parents have the human need to adapt stress.
2. That parents are often unable to effectively adapt to the stress that accompanies the chronic illness of a child.
3. That parents are able to perceive when they are unable to adapt to the stress which accompanies a child's chronic illness.
4. That parents gave candid and honest responses.

### Limitations

The limitations of this study were:

1. Since SASP was mailed to many of the parents, a self-selection bias may have occurred. There may be a difference between the parents that chose to participate and those that did not.
2. The answers to the questionnaire may vary with daily circumstances.

### Literature Review

A number of tools have been developed to measure stress, uncertainty, impact of illness, coping behaviors, and attitudes of parents. The Holmes-Rahe Social Readjustment Rating Scale, developed in 1967, was used to assess the number of stressors affecting a person. The stressor items used in the tool dealt with major events such as birth, marriage, moving, death, major illnesses, and the loss of a



job. Each item had a numerical value attached to it. The person completing the tool would indicate those stressors that were pertinent to him/her and then total the score. The total indicated whether the individual was overstressed. The scale did not identify the stressors pertinent to chronic illness, childhood illness, nor a parent's attempt at adapting (Green, 1982; Holmes & Rahe, 1967).

Stein and Riessman (1980) developed a scale to measure the impact of chronic illnesses on families. The form used was a four-point Likert scale with each item being evaluated from strongly agree to strongly disagree. The scale had four dimensions identified with factor analysis: (1) financial; (2) social/familial; (3) personal strain; and, (4) mastery. Validity was determined by a panel of experts on chronic childhood illness and experts on research methodology. Internal reliability was explored with Cronbach's alpha. The alpha coefficient for the entire tool was .88; however the category of mastery had an alpha coefficient of only .60. The pilot study used a population of 100 mothers. A formal study testing the tool was not done. The 24 items in the scale assessed impact rather than how the parent with a chronically ill child adapted to stress. The scale required further testing for validity and reliability (Stein & Riessman, 1980).

The Maternal Self-Rating Scale, developed by Judson (1980), contains 25 items on a 7-point Likert scale which assesses the attitudes of parents with handicapped children.

The four dimensions which were identified within the tool were: (1) the mother's own feelings, (2) the mother's interaction with the handicapped child, (3) the mother's perception of the child's progress, and (4) the mother's relations with others, specifically, experts. These four dimensions were not tested using factor analysis. The tool was pilot tested on seven mothers, then test-retest was assessed twice using three and five mothers. Validity was determined by mothers and professionals stating that the items were relevant. The scores on the Maternal Self-Rating Scale were correlated at .88 with scores on the Malaise Inventory by Rutters (1970). The tool requires more reliability and validity testing. The Maternal Self-Rating Scale used only with mothers does not evaluate stressors or coping mechanisms of parents (Judson & Burden, 1980).

The Coping Health Inventory for Parents (CHIP) was developed by McCubbin, McCubbin and Cauble (1983) in order to assess the coping patterns of parents with a chronically ill child. CHIP consisted of a 45-item 4-point Likert scale which listed coping measures often used by parents with chronically ill children. The parents identified how helpful each coping measure had been for them. The scale ranged from 0 to 3 with "not helpful" being 0 and "extremely helpful" being 3. Three patterns of coping measures emerged through factor analysis: (1) the maintenance of family cooperation, optimism, and integration; (2) maintenance of self-esteem, social support and psychological stability;

and, (3) understanding of the medical situation. The applicability of the tool was assessed by parents of children with cystic fibrosis. Internal consistency was measured using Cronbach's alpha with scores of .79, .79, and .71. Test-retest reliability was not performed. The questionnaire identified selected coping measures that were helpful but did not identify coping as being effective or ineffective in reducing specified areas of stress (McCubbin et al., 1983).

Mishel (1983) developed the Parent Perception of Uncertainty Scale (PPUS). This 31-item Likert-format scale measured the perceptual variable which was thought to influence how the parent responded to the child's illness and hospitalization. The conceptual basis for this tool was the model of perceived uncertainty which proposes that uncertainty may be due to ambiguity, lack of clarity, lack of information, and unpredictability. Validity of the tool was established by a group of pediatric nurses. The questionnaire was given to 272 parents of hospitalized children in a large metropolitan city. Four factors of perceived uncertainty were identified by factor analysis: (1) multi-attributed ambiguity, (2) lack of clarity, (3) lack of information, and (4) unpredictability. The entire tool received an alpha of .91 and the four categories received an alpha score of above .70. This tool deals with identifying areas of uncertainty but does not actually deal with adapting to stress (Mishel, 1983).

The Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) developed by Hymovich (1984) was composed of 167 questions divided into three categories to measure stressors, coping mechanisms, and values/attitudes/beliefs. This questionnaire was developed in order to measure the effect a chronically ill child had on the parents. The conceptual basis used for this tool was a modification of Hymovich's framework consisting of: (1) developmental tasks of the individual and the family; (2) the impact variable influential in the effect the child's chronic illness has on the family; (3) coping strategies; and, (4) intervention needed by the families of the children with chronic illnesses. Content validity was established by a panel of experts consisting of a clinical psychologist, three master's prepared nurses who worked with chronically ill children, and a doctorally prepared nurse who worked with chronically ill children. The tool was pilot tested three times, but was not tested in a formal study. The Hoyt's coefficient for reliability on the third revision was .95 for the entire tool and above .70 for the three categories. The CICI:PQ took an average of 23 minutes to complete in its final form. The tool was found to have some overlapping items and test-retest reliability needs to be established. The tool does not focus on whether parents adapt to stress in an effective or ineffective manner (Hymovich, 1984).

These six tools are the most frequently cited in the

literature for evaluating the coping behaviors or stressors of families or parents of ill children. The tools do not identify whether the parent has been able to adapt to each stressor in an effective or ineffective manner. A human need framework has not been used in any of the studies. From the perspective of Nursing's Human Need Theory, adapting to stress is a requirement for maintaining optimal health and well-being of the parent or family.

### Hypotheses

1. The overall internal consistency reliability (Cronbach's alpha) will be .70 or greater for the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP) and for each of the subcategories of health care, social, personal, familial, financial, and spiritual.
2. The stability of SASP in time 1-time 2 testing will demonstrate Pearson correlation of .70 or greater.

Chapter 2 discusses the design, settings, samples and procedure used to develop and test the Stress Adaptation Scale for Parents with Chronically Ill Children. It further describes the format used in SASP and how it was scored.

## Chapter 2

### Methodology

The purpose of this study was to develop and test a questionnaire which measured adaptation to stress in parents with chronically ill children. The Stress Adaptation Scale for Parents with Chronically Ill Children (SASP) was developed and the six categories of health care, social, personal, familial, financial, and spiritual stress were identified by the researcher.

### Design

A methodological approach was used in this research study which consisted of four phases used to develop and test a tool to measure adaptation to stress in parents with a chronically ill child. A methodological design is used to develop a method of organizing, obtaining, or analyzing data. This design deals with the development, validation, and assessment of tools or strategies. The focus is on increasing the store of knowledge regarding methods used to collect data (Polit & Hungler, 1983).

The Stress Adaptation Scale for Parents of Chronically Ill Children (SASP) was developed in four phases. In Phase I, the questionnaire was developed. In Phase II, SASP was evaluated for content validity by a panel of experts. Phase III consisted of administering SASP to 30 parents in order

to test it for reliability and face validity. Phase IV dealt with the testing of SASP for reliability following its administration to 216 parents.

### Sample

The target population for this study was all parents of children with chronic illnesses. The accessible population used in Phase III was parents acquainted with the researcher through nonhealth related community programs. The parents had children living with them who were dependent on them for care related to their chronic illness.

