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UNIVERSITY OF ALBERTA

FAMILIAL CAREGIVERS' COPING RESPONSE TO MENTAL ILLNESS: CHRONICITY, SEVERITY, AND PERCEIVED SOCIAL SUPPORT

BY

P. LYNN DAMBERGER

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE
in
FAMILY LIFE EDUCATION

DEPARTMENT OF FAMILY STUDIES

EDMONTON, ALBERTA
SPRING, 1990

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OFFICE OF THE DEAN

January 31, 1990

Lynn Damberger
9120-80 Ave.
Edmonton, Alberta
Canada T6C OT8

Dear Mr. Damberger:

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We would appreciate your sending group scores to add to our data base or any other information you feel may be useful, when they are available to Dr. Marty Rossmann. If you would like information about scoring and means developed thus far, please contact:

Dr. Marty Rossmann
Associate Professor and Director of Special Services
University of Minnesota
Dept. of Vocational and Technical Education
Office of Special Services
Vocational and Technical Education Bldg.
1954 Buford Ave., Room 210
St. Paul, MN 55108

If I could be of any further assistance to you, please let me know.

Sincerely,

Hamilton I. McCubbin
Dean

HIM/kme

Enclosures

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New York State
Psychiatric Institute
722 WEST 168TH STREET, NEW YORK 10032
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February 7, 1990

Ms. Lynn Damberger
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Canada T6C 0T8

Dear Ms. Damberger:

Thank you for the data on the Rejection Scale,

While I am interested in the frequencies and means of the responses to the Patient Rejection Scale, of greater importance is the distribution of the scores on the entire scale and the relationship of the scale to your other measures, particularly those mentioned in your title, I would very much like to know those and would like a copy of your complete instrument so that I know what the variables are.

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Best wishes,

Sincerely,

Dolores Kreisman, Ph.D.
Associate Research Scientist

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TITLE OF THESIS: Familial Caregivers´ Coping Response to Mental Illness: Chronicity, Severity, and Perceived Social Support

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UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled: FAMILIAL CAREGIVERS´ COPING RESPONSE TO MENTAL ILLNESS: CHRONICITY, SEVERITY, AND PERCEIVED SOCIAL SUPPORT submitted by P. LYNN DAMBERGER in partial fulfillment of the requirements for the degree of Master of Science in Family Life Education.

Dianne K Kieren
Dr. Dianne Kieren, Supervisor

Brenda C. Munro
Dr. Brenda Munro

Lorne Warneke
Dr. Lorne Warneke

Date: January 30, 1990

DEDICATION

To my husband,
Francis Damberger,
whose unending support, love
and encouragement has assisted
me throughout this project.

ABSTRACT

Family stress theory was used to guide an exploration of the coping response of one familial caregiver to the crisis of hospitalization of a family member for the treatment of a mental illness. The specific group of mental illnesses that is focused upon is affective disorders. This research examines the interrelationships between two stressor variables associated with the affective disorder (chronicity and severity of the illness), the resources of perceived social support, and the acceptance/rejection coping response of one familial caregiver to the stressful situation of hospitalization of the ill family member.

The sample consisted of 43 patient - familial caregiver pairs. Data were collected through the use of standardized instruments that were incorporated into a structured questionnaire that was administered by the researcher. Additional data were collected through retrospective analysis of the patients´ health records. The familial caregivers´ acceptance/rejection coping response was quantified through the use of Kreisman, Simmons, and Joy´s Patient Rejection Scale (1979). The Social Support Inventory

developed by McCubbin, Patterson, Rossman, and Cooke (1982) was used in order to measure the perceived social support of the familial caregiver. The degree of chronicity and severity of the hospitalized family member's illness were assessed by identifying the common indicators of these variables from the patients' health records. The statistical analysis used included descriptive statistics, analysis of variance, and Pearson product moment correlations.

There were no statistically significant results from the analysis of the interrelationships between the four variables. Although there were no significant relationships found, the description of the variables of the acceptance/rejection coping response and perceived social support provide interesting points of discussion. The negative results of this research raise questions that require further investigation as well as suggest some potential implications for clinical practice.

ACKNOWLEDGEMENTS

I wish to express by gratitude to the following people for their contribution to this thesis. First to Dr. Dianne Kieren, my advisor, for her guidance and encouragement throughout the research process. I also thank my committee members, Dr. Brenda Munro and Dr. Lorne Warneke, for their insightful questions and valuable suggestions.

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Finally, appreciation is extended to my employer, the participating hospital, for granting the author permission to collect data within their organization as well as to complete the project while continuing my duties with the organization. Last and by no means least, I would like to thank all of the patients and their caregivers, whose participation contributed to a greater understanding of this family crisis.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I - INTRODUCTION AND STATEMENT OF THE PROBLEM

Families are systems that almost all individuals have experience in, and interact with in ways to ensure that their social and emotional needs are met. As family systems move through time and space, they encounter different situations that require change by the family. These events, behaviors, and contexts are often called stressors. How families cope with these stressors may not only affect the well-being of the family system as a whole, but also the well-being of its members (Litman,1974).

Mental illness of one member of the family is one type of stressor that often has a profound impact upon not only the family member afflicted with the illness (the patient), but also on the other family members or significant persons with whom that individual interacts (Litman, 1974). This chapter will include a description of the problem of mental illness as a potential stressor to the family as well as a description of how this research will address the problem. In addition to outlining the purposes of the research, the concepts that will be utilized and the specific research questions will be presented.

Family and Familial Relationships

Before discussing the stressor of mental illness upon families, it is necessary to define what is meant by family in this research. Although all individuals have experience in families, perceptions of what a family is and what purposes a family serves vary widely from individual to individual. Traditionally, in North America, the family has been defined sociologically by the nature of the relationships and/or the functions of those relationships. A common definition has been "two parents living with their offspring under one roof with the father earning the living and mother taking care of the children and the home" (Boss, 1988, p.12). Rapid social changes which are occurring both internally and externally to the family have made the above definition too narrow to describe all but a minority of families.

Eichler (1983) suggests that a more realistic and applicable approach by which to conceptualize and define families is by dimensions of familial interaction. She believes that the six most important dimensions of familial interactions include:

(a) procreative dimension - ranges from a couple having children together to having no children.

(b) socialization dimension - ranges from both partners involved in parenting to having no children to socialize.

(c) sexual dimension - ranges from a marital couple having sex only with one another to celibacy.

(d) residential dimension - ranges from all family members sharing the same residence to all living in completely separate residences.

(e) economic dimension - ranges from support obligations and provisions of financial support being met by only one member to all family members being financially independent.

(f) emotional dimension - ranges from all family members being positively emotionally involved to no emotional involvement, negative emotional involvement, or asymmetrical emotional involvement between members.

Although allowing for the range of variation on each of these particular dimensions assists in a broader understanding of familial relationships, the particular dimension of familial interaction that will be focused upon in this research is the emotional dimension. Although the families involved in this research may or may not share some or all of the other dimensions identified by Eichler (1983), the specific dimension that will be examined in the familial relationships of the primary caregiver to the mentally ill family member is the emotional dimension in terms of their emotional coping response of acceptance or rejection of the family member.

Mental Illness and Families

The diagnosis and hospitalization of an individual for mental illness operates as a stressor for the individual (the patient), as well as for the family members or significant persons with whom that individual interacts. A stressor is defined as "those life events or occurrences that are of sufficient magnitude to bring about change in the family system" (Hill, 1949). The effects and relationships during the stressful event of hospitalization of a family member for mental illness are complex, with both the patient and family members mutually influencing each other continuously over time. Much research has been directed to document the possible effects of this stressor on these two units. The previous research with families of of the mentally ill has often conceptualized these relationships in a linear or "cause and effect" model.

