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Identification of Family Member's Self-Care Knowledge: A Qualitative Study

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**IDENTIFICATION OF FAMILY MEMBER'S SELF-CARE KNOWLEDGE:
A QUALITATIVE STUDY**

By

Bradley S. Corbin

A THESIS

**Submitted to
Grand Valley State University
in partial fulfillment of the requirements for the
degree of**

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ABSTRACT

IDENTIFICATION OF FAMILY MEMBER'S SELF-CARE KNOWLEDGE:

A QUALITATIVE STUDY

By

Bradley S. Corbin

A Family Adaptive Potential Assessment Tool (FAPAT) based on Modeling and Role-Modeling theory has been developed to assist nurses in their holistic approach to nursing. The purpose of this research was to begin to test one of the propositions on which the FAPAT was based: Families are able to identify what will be helpful for them during a time when they are trying to cope with a significant life event.

Families were generally able to identify what would be helpful. A modified grounded theory approach assisted to identify four themes that emerged under external support and three themes under internal support. External support themes were: (a) formal supportive relationships, (b) informal supportive relationships, (c) information, and (d) a supportive health care structure. Internal support themes were: (a) intra-individual family member support, (b) intra-family support, and (c) a supportive family organization.

Dedicated to my Son

- Matthew Corbin -

- give yourself credit -

- when you do your best -

- and -

- give yourself a chance -

- to learn your own limitations -

Acknowledgements

I would like to thank Dr. Patricia Underwood, my advisor, for her patience and flexibility. Dr. Underwood allowed me to challenge myself yet brought me back to earth when the challenge was beyond the scope of the degree. Without her guidance, this thesis would not have come about.

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To my mother and sister, thank you for all the long distance telephone calls and cards of support. I needed your faith that I could do all that I set out to do, thank you both for being there.

And to my son, thank you for your understanding and loving support in all the changes that we have gone through these past few years. Remember Matt, if your old man can do what he set out to do, so too, you can do all that you set out to do. I love you very much.....

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CHAPTER I

PURPOSE

Assessment tools exist within the clinical setting that measure the human responses to illness. These tools form the cornerstone to the nursing process of patient-centered nursing care. Clinical in nature, accepted by the staff nurse, these tools fall short in their commitment to holistic nursing. The reasons for this shortfall are that they are not based on sound nursing theory and do not adequately assess the needs of the family.

Assessment tools most commonly utilized within the acute care setting tend to omit the family, utilize the family to gather further data about the patient, or provide superficial assessment of the family's needs. If nurses had a tool that would accurately assess families of patients within the acute care setting, they would be more likely to include the family in their assessment process.

Maintaining a holistic approach to caring for individuals, groups and societies sets nurses apart from other health care team members. The intricate component in the holistic assessment of the human response to illness is the inclusion of the family within the assessment process. There are many instruments that have generalized the needs

and the perceived needs of families facing situational and maturational events (Artinian, 1989; Stillwell, 1984; Wright, 1987). There are few tools within the literature that assist the nurse in assessing the requirements of families and thus establishing an individualized plan of care for families. The commitment to maintain a holistic approach to nursing is drained when there are not enough tools to assist nurses.

Acute care settings in themselves can be a stressor on families (Clifford, 1986), and families often come to the acute care setting with a pileup of stressors (McCubbin & Patterson, 1982). The ability to accurately assess the adaptive potential of the family requires the nurse to understand the world of the family.

A Family Adaptive Potential Assessment Tool (FAPAT) has been developed to assist nurses in their holistic approach to nursing. The purpose of this research is to begin to test the FAPAT - to test one of the propositions on which it was based. The tested proposition is: Families are able to identify what would be helpful for them during a time when they are trying to cope with a significant life event. An assumption of this study is that individuals and families possess self-care knowledge. A proposition for future testing is that: At some level, families are able to identify the stressors in their lives and will be able to identify what will help them cope (Erickson, Tomlin, & Swain, 1983). Another assumption of this study is that the

family's level of knowing is an indicator of their adaptive potential and their "state" of coping. A modified grounded theory approach will assist to identify the themes that emerge related to support/help as identified by the families.

CHAPTER II

LITERATURE REVIEW

Nursing theory Modeling and Role-Modeling (Erickson et al., 1983) and Family Stress theory (McCubbin, & Patterson, 1982) guide the definition of terminology and the consideration of implications of significant life events for families and the individuals who comprise the family. McCubbin and Patterson's (1982, 1983) Double ABCX model of family stress and adaption was useful in integrating family concepts within the nursing theory of Modeling and Role-Modeling.

Theoretical Framework

Holism is a "concept, that a multi-system person is more than the mere sum of subsystem parts and inherent bases; it stresses the dynamic interaction of subsystems and inherent bases" (Erickson et al., 1983, p. 245). A holistic approach to nursing practice takes into account the biophysical, psychological, social, and cognitive subsystems of the individual with the genetic base and spiritual drive running through all overlapping subsystems (see Figure 1) (Erickson et al., 1983).

Within the acute care setting the biophysical subsystem is often the focus of the critical care team. The ability

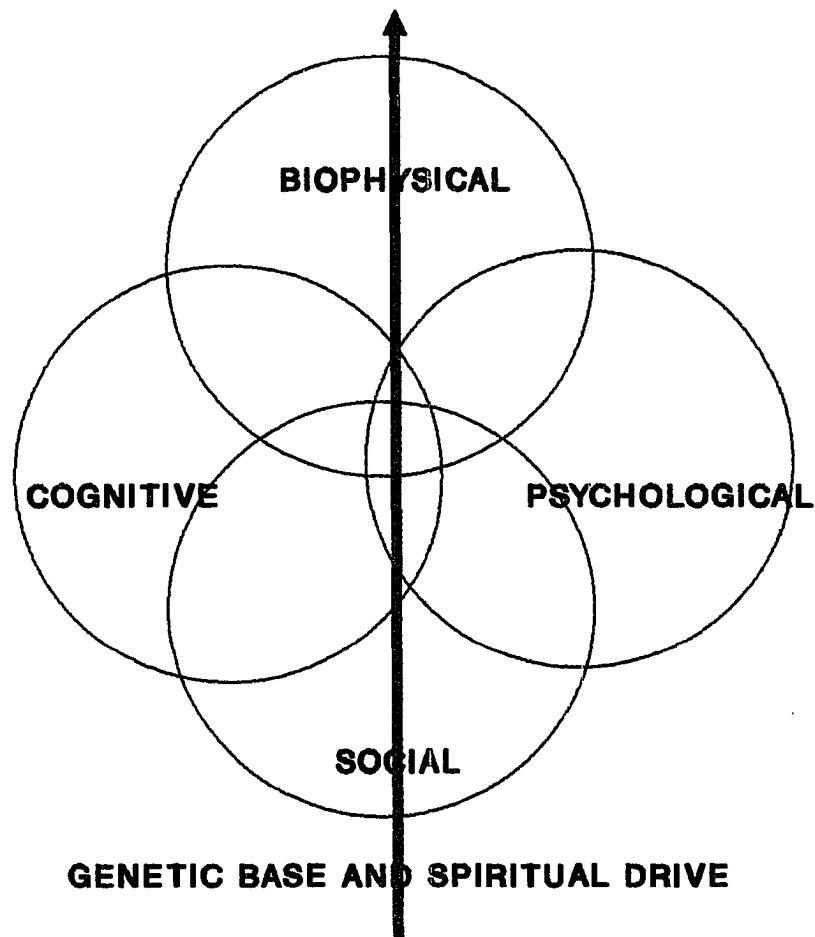


Figure 1

A HOLISTIC MODEL

Erickson et al., 1983, p. 45

of the nurse to call upon the adaptive potential of the psychological and social support systems may actually benefit the depleted biophysical subsystem. "When needs are not met within one subsystem a potential exists for the individual to draw energy from another subsystem in order to maintain himself or herself" (Erickson et al., 1983, p. 55). The social subsystem is that part of the individual which maintains affiliations with support systems while simultaneously maintaining individuation (Erickson et al., 1983). To understand the social support system of the individual one needs to understand the world with which the client is maintaining affiliation. In significant life events, the family is often described by the individual as their primary affiliation. A healthy family system can provide the support system from which the individual can draw energy.

Family Reciprocity

The family is a system of both internal and external relationships. McIntyre (1966) emphasizes that there are internal relationships within the family, developed to perform individual-serving functions. This reciprocity within the family is, in turn, necessary for establishment of reciprocal relationships between the family and society (external family support systems). Reciprocity may break down in a family experiencing internal or external disequilibrium. Walker (1985) emphasizes the interdependence of the family members as potential resources

and suggests the importance of studying the family qualitatively in order to better understand these reciprocal relationships. Such study would not only help to understand how the reciprocal relationships are affected by internal and external stressors, but might lead to the identification of potential sources of support within the family. The identification of internal resources may provide one indication of the family's ability to cope with situational stressors.