The accessible population for Phase IV was parents with a chronically ill child receiving care from selected clinics or who were participating in selected support groups. These parents also had children living with them who depended on them for care related to their chronic illness. In this study, a chronically ill child was defined as an unmarried person who had a disease which continues indefinitely, but may have periods of remission. A terminal illness was considered to be chronic. Examples of chronic illnesses used in this study were: cystic fibrosis, diabetes, leukemia, arthritis, spina bifida, renal failure, asthma, Down's syndrome, cerebral palsy, seizures, cleft lip and palate, hearing impairment, and multiple sclerosis. The parents in this study were required to be able to write and read English.

### Setting

The study was conducted in the southeastern United

States at the parents' homes for Phase III. In Phase IV, the study was conducted in the southeastern United States in clinics and at support group sessions. The questionnaire was administered in: (1) a pediatric clinic which dealt with cystic fibrosis, facial deformity, hearing impairment, and polycystic kidney disease and (2) in selected support groups which dealt with arthritis, diabetes, cerebral palsy, cleft palate, schizophrenia, seizure disorders, and spina bifida.

### Tool

The Stress Adaptation Scale for Parents with Chronically Ill Children (SASP) was developed from a review of the literature and the researcher's professional experience (Appendix A). The initial questionnaire contained 56 items but was reduced to 42 items during the study. The Stress Adaptation Scale for Parents with Chronically Ill Children contained items on a four-point Likert scale listing the human need to adapt to stress in the met or unmet state. The questions in the unmet state were reverse scored in order to evaluate all items in the met state. A number one indicated that the item was seldom true and a number four indicated the item was frequently true for the parent. Total scores were computed for the tool as a whole and for each of the six categories of health care, social, personal, familial, financial, and spiritual stress. If the total scores for the tool or a category were in the lower third of the possible scores, the parents were considered to be unable to meet their human need to adapt to stress on the



whole or in regards to that category. If the scores were in the middle third of the possible scores, the parents were partially meeting their need to adapt to stress. If the scores were in the upper third of the possible scores, the human need to adapt to stress was considered to be in the met state. Table 1 shows the range of scores and what the scores indicated. Scores for the entire tool ranged from

Table 1

Ranges of Scores for the Stress Adaptation Scale for Parents of Chronically Ill Children (SASP) and its Six Categories

Scores	unmet need	partially met need	met need
Total tool	42-83	84-125	126-168
health care	6-11	12-17	18-24
social	5-9	10-14	15-20
personal	13-25	26-38	39-52
familial	11-21	22-32	33-44
financial	4-7	8-11	12-16
spiritual	3-5	6-8	8-12

42-168. Scores of 42-83 were in the lower third of possible scores which indicated that the person was unable to meet their human need to adapt to stress. Total scores of 84-125 indicated the human need was partially met and a total score of 126-168 indicated the human need was in the met state. Specific scores were also applied to the categories of

health care, social, personal, familial, financial, and spiritual.

In this study, a demographic data sheet was also developed by the researcher for use with SASP (Appendix B). The demographic data sheet was developed for the purposes of: (1) determining if the parents met the criteria established for this study, and (2) describing the population in regard to age, education, salary range, gender, length of child's illness, relationship to the child, race, religion, marital status, number of children and child's illness.

#### Procedure

The Stress Adaptation Scale for Parents with Chronically Ill Children was developed in four phases. Phase I dealt with developing the questionnaire and the demographic data sheet. Phases II, III, and IV dealt with testing SASP for validity and reliability.

##### Phase I.

In Phase I, a demographic data sheet and SASP were developed from a review of the literature and the researcher's professional experience (Appendices A & B). The researcher identified six categories of stress within SASP as described in Table 2. Also during this phase, a proposal was developed and approved by the Committee for the Protection of Human Subjects at the Old Dominion University School of Nursing.

Table 2

Categories with Descriptions in the Stress Adaptation Scale  
for Parents with Chronically Ill Children (SASP)

Categories	Descriptions	Tool Items
Health Care	Contains issues related to knowledge the parent has on health care, the parent's concern for the child's health, the health care personnel, and the home environment as conducive to the child.	1-6
Social	Contains issues on the relationship the parent has with friends, availability of friends as support systems, and parent's ability to participate in social functions.	7-11
Personal	Contains health, psychoemotional and leisure issues that are pertinent to the parent.	12-24
Familial	Contains issues that are pertinent to the spouse, the children, the extended family, and the family as a whole.	25-35
Financial	Contains issues pertinent to the income and expenses of the family.	36-39
Spiritual	Contains issues pertinent to the church or synagogue and the parent's belief in a superior being.	40-42

### Phase II.

In Phase II, content validation was explored using a panel of experts. The panel consisted of two master's prepared pediatric nurse practitioners, a pediatrician, and a chaplain who worked with parents of ill children at a large metropolitan hospital. The panel assessed the items on SASP for importance, clarity, and relevance using the researcher-developed scale (Appendix, C). The panel also used a researcher-developed scale to classify each item as health care, social, personal, familial, financial, or spiritual (Appendix, D). Any item that was not placed in the conceptual category or was not rated as clear, important, and relevant by 75% of the panelist was revised or discarded.

### Phase III.

In Phase III, the researcher assembled a questionnaire packet which included SASP, a demographic data sheet, an explanation sheet, and an evaluation form on the ease with which each item on SASP was understood (Appendices A, B, E, F). The explanation sheet described the nature and purpose of the study, as well as the risk-benefit ratio. Benefits included aiding in the development of a tool which would enable health caregivers to assess stress of parents with a chronically ill child. The risk of psychological discomfort in completing SASP was deemed minimal. The explanation sheet explained that completion of the tool implied consent for participation in the study. The parents were informed

that participation was voluntary and they could withdraw from the study any time without penalty. Completion of SASP took 15-20 minutes. Results of the study were made available to parents if they called the School of Nursing at Old Dominion University and left their address.

In this phase, 30 parents of chronically ill children were contacted at home by phone in order to set up a visit. During the visit, the parents were given the questionnaire packets. They were asked to complete all the forms included in the packet and mail them back to the researcher in the stamped addressed envelope. The parents were informed of the importance of completing SASP a second time in a month. Twenty-six of the 30 parents (87%) completed the questionnaire packets. These parents completed the questionnaires in the privacy of their own homes. The Stress Adaptation Scale for Parents with Chronically Ill Children and the demographic sheet were numbered in order that the researcher could send a second questionnaire to the parents. The parents' names, addresses, and identifying numbers were kept in a notebook seen only by the researcher to insure confidentiality. A month later, SASP was mailed to the 26 parents a second time for completion. Twenty-two (85%) questionnaire packets were then returned by mail.

In evaluating the data from phase III, the items on the tool that were not considered easy to understand by 75% of the parents were revised or discarded. The SASP was evaluated for internal consistency using Cronbach's alpha.

After the parents completed SASP a second time, stability was assessed with Pearson correlation. Plans were made to revise SASP if it did not obtain a Pearson  $r$  of .70 or better. Internal consistency of SASP was evaluated again in Phase IV of the formal study.

#### Phase IV.

In Phase IV, SASP was administered to 216 parents who attended selected clinics or support groups. In order to get approval for the study, a letter and abstract explaining the study and requesting use of the facility were mailed to each setting (Appendices G & H). A mutually acceptable protocol for administering SASP was established with each setting.

The following protocol was used in all of the settings in Phase IV. The questionnaire packet containing SASP, a demographic data sheet, and a consent form was delivered to the parents by the researcher or a designated person from the selected facility (Appendices A, B, & I). During support group sessions, the researcher explained the study to the parents and then gave them the questionnaire packets. The researcher had a designated person such as the president of the support group deliver the packet to the parents that were not available to the researcher. It was left up to the designated person to decide if each parent met the requirements which were discussed under the section on the sample. Parents were asked to complete the questionnaire in the privacy of their home without the assistance of their

spouse or anyone else. Then each parent mailed the questionnaire and demographic data sheet back to the researcher in the stamped, addressed envelope. In that no numbers or names appeared on the forms and they were returned in a sealed envelope, anonymity was assured.

In the clinical settings, the researcher discussed the study with each parent attending the clinic and asked them to complete the questionnaire packet while they waited for their child's appointment. The parents returned the questionnaires to the researcher in sealed envelopes. Again, anonymity was assured.

One hundred and ten (51%) of the 216 parents completed the questionnaire packets and returned them to the researcher. The Stress Adaptation Scale for Parents with Chronically Ill Children was assessed again using Cronbach's alpha with an acceptance level of .70.

Chapter 3 describes the samples used in Phase III and IV. It discusses the statistical procedures used to assess SASP for reliability and validity. The results of the statistical procedures are identified and then interpreted.

## Chapter 3

### Results

This study dealt with the development and testing of the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP). The development of SASP consisted of four phases.

#### Phase I

In Phase I, a demographic data sheet and SASP were developed from a review of the literature and the researcher's professional experience. The researcher identified six categories within SASP. The six categories consisted of health care, social, personal, familial, financial, and spiritual. During this phase, the proposal for this study was developed and approved by the Human Subjects Committee in the School of Nursing at Old Dominion University.

#### Phase II

Phase II dealt with establishing the content validity of SASP. Content validity determines how representative the items on the test are of all questions that could be asked on that topic. In order to determine content validity, experts in the content area may be called upon to analyze the items to determine if they represent the topic (Polit & Hungler, 1983).



Content validity of SASP was explored by a panel of experts on chronic childhood illness. The panel consisted of a pediatrician, two master's prepared pediatric nurse practitioners, and a chaplain employed to work with families of chronically ill children in a large metropolitan children's hospital. All of the items in each of the six categories were labeled as important and relevant by at least 75% of the panel, and therefore none were discarded or revised. Five items, interspersed through the six categories, were identified as clear by 50% of the panel resulting in the rewriting of three of these items and discarding of two. Each item was placed in one of the six categories by 75% of the panel so no changes were made based on the categorization.

### Phase III

In Phase III, SASP was tested for face validity and reliability. The accessible population used in this phase was 30 parents of chronically ill children. These parents were acquainted with the researcher through nonhealth related community programs. Their chronically ill children lived with them and were dependent on them for psychological or physical care related to their chronic illness. Of the 30 parents, 26 (87%) returned the questionnaire packet after it was administered the first time and 22 (85%) returned the questionnaire packet following the second administration.

Table 3 shows the demographic characteristics of the parents participating in Phase III and IV of the study. The

Table 3

Demographic Characteristics of Parents Sampled in Phases III and IV

Characteristics	Phase III Number/Percent n=26	Phase IV Number/Percent n=110
<b>Parent's Age</b>		
21-30 years	1 (4%)	28 (25%)
31-40 years	8 (33%)	41 (42%)
over 40 years	15 (63%)	37 (33%)
<b>Parent's Gender</b>		
Male	11 (42%)	31 (29%)
Female	15 (58%)	76 (72%)
<b>Religion</b>		
Protestant	17 (71%)	62 (56%)
Catholic	5 (21%)	21 (19%)
Other	2 (8%)	27 (25%)
<b>Marital Status</b>		
Married to Parent	24 (92%)	85 (80%)
Married not to Parent	1 (4%)	5 (5%)
Divorced	1 (4%)	16 (15%)
<b>Number of Children</b>		
1 or 2	10 (39%)	58 (54%)
3 or 4	16 (61%)	43 (40%)
More than 4	0 (0%)	6 (6%)

demographic characteristics of the parents in Phase IV will be discussed later in this chapter. In Phase III, a wide range of ages was represented with over half of the parents (63%) being over 40 years of age. There were more females (58%) than males (42%). Most of the parents were protestant (71%) and all were caucasian. Most of the parents were married to the child's other biological parent (92%). The parents had at least two children (39%) and no more than four (61%).

Table 4 shows the demographic characteristics of the respondents in the areas of education and financial status. All the parents had attended some level of high school. Most of the parents were white collar workers (52%) or blue collar (36%). More than half of the parents reported salaries above \$41,000.

Table 5 shows the demographic characteristics of the chronically ill children of the parents in Phases III and IV. In Phase III, the children were equally distributed between males (50%) and females (50%). The children were of a wide range of ages and most had been diagnosed at least 48 months (85%). Some of these children had physical illnesses (81%) such as diabetes, juvenile rheumatoid arthritis, and epilepsy. Others had mental illnesses (19%) such as schizophrenia. All but one child was the natural child of the parent.

#### Validity.

Face validity testing was explored with this sample.

Table 4

Demographic Characteristics of Parent Respondents in Phases III and IV

Characteristics	Phase III Number/Percent n=26	Phase IV Number/Percent n=110
<b>Education</b>		
9th-12th Grade	9 (36%)	2 (2%)
1-4 years College	13 (52%)	42 (40%)
Some Graduate Work	1 (4%)	41 (39%)
Master's Degree	2 (8%)	11 (11%)
Doctoral Degree	0 (0%)	8 (8%)
<b>Salary</b>		
<\$10,000	0 (0%)	7 (7%)
\$11-20,000	0 (0%)	27 (26%)
\$21-30,000	3 (13%)	30 (29%)
\$31-40,000	4 (17%)	14 (14%)
\$41-50,000	7 (29%)	12 (12%)
Over \$50,000	6 (25%)	13 (12%)

The 26 parents evaluated each item for ease of understanding using a researcher developed scale (Appendix, E). All 57 items were judged to be easy to understand by at least 75% of the parents. Based on these findings, none of the items were rewritten or discarded.

Internal Consistency Reliability.

Cronbach's alpha was used to measure the internal

Table 5

Demographic Characteristics of Children of Parents in  
Phases III and IV

Characteristics	Phase III Number/Percent n=26	Phase IV Number/Percent n=110
<b>Child's Gender</b>		
Male	13 (50%)	69 (66%)
Female	13 (50%)	36 (34%)
<b>Child's Age</b>		
1-4 years	2 (8%)	32 (30%)
5-9 years	4 (15%)	22 (21%)
10-18 years	13 (50%)	29 (27%)
over 18 years	7 (27%)	24 (22%)
<b>Time Since Diagnosis</b>		
13-23 months	1 (4%)	20 (19%)
24-48 months	3 (11%)	30 (29%)
over 48 months	22 (85%)	54 (52%)
<b>Child's Illness</b>		
Mental	5 (19%)	---
Physical	21 (81%)	---
<b>Relationship to Child</b>		
Parent	25 (96%)	101 (98%)
Stepparent	1 (4%)	2 (2%)

consistency or homogeneity of SASP and of the six categories of health care, social, personal, familial, financial, and spiritual (Table 6). The alpha coefficient was above .70 for the entire tool (.93) and the categories of personal (.85), social (.78), familial (.74), and financial (.74). Since these scores were above .70, it suggested that SASP and these four categories are internally consistent or that all the subparts are measuring the same characteristic (Polit & Hungler, 1983). Each of the four categories can be used independently to measure a specific characteristic since they are internally consistent as indicated by the alpha coefficients. The categories of health care (.66) and spiritual (.52) did not reach the .70 acceptance level so they were not considered to be internally consistent. These two categories can be used only when administered with the other four categories.