In such studies, mental illness was focused upon:

(a) as having an impact on the family in such a way that created particular patterns of response or reaction on the part of the family;

(b) as a burden that the family must somehow react to, bear, and endure, or;

(c) in terms of some dysfunctional family processes that may have contributed to the etiology of an individual's mental illness.

Very few researchers have examined the complex and interactive process of how mental illness impacts on family relationships. Current deficits in research techniques and the complexities of processes in family relationships make it difficult to capture what is undoubtedly a complex interrelationship. At present, we can only target the study of small portions of the process and have difficulty measuring the full extent of relationships.

At present, it is particularly appropriate to continue to explore the relationships between various aspects of the mental illness of an individual and the qualities and characteristics of the situation that the patient and family members must cope with. Little is known about how family members cope with the caregiving of a mentally ill member. Although families have always played a major role in the caregiving of a mentally ill member, a recent confluence of theoretical, economic, and clinical factors have forced families to take an even more active caregiving role. Research in biochemistry, pharmacology, genetics, as well as psychosocial relationships have demonstrated that factors other than the family environment contribute to the etiology of mental illness in an individual (Chelsa, 1989).

There has been a theoretical shift in that the family is no longer believed to play the role of a "causal" agent in mental illness (Chelsa, 1989). The deinstitutionalization movement of the past 20 - 30 years, decreased numbers of hospital beds, and the increased demand for the use of those beds for acute illnesses have all necessitated early discharge of mentally ill individuals to their homes. It is with increasing frequency that families have their mentally ill relative return home at earlier stages in the individual's recovery from illness (Goldman, 1982; Group for the Advancement of Psychiatry, 1986; Gubman, Tessler, & Willis, 1987; Hatfield, Fierstein, & Johnson, 1982; Kane, 1984). There is no doubt that family members must make responses to a situation where one family member is experiencing a mental illness. For example, roles may change or finances may be affected. In view of these changes in policy and family impact, it is extremely important to examine the potential effects that the patient's illness may have on the family system as well as the manner in which the familial caregivers respond to the patient and illness. This response may be viewed as coping.

Coping is defined as:

> "those efforts that are directed at (a) eliminating and/or avoiding stressors and strains; (b) managing the hardships of the situation; (c) maintaining the family system's integrity and morale;(d) acquiring and developing resources to meet demands; and (e) implementing structural changes in the family system to accommodate the new demands" (McCubbin & Patterson, 1983, pp.16-17).

It is important to know the ways in which the family is able or not able to cope with the illness of a family member, and what variables, internal and external to the family, facilitate the coping process. This research will only begin to explore what impact the patient's illness has upon one other family member, the primary familial caregiver. This research will focus upon the study of the potential effects of mental illness as it is represented in a particular coping response of a familial caregiver. Such a study is limited to the dyadic relationship between the patient and the primary caregiver rather than the relationships between the patient and the whole family. This research however, may assist in determining variables that may be examined within the entire family system in the future.

Purposes of This Research

This study views the mental illness of a family member as a stressor event which has the potential of generating coping responses on the part of the primary caregiver. While it is acknowledged that a caregiver may effect many coping responses, only one particular type of coping response will be studied. The caregiver's coping response of acceptance/rejection of the patient has previously been identified as a predictor to the patient's illness outcome, with certain levels of rejection being positively correlated with recovery or relapse of the patient's illness. For this reason, acceptance/rejection was selected as the coping response of interest in this study.

Two variables associated with the pile-up aspect of the stressor of mental illness, chronicity and severity of the illness, will be examined along with the resources of social support in order to determine what influence these factors have on the primary caregiver´s coping response of acceptance/rejection. By examining these variables together, it may be possible to capture the more complex, systemic nature of the relationships.

Specific Variables To Be Examined

This study will examine four separate variables and their relationships to one another. The four variables include the chronicity of the patient´s illness, the severity of the illness, the perceived resource of social support available to the primary caregiver, as well as the primary caregiver´s coping response in terms of acceptance/rejection. Each of these variables will be described in more detail in this section.

The stressor event of hospitalization of one family member is an event with multiple ramifications not only for the patient but also for other members of that person´s family system. As pointed out by McCubbin and Patterson (1983), the family seldom deals with a single stressor but often experiences a pile-up of stressors. Two such pile-up factors that may be associated with the hospitalization of the patient are the chronicity and severity of the illness. Although these variables could be examined in combination with each other, in this research they will be examined individually as the individual effects of these variables are not known. Chronicity is commonly defined as the ongoing or unremitting nature of symptoms associated with an illness or may include frequent relapses of symptoms. Severity is generally considered to be a characteristic of an illness that describes the relative seriousness in terms of its symptomatology. That is, the symptoms may (a) markedly interfere with the individual´s usual occupational and social activities and relationships with others, (b) create more risk to the well-being of the patient, and/or, (c) contribute to the long-term outcome of the illness. Since both chronicity and severity may or may not be associated with the hospitalization of the ill patient (the stressor event), both will be utilized in this research.

The primary caregiver´s accepting/rejecting response to the patient/illness may not only be exemplary of the degree of their ability to cope with the stressor, but may also have an influence on the outcome of the stressor situation. The expression of hostile or critical feelings towards the patient by family members, referred to as expressed emotion or EE, has been linked to poorer outcome in the patient´s recovery from the illness (Vaughn & Leff, 1976). What has not been examined in terms of the rejecting response of EE, is the interactive nature of this particular response. Although a relationship of the family member´s EE to the patient´s illness has been determined, the patient-related or resource-related variables that may be associated with expression or non-expression of critical feelings has not been investigated. This research will examine the interrelationships of the primary caregiver´s coping response with other variables that may have an effect on the process of adaptation, specifically the impact that chronicity and severity of the patient´s illness as well as the resources of social support to the primary caregiver have on this relationship.

The family is always part of a larger social system. Although family members support each other, there are also other sources of support for family members. Social support, or the information and resources provided by other persons (Cohen & Syme, 1985), appears to influence an individual´s or family´s adjustment to specific stressor events. Research which specifically focuses on the role of social support in the family member´s adaptive coping response to mental illness is becoming more prevalent, especially research on the use of support groups for these families. There is still uncertainty as to the extent that social support acts directly upon the effects of mental illness, or whether it acts as a buffer to mediate this relationship. This study will attempt to further explore these relationships.

The most extensive research on families and mental health has been conducted on the mental illness of schizophrenia. This research will not focus on the more frequently studied illness of schizophrenia, but rather will examine the more prevalent illnesses of affective disorders. Affective disorders are defined as disorders of mood, commonly known as depression or manic-depressive illness. Considering that the lifetime prevalence for schizophrenia in the general population is only 1% (Kaplan & Sadock, 1985), with an even lower lifetime prevalence of 0.6% in Edmonton (Bland, Newman, & Orn, 1988), it seems surprising that the majority of research conducted on family difficulties in dealing with mental illness has focused specifically on schizophrenia. Affective disorders are much more prevalent, with lifetime prevalence rates estimated as high as 17-20% (Hirschfield & Cross, 1982) and most recently estimated as 10.2% in Edmonton (Bland et al., 1988). Therefore, it appears that more families are experiencing the stressor event of a family member being diagnosed and treated for an affective disorder than for schizophrenia. This research will focus on the primary caregiver´s response to a relative diagnosed with an affective disorder.

Statement of the Problem

There has been some research on the impact of hospitalization of a mentally ill family member on the rest of the family. Also, the positive benefits of social support have been documented in the research on the families of the mentally ill, particularly on the use of support of mutual help groups (Anderson, 1977; Gartner & Reissman, 1981; Hatfield, 1981; Rose, Finestone, & Bass, 1985; Thornton, Plummer, Seeman, & Litman, 1981; Walsh, 1987). What has not been examined in past research is the interrelationships between the hospitalization of a family member who has an affective illness upon the coping of the primary familial caregiver and how social support to the caregiver impacts on this relationship. This thesis will explore the interrelationships between two stressor variables associated with affective disorder (chronicity and severity of that illness), the resources of social support, and one coping response of the primary caregiver to the stressful situation of hospitalization of the ill family member.

The general research question of this thesis is:

> What is the relationship between the chronicity and severity of the patient´s illness, perceived social support to the caregiver, and the coping response of the primary caregiver?

In order to address the broader question, the following questions are posed:

1. What is the nature of the chronicity and severity of the illness in the patients in this sample?
2. What is the nature of the acceptance/rejection response of the primary caregiver and how does this vary by diagnosis of patient, relationship to patient, and living arrangement?
3. What is the relationship of chronicity and severity of the patient´s illness with the

primary caregivers´ acceptance/rejection coping response?

4. What is the nature of the perceived social support available to the primary caregivers?
5. Are there any aspects of social support that influence the relationships of the primary caregivers´ coping response to the variables of chronicity and severity of the patient´s illness?

Definition of Terms

Throughout this thesis, the terms that will be utilized are defined as follows:

psychiatric patient/patient - the person who has been diagnosed and hospitalized for the treatment of an affective disorder.

affective disorder - disorder of mood as classified by the American Psychiatric Association´s (1987) criteria and diagnosis. This group includes patients with the following clinical diagnoses:

Manic episode
Major Depressive Episode
Bipolar Disorders
Cyclothymia

Major Depression

Dysthymia

<u>primary caregiver/primary familial caregiver</u> - the family member identified by the patient as the most emotionally supportive throughout the hospitalization.

<u>chronicity</u> - the relative degree of ongoing or unremitting nature of the symptoms associated with the affective disorder; may or may not include frequent relapses of symptoms.

<u>severity</u> - characteristic of an illness that describes the relative seriousness of the illness in terms of its symptomatology. That is, how much do the symptoms:

(a) markedly interfere with the individual's occupational or social activities and relationships with others,

(b) create more risk to the well-being of the patient, and/or

(c) contribute to the long-term outcome of the illness.

primary caregiver´s coping response - the caregiver´s efforts at managing the hardships of the situation of mental illness. This is measured in this research by the relative level of expressed acceptance/rejection towards the patient and/or the illness. This coping response of acceptance/rejection has been previously correlated with expressed emotion.

expressed emotion (EE) - expression of hostile or critical feelings towards the patient by family members.

social support - information and/or resources provided by other persons. The amount, types, and sources of social support provided to the primary caregivers´ will be focused upon in this research.

CHAPTER II - CONCEPTUALIZATION

The basic assumption behind the conceptualization of this research is that the identification of mental illness of an individual in the family and that individual´s subsequent hospitalization is a disturbing event for the family which must be responded to in some way. For this reason, the conceptual model to be used comes from family stress research and theoretical developments. This chapter will place the current study in the context of the larger domain of family stress research and outline the specific family stress model that will be used to guide this research.

Family Stress Research

The study of family stress and crisis has been an important area of research for at least 60 years. Boss (1987) and McCubbin et al. (1980) have indicated that Hill´s (1949, 1958) ABCX family crisis framework has continued to be the basis of family stress research since its conception 40 years ago. Research conducted since Hill´s original conceptualization has attempted "to identify which families, under what conditions, with what resources, and involving what coping behaviors are better able to endure the hardships of family life." (McCubbin et al., 1980, p.855).

The original ABCX model attempted to account for the variability in familial adaptation to stressful situations by focusing on the interacting variables of the stressor event (A), the family's crisis meeting resources (B), and the definition the family made of the event (C) in the production of the crisis (X). During their application of this model in a longitudinal study of families in crisis, McCubbin and Patterson (1982, 1983) found there were at least four additional factors that appeared to influence the course of family adaptation to crisis. By adding the four post-crisis variables to Hill's ABCX Model, McCubbin and Patterson (1982, 1983) have extended the original framework to the Double ABCX Model. The four factors that were added as post-crisis variables include:

> (a) additional life stressors and strains;
> (b) psychological, intrafamilial, and social resources families acquire and employ over time in managing crisis situations;
> (c) changes in definition and meaning families develop in order to make sense out of the stressful situation;
> (d) the coping strategies families employ (p.11).

These were added in an effort to describe the range of possible outcomes to the crisis. Because this research focuses on events that occur after the crisis of recognition of mental illness in one family member, the Double ABCX Model will be used (see Figure 1).

The Double ABCX Model

McCubbin and Patterson (1983) suggest that in order to best study the family's adaptation to stress, it is necessary to employ a multivariate model. In such a model, previously identified variables of a psychological, intrafamilial, and social nature would be examined together, in order to identify the individual and collective contribution of these variables. The purpose of this research is to examine the stressor of mental illness, specifically an affective disorder, in the family in a manner which examines the effects and interaction effects of certain variables. The variables associated with the pile-up of this stressor (chronicity and severity of illness), the perceived social support, and the familial caregiver's adaptive coping response will be examined for both direct effects and interaction effects (see Figure 2). Although the process of adaptation to the affective disorder in one family member will not necessarily be

Figure 1

The Double ABCX Model (McCubbin & Patterson, 1982)

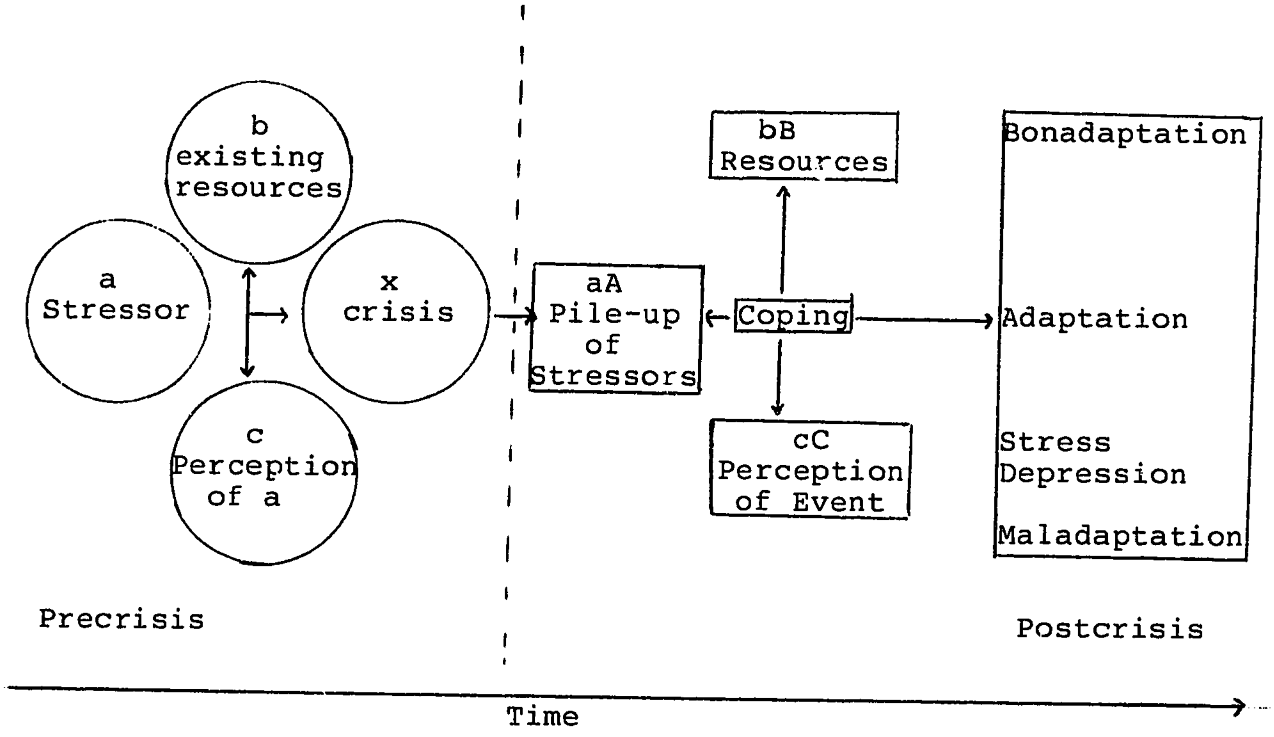

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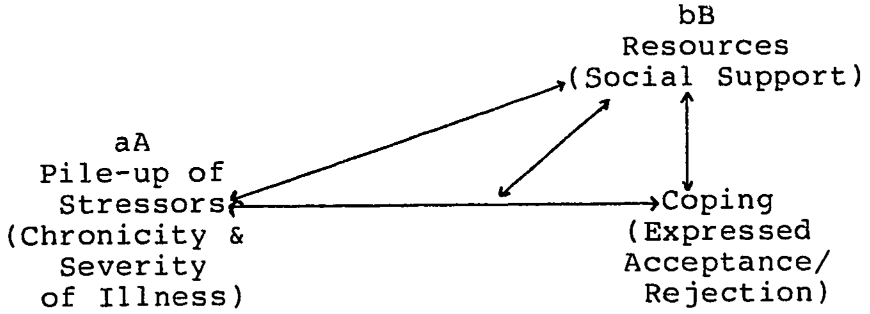
Figure 2

The Conceptual Model for This Study



captured by this research, the research will examine the interrelationships in a different manner than has been done previously. The specific parts of the Double ABCX Model that will be utilized in this research include the double A factor (pile-up), the double B factor (resources), and one coping response of the familial caregiver. Each part of the model to be used will be described in the following section.

The Double A Factor - Pile-up

Starting with the concept of "pile-up", the Aa factor in the Double ABCX Model, McCubbin and Patterson (1983) suggest that families are seldom dealing with single stressors, but rather experience a pile-up of stressors and strains. Boss (1987) defines chronic stressors as "stressful situations that have inherent qualities of long duration, high probability of pile-up with other events, and the potential of being highly ambiguous in etiology, development, and conclusion" (p. 700).

The chronicity of a family member's illness is considered to be one stressor that contributes to pile-up in the family system. The family is not just dealing with the illness of the family member, but other stressors as well. The more prolonged and complicated the illness, the more likely familial roles will be affected (Litman, 1974). The stressor of hospitalization of the ill relative has initial hardships upon the family system such as the need to arrange for child care, for disability pay from employers, or to redistribute household tasks. As the stressor situation persists or is unresolved (increased length of time in hospital and/or frequent readmissions to hospital), primary caregivers may feel additional strain and hardship in taking on the ill relative's roles and responsibilities within the family. For example, if the patient earns the primary source of income for the family, his or her absence from employment and lack of income may put considerable strain on the family's finances and may create hardships for all family members. The uncertainty or ambiguity of the patient's return to the family after hospitalization may also contribute significantly to the pile-up of stressors. The longer the ill relative is hospitalized and remains ill, the more ambiguous their role in the family may seem.

Another stressor that could be associated with the pile-up factor is the relative severity of the illness affecting the patient. That is, if the patient´s illness is more severe, this may be more (or less) stressful than if the illness was of a less severe nature. A high severity of mental illness occurs when an illness has more extreme or serious symptoms. If primary caregivers have to cope with considerably more intense symptoms such as suicidal thoughts/behaviors, or delusional thinking (false, persistent beliefs that are not substantiated by sensory or objective evidence), this may contribute to pile-up, especially if such symptomatology continues over time.

The Double B Factor - Family Adaptive Resources

Each family unit has many potential resources. These resources become important when mental illness is diagnosed and experienced by a family member. For example, economic security, health, intelligence, proximity to treatment, and a spirit of cooperation have all been identified as assets that the family members may draw upon at the time of crisis/stressful events (Boss, 1987). This research will specifically focus upon the family adaptive resource (the double B factor) of social support. Social support is generally viewed as playing a beneficial role in the process of adaptation to stress. For example, emotional support is repeatedly cited as being a correlate with emotional health (Leavy, 1983). On the other hand, Bruhn and Philips (1984) document that too much social support can have negative effects, such as stifling creativity and and spontaneity. Boss (1987) identified that having resources available does not imply how the family will use them. Because the availability and amount of resources such as social support are variables that can easily be assessed by researchers due to the ability to isolate these variables at a specific point in time, social support resources are often measured in this static manner (Boss, 1987). The main dispute in social support research is determining whether social support is directly related to coping in the stress process (McCubbin et al., 1980) or if it plays a protective or mediating role against the effects of stress (Alloway & Bebbington, 1987). In this study, the effects of social support as perceived by the primary caregiver will be examined for both direct effects and mediating or buffer effects.

The Family´s Adaptive Coping Response

Boss (1987) defines coping as the process of "managing to hold the degree of stress to a tolerable level" (p.695). Coping is a very complex process that has become more of a focal point in family stress research. Rather than focusing on why families fail to handle stress, researchers are becoming more concerned with why families succeed (Boss, 1987; McCubbin, 1979; McCubbin et al., 1980). Coping refers to what family members do with available resources, and the coping of familial members in the stressful situation is really an interaction of perceptions, resources, and behaviors (McCubbin & Patterson, 1983).

Coping has both cognitive, emotional, and behavioral components. Although Lazarus´ (1977) theoretical work on coping is directed to stress on individuals, his emphasis on cognitive reappraisal, emotional reaction, and coping behavior as components of the coping process is also relevant to family stress models such as the Double ABCX Model. An important part of the family coping response is an individual family member´s subjective definition of the stressful situation and perception of how it affects them. Often family members experience some emotional response as they are perceiving the stressor and this may bring about some action or behavior. In the stressor event of the hospitalization of a relative with an affective disorder, the coping response of expression of hostile or rejecting feelings (expressed emotion) towards the patient/illness have been documented (Hooley, Orley, & Teasdale, 1986; Vaughn & Leff, 1976). The relative level of accepting/rejecting feelings expressed will be the specific coping response that this research will explore.

An acknowledegment must be made that family coping is distinct from the coping of individual members (Gilliss, Rose, Hallburg, & Martinson, 1989). Individual coping takes into account the perceptions and assessments made by the individual, dependent upon his or her internal psychological state as well as external factors (McCubbin et al., 1980). Family coping is much more complicated, involving the balancing of behaviors and strategies that will benefit the family as a unit, but also needing to promote individual members' growth and development (McCubbin et al., 1980). In spite of the differences between the individual level of coping and the group level of coping in the family system, family coping is often dependent on the coping of individuals within the family system. Thus, the perceptions and expressed feelings of the primary caregiver about the patient and their illness will be utilized as an indication of coping response in this research.

In summary, this research will utilize the Double ABCX Model of the family stress process in order to more completely explore and understand specific elements that are involved in the crisis of hospitalization of one family member for the treatment of an affective disorder and one coping response of the primary caregiver. The specific parts of the model that will be utilized include the pile-up factors (Aa factor) of chronicity and severity, the resource (Bb factor) of social support that is perceived available by the primary caregiver and the coping response of acceptance/rejection by the primary caregiver.

CHAPTER III - LITERATURE REVIEW

In order to fully understand the relationships that are to be investigated, as well as to place the research questions in the context of previous research, two separate bodies of literature need to be reviewed. First, the research on mental illness and family relationships will be examined. Although theories and research on families of the mentally ill originated prior to Freud's work, the majority of this research proliferated with the deinstitutionalization movement of the 1950's and has continued to increase since that time. The main themes and findings from this literature, including the review of the coping responses of family members to the stressor of mental illness, will be summarized. The second body of literature that will be reviewed is the research investigating the relationships between social support and mental illness. A specific focus on the role of social support for caregivers of family members with a mental illness will be taken when reviewing this area of research.

Mental Illness and the Family

The family members of the mentally ill have always been affected by their relatives´ illnesses. In her documentation of the changing philosophy of care for the mentally ill, Hatfield (1987) acknowledged that society´s views of mental illness and recommended treatment has affected family members and their role in caregiving for centuries.

> "Originally families were the sole source of care and the community took little responsibility; then a movement toward institutional care removed most patients from the home in the 19th and early 20th centuries; and finally, in another sharp reversal in the 1950´s, home and community were once again the favored place and patients were rapidly deinstitutionalized" (Hatfield, 1987, p.4).

In spite of the crucial role that the family plays in the caregiving of the mentally ill, the research with the families of the mentally ill has been relatively recent and appears to have three central themes:

(1) the family has certain responses or reactions to living with a mentally ill family member,

(2) the family experiences many burdens associated with caring for a family member who is mentally ill, and

(3) the family plays an influential role in the etiology and outcome of the mental illness of one family member.

The literature will be summarized within these three themes, and the major findings highlighted in each area. Any specific problems within that particular research will also be discussed. In addition, the literature on severity and chronicity of mental illness and the potential role these factors have upon the adaptive coping response of the family to mental illness will be reviewed.

Families of the Affectively Disordered Patient

Most research with families of the mentally ill has focused on families whose mentally ill member was diagnosed with schizophrenia or some other undefined mental illness. However, there has been much less research dealing with families of patients with affective disorders. Coyne, Kahn, and Gotlib (1987) suggest that the lack of research examining the families of patients with affective disorders may be related to a bias within psychiatry and psychology to consider depressed patients in isolation and without an interactional context. As family theories initially evolved with studies of schizophrenia, it is logical that the majority of research became focused on that illness (Chelsa, 1989). Chelsa (1989) states that the lack of focus on the families of patients with an affective disorder is likely due, in part, to the success of research and treatment with individual biologic models in these types of illnesses. Thus, the absence of research may not be as much a resistance to considering psychosocial contexts of depressed patients by psychiatry, as related to the relative success in clinical outcomes of patients with depression when treated with biological or somatic treatments. As well, it must be recognized that the illness of schizophrenia was overdiagnosed in North America during the 1950's through to the 1970's (Warneke, 1985), thus increasing the apparent incidence and subsequent research in the area.

Whenever possible, specific research on the families of affectively disordered patients will be reviewed. Due to the lack of extensive research in this specific area, the literature on families of patients with schizophrenia or other mental illnesses will also be reported in each section.

The Family as a Reactor to Mental Illness

Up until 1955, there was very little published literature dealing with the impact of mental illness on the family. The deinstitutionalization movement transferred the care of the mentally ill to the community, and most often the family became the community caregiver (Goldman, 1982; Kane, 1984). Since Clausen and Yarrow´s (1955) initial study of the process of adaptation of the family to mental illness, several other attempts have been made to describe this process (Asai, 1983; Doll, 1976; Freeman, 1961; Freeman & Simmons, 1958a; 1958b; 1959; Gubman, Tessler, & Willis, 1987; Hatfield, 1978; Kane, 1984; Kreisman & Joy, 1974; Lamb & Oliphant, 1978; Leavitt, 1874; Lefley, 1985; Lewis & Zeichner, 1960; Rose, 1959; Rose, 1983). Plagued with inconsistency in methodology, samples, definitions, and criteria for measurement of variables, the findings of these studies are generally impressionistic, inconsistent, and descriptive rather than explanatory (Kreisman & Joy, 1974). The similarity that runs throughout the studies though, is the focus on the family as a reactor rather than a causal agent in the process of adaptation to mental illness. This research has concluded that families have continued to care for their ill relative inspite of considerable physical and emotional hardship, uncertainty, and lack of direction about the future.

In their comprehensive review of the literature on family response to mental illness, Kreisman and Joy (1974) document that shame and social rejection of the patient were the two most common familial responses investigated. Although researchers often looked for reactions of shame from such families, it was not a prominent response of the family members who were sampled. Social rejection was examined in reports of social distance, visiting patterns, and the willingness of the family to accept the psychiatric patient back into the home (Clausen & Yarrow, 1955; Freeman & Simmons, 1965; Kreisman & Joy, 1974; Rose, 1959). In terms of social distance, Kreisman and Joy (1974) concluded that there was a slight trend for people who have had close contact with the mentally ill to be less rejecting than those without previous experience with the mentally ill. With regard to visiting, Rose (1959) discovered that younger patients and those with fewer years of hospitalization had more family contact through visiting, especially when the principal visitor was a parent rather than a spouse. Clausen and Yarrow (1955) found a contrary pattern in that spouses and children visited more often than parents and in-laws in their sample.

Kreisman and Joy (1974) suggest that investigation of "the relationship between visiting and the propensity to accept the patient on discharge would appear to yield a useful index of attachment or rejection to the patient" (p.45). They documented mixed findings on the willingness of families to accept the patient back into the home. Rose (1959) stated that although most families were verbally agreeable to the idea of discharge, they showed resistance to take the patient home once discharge was a reality. He also found that reluctance to take the schizphrenic patient home increased with the number of years the patient had spent in hospital. In contrast, Freeman and Simmons (1963) found that 95 percent of the family members they studied wanted the patient to return home. Brown, Bone, Dalison, and Wing (1966) reported similar results in that 90 percent of the families in their sample welcomed and accepted the patient home, in spite of having had recent experience with severe symptoms (in 30% of the cases) and patients who had multiple readmissions (in 59% of the cases). Kreisman and Joy (1974) conclude that "both social acceptance and rejection has been reported in the literature, but the overall impressions seem to differ, depending on the values and experiences of the researchers" (p.47).

One problem with the research on the familial response to living with the mentally ill member is related to the inconsistent methods used by researchers. Because the process of adaptation to the mental illness of one family member involves an extremely complex set of interacting variables, early critics recommended multivariate research which looked not only at main effects but also the interaction effects of variables (Kreisman & Joy, 1974). This recommendation has yet to be actualized as recent studies continue to explore responses through descriptive studies without conducting follow-up studies to test specific relationships and interrelationships between variables. This research will attempt to look at multiple variables for both direct and interacting effects in order to better demonstrate the complexity of the process of adaptation to affective disorder of a family member.

The process of adaptation has often been looked at in terms of the familial or specific family members' coping response. It must be acknowledged at this point that the coping response of acceptance/rejection is only one of a multitude of possible coping responses that family members may exhibit toward the patient or their illness. Lewis and Zeichner (1960) observed that the coping response of denial was so prominent in some family members that it was a physician or someone else external to the family who recognized that the patient was ill. Kreisman and Joy (1974) document that a reaction of fear has been evident in family members of patients who have extremely bizarre or unpredictable symptoms. Some researchers have identified families who cope by attempting to hide the diagnosis of mental illness from individuals outside the family (Clausen & Yarrow, 1955) whereas others have refuted this (Freeman & Simmons, 1961; Rose, 1959). Although there is value in exploring these other coping responses which family members possibly make to the patient or their illness, the specific coping response of acceptance/rejection has particular salience as it has been linked with the patient´s illness outcome. It is therefore important to examine this coping response in terms of other variables that may have influences on this process of adaptation.

The Burden on the Families of the Mentally Ill

A small body of research has focused on the effect that the patient´s illness has on the family in terms of burden (Creer, Sturt, & Wykes, 1982; Fadden, Bebbington, & Kuipers, 1987a; Grad & Sainsbury, 1966; Hatfield, 1979; Hoenig & Hamilton, 1966; Kuipers & Bebbington, 1985; Potasznik & Nelson, 1984; Thompson & Doll, 1982). Burden has been defined in various ways but generally refers to "the presence of problems, difficulties, or adverse events which affect the life(lives) of the psychiatric patient´s significant other(s)" (Platt, 1985, p.383). As pointed out by Gubman & Tessler (1987), this burden is in excess of what is typical or expected for that kin, age, and gender.

Fadden et al. (1987a) summarize that the major findings of the burden research with families of patients with schizophrenia or other mental illnesses are:

(a) that family members typically tolerate a great deal of difficult behavior, with the less clear-cut symptoms of illness being the most frequent and difficult to bear,
(b) that family members lack knowledge about the nature of the patient´s illness but receive little help from professionals in managing this,
(c) that family members who are coping with an ill

relative frequently experience adverse effects on their own physical and psychological health.

There are similarities in the findings of the burden research conducted with families of affectively disordered patients. What appears to be most profoundly burdensome to families of individuals with affective disorders are the "negative symptoms" (Fadden et al., 1987b; Jacob, Frank, Kupfer, & Carpenter, 1987; Kuipers, 1987). Negative symptoms are those symptoms which are felt to be lost normal behaviors such as apathy, decreased interest, diminished energy, and poor communication. These are the symptoms that are reported as difficult for relatives to understand and tolerate. Anderson et al. (1986) state that "depressive behaviors are less likely to be viewed as symptoms of illness than behaviors of schizophrenia and are more likely to be viewed as negative personality traits or to be thought of as willful" (p.188). These same authors hypothesize that while a depressed patient may be less stigmatized and less embarrassing to the family than the schizophrenic patient, the interpersonal impact of the illness may be greater and even more burdensome than schizophrenia.

Several researchers found that relatives living with the depressed patient reported more burden than noncohabitating relatives (Coyne et al., 1987; Fadden et al , 1987b; Jacob et al., 1987). Fadden et al. (1987b) reported that female relatives reported more burden than male relatives. Targum, Dibble, Davenport, and Gershon (1981) noted that there may be a tendency for relatives of more chronically ill bipolar patients to report more profound burden. Miller, Kabacoff, Keitner, Epstein, and Bishop (1986) found that families of depressed patients report more severe and consistent impairment than families of other diagnostic groups.

The major assumption made by researchers in the burden research is that the caregiving of the patient by the family members is a negative experience. Family members that view the caregiving in terms of providing concern and support to their ill relative may be prompted into reporting their caregiving as burdensome when answering questionnaires that are worded in a negative fashion (Chelsa, 1989). Also, the family members of psychiatric patients sampled in the burden studies are often involved in support groups or self-help groups. Because the make-up of such groups generally includes very verbal and knowledgeable families, their reports of burden may not reflect the experience of all families and may even bias the results of these studies.

The present research will not address the effects that the psychiatric patient's illness has upon the family in terms of burden. Although the burden studies have found consistent patterns of impairment in the family interaction when coping with the illness of a relative, these findings are only looking at the impact of the illness on the other family members. This study will focus on the impact of the illness on the familial caregiver in terms of the expressed emotion (EE). (This particular coping response is more desirable to study in that it has previously been shown to have an impact on the patient's illness outcome.) EE has not been examined in previous research from the point of view that it may be the coping response to the illness rather than as an etiological factor in the outcome of illness. The next section will outline the familial coping response of EE.

The Family in Etiology and Outcome of Mental Illness

Early research and theories on the family in relation to the mental illness of a relative focused on the family processes that may have an effect on either the etiology or outcome of the disorder. Falloon, Boyd, and McGill (1984) document that beginning with Freud, it was suggested that harsh child rearing methods contributed to the development of "delusional disorders". One of Freud's followers, Sullivan (1927), postulated that patients diagnosed as schizophrenic needed corrective family experiences. Fromm-Reichmann (1948), a student of Sullivan, continued to implicate the family as a crucial factor in the development of schizophrenia with her description of "the schizophrenogenic mother". Four prominent family theorists, Bateson (1956,1968), Lidz (1965), Bowen (1960), and Wynne (1958, 1965, 1981) began to build theoretical justification for this theory. This work was reviewed by Chelsa (1989) who summarized:

> "Each suggested that a particular pattern of family relations might cause schizophrenia in a family member. Although many family factors, such as patterns of power, role relationships, and family structure were thought to contribute to the disorder, only disordered family communication has been consistently linked to schizophrenia in a family member" (p.382).

Thus, the structure of communication within the family has been considered in terms of its potential role in the onset of schizophrenia in the family.

With regard to affective disorders, Kuipers (1987) reviewed the theories that suggest certain family interactions may be "depressogenic", that is, cause the depressive symptomatology. Research on high levels of negative communication in couples, one partner of whom is depressed, has led to the development of terms such as "the melancholy marriage" (Hinchcliffe, Hooper, & Roberts, 1978). More recent research examined family factors which influenced the onset, course, and vulnerability of affective disorders in the offspring of depressed patients (Beardslee, Bemporad, Keller, & Klerman, 1983; Buckwalter, Kerfoot, & Stolley, 1988; Keller, Beardslee, Dorer, Lavori, Samuelson, & Klerman, 1986; Laroche, Sheiner, Lester, Benierakis, Marrache, Engelsmann, & Cheifetz, 1987). These studies not only focus on the structure of family communication as a contributing factor, but also focus on other factors related to the marital communication, characteristics of the depressive disorder affecting the parent, and resources available to the child at risk. Although these studies have been consistent in their findings that children from families where a parent has a mental illness are significantly impaired and at risk for developing an affective disorder, follow-up studies of these children into adulthood are needed to determine actual outcomes (Beardslee et al., 1983).

In addition to the theories and empirical research that suggest that the structure of the communication in the family may potentially bring about the onset of the illness, another group of researchers have examined the emotional quality of family communication and its contribution on the course of the family member´s illness (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976; 1981; Vaughn, Snyder, Jones, Freeman, & Falloon, 1984). The emotional quality examined is called "expressed emotion" (or "EE"). The EE studies measure the number of critical comments, hostile remarks, and estimates the degree of emotional overinvolvement of the closest relative or significant other with the patient. High levels of EE by the family member considered most significant to the patient with schizophrenia has been shown to be positively correlated with relapse and readmission.

The role of EE has been minimally explored in the families of individuals who are diagnosed with an affective disorder (Hooley, Orley, & Teasdale, 1986). Vaughn and Leff´s (1976) original research on EE with schizophrenics found that depressed patients used as controls were also sensitive to critical comments made by their spouses and that this was predictive of relapse. Hooley et al. (1986) replicated this study and found similar rates of relapse and readmission in depressed patients with expressive relatives who were critical. This replication study also confirmed the earlier finding that depressed patients relapsed with lower levels of criticism than schizophrenic patients. Hooley et al. (1986) speculated that this increased sensitivity to criticism "may be less a reflection of diagnosis than of domestic situation" (p.646). That is, depressed patients are more likely to be living with and involved with a spouse than with parents, whereas schizophrenic patients are usually interacting with parents (Coyne et al., 1987; Hooley et al., 1986).

Hooley et al. (1986) propose that some possible explanations for the increased sensitivity of depressed patients include:

(a) that repeated and habitual criticism from parents over a developmental period makes later criticism less distressing, and perhaps patients whose caregiver is a parent are therefore desensitized to criticism,

(b) that there is increased probability of termination of a conjugal relationship when compared with the termination of a parental one, therefore criticism from a spouse may be perceived as more threatening and risky to the patient,

(c) prior problems in the marital relationship may increase feelings of insecurity that occur with criticism from spouses.

In addition to the lack of explanation for the increased sensitivity to criticism by depressed patients, it does not appear that there has been a comparison of the amount of criticism from spousal caregivers as opposed to other familial caregivers (parental, sibling, or other relationship). It is unknown whether any particular type of familial caregiver is potentially more or less critical than another.

The major problem with the research on the family´s role in the etiology and outcome of the mental illness of one family member is the assumption that the onset or outcome of the individual´s mental illness is the dependent variable (Gerace, 1988; Steinglass, 1987). That is, family factors play a `causal´ role in the development or exacerbation of the illness in one member. What these studies fail to acknowledge is that:

(a) the reverse may be true. That is, "patterns of communication may be reflective of living with the disease rather than causing the disease" (Chelsa, 1989, p.383),

(b) other variables such as the individual´s psychological and biological makeup may be intervening in the relationship,

(c) this pattern of family factors is only one part of a larger process of interacting variables and the full impact of each factor cannot be studied without considering the many other interacting variables.

Focusing on the patient or illness related factors as outcome variables also creates problems. For example, defining relapse as rehospitalization, excludes all those individuals that may have relapsed but who were not admitted. Many depressed patients become "quietly ill" and withdraw. Patient or illness related factors may contribute to the overall process of adaptation in the family and by examining them only as the outcome of adaptation restricts full examination of their possible effects. Therefore, the present study will use the patient and illness factors, chronicity and severity, as independent variables.

The Severity of Mental Illness and the Family

The severity of an affective disorder has been minimally studied in terms of the impact it may have on the adaptation of family members to the stressful situation. Keitner, Baldwin, Epstein, and Bishop (1985) reviewed family functioning in affective disorders and commented that an acute or severe episode of an affective disorder is often accompanied by significant family dysfunction. These authors further stated that "in many cases, these disturbances in family functioning tend to resolve as the affective episode passes or is treated" (p.429).

Because the role of the severity of an affective disorder has not been strongly established in research, this study will attempt to examine the possible role it may play in the primary caregiver´s coping response in the event of the hospitalization of a depressed patient.

The Chronicity of the Mental Illness and the Family

Affective disorders appear to be less benign in course than previously believed (Cassano, Maggini, & Akiskal, 1983). That is, clinical experience and research now indicates that although most patients do recover from episodes of depression, a substantial number do not recover and suffer a chronic form of the illness (Fadden et al., 1987; Jacob et al., 1987; Keller et al., 1984; Kuipers, 1987). Keller et al. (1984) report that estimates of the rate of chronicity varies from 1 - 28%.

Chronicity is typically defined by the presence of depressive symptomatology that is nonremitting for a period of two years or more (Akiskal, 1982; Cassano et al., 1983; Keller et al., 1984). Billings and Moos (1984) state that chronicity is not only due to unremitting symptoms but also to recurring episodes of illness. Research on chronicity often focuses on it as the dependent variable and tries to determine what psychosocial variables predict the unremitting and recurrent nature of depression (Akiskal, 1982; Billings & Moos, 1984; Cassano et al., 1983; Garvey, Tolleston, & Tuason, 1986; Hirschfield, Klerman, Andreason, Clayton, & Keller, 1986; Keller et al., 1984; Scott, Barber, & Eccleston, 1988). There is some indication that a long period of illness prior to initial assessment and treatment may be the most reliable predictor of a chronic course (Hirschfield et al., 1986; Keller et al., 1984). Others state that the number of previous illness episodes (Billings & Moos, 1984; Garvey et al., 1986), especially in females Scott et al., 1988), and a familial history of an affective disorder (Akiskal, 1982; Scott et al., 1988) have been associated with a chronic course of the illness. A recent study (Scott et al., 1988) showed an increased incidence of undesirable or negative life events to be associated with chronicity, although previously this had not been shown to be significant (Billings & Moos, 1984). Age of onset is also an uncertain predictor of chronicity. Garvey et al. (1986) clearly found that chronic depressives had an earlier age of illness onset, although Akiskal (1982) and Keller et al. (1984) found age not to be significant.

The research does not provide a clear answer to the question of what impact, if any, does the chronicity of the patient´s illness have upon the family members´ coping response. While researchers have estimated that affective disorders take a chronic course in up to 20% of all cases (Goldman, 1982), there is no clear picture of what this means in terms of family coping.

Jacob et al. (1987) specifically sampled family members of patients who had recurrent depressive disorders in order to study the burden experienced by them as well as their attitudes and beliefs about the illness. These researchers compared cohabitating family members' responses to noncohabitating members' responses, and found that spouses (85% of the group) who lived with the patient and other family members who lived with the patient reported greater distress in terms of worry, annoyance, and discouragement than the individuals who did not live with the patient. Unfortunately, Jacob et al. (1987) did not compare responses of family members with a chronically ill relative to responses of family members with a nonchronically ill relative. Targum et al. (1981) studied 19 ccuples in which one partner had been diagnosed with a bipolar illness. They make an anecdotal note that the longer the well spouse had coped with the illness, the more likely he or she was to perceive the illness as disruptive and burdensome. This has not been tested further. Krantz and Moos (1981) attempted to determine if spouses of remitted affectively disordered patients do as well or better than spouses of nonremitted affectively disordered or controls. Although they found that spouses of patients who remained ill (nonremitted) had significant impairments that slightly worsened at follow-up, Krantz and Moos (1981) did not find any improvement in either the remitted spouse group or the control group.

As with other chronic illness, there is evidence that suggests that family members are most influential in providing support to an individual experiencing chronic mental illness (Stuifbergen, 1987). The literature on affective disorders identifies that both spouses and parents are supportive in caregiving whereas the literature on schizophrenia and other mental illnesses focus on the support and caregiving of parents, especially mothers. Not only are family members identified as an important source of support to patients during their hospitalization for the illness, there is also evidence that the social support perceived by family members may have an impact upon how well the family members cope with that mental illness. This literature will now be reviewed.

Social Support

Research on the influence of social support upon the individual´s or family´s adjustment to specific stressor events has focused on the direct effects, as well as the interactive or buffering effects of social support (Broadhead et al., 1983; Brownell & Schumaker, 1984). The literature on social support will be reviewed in terms of theoretical development and conceptualization, which will lead into the specific research applications of social support in mental health and families of the mentally ill.

Development and Conceptualization of Social Support

Durkheim´s (1951) research on suicide began the examination of the protective or beneficial role played by close relationships (social support) on the well being of individuals. This protective and beneficial function of close relationships may be termed social support. As outlined by Gottlieb (1983), research in North America historically has focused and bolstered the continued study of social support. Such research recognized that individuals with emotional problems often sought assistance from family, friends, and religion prior to seeking help from professionals. Three papers in the mid-1970´s (Caplan, 1974; Cassel, 1976; Cobb, 1976), reviewed the mounting evidence that social support had direct effects on health status as well as serving as a buffer against the effects of psychosocial and physical stress on the mental and physical health of an individual. Health and well-being was believed to be enhanced directly by the perception of social support irrespective of the stress level experienced by the individual. Cohen and Syme (1985) indicated that a perception that others are willing to help could result in increased overall positive affect, elevated sense of self-esteem, and an increased stability and control over the environment that may in turn influence susceptibility to illness through physiological functioning or changes in health promoting behaviors. Social support is also believed to have buffering effects which protect individuals from the pathogenic effects of stress. For example, social support may buffer the impact of a stressful experience by reducing the importance of the perception that a situation is stressful, by tranquilizing the physiological systems so that individuals are less reactive to perceived stress, or by facilitating healthful behaviors such as exercise, nutrition, or rest. Since the mid-1970's, research on social support and health has proliferated within many disciplines, including the field of mental health.

Social support is not a one-dimensional concept but consists of multiple elements that interact with one another. Cohen and Syme (1985) have differentiated these particular elements as structural or functional. Structural elements of social support are described as the more `objective´ interconnections of social ties or networks, such as marital status or the number of relationships with others. Functional elements are described as the subjective, perceptual, or psychological representations of social support, such as provision of affection or financial assistance. Although the value of ´objective´ measures of actual interactions or contacts with social ties has been documented (Cohen & Syme, 1985), House (1981) suggests that "social support is likely to be effective only to the extent that it is perceived" (p.27).

Additionally, social support can be differentiated into types or kinds of support which are available from many potential sources (Cooke, Rossman, McCubbin, & Patterson, 1988). Definition and differentiation of the types or kinds of social support has varied widely among researchers. Broad types that have been identified include:

(a) emotional or affectional support - provision of empathy, caring, love, and concern (Caplan, 1974; Cobb, 1976; Cooke et al., 1988; House, 1981; Kahn

& Antonucci, 1980; Wills, 1985),

(b) esteem support - provision of value and respect (Cobb, 1976; Cooke et al., 1988; Wills, 1985).

(c) network or companionship support - provision of sense of belonging and mutual obligation (Cobb, 1976; Cooke et al., 1988; Wills, 1985).

(d) appraisal or affirmational support - provision of affirmation feedback, social comparison, and self-evaluation (Cooke et al, 1988; House, 1981; Kahn & Antonucci, 1980; Wills, 1985).

(e) instrumental support - provision of aid in kind, money, time, or any direct help (Caplan, 1974; House, 1981; Kahn & Antonucci, 1980; Wills, 1985).

The potential sources from which individuals obtain social support generally depend upon each individual´s social network. Cooke et al. (1988) define a social network as "a unit of social structure that includes persons or groups and ties of emotional support which connect the individuals or groups" (p.212). As recommended by these authors, any assessment of social support should consider the various kinds of support from as many potential sources that are available.

The consideration of the different elements of social support has been applied in the study of social support and mental health. As pointed out by Kessler and McLeod (1985) in their review, specific research on social support and mental health has grown. Leavy (1983) differentiates five research strategies which have been utilized to examine the role of social support in mental health:

(a) comparing clinical populations to ´normal´ populations,

(b) examining only those with specific forms of illness,

(c) assessing support systems of the general population,

(d) studying the coping responses of those who have experienced the same stressful life events,

(e) differentiating coping responses by demographic variables such as gender.

Whether the research method samples clinical vs. nonclinical populations, populations with specific disorders or those who have experienced specific life events, one finding has been consistently reported: "the absence of social supports is associated with increased psychological distress" (Leavy, 1983, p.15).

Due to the wide variation in theoretical, methodological, and interpretational strategies used in the area, there is still uncertainty as to the extent which social support acts directly upon or buffers the effects of mental illness.

The direct effects hypothesis argues that support enhances mental health and well-being irrespective of stress level (Cohen & Syme, 1985). These direct effects generally occur when examining the degree to which a person is integrated into a social group. The stress-buffering hypothesis argues that only when stressful life conditions are severe will social support differentiate between people who adapt well and those who adapt poorly (Potasznik & Nelson, 1984). Thus, social support will protect or buffer the effects of the stress that may contribute to the development or exacerbation of mental illness at higher levels of stress.

Social Support and Mental Health

Although it has been suggested that social support can protect an individual against mental illness (Andrews, Tennant, Hewson, Schoenell, 1978; Billings & Moos, 1981; Gottlieb, 1983; Kaplan, Cassel, & Gore, 1977; Kessler & McLeod, 1985; Leavy, 1983; Lin & Dean, 1984; Lin, Simeone, Ensel, & Kuo, 1979; Miller & Ingham, 1976; Wilcox, 1981), most studies focus on the illness of an individual as the outcome of stressful life events or stressors. Family stress research has examined familial coping in the event of various stressors. For example, Boss (1987) documents that mental stressors such as the birth of a child (Ventura & Boss, 1983), unexpected stressors such as a nuclear accident (Bartlett, Houts, Byrnes, & Miller, 1983), cr chronic stressors such as having a family member with a dementing illness (Stephens, Kinney, Norris, Ritchie, & Grotz, 1988) have been examined in terms of how social support assists in the adaptive coping of family members to such stressful events. Other than a single descriptive study by Potasznik and Nelson (1984), there does not appear to be any investigation of mental illness as the stressor event and the impact that social support has, if any, on the coping response of the family members to this illness. In other words, the role of social support provided BY the family members to the mentally ill individual has been well-investigated but the role of social support TO the family members during the mental illness of one member has not.

Study of social support as a resource during the experience of a stressor within the family has evolved out of family stress theory which was reviewed in the previous chapter. Although some thecretical conceptualizations of the resources of social support to the family have been developed (Boss, 1987; Cooke et al., 1988; McCubbin et al., 1988), Kane (1988) points out that little investigation of the family social support system has occurred due to the difficulty in directly applying the concepts relating to social support of individuals to the social support of the family unit.

The beneficial role of social support to groups of families of the mentally ill has been well-documented only in relation to the clinical application of social support through mutual-help or support groups (Anderson, 1977; Atwood & Williams, 1978; Gartner & Reissman, 1981; Hatfield, 1981; Huberty, 1974; Rose, Finestone, & Bass, 1985; Shapiro, Possidente, Plum, & Lehman; Thornton, Plummer, Seeman, & Littman, 1981; Walsh, 1987). Gottlieb (1985) has argued that intervention experiments should be grounded in knowledge, or at least strong inferences, about which specific aspects of support are likely to be helpful. The application of support through groups was initiated without specific investigation of the impact that social support has on the family's coping in the event of hospitalization of an ill relative. In spite of the lack of investigation regarding the kinds, sources, and amounts of social support that may benefit these families, there has been a proliferation of guidebooks written, extolling the virtues of social support for the families of the mentally ill through group applications (Bernheim, Lewine, & Beels, 1982; Group for the Advancement of Psychiatry, 1986; Hatfield, 1986; Hatfield & Lefley, 1987; Kanter, 1984; Levitt, 1982; Wasserman & Danforth, 1988; Vine, 1982; Yogman & Brazelton, 1986). These group applications have been reported to be helpful by participants but there has yet to be full investigations and systematic evaluations as to why they are helpful.

In summary, the literature on social support and mental health has found evidence that social support may protect an individual against mental illness. What previous research has failed to investigate is the role of social support when it is provided to the family members who are experiencing the stressor of an affective disorder in a family member. Although applications of social support through group interventions have been implemented in clinical practice and are documented in the literature, there has been little investigation regarding the kinds, sources, and amounts of social support that may benefit the family members who are providing caregiving for the patient. Thus, the present research will attempt to specifically explore the impact of the different amounts, kinds, and sources of social support on the accepting/rejecting coping response towards the patient/illness of affective disorder by the primary familial caregiver.

CHAPTER IV - METHODOLOGY

This chapter includes a description of the research methodology used to address the research questions. The research design will be reviewed and explained. The remainder of the chapter will include a description of the selection process and characteristics of the sample, a review of the procedures by which the data were collected, a description of the instrumentation utilized, as well as the planned statistical analysis of the data.

Design

The research utilized a survey design. Three independent variables were examined - the chronicity and severity of the affective illness of the patient and the perceived social support available to the primary caregiver of the patient. The family member's coping response, as measured by the expressed acceptance/rejection of the primary caregiver, was the dependent variable.

Sample

The population under study included the primary caregivers of those patients hospitalized with a diagnosis of affective disorder in a major hospital in Edmonton. All patients from that particular diagnostