

EFFECTS OF A SELF-MANAGEMENT INTERVENTION
ON UNCERTAINTY, SUPPORT, AND STRESS IN
RONALD MCDONALD HOUSE MOTHERS

By

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by

Natalie Settimelli Small

To Joseph and Edmea Settimelli

my very special parents

Whose gift to future generations has been

a tradition of love--

Love of family, love of nature, and

love of learning.

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TABLE OF CONTENTS

	PAGE
ACKNOWLEDGMENTS.....	iv
LIST OF TABLES.....	viii
ABSTRACT.....	ix
CHAPTERS	
I INTRODUCTION.....	1
Statement of the Problem.....	10
Purpose of the Study.....	13
Research Questions.....	13
Importance of the Study.....	14
Definition of Terms.....	15
Organization of the Study.....	17
II REVIEW OF THE LITERATURE.....	18
Crisis Intervention Theory and Illness.....	18
Impact of a Child's Hospitalization on Mothers.....	24
Dealing with Pain and Incapacitation.....	27
Dealing with the Hospital Environment and Special Treatment Procedures.....	28
Developing Adequate Relationships with the Professional Staff.....	28
Preserving a Reasonable Emotional Balance.....	28
Preserving a Satisfactory Self-image.....	29
Preserving Relationships with Family and Friends.....	30
Preparing for an Uncertain Future.....	32
Coping and Mothers.....	33
Uncertainty.....	36
Social Support.....	39
Stress (Strain).....	44
Counseling Interventions.....	48
Ronald McDonald Houses as Therapeutic Milieus.....	50
Summary.....	53

III	METHODOLOGY.....	55
	Design of the Study.....	55
	Population and Sample.....	57
	Procedures.....	59
	Control Group.....	59
	Experimental Group.....	62
	Treatment Variables and Instruments.....	63
	Dependent Variables.....	65
	Uncertainty.....	66
	Social Support.....	68
	Stress (Strain).....	69
	Research Hypotheses.....	71
	Data Analyses.....	71
IV	RESULTS.....	73
	Description of the Sample.....	73
	Testing the Null Hypothesis.....	75
	Uncertainty.....	75
	Social Support from Family.....	78
	Social Support from Friends.....	78
	Stress (Strain).....	80
	Summary.....	81
V	DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS.....	84
	Discussion.....	85
	Total Population.....	85
	Booklet Use.....	85
	Uncertainty.....	87
	Social Support from Family.....	88
	Social Support from Friends.....	91
	Stress (Strain).....	92
	Limitations.....	94
	Conclusions.....	95
	Recommendations.....	95
	Future Research.....	97
APPENDICES		
A	1985 RONALD MCDONALD HOUSE SURVEY.....	99
B	DEMOGRAPHIC DATA.....	104
C	INTERVENTION AND EVALUATION.....	107
D	INSTRUMENTS.....	116
	REFERENCES.....	124

LIST OF TABLES

TABLE		PAGE
3-1	Summary Statistics of the Mothers' Characteristics.....	60
4-1	Pretest and Posttest Means, Standard Deviations, and Ranges of Scores for Dependent Variables for Total Population.....	74
4-2	Pretest and Posttest Means and Standard Deviations for Total Scores and Subscales of Uncertainty.....	76
4-3	Source Table for Analysis of Covariance of Uncertainty...	77
4-4	Pretest and Posttest Means and Standard Deviations for Scores on Social Support from Family and Social Support from Friends.....	79
4-5	Source Table for Analysis of Covariance of Social Support from Family and Social Support from Friends....	79
4-6	Pretest and Posttest Means and Standard Deviations for Scores on Stress (Strain) Measures.....	82
4-7	Source Table for Analysis of Covariance of Stress (Strain).....	83

Abstract of Dissertation Presented to the Graduate School
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By

Natalie Settimelli Small

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The purpose of this study was to determine the effects of a self-management booklet on mothers who were registered at the Gainesville, Florida, Ronald McDonald House. Ronald McDonald Houses, a recent advancement, provide a home-away-from-home for families with a hospitalized child.

Research has demonstrated that mothers who successfully cope with a sick child typically adopt three behaviors: they learn the medical situation through communication with medical staff and other mothers (i.e., cope with uncertainty), they establish a social network (i.e., maintain social support), and they adopt a positive outlook (i.e., cope with stress). The booklet Mothers Know Best was developed by the author

to educate mothers about these coping behaviors. Its purposes were to encourage mothers to adopt a proactive role in asking questions of the medical staff to reduce uncertainty, to take actions to promote their own well-being, and to interact with other mothers at the Ronald McDonald House.

This study determined the impact of the booklet Mothers Know Best on decreasing uncertainty and stress and on increasing social support from family and friends. The four instruments used in this study were Mishel's Parent/Child Uncertainty Scale, Lefebvre and Sandford's Strain Questionnaire, and Procidano and Heller's Social Support from Family and Social Support from Friends Scales. The instruments were administered as pretests and 1 week later as posttests to 59 mothers. Following the administration of the pretest to the 29 treatment group mothers, they were given the booklet and asked to read it and use it.

Analyses of covariance revealed that the treatment group mothers who used the booklet Mothers Know Best had significantly lower uncertainty concerning their child's disease and higher levels of perceived social support from friends than the control group. The booklet did not have a significant effect on the mothers' perceptions of social support from family or their stress. Because the booklet proved to be beneficial to the mothers in this study, it was recommended that it be used in the Ronald McDonald Houses and further tested in other, comparable facilities.

CHAPTER I INTRODUCTION

If you can't have Christmas at home, the next best thing is the Ronald McDonald House. I love being home this year, but I'm frustrated because I don't have people to talk to. People with healthy children just don't understand.

(A Christmas note from a mother who stayed at
a Ronald McDonald House for 13 months)

Hospitalization of seriously ill children has a profound effect on mothers. Emotional contagion between a mother and child, as well as personal and family problems that often arise simultaneously with the medical problem, may result in maladaptive coping behaviors. When hospitalization means that a mother and child are far from home and all that is familiar, negative effects from hospitalization can be exacerbated. To help this segment of the population--parents and children in hospitals far from home--100 Ronald McDonald Houses have been built and another 50 are in the planning stages (Jones, 1986). These houses are safe, comfortable, and inexpensive. They are "a home away from home" for families going through a medical crisis. Based on crisis intervention theory, the question arises as to whether emotional support can be enhanced in these Ronald McDonald Houses?

The high degree of maternal stress associated with children's hospitalization is of concern to counselors and researchers not only because maternal stress can be transmitted to children and contribute to

the distress of the pediatric patient, but also because of the effect on the mothers themselves (Shaw & Routh, 1982). The magnitude of this problem is indicated by the quantity of hospital admissions of children. Each year in the United States, more than 5 million children are admitted to hospitals for diagnosis or treatment. According to the 1986 annual report of the National Center for Health Statistics, in 1984, there were over 14 million patient days for children under the age of 15 in short-stay (less than 30-day) hospitals.

A review of the relevant literature reveals that hospitalization, or other health care experience, results in at least transitory changes in family behavior, in the subjective assessments of family members, and possibly in physiological indicators frequently associated with upset (Thompson, 1986). A child's encounter with a health care setting also often involves stress caused by separation from what is familiar; painful experiences, such as injections; and the need to cooperate with various procedures (Melamed & Bush, 1985). Mattsson and Weisberg (1970) found children's behavior during an illness treated at home to be unrelated to previous experience of maternal separation. However, children who had limited experience with normal separation (e.g., being left with a sitter or visiting away from home overnight) experienced more anxiety in the hospital than those with separation experience (Dearden, 1970). Children respond differently to illness and hospitalization depending on their age, developmental level, and disease entity. At least some portion of a child's reaction can be attributed to the aversive properties of the setting itself (Traugber & Cataldo, 1982). In addition, hospitalized children, regardless of their age,

often feel abandoned by their parents, thus intensifying their anxiety (Astin, 1977; Menke, 1981). As a result of the responses in their children, mothers may exhibit anger, fear, and guilt.

Lack of understanding can hamper both mothers' and children's coping ability and promote maladaptive coping behavior. When maternal anxieties concerning treatments and medications are communicated to the child, there can also be serious impact on the child's illness (Langford, 1961; Rae, 1981; Skipper & Leonard, 1968). The emotional contagion of a parent's inability to cope can coincide with a child's inability to understand and accept illness (Barnes, Kenny, Call, & Reinhart, 1972). Insight into emotional contagion in mother-child interaction has been gained from recent studies of the relationship between mothers' style of interaction or discipline with their children and children's responses to treatment in medical or dental settings (Thompson, 1986). Children exhibited more active exploration of the medical situation when calm mothers provided their children with information and distraction rather than reassurance. Maternal reassurance of children and overt maternal agitation were associated with maladaptive child responses (Bush, Melamed, Sheras, & Greenbaum, 1986).

As hospital visitation and rooming-in policies become more liberal, mothers of hospitalized children face new conflicts. Some mothers, for whom hospitals are an aversive stimulus, try to avoid visiting their children. Robinson (1968) concluded that fearful mothers do not take advantage of hospital opportunities to be with their children, and Astin (1977) found that stressed parents may subconsciously withdraw from

their children. Anxious mothers who do not visit their hospitalized child may miss opportunities for gathering information about their child's illness, which may then intensify anxiety (Alexander, White, & Powell, 1986). In their research, Petrillo and Sanger (1980) found that it may be advantageous for parents to be nearby, but not at, the sick child's bedside. Confirming the beneficial effect of parents being close to their hospitalized child, Oremland and Oremland (1973) concluded that parents should be encouraged to remain nearby, but to leave their child periodically so that the child develops trust in parents and staff and learns that the parents approve of hospital routines and the staff.

While researchers have revealed the importance of parents remaining close to their hospitalized child to reduce the child's anxiety, problems associated with parental anxiety continue to surface. Maternal stress and maladaptive coping may be intensified when a child has a chronic illness, such as cancer or cystic fibrosis, that requires multiple or extended hospitalizations. Long-range hospitalization of a child, with its resultant separation, has a stressful effect on every member of the family (Ack, 1983). While different coping strategies may be appropriate for different individuals, the method chosen by each family member influences the adjustment of all others, and particularly difficult problems may be caused by highly discrepant coping among family members (Melamed & Bush, 1985). For the mother of a hospitalized child, there is a cluster of concerns that have to do with the seriousness of the problem, the physical burdens of the illness (such as special diets or protocols), and the financial strain attached to

hospitalization. The mother must often cope with her uncertainty about outcome; try to mitigate the child's fears, pain, and discomforts; juggle her own expectations and past experiences; and maintain continuing familial, occupational, marital, and personal role behaviors. Although use of psychological preparation of children for hospital procedures has become commonplace, the assumption that all preparation is "good" has been questioned by research (Melamed, Robbins, Small, Fernandez, & Graves, 1980). Cognitive level, age of the child, and previous hospital experience play a role in the child's adaptation to hospitalization and have an effect on the behavior of the mother of the hospitalized child.

Personal and family problems during the hospitalization of a child can intensify the stress of mothers. Mothers undergoing the anxiety associated with a catastrophic illness are often enmeshed in the role conflicts associated with being a wife, daughter, employee, mother of a hospitalized child, and mother of well siblings (Chan & Leff, 1982). Dependent, submissive mothers may suddenly find themselves in a strange, dual role of mother/father for extended periods of time. Kubistant (1981) maintained that the loneliness of separation from a primary relationship can be actually physically painful for wives and husbands. For divorced mothers, obligatory decision making with an ex-spouse concerning the sick child may force continuation of a relationship that would have ceased (Ahrns, 1981).

Loneliness and isolation are themes found throughout the literature on mothers and the hospitalization of children. A mother who is isolated from contacts with family and friends may find it easy to deny

the reality of her child's fatal illness. Far from home, a mother may refuse to acknowledge that a child has a serious illness and delay getting the help needed to carry on a normal lifestyle (Halligan, 1983). Depression, overeating, smoking, and drinking--behaviors that may be self-managed at home--can become a problem in the isolation of the hospital environment (McBrian, 1981). Lonely mothers were found to have lowered self-esteem, to be sensitive to rejection, and to be anxious making decisions (Booth, 1983).

The press of past events also determines how a mother responds to the present crisis of a child's illness and the regression, withdrawal, and displacement defense mechanisms she may employ. These defense mechanisms, in turn, can alter mothers' perceptions of their situation (Adams, 1979). When a mother finds herself watching her child face death, a sense of tragic absurdity prevails. Not only is time shortened, but its order is shattered as a mother realizes that her child has not had time to begin to form life goals (Sourkas, 1982). Finally, one of the greatest problems in maternal adaptation occurs with the single parent who often lacks emotional support from a partner, has socioeconomic problems, and depends on the seriously ill child for emotional support (Adams, 1984).

Although they can play an important role in children's hospitalization, until recently, fathers have been neglected in research. Freudian theory, with its emphasis on the mother-child relationship, has guided research on the parents of hospitalized children. Research on the effect of separation on the hospitalized child is rooted in the mother-child tradition and, therefore, almost

universally attributes the negative responses of children to separation from mother rather than other attachment figures. As hospitals have increasingly encouraged parent participation in the care of sick children, a greater number of mothers than fathers have involved themselves in their child's care, thus reflecting American society's traditional view of parenting (Thompson, 1985).

Breaking from the tradition of mother-child research, Azarnoff, Bourque, Green, and Rakow (1975) studied fathers' anxiety concerning the hospitalized child, but found difficulty in getting father participation in hospital-based research. Roskies, Mongeon, and Gagnon-Lebeuvre (1978) determined that the level of father participation with a sick child can be increased through an intervention targeted for mothers. Lord and Schowalter (1982) have reported increased participation by fathers with hospitalized adolescents in recent years. However, in 1985, more than one-fourth of American families with children and more than 60% of those who are black were headed by a single parent. According to the United States Census Bureau (1986), the overwhelming majority of the 8.8 million single-parent families are headed by women. These statistics are influenced by the current trend of unmarried women choosing to keep their babies and the increase in the divorce rate in the United States ("One-parent Families," 1986). It can be anticipated, therefore, that mothers will continue to be the chief caretakers of children when they are hospitalized and will continue to need assistance with their coping skills.

Health professionals who have seen the beneficial effects of the Ronald McDonald House concept are advocating that use of community

services, like Ronald McDonald Houses, should be seen by health care providers as an integral part of family support (Alexander et al., 1986). By initiating environmental support, the McDonald Corporation established the first, large American corporate effort to address the needs of families with a hospitalized child. Ronald McDonald Houses were founded to provide parents of hospitalized children with a homelike atmosphere close to the hospital. Parents whose children are receiving daily outpatient treatments in the hospital, such as chemotherapy and radiation therapy, may stay at the houses with their children. Also, in an effort to maintain family solidarity during the hospitalization of a child, parents may bring siblings for weekend stays at the houses. The first Ronald McDonald Houses opened in Philadelphia in 1974. Since then, 100 houses have opened, including 10 in Canada, 2 in Australia, and 1 each in Germany and the Netherlands. Seventeen houses opened in 1985 and of the 100 houses, none has closed. Attesting to the success of the Ronald McDonald Houses is the fact that more than a million families have chosen to stay at them (Jones, 1986).

Gainesville, Florida, a university town with a population of about 100,000 people, has 155 pediatric beds in its 450-bed, tertiary care, Shands Hospital at the University of Florida. As of July 1987, approximately 4,500 families have been housed in the 28-bedroom Gainesville Ronald McDonald House (F. Armes, personal communication). The study by Small (1985b) of 340 families who stayed in the Gainesville house revealed that 15% of the respondents viewed the Ronald McDonald House as a motel-like facility, whereas 48% viewed it as a place to garner social support. Social support has been established as an

essential element in the management of crisis situations (McCubbin & Figley, 1983). Therefore, it can be suggested that the Ronald McDonald House is providing social support to families, and thus, helps reduce the crisis experience of parents.

From a theoretical framework, crisis intervention theory and social support theory provide a paradigm, or structure, for the development of further research on mothers of hospitalized children (McCubbin & Figley, 1983). Proponents of crisis theory maintain that whenever stressful events which threaten biological, psychological, or social integrity occur in a person's life, disequilibrium occurs to some degree along with the possibility of a crisis (Aguilera & Messick, 1986; Melamed & Bush, 1985). In crisis, a person may be confronted with many stressful events occurring simultaneously. The person may be filled with uncertainty and not know what has occurred, let alone which event requires priority in problem solving (Aguilera & Messick, 1986).

In his study of the crisis experience, Davis (1963) maintained that a central emotional theme of families indicating a need for intervention was the feeling that the family was no longer "like everyone else." The shift in the family's self-image, from a group more or less like other families with a "normal" quota of satisfactions and troubles, to one that had been "singled out" for misfortune constituted one of the most alienating features of the crisis experience.