Internal and External Family Resources

A clear definition of internal and external family resources is a prerequisite of assessment. McCubbin and Patterson (1983), in describing family adaptive resources (Bb factor), define three kinds of resources that affect the ability of a family to adapt. These resources are: "(a) family member's personal resources; (b) the family system's internal resources; and (c) social support" (p. 16).

A family member's personal resources are defined as the individual member characteristics that can potentially be made available to any other member within the family system during a crisis. The broad range of characteristics of the individual fall into four basic components of financial security, educational capabilities (cognitive and problem-solving skills that allow for realistic perceptions of situations), health (both physical and emotional well-being), and psychological resources (personality characteristic including self-esteem and mastery or

perceived control over one's life) (McCubbin & Patterson, 1983).

Family system resources are the characteristics of the family system that allow for internal flexibility (adaptability) and cohesion. Individual members have defined roles, yet are able and willing to move between roles as the need arises. There is a positive balance between member independence and cohesion (balanced affiliated-individuation) (McCubbin & Patterson, 1983).

Social support comes from outside the family. It provides emotional, esteem, and network support, giving the family a feeling of love and belonging, worth, and mutuality of understanding and obligation. Networking provides the family contacts for help from within the community in which the family resides. Support networks may include neighbors, church affiliations and other support groups. The extent to which a family will utilize social support systems may vary due to availability (convenience or presence) within the community and/or the reciprocal ability of the networks to provide for the support. Included in the social resources are the extended family support or "intergenerational support" (McCubbin & Patterson, 1983).

Definitions

For the purposes of this study, internal family resources will be defined as the characteristics of the family system and the individuals within the family system that are identified by the family as being helpful. A

balanced and reciprocal relationship between the demands of individual members and the capabilities of the other members to meet those demands constitutes a healthy internal support system. An imbalance between demands and capabilities may translate into an inability to identify internal support systems and or in dissatisfaction with support from within.

External family resources will be defined as help which is derived outside of the family system. An open family system with a balanced reciprocal relationship (affiliated-individuation) with the society in which the family resides, constitutes a present or strong external support system. A closed family system with an imbalanced relationship with society constitutes a lacking or diminished external support system.

Modeling and Role-Modeling Nursing Theory

The assessment of the family, including internal and external resources, is a natural extension of the model Erickson et al.(1983) have developed to assist nurses in working with individuals. Within Modeling and Role-Modeling theory, modeling is referred to as the conscious effort to develop an understanding of the client's world. It infers a complete acceptance of the client's stated perceptions of his/her framework and requires active and concise communication skills. To model the client's world, the nurse is required to aggregate and analyze the data gathered about the client's world (Erickson et al., 1983). In assessing families this process is no less important. The

Double ABCX Model of Family Stress and Adaptation delineated a pileup of stressors as negatively correlated to adaptive potential (Lavee, McCubbin & Patterson, 1985). If one is to view the situational events within the acute care setting as the only significant factors influencing the crisis adaptive potential of the family, then one would not have the total model of the family's world. It would follow that conclusions and diagnoses would be incomplete.

Role-modeling occurs only after the nurse has "modeled" the family's world. While role modeling requires the nurse to totally accept the family's perception of their world, it also requires the nurse to understand the family's ability and capability to utilize and develop internal (within the family structure) and external resources. Rather than understanding the individual's developmental level, the nurse is charged with understanding the family's "stage of family life cycle" (Duvall, 1977). A family may be facing developmental events that have tapped the resource potential of the individual members (internal resources) and possibly those of their external resources or their ability to mobilize these resources. Failure to assess this model of the family's world would diminish the nurse's ability to role model. With this understanding and trusting relationship developed from total acceptance, the nurse then can facilitate the growth of the family through role-modeling (Erickson et al., 1983).

Families may have resources available, ideas on how outcomes can be achieved, and abilities to cope with the situation. However, due to the pileup of events, they may be unable to mobilize or recognize their capabilities. Role-modeling begins the planning stages of the nursing process when the nurse suggests strategies for coping which may be facilitation of resource acquisition through mutual contracting with the family. Ultimately, the nursing goal is to promote a healthy family system through a mutual trusting relationship.

The process of modeling the client's world is based on the data gathered utilizing a tool derived from Modeling and Role-Modeling theory developed by Campbell, Finch, Allport, Erickson and Swain (1985). Likewise, the modeling of the family's world would be facilitated by a comprehensive tool incorporating all dimensions of the family system including internal and external resources. Such a tool would not only provide data but would emphasize the value and importance of family assessment.

Family Assessment Tool Development

A search of the literature failed to uncover an assessment tool designed to assist the practitioner in assessing the needs of the family facing a significant life event. There are many articles that report findings related to the special needs of families facing crises (Artinian, 1989; Bouman, 1984; Daley, 1984; Hampe, 1975; Mathis, 1984; Molter, 1979; Prowse, 1984; Stillwell, 1984;

Wright, 1987). The research cited within these studies is based on responses to Likert-type scale questionnaires of prepared statements. These tools are clinically useful as a means to awaken the staff nurse to the special needs of the family within the critical care setting and/or facing situational crises. They are not helpful, however, in understanding the individual needs of families as they face the rigors of the acute care setting.

Several studies have utilized tools to predict the family's coping capabilities. Hymovich (1983) studied the impact of chronically ill children on parents using the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ). There have been reports of the use of the Family APGAR (Smilkstein, 1978; Speer & Sachs, 1985), the Family Adaptability and Cohesion Evaluation Scale (FACES) (Mountain, 1982; Speer & Sachs, 1985) and FACES-III (Philichi, 1989) to evaluate family functioning. Philichi (1989) also used the Family Crisis-Oriented Personal Evaluation Scale (F-COPES) to study the coping ability of families of patients in a pediatric intensive care unit. None of these tools provided a comprehensive model of the family's world.

Speer and Sachs (1985) evaluated nine instruments for their clinical utility. Although they identified the Family Environment Scale and FACES as the two tools with the most psychometric testing, the authors cautioned that there was little empirical validation reported for these tools.

Recently McCubbin, McCubbin, and Thompson (1987) developed a Family Hardiness Index which may hold promise for predicting the adaptive potential of a family. None of these tools, however, demonstrate practical application in assessment of the needs and/or coping capabilities of families facing acute crisis.

Ferraro and Longo (1985) explored the Family Power Resources Model, based on the work of Miller (1983) as an alternative model for assessing family's needs. This model was empirically presented as an optional way to view a family with a chronically ill member. The assumption of the authors was that families have developed coping skills based on the chronicity of dependents and that these families utilize these coping skills when they are faced with an acute situation. The model challenges the practitioner to utilize the "power" of the family to assist them in coping with the acute crisis. Although this gives us a model and is a useful empirical report, there is no assessment process reported and no tool given to assist in delineating the family's "power" abilities.

Hodovanic, Reardon, Reese, and Hedges (1984) recognized that there was a need to assist families within a medical intensive care unit facing the situational acute care with potential for crisis. The authors reported on the implementation of a Family Crisis Intervention Program from which a family assessment sheet was developed. The purpose of the assessment tool, as reported by the authors, was to

provide staff nurses with information from the family about the patient. Contrary to the individualized assessment, the family was provided information and emotional support based on literature documentation of the perceived needs of the family members.

Wright (1987), in gathering family information for her research study, asked family members what their most important need was right now. The open-ended question was asked of her participants prior to their completing the needs assessment tool. The American Heritage Dictionary's (1985) definition of need is a "lack of something required or desirable" or as "something required or wanted" (p. 835). Resources are something that can be turned to for support when there is a need identified. The needs of family members were well documented in this study as well as the other studies cited. The studies do not assess the family's ability to identify their self-care knowledge of internal and external support.

Leavitt (1990) combined standard measures - Family APGAR, Family Inventory of Resources for Management (FIRM), F-COPES, and a grounded theory approach (field observation and family interview) to study family coping in relationship to the "family's health care role" in the patient's recovery from major vascular surgery. Family resource utilization was measured using the F-COPES and APGAR, both utilizing a Likert rating system within a preconceived instrument. The interviews, conducted separately, looked at family coping

strategies, rather than independently seeking validation of the two standard tools. The author reported "containment" behavior emerged as a major and pervasive coping pattern among the families (Leavitt, 1990).

One obvious bias in the previous grounded theory study was the preconception of themes from the use of the standard instruments. Leavitt (1990) also suggests from her findings that families often isolate themselves from their internal and external resources as a means of coping (containment theory). She indicates that the "containment" construct supports and gives dimension to the Double ABCX theoretical model. There was no discussion noted in consideration of the potential of the families to be experiencing a pileup of stressor events and/or going through family developmental changes. Depleted resources due to this pileup of events may affect the ability of the family to identify and/or mobilize resources; this may be a second bias in the study.

While a variety of family assessment tools exist, none appear to facilitate the development of a comprehensive model of the family's world. In addition, tools frequently were structured in a closed format which makes the omission of needs and/or resources more likely. A strong theoretical basis was also not consistently evident. For these reasons, the Family Adaptive Potential Assessment Tool (FAPAT) was developed based on Modeling and Role-Modeling theory to assist the practitioner in modeling the family's world. This tool assumes that clients have self-care knowledge. It

is important that this tool be evaluated for content validity according to the theory from which it was derived and tested for interrater reliability. It also needs to be evaluated for clinical utility.

Research Question

The FAPAT provides the nurse with the means to collect data necessary to begin the nursing process. If the tool is to be most useful, nurses may need more specific guidance in going from the open-ended data to being able to make judgments about what families are communicating. The ability of the family members to verbalize their self-care knowledge may indicate their "state" of coping. An important part of self-care knowledge is the ability to identify internal and external support. Help and support are conceptually the same and are used interchangeably. The term help is used in relationship to the subjects because it is more understandable to people as a whole. The research question to be asked then is:

What types of internal and external help/support needs are families of intensive care unit patients and pediatric patients able to identify?

The qualitative approach will allow for emerging themes to be identified and hypotheses to be generated. These hypotheses will then become the catalyst for future quantitative research.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore qualitatively and inductively the self-care knowledge of family members of patients within the adult intensive care unit and the pediatric unit. The FAPAT assesses the family's self-care knowledge within a theoretical framework.

Design

The study used a modified grounded theory approach and employed a constant comparative method of analysis. The modification of grounded theory approach rests with the restrictions on the sample and the initial review of the literature. It also rested with two sensitizing areas identified as internal and external support. Emerging themes were categorized under either internal or external support.

Criteria established by Glaser and Strauss (1967) were followed, and the constant comparative method of analysis was used to determine the number of subjects. Subjects were invited to participate, and their responses were compared for emerging themes. The interviewing process stopped when it was determined that redundant themes emerged. There was also an attempt to invite a representational population of

family members that visit the adult intensive care unit and pediatric unit.

In grounded theory, research begins with the gathering of information for hypothesis development. The process of the qualitative study will drive the instrument development and correlation studies to come. If categories of support were to be developed from a literature search and were tested quantitatively, there would be a risk that some themes would be missed.

Population and Sample

A Southern hospital system within a large city was the study site for the research. The 1,204 bed hospital system consists of a downtown medical center, two regional hospitals, and an institute for health education. The units from which the subjects were drawn are located in the downtown medical center of the hospital system. The subjects for this study came from a purposeful sample of families of patients admitted to a surgical intensive care unit (SICU) and pediatric unit chosen for the project. The intensive care unit in this study includes a 10-bed cardiac surgical wing and a 10-bed general surgical wing. The pediatric unit is a 12-bed unit with the capacity to expand to 16 beds.

A purposeful sample method of selection was used to solicit potential subjects. An attempt was made to invite a cross section of subjects who represented the traditional family matrix who would be found visiting an adult intensive

care unit, i.e., father, mother, brother, wife etc.. Excluded from the interview were family members who declined and/or were identified by the interviewer as at risk resulting from cognitive, emotional or physical impairment. Thus a potential subject, identified as a husband, was excluded when it was discovered through the interview of the patient's daughter that he was dysphasic.

The age range of the subjects who agreed to be interviewed was from 26 to 62 years. The number of subjects (n) equaled 16 with a mean age of 42. There were 9 male subjects and 7 female subjects. All were able to understand and speak English.

The principal investigator approached potential subjects from the family waiting area of SICU. The assistant investigator approached potential subjects from families of the pediatric patients who were within the pediatric patient rooms. During the interviewing process, the relationship to the patients was determined by the collection of demographic information. The characteristics of the subjects are identified in Table 1.

Permission for access to the intensive care and pediatric units was made through the research committee of the hospital. The Director of the Adult Intensive Care and Pediatric Unit along with the head nurses of the respective units, was notified of the study per hospital policy by the researcher in a memorandum.

Table 1

Demographic Information

	AGE	RELATIONSHIP TO PATIENT	NUMBER IN FAMILY
SICU FAMILIES	26	SON	5
	33	DAUGHTER	8
	35	SON-IN-LAW	6
	38	DAUGHTER	4
	41	SON-IN-LAW	4
	41	SON	2
	43	DAUGHTER	7
	45	WIFE	4
	50	DAUGHTER	4
	52	BROTHER	4
	56	WIFE	5
	61	DAUGHTER-IN-LAW	3
	62	SON	3
	PEDIATRIC FAMILIES	28	FATHER
31		FATHER	4
33		MOTHER	4

Instruments

A work sheet was developed to collect data (Appendix A). This work sheet is based on the FAPAT (Appendix B). Because the study was testing one proposition from the FAPAT, it was felt that the questions on self-care knowledge and demographic information only need be asked.

The work sheet varied from the FAPAT by the use of the question, "What would you find more helpful at this time?" substituted for, "What would you find more supportive at this time?" Help was substituted for support because it would be more universally interpretable. The interviewer was aware of the need to utilize other cues during the

interviewing process in order to illicit responses of internal and external family resources from the subjects. The open-ended question was used initially with such prompts as, "Is there anything else that you might identify as helpful?" and "Can you tell me what has been helpful?" Other prompts, such as, "Is there anything else you would like to add?" were also used.

Procedures

The interviewing process began with the investigator identifying potential subjects from within the family member waiting room. The investigator introduced himself; and with the use of the verbatim statement (Appendix C), the purpose of the interview was presented and assurances of confidentiality were made. Time was allowed for questions and answers. The potential subjects were then invited to participate in the study, and those that accepted were asked to sign a consent form (Appendix D).

Spradley (1979) recommends that the interviewing process begin with a broad opening statement. Once the family members provided the demographic data, the opening statement to the tape recorded interview was a general statement such as, "I am most interested in what you have to tell me. I would like to get the recorder ready and then we can begin." The interview was guided by the following questions: (a) What is your chief concern? and (b) What would you find more helpful at this time? It was necessary

to utilize cues as described earlier to facilitate expansion of the ideas generated by the questions (Spradley, 1979).

A code number assigned to the subjects was part of the introduction to the tape-recorded interview and also closed the tape-recorded interview. The tape-recorded interview was then reviewed by the principal investigator, and all references that could link a specific family to the interview were deleted before turning it over to the transcriptionist. The experienced transcriptionist was certified under the guidelines for employment by the hospital to work in this capacity.

The interviews took place over a two-day weekend period to take advantage of the increased family presence at those times. The time allotted for the interview, including verbatim explanations and informed consent, took between 15 and 30 minutes. The associate investigator was a colleague of the principal investigator. Her qualifications include a Master of Science in Nursing and a faculty member at the hospital-based school of professional nursing, with a specialty in pediatric care. The associate investigator had been briefed on the interviewing procedure and on the procedure for maintaining subject confidentiality.

Security

Confidentiality is paramount in any research process. For this reason, strict security was maintained during the assessment process and the tabulation of the information. The family received a code number along with their consent

form (Appendix D). The interview process was tape recorded, and reference to the individual being interviewed was by code number only. Tape recordings were transcribed by a transcriber that had access only to the coded number. At all times when the recordings were not in use, the tapes were kept under lock and key. The consent forms were filed by case number and are kept in a locked filing cabinet. Subjects were instructed to use their code number when corresponding with the principal investigator. The investigator's address and telephone number were provided as part of the consent form.

Although confidentiality is paramount, safety of the family and the patient is equally paramount. There was no information gained from the interview that was deemed essential to protect the safety of the family or patient. The subjects did not express any discomfort with the interviewing process. Some of the subjects voluntarily assisted the interviewer by introducing potential subjects to the investigator and/or identifying family members within the family waiting room.

CHAPTER IV
DATA ANALYSIS

The data were analyzed using the constant comparative method. Data were transcribed from the tape-recorded interview and examined for items related to the family's identified help/support needs. These data bits were transferred to index cards and initially categorized as internal or external support. Then, each data bit was compared with previous data bits for its equivalence. As a theme became evident in relation to a category, a memorandum was written as to a possible definition of the category. Data collection concluded when no new categories emerged. Upon completion of data collection, categories were re-examined, collapsed, and new thematic definitions were generated.

The research question, "What types of internal and external help/support needs are families of intensive care unit patients and pediatric patients able to identify?" was looked at qualitatively from responses to the question, "What would you find helpful/supportive at this time?" The subjects were able to identify both internal and external help/support needs.

Themes within the general categories of internal and external support needs emerged and, with analysis, were condensed to four themes under external support and three themes under internal support. Internal and external support were the initial sensitizing areas to be identified. External family support is defined as help which is derived outside of the family. Internal family support includes the characteristics of the family system and the individuals within the family system that are identified by the family as being helpful.

External Family Support/Help

Four major themes were identified under external support needs. The four themes under external support needs are: (a) formal supportive relationships, (b) informal supportive relationships, (c) information, and (d) a supportive structure within the health care system (see Table 2).

Formal Supportive Relationships

Formal relationships are shared relationships that develop between family members and other persons (i.e., professional and non-professional) who are part of a formal system (i.e., health care system) from which the family has sought help in relation to a critical life event (i.e., illness of a family member). In order for these relationships to be perceived as supportive/helpful, the provider must be perceived as being qualified (i.e., having special knowledge or training to render help in the specific

Table 2

Categories of Family Support Needs: Identified Under Internal and External Support

		EXTERNAL SUPPORT	INTERNAL SUPPORT	
FORMAL SUPPORTIVE RELATIONSHIPS		INDIVIDUALS Doctors, Nurses, Chaplain	SPIRITUALITY Individual faith and hope.	INTRA-INDIVIDUAL FAMILY MEMBER SUPPORT
		NATURE OF BEHAVIOR Caring, Dedicated, Qualified, Available	BIOPHYSICAL Rest, food	
INFORMAL SUPPORTIVE RELATIONSHIPS		INDIVIDUAL Family waiting room peers, Friends	INDIVIDUAL Brother, sister, aunt, Significant other, etc.	INTRA-FAMILY SUPPORT
		NATURE OF BEHAVIOR Caring, Empathetic, Giving	NATURE OF BEHAVIOR Caring, Available	
INFORMATION		TYPE Honest, Consistent, SOURCE Professional, Advocate	OPEN FAMILY Information sharing Designated Spokesperson	FAMILY ORGANIZATION
		HOSPITAL PHYSICAL Comfortable waiting area, Nearby & inexpensive motel, Food tray or nearby cafeteria ORGANIZATIONAL ↑ visitation, patient/family advocate	Task delegation	
STRUCTURE OF SYSTEM				

situation), confident and dedicated. The provider's behavior must also reflect appropriate availability, ability to anticipate the needs of family members, and his behavior must be caring.

External formal supportive relationships were defined by type of individuals and by the nature of behavior of the individuals as they carried out their respective roles. The types of individuals who were identified as giving external formal support were doctors, nurses, chaplains, and ancillary staff of the institution. These relationships occurred as a result of the nature of the institution and its structure. One family member stated: "The nurses and doctors here are great, they really are helpful." It was also important for the families to trust that the professional staff (doctor, nurses, etc.) had appropriate credentials and qualifications. An example of the comments made is:

It's helpful when the doctors and nurses seem confident in what they are doing. I mean, I trust the doctors and nurses here, but at this other hospital I felt that they were probably good nurses but they must have been new to the unit because they didn't seem to always know what they were doing.

Another professional identified as being helpful was the chaplain assigned to the unit: "The chaplain is there, you know, is supportive for your spiritual needs."

Family members also identified patient/family advocates as helpful if they were part of the system. A patient/family advocate was defined by families with statements such as: "It would be nice to have someone that would be able to set limits. When my dad is tired and they come to visit, that this person will not let visitors in to see him." A more detailed definition of family/patient advocate was presented by one family member as:

Daily contact, especially when my brother and I cannot be at the hospital, by someone in the capacity other than nurses coming in to take the vital signs and all of that, acting like they truly, really care how it's going. You know that really, truly you can tell when people care . . . and will say to my mother "why don't you go down and get something to eat" or "why don't you go outside and take a walk" and so she can have assurance that he (husband) would be watched while she was gone.

One family member identified someone to look in on the family as being helpful: "I would feel better if someone would come in and check on me every once in a while. . . . I feel isolated at times and don't know what is going on." Another family member identified an individual who could be assigned to them while their mother was in surgery. This person would be able to inform them on the progress of their mother and assist them to the various places they may need to go. The family member implied that the present system

appeared to fail at a crucial time -- while her mother was in surgery -- due to not having anyone identified to help the family through this day:

After waiting for a long time, being sent to the wrong waiting area initially, and missing an interim report about how the surgery was going, someone (the chaplain) finally came in and asked me why we were still waiting here. He also said that we should have been in the SICU waiting area by now because that's where the doctors come to talk to us after surgery was over. My mother had been out of surgery for about an hour and we didn't even know it. If someone would have been available to stay with us, to check to see if we were in the right place, to even check to see how we were doing, I would have felt better about the situation.

The underlying need to be filled by the advocate was for someone to express affection and to listen attentively.

It became apparent that formal supportive relationships were also defined in terms of the nature of the behavior of individuals carrying out their jobs. The professionals not only needed to be qualified to be supportive, but the manner of their behavior should convey a caring attitude. Staff who were identified by families as being the most supportive: (a) treated families as individuals or as important -- "Those that make you feel you are the only ones

right now, that you are important, and that you are an individual"; (b) were dedicated -- "Nurses that view their profession as a "calling" and are more caring and supportive"; (c) were supportive -- "Doctors and nurses who act as though they care"; (d) spent time with the families -- "I know that they (the nurses) are busy, but some will take a minute or two to talk with you, or will come out to the waiting room to check on you"; (e) met the needs of families and patients --

When my husband has a concern, then it's my concern.

The nurses that meet his needs are most helpful to me because I don't have to worry about him getting enough sleep. They (the nurses) have got to care about their patients, if they don't, then they are making a lot of noise all night long and my father doesn't sleep, then I'm concerned.

Some families were able to identify individuals that helped them the most: "The ladies on the eighth floor, the nurses and there was another nurse . . . that were extremely nice and went out of their way to support us." It was as though the families appreciated individual attention by the professional staff yet recognized that the nurses and doctors were busy and could not spend too much time with them.

Informal Supportive Relationships

Informal supportive relationships are those which exist apart from the formal event specific structure. Support may

be obtained through two types of relationships which are:
(a) friend relationships -- previously existing friendships which may be a source of direct help during a critical time -- and (b) peer relationships -- relationships that develop between family members and previously unknown persons due to proximity and sharing of a common critical life event. The relationships are characterized by mutuality and spontaneity and convey caring, understanding, and empathy.

External informal supportive relationships were also defined both by type of individual and by the nature of behavior of the individual. Families identified friends and peer support from individuals within the family waiting room who were going through the same experience. A mother from the pediatric unit related a need for transportation and turned to a friend for help. She stated, "It's hard for me to be here because I live so far away. I borrow a car from my friend down the street, that helps, but it's pretty expensive going back and forth." Another family member who lived out of town stated, "It's helpful because I used to live here, I have a friend I can stay with, I don't have to pay for a room."

Peer support came from families within the waiting area: "Knowing all the other relatives who are out there are going through the same thing I'm going through."

I guess some of the moral support you get is from some of the people out there waiting in the intensive care unit waiting room that also have

loved ones back here. They make you feel as though you are not going through this alone.

The nature of the behavior was also defined as caring and supportive. One family member described the supportive behavior this way:

I was at the elevator, there was a woman that had a young son in the unit. I just, you know, touched her hand and she grabbed me and hugged me. . . . I didn't know this woman from Adam, but I think that they can feel that "care" and that "concern." I think that human touch is important . . . from someone in like circumstance.

The relationships that were established within the family waiting room appeared to be spontaneous: "After awhile, you get to know who is here, you answer the phone, take messages for other family members" and "There was a crossword puzzle in the waiting room, everyone got into completing it. We began to talk to each other, everyone is going through what you are going through, it was nice." The opportunity to develop these networking relationships with individuals going through like circumstances was reported as an important source of support for many of the subjects interviewed.

Information

Information is defined as the knowledge which is necessary to understand the patient's condition and all aspects of treatment. To be viewed as supportive, the

information must be accessible, consistent, conveyed honestly, and without having to be solicited. Information comes from formal sources. Families consistently identified information as helpful. One family member stated that:

the most helpful thing is being able to communicate with the nursing staff and communicate with the doctors. Instead of getting short answers, I would appreciate getting a full explanation for what is going on and what they are doing.

Another talked about the difficulty in not knowing what all the machines were as being a source of stress, that when he understood their function it was helpful:

I think there could have been a little more time when they could have come out and said, "Hey, this is what we're doing and this is why". . . . We're not doctors, we're not nurses, we don't know what all this stuff is that she is hooked up to. . . . After we found out what the things do, as we go into see her, you look at her blood pressure, you look at her heart rate, you look at all the other things, you get to know what they are doing and can sense whether things are improving or getting worse. I think that helps a lot, just knowing what all that is, if they would have told us up front . . . I think they probably expected us to ask about it first.

To be offered an explanation without having to ask for it was a common theme:

When you're concerned you want someone, the doctors or the nurses, to give you the right answers. . . . I don't know that it's ok to wait twelve hours for surgery without eating. . . . You feel if they are going to surgery they should have some energy, I mean nourishment in their body before surgery, but nobody comes to tell you it's ok. . . . I remember his first surgery and he had just liquids, his pressure went down and he didn't eat. . . . If you would have some kind of communication maybe with the floor nurses or a doctor or somebody to come and tell you, you know "Don't panic, it's all right, he'll be all right."

Dependable and congruent information and a system to allow access to the information was considered highly supportive. Anxieties were reduced when the mystery was eliminated: "If they don't know, why don't they say so . . . they do all of these tests and still don't know anything, then they blame it on her age."

Supportive Health Care System

A supportive health care system is a health care system which is structured so that individual needs can be met. Specifically, the physical structure and policies make it possible for the family to see the patient, interact with

each other and have physical needs for comfort, food and shelter met.

Support for individual needs was defined as: (a) a comfortable waiting room -- "It would be nice if the waiting rooms had more comfortable chairs"; (b) distractors or things to do while they wait --

It was nice when there was a crossword puzzle to do. . . . The magazines are so old, 1986 or something like that, if they had more to do while we are waiting we wouldn't have to think about it so much;

(c) food trays or nearby facilities for food -- "If I could have a tray brought in for me, they do it at other hospitals, then I could stay here with my baby"; and (d) affordable and accessible place to stay nearby -- "If we didn't have to go so far to sleep, they might provide housing nearby that's affordable, but they could get us if we were needed." Although financial concerns were for the most part not a priority, there was at least one family member that felt knowledge that she would be paid for sick time would be helpful:

Monday I'll be calling my boss and once she tells me there's no problem with me utilizing my sick leave for my time down here then that relieves a lot of (financial) pressure . . . that will also allow me two or three weeks to get things lined up.

A supportive health care system allowed families to see the patient more often. It also was defined as a system that fostered the informal supportive structure of the family waiting room. Nearly all of the subjects reported that they felt that it would be helpful to see the patient more often: "Ten minutes every two hours isn't enough. . . . If I could just look in on her, not bother her, it's better to see for yourself how she is doing." "Ten minutes every two hours during the day translates into a lot of waiting time in between. . . . Not knowing for yourself is hard, he changes so quickly." One subject when talking to his wife stated;

The nurses are fairly lenient about the time you spend with your mother, they don't kick you out right at ten minutes, but it would be better if you didn't have to wait so long in between visits.

The families relayed the feeling that it was helpful to them to just see their family member and that visitation (talking to the patient) was not always necessary.

The opportunity to associate with other family members was also perceived as helpful as described earlier under informal supportive relationships. The system structure of the waiting area was perceived as fostering or capable of fostering these relationships. Distractors within the waiting area for families along with comfort of the furniture and the telephone were perceived as positive,

environmentally supportive of the affiliation with other family members.

Biophysical support was more implied within the responses from families in statements that referred to the need to be provided a comfortable place to stay while in the waiting area or a place close by that they can retire to:

Like my mom, most of the time you can't pry her out of here. . . . I wish there were somewhere, you know, maybe people could afford to stay. . . . If they had a place to stay nearby, they could go and rest, but not too far away, more convenient.

Internal Family Support/Help

Internal support systems were identified but with less frequency than external support systems. Themes identified within internal support were (a) intra-individual family member help/support needs, (b) intra-family help/support needs, and (c) supportive family organization (see Table 2).

Intra-individual Family Member Help/Support Needs

Intra-individual family member help is support that comes from within the individual family member and is described in terms of personal strengths. Intra-individual support came from the strong individual spirituality, a strong sense of faith and hope. Family members that expressed faith did so with great vigor: "I have faith in God, I turn most everything over to Him" and "I trust in what He has to say, it's important for me to continue to have faith in God." Faith in the judgment of the surgeons

and nurses, as given to them by the "Lord," was also expressed as supportive: "You have confidence in the surgeons and nurses that are working here, you have to have faith in their judgment and just pray to the Lord that He gives them the right judgment."

Hope was identified but was also tempered with realistic hope. One family expressed hope, in the face of the death of their mother, as a hope that their mother would pull through: "You always have hope. Back in your mind you have these reservations too." Another expression of hope was for an easy passing: "You know her time to cross over is going to be soon, she is eighty-eight years old, you just hope it is soon or that she doesn't have pain." In either case, there was a strong need expressed to have hope and that hope was helpful.

Intra-family Help/Support Needs

Intra-family help/support needs are derived from relationships among family members. The relationships are characterized by feelings of closeness and caring and are perceived as supportive when there is a perception that members are available to provide direct help.

Social support within the family came from intra-family member supportive relationships and were most often identified in terms of the entire system. Statements from family members were like: "We have a close family . . . so usually we have each other to support each other" and "I think our family is supportive of each other, when it comes

to our dad we all support each other" or "my family is there as support." Families also identified specific individual family members as supportive: "My brother, when he gets here, will be a great help" or "Either my wife or I are here at the hospital, so I know that my baby always has someone with her." Support indicated was for someone available to be at the hospital at all times:

Until my brother is able to return from Saudi Arabia, my aunt and uncle have been taking shifts, but they will need to go back home soon. . . . They live a ways away and it's been hard on them too.

Supportive Family Organization

Supportive family organization facilitates the sharing of information (i.e., having someone designated to pass on the information received from the doctors and nurses to other family members) and carrying out designated tasks (i.e., sitting with the patient).

Family organization provided the support for the need to be close to someone -- "Luckily we have a pretty close family ... we usually kind of stick together . . . we have each other to support each other" and "I'll need to make arrangements with my aunt and uncle, with those folks to be coming back at the time that I leave so that there is some kind of coverage after I'm gone." Family as a support system was not referred to in any great frequency; and when it was, it was more generalized.

Family members needed to be informed about what was going on with the patient with open and honest answers to their questions. Information was also facilitated between family members as families changed "shifts" or by individuals designated as available to speak for the family and obtain information for the rest of the family: "Either my sister or I are here, we talk to the doctors and nurses and everyone else in the family asks us" and "We are here through the night, until my father, uncle and aunt get here. Everyone gets updated when we get together."

Summary

For the most part, family members were able to identify what would be helpful/supportive to them. Four categories were identified under external help/support needs and three categories were identified under internal help/support needs. Family members tended to identify external sources of help more often than internal sources of help. External family help came from relationships that were caring, available, qualified, etc. Professionals and other individuals needed to have these attributes before they were considered to be helpful. Another form of external support came from honest and unsolicited information. The last category of external support identified was the health care structure which was perceived as supportive if it fulfilled individual needs as well as the need to affiliate with peers and the patient.

Internal family sources of help were not identified as often as external sources of help. Internal family sources of help were most often reported in terms of either the total family structure as being supportive or of the intra-individual family member strengths (hope and faith). Inter-family communication as well as family organization (open family) were more inferred rather than actually stated as being helpful.

CHAPTER V
DISCUSSION

The purpose of this study was to learn if family members were able to identify internal and external help/support needs. It is an assumption of this study, driven by Modeling and Role-Modeling theory, that individuals and families possess self-care knowledge and the ability to identify what their concerns are and what would be helpful to them. This assumption has assisted in defining the proposition that families are able to identify what would be helpful for them during a time when they are trying to cope with a significant life event. Within this study, families of patients in the adult intensive care unit and pediatric care unit were able to identify what would be helpful to them. Themes emerge under both internal and external support as the family members identified what would be supportive or helpful to them. Subcategories tended to define characteristics within the major themes. Internal and external support were the sensitizing factors within the study.

The major themes to emerge under external support were: (a) formal supportive relationships, (b) informal supportive relationships, (c) information, and (d) a supportive health

care system. Formal relationships are shared relationships that develop between family members and other persons (i.e., professional and non-professional) who are part of a formal system (i.e., health care system) from which the family has sought help in relation to a critical life event (i.e., illness of a family member). In order for these relationships to be perceived as supportive/helpful, the provider must be perceived as being qualified (i.e., having special knowledge or training to render help in the specific situation), confident and dedicated. The provider's behavior must also reflect appropriate availability, an ability to anticipate the needs of family members, and his behavior must be caring.

Informal supportive relationships are those which exist apart from the formal specific structure. Support may be obtained through two types of relationships which are: (a) friend relationships -- previously existing friendships which may be a source of direct help during a critical time -- and (b) peer relationships -- relationships that develop between family members and previously unknown persons due to proximity and sharing of a common critical life event. The relationships are characterized by mutuality and spontaneity and convey caring, understanding, and empathy.

Information is defined as the knowledge which is necessary to understand the patient's condition and all aspects of treatment. To be viewed as supportive, the information must be accessible, conveyed honestly,

consistent, and without having to be solicited. Information comes from formal sources. Families consistently identified information as helpful. One family member stated that:

A supportive health care system is a health care system which is structured so that individual needs can be met. Specifically, the physical structure and policies make it possible for the family to see the patient, interact with each other and have physical needs for comfort, food and shelter met.

The major themes to emerge under internal support were: (a) intra-individual family member support, (b) intra-family support, and (c) a supportive family organization. Intra-individual family member support is support that comes from within the individual family member and is described in terms of personal strengths. Intra-family help/support needs are derived from relationships among family members. The relationships are characterized by feelings of closeness and caring and are perceived as supportive when there is a perception that members are available to provide direct help. Supportive family organization facilitates the sharing of information (i.e., having someone designated to pass on the information received from the doctors and nurses to other family members) and the carrying out of designated tasks (i.e., sitting with the patient).

Dimension of the Study

The purpose of a grounded theory methodology of research is to generate theory through fact gathering.

Interview and observational methods were used to gather data; the data was then analyzed through a system of constant comparison until data produced redundant themes. The researcher was then charged with consulting the literature for additional themes. It was important that the researcher not force theory onto the study data but rather allow the data to generate theory (Stern, 1985).

A search of the literature failed to identify sources of support that would not fit within one of the themes identified within this study. Much has been reported on the perceived needs of families of patients within intensive care units. McIvor and Thompson (1988) utilized a questionnaire divided into 6 need categories and with a total of 46 statements. The questionnaire was derived from the work by Daley (1984), and the questions were scored utilizing a Likert Scale (not important--1 to very important--4 and NR-no response). The authors used a convenience sample of 24 family members, age 23 to 63 years old, and made up of a mix of identified significant others (i.e., mother, father, son, daughter, brother, sister, close friend, etc.). The six categories of need identified were ranked from most important to least important and are identified here as: (a) the need for relief of anxiety, (b) the need for information, (c) the need to be with the patient, (d) the need to be helpful to the patient, (e) the need for support and ventilation, and (f) personal needs (McIvor & Thompson, 1988).

A relationship exists between the categories of perceived needs identified by McIvor and Thompson (1988) and the themes identified by this author as support. No new themes appeared as a result of potential unmet needs that would not be classified into the support themes identified. McIvor and Thompson (1988) and Daley (1984) identified the doctor and nurse as being most likely to assist them to meet their needs for information and anxiety reduction. This author's study identified formal relationships and information as two of the themes of potential support. Formal relationships were identified as the professional staff within the health care system (doctors, nurses, etc.). For the formal relationships to be perceived as supportive, the professionals needed to be dedicated and demonstrate a caring and supportive attitude. Information was also perceived as coming from doctors and nurses, yet it was often perceived that the information was often incomplete, not completely honest, and often did not answer all the questions the family had. The families in this author's study also identified a source of information other than the doctors and nurses as potentially being helpful if it was perceived as consistent, available and honest in answering all of the questions the families had (even if the answer was "I do not know").

There were many articles that reported findings related to the special needs of families facing crises (Artinian, 1989; Bouman 1984; Daley, 1984; Hickey, 1990; LaMontagne &

Pawlak 1990; Mathis, 1984; Molter, 1979; Prowse, 1984; Stillwell, 1984; Wright, 1987). The needs identified within these articles would be met within the themes of support identified by this author's study. If support is given for the needs of family members, it would follow that family coping abilities would increase.

Underwood and Gruizenga (1989) in a study presented at the 13th Annual Midwest Nursing Research Society Conference reported on a qualitative study to identify the perceived unmet needs of healthy, married, Caucasian women. The researchers utilized a grounded theory approach to study the ways people could have been more helpful during their pregnancy. Four themes emerged: (a) conservation of physical energy, (b) conservation of emotional energy (c) acquisition of event specific knowledge, and (d) supportive professional transactions.

The study by Underwood and Gruizenga (1989) provided validation for the findings of this investigator. Similar support was identified in both studies. Health care structure support would conserve physical energy by providing comfortable waiting rooms, nearby place to stay, distractors, etc. Emotional energy would also be conserved if the structural support provided for more frequent and/or longer visitation of patient. The structure support would also provide for supportive professional transactions (time to interact with professionals and patient). Informal and formal supportive relationships would conserve physical and

emotional energies such as: friends/relatives providing transportation, knowledge of job security, peer support within the waiting room, caring attitudes of competent professionals, etc. Formal supportive relationships would provide for supportive professional transactions through the nature of their behavior (available, caring, knowledgeable, mutual respecting). Informational support would provide event specific knowledge by delivery of honest, concise answers.

Hypothesis Generation

Family members were generally able to identify what would be helpful to them. One theme of support that the family members were able to identify was relationships established as a result of the situational event within the acute care setting: (a) formal supportive relationships, such as doctors, nurses, chaplains, and significant intrafamily members; and (b) informal supportive relationships, such as family waiting room peer support, friends, and extended family members. On the other hand, the families also identified the nature of behavior of the professionals and family members as being important for the relationships to be supportive. The family members needed to have confidence that the professional staff were well qualified for their roles, that they demonstrated individual and caring behavior, and that they were dedicated (had a calling) and caring. It appears that there is a relationship between supportive professional behavior, as

perceived by family members, and family member functioning during a stress producing event.

Gilliss, Neuhaus, and Hauck (1990) conducted a study to determine if increasing nursing care to heart transplant patients and their spouses would improve family functioning during recovery from cardiac surgery. Increased nursing care consisted of an additional slide-tape program designed for the study and a post-slide show discussion period, conducted by the study nurse, between husband and wife about their experience with the surgery. The experimental group also received prescheduled telephone calls at 1, 2, 3, 4, 6 and 8 weeks post-discharge by the study nurse to: "(1) monitor the patients for complications, (2) reinforce in-hospital education regarding diet, exercise, medication, and recovery care, and (3) facilitate resolution of relationship difficulties occurring between patient and spouse" (Gilliss et al., 1990, p. 650). All participants received the usual care, nursing interventions, and education that were in place at the time of the study.

As an outcome of the study by Gilliss et al. (1990), no significant difference was noted in family functioning as measured by the APGAR or in family resources as measured by the FIRM. Using the Marital Adjustment Scale, the investigators reported that the patients experienced an increase in marital adjustment scores between baseline and 6 months where as the spouse's scores decreased over time. This study appeared inconclusive in measuring the effects of

increased nursing interventions as provided by the investigators. The investigators utilized the literature to identify the perceived needs of families and patients and planned interventions based on this information. They failed to assess the needs of families and patients and plan their interventions based on the expressed needs of the patients and family members.

The purpose of this investigator's study was to discover what was identified by the family members as being helpful/supportive. Information was found to be one of the themes of support. However, the information that was wanted by the family members was event specific and had to do with the condition and prognosis of the patient and the equipment within the intensive care setting. In the study by Gilliss et al. (1990), presuming that cardiac transplant is a significant life event, the need to know the prognosis of the patient may take precedence to the need to know the impact of surgery on patient and spouse relationship. Event specific information may be considered helpful and may lead to an increase in family functioning.

A consistent theme of support identified by most of the subjects was information. The information needed to be honest (even if it was "I don't know"), factual, and available. Availability could be from someone the family members identified as being a designated information source and that also responded when the family perceived a need to understand. Although the family members identified the

nurses and doctors as a source of informational support, they also perceived that these people were often too busy, not able or willing to offer information, and/or not always giving family members the information they wanted or asked for. One family member stated that the hospital already had someone that he could call to find out the condition of the patient, but that he felt that he needed more than: "He is improving" or "He is still critical." His perception was that he needed information about the patient more frequently than every few hours, especially if he chose to stay in the family waiting room. Another family member stated that there could have been more help/support if someone would have assisted her during the time of her mother's surgery. This designated person would be an information liaison between the surgery team and family. The supportive person would also ensure that the family was in the correct place at the correct time. The underlying need to be filled by the advocate was at the love and belonging level -- someone to express affection and to listen attentively.

During the interviews, the families also identified the perceived amount of lag time between information updates as being a source of stress. If the health care system offered a honest and consistent source of information, then it may follow that the family would perceive an increase in family functioning.

Increased contact from nurses and doctors was also identified as supportive by this investigator. The nature

of the behavior of the health care givers was reported to be an important source of support if the care givers were caring, supportive, and qualified. At least two subjects stated that an individual patient/family advocate, other than nurses or doctors, could provide consistent and honest information about the patient's condition as well as administer caring attention to the family and patient. Gilliss et al. (1990) found no significant improvement in family functioning as a result of an increase in nursing care for families. They caution that there may have been a number of biases to the study. The investigators further state that a question not addressed by their design was whether there was an effect from telephone calls from a "friendly visitor" (Gilliss et al., 1990, p. 653). It may have met the affiliated need of the family to feel that there is someone available who cares.

This author's study reported that support for the family could come from individuals who demonstrated caring behavior. There is a need to investigate the relationship of caring behavior by professional staff within the acute care setting to family functioning. There is also a need to investigate the relationship of a designated individual as family informant and advocate to family functioning.

Another support system identified by family members was for the health care system to allow for an increase in patient contact by the family, even if the contact was to be able to "see" the patient. Simpson and Shaver (1990)

quantitatively studied the effect of family visitation on patients. They indicated that there were no significant adverse cardiovascular consequences in a general sample of coronary care patients who had experienced cardiovascular problems with an increase in visitation by family members. Although this was a small sample and there were some limitations to the study, it suggests that there may be a need to reevaluate the policies on restricting family visitation within the acute care setting. A hypothesis that needs to be tested is the relationship of increasing patient's visitation to family member's function; will it reduce family stress and be perceived as supportive?

Families stated that other families who were undergoing similar experiences within the family waiting room were a source of support. Underwood and Gruizenga (1989) also obtained information which indicated that there was a connection between peers with like experiences and perceived support. Peers within the family waiting room were providing support at the love and belonging level. This phenomena would need to be explored in relationship to the family's ability to cope with significant life events.

It was interesting to note that the internal family support came from within the individual and was identified as hope and faith. A strong faith in God was reported as an important source of support as was the need to believe that the work of the professionals was guided by God. The family members also needed to have hope. Hope was defined as

either a hope for the patient to recover -- tempered with a realistic outlook -- and a hope that the patient would die peacefully -- without prolonged suffering. A quantitative approach would be needed to determine the relationship between family spirituality and family's ability to cope with a situational significant event.

The health care and family structure was a potential source of support identified by the family members. Supportive structural changes would be: (a) a greater amount of family and patient contact, even if it was just to be able to look in on the patient, (b) comfortable waiting room and furnishings, with distractors such as updated magazines or crossword puzzles, (c) nearby places to rest that would also be affordable, and (d) nearby facilities for dining and/or having a tray brought to the patient's room for the family member. A patient/family advocate would also be supportive. The advocate would restrict visitors other than family members and provide caring support for both family and patient.

Underlying Hypothesis

One underlying hypothesis that emerges is: If families have the ability to identify what would be helpful to them when faced with a situational significant event, then the mobilization of these support systems would assist families toward secure attachment and growth. A second hypothesis that emerges is: A trusting relationship will develop

between the care giver and family if support is given for the family's perceived needs.

Limitations

One limitation of this study may rest with the modification of the grounded theory approach by the initial literature search and the identification of the sensitizing areas of internal and external support. The purpose of grounded theory is to generate hypotheses without prejudice. The initial literature search failed to uncover research related to the family's ability to identify support. Therefore, themes emerged solely from the generated response of the subjects after initial separation of responses into internal and external support.

Another of the limitations of the study may be the regional nature of the hospital setting. This study site was within a distinct southern religious conservative hospital system. There is perhaps a more restricted visitation policy than is being reported within other regions. The physicians may also lean toward being more conservative and may be less willing to discuss the patient's illness with the family. There may also be a cultural propensity within the community for the strong faith and trust in God as a source of help. However, the correlation with other studies of the needs of family members suggests that this may not be a true limitation.

Perhaps the lack of cross culture subjects is a final limitation of the study. The location of a study in an area

where a there are multiple cultures may generate new themes not noted. There was no attempt to utilize foreign literature to verify the themes. With the vastly narrowing of travel time and the mix of cultures within the our country, there may be a need to do another qualitative study that takes into account the cultural aspect when choosing subjects.

Application to Practice

The FAPAT is based on Modeling and Role-Modeling Theory and as such, guides the nurse practitioner toward assessing the model of the family's world. The family members' ability to identify sources of support is addressed in the FAPAT with the open ended question: "What would you find more supportive at this time?" A family's ability to verbalize sources of support may be related to their state of coping at the time of the assessment. A pile-up of stressors beyond that of the acute situational event and the family's perception of the situational event may be the factors affecting the family's ability to cope. It is up to the nurse to be able to assist the family in identifying all potential sources of support. The themes identified within this study can act as cues for the nurses to use in assisting the family to identify sources of help/support needs or in providing help based on the specific needs of the family.

There have been a number of studies that report the range of needs as expressed by families of patients within

the acute care setting. The themes of this author's study provide the nurse with a range of support that was identified by family members within the acute care setting. The most important finding may be that family members are able to identify what would be helpful to them. Nurses need to assess and plan interventions based on the individual help wanted by the family. Nurses should learn to model the family's world, developing a trusting relationship in the processes, rather than basing interventions on assumptions, personal beliefs or generalized studies. Mutually contracted interventions between family members and nurses can then be tested quantitatively for effectiveness. It should follow that if nurses truly base interventions on the specific help wanted by the family, then family functioning will improve.

A trusting relationship with a client begins by accepting the world of the client as described by the client according to Modeling and Role-Modeling theory. The family as a client is also deserving of a trusting relationship with all health care workers. Attending to the needs of family members by assisting the family to identify and utilize support systems, appears to provide the family with a means to cope. If the family were not able to or were not assisted to establish support systems, then there is a risk for the family to move toward disfunction. If this happens, the family may not have coping capabilities sufficient to

meet the demands of the situation and may become impoverished.

In a preliminary report of a study by Forester, Murphy, Price, and Monaghan (1990), the authors suggest that there may be a difference between the perceptions by nurses of family member needs and the actual family stated needs. A nurse/family confederate paired study of perceived family needs as reported by nurses and family members is currently taking place. Preliminary findings from this study defend the need to accept the model of the family's world rather than force support based on the needs of the family as the nurse may perceive them to be.

Two questions were asked of the families but not addressed within this study. The questions that were asked of the families were: (a) What is your chief concern at this time? and (b) What other concerns do you have at this time? Self-care knowledge includes being able to identify that which concerns them (what is making them sick). All the families identified the patient as being their chief concern or one of their main concerns. One family member stated that she was mostly concerned that she would need to be "the peace keeper between my sister and my mother (the patient)". However, she related that this was because she was concerned that her mother would not get well if she was bothered by her sister. The interesting preliminary findings from these questions were that more than half of the family members did not choose to identify other concerns

besides their concern for the patient. Their response to probing questions was generally to state that they were not concerned about anything else right now or that they would worry about everything else later.

Leavitt (1990) hypothesized from grounded theory analysis that families may limit the impact of a crisis situation by the use of the coping strategy of "crisis containment" (p 487). With crisis containment, the families could minimize events surrounding the crisis situation and the family would demonstrate specific behavior (i.e., behaving properly within the acute care setting or the resistance to asking for help even if there was a conflict in how to care for the patient once discharged). This behavior appeared to be related to family openness and the chronicity of the patient's condition. Crisis containment may be the phenomena that would explain the families inability or unwillingness to express concerns beyond that of the patient. The families who this author interviewed did state that other concerns appeared to support the hypothesis that family members do come to the acute care setting with a pileup of concerns.

Conclusion

It has been discovered within this study that family members of patients within the intensive care unit and pediatric unit are generally able to identify what would be helpful to them. A modified grounded theory approach was used and a constant comparative method of analysis of data

identified themes of support. Internal and external support were the sensitizing areas identified within an initial literature search. Under external support the themes are: (a) formal supportive relationships, (b) informal supportive relationships, (c) information, and (d) a supportive health care structure. Under internal support the themes are: (a) intra-individual family member support, (b) intra-family support, and (c) a supportive family organization.

Nurses can assist families to mobilize resources by first trusting that they are capable of identifying sources of help. Quantitative research is needed to isolate sources of support that would affect the greatest help as perceived by the family. We then need to relate these sources of support to family functioning and growth during the times of significant life events. Support given for the family's identified needs, modeling the family's world, will better assist the nurse to role-model a healthier world for the family.

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APPENDIX A
FAMILY QUESTIONNAIRE FORM

Family member's:

1. Gender (1) Male ___ (2) Female ___
2. Age in years _____
3. Relationship to patient _____
4. Years lived with patient _____
5. Years lived apart from patient _____
6. How many people are in the patient's immediate family? _ _
_ _
7. What are the relationships to the patient of the people within the immediate family? _____

8. What is your chronological placement within the family? (i.e., oldest, youngest, middle. _____

9. Within the family, who is the usual spokesperson?

10. Do you feel that you can speak for the rest of your family?
(a) Yes ___ (b) No ___
11. If no, who do you feel is the spokesperson for the family? _____
12. Has any-one in your family been hospitalized before?
(a) Yes ___ (b) No ___
13. Has any one in your family been hospitalized and in the intensive care unit before?
(a) Yes ___ (b) No ___
14. Has any one in your family been hospitalized and in the pediatric unit before?
(a) Yes ___ (b) No ___

The following are the research questions: At this time, I would like to turn the tape recording on to record your responses to the following questions. Do you have any questions before we begin?

It is believed that individuals can identify their concerns and be able to suggest ways that will be able to help them with their concerns. The following questions will help determine if this is true. You may feel free to answer any or none of the following questions.

15. What is your chief concern at this time?
16. What other concerns do you have at this time?
17. What would you find helpful, supportive at this time?

**APPENDIX B
FAMILY ADAPTIVE POTENTIAL ASSESSMENT TOOL**

FAMILY MEMBERS PRESENT:

NAME _____	AGE _____	NAME _____	AGE _____
NAME _____	AGE _____	NAME _____	AGE _____

SPOKESPERSON(S): _____

PATIENT _____

**Family Description
(prioritized as expressed)**

**Nursing
(Observation
& Congruency)**

I. FAMILY SYSTEM

ASSESSMENT:

A. Chief Concern:

**B. Self Care
Knowledge:**

**C. Expected
Outcomes:**

**D. Coping:
Effective
techniques as
described by
family:**

**E. Family's style
of doing
business:**

**F. Quality of
Bonding:**

G. Support System: Family:	Current	Potential
---------------------------------------	----------------	------------------

Social:

Financial:

Spiritual:

Transportation:

Other:

Family Management Plan Nursing Actions

II. What would
you find more
supportive at
this time?

III. What would be
supportive for
future care?

A. Self care
expectations?

B. Continuing
support
expectation?

IV. Summary of Impressions

V. Nursing Diagnosis

Patient Demographic Information:

Patient Age _____ Sex _____ Occupation _____

Medical Diagnosis: _____

Follow up appointment/plan: _____

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APPENDIX C
FAMILY MEMBER VERBATIM EXPLANATION

Hello my name is Bradley Corbin. I am a registered nurse and a graduate student at Grand Valley State University in Michigan. I am currently on the faculty at the Baptist Memorial Hospital School of Professional Nursing. As a registered nurse who has worked in intensive care units, I am interested in learning more about the expectations of families as they experience the hospitalization of their family members.

I would like to invite you to participate in a study. If you choose to participate, I will be asking you some questions that may assist nurses understand how to help families of patient's in acute care facilities. The Baptist Medical Center Nursing Research Committee has given me permission to invite all family members of SOCK and pediatric patients to participate in this study.

The decision to participate is completely yours. What you decide will not be revealed to the nurses or any hospital staff. Your decision will not affect the care that you or the patient receives. If you agree to participate, I would like to meet with you at your earliest convenience.

If you do agree to participate, all your answers will be kept confidential. The possible exception to confidentiality is if the information you give may be essential to protect the safety of you or your family member. Otherwise your answers will be used for research purposes only. A code number will be used with all information collected. Anything connecting your name with the code number will be destroyed upon completion of the research.

I would like to use a tape recorder as a means to accurately gather the answers you give. The answers will be transcribed by a transcriptionist. The transcriptionist will have access to your answers and the identifying code number only. All other identifying information will be deleted from the taped interview.

An interviewing process such as this may produce temporary uneasiness or anxiety, no more than what is experienced in day to day life situations. This discomfort usually subsides by the end of the interview. If you feel the need for further counsel, I will be available to assist in the referral of your choice. If you do feel discomfort, you are free to withdraw from the interview at any time and that decision will not in any way affect the care the patient receives. You are also free to refuse to answer any questions that are asked and this will not in any way affect the care the patient receives. During or after the interview, you are free to ask any question of me. Consent may be withdrawn after completing the interview by calling and giving me your code number to do so. You may withdraw the information by giving me your code number up until the

point of data analysis. Do you have any questions at this point?

Would you be willing to participate? If so please read and sign this consent form.

"APPENDICES"

FAMILY MEMBER VERBATIM EXPLANATION

Hello my name is Peggy Williams. I am a registered nurse and I am currently on the faculty at the Baptist Memorial Hospital School of Professional Nursing. I am assisting a fellow faculty member, Bradley Corbin, who is a graduate student working on a research project for completion of his Masters of Science in Nursing Degree. As a registered nurse and a nursing faculty who has worked in pediatric care units, I am interested in learning more about the expectations of families as they experience the hospitalization of their family members.

I would like to invite you to participate in the study. If you choose to participate, I will be asking you some questions that may assist nurses understand how to help families of patient's in acute care facilities. The Baptist Medical Center Nursing Research Committee has given me permission to invite family member(s) of SOCK and pediatric patients to participate in this study.

The decision to participate is completely yours. What you decide will not be revealed to the nurses or any hospital staff. Your decision will not affect the care that you or the patient receives. If you agree to participate, I would like to meet with you at your earliest convenience.

If you do agree to participate, all your answers will be kept confidential. The possible exception to confidentiality is if the information you give may be essential to protect the safety of you or your family member. Otherwise your answers will be used for research purposes only. A code number will be used with all information collected. Anything connecting your name with the code number will be destroyed upon completion of the research.

I would like to use a tape recorder as a means to accurately gather the answers you give. The answers will be transcribed by a transcriptionist. The transcriptionist will have access to your answers and the identifying code number only. All other identifying information will be deleted from the taped interview.

An interviewing process such as this may produce temporary uneasiness or anxiety, no more than what is experienced in day to day life situations. This discomfort usually subsides by the end of the interview. If you feel the need for further counsel, I will be available to assist in the referral of your choice. If you do feel discomfort, you are free to withdraw from the interview at any time and that decision will not in any way affect the care the patient receives. You are also free to refuse to answer any questions that are asked and this will not in any way affect the care the patient receives. During or after the interview, you are free to ask any question of me. Consent may be withdrawn after completing the interview by calling and giving me your code number to do so. You may withdraw the information by giving me your code number up until the point of data analysis. Do you have any questions at this point?

Would you be willing to participate? If so please read and sign this consent form.

APPENDIX D
WRITTEN CONSENT FORM

The research project entitled "The Development and the Testing of a Family Adaptive Potential Assessment Tool" conducted by Bradley Corbin R.N., B.S., M.S.N.c. has been explained to me. I understand that if I agree to participate, I will be answering a set of questions about myself, my family and my thoughts, feelings, and experiences within the SOCK or the pediatric unit. I expect that the interview will take about thirty minutes in a conference room near the SOCK and/or pediatric unit.

I understand that an attempt is being made to find out how nurses can be more of an assistance to families experiencing the hospitalization of a family member. The research questions are used to gather information to learn more about the expectations of families as they experience intensive care and pediatric units. I may also learn about myself and my family as part of the interviewing process.

I understand that if I sign this form:

- * All information gained from the research is confidential and my identity will not be revealed, nor will the identity of the patient be revealed. Information used is generalized and not specific to the informants and there will be no link between my specific answers and the research questions asked. I understand that this confidentiality is protected unless information I give may be essential to protect myself or a family member.
- * Consent forms and recordings will be kept under lock and key and are only available to the researchers and transcriptionist.
- * That my participation is voluntary and that I can withdraw my consent even after signing this consent form and on up to the time that the data is analyzed.
- * My decision to participate does not affect the care or services that the patient or I will receive.
- * A code number will be used with all the information collected including on the tape recording and that anything connecting my name to the code number will be destroyed upon data analysis.
- * That if I feel anxiety and/or uneasiness with the interviewing process, I am free to discontinue the interview without explanation at any time and/or refuse to answer a question. I will be assisted in a referral for counsel if I so feel the need.
- * Any questions that I have about the project will be answered.

I have been given the opportunity to ask any questions about my participation in the study and I understand the information presented on this consent form.

I agree to participate in this study: Signed: _____

Date: _____

Bradley Corbin R.N., MSNc.
Baptist Memorial Hospital
School of Professional Nursing
The researcher can be reached Mon-Wed
0700 AM to 1500 PM 222-8431 ext. 5850
cc:participant and investigator's files

Refer to case number