#### Reduction of SASP.

In that the alpha coefficients for the tool (.93) and the category of personal (.85) were well above the .70 level, the researcher used the Spearman-Brown formula to reduce the number of items in the personal category from 24 to 13. As shown in Table 6, the eleven items in the personal category which contributed the least to the variance were deleted resulting in an alpha level of .86. Two items were deleted from the health care section resulting in a six-item category with an alpha level of .80. Two items, one from the spiritual (.52) and one from the familial (.74)

Table 6

Descriptive Statistics of SASP in Phases III and IV

Construct	n	Possible Range of Score	Actual Range of Scores	$\bar{X}$	Alpha
<b>Healthcare</b>					
8 items	22	8-32	18-32	26.68	.66
6 items <sup>a</sup>	19	6-24	12-24	19.68	.80
6 items <sup>b</sup>	106	6-24	7-24	18.89	.78
<b>Social</b>					
5 items	26	5-20	10-20	17.65	.78
5 items <sup>b</sup>	107	5-20	5-20	15.53	.82
<b>Personal</b>					
24 items	25	24-96	66-96	85.16	.85
13 items <sup>a</sup>	22	13-52	29-48	44.55	.86
13 items <sup>b</sup>	95	13-52	17-52	40.26	.74
<b>Familial</b>					
12 items	22	12-48	27-48	40.09	.74
11 items <sup>a</sup>	20	11-44	11-44	36.85	.75
11 items <sup>b</sup>	90	11-44	11-44	30.84	.72
<b>Financial</b>					
4 items	24	4-16	6-16	13.75	.76
4 items <sup>b</sup>	93	4-16	4-16	10.77	.79
<b>Spiritual</b>					
4 items	25	4-16	9-16	14.80	.52
3 items <sup>a</sup>	21	3-12	9-12	10.86	.60
3 items <sup>b</sup>	106	3-12	3-12	9.36	.71
<b>Entire Tool</b>					
57 items	18	57-228	157-224	195.72	.93
42 items <sup>a</sup>	16	42-176	109-164	141.86	.93
42 items <sup>b</sup>	72	42-176	51-166	125.18	.90

**Note.** The number of items demonstrate the size of that category each time SASP was administered. SASP was administered three times. The first group of items was in Phase III before SASP was shortened based on reliability testing results.

<sup>a</sup>Results of shortened SASP when administered in Phase III.

<sup>b</sup>Results of shortened SASP when administered in Phase IV.

category, were deleted resulting in an alpha level of .60 for the 3-item spiritual category and .75 for the 11-item familial category. This left a 42-item tool with an alpha level of above .70 for the entire tool and the five categories of health care, personal, social, familial, and financial. The category of spiritual continued to have an alpha level below .70.

#### Stability.

In order to explore the stability of SASP over time, SASP was mailed to the 26 parents a second time a month later. Twenty-two of the questionnaires (85%) were returned by mail. The Pearson correlation between time 1-time 2 testing of SASP was .85 ( $p < .000$ ). This was well above the acceptable level of .70. A high Pearson correlation, above .70, indicated that the scores by all of the subjects do not differ dramatically when the scores are correlated between tests given a month apart (Polit & Hungler, 1983). In that SASP had a high correlation when given twice, this suggested that SASP was stable over time and should be able to measure the effects of intervention without concern over the tool's stability.

#### Phase IV

Phase IV dealt with further revisions of SASP. This phase was carried out in a large metropolitan city in the southeastern United States. The accessible population consisted of 216 parents of chronically ill children receiving care from selected clinics or who were



participating in selected support groups. One hundred and ten (51%) of the parents returned the completed questionnaire packet to the researcher.

As shown in Table 3, the Phase IV sample consisted of more females (71%) than males (29%). Ninety-eight percent of the parents attended college with 19% having a master's degree. Ages of the parents ranged from 19-77 years of age with the mean age of 39 (s.d. .46). Most of the parents were caucasian (90%), and over half of the parents were Protestant (59%). The parents had between one and seven children with a mode of two. Over half of the parents were white collar workers (52%). Most of the parents (80%) were currently married to the child's other biological parent.

The chronically ill children of these parents consisted of more males (66%) than females (34%). The children ranged in age from 0-42 years of age with a mean age of 11 (s.d. 10.27). The length of time the children had been diagnosed with their chronic illness ranged from 0 to 33 years with a mean of 6 years (s.d. 5.53). The sample consisted of children with physical illnesses (76%) and with mental illnesses (24%). The chronic illnesses of the children in this study consisted of cystic fibrosis (22%), diabetes (11%), juvenile rheumatoid arthritis (6%), spina bifida (19%), renal failure (4%), cleft palate (6%), hearing and speech impairment (7%), epilepsy (5%), leukemia (2%), and schizophrenia (18%).

### Reliability.

Cronbach's alpha was used to measure the internal consistency of SASP and the six categories of health care, social, personal, familial, financial, and spiritual. As shown in Table 3, the alpha coefficients were above .70 for the entire tool (.90) and the six categories of health care (.78), personal (.74), social (.82), familial (.75), financial (.79), and spiritual (.71).

Internal consistency is a form of reliability which determines if the items or categories measure the same attribute (Polit & Hungler, 1983). In that each category and the entire tool demonstrated an alpha level above .70, the SASP and each category was judged to be internally consistent. Thus, each category can be used independently to measure a specific attribute of stress.

The finalized tool consisted of 42-items with the six categories of health care, social, personal, familial, financial, and spiritual. The completed tool is on the following pages.

STRESS ADAPTATION SCALE FOR PARENTS (SASP)

**DIRECTIONS:** Circle the number that is appropriate to indicate how well each statement applies in general to you in regard to your child's illness.

1 indicates that it is rarely true for you.

2 indicates that it is slightly true for you.

3 indicates it is moderately true for you.

4 indicates it is usually true for you.

	Rarely true		Usually true	
1. The physicians have not been as informative as I had hoped.	1	2	3	4
2. Physicians have been supportive.	1	2	3	4
3. The nurses have been as helpful as I desire.	1	2	3	4
4. My questions have been answered in regards to my child's health problem.	1	2	3	4
5. I am not confident of the judgment of my child's physician.	1	2	3	4
6. I understand what to expect with my child's illness.	1	2	3	4
7. I socialize with friends as often as before I had a child with a health problem.	1	2	3	4
8. My friends treat me the same way they did before I had a child with a health problem.	1	2	3	4
9. I feel comfortable entertaining in my home.	1	2	3	4
10. I am able to participate in pleasurable activities as I did before I had a child with a health problem.	1	2	3	4
11. I feel my child is accepted by peers.	1	2	3	4
12. I have at least one person I can talk to when I am troubled.	1	2	3	4

	Rarely true		Usually true	
	1	2	3	4
13. I feel comfortable leaving my child when I attend functions away from home.				
14. I sleep well at night.	1	2	3	4
15. My health has not been the same.	1	2	3	4
16. I feel good about myself.	1	2	3	4
17. I am comfortable caring for my child's health needs.	1	2	3	4
18. I am optimistic about my child's future.	1	2	3	4
19. I am not able to spend time by myself.	1	2	3	4
20. I am able to handle my emotions.	1	2	3	4
21. I am able to handle situations that may come up pertaining to child's health problem.	1	2	3	4
22. I feel that others who spend time with my child (teachers/babysitters) are able to take good care of him/her.	1	2	3	4
23. I feel I am a good parent.	1	2	3	4
24. My energy level is the same.	1	2	3	4
25. My child/children and I have a different relationship than we had before we had a child with a health problem.	1	2	3	4
26. My relationship with my spouse has remained the same.	1	2	3	4
27. My extended family has been available when I need them.	1	2	3	4
28. I am not able to spend as much time as I would like with my spouse.	1	2	3	4
29. My spouse and I communicate well.	1	2	3	4

		Rarely true			Usually true
30.	I do not feel that my child has adjusted to his/her illness.	1	2	3	4
31.	I am able to spend as much time as I would like with my child/children.	1	2	3	4
32.	I feel comfortable talking to other family members about my child's illness.	1	2	3	4
33.	I do not treat all the members of my family the same as before I had a child with a health problem.	1	2	3	4
34.	I feel that other members of my family are capable of caring for my child when he/she gets sick.	1	2	3	4
35.	I feel the other family members are able to perform their daily activities (school/work) as before.	1	2	3	4
36.	I am not able to miss work when my child needs me without concern over finances.	1	2	3	4
37.	I am able to pay for my child's medical expenses.	1	2	3	4
38.	I am able to buy items I desire with the same concern for finances as before I had a child with a health problem.	1	2	3	4
39.	I am able to pay my bills.	1	2	3	4
40.	My feelings toward the church/synagogue have changed.	1	2	3	4
41.	My feelings toward God have remained the same.	1	2	3	4
42.	I turn to the church for comfort the same as I did before I had a child with a health problem.	1	2	3	4

### Other Findings

The sample of 110 parents of chronically ill children was divided into nine groups. The groups were parents of children with: (1) diabetes, (2) juvenile rheumatoid arthritis, (3) cystic fibrosis, (4) hearing and/or speech impairment, (5) spina bifida, (6) schizophrenia, (7) cleft palate, (8) seizure disorders, and (9) polycystic kidney disease. The ranges of scores of each group were computed and evaluated. Table 7 shows the ranges of scores.

In comparing the ranges of scores for the varying diseases, there were several interesting findings. More than 50% of the parents of children with schizophrenia (Group 6) had their need to adapt to stress unmet or partially met in all of the categories except spiritual. The parents of children with spina bifida (Group 5) had the second highest level of stress with 40% having their needs unmet or partially met in the categories of social, financial, and health care. The parents of children with juvenile rheumatoid arthritis, cleft palate, and seizure disorders (Groups 1, 7, & 8) had very little stress as indicated by their scores on SASP. This suggested that cognitive impairment may produce more stress than physical illnesses.

### Hypotheses

The first hypothesis stated that the overall internal consistency reliability (Cronbach's alpha) would be .70 or greater for SASP and for the categories of health care,

Table 7

Ranges of Scores on the SASP and Each Category as obtained by Sample  
Grouped According to Diagnosis of the Child

Categories	Groups								
	1 n=12	2 n=6	3 n=24	4 n=8	5 n=21	6 n=20	7 n=6	8 n=6	9 n=7
<b>Health Care</b>									
Unmet	0	1	0	1	2	2	0	0	0
P. Met	4	0	2	2	8	11	0	3	3
Met	8	5	22	5	11	7	6	3	4
<b>Social</b>									
Unmet	0	1	0	1	4	7	0	2	0
P. Met	0	0	5	2	5	3	0	2	1
Met	12	5	19	5	12	10	6	2	6
<b>Personal</b>									
Unmet	0	0	0	1	0	0	0	0	0
P. Met	1	0	6	3	9	14	1	2	2
Met	11	6	18	4	12	6	5	4	5
<b>Familial</b>									
Unmet	0	0	2	1	1	4	0	0	0
P. Met	8	2	13	4	15	11	3	2	4
Met	4	4	9	3	5	5	3	4	3
<b>Financial</b>									
Unmet	0	1	7	3	9	4	1	0	1
P. Met	3	1	5	5	6	6	1	2	4
Met	9	4	11	0	6	9	4	4	2
<b>Spiritual</b>									
Unmet	2	1	2	1	4	3	0	0	1
P. Met	4	1	7	1	4	2	0	0	0
Met	6	4	13	6	13	14	6	6	6
<b>Stress</b>									
Unmet	0	0	0	1	0	1	0	0	0
P. Met	2	1	11	3	16	13	1	3	4
Met	10	5	13	4	5	6	5	3	3

**Note.** Group 1 = diabetes; Group 2 = juvenile rheumatoid arthritis; Group 3 = cystic fibrosis; Group 4 = hearing/speech impairment; Group 5 = spina bifida; Group 6 = schizophrenia; Group 7 = cleft palate; Group 8 = seizure disorders; Group 9 = polycystic kidney disease.

social, personal, familial, financial, and spiritual. In Phase IV, the entire tool and all of the categories achieved an alpha level of greater than .70. Thus, the first hypothesis was supported.

The second hypothesis stated that stability of SASP over time would demonstrate a Pearson correlation of .70 or greater. In Phase III, the SASP demonstrated a Pearson correlation of .85 ( $p < .000$ ) following time 1-time 2 testing. The second hypothesis was also supported.

The support of the two hypotheses by this study suggested the SASP may have sufficient reliability and validity for use in research with parents with chronically ill children. Further research is needed in order to confirm its usefulness.

Chapter 4 compares the results of this study to the literature reviewed and relates it to the theoretical framework. Recommendations for future studies are made.



## Chapter 4

### Discussion

The purpose of this study was to develop and test the Stress Adaptation Scale for Parents with Chronically Ill Children (SASP). The six categories of stress identified by the researcher consisted of health care, social, personal, familial, financial, and spiritual.

### Conclusions

In this study, the SASP was developed and tested for reliability and validity. The Stress Adaptation Scale for Parents with Chronically Ill Children appeared to be both reliable and valid as an instrument for use in research and clinical practice settings with parents of chronically ill children. Reliability was established using Pearson correlation and Cronbach's alpha. By demonstrating a Pearson  $r$  of .85 ( $p < .000$ ), SASP appeared to be stable over time. A high Pearson correlation, above .70, indicated that the scores by all of the subjects did not differ dramatically when the scores were correlated between tests given a month apart (Polit & Hungler, 1983). Since SASP had a high correlation when given twice, it suggested that SASP was stable over time and should be able to show the effects of intervention without concern over the tool's stability.

Cronbach's alpha was used to measure the internal

consistency or homogeneity of SASP and of the six categories of social, familial, personal, health care, spiritual, and financial. The alpha coefficient from phase IV was above .70 for the entire tool and all six categories. Since these scores were above the .70 level, it suggested that SASP and the categories were internally consistent or that all the subparts were measuring the same characteristic (Polit & Hungler, 1983). Each of the categories can be used independently to measure a specific characteristic since they are internally consistent as indicated by the alpha coefficients. The category with the lowest alpha score was spiritual. This could be due to the low number of items in that category. The spiritual category contained only four items in Phase III and three items in Phase IV.

The validity of SASP was evaluated by 26 parents of chronically ill children and by an expert panel. Each item was evaluated as easy to understand by at least 75% of the parents thus face validity was suggested. At least 75% of the expert panel evaluated each item on SASP as relevant, clear, and important thus suggesting content validity. Content validity is the degree to which items on a tool represent the universe of content (Polit & Hungler, 1983). According to the results from the expert panel, the items on SASP were representative of stress experienced by parents of chronically ill children. Construct validity through factor analysis was not evaluated with the SASP at this time due to

the sample size. Factor analysis should be performed with the SASP in order to strengthen the view that the tool contains six categories. As of this time, it is only the opinions of the researcher and the expert panel which supports the premise that there are indeed six categories represented in the tool.

The theoretical frameworks used in this study were Nursing's Human Need Theory by Yura and Walsh and Stress Theory by Hans Selye. Based on Nursing's Human Need Theory, the scores obtained on SASP indicated the parent's level of adaptation to stress. If this human need was in the unmet state, the welfare of the person was considered to be in jeopardy (Yura & Walsh, 1988). The results of the study suggested that the parents of children with schizophrenia were unable to adapt to the stress in the categories of health care, social, personal, familial, and financial. Based on these findings, the welfare of these parents was thought to be threatened. The nurse had a responsibility to support, facilitate, foster, and intervene with these parents in order to assist them in fulfilling their human need to adapt to stress. Further testing of SASP using contrasting groups should be performed in order to confirm the findings of this study in regard to parents of schizophrenic children having the highest level of stress.

Based on Stress Theory by Hans Selye, each stressor must be dealt with in order to minimize the progression towards exhaustion (Auger, 1976; Hogan, 1983). The results of this

study suggested that SASP could assist health care personnel in identifying those parents who were moving towards the stage of exhaustion. The scores obtained in Phase IV indicated that the parents of children with schizophrenia had the highest levels of stress. These parents were in need of immediate nursing intervention to minimize their stress level and thus prevent the potential exhaustion.

There is a need for further research comparing varying illnesses and level of adaptation to stress. Literature currently available deals with the stress level of parents of children with certain diagnosis but does not compare parents of children with one diagnosis to parents of children with a different diagnosis.

Research done by Hatfield (1979) on mental illness showed that families with a mentally ill member often experience severe stress. According to Hatfield's study, the parents must often deal with feelings of blame, marital unrest, lack of information on the disease, absence of social support, and personal strain. There is no opportunity for leisure or interpersonal relationships (Hatfield, 1979). The findings of Hatfield's study support the findings obtained with the SASP in that the parents of children with schizophrenia had high levels of stress in the health care, social, personal, and familial categories.

Past research in tool development supported the view of the researcher that there are certain categories of stress prominent for parents of chronically ill children. The

Coping Health Inventory for Parents (CHIP) consisted of three parental coping patterns identified with factor analysis. Among these three patterns were the topics of family integration, maintaining social support and understanding the health care situation (McCubbin et al., 1983). These three areas were found in SASP in the familial, social and health care categories. The Cronbach's alpha was above .70 for CHIP and for the three coping patterns (McCubbin et al., 1983). Cronbach's alpha was also above .70 for SASP and the categories of familial, social, and health care.

The Impact-on-Family Scale by Stein and Riessman (1980) had four dimensions of impact identified by factor analysis. Three of the four categories were financial, social/familial, and personal strain. These categories were consistent with the SASP categories of social, personal, familial, and financial. These categories received an alpha coefficient of above .70 in both tools (Stein & Riessman, 1980).

The Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) had four major categories with one being stressors. Several categories in SASP were found in the stressors category of the Chronicity Impact and Coping Instruments: Parent Questionnaire. The stressors category of CICI:PQ consisted of knowledge of illness, family adjustments, family relationships, and managing the child's condition. These are similar to the categories of family

and health care found in SASP. The Hoyt's coefficient for the category of stressors was .94 (Hymovich, 1984).

There were no tools identified which addressed all of the categories found in the Stress Adaptation Scale for Parents with Chronically Ill Children. Some of the tools addressed one or several of the categories of health care, social, personal, familial, and financial, but no tool addressed spiritual.

### Recommendations

Based on the findings in this study there are several recommendations for further research.

1. The Stress Adaptation Scale for Parents with Chronically Ill Children should be evaluated for construct validity using a larger sample in order to determine if there are indeed six separate categories of the construct.
2. Special emphasis should be placed on clarification of spiritual stress as a category. More items should be added to the spiritual category and then the category should be retested for internal consistency.
3. The questionnaire could be used with contrasted groups in order to test the premise that low scores on SASP indicate the inability of parents to adapt to stress and that high scores indicate ability to adapt to stress. Such groups might consist of parents with children in the hospital versus parents with children with a stabilized chronic illness or parents of newly diagnosed children versus those diagnosed for a longer time.

4. The SASP should be administered to a large population to further confirm the reliability and validity as well as test the hypotheses.
5. Sasp should then be used in intervention studies in order to evaluate the effectiveness of an intervention in reducing stress using time 1-time 2 testing.
6. The Stress Adaptation Scale for Parents with Chronically Ill Children may be used in studies comparing parents of children with varying diagnosis such as mental illness versus physical illness or terminal illness versus chronic nonterminal illness.

The data gathered up to this point on SASP suggests that it has potential as a valid and reliable tool. Further testing is necessary to confirm its usefulness for research. Health care providers may be able to identify when a parent's well-being is threatened by the inability to meet the human need to adapt to stress. The SASP may prove to be useful in measuring such inability. Once inability to adapt to stress has been identified, health care providers can assist parents in dealing with the stress associated with the chronically ill child.

Nurses as family care providers need reliable and valid instruments to measure the parent's ability to adapt to the stress associated with a child's chronic illness. The SASP may well be the instrument needed for such evaluation of parents.

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## **Appendices**

## **Appendix A**

## Appendix A

ORIGINAL - STRESS ADAPTATION SCALE FOR PARENTS (SASP)

**DIRECTIONS:** Circle the letter that is appropriate to indicate how well each statement applies to you in regards to your child's illness. 1 indicates that it is rarely true for you. 4 indicates it is usually true for you.

	Rarely true	2	3	Usually true
1. I am able to afford my child's medical expenses.	1	2	3	4
2. I am able to miss work when my child needs me without concern over finances.	1	2	3	4
3. I am able to spend the same amount of money that I spent before my child's illness.	1	2	3	4
4. I see my friends as often as before my child's illness.	1	2	3	4
5. My friends treat me the same way they did before my child's illness.	1	2	3	4
6. I have people that I can call on when I need support.	1	2	3	4
7. I have at least one person I can talk to when I am troubled.	1	2	3	4
8. I feel comfortable leaving my child when I attend functions away from home.	1	2	3	4
9. I feel comfortable entertaining in my home.	1	2	3	4
10. My health has been the same or better.	1	2	3	4
11. I sleep well at night.	1	2	3	4
12. I eat the same or better than I did.	1	2	3	4
13. I am able to participate in the activities I enjoy.	1	2	3	4

		Rarely true		Usually true	
14.	I am able to spend time by myself.	1	2	3	4
15.	I am able to satisfy my needs.	1	2	3	4
16.	I feel good about myself.	1	2	3	4
17.	I am comfortable caring for my child's medical needs.	1	2	3	4
18.	I understand what to expect with my child's illness.	1	2	3	4
19.	I have people to turn to for information about my child's illness.	1	2	3	4
20.	I am optimistic about my child's future.	1	2	3	4
21.	The health care personnel have been informative.	1	2	3	4
22.	Health care personnel have been supportive.	1	2	3	4
23.	I know what I want to know about my child's illness.	1	2	3	4
24.	I am confident of the judgment of my child's physician.	1	2	3	4
25.	I take my child for all the health related appointments.	1	2	3	4
26.	I have been able to establish a home environment appropriate for my child's illness.	1	2	3	4
27.	I have been able to adapt to environmental changes necessary due to my child's illness.	1	2	3	4
28.	My feelings toward God have remained the same.	1	2	3	4
29.	My feelings toward the church/synagogue have remained unchanged.	1	2	3	4

		Rarely true		Usually true	
30.	My relationship with my spouse has remained the same or improved.	1	2	3	4
31.	My extended family has been supportive.	1	2	3	4
32.	I am able to spend as much time as I would like with my spouse.	1	2	3	4
33.	My spouse has supported me emotionally.	1	2	3	4
34.	I communicate well with my spouse.	1	2	3	4
35.	My attitude toward having more children has not changed.	1	2	3	4
36.	I am able to spend as much time as I would like with my child/children.	1	2	3	4
37.	My relationship with my child/children is unchanged or better.	1	2	3	4
38.	I treat my child as if he/she were not ill.	1	2	3	4
39.	I allow my child to participate in physical activities.	1	2	3	4
40.	I allow my child to spend time with other children.	1	2	3	4
41.	I feel comfortable talking to other family members about my child's illness.	1	2	3	4
42.	I treat all the members of my family the same as I did before my child became ill.	1	2	3	4
43.	I feel that other members of my family are capable of caring for my child when he/she has a medical problem.	1	2	3	4

		Rarely true		Usually true	
44.	I feel my child is accepted by peers.	1	2	3	4
45.	I feel the other family members are able to perform their daily activities (school/work) as they did.	1	2	3	4
46.	I feel that my child has adjusted to his/her illness.	1	2	3	4
47.	I am able to handle my emotions.	1	2	3	4
48.	I do not dwell on my child's disease.	1	2	3	4
49.	I can handle any situation that may come up pertaining to my child.	1	2	3	4
50.	My work/home performance has remained the same or has improved.	1	2	3	4
51.	I feel that others who spend time with my child ( teachers/ babysitters) are able to take good care of him/her.	1	2	3	4
52.	I remain reasonably calm in crisis.	1	2	3	4
53.	I am a good parent.	1	2	3	4
54.	I am able to pay my bills.	1	2	3	4
55.	I turn to the church for comfort the same as I did before my child became ill.	1	2	3	4
56.	I attend church as regularly as I did before my child became ill.	1	2	3	4

Please, comment on any additional areas that you feel should be included in this questionnaire.

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## **Appendix B**



## Appendix B

## DEMOGRAPHIC DATA SHEET

1. Identify your child's illness: \_\_\_\_\_
2. Your age at your last birthday: \_\_\_\_\_
3. Your child's age at last birthday: \_\_\_\_\_
4. Your gender:
  - \_\_\_\_\_ male
  - \_\_\_\_\_ female
5. Your child's gender:
  - \_\_\_\_\_ male
  - \_\_\_\_\_ female
6. Race:
  - \_\_\_\_\_ caucasian
  - \_\_\_\_\_ hispanic
  - \_\_\_\_\_ black
  - \_\_\_\_\_ other
7. How long has your child's illness been diagnosed?  
\_\_\_\_\_
8. Your Religion:
  - \_\_\_\_\_ protestant
  - \_\_\_\_\_ catholic
  - \_\_\_\_\_ jewish
  - \_\_\_\_\_ other
9. Relationship to child:
  - \_\_\_\_\_ parent
  - \_\_\_\_\_ stepparent
  - \_\_\_\_\_ fosterparent
10. Your Marital Status:
  - \_\_\_\_\_ single
  - \_\_\_\_\_ married to child's other parent
  - \_\_\_\_\_ married (not child's other parent)
  - \_\_\_\_\_ divorced/separated
  - \_\_\_\_\_ widow (not married)
11. Your education level:
  - \_\_\_\_\_ 1st - 8th grade
  - \_\_\_\_\_ 9th - 12th grade
  - \_\_\_\_\_ 1-4 years college
  - \_\_\_\_\_ some graduate work
  - \_\_\_\_\_ master's degree
  - \_\_\_\_\_ doctoral degree
  - \_\_\_\_\_ other: \_\_\_\_\_
12. Your living arrangement when child hospitalized:
  - \_\_\_\_\_ live at home
  - \_\_\_\_\_ live away from home
13. Do you attend meetings about your child's illness?  
\_\_\_\_\_ no \_\_\_\_\_ yes, specify: \_\_\_\_\_
14. Salary range for household:
 

_____ under \$10,000	_____ \$21-30,000	_____ \$41-50,000
_____ \$10 - 20,000	_____ \$31-40,000	_____ \$51,000 up
15. Occupation, specify.  
Yours: \_\_\_\_\_  
Spouse's: \_\_\_\_\_
16. How many children do you have? \_\_\_\_\_

## **Appendix C**

## Appendix C

## EVALUATION SCALE FOR SASP

Information: Evaluate the SASP for importance, clarity and relevance.

Importance - Please evaluate each item as to how important it is for health care providers to know in order to improve their care of a chronically ill child and family.

Clarity - Please rank each item on its clarity and ease of readability.

Relevance - Please rank each item as to how relevant it is for inclusion in an instrument which measures stress in parents with chronically ill children.

Directions: -Circle 1 if the item is not important, not clear or not relevant.

-Circle 2 if the item is important, is clear, or is relevant.

	important		clear		relevant	
	no	yes	no	yes	no	yes
1.	1	2	1	2	1	2
2.	1	2	1	2	1	2
3.	1	2	1	2	1	2
4.	1	2	1	2	1	2
5.	1	2	1	2	1	2
6.	1	2	1	2	1	2
7.	1	2	1	2	1	2
8.	1	2	1	2	1	2
9.	1	2	1	2	1	2
10.	1	2	1	2	1	2
11.	1	2	1	2	1	2
12.	1	2	1	2	1	2
13.	1	2	1	2	1	2
14.	1	2	1	2	1	2

	important		no	clear		no	relevant	
	no	yes		yes	yes		no	yes
15.	1	2	1	2	1	2		
16.	1	2	1	2	1	2		
17.	1	2	1	2	1	2		
18.	1	2	1	2	1	2		
19.	1	2	1	2	1	2		
20.	1	2	1	2	1	2		
21.	1	2	1	2	1	1		
22.	1	2	1	2	1	2		
23.	1	2	1	2	1	2		
24.	1	2	1	2	1	2		
25.	1	2	1	2	1	2		
26.	1	2	1	2	1	2		
27.	1	2	1	2	1	2		
28.	1	2	1	2	1	2		
29.	1	2	1	2	1	2		
30.	1	2	1	2	1	2		
31.	1	2	1	2	1	2		
32.	1	2	1	2	1	2		
33.	1	2	1	2	1	2		
34.	1	2	1	2	1	2		
35.	1	2	1	2	1	2		
36.	1	2	1	2	1	2		
37.	1	2	1	2	1	2		
38.	1	2	1	2	1	2		
39.	1	2	1	2	1	2		

	important		clear		relevant	
	not	very	not	very	not	very
40.	1	2	1	2	1	2
41.	1	2	1	2	1	1
42.	1	2	1	2	1	2
43.	1	2	1	2	1	2
44.	1	2	1	2	1	2
45.	1	2	1	2	1	2
46.	1	2	1	2	1	2
47.	1	2	1	2	1	2
48.	1	2	1	2	1	2
49.	1	2	1	2	1	2
50.	1	2	1	2	1	2
51.	1	2	1	2	1	2
52.	1	2	1	2	1	2
53.	1	2	1	2	1	2
54.	1	2	1	2	1	2
55.	1	2	1	2	1	2
56.	1	2	1	2	1	2

Please, write any suggestions you have for the SASP on the back (format, clarity of directions, thoroughness or other)

## Appendix D

## Appendix D

## CONTENT DISTRIBUTION SCALE

Directions: Circle the letter that corresponds with the category which each item on the SASP in your opinion belongs to.

Categories: Financial-Contains income and expenses of the family.  
Personal-Contains health, leisure, and psychoemotional issues that are pertinent to the parent.  
Familial-Contains issues that are pertinent to the spouse, the children, the extended family, and the family as a whole.  
Spiritual-Contains issues pertinent to the church or syngogue and the parent's belief in a superior being.  
Health Care-Contains issues related to the knowledge the parent has on health care, the parents concern for the child's health, the health care personnel, and the home environment being conducive to the ill child.  
Social-Contains issues on the relationship the parent has with friends, availability of friends as support systems, and parent's ability to participate in social functions.

	finance	personal	family	spiritual	health care	social
1.	a	b	c	d	e	f
2.	a	b	c	d	e	f
3.	a	b	c	d	e	f
4.	a	b	c	d	e	f
5.	a	b	c	d	e	f
6.	a	b	c	d	e	f
7.	a	b	c	d	e	f
8.	a	b	c	d	e	f
9.	a	b	c	d	e	f
10.	a	b	c	d	e	f
11.	a	b	c	d	e	f

	finance	personal	family	spiritual	health care	social
12.	a	b	c	d	e	f
13.	a	b	c	d	e	f
14.	a	b	c	d	e	f
15.	a	b	c	d	e	f
16.	a	b	c	d	e	f
17.	a	b	c	d	e	f
18.	a	b	c	d	e	f
19.	a	b	c	d	e	f
20.	a	b	c	d	e	f
21.	a	b	c	d	e	f
22.	a	b	c	d	e	f
23.	a	b	c	d	e	f
24.	a	b	c	d	e	f
25.	a	b	c	d	e	f
26.	a	b	c	d	e	f
27.	a	b	c	d	e	f
28.	a	b	c	d	e	f
29.	a	b	c	d	e	f
30.	a	b	c	d	e	f
31.	a	b	c	d	e	f
32.	a	b	c	d	e	f
33.	a	b	c	d	e	f
34.	a	b	c	d	e	f
35.	a	b	c	d	e	f
36.	a	b	c	d	e	f
37.	a	b	c	d	e	f



	finance	personal	family	spiritual	health care	social
38.	a	b	c	d	e	f
39.	a	b	c	d	e	f
40.	a	b	c	d	e	f
41.	a	b	c	d	e	f
42.	a	b	c	d	e	f
43.	a	b	c	d	e	f
44.	a	b	c	d	e	f
45.	a	b	c	d	e	f
46.	a	b	c	d	e	f
47.	a	b	c	d	e	f
48.	a	b	c	d	e	f
49.	a	b	c	d	e	f
50.	a	b	c	d	e	f
51.	a	b	c	d	e	f
52.	a	b	c	d	e	f
53.	a	b	c	d	e	f
54.	a	b	c	d	e	f
55.	a	b	c	d	e	f
56.	a	b	c	d	e	f

## Appendix E

**Appendix E****EXPLANATION OF STUDY: PHASE III**

I am a graduate nursing student at Old Dominion University. I am developing a questionnaire to identify the types of stress present for parents of children with a health problem.

Your participation in this study would require you to complete a questionnaire, now and again in a month, on the stress you experience as a parent of a child with a health problem. With this information, I will develop a questionnaire that will enable health professionals to identify and assist in minimizing the stress affecting similar parents. You will also complete a form evaluating the ease with which you understood each item on the questionnaire.

I will give the questionnaire to you for completion at your own convenience. Please, do not discuss the questionnaire with anyone while you have it. Please, return the completed questionnaire in the stamped envelope within the next two weeks (by June 4). It should take 15-20 minutes to finish.

The completion of the questionnaire implies your consent for participation in the study. If you participate, neither you nor your family will be identified in any of the study presentations. Your participation is voluntary and you may withdraw at any time. If you choose not to participate, the care you and your child receive from a health care agency, the nurses or your physician will not be affected.

If you have any question or would like a summary of the results of my study, you may leave a message at 440-4297, the School of Nursing at Old Dominion University in Norfolk, Virginia.

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**Carolyn M. Rutledge, BSN  
Graduate Nursing Student  
Old Dominion University**

## Appendix F

## Appendix F

## EASE OF UNDERSTANDING SCALE

Directions: -Circle 1 if the item is difficult to understand.  
 -Circle 2 if the item is easy to understand

	difficult	easy		difficult	easy
1.	<u>1</u>	<u>2</u>	29.	<u>1</u>	<u>2</u>
2.	<u>1</u>	<u>2</u>	30.	<u>1</u>	<u>2</u>
3.	<u>1</u>	<u>2</u>	31.	<u>1</u>	<u>2</u>
4.	<u>1</u>	<u>2</u>	32.	<u>1</u>	<u>2</u>
5.	<u>1</u>	<u>2</u>	33.	<u>1</u>	<u>2</u>
6.	<u>1</u>	<u>2</u>	34.	<u>1</u>	<u>2</u>
7.	<u>1</u>	<u>2</u>	35.	<u>1</u>	<u>2</u>
8.	<u>1</u>	<u>2</u>	36.	<u>1</u>	<u>2</u>
9.	<u>1</u>	<u>2</u>	37.	<u>1</u>	<u>2</u>
10.	<u>1</u>	<u>2</u>	38.	<u>1</u>	<u>2</u>
11.	<u>1</u>	<u>2</u>	39.	<u>1</u>	<u>2</u>
12.	<u>1</u>	<u>2</u>	40.	<u>1</u>	<u>2</u>
13.	<u>1</u>	<u>2</u>	41.	<u>1</u>	<u>2</u>
14.	<u>1</u>	<u>2</u>	42.	<u>1</u>	<u>2</u>
15.	<u>1</u>	<u>2</u>	43.	<u>1</u>	<u>2</u>
16.	<u>1</u>	<u>2</u>	44.	<u>1</u>	<u>2</u>
17.	<u>1</u>	<u>2</u>	45.	<u>1</u>	<u>2</u>
18.	<u>1</u>	<u>2</u>	46.	<u>1</u>	<u>2</u>
19.	<u>1</u>	<u>2</u>	47.	<u>1</u>	<u>2</u>
20.	<u>1</u>	<u>2</u>	48.	<u>1</u>	<u>2</u>
21.	<u>1</u>	<u>2</u>	49.	<u>1</u>	<u>2</u>
22.	<u>1</u>	<u>2</u>	50.	<u>1</u>	<u>2</u>

	difficult	easy
23.	<u>1</u>	<u>2</u>
24.	<u>1</u>	<u>2</u>
25.	<u>1</u>	<u>2</u>
26.	<u>1</u>	<u>2</u>
27.	<u>1</u>	<u>2</u>
28.	<u>1</u>	<u>2</u>

	difficult	easy
51.	<u>1</u>	<u>2</u>
52.	<u>1</u>	<u>2</u>
53.	<u>1</u>	<u>2</u>
54.	<u>1</u>	<u>2</u>
55.	<u>1</u>	<u>2</u>
56.	<u>1</u>	<u>2</u>

## Appendix G

## Appendix G

## LETTER TO GROUP LEADERS

School of Nursing  
Graduate Program  
Old Dominion University  
Norfolk  
Virginia 23508

To Whom It May Concern:

I am a graduate nursing student at Old Dominion University. I am developing a questionnaire to identify how well parents of chronically ill children are adapting to stress. I feel this study will give insight into the types of stress that parents experience so that we, as nurses, can assist parents in coping. In order to verify the reliability of the questionnaire, I will require parents with chronically ill children to complete it. I have chosen your facility in which to administer the questionnaire. I would like to meet with a designated staff member to review the protocol I will use in administering the questionnaire. I have enclosed an abstract of the study for your convenience.

Please, let me know if you have any questions. I may be contacted at 440-4297. You will be given a copy of the results obtained in order that nurses in your facility will be aware of possible stressors when caring for parents of chronically ill children. I look forward to receiving your permission to carry out the study in your facility.

Sincerely,

Carolyn M. Rutledge, BSN  
Graduate Nursing Student  
Old Dominion University



## Appendix H

## Appendix H

## ABSTRACT FOR DEVELOPMENT OF SASP

This methodological study deals with the development of an instrument to measure stress in parents with a chronically ill child. The tool is developed in four phases. The first phase consisted of developing the items on SASP from a review of the literature and the researchers professional experience. Phase II consisted of a panel of experts evaluating the importance, clarity and relevance of the items on SASP in order to establish content validity. In phase III, 26 parents of chronically ill children filled out the questionnaire and evaluated the ease with which SASP can be used. In phase IV, a formal study with 100 parents will be carried out using the tool. From the formal study, the effectiveness of the tool will be assessed and conclusions will be drawn. Cronbach's alpha will be used to test internal consistency of the entire tool and then to test the six categories of stressors which consist of financial, social, spiritual, personal, familial, and health care. Stability will be assessed using Pearson's correlation. On completion of this study, a valid and reliable tool will be developed for use in health care settings to identify the stressors that parents of chronically ill children experience.

## Appendix I

## Appendix I

## EXPLANATION OF STUDY: PHASE IV

I am a graduate nursing student at Old Dominion University. I am developing a questionnaire to identify the types of stress present for parents of children with a health problem.

Your participation in this study would require you to complete a questionnaire on the stress you experience as a parent of a child with a health problem. With this information, I will be able to develop a questionnaire that will enable health professionals to identify and assist in minimizing the stress affecting similar parents.

The questionnaire and a demographic data sheet will be given to you for completion at your own convenience. Place the questionnaire in the enclosed envelope and mail it to me when you have completed it. Please, do not discuss the questionnaire with your spouse or anyone else while you have it. It should take 15-20 minutes to complete.

The completion of the questionnaire implies your consent for participation in the study. If you participate, neither you nor your family will be identified in any of the study presentations. Your participation is voluntary and you may withdraw at any time. If you choose not to participate, the care you and your child receive from the health care agency, the nurses or your physician will not be affected.

If you have any question or would like a summary of the results of the study, you may leave a message at 440-4297, the School of Nursing at Old Dominion University in Norfolk, Virginia.

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Carolyn M. Rutledge, BSN  
Graduate Nursing Student