Moos and Tsu (1977) proposed that illness in a family constellation constitutes a life crisis that exacerbates any ills evident in the family system. The cognitive operations and coping skills of a family will determine whether, when challenged by illness, the family members

adopt adaptive or nonadaptive behaviors in dealing with the stress of illness. Consequently, for the mother of the hospitalized child, the counselor who wishes to enhance coping skills may introduce an intervention that encourages mothers to take a proactive role in solving problems associated with the stress or strain of illness.

When a child is hospitalized, it is a time of crisis which calls for coping by the entire family, but especially by the mother. Ronald McDonald Houses are now available so that mothers can remain close to their hospitalized children and families need not be totally disrupted during a child's serious illness. However, the question arises as to whether the coping of mothers at the Ronald McDonald House can be enhanced.

Statement of the Problem

In determining whether the coping of mothers at the Ronald McDonald House can be enhanced, it is of interest to examine the known means by which mothers of sick children cope. They cope by understanding the medical situation through communication with medical staff and with other mothers (coping with uncertainty), by maintaining a positive outlook (coping with stress), and by maintaining social support (Figley & McCubbin, 1983).

As reported in research studies on stress by Figley and McCubbin (1983) on over 500 families with children with chronic illness, three coping patterns, made up of coping behaviors, were identified that parents use to manage family life. Maintaining a positive outlook on life, maintaining social support and self-esteem, and understanding the

medical situation through communication with other parents are means by which mothers of sick children retain their focus on family life.

Mothers' coping is directed at the maintenance of the family integration, cooperation, and optimism; at the maintaining of social support, esteem, and emotional stability; and at understanding the medical aspects of the illness (Figley & McCubbin, 1983).

Family crisis theory can provide a base for counseling interventions when a child is hospitalized. From such a crisis framework, then, and keeping in mind the coping mechanisms which Figley and McCubbin (1983) report in families with chronic illness, it can be speculated that coping needs of a mother are related to cognitively dealing with her uncertainty about her child's health, to management of her own levels of stress, and to utilization of social support networks.

Research has been done on several interventions that have sought to increase mothers' coping with hospitalized children. Although anxiety can be intensified by the hospital system itself, current trends in hospital practice (Roskies et al., 1978), as well as in psychological, stress-point preparation for elective surgery (Wolfer & Visintainer, 1975), place increased emphasis on the role of mothers to alleviate stress in hospitalized children. In the case of the child who requires hospitalization, a mother may have varying degrees of involvement ranging from delivering and retrieving the child to being an intrinsic part of the child's care team with detailed instruction in the child's medical protocol or surgical procedure. Coping may be even more difficult for the conscientious mother with a sick or handicapped child. Pressure may be heightened for her to cope well, because of her

knowledge of research which shows that parent-child interaction, education, and preparation for hospitalization results in a less anxious child (Gross, Stern, Levin, Dale, & Wojnilower, 1983; Kaplan, Smith, Grobstein, & Fischman, 1976).

Didactic instruction, filmed modeling, support groups, skill-building groups, media instruction, and booklets have been used with mothers and children to reduce stress and have been found to be generally beneficial (Meng & Zastowsky, 1982; Skipper, Leonard, & Rhymes, 1968; Thompson, 1985; Visser, 1980). However, much maternal anxiety around hospitalization is attributable to the "space" between health care workers' understanding of parents' experience and parents' own comprehension (Hayes & Knox, 1984). Often, hospital personnel are unaware of the uncertainty and stress that fills a mother when her child is an emergency admission (Rogers et al., 1984). It becomes obvious, therefore, that interventions that help mothers to strengthen their adaptive behavior should help them cope with the stress associated with hospitalization of their children.

The Ronald McDonald House intends to provide physical and emotional support to mothers (Small, 1985b). The Ronald McDonald House is a major new approach but nobody has produced materials to increase Ronald McDonald House effectiveness. In spite of the number and variety of coping interventions available, no published research has revealed use of a self-management booklet in the therapeutic milieu of the Ronald McDonald House as an intervention to enhance mothers' coping. It should be useful to combine a self-management booklet and the Ronald McDonald House to help mothers who have a hospitalized child.

A self-management booklet was written that adapts the methods of Anthony and Carkhuff (1976) for Ronald McDonald House families. Anthony and Carkhuff translated knowledge about human relations skills into a systematic training program for health professionals through structured written exercises. In the self-management booklet, Anthony and Carkhuff's goals of caring, communication, and comprehension are incorporated to address the uncertainty, social support, and stress of mothers while they are at the Ronald McDonald House.

Purpose of the Study

The purpose of this study was to determine the effect of a self-management booklet on the coping of mothers who had a hospitalized child and were staying at a Ronald McDonald House. The study was designed to determine the impact of a self-management booklet on decreasing uncertainty and stress (strain), and increasing social support from family and friends.

Research Questions

This author addressed the effect of a self-management booklet on mothers' perceptions of uncertainty, social support, and stress (strain). Specific research questions were as follows:

1. Is there a difference in levels of uncertainty, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not?
2. Is there a difference in levels of perceived support from family, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not?

3. Is there a difference in levels of perceived support from friends, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not?

4. Is there a difference in levels of stress (strain), after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not?

Importance of the Study

Mothers who stay at the Ronald McDonald House have children with problems that range from requiring relatively simple, nonthreatening, noninvasive diagnostic procedures to children with terminal illness who will die during the current admission. Crisis intervention theorists such as Lindeman (1944) and social support theorists such as Lazarus and Folkman (1984), have maintained that individuals undergoing personal upheaval experience changes in their social support, tolerance for stress, and ability to cope with uncertainty. Mothers of hospitalized children confirm that contention. A self-management booklet that addresses uncertainty, social support from family and friends, and stress (strain) among mothers at the Gainesville Ronald McDonald House could have several implications. Knowledge about the parents' levels of uncertainty, reaction to stress, and social support could help health care providers (counselors, psychologists, social workers, nurses, and physicians) institute guidelines for educating and nurturing mothers of hospitalized children. With a clearer picture of what the hospital experience is for mothers, health care providers may teach the mother of the hospitalized child how to be more assertive in getting answers to

medical questions surrounding the child; how to recognize the behavioral, cognitive, and physical responses illness of their child provokes in themselves; and how to find, promote, and utilize a social support system.

Also, with poor doctor-patient communication as the single most common cause of malpractice suits (Starr, 1982), this study may, in a broader sense, assist in the delivery of health care in a new age of medical cost containment, when economics is determining length of hospital stay and supportive services following hospital discharge (Freyman, 1986). Children are, and will continue to be, discharged from hospitals "quicker and sicker" and the demands made on the families of patients will intensify. In addition, a self-management booklet could be disseminated to all Ronald McDonald Houses at a relatively low cost. Also, the study has implications for the further use of crisis intervention and social support theory as it relates to the Ronald McDonald Houses. Finally, the study has implications for further research.

Definition of Terms

A number of terms are used throughout this research and deserve further elaboration and definition.

Mother--The natural, adoptive, or foster female caretaker with legal custody of a hospitalized child.

Pediatric--Medical services treating diseases of children from birth to 21 years of age. These include the divisions of gastroenterology, neonatology, genetics, pulmonology, infectious

disease, general pediatrics, cardiology, hematology/oncology, nephrology, neurology, endocrinology, surgery, and psychiatry.

Pediatric patient--A person of either sex, under the age of 21, and single. These people and their families are entitled to use a Ronald McDonald House facility.

Perceived social support--The extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled.

Ronald McDonald House--An inexpensive, convenient, comfortable hostelry for parents of hospitalized children. Built with corporate and local funding, governed by a board of directors, and maintained by a house manager, more than 100 Ronald McDonald Houses provide 1,300 bedrooms a night for families in crisis (Jones, 1986).

Self-management booklet--A booklet, written by the researcher and judged appropriate by a panel of educational, counseling, and media experts, that encourages mothers staying at the Ronald McDonald House to take a proactive role in reducing uncertainty about their child's illness, reducing their individual stress, and increasing their social support.

Strain (stress)--A syndrome of physical, behavioral, and cognitive symptoms that are elicited to varying degrees by environmental demands upon an individual.

Uncertainty--In the model of perceived uncertainty in illness as proposed by Mishel (1981), the characteristics of uncertainty in illness reside in the nature of the stimulus, the characteristics of the perceiver, or an integration between stimulus and perceiver in relation

to four illness events: vagueness, lack of clarity, ambiguity, unpredictability.

Organization of the Study

The remainder of this study is organized into four chapters. Chapter II is a review of the relevant literature on crisis intervention theory and illness; hospitalization; uncertainty, stress, and social support; counseling interventions; and Ronald McDonald Houses. In chapter III the methodology of the study, including a description of the population and sample, the sampling procedure, the instruments, the data collection procedures, and the proposed data analysis are presented. The results of the study are presented in chapter IV. In the final chapter, chapter V, a discussion and interpretation of the results, the limitations of the study, and recommendations for future research are described.

CHAPTER II REVIEW OF THE LITERATURE

In this chapter, literature related to this study is reviewed in five topical areas: (a) crisis intervention theory and illness; (b) impact of a child's hospitalization on mothers; (c) coping and mothers: uncertainty, social support, and stress (strain); (d) counseling interventions; and (e) Ronald McDonald Houses as therapeutic milieu.

Crisis Intervention Theory and Illness

According to crisis theory, three things happen: (a) a person in crisis perceives a difficulty; (b) there is significance to the threatening situation; and (c) there is a loss of resources for immediate coping with the situation (Caplan, 1961). Crisis intervention therapy is employed to restore a sense of equilibrium in the individual. The work of Caplan (1961) and Lindemann (1944) form the background for research in crisis intervention and gives insight into the impact of serious illness on a family.

When facing a crisis, a person may be confronted with stressful events occurring simultaneously with no awareness of what has occurred and which event requires priority in problem solving. This state of disequilibrium is accompanied by anxiety and depression. Balance can be restored when the distressed person has a realistic perception of the stressful event plus adequate situational support and adequate coping

mechanisms. This combination results in resolution of the immediate problem, regaining of equilibrium, and dissolution of the crisis (Caplan, 1961).

The Chinese characters that represent the word "crisis" mean both danger and opportunity. Crisis is a danger because it threatens to overwhelm the individual. It is also an opportunity because, during times of crisis, individuals are more receptive to therapeutic influence (Aquilera & Messick, 1986). Transitions over the life span predictably create stress within a family system and may move an individual or whole family unit to a state of crisis. When an individual in crisis is at a turning point and facing a problem that cannot be resolved by using coping mechanisms that have worked before, tension and anxiety increase and the person is caught in a state of great emotional upset, unable to take action to solve the problem (McCubbin & Figley, 1983). Crisis theorists have maintained that the situational precipitating event for crisis may be "accidental" (e.g., sudden illness or death of a loved one) or "developmental" (e.g., entry into marriage or birth of a child) and its potential for instituting a crisis is a function of the emotional reaction of the individual and not necessarily the event itself (Caplan, 1961).

Since a state of crisis is conceived to have growth-promoting potential, in developing crisis theory, authors have most heavily emphasized the nature of the individual reaction to whatever stressful situation may have occurred (Calhoun, Selby, & King, 1976). Crisis theory offers the advantage of characterizing a state which occurs frequently in the life cycle of the individual or family and during

which the helping professions are apt to have access to people and are likely to be active.

In a historical overview, Aguilera and Messick (1986) emphasized the broad base of knowledge that has gone into the development of the crisis approach to therapeutic intervention. Freud's principle of causality stated that every act of human behavior has its cause in the history and experience of the individual. An ego analyst versed in Freud's theoretical contributions, Heinz Hartmann, postulated that a person's adaptation in early childhood, as well as the ability to maintain adaptation in later life, had to be considered. Sandor Rado, in developing the concept of adaptational psychodynamics, emphasized the immediate present without neglecting the influence of the developmental past. Primary concern is with failures in adaptation "today." It was Erik Erikson, however, who furthered the theories of ego psychology by focusing on eight stages of psychosocial development, each with its specific developmental tasks, that span the life cycle (Erikson, 1950). Erikson's theories provided a basis for the work of Caplan (1961) and Lindemann (1944) and their consideration of situational crises and individual adaptation to current dilemma.

Caplan maintained that all the elements that compose the total emotional milieu of the person must be assessed in an approach to preventive mental health. The material, physical, and social demands of reality, as well as the needs, instincts, and impulses of the individual, must be considered as important behavioral determinants. From his research, Caplan evolved the concept of the importance of crisis periods in individual and group development.

Lindemann's (1944) theory of "preventive intervention" was intended to prevent psychopathology and gave rise to the concept of contemporary crisis intervention. Recognizing the potential for utilizing preventive intervention programs, Lindemann and Caplan established the Wellesley Project in 1946 which was the first community-wide program of mental health of its kind (Aquilera & Messick, 1986). Lindemann chose to study bereavement reactions in his search for social events or situations that predictably would be followed by emotional disturbances. In his classic study of bereavement reactions among the survivors of the 1942 Boston Coconut Grove nightclub fire, Lindemann described both brief and abnormally prolonged reactions in different individuals as a result of a loss of a significant person in their lives.

The concept of crisis as formulated by Lindemann and Caplan refers to the state of the reacting individual who is in a hazardous situation. Not all individuals in a hazardous situation will be in crisis, though there are certain conditions, such as death, that induce a state of crisis of greater or lesser intensity to nearly all individuals. Lindemann maintained that although pathological sequelae might appear, the reactions are transitory adjustment struggles during a time of crisis. Sequelae could be avoided by intervention that helped the individual in crisis to identify, understand, and master psychological tasks posed by the stressful situation.

Much of the work in intervention is, therefore, aimed at raising the client's self-esteem by emphasizing the concrete facts of the current situation and assisting the client's own efforts at changing them by teaching specific skills in an organized, systematic way

(Puryear, 1979). Rapoport (1971), in discussing crisis intervention, reported that adaptive resolution, that which serves to strengthen the individual's or family's adaptive behavior, requires (a) accurate appraisal of the crisis creating situation, (b) appropriate management of affect to reduce tension while allowing for problem solving, and (c) willingness to seek and accept help while mastering the problem. The continuing research on life transitions and therapeutic intervention underscores the importance of promoting individual strengths and capabilities so that a person can successfully resolve crises on their own, if possible (Figley & McCubbin, 1983).

As psychotherapy, crisis intervention is the informed and planful application of techniques derived from the established principles of crisis theory by persons qualified through training and experience to understand these principles with the intention of assisting individuals or families to modify personal characteristics such as feelings, attitudes, and maladaptive behaviors (Ewing, 1978). A low-cost, short-term therapy, crisis intervention is involved with solving the immediate problems facing a client (Aguilera & Messick, 1986). From the standpoint of intervention, the task is not to end the crisis, for nature takes care of that. The task is to maximize the level of functioning when the crisis does end (Jacobson, 1980).

As with the events around mass disasters, such as floods and tornados that constitute crisis, the paradox of "ordering reality" versus the "unreality of order" frustrates the investigator who tries to describe the overlapping and disturbing events that occur when serious illness strikes a family (Davis, 1963). The terminology of the

perceptual/interpretative process of crisis may be employed in describing the process mothers undergo within the framework of a child's illness. To see one's child healthy and active one day and to be forced, a day or two later, to consider the likelihood of a child becoming permanently handicapped or dying entails an alteration in fundamental perceptions. Following, in part, the terminology used in human disaster studies, Davis (1963) designated the developmental stages of illness as crisis in families: the Prelude Stage, the Warning Stage, the Impact Stage, and the Inventory Stage.

The Prelude Stage extends from the time mothers, in a state of equilibrium, become aware that the child is not feeling well until they apprehend some cue that the indisposition is not ordinary. The commonplace appearance of the prodromal symptoms, such as a ubiquitous virus with accompanying vomiting and diarrhea, often impart elements of unreality to the whole crisis experience when an illness later proves to be fatal.

Symptomological (i.e., dragging a leg), behavioral (i.e., a 4-year-old outdoing a 6-year-old in a tussle), environmental (e.g., a local outbreak of an epidemic), or authoritative (e.g., an explanation by a doctor) cues that block the mother's common sensical diagnosis of the illness identify the Warning Stage. The more that a pathological state is "brought on" through the willful action of the individual, the more likely it is that the condition will be defined as a moral or behavioral deviation rather than an illness (Yarrow, 1955). The Impact Stage occurs when the passage of time and exacerbation of symptoms convinces mothers of diagnosis. Interaction between doctors and mothers

during impact may produce ambiguous communication. Mothers may arrive at the hospital determined to prove a doctor wrong and with a definite agenda as to their child's care. Parents become initiated in the art of "hearing between the lines." Within a few days of Impact, with its accompanying feelings of despair, the Inventory Stage, with hopefulness, occurs creating within mothers a fluctuating internal dialectic, as well as the realization that the family has been singled out for misfortune. This crisis of illness, in spite of its feelings of alienation, can be a time of re-evaluation of the self and one's bonds with one's "fellow man" (Davis, 1963).

Impact of a Child's Hospitalization on Mothers

In her family systems approach to therapy, Virginia Satir (1972) likened the family to a mobile.

In a mobile all the pieces, no matter what size or shape, can be grouped together in balance by shortening or lengthening the strings attached, or rearranging the distance between the pieces. So it is with a family. None of the family members is identical to any other; they are all different and at different levels of growth. As in a mobile, you can't arrange one without thinking of the other. (p. 119)

For the mother of a sick child, hospitalization demands adaptations that touch every aspect of her role as a woman and her relationships with each member of the family constellation.

The maternal role may be one of the most difficult and complex roles in our society today (Pasley & Gecas, 1984). Besides demanding insight and energy, parenting is further complicated by the fact most couples are not prepared to assume the responsibilities of the role (LeMasters & DeFrain, 1983). The maternal role becomes even more

complicated when a sick or handicapped child appears affecting each individual within the system. In regard to research or practice, counseling has not kept pace with other fields, such as pediatrics and social work, on the effect of handicapped children on parents (Seligman, 1985). Goode (1984), in his study, observed that much family energy was absorbed in deciding how best to present a handicapped child to others and that the family's identity was inextricably tied to the identity of the sick child. Presentation of the sick child differed according to specific situations and audiences, and for the family, the whole point of managing their presentation of the child was to understand what the child's image (and thus their own) meant to others. Maternal behavior may also hamper family function and contribute to the immaturity of the family system by holding the disabled child less responsible than a less disabled child for his or her behavior (Roessler & Bolton, 1978).

Researchers have shown that to study the hospitalized child it is necessary to look at the effect of hospitalization on the individual parent of the sick child. Gofman, Buckman, and Schade (1957) reported the incidence and degree of maternal anxiety to be great in their study to assess the prevalence of anxiety among mothers of hospitalized children. Of 100 surveyed parents, all expressed some anxiety about the hospitalization and 57% considered the anxiety to be overwhelming. More recently, several investigators have looked at maternal concern around child hospitalization. Skipper et al. (1968) found mothers' anxiety to be high during children's surgery. In another study, Kessler (1969) found maternal anxiety high in mothers with young children hospitalized for the first time. Eighty percent of the mothers in Kessler's study

were moderately or severely stressed by the situation with anxiety varying with social class. Middle-class mothers were more anxious than either upper- or lower-class mothers. Frieberg (1972), in a survey of mothers of hospitalized children, found the factors most commonly cited by mothers as contributing to their anxiety were lack of information about diagnosis and procedures, treatments, and children's medical condition. Kazak and Marvin (1984) found that mothers of handicapped children tended to be more vulnerable to the effects of stress than were mothers in a control group or fathers in either a treatment or control group.

Recent researchers have explored the emotional contagion that can exist between the ill child and his/her mother. In a study of diabetic children by Margalit (1986), the anxiety levels expressed by 20 diabetic children, the level of anxiety ascribed by their mothers, and the anxiety levels of 20 healthy children were studied. The children in the diabetic study did not form an emotionally deviant group in terms of their expressed anxiety, although their mothers viewed them as significantly more anxious than they judged themselves. The mothers' own anxiety was the best predictor of their perceptions of their children's anxiety. Bush et al. (1986), in an outpatient clinic study, found that mothers who were agitated provided less information and ignored their children more, suggesting a pattern of parenting rendered less effective by the disorganizing influences of maternal anxiety.

Research on children and hospitalization supports the contention that a person's cognitive approach to tasks and the choice of coping skills will determine how one recovers from an illness (Thompson, 1986).

The impact of the hospitalized child on mothers may be appreciated through examining the model of illness presented by Moos and Tsu (1977) in which they outlined seven major adaptive tasks concerned with illness. Adaptive problems the sick child's family encounters are as follows: (a) dealing with pain and incapacitation, (b) dealing with the hospital environment and special treatment procedures, (c) developing adequate relationships with the professional staff, (d) preserving a reasonable emotional balance, (e) preserving a satisfactory self-image, (f) preserving relationships with family and friends, and (g) preparing for an uncertain future.

Dealing with Pain and Incapacitation

Most children report the injection to be one of the most threatening experiences in health care (Ellerton, Caty, & Ritchie, 1985). In a study of 128 school-aged children, 86% rated the needle as stressful and 36% rated physicians as stressful. Shaw and Routh (1982) studied the effects of parental presence during an injection on the behavioral responses of 18-month-old and 5-year-old children. Crying during the injection was found to be significantly more common among children of both ages when parents were present. The researchers interpreted these findings as supportive of maternal presence, proposing that, under the stress of an injection, children may be more emotionally upset in the sense of physiological arousal when their mothers are absent than when they are present. The presence of mothers, they suggested, may serve as a disinhibitor which permits free expression of children's feelings.

Dealing with the Hospital Environment and Special Treatment Procedures

Separation from parents was identified by Vernon, Foley, Sipowicz, and Schulman (1965) as a major factor contributing to the immediate and posthospital psychological upset of preschool children. Research on the impact of rooming-in to avoid separation anxiety has produced mixed results. Thompson (1985) and Lehman (1975) reported that children of rooming-in parents were more aggressive in the hospital than were others. This is, Lehman (1975) suggested, a reflection of the greater security felt by the children in the presence of the parent. Research on posthospital effects associate rooming-in with a reduction of postoperative complications (Brian & Maclay, 1968; Lehman, 1975).

Developing Adequate Relationships with the Professional Staff

As with the family with a child on hemodialysis, Levy (1979) found that family members are often extremely angry for being taken for granted and having expectations placed on them without any exploration concerning the impact of illness directly upon themselves as opposed to its impact upon the ill member. Many family members have expressed a great degree of anger that the congratulations of the professional team for success of the patient in treatment is rarely expressed to the family member whose role may have been a great one in augmenting or even being instrumental in the patient's coping with and successful adherence to the medical regimen.

Preserving a Reasonable Emotional Balance

The unspoken quid pro quo of the marital relationship may be disrupted by the emotional demands of a child's illness. Walker (1983)

maintained that guilt, helplessness, difficulty in reversing an established pattern of anticipatory mourning, and a feeling of isolation all play their part with the mother of the hospitalized child. It is only by examining the individual ways in which the parent-child coalition is maintained, protected, and even intensified by interaction with other systems (e.g., the nuclear and extended family systems, the family system in the previous generation, and the medical system) that we can understand why some coalitions have become so resistant to change. In a study by Velasco de Parra, Davila de Cortazar, and Covarrubius-Espinoza (1983) on adaptive patterns of 10 families with a leukemic child, all parents described a decrease in their activities as a couple, as well as a diminution in the frequency and quality of their sexual relations. The main topic of conversation and/or discussion, if not the only one, became the child's disease, and in 80% of the cases, the patient began to sleep with the parents soon after the leukemia was diagnosed. Many parents seem to be grieving for a lost child even as they interact with their living-but-sick or handicapped child. In the case of seriously ill newborns, the perfect child fantasized by both parents, independently, sometimes unconsciously, throughout the pregnancy, has died before he or she could ever come fully to life (Trout, 1983).

Preserving a Satisfactory Self-image

Young children who are not given reasons for hospitalization may conclude they are being punished or sent away because they misbehaved. This may contribute to a set of assumptions about their worth,

reciprocity, and their capacity to limit helplessness and gain nurturance (Frears & Schneider, 1981). Difficulty in maintaining a positive self-image can be intensified when the person who is ill is separated from the family or undergoes changes in appearance and bodily functions as well as such unpleasant feelings as anger, guilt, and helplessness (Feuerstein, Labbe, & Kuczmierczyk, 1986). Loss of hair, jaundice, stunted growth, obesity, or amputation are sources of great distress for both the child and the parent. Each family member must find ways of coping and maintaining a positive self-image. Many parents are counseled now about the positive value of school in the overall adjustment of even seriously ill children (Waechter, 1984). Waechter also found that those children with fatal illness who had a greater opportunity to discuss their fears and concerns about their future and present body integrity expressed less specific death anxiety. This finding supported the hypothesis that understanding acceptance or permission to discuss any aspect of an illness may decrease feelings of isolation, alienation, and the sense that the illness is too terrible to discuss. Thus, each member of the family is involved in the task of preserving a satisfactory self-image.

Preserving Relationships with Family and Friends

Although intrapersonal factors such as an individual's age, personality style, and mechanisms for coping with the mourning and adjustment processes are significant for the patient's rehabilitation after injury, a major interpersonal factor in recovery is the patient's family (Hendrick, 1981). This applies even when the family members are

going through a traumatic event themselves. The family of the spinal cord-injured patient experiences a shock reaction which parallels that of the patient (Eisenberg & Gilbert, 1978). In a study of 30 families with chronic illness, Penn (1983) found over one-half the families with chronic illness were extremely resistant to change. Two coalition configurations surrounding, as well as within, the families were observed. The expected coalitions form inside the family (e.g., parent and child); however, due to the permeable boundaries of a family with a chronic illness, coalitions also occur outside the family dynamics between a family member and people outside the immediate family circle. In tracking interactional events around the coalitions inside the family, Penn (1983) discerned a form of binding interaction that acts to hold the family in stasis. The family's resistance to change seems equal to the strength of these interactions holding them in stasis. In families with chronic illness there is an open sanction for the parent and child alliance. It does not have to become covert since the system is not considered pathological; there is no secrecy, no disqualification of meaning, and the parents do not change sides as they do in pathological systems. Somehow the members of the system refuse the choice of other alliances during the span of the illness, as if to change any other part in the system would further injure the family and its ill member. It is within this framework that a family will determine whether it will manage an illness or be managed by it.

Siblings of ill children report a high number of changes in feelings and behavior (Craft, Wyatt, & Sandell, 1985). Siblings who receive limited explanations of the ill child's condition reported more

changes than those given no explanation. It is possible that a vague explanation by parents creates anxiety. Of particular importance, the most desirable outcome resulted from open explanations. Sibling perceptions of parenting showed parents to be less lenient, preoccupied, spending less time with the siblings, and less easily angered. The effects of parenting on sibling reaction are illustrated by the finding that siblings who perceived their parents to be angered more easily reported increased changes. When siblings are not told about the seriousness of the disease while the leukemic child is alive, problems between parents and children are likely to arise after death (Kaplan, Grobstein, & Smith, 1976).

Preparing for an Uncertain Future

Once the determination has been made that death of a hospitalized child is inevitable, parents report they want intervention to help them manage the issues around child death (Small, 1985a). Parents may begin to refer to the child in the past tense, showing evidence of anticipatory grief (Adams, 1974). There are parents who refuse categorically to accept the idea of death and are sustained by a level of denial that is catastrophic when the actual loss occurs (Koch, Hermann, & Donaldson, 1974). Even where there is genetic counseling for parents with a child with an inherited disease, outcomes are uncertain. Although parental emotions around the uncertain future of their child range from denial to anticipation, researchers have shown that parents' perception of information governs their thinking even when they have some control over the future of a child. Evers-Kiebooms and van der

Berghe (1979) showed that with 200 couples, past reproductive experience and parental desire for children explained much more of the variance in reproductive outcome than did such variables as reproductive risk, burden of the genetic disorder, education, background, or socioeconomic status. Furthermore, the psychological state of parents under stress and how they perceived the factual information seemed more important for their decision than what the facts were (Lippman-Hand & Fraser, 1979). When these adaptive measures around illness are demonstrated, it is obvious the mother of the seriously ill child is contending with a multitude of issues calling for her to exhibit maternal adaptation and expertise (Sourkas, 1982).

Coping and Mothers

Coping resources are generalized attitudes and skills that are considered advantageous across many situations. They include attitudes about the self and the world and intellectual skills. Coping styles are generalized coping strategies and coping efforts are specific actions taken in specific situations that are intended to reduce a given problem or stress. Meng and Zastowsky (1982) reported that subjects trained in coping skills displayed less anxiety than did subjects in another, unspecified control group. Coping strategies have been conceptualized in many different ways and effective coping strategies could be of value in lowering the anxiety of mothers of hospitalized children.

Coping, as defined by Lazarus and Folkman (1984), consists of the constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or

exceeding the resources of the person. They made a distinction between coping and automatized adaptive behavior. Coping is an effort to manage, thus coping includes anything that the person does or thinks, regardless of how well or badly it works. By using the word manage, the researchers avoid equating coping with mastery. Managing can include minimizing, avoiding, tolerating, and accepting the situation as well as the environment. Coping is hypothesized to have two functions: (a) the alteration of an ongoing person-environment relationship (problem-focused coping) and (b) the control of stressful emotions or physiological arousal (emotional regulation). An example of emotional regulation would be a visibly anxious mother of a hospitalized child visiting the intensive care unit in tears before her child's surgery. An example of problem-oriented coping would be a mother asking the doctor questions about her child's diagnosis, medical regimen, and prognosis in order to gather information for her own education before her child has surgery. It is often the combination of both forms of coping that influence the outcome of stress (Feuerstein et al., 1986).

Lazarus and his associates have perhaps had the greatest impact on the study of stress and coping (Feuerstein et al., 1986). According to Lazarus and Folkman (1984), cognitive appraisal, or evaluation, of potentially stressful events mediates psychologically between the individual and the environment when the individual encounters a stressful event. It is the individual's evaluation that determines whether a stressor is harmful. The evaluation is, in turn, partly a function of the resources available to the individual to neutralize or tolerate the stressor. The individual continually re-evaluates

judgments made about demands and constraints characteristic of various interactions with the environment and the various options and resources available to meet the demands. The extent to which an individual experiences psychological stress is determined by the evaluation of both what is at stake (primary evaluation) and what coping resources are available (secondary appraisal). Primary appraisal addresses the question, "Am I OK or am I in trouble?" while secondary appraisal asks, "What can I do about this situation?" Factors that can influence secondary appraisal are a function of the individual's previous experience with similar situations, general belief patterns, and the availability of coping resources at that particular time such as personal health, material resources, problem-solving skills, and level of energy (Folkman, 1984).

The diversity of coping efforts available to the individual is enormous and interest is aroused as to how mothers of hospitalized children cope. Billings and Moos (1981) used a representative adult community sample to focus on the role of coping responses and social responses as intervening variables mediating the effect of life events on personal functioning. Small but significant sex differences were found. Women reported more use of active-behavioral avoidance and emotion-focused strategies than men. Higher levels of education were related to active-cognitive and problem-focused coping and less to avoidance coping. Only modest differences in type of coping used were revealed among different types of events. More active and task-oriented responses were noted in coping with an illness than a death.

Folkman and Lazarus (1980) also found that health-related stressors elicited fewer problem-focused and more emotion-focused coping than work

or family stressors. However, they noted that women were more likely to use avoidance coping, which was associated with greater impairment of functioning. This is congruent with the findings of Pearlin and Schooler (1978), who also identified a tendency for women to use less effective methods of coping than men. In the Holahan and Moos (1981) study, these results may be accounted for by the fact that a majority of the men were employed while a majority of the women were homemakers. Assessment of the effectiveness of coping must consider the individual's baseline level of functioning as well as the context in which coping takes place. Thus, research on the coping of women with hospitalized children could alter what is generalized about women and coping.

Uncertainty

Perceived uncertainty, a judgment about an event or situation, was identified as one of the conditions contributing to a stress response in hospitalized adult patients (Mishel, 1981). The characteristics of uncertainty, as proposed by Mishel, may reside in the nature of the stimulus, in the characteristics of the perceiver, or in an interaction between stimulus and perceiver in relation to four general classes of illness-treatment events. When an event generates uncertainty, it will be judged as containing one or more of the following characteristics: (a) ambiguity, (b) lack of clarity, (c) lack of information, or (d) unpredictability. Successful psychological management of the ill child is influenced by the effectiveness of the parents' coping with the illness events (Wolfer & Visintainer, 1975). The general assumption in the literature is that children are very sensitive to the emotions of

adults, particularly parents. When parents are able to cope with their feelings, they can serve to reassure their child. Research results indicate that mothers of hospitalized children live with considerable uncertainty. Frieberg's (1972) research indicated that uncertainty regarding procedures and treatment and lack of information was a source of maternal anxiety. In a study by Falvo, Woehlke, and Deichmann (1980) on patient compliance, the most important indication was the trend of the relationship between patient compliance and perception of the physician giving clear explanations about treatment and disease.

In a study by Barbarin and Chesler (1984) on families with childhood cancer, a stronger association between coping and the quality of relationships with medical staff was found than with any of the other psychosocial outcomes associated with uncertainty, such as information seeking and problem solving. Perceived uncertainty in parents of hospitalized children can hamper their appraisal of events and coping mechanisms (Mishel, 1983). Parents of seriously ill children may feel they have lost control of their child's care. Parental role deprivation can contribute to anxiety (Brazelton, 1976). Within the hospital setting, tests and treatments done off-schedule or tests ordered without the mother's knowledge or consent serve to enhance ambiguity.

During the past decade, there has been an increase in research in the area of families of dying children. The advances in cancer therapy, while prolonging life, have increased the uncertainty for families whether or not their child will survive (Schowalter, 1986). Cure is now spoken of in acute lymphocytic leukemia (ALL) where this was not possible before. Koocher and O'Malley (1981), in "The Damocles

Syndrome," discussed the ambiguity and uncertainty of parents and the pressures felt when a child has an illness that might or might not prove fatal. It is still difficult, if not impossible, to kill cancer cells without killing or damaging normal cells. Children treated for brain tumors, especially young children, show diminished intellectual and academic functioning (Eiser, 1981). Cranial irradiation and intrathecal chemotherapy, especially when used in combination, are particularly damaging to cognitive abilities in the treatment of ALL (Meadows & Evans, 1976). There is still considerable debate as to how much psychosocial disability accrues to children from exposure to severe, repeated, or chronic physical illness. Koocher and O'Malley (1981) indicated that more than one-half the survivors in their study show at least mild psychiatric symptom formation.

Uncertainty will continue. With cost containment becoming a major criterion for choice of treatment mode, one can assume that earlier home care will become increasingly common for financial as well as psychosocial reasons (Schowalter, 1986). Coupled with this knowledge is the tension illness adds to family dynamics. Although some couples claim that the issues around a dying child bring them together, most couples experience significantly more disharmony in their marriage as a result of the physical and psychological pressures that accrue (Koocher & O'Malley, 1981). Thus, it would appear that maternal uncertainty around hospitalized children will continue to be a problem for mothers.

To recover from the crisis presented by their child's illness, parents must be able to understand and manage the situation (Hymovich, 1976). They need to receive specific explanations of the illness,

course of the disease, prognosis, and treatments and procedures the child is receiving and also perceive, and accurately understand, the information provided (Comaroff & Maguire, 1981). Although the need to assess parents' comprehension, perception, and coping strategies has been recognized, the role of parental perceptions concerning their child's illness is sparse. To develop a theory on coping in parents of ill children, quantitative measurement tools need to be developed and significant perceptual variables influencing parents' responses need to be identified (Mishel, 1982).

Social Support

Thus far, investigators have shown that social support is an important means for helping parents cope positively with the stresses of parenting. In her study of young mothers, Colletta (1981) found that those with high levels of social support were more affectionate, closer, and more positive with their children, while those with low levels of support were more indifferent, hostile, and rejecting of their children. Although support did not have a direct effect on parenting behaviors, it did serve to mediate the effects of stress and depression. Support can be thought of as the degree to which the individual has access to social resources, in the form of relationships with others.

Cobb (1976) described social support in terms of benefits associated with feelings of being loved and valued and belonging to a network of communications and mutual obligations to others. In distinguishing quantity versus quality of social support, Schaefer, Coyne, and Lazarus (1981) suggested using the terms "social network" and

"perceived social support." Perceived support is more important than received support in predicting adjustment to stressful life events (Wethington & Kessler, 1986). A social network can be thought of as the set of relationships of one individual and defined in terms of its composition and structure (e.g., the number of people involved and the number who know each other) or by the content of particular relationships (e.g., friendship and kinship) (Schaefer et al, 1981). Perceived social support involves the individual's feelings and thoughts of how helpful the interactions or relationships are within the social network.

Although there is no general agreement on what constitutes social support, there is considerable evidence that an individual's interactions with others plays an important role in that person's response to stress. A lack of consensus continues to exist on what actually constitutes social support (Vaux, 1985). Vaux viewed social support as a metaconstruct with at least three facets: resources, behaviors, and subjective appraisals. Support resources include relationships and involvements that are potential sources of supportive behaviors and feelings that one is supported. These resources are assessed through network measures. Supportive behaviors are specific acts such as listening and comforting. Subjective appraisals involve the individual's perception of the amount and quality of support and focus on satisfaction received and perceived quality. It includes the belief that one is cared for and the availability of support. Vaux (1985) further contended that it is important to distinguish between the facets of support (resources, behaviors, and perceptions) and the modes

of support (emotional or advice/guidance) to analyze social support. Vaux concluded that even when women report more support than men, they do not necessarily report less distress. This variation in social support across gender may be a function of biological sex differences, but is more likely a function of gender differences in social roles (i.e., one gender predominates in the role). Therefore, support may have a greater impact on well being for women.

Zarski, Bubbenzer, and West (1986), in a recent review of social interest, stress, and the prediction of health status, reported conflicting research results when frequency of hassles are associated with poor overall health and number of somatic symptoms. Social interest was consistently associated with high overall health, fewer somatic symptoms, and high energy level. By using intervention strategies designed to enhance the client's social interest, the health practitioner can effect changes in the client's lifestyle.

In a study of 148 married adults, Ferrari (1986) found that parents of chronically ill children perceive a lesser amount of social support than do adults who parent healthy children. Ferrari's research explains, in part, why moderately handicapped children and families are likely to go longer before receiving intervention as social support networks frequently respond in a supportive way when they perceive a lot of support is needed.

A striking example of the mediating influence of social support on stress is associated with the nuclear power plant accident at Three Mile Island and the comprehensive study of that incident by Fleming, Baum, Gisriel, and Gatchel (1982). They conceptualized the Three Mile Island

event as stressful because the residents reported a number of stress symptoms after the accident (Flynn & Chalmer, 1980). The measure of social support used was a 6-item scale assessing an individual's perception of social support. The results indicated that three Three Mile Island groups demonstrated greater evidence of stress across psychological, behavioral, and biochemical measures than did the control groups. Also, minimal social support was associated with a greater frequency of stress-relevant problems for Three Mile Island residents, whereas Three Mile Island residents with moderate or high levels of social support reported fewer stress-relevant problems. The moderating effect of social support was not uniform across all components of the stress response, since all of the Three Mile Island residents had high catecholamine (epinephrine and norepinephrine) levels by urine test. Fleming et al. (1982) concluded that perceived support serves to facilitate coping (psychologically and behaviorally), but does not protect individuals from a greater degree of physiological arousal, as indicated by high catecholamine levels.

In examining the role of social support and its significance for mothers of hospitalized children, one has only to look at the work of Bruhn and Philips (1984) to see its relevance. Bruhn and Philips concluded the following:

1. Social support is dynamic, with its form and quantity varying over time.
2. Social support has interactive, qualitative, and quantitative dimensions that should be simultaneously addressed.
3. Perception of availability and need of support are important factors for use of such support.

4. The need for support varies across life situations and life cycle.
5. Social support is an aspect of daily living, although the need for such support may vary in times of stress.
6. Changes in physical, psychological, and social functioning can influence perception of need and availability of social support.
7. Individuals, groups, institutions, and communities must be considered, from a systems perspective, to define social support adequately.
8. Social support can exert positive and negative effects.
9. Social support can vary as a function of culture and sociocultural factors must be considered when attempting to measure it.
10. Research should focus on the mechanisms of action of social support in addition to its effects.
11. Longitudinal studies that incorporate psychosocial and biological measures on cohorts over long periods of time are needed.

In recent research, Thoits (1986) reconceptualized social support as coping assistance. If the same coping strategies used by individuals in response to stress are those that are applied to distressed persons as assistance, models of coping and support can be integrated. In problem-focused coping, one can reinterpret existing circumstances so they seem less threatening to the self or they can shift attention to comparison with others less fortunate. Thoits would argue that sympathy or empathy from similar others is a crucial condition for the seeking and acceptance of coping assistance. Because others share the same feelings, despite the social unacceptability of feelings, others are

less likely to reject the person experiencing them. Thoits proposed that individuals must perceive empathic understanding in others before coping assistance will be sought and accepted. Also, others who are socioculturally or experientially similar to a distressed individual are most likely to be perceived to be empathic.

This factor has particular relevance for the mothers of hospitalized children and suggests that mothers may be a strong resource for other mothers. Thoits's (1986) findings appear to corroborate the findings of Lehman, Ellard, and Wortman (1986). They found that the support provider is likely to be unhelpful if he or she is made to feel anxious or threatened by the plight of the support recipient. This finding is important because the social support field, until now, has not considered the impact of stressful events on anyone other than the individual experiencing those events (Heller, Swindle, & Dusenbury, 1986). Also of interest, and relevant to examining support for mothers, is the work of Coyne and DeLongis (1986) which revealed that those who most need social support may be too extended by their role overload or poverty to be able to take advantage of support when it is available.

Stress (Strain)

A general review of stress (strain) can lend insight into the impact a child's hospitalization has on mothers. Hans Selye (1956), a pioneer stress researcher, viewed stress in terms of a nonspecific, adaptive response of the body to any agent or situation. The degree of response may vary as a function of the intensity of the demand for adjustment. The same systemic reaction (general body response) can be

triggered by stress-producing agents (stressors) that are pleasant or unpleasant. The theme of general stressors, or specific situations that require some form of adjustment, were shown in the research of Holmes and Rahe (1967) and continued in the work of Pearlin and Schooler (1978) on individuals in multiple roles such as marriage partners, parents, and workers. The stress-response is a complex pattern that may have psychophysiological, behavioral, and cognitive components. Psychophysiological response according to Pearlin and Schooler is conceptualized as either a nonspecific or specific response to physical as well as to psychological stressors.

Selye (1974) maintained that the choice of which type of behaviors to observe is often complicated. Although many aspects of an individual's behavior relative to stress could be important, no comprehensive source of data has been available on the use of self-report of behavior in studying stress (Feuerstein et al., 1986). Cognitive assessment can refer to a wide variety of measures designed to measure thoughts, beliefs, attitudes, and mood. Averill (1973) placed emphasis on two components of cognitive control--information gain and anticipated response--as determining mood. When female subjects kept diaries, Eckenrode (1984) found that concurrent daily stressors and physical symptoms, in addition to previous levels of psychological well-being, were the most important direct determinants of mood. Life events and chronic stressors indirectly affected mood through the influence of daily stressors, physical symptoms, and psychological well-being.

In examining stress in mothers of hospitalized children, the search may have more meaning if stress can be associated with a theoretical

model. Reaching a generally accepted definition of stress or strain is difficult, since there are several approaches or models to understanding the concept of stress: response-based, stimulus-based, transactional, and information-processing models. In order to understand mothers of hospitalized children, it is useful to examine the interactional model of stress for its proponents maintain that stress occurs through a particular relationship between the person and the environment.

One version of the interactional model is the transactional model of stress as proposed by Lazarus and Folkman (1984). They proposed a cognitive theory of psychological stress, although stress is usually defined as either stimulus or response. Lazarus and Folkman emphasized stress as a relationship between the characteristics of the person, on the one hand, and the nature of the environmental event on the other. The individual is thought of as an active agent in the stress process, and it is postulated that self-management of cognitive, behavioral, and emotional coping strategies influence the impact of the stressor. Lazarus and Folkman have identified three kinds of cognitive appraisal: primary, secondary, and reappraisal. Primary appraisal determines whether an event is irrelevant or stressful and the extent of the demand on the person. Secondary appraisal is a judgment concerning what might and can be done with available resources and reappraisal refers to a changed appraisal based on new information from the person or the environment. How the person responds to stress is thought to have short-term and long-term consequences in terms of social and moral functioning as well as somatic health. The interactional model allows for individual differences and helps explain why all people under stress do not experience ill effects.

Cox (1980) proposed models that focus on the transactional and ecological nature of stress as well as the importance of the individual's cognitive and psychological sets in evaluating the stressors. The Cox model also specifies the existence of feedback components, therefore, describing a cyclical rather than a linear system. The model has five discernible stages. In the first stage Cox identifies the existence of demands or stressors placed on the individual, such as a family member who constantly requires one's involvement. The second consists of a person's perception of internal and external demands and of the ability required to meet the demands, such as a mother wanting to be with her hospitalized child when her employer is threatening to dismiss her. Stress occurs when an imbalance between perceived demand and perceived coping ability exists. Such variables as personality, ego strength, and intelligence account for individual variations in the cognitive appraisal of stress. The third stage of the model represents the stress response, which is a method of coping with multiple stressors, such as when a mother of a hospitalized child wants or needs to work, but chooses to give up her job to be with her child while self-medicating to stop migraine headaches. The subjective emotional experience of stress is accompanied by cognitive, behavioral, and physiological changes. The fourth stage is concerned with both the actual and perceived consequences of the coping responses, such as when the mother realizes that, regardless of what she does, she will soon be both jobless and childless. Stress may continue when demands are not met or negative consequences from failure are anticipated. The fifth stage consists of the feedback that occurs throughout the system and may

shape events at any point in the system, such as when the mother acknowledges to herself that her child probably will die, but that she must go on living for the rest of her family. Feedback of appropriate responses can enhance the individual's ability to adapt. Feedback of inappropriate responses may intensify the stress response and cause greater damage or may alert the individual to change a response, if possible, or to seek intervention (Feuerstein et al., 1986).

Figley & McCubbin (1983), in their extensive review on the family coping with catastrophe, reported on the results of McCubbin's study of 500 families with a child with chronic illness. This investigator identified three coping patterns that parents use to manage life when a child has a chronic illness: (a) maintaining an optimistic outlook, (b) maintaining social support and self-esteem, and (c) understanding the medical situation through communication with other parents and consultation with the medical staff.

Counseling Interventions

A search of the relevant literature reveals little information on interventions in use to decrease the uncertainty, decrease the stress (strain), and increase the social support of parents of hospitalized children. Many of the counseling and information-giving methodologies surrounding a child's hospitalization have centered around prehospitalization tours, hospital-oriented play, play therapy, interviews, and support groups intended to lower stress for parents and children, but few have been scientifically evaluated (Azarnoff et al., 1975; Peterson & Shigetomi, 1982; Schmeltz & White, 1982; Thompson,

1985). Modeling films of children talking about their concerns facing surgery have been evaluated and are in use at some hospitals (Melamed, Dearborn, & Small, 1981; Melamed, Robbins, Small, Fernandez, & Graves, 1980; Vernon et al., 1965). These films, using real patients as actors to insure cultural authenticity, are intended for children and parents. They verbalize the feelings of children before surgery and desensitize the family to the surgical procedure by taking a filmed tour for the child through the preoperation procedures, the operating room up to the point of the administration of anesthesia, and through a successful postsurgical course (Small, 1980). Although little validated information on interventions for mothers exist, from a study of pediatric hospitalization and health care, Thompson (1986) concluded that the likelihood of parents obtaining a maximum amount of information or otherwise actively participating in their child's hospitalization, is dependent on family demands and social characteristics, as well as personal qualities of the parents. The cost of transportation and other cultural and economic factors, rather than fewer coping skills, are just as apt to be the reasons parents from lower social classes participate less in their children's hospitalization than do parents in other social classes (Earthrowl & Stacey, 1977).

In light of some of the research being done on the cost-effective use of booklets for patient education, booklets might be considered as a mode of intervention for enhancing the coping of mothers of hospitalized children. A concerted effort for use of booklets as an intervention strategy for enhancing the coping of patients, as part of an educational, developmental approach to common problems has been

developed in the Netherlands for patient education (Visser, 1980). Of particular interest is the fact that these booklets have been evaluated for their effectiveness. Designed with specific goals and information on a limited, structured amount of information, booklets were found to be appreciated and read by most of the patients and the information given was absorbed. Allen and Sipich (1987) have reported on a process by which a university counseling center used and evaluated self-management brochures that received a positive response. The researchers found that one limitation to the use of self-management brochures was that users may expect the brochures to present magical solutions to complex problems. Self-management booklets may be more effective than one-on-one contact with patients, they may be more cost-effective, and considering shortened lengths of stay under prospective pricing systems, they may have a particular appeal. Pardeck and Pardeck (1984), in their research, found that bibliotherapy is effective in treating sexual dysfunction, in increasing assertiveness, promoting attitudinal and behavioral change, and in fostering self-development.

Ronald McDonald Houses as Therapeutic Milieus

A recent advancement that has appeared on the American medical scene to provide a therapeutic milieu for families with a hospitalized child is the concept of the Ronald McDonald House. In 1969, when Fred Hill of the Philadelphia Eagles football team had a 3-year-old daughter with acute lymphatic leukemia, the Hills slept in waiting rooms and ate out of vending machines during the frequent hospitalization of their

child. From this experience, Hill realized the need for a home where parents could go to get away from the hospital for a time, to cook, do laundry, and to talk to other parents. In essence, what was needed was a homelike therapeutic milieu during the traumatic days of the hospitalization of a child. Hill, with the support of his fellow Eagles, raised funds for a house to be purchased for the families of children who were hospitalized. When local McDonald owners and operators became involved, the first Ronald McDonald House became a reality in 1972 (Small, 1985b).

In Gainesville, Florida, families referred to Shands Hospital from throughout the United States were sleeping in waiting rooms and eating out of vending machines. A feasibility study and a pledge of seed money by the McDonald Corporation encouraged a group of local citizens to form a not-for-profit corporation to build a Ronald McDonald House (Small, 1985b).

In 1982, the 37th Ronald McDonald House opened in Gainesville, with an expansion to the house added 2 years later, making a nightly refuge for 28 families. Ronald McDonald Houses are mostly occupied by parents, grandparents, and siblings visiting the hospitalized child. However, children undergoing treatment, such as chemotherapy, may stay in the houses while receiving daily treatments at the hospital. Ronald McDonald Houses provide facilities where families, disrupted by illness, can be reunited in an effort to bring order into their lives. The house provides each family with a bedroom, with beds for a maximum of two adults and two children, and a private bath. Guests are provided with linens when they arrive and use the laundry facilities to return clean linens when they check out of the house. Meals can be prepared in the

fully equipped kitchens where a selection of food is available, at no cost, to families who cannot provide their own food. An optional donation of \$10 a night per family is requested to help meet the operating expenses of the house (Small, 1985b).

Although each of the 100 Ronald McDonald Houses is operated by a board of managers and has a house manager to oversee the functioning of the house, these therapeutic settings, founded through corporate initiative and maintained by corporate and local efforts, have no equivalent in America today (Jones, 1986). The homes are currently hospices for families in the United States, Germany, the Netherlands, and Australia. However, the purpose for their existence is the same. The houses are a home-away-from-home for families with a hospitalized child and families perceive them as a source of support during a time of family crisis (Jones, 1986). In a pleasant, homelike atmosphere, families get to know other families with whom they have one thing in common--concern for a sick child.

Therapeutic milieus are playing an increasingly important role in the growth of 20th century pediatrics (Brodie, 1986). Since 1979, there has been a sharp break in the pattern of government support for the nation's children and elderly. Programs that aid children have suffered drastic curtailment while those that support the elderly have risen significantly. The 1983 federal benefits were estimated to be at \$7,700 per person over 65 years and \$770 for children. The government has left to the family, regardless of its circumstances, the responsibility for children. Advances in child health occur only when people dedicate themselves to the task of protecting and providing for their future.

Reports on the future of American medicine indicate that by the start of the next century hospitalizations will be limited to the very ill and those with chronic illness (Starr, 1982). Much of the care currently provided in the hospital will be relegated to ambulatory settings (DeAngelis, 1986). The conflict between wanting to room-in, or even to visit their child, and not being able to do so for economic reasons, may increase anxiety levels of parents. Even when vast resources exist to help parents with children at time of family crisis, the nature of bureaucratic protocol necessitates manipulation to maximize efficiency. Advanced technology will increase the lifespan of many children, but will necessitate mothers spending time at the hospital to become educated and more knowledgeable about care of their sick child. In preparation for these trends for the future of pediatric medicine, researchers are already advocating that health care providers need to reach beyond the hospital to intensify efforts in urging families to use community and social services, such as Ronald McDonald Houses, as an intrinsic part of the family support system (Alexander et al., 1986).

Summary

The results of published studies confirm that the hospitalization of a child is a traumatic event for a mother and can often precipitate a situational crisis for the whole family. An examination of the coping strategies of mothers revealed that decreased uncertainty about their child's illness, decreased stress, and increased social support can assist mothers in coping with their child's hospitalization. There was

some indication that a booklet could be effective in providing information and counseling in a convenient, low-cost manner. Since 1972, 100 Ronald McDonald Houses have been established to provide therapeutic milieus for mothers of hospitalized children. The work of this researcher was the first attempt at a self-management booklet to enhance the effect of the Ronald McDonald House for mothers.

CHAPTER III METHODOLOGY

This study was designed to determine whether a self-management booklet introduced to mothers at the Gainesville Ronald McDonald House could help them cope with having a hospitalized child. Of interest was the immediate impact of the booklet on four dimensions of the stress process that affect mothers of seriously or terminally ill children: uncertainty about their child's illness, perception of social support from family, social support from friends, and stress (strain). Described in this chapter is the design of the study, the population and sample, procedures, treatment, instruments, research hypotheses, and data analyses of the study.

Design of the Study

A pretest-posttest design (Ary, Jacobs, & Razavieh, 1979), as illustrated in Figure 3-1, was used in this study. The first 30 mothers, meeting the sampling criteria, who registered at the Ronald McDonald House, formed the control group. After all of these mothers completed the study, the next 30 mothers who registered and met the sampling criteria received the treatment. This quasi-experimental design was utilized because of the potential problem of contamination if a random sample of only some of the mothers in the residential facility

(30C)	01 02 03 04	Tc	01 02 03 04
(30E)	01 02 03 04	T1	01 02 03 04

30C = 30 control subjects

30E = 30 experimental subjects

01 = Uncertainty in Illness Scale--Parent/Child Form

02 = Perceived Social Support from Friends Scale

03 = Perceived Social Support from Family Scale

04 = The Strain Questionnaire

TC = Control, Ronald McDonald House only

T1 = Receive the self-management booklet Mothers Know Best while at
Ronald McDonald House

Figure 3-1. Experimental design for study

were receiving the treatment. The temptation to share the treatment with a nontreatment mother would be great. This design separated the treatment and control groups, preventing contamination.

Population and Sample

The population studied were mothers who stayed at a residential facility--the Gainesville, Florida, Ronald McDonald House--a "home-away-from-home" for families with hospitalized children. This population consisted of mothers who were under stress, due to the nature of their child's illness, the separation anxiety of being away from home, and anxiety at not being able to spend nights at the child's bedside. The population sample consisted of English-speaking mothers, with a minimum ninth-grade education, staying at the Gainesville, Florida, Ronald McDonald House for a minimum of 7 days. The children of these women were being treated at Shands Hospital, a tertiary care center at the University of Florida. This population closely resembled the characteristics of 340 parents who stayed at the Ronald McDonald House and who completed and returned surveys in 1985 for an earlier pilot study (Small, 1985b). The survey was conducted by this researcher in her capacity as a doctoral student in counselor education, as a licensed mental health counselor in the pediatric division of the Department of Social Work Services of Shands Hospital, as a member of the Ronald McDonald House Board of Directors (fund-raising, decorating, and operations committees), and as the pediatric liaison between Shands Hospital and the Ronald McDonald House.

The pilot study (Small, 1985b) had revealed a number of issues relevant for producing and evaluating an intervention for decreasing

stress in mothers. Mothers usually stay at Ronald McDonald Houses because they live too far from the hospital to commute daily and because they cannot spend the night with their child in a restricted or isolated unit such as the newborn intensive care unit, the burn unit, the pediatric intensive care unit, or the bone marrow transplant unit.

Presented in Table A-1 (Appendix A) are the characteristics of the residents of the Ronald McDonald House and their responses to the 1985 survey items. Of particular interest, relevant to social support at the Ronald McDonald House, was the fact that up to 2 years after leaving the Ronald McDonald House, parents reported maintaining a contact made while at the House. Also, 21% of the respondents reported that they perceived another parent as the person they would go to at the Ronald McDonald House if they had a personal problem.

A review by the researcher of recent Ronald McDonald House statistics revealed that as of February, 1987, the average stay was 6.1 days. Although children are going home from the hospital "sicker and quicker" due to cost containment, use of sophisticated medical procedures, such as bone marrow transplants, mean extended stays at the Ronald McDonald House for some families.

All possible participants for the current study were identified through the Shands Hospital admissions office, where mothers register to stay at the Ronald McDonald House on a first-come, first-served basis. Mothers at the Ronald McDonald House are anxious to be with their children as much as possible. Therefore, for the mother's convenience, data were collected at the hospital.

The sensitive nature of this research (mothers with seriously or terminally ill children in very restricted areas of the hospital)

necessitated this study being carried out alone by the researcher who has a counseling background, has a knowledge of hospital protocol and infection control techniques, and has access to Ronald McDonald House mothers. None of the subjects had met the researcher before being asked to participate in the study. The data collection period to obtain 60 subjects (30 control and 30 experimental) was from February 24, 1987 to June 7, 1987.

Although the nature of the study prevented random selection of subjects, there were close similarities between the control and treatment groups in terms of demographic variables. The mothers ranged in age from 19-52 years with the control group mothers having a mean of 31.60 years of age and the treatment group 29.80. Although the mothers' range of years of education was 9 to 17 years, the mean years of education was 13.30 in the control group and 12.7 in the treatment group. Mothers in the control group came a mean of 197.60 miles from home and in the treatment group 177.60 miles from home. The mean age of the sick child in the control group was 6.50 years and in the treatment group was 5.20 years. The children of mothers in the control group had a mean of 1.36 siblings and in the treatment group a mean of 1.03 siblings. The summary statistics of the variables are located in Table 3-1.

Procedures

Control Group

Within approximately 48 hours of registering at the Ronald McDonald House, 30 eligible mothers were approached at the child's bedside by the

Table 3-1
Summary Statistics of the Mothers' Characteristics

Variable	Total (n = 59)	Control (n = 30)	Treatment (n = 29)*
Race			
Black	8	5	3
White	51	25	26
Marital Status			
Married	50	25	25
Divorced	1	1	0
Single	6	3	3
Separated	2	1	1
At RMH Before	15	7	8
Deaths During Study	2	1	1
Adopted Children	3	1	2
Transferred from Other Hospitals	9	4	5
Reason for Current Hospitalization			
Medical	27	14	13
Surgical	24	12	12
Diagnostic	8	4	4
Child's Diagnosis			
Malignant tumor	14	9	5
Nonmalignant tumor	2	1	1
Lymphatic cancer	4	2	2
Cystic fibrosis	5	4	1
Neurological disorder	6	3	3
Cardiac malformation	16	9	7
Gastrointestinal abnormality	3	0	3
Respiratory abnormality	5	1	4
Another diagnosis/burns, spinal cord injuries	4	1	3

*One mother failed to provide data.

researcher and asked to participate in this study. The first 30 mothers who agreed to participate formed the control group. After verbal consent was received from each mother, demographic information "A" (Appendix B) was collected and each mother received a coded packet of four questionnaires printed on machine-read forms. Although instructions were printed on the instrument form, instructions were reviewed with each subject and assistance was given, when necessary, in filling out forms. This was done to facilitate the procedural aspect of the study and to determine literacy of mothers. The forms were (a) the Uncertainty in Illness Scale--Parent/Child Form, (b) the Social Support from Friends Scale, (c) the Social Support from Family Scale, and (d) the Strain Questionnaire. All subjects were advised that information would be kept confidential and that the researcher would be the only person to have access to identifying information.

The 30 control group mothers had private rooms in the Ronald McDonald House and spent their days at Shands Hospital with their sick children who were receiving appropriate patient services. Seven days after registering at the Ronald McDonald House, mothers received a second set of the questionnaires which were administered in the same manner as the first set. Demographic information "B" (Appendix B) was also collected at this time. Due to the vulnerability of mothers undergoing life-threatening experiences with their children, the researcher followed the administration of the posttest questionnaires by counseling the subjects on any topics of particular concern to them.

Experimental Group

When all the data had been collected from the control group, 30 eligible mothers were obtained in the same manner for the experimental group. The final treatment group sample consisted of 29 mothers as number 30 did not complete the study when her child was discharged prior to the seventh day. Demographic data "A" were gathered and coded packets of the four questionnaires were administered to the mothers.

Mothers in the experimental group were given a copy of a self-management booklet Mothers Know Best (advice from mothers who have stayed at the Ronald McDonald House) and asked to read the suggestions and to follow them. To assure that mothers read the booklet, they were asked to write responses to the booklet's suggestions in designated places in the booklet itself (Anthony & Carkhuff, 1976). The mothers in the experimental group also had private rooms at the Ronald McDonald House and spent their days with their children at Shands Hospital. Seven days after administration of the questionnaires and receiving the booklet, a second set of the questionnaires were completed by the subjects and returned to the researcher. At the time the questionnaires were completed and returned to the researcher, demographic information "B" was gathered and the booklet was collected. As with the control group, if desired, subjects received counseling on particular concerns at this time. The booklet was then checked to see if the subject had written in the booklet as directed. The number of entries the mother addressed concerning uncertainty about the child's illness, social support, and stress were recorded. The booklet was then photocopied and the original returned to the subject to keep.

The University of Florida Health Center Institutional Review Board determined that it was not necessary to obtain informed consent from the subjects for this study as they viewed willingness to participate as implied consent. Mothers were assured that participation was confidential, and voluntary, and was not a patient charge. This project received the approval of Hon. Maurice Giunta, President, Friends of Ronald McDonald House, Inc.; Dr. Ian Burr, Chairman, Department of Pediatrics, University of Florida College of Medicine; Jodi Mansfield, Shands Hospital Vice-President of Operations; Jerald Mitchell, Shands Hospital Director of Ancillary Services; and Susan Fort, Director, Shands Hospital Department of Social Work Services. One hundred fifty children's physicians at Shands Hospital were also notified of the project.

Treatment Variables and Instruments

This study had one independent treatment variable with two levels: (a) control which involved no treatment and (b) experimental which was the self-management booklet. The treatment consisted of receiving and using Mothers Know Best, a self-management booklet, for 7 days. The booklet was designed to help mothers cope by structuring their current coping strategies. The booklet guided mothers to organize and ask the questions they had about their child's illness (increase information), to take actions to preserve their own well-being (preserve health), and to take the initiative to meet other parents at the Ronald McDonald House (increase social support).

A booklet format was chosen as the form of intervention because of the convenience of use, its cost-effectiveness, and its potential to be

disseminated and used in the other Ronald McDonald Houses. The booklet distributed to the experimental group was written by the present investigator as part of this doctoral research project. It incorporated 10 years of counseling experience with the population being studied and 7 years of association with Ronald McDonald Houses in several major capacities. The booklet was based on the observation that even highly educated mothers report that they often become disorganized, isolated, and stressed when their child is seriously ill. The booklet was designed to be a structured, self-directed process that assists mothers in organizing coping efforts.

The reading level of the booklet is approximately seventh to eighth grade as assigned by the McLaughlin SMOG Vocabulary Test which predicts grade level difficulty of a passage within 1.5 grades in 68% of the passages tested (Doak, Doak, & Root, 1985). According to Pichert and Elam (1985), the SMOG formula is as good as any, and was recommended by the U.S. Department of Health and Human Services for their 1981 book on communication with cancer patients. Although the Ronald McDonald House intervention booklet was intended for women with a minimum of a ninth-grade education, the reading level was maintained at an approximate seventh- to eighth-grade level as a result of the Norfolk study of 100 samples of patient education materials wherein even patients who stated they were high school graduates had, on the average, a seventh-grade word recognition level (Doak et al., 1985).

After initial development, the first form of the booklet was rated by a panel of seven experts for appropriateness of format, vocabulary level, clarity of presentation of ideas, overall design, accuracy of

information presented, and value as a teaching tool for stressed mothers. The panel consisted of a Ronald McDonald House coordinator, a professor of counselor education, a professor of clinical psychology, a pediatric intensive care social worker closely involved with the parents at the Ronald McDonald House, a pediatrician, a graduate student in media, and a doctoral-level professional in media production. Raters were asked to rate each aspect (format, vocabulary, ideas, design, accuracy, and value) on a 5-point Likert scale (excellent = 5 to poor = 1). The overall mean score for the booklet was 4.1. The booklet was then piloted with 15 mothers of hospitalized children and given a good to excellent rating. The final form was then constructed using suggestions of the panel of experts and mothers (Appendix C).

Dependent Variables

There were four dependent variables in this study thought to mediate coping: (a) uncertainty about the child's illness, (b) social support from family, (c) social support from friends, and (d) stress (strain). In this study the term stress (strain) was used to discuss the concept of stress. To measure these variables, the subjects were asked, within approximately 48 hours of admission to the Ronald McDonald House and again 7 days later, to answer a total of 119 items on four questionnaires which covered uncertainty about the child's illness, strain, and social support from family and friends. The questionnaires assessing uncertainty, social support from family and friends, and stress (strain) were all used with the permission of their authors.

Uncertainty

The Parent-Child Uncertainty in Illness Scale (PCUS) (Mishe1, 1982) was used to measure parents' perceptions of uncertainty concerning their hospitalized child. This instrument is also called the Parents' Perception of Uncertainty Scale, but is referred to as the PCUS in this study. The PCUS is a 31-item, self-report, paper-and-pencil test in which uncertainty is conceptualized as a syndrome of ambiguity, lack of clarity, lack of information, and unpredictability. Perceived uncertainty, a judgment about an event or situation, was identified as one of the conditions contributing to a stress response in adult patients (Mishe1, 1981). The PCUS was developed by Mishe1 to measure this perceptual variable believed to influence parents' responses to their child's illness and hospitalization.

The PCUS is composed of four subscales (ambiguity, lack of clarity, lack of information, and unpredictability) plus the total score for the scale. Respondents are asked to mark items regarding how they are feeling about their child today, on a 5-point Likert scale of agreement from strongly agree to strongly disagree. Responses are assigned numerical equivalents (1-5) and summed to obtain a total score. Scores on four subscales are derived from answers to four subsets of questions. Thirteen questions address ambiguity, such as "It is difficult to know if the treatments or medications my child is getting are helping" and "It is vague to me how I will manage the care of my child after he/she leaves the hospital." Nine questions cover lack of clarity, such as "The explanations they give about my child seem hazy" and "The doctors and nurses use everyday language so I can understand what they are

saying." Five questions cover lack of information, such as "I don't know what is wrong with my child" and "My child's treatment is too complex to figure out." Unpredictability is obtained by adding the scores on subjects' responses to four items such as "I usually know if my child will have a good or bad day" and "My child's physical distress is predictable. I know when it is going to get better or worse."

To assess parents' perception of uncertainty, Mishel (1983) adapted the Mishel Uncertainty in Illness Scale (MUIS) and administered it to 272 parents of hospitalized children. A large number ($n = 218$) were mothers, probably because data collection occurred during the afternoon hours. All parents were high school graduates. Following item analysis, the data were subject to factor analysis. For the total scale, the standardized alpha was .91. Ambiguity had an alpha of .87, lack of clarity had an alpha of .81, lack of information had an alpha of .73, and unpredictability had a standardized alpha of .72. The reliability of the scale was determined using four estimates of internal consistency: coefficient alpha, coefficient theta, item subscale, and subscale-subscale correlations. As this was a new scale, the criterion level used for coefficient alpha was .70 or above. Coefficient theta was also used as a reliability estimate because theta provides reliability coefficients based on factor analysis with the potential for overcoming the limitations associated with alpha reliability. The overall findings concerning reliability indicate that the subscales are internally consistent. Although this was a relatively new tool, the initial findings indicated that this tool provided a means for evaluating the perception of uncertainty in one person concerning a significant other.

Social Support

The Perceived Social Support from Family (PSS-Fa) and Perceived Support from Friends (PSS-Fr) scales, by Procidano and Heller (1983), were used as measures of social support. Perceived social support refers to the impact networks have on the individual and can be defined as the extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled (Procidano & Heller, 1983). Each 20-item scale in the PSS-Fa and the PSS-Fr consists of statements to which the individual answers "yes," "no," or "don't know." The response indicative of perceived support is a +1. The scores are the sum of the responses and range from 1-20. "I rely on my family for emotional support" and "My friends are good at helping me solve problems" are examples from the scales. Measures of perceived social support from family (PSS-Fa) and from friends (PSS-Fr) were developed and validated using a population of over 200 students. The PSS-Fr and PSS-Fa proved to be homogeneous measures with Cronbach's alpha coefficients of .88 and .90. Construct validity was shown using the same sample and the authors report that both PSS-Fa and PSS-Fr were negatively related to symptoms as measured by the Langner screening instrument. The PSS-Fr was positively related to social assets as measured by the California Psychological Inventory and the Dating and Assertion Questionnaire. The PSS-Fr was found to be negatively related to psychopathology as measured by the psychasthenia and schizophrenia scales of the short form Minnesota Multiphasic Personality Inventory (MMPI), while the PSS-Fa was negatively related to depression, psychasthenia, and schizophrenia scales (Procidano & Heller, 1983).

Stress (Strain)

Stress was measured by use of the Strain Questionnaire (SQ) (Lefebvre & Sandford, 1985). The development of the SQ was guided by the conceptualization of stress (strain) as a syndrome of physical, behavioral, and cognitive symptoms that are elicited, to varying degrees, by environmental demands upon the individual. The stress syndrome is relatively independent of concomitant emotional states (e.g., anxiety, depression), and is not severe or chronic enough to have resulted in clinical diagnosis. The respondent for this 48-item, self-report, paper-and-pencil test is asked to rate how many times in the last week they experienced each of the 48 physical, cognitive, and behavioral symptoms on a frequency scale of never to every day. Responses are assigned numerical values of 1-5 and are summed for each of the three subscales and then totaled for an overall strain score. The higher the score, the greater the level of strain.

Physical signs of strain, such as pain in heart or chest and headaches, are addressed by 28 questions. Behavioral symptoms, such as impulsive behavior and inability to sit still, are covered by 12 questions. Cognitive symptoms, such as believing the world is against you and feeling out of control, are assessed by 8 questions. Lefebvre and Sandford (1985) have reported initial reliability and validity studies on the SQ based on a total of 412 subjects including undergraduate and graduate students, teachers, engineers, and insurance agents of both sexes. Alpha coefficients were reported to be .71 for the behavioral subscale, .86 for the the cognitive subscale, and .92 for the physical subscale. The full scale had an alpha coefficient of .94.

Reliability tests included internal consistency and test-retest over a period of 1 month. Test-retest reliabilities were .73 for the cognitive subscale, .75 for the physical subscale, and .77 for the behavioral subscale.

Using a sample of 48 business students, Lefebvre and Sandford (1985) established concurrent validity. Correlations between the SQ, its three subscales, and the Beck Depression Inventory (BDI) were significant ranging from .63 to .78. These data indicate a moderate degree of shared variance by the two instruments which is primarily attributable to the overlap of cognitive symptoms. Discriminant validity was determined by comparing subgroups of the sample who were under stress with subgroups who were not when they completed the SQ. The nonstressed group scored significantly lower than the other subgroups for the SQ and the cognitive and behavioral subscales. On the physical subscale, one of the stressed groups and the nonstressed group scored lower than the other three stressed groups. Behavioral subscale items present the most inconsistent findings of these studies, as behaviors such as prescription drug use may be due to the presence of a chronic medical condition rather than a result of stress. While it was being researched, the SQ was one of the few brief, self-report instruments available to measure stress which had empirical evidence of being reliable and valid. Lefebvre and Sandford encourage the use of the SQ in clinical settings to identify specific stress symptoms and suggest intervention strategies.

Research Hypotheses

The researcher posed the following null hypotheses:

1. There is no significant difference in levels of uncertainty, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.
2. There is no significant difference in levels of social support from family, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.
3. There is no significant difference in levels of social support from friends, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.
4. There is no significant difference in levels of stress (strain), after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.

Data Analyses

Descriptive statistics were used to describe the sample on each of the demographic variables. All four research questions and hypotheses were answered utilizing an analysis of covariance. The pretest scores on each dependent measure were utilized as a covariate in order to adjust the posttest scores for any variation between the two groups prior to treatment. The adjusted posttest scores for the experimental group were then compared with the scores of the control group to determine if they were significantly different ($p < .05$). In all cases the analysis of covariance model was shown to be significant ($p < .0001$) and the linear relationship between the pretest and posttest scores was

also shown to be significant ($p < .0001$). A t test was utilized for comparison of the two groups.

CHAPTER IV RESULTS

The purpose of this study was to explore the effect of a self-management intervention on levels of uncertainty, perceived social support, and stress in mothers of hospitalized children while the mothers were registered at the Gainesville, Florida, Ronald McDonald House. The research sample, the results of the analysis of covariance used to test the hypotheses that the intervention booklet will lower uncertainty and stress and increase social support from family and friends, and a summary of the results are described in this chapter.

Description of the Sample

Every eligible parent approached for this study agreed to participate and 15,307 items of information were collected from 59 mothers. Summarized in Table 4-1 are the means, standard deviations, and ranges of scores on the four dependent variables for the total sample.

From pretest to posttest (1 week) the mean scores for the total sample decreased for uncertainty from 87.66 to 84.49 and decreased for strain from 91.24 to 84.71. In contrast, mean social support from family and social support from friends increased during that same period from 14.71 to 14.88 and 13.80 to 14.36, respectively. None of these changes were statistically significant.

Table 4-1
 Pretest and Posttest Means, Standard Deviations, and
 Ranges of Scores for Dependent Variables
 for Total Population

Variable	Mean	SD	Range
Uncertainty			
Pretest	87.66	15.33	86.00
Posttest	84.49	14.89	74.00
Social Support, Family			
Pretest	14.71	5.30	19.00
Posttest	14.88	5.89	20.00
Social Support, Friends			
Pretest	13.80	4.94	19.00
Posttest	14.36	5.16	18.00
Stress			
Pretest	91.24	27.57	110.00
Posttest	84.71	28.51	103.00

Testing the Null Hypothesis

In this study four null hypotheses were proposed which examined the effects of a self-management intervention on (a) uncertainty, (b) social support from family, (c) social support from friends, and (d) strain of mothers of hospitalized children. An analysis of covariance was used to compare the adjusted posttest means of the control and treatment groups for the four dependent variables and their subscales (Huck, 1974).

Uncertainty

Hypothesis 1--There is no significant difference in levels of uncertainty, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.

To test the effect of the intervention booklet Mothers Know Best on uncertainty, an analysis of covariance was performed on the dependent variable uncertainty, using the pretest of uncertainty as a covariate. The means and standard deviations of each group's uncertainty scores are shown in Table 4-2. The source table of this analysis of uncertainty, and of separate analyses for each subscale (ambiguity, lack of clarity, lack of information, and unpredictability), are presented in Table 4-3.

For the total scale of uncertainty, the analysis of covariance was performed with an obtained $F = 5.68$. and $p = .0205$. Since the F ratio of 5.68 for uncertainty was significant at the .05 level, this null hypothesis could be rejected. For the uncertainty subscale of ambiguity, the analysis of covariance was performed with an obtained $F = 6.46$ and a $p < .0001$. The F ratio of 6.46 was significant. For the other three subscales, however--lack of clarity, lack of information,

Table 4-2
 Pretest and Posttest Means and Standard Deviations for
 Total Scores and Subscales of Uncertainty

Variable	Control		Treatment	
	Mean	SD	Mean	SD
Uncertainty Total				
Pretest	85.43	16.50	89.97	13.95
Posttest	85.60	15.53	83.34	14.38
Ambiguity Subscore				
Pretest	37.73	8.92	39.45	7.40
Posttest	37.63	9.15	35.31	7.15
Clarity Subscore				
Pretest	23.30	5.15	24.31	3.91
Posttest	23.93	4.85	23.45	4.15
Information Subscore				
Pretest	11.10	3.10	12.79	3.70
Posttest	10.83	2.48	12.03	3.52
Unpredictability Subscore				
Pretest	13.30	2.93	13.41	2.64
Posttest	13.20	2.76	12.55	3.11

Table 4-3
Source Table for Analysis of Covariance of Uncertainty

Source	<u>df</u>	<u>MS</u>	<u>F</u>	<u>p</u>
Group - Uncertainty	1	480.98	5.68	.0205
Within	56	84.61		
Total	58			
Group - Ambiguity	1	191.24	6.46	.0001
Within	56	29.64		
Total	58			
Group - Clarity	1	17.73	1.39	.2433
Within	56	12.75		
Total	58			
Group - Information	1	.012	.00	.9547
Within	56	3.72		
Total	58			
Group - Unpredictability	1	7.80	1.58	.2143
Within	56	4.94		
Total	58			

and unpredictability--the F ratio was not significant. Inspection of the means revealed that the treatment group had significantly lower levels of uncertainty and ambiguity than the control group after using the booklet Mothers Know Best.

Social Support from Family

Hypothesis 2--There is no significant difference in levels of social support from family, after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.

The hypothesis pertaining to social support from family was also tested using an analysis of covariance, with the pretest scores on perceived support as the covariate. The mean levels of the perceived social support from family are listed in Table 4-4 and the source table of this analysis is located in Table 4-5.

The analysis of covariance was performed with an obtained $F = .00012$ and a $p < .9913$. Since the F ratio of $.00012$ was not significant at the $.05$ level, there was not a significant difference between the control and treatment groups, and this null hypothesis could not be rejected.

In summary, the analysis of covariance indicated that social support from family did not change significantly with the treatment.

Social Support from Friends

Hypothesis 3--There is no significant difference in levels of social support from friends, after a 7-day stay, between mothers at the

Table 4-4
 Pretest and Posttest Means and Standard Deviations for Scores
 on Social Support from Family and Social Support from Friends

Variable	Control		Treatment	
	Mean	SD	Mean	SD
Social Support, Family				
Pretest	14.77	5.24	14.66	5.47
Posttest	14.93	5.74	14.83	6.14
Social Support, Friends				
Pretest	13.57	5.05	14.03	4.91
Posttest	13.20	5.44	15.55	4.64

Table 4-5
 Source Table for Analysis of Covariance of Social Support
 from Family and Social Support from Friends

Source	df	MS	F	p
Social Support - Family				
Group - Social Support, Fa	1	.0007	.00012	.9913
Within	56	6.07		
Total	58			
Social Support - Friends				
Group - Social Support, Fr	1	60.44	4.34	.0418
Within	56	13.93		
Total	58			

Ronald McDonald House who receive a self-management booklet and those who do not.

The hypothesis pertaining to social support from friends was also tested using an analysis of covariance with the pretest scores on perceived support as the covariate. The adjusted means of each group's perceived level of social support from friends is listed in Table 4-4. The source table of this analysis is located in Table 4-5.

Examination of the means shows that perception of social support from friends increased for the treatment group while the control group level decreased slightly. The analysis of covariance was performed with an F value = 4.34 and a p value = .0418. The F value of 4.34 was significant at the .05 level. Therefore, this null hypothesis could be rejected.

In summary, the analysis of covariance and an examination of the means indicated that the treatment, the Mothers Know Best booklet, had a beneficial effect on mothers' levels of perceived support from friends.

Stress (Strain)

Hypothesis 4--There is no significant difference in levels of stress (strain), after a 7-day stay, between mothers at the Ronald McDonald House who receive a self-management booklet and those who do not.

To test the effect of the intervention booklet Mothers Know Best on strain, an analysis of covariance was performed on the dependent variable, strain, using the pretest of strain as a covariate. The means of the strain scores are shown in Table 4-6. Results of this analysis

of strain, and its subscales of physical, behavioral, and cognitive components of strain are presented in Table 4-7.

The computed F value for effect due to strain was .01 with a p value of .9334. The physical, behavioral, and cognitive subscales did not have significant F ratios. Since the F values were not significant at the .05 level, Hypothesis 4 could not be rejected.

Thus, analysis of covariance for stress indicated that posttest levels of stress (strain) were not significantly different for the treatment and control groups.

Summary

To summarize, four hypotheses that were tested using an analysis of covariance for each of the four dependent variables investigated in this study were discussed in this chapter. Significant differences between treatment and control group on adjusted posttest means for both uncertainty and social support from friends were found, with the levels of uncertainty significantly lower and the level of social support from friends significantly higher for the treatment group. Scores on social support from family and stress (strain) scores were not significantly different for the two groups. Within the construct of uncertainty, scores on the subscale ambiguity were also significantly lower for the treatment group. Thus, the self-management intervention Mothers Know Best did have a beneficial effect on mothers in the treatment group on the dimensions of uncertainty and social support from friends, but did not have a significant effect on social support from family or on stress (strain).

Table 4-6
 Pretest and Posttest Means and Standard Deviations for
 Scores on Stress (Strain) Measures

Variable	Control		Treatment	
	Mean	SD	Mean	SD
Stress (Strain)				
Pretest	89.80	25.66	92.72	29.80
Posttest	83.80	28.33	85.66	29.16
Physical Subscore				
Pretest	51.80	15.59	51.90	19.01
Posttest	48.40	17.00	50.38	19.35
Behavioral Subscore				
Pretest	20.47	5.83	22.17	7.42
Posttest	19.93	5.85	20.55	7.53
Cognitive Subscore				
Pretest	17.53	8.71	18.66	7.52
Posttest	15.47	7.94	14.72	6.93

Table 4-7
Source Table for Analysis of Covariance of Stress (Strain)

Source	df	MS	F	p
Group - Stress (Strain)	1	2.58	.01	.9334
Within	56	366.21		
Total	58			
Group - Physical	1	53.62	.32	.5710
Within	56	165.08		
Total	58			
Group - Behavioral	1	8.68	.54	.4662
Within	56	16.12		
Total	58			
Group - Cognitive	1	28.98	.88	.3535
Within	56	33.11		
Total	58			

CHAPTER V
DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

The purpose of this study was to determine if a self-management booklet for mothers staying at a Ronald McDonald House had an effect on the mothers' uncertainty about their child's illness, their social support from family and friends, and their stress (strain). The use of the booklet, while staying in the supportive atmosphere of the Ronald McDonald House, was the method of helping mothers to cope with the hospitalization of their child.

The booklet was written with the underlying goal of promoting individual strengths and capabilities of mothers by encouraging them to take a proactive role in coping with the present hospitalization of their child. In the booklet the author addressed three coping patterns that, as shown by previous research, increase mothers' ability to manage life when a child has a chronic illness: maintaining well-being, maintaining social support, and understanding the medical situation (Figley & McCubbin, 1983). Presented in this chapter is a discussion of the research results and the limitations of the study, conclusions, and recommendations for future research on both the stress associated with the hospitalization of a child and on Ronald McDonald Houses.

Discussion

Total Population

For the total study population, the status of the mothers showed a trend of improvement during the week they stayed in the supportive environment of the Ronald McDonald House. Their mean scores for uncertainty decreased from 87.66 to 84.49. Mean scores on social support from family increased from 14.71 to 14.88 and on social support from friends increased from 13.80 to 14.36. Stress mean scores decreased from 91.24 to 84.71. The changes in these scores, for the total population, were not statistically significant.

Booklet Use

The author wrote a booklet for mothers, bearing in mind that crisis intervention therapy is involved with solving the immediate problems facing the client (Aguilera & Messick, 1986). The self-management booklet given to the treatment group in this study encouraged mothers to ask questions about the medical problems afflicting their children in order to decrease maternal uncertainty. Mothers were also encouraged to take actions to promote their own emotional and physical well-being, and to make an effort to get to know other mothers at the Ronald McDonald House to increase their support. In order to help mothers focus global anxiety, and in order to determine whether they had used the booklet, mothers were encouraged to write in the booklet in spaces provided for their answers. Mothers were also asked to use the booklet in any other way that would be helpful to them. This problem-oriented activity was

instituted to help mothers order their priorities and regain some balance in, and control over, their lives.

Surprisingly, all but six mothers in the treatment group wrote in the booklet, in spite of the fact the booklet was introduced to mothers during the early adjustment period of their child's hospitalization. All subjects claimed to have read the booklet. The 23 mothers in the treatment group who wrote in the booklet entered a mean of 2.91 questions on uncertainty, 2.33 names of people met at the Ronald McDonald House, and 3.13 actions for reducing their stress. Individual mothers also used the booklets for recording names of physicians, telephone numbers, addresses of medical supply stores, visiting hours of restricted areas of the hospital, reactions to formula changes, times of medical procedures, suggestions for other mothers, a complaint about parent/physician communication, and an inspirational verse for parents of "special" children. Two subjects underlined booklets where the text acknowledged mothers' concern about their family at home and their feelings of guilt. One mother expressed gratitude for the booklet and felt its social support suggestions had been a major factor in her coping. Another mother admonished the researcher to be sure to return the booklet to her, as it was to go into a scrapbook.

The six mothers who did not write in the booklet gave the following reasons: lost booklet, "burnout" after 7 months of hospitals, lack of interest, depression over a diagnosis of mental retardation, anxiety over a quadraplegic son, and resistance to reading anything but the Bible. The ready acceptance of this easily read booklet is consistent with the success in the Netherlands, where written communications have

gained prominence in working with patients and their families (Visser, 1980).

Uncertainty

The analysis of covariance, and an examination of the means, showed that there was a significant decrease in the treatment group, compared with the control group, for the total uncertainty scale. This is most likely due to the self-management booklet because it had specifically addressed uncertainty. In Mothers Know Best, mothers were advised to write in the booklet questions they had about their child's illness so they would remember to ask them when they saw the doctors.

Within the subscales of uncertainty, there was a significant decrease in ambiguity. There was not a significant decrease for the subscales of lack of clarity, lack of information, and unpredictability. The ambiguity subscale had 6 disease-related and 7 disease- and communication-related items. Thus, the ambiguity subscale had a total of 13 items. The clarity subscale had 9 items, lack of information had 5 items, and unpredictability had 4 items. The limited number of subscale items in the latter three subscales may account for the fact that the booklet had impact on ambiguity more than on the other subscales.

Mishel's Parent/Child Uncertainty Scale (Mishel, 1983) is unique in that one person evaluates the uncertainty experienced concerning another person (i.e., a mother rates her uncertainty about her child). According to personal communication with Dr. Mishel, the current study was the first time the scale had been used as both a pretest and a

posttest. The mean scores for the Gainesville total group pretest were 87.66 and for the posttest were 84.49. Comparing these to the mean score for the 410 parents on whom the Uncertainty Scale was normed, which was 78.76, both the Gainesville pretest and posttest means are significantly greater than Mishel's means ($p < .01$ and $p < .05$, respectively). Information was not available concerning the exact conditions under which Mishel's mothers were interviewed. The difference between Mishel's mothers and the Gainesville mothers could have been due to differences in the severity of the illness of the children, differences in the timing between hospital admission and test administration, and differences in education and medical sophistication of mothers.

Social Support from Family

Analysis of covariance for Prociano and Heller's (1983) Social Support from Family Scale showed there was no significant difference in the adjusted posttest scores between the control and the treatment groups. Perhaps it cannot be expected that intrinsic feelings of family support would be changed by a booklet over the course of 1 week. Mothers expressed definite feelings that they either had or did not have family support, depending on how demanding the mother, and her sick child, were on the family's resources.

Despite the lack of significant differences in reported perceptions of social support from family, demographic data collected during the posttest revealed that the mean score of visits from family for the control group and treatment group was 3.43 and 5.59, respectively. This

was significant ($p = .0038$). The increase in family visitors in the treatment group could possibly have been an effect of the booklet which encouraged mothers to have their family visit them at the Ronald McDonald House. However, any inclination to generalize on family visits should be tempered by the realization that serious illness places grave economic restraints on most families. Lack of money for telephone calls and transportation could also have an effect on perceived family support.

The control group had a mean of 6.60 calls to family while the treatment group had a mean of 5.21 calls to family. There is no statistically significant difference between these numbers. Although the booklet encouraged mothers to call home, not all mothers readily use telephones, nor did all mothers wish to maintain contact with home. Telephone calls home that elicited responses such as "Call us if he dies," "I hear he's retarded," and "Does a shunt mean my baby will never play football?", although they came from family, were not perceived as supportive by the mothers.

It became apparent to the researcher that although the Social Support from Family instrument is concerned with family support, for the mothers in this study, at a traumatic time in their lives, the instrument was inadequate for measuring support from husbands. In discussions after the posttest, at least a dozen mothers reported having coalitions with family members other than husbands. Although 50 of the 59 mothers reported that they were married, mothers reported that their mates ranged from nothing more than a biological contributor to the conception of a child to being perceived as a mother's closest

companion. Sixteen mothers reported they were closer to their mothers-in-law, the sick child, or other relatives, than to their husbands. These data are consistent with Penn's (1983) research about families of children with chronic illness forming coalitions.

Although husbands could be nurturing and supportive to the women at the Ronald McDonald House, their presence was not necessarily perceived as support. They were sometimes viewed as detriments to the coping of mothers. Mothers stated that husbands could be supportive, loving men capable of managing the family at home. However, one husband threatened divorce and another used punishing behavior with his wife, such as forbidding telephone conversations with the children at home, when the mother chose to be with the sick child rather than with her husband. One mother expressed anger when the "prodigal," gift-laden father appeared at the hospital, after a year's absence, and proceeded to become the favorite, obeyed parent, while resurfacing all the pathological behavior that had caused the couple to separate. These anecdotal data are consistent with the research findings of Moos and Tsu (1977) that illness exacerbates any ills evident in the family system.

For the mother reunited with her husband when the Red Cross brought him home on emergency leave from Germany and the mother whose husband stayed at the Ronald McDonald House and became involved in the care of their child for the first time in 8 years, the hospitalization of a child was a positive experience. Consistent with the work of Koocher and O'Malley (1981), every mother expressed the belief that the illness of her child had, in some way, changed her marriage or her relationship with the significant male in her life.

Social Support from Friends

The effect of social support from friends on mothers at the Gainesville Ronald McDonald House had been previously investigated in a pilot study (Small, 1985b). Other parents had been seen as supportive and, 2 years after leaving the Ronald McDonald House, 61% of the 340 parents who returned questionnaires reported that they maintained contacts made at the Ronald McDonald House. Mothers residing at the Ronald McDonald House have an opportunity to engage in two coping strategies that research has shown to be beneficial to people facing life crises: (a) the opportunity to discuss feelings and (b) contact with people who have faced similar life crises (Lehman et al., 1986). Zarski et al. (1986) reported that social interaction was consistently associated with high overall health and fewer somatic symptoms.

It is of interest to note, that in the current research, the treatment group had a significant increase in perceived social support from friends, relative to the control group. Therefore, the intervention booklet Mothers Know Best further increased perception of social support from friends.

Procidano and Heller (1983) found that perceived support led to greater disclosure to companions. Sympathy or empathy from similar others is a crucial condition for accepting coping assistance. Others who are experientially similar to a distressed individual are most likely to be perceived as empathic (Thoits, 1986). Some debate exists over whether support at the Ronald McDonald House is perceived or received. Perhaps the perception of support availability at the Ronald McDonald House allowed these self-reliant treatment group mothers to

pursue the practical resolution of their problems and seek out social support.

Stress (Strain)

The results of this study did not show a significant difference between the control group and the treatment group on measures of stress, either on its total score or in any of its subscales. Thus, the booklet did not appear to have an effect on mothers' stress. Retrospectively, this might have been expected since mothers said their stress was dependent on a number of factors. In many cases, the primary factor appeared to be the severity of the child's illness. In other instances, the mother's current stress was related to stressors outside the hospital setting (e.g., diagnosis of cancer in mother's husband). In still other instances, coming to the hospital, in and of itself, appeared to increase or decrease mothers' stress. Clearly, the booklet could not have had an effect on these factors.

However, interesting anecdotal information is linked to the very broad range of scores on this measure. On the physical subscale of the Strain Questionnaire (Lefebvre & Sandford, 1985), which had mean sample pretest and posttest scores of 51.84 and 49.37, respectively, three mothers scored over 90. One mother whose pretest score was 105 had been told upon admission from another hospital that her child could die from previous medical mismanagement. Two mothers who scored 96 and 106, respectively, on the posttest were told during the week of the study that their children had fatal illnesses. Additionally, for the cognitive subscale, the sample pretest and posttest means were 18.08 and

15.10, respectively. Three mothers who had the lowest pretest and posttest scores (8) on the cognitive subscale were over 40 years of age, with one having been a foster mother to 23 children, pointing to the possibility that maturity and experience can have an effect on the cognitive subscale of stress. These low scores conflict with the findings of Frieberg (1972), wherein, all mothers reported uneasiness, even if specific frightening events had not occurred.

Lefebvre and Sandford (1985) contended that the most inconsistent findings in the self-report Strain Questionnaire are the behavioral subscale scores. The anecdotal results from this study are consistent with that belief. For example, prescription drug use, one of the items in the behavioral subscale, may not be associated with stress, but could be the result of a chronic condition of the mother. Also, rules of the Ronald McDonald House prohibit use of alcohol in the house. It is highly unlikely that the 90% of the women who claimed no alcohol use were, in fact, abstainers from alcohol during the week before and during the week of the study. Thus, although participants in this research were all volunteers, their responses reflected self-protective behavior. One parent expressed a desire not to have further information about her child's leukemia because "my nerves can't take it and God will take care of everything." This is consistent with Folkman (1984) who asserted that forcing control can heighten stress. This same mother's unwillingness to acquire information and take control, however, led to misunderstanding and conflict between the mother and the medical personnel about responsibility for the child's cancer treatments.

Limitations

Attention must be paid to the limitations of this study. An examination of the research design and procedure reveals several threats to internal validity. Population mortality was a limitation. Originally, the study was designed with 30 subjects in the control group and 30 in the experimental group. Over the course of the period of data collection, pretests from 37 mothers were gathered in an effort to obtain the 30 subjects. In seven cases, medical reasons, such as cancellation of surgery, cancellation of a bone marrow transplant, transfer to a larger burn unit, referral to a hometown physician, etc., resulted in early discharge of mothers from the Ronald McDonald House. One mother in this group, uncomfortable with the rules of the Ronald McDonald House, chose to go to a motel.

Differential selection of subjects was possible through the lack of randomization. This risk was taken in order to avoid contamination, which was viewed to be a greater threat to validity. Therefore, the treatment group of mothers were not approached to be in the study until the control group had completed the study. However, as discussed in chapter III, there were striking similarities between the mothers who made up the control and treatment groups. Another threat to internal validity was history. Anecdotal accounts of events that could have affected mothers' responses between the pretest and the posttest were loss of insurance coverage, repossession of household goods, loss of mate's job, a sibling suicide attempt, loss of mother's job, and loss of a reliable housekeeper. However, the occurrence of these events should have been randomly divided between the control and treatment groups. In

addition, pretesting may have affected mothers' performance on the second test, regardless of the experimental treatment. The use of an identical pretest and posttest may have caused sensitization to the content of the treatment. Again, both the control and treatment groups should have been equally affected by this.

The sample in this study was limited to one Ronald McDonald House. Thoughtful attention must be paid to the external validity of this experiment, to avoid the tendency to overgeneralize these experimental findings to all mothers of hospitalized children based on the data from the Gainesville Ronald McDonald House. Two mothers who were not eligible and five fathers asked to participate in the study, which could indicate that the study had a halo effect.

Conclusions

Analysis of the research results of this study of mothers at the Ronald McDonald House reveals that the use of the booklet Mothers Know Best decreased mothers' uncertainty concerning their child's illness, especially its ambiguity component. The booklet also increased mothers' perception of their social support from friends. Overall, it can be concluded that the self-management intervention booklet Mothers Know Best, used as a treatment to help mothers at the Gainesville, Florida, Ronald McDonald House, was effective.

Recommendations

The high cost of medical care is necessitating shorter hospital stays for children as well as adults. By the year 2010, hospitals will

have become, for all practical purposes, intensive care units (Freyman, 1986). Even now, mothers who register at Ronald McDonald Houses for a period as short as 1 week, have seriously ill children. Time and personnel are not always available to counsel mothers individually to use their strengths and capabilities and to take a proactive role in ascertaining what is happening medically to their children, to take actions to maintain their well-being while they are in the miasma of the hospital setting, and to facilitate their meeting potentially supportive mothers in similar situations.

The use of a booklet to assist mothers is a time-efficient, cost-effective method of reaching every mother who registers at the Ronald McDonald House. The self-management intervention booklet used in the experiment at the Gainesville Ronald McDonald House was effective on two of four studied dimensions: uncertainty and social support from friends. The other two dimensions are less tractable. The following recommendations are made: (a) The booklet Mothers Know Best should be used at the Gainesville Ronald McDonald House, and (b) the booklet should be offered to all literate mothers, regardless of their length of stay, when they register and are oriented to the Ronald McDonald House.

There are no data to prove whether the intervention used in this study would be effective in the other Ronald McDonald Houses. However, these facilities are all designed to house families in a friendly, safe, supportive, and inexpensive environment when families have seriously ill, hospitalized children. More than 1 million families have stayed at Ronald McDonald Houses. Since the majority of people who register at the Ronald McDonald House are mothers (Jones, 1986), it may be possible

that thousands of women going through the ordeal of having a hospitalized child could benefit from using Mothers Know Best. It would appear that use of the Gainesville intervention booklet Mothers Know Best in other Ronald McDonald Houses would be appropriate.

Future Research

The results of this study suggest areas for future research focused around the following topics:

1. Research on Mothers Know Best. Further research could be conducted on the effectiveness of the booklet at Ronald McDonald Houses and comparable institutions. The booklet could also be modified and tested on grandmothers and fathers who come to the Ronald McDonald House as the main caretaker of the hospitalized child. Research could be conducted on the relative effectiveness of the booklet with black and white mothers. The researcher's experience at the Gainesville Ronald McDonald House pointed out the need for the booklet to be available in Spanish. Comparisons of the use of the booklet by mothers under age 30 and age 30 and over, as well as its use by high school and college-educated women may garner interesting data on coping in these groups.

2. Research on intercorrelations of the data from this study using the scales and subscales. Further analysis of these data might provide insight into the components of uncertainty, social support, and stress in families with hospitalized children.

3. Research on hospital staff/parent perception of severity of illness. A study of the relationship of a hospital staff member's perception of a child's condition on day of admission, 1 week later, and

prediction for condition 1 year later, as related to the mother's perceptions at the same intervals, could provide insight into hospital/parent communication problems.

4. Research on the Gainesville, Florida, Ronald McDonald House. Future research might determine who benefits most from Ronald McDonald House use, in order to best utilize the limited number of rooms available. The effectiveness of the Ronald McDonald House might be enhanced by the introduction of exercise and relaxation classes for mothers who scored high on the physical subscale of the Strain Questionnaire. Research could also be conducted on the response of parents to the introduction of counseling opportunities within the setting of the Ronald McDonald House.

APPENDIX A
1985 RONALD MCDONALD HOUSE SURVEY

Table A-1
 1985 Ronald McDonald House Survey
 Characteristics of the Population Sample

Variable	Category	Percentage
Caretaker parent (Respondent)	Mother	82
	Father	18
Miles from home	<25	1
	25-50	2
	50-75	8
	Over 75	81
	Out of state	8
Marital status	Married	82
	Unmarried	4
	Divorced	11
	Widow	1
	No response	2
Parents in home	Mother	97
	Father	93

Table A-1--continued

Variable	Category	Percentage
Highest school grade	8th	2
	9th-12th	44
	Jr.college	18
	College	27
	Other	9
Child's diagnosis by service	Hematology/Oncology	21
	Cardiology/Card.Surgery	21
	Neonatology/Birth Defects	11
	Surgery	11
	Neurology	7
	Pulmonology	6
	Nephrology/Transplants	6
	Infectious Disease	5
	Gastroenterology	5
Ambiguous	5	
Date of diagnosis	Present hospitalization	10
	<6 months	8
	6-12 months	16
	1-3 years ago	43
	>3 years ago	22

Table A-1--continued

Variable	Category	Percentage
Child's health at present	Excellent	18
	Good	36
	Fair	27
	Poor	6
	Deceased	13
RMH room occupants*	Mother	92
	Father	81
	Sibling	39
	Grandmother	75
Length of stay at RMH	1-3 days	25
	4-7 days	27
	8-12 days	15
	13-21 days	13
	Over 21 days	20
Child's status	Inpatient	87
	Outpatient	4
	Both	9

Table A-1--continued

Variable	Category	Percentage
Contacts made at RMH maintained	Yes	61
	No	31
	No answer	8
Problem solver at RMH	Volunteer	5
	Manager	40
	Other parent	21
	Hospital personnel	10
	Other	7
	No one at RMH	5
	No one	12
Most memorable feature of RMH	Support from others	48
	Support to others	7
	Quality of facility	14
	Social	10
	Other	21

*Note: Room occupancy is limited to three people or two adults and two small children at any one time.

APPENDIX B
DEMOGRAPHIC DATA

Demographic Information - A

Your name _____

Address _____

City _____ State _____ Zip code _____

Phone (____) _____ Your age _____ Miles from home _____

Name of child at Shands _____ Age _____

Date of Shands admission _____ Hospital No. _____

Names of other children who live with you: _____ Age _____

Your marital status: Unmarried Married Divorced Widow

When your sick child is at home, who is the main caretaker?

How many adults (21 and over) live in your house with you? _____

What is the highest school grade you finished? _____

What is your child's diagnosis? _____

When was your child diagnosed? _____

Demographic Information - B

Code # _____

Including this time, how many days has your child been hospitalized at Shands? _____

Have you made any phone calls in the past week? If so, about how many to home? _____ to friends? _____ to clergy? _____

Have you had visitors from outside Gainesville in the past week? _____

If so, how many family members? _____ friends? _____ clergy? _____

If you had a personal problem at RMH, with whom would you discuss it?

***** Using the following scale, please tell us about your child's condition: Put a circle around your answers.

Excellent = Feeling great. Able to physically and mentally keep up with his/her age group in most things.

Good = Feeling good. If old enough, can attend school most of time.

Fair = Up and around, but mostly stays at home.

Poor = Bed-bound, unable to care for self, or not developing way he/she should.

Very ill = Terminally ill or restricted life span.

How was your child a week ago?	How is your child today?	How do you expect your child to be in a year?
--------------------------------	--------------------------	---

Excellent

Excellent

Excellent

Good

Good

Good

Fair

Fair

Fair

Poor

Poor

Poor

Very ill

Very ill

Very ill

APPENDIX C
INTERVENTION AND EVALUATION

Mother's Name _____

Mother's Know Best

Advice from Mothers Who Have Stayed at the Ronald McDonald House

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Your child's name _____

Your RMH room number _____

MOTHERS KNOW BEST

Advice from mothers who have stayed at the Ronald McDonald House

Keep this booklet with you to help you, your child, and your family during your stay at the Ronald McDonald House.

MAY ALL WHO ENTER HERE FIND STRENGTH IN OUR FAMILY AND HOPE
IN TOMORROW

Welcome to the Ronald McDonald House!

If you are like most mothers staying here, you are glad to have an inexpensive, clean, comfortable room to stay in close to the hospital and your sick child. If you are like all of the mothers staying here tonight, you are concerned about your child's illness. Mothers who are here for their children to have tests, treatments or surgery know their children are getting good care, but still they worry.

Some mothers worry about being away from the rest of their family. Some mothers are anxious because they have never spent a night alone. Some mothers are very worried about money, job or family problems.

Many parents feel guilty because they think something they did, or did not do, made their child sick. Lots of parents feel angry at their child for being sick or having an accident and upsetting all the family. When a child is hospitalized, the whole family is upset. We have mothers who tell us even the family pets are upset when one of the children is hospitalized.

Many mothers find that when lots of things are happening at once, writing down feelings and thoughts and making lists of questions, ideas and people can be helpful. We hope this booklet will help make your life easier. Add any information to your booklet that helps you. The booklet is yours to keep!

Think a moment about how you are feeling right now. Put an X next to the words that describe how you feel.

Glad ___ Nervous ___ Relaxed ___ Sad ___ Worried ___ Happy ___
 Guilty ___ Angry ___ Frightened ___ Other ___ (What are they?)

Many parents find it hard to admit all their feelings, even to themselves. They may keep asking themselves and other people, "Why my child, why me?". We wish we could answer that for you, but we can't.

Instead, we can only tell you that 5,000,000 - yes, five million, children will be hospitalized this year in the U.S. and their parents are asking the same questions you are asking.

It can be frightening being a mother with a sick child - far from family and friends. You may not feel very well yourself. You may feel depressed and lonesome and just want to be left alone. Sometimes mothers of hospitalized children feel a deep sadness, as if no one cares.

When you are feeling depressed and/or lonesome, would you rather be alone ___ or with other people ___? In the past, when you have been depressed and/or lonesome, what has helped you to feel better? _____

As a mother you cope with many feelings. Since being here may be a new experience for you, we want to help you cope with any feelings you're having. If you will take a few minutes, now, to read this booklet, what follows can help you with your child.

Over one million families have stayed at the 100 Ronald McDonald houses. We've talked to hundreds of mothers who have been upset about their hospitalized child. They tell us that there are 3 actions you can take to HELP YOUR CHILD, YOUR FAMILY AND YOU:

1. LEARN ABOUT YOUR CHILD'S ILLNESS
2. THINK ABOUT YOURSELF
3. MEET OTHER PARENTS AT THE RONALD MCDONALD HOUSE

Let's take them one at a time!

ACTION #1: LEARN ABOUT YOUR CHILD'S ILLNESS

The doctors and other care-givers want to help you understand your child's problem. In a busy hospital people may sometimes forget to tell you who they are and what they are doing for your child. They may even forget and use words you don't understand. Ask the medical staff any questions you have so you can help your child know what is happening. There is no such thing as a dumb or bad question.

Take time now to write in your booklet a list of questions you have for the doctor about your child's illness, treatment, drug side-effects, home care, future care, etc., so you won't forget them when the doctors are around. Keep this booklet handy in your purse.

Write down ANY questions you have about your child's illness. Each day you may want to add new questions for the doctor. When you get the answers, WRITE THEM DOWN so you won't forget them after you leave here. Use the extra page and the backs of pages for more space. For example:

1. How long will my child have to stay in the hospital? _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

ACTION #2 THINK ABOUT YOURSELF

Even if you think you should be with your child all day, take time out of every day for yourself. Go eat a meal, find a quiet place, read a book, take a shower, get some exercise - even if it is just walking around the hospital. A change of scenery can keep you from getting all kinds of aches - from headaches to backaches. Mothers and children need time away from each other in the hospital just the way they do at home. You may think your health doesn't count right now, but if you get sick, who would be able to stay with your child?

Sometimes talking to someone you care about is what you need most to help you to help yourself. Phone calls can make you and the people at home seem closer. The sound of someone you love, even when they are complaining, can sound good when you are far from home. If it can be arranged, have your family visit you at the Ronald McDonald House.

WRITE DOWN, right now, something you will do for yourself tomorrow. When you have done it, put a mark (x) next to it on your list. Add to your list each day you are here.

<u>What I'll Do for Myself</u>	<u>I Did It!</u>
For example: 1. <u>Spend 15 minutes walking quickly from RMH to the hospital.</u>	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____
_____	_____

ACTION #3 MEET OTHER PARENTS AT RONALD MCDONALD HOUSE

If you have questions about the Ronald McDonald house, the staff and volunteers are happy to answer them. Speak to other people you see in the house. Don't wait to be introduced. We are like one big family here. Our parents find that they often feel less depressed and lonesome when they talk to each other. Remember, the other parents feel depressed and lonesome, too.

A mother told us that the time here was the worst and best of her life. Her son was very sick while she was at RMH, but she made close friends who had sick children, too, and knew how she felt. These were friends who understood her worries and helped her feel good about herself as a mother.

To help you remember the new friends you meet, WRITE DOWN the names (and addresses and phone numbers, if you want them) of people, as you meet them, at the Ronald McDonald House. Remember to use the page at the end if you need more space.

For example:

1. Faye and Pete Armes, Managers, RMH, 1600 SW 14 St. Gainesville, FL 32605. Telephone: (904) 374-4404

2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Mothers who have had a hospitalized child are the ones who can really help you cope during this difficult time. The mothers who were here before you strongly advise that you re-read this booklet and try out its suggestions. They think the hospitalization of your child will be easier for you if you LEARN ABOUT YOUR CHILD'S ILLNESS, THINK ABOUT YOURSELF, and MEET OTHER PARENTS AT THE RONALD MCDONALD HOUSE.

The love of many people has built this house and keeps it going. We hope the Ronald McDonald House will always have a special place in your memory and that here you will find

STRENGTH IN OUR FAMILY

and

HOPE IN TOMORROW

Evaluation Form for Intervention Booklet
with Ratings (Mean Scores) of Seven Experts

In 10 years of working with hospitalized children, I have found that even the most highly educated of their parents become disorganized and confused when their child is seriously ill. A global anxiety often overtakes parents and interferes with normal functioning at even an elementary level. Parents at the Ronald McDonald House report that they forget to ask the doctors questions, forget to eat, and forget the names of close friends they have made here. The booklet is designed to be kept in the child's mother's purse during her stay at the Ronald McDonald House. This is a rough draft of the finished booklet.

DESIRED OUTCOME: Mothers will decrease uncertainty and stress and increase social support.

ANTICIPATED BEHAVIOR CHANGE: Mothers will make lists of their questions for the doctors, make lists of activities they will do to increase their own stress while in the hospital, and make lists of friends met at the Ronald McDonald House.

The booklet, designed for mothers with a high school education, is currently being field tested with mothers. Your suggestions and advice are welcome! Please read the booklet, fill out the form and return to me in the enclosed envelope. Thank you. Natalie Small

Please use the following scale to rate the brochure:

Excellent - 5; Good - 4; Average - 3; Below average - 2; Poor - 1.

	Mean Score
Rate the appropriateness of the booklet format.	<u>4.4</u>
Rate the vocabulary for high school level readers.	<u>4.0</u>
Rate the clarity of presentation of ideas.	<u>4.0</u>
Rate the overall design of the booklet.	<u>3.9</u>
Rate the accuracy of information presented.	<u>4.4</u>
Rate the value as a teaching tool for stressed mothers.	<u>4.0</u>
Total	4.1

Your name _____

Title _____

APPENDIX D
INSTRUMENTS

23. I can generally predict the course of my child's illness.
24. Because of the treatment, what my child can do and cannot do keeps changing.
25. I'm certain they will not find anything else wrong with my child.
26. They have not given my child a specific diagnosis..
27. My child's physical distress is predictable, I know when it is going to get better or worse.
28. My child's diagnosis is definite and will not change.
29. I can depend on the nurses to be there when I need them.
30. The seriousness of my child's illness has been determined.
31. The doctors and nurses use everyday language so I can understand what they are saying.
- 32.
- 33.
- 34.
- 35.
- 36.
- 37.
- 38.
- 39.
- 40.
- 41.
- 42.
- 43.
- 44.
- 45.

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U. OF FLORIDA
HEALTH CENTER
FORM NUMBER 004-EVAL

MARKING INSTRUCTIONS

- 1 USE A STANDARD NO. 2 LEAD PENCIL
- 2 KEEP ALL MARKS WITHIN THE BUBBLES
- 3 MAKE HEAVY BLACK MARKS THAT FILL THE BUBBLE
- 4 MAKE NO STRAY MARKS ON THE ANSWER SHEET
- 5 DO NOT FOLD, STAPLE OR ATTACH CLIPS TO THIS FORM

CORRECT



INCORRECT



1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18

THE STRAIN QUESTIONNAIRE

Please read the following list and blacken-in the number that most closely corresponds to how often in the past week you have experienced or felt each of the items listed. Use this rating scale:

- (1) Not at all (3) 3 or 4 days (5) Everyday
 (2) 1 or 2 days (4) 5 or 6 days

	1	2	3	4	5
1. backaches	1				
2. muscle soreness	2				
3. numbness or tingling in body	3				
4. heaviness in arms or legs	4				
5. weakness in body parts	5				
6. tense muscles	6				
7. pain in neck	7				
8. nausea or upset stomach	8				
9. diarrhea or indigestion	9				
10. tight stomach	10				
11. loss of or excessive appetite	11				
12. pain in heart or chest	12				
13. shortness of breath	13				
14. faintness, dizziness	14				
15. racing heart	15				
16. light headedness	16				
17. headaches	17				
18. hot or cold spells	18				
19. lump in throat	19				
20. dryness of throat and mouth	20				
21. teeth grinding	21				
22. trembling or nervous tics	22				
23. sweating	23				
24. sweaty hands	24				
25. itching	25				
26. cold or warm hands	26				
27. frequent need to urinate	27				
28. pre-menstrual tension or missed cycles	28				
29. spent more time alone	29				
30. irritability	30				
31. impulsive behavior	31				
32. easily startled	32				
33. stuttering/other speech dysfluencies	33				
34. insomnia	34				
35. inability to sit still	35				
36. smoking	36				
37. use of recreational drugs	37				
38. use of prescription drugs	38				
39. use of alcohol	39				
40. accident proneness	40				

CONTINUE WITH QUESTIONNAIRE ON OTHER SIDE.

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BIOGRAPHICAL SKETCH

Natalie Settimelli Small was born in 1933 and raised in Quincy, Massachusetts. She attended Tufts University where she was the first woman editor of the Tufts yearbook. Following graduation in 1955, she spent a year as a Stewart scholar studying in Florence, Italy. Married in 1956 to Parker Adams Small, Jr., M.D., Natalie spent a nomadic life teaching in Cincinnati and Philadelphia and raising three children in Washington, D.C., England, Switzerland, and Gainesville, Florida. She earned an Ed.S. in counseling at the University of Florida in 1976.

As a member of the Department of Pediatrics of the University of Florida College of Medicine and the Department of Social Work Services at Shands Hospital, Natalie has been counseling families with chronic illness since 1976. Her interest in cost-effective counseling resulted in her developing booklets and slide tapes for patient education on intensive care units, diabetes, hospital orientation, and preparation of children for surgery. She is involved in teaching the psychosocial aspects of serious illness and death to medical students and is a founding member of the Board of Directors of the Gainesville Ronald McDonald House.

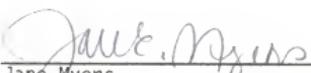
In 1980, Natalie accompanied Virginia Satir and spent 3 weeks examining health care systems and family life in China. Natalie was

invited to Nigeria, in 1982, where she was a consultant on cost-effective counseling at the University of Lagos. Natalie's research on helping families to cope with chronic illness led to her receiving her Ph.D. in counseling in 1987.

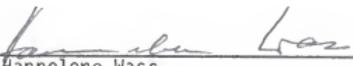
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I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


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This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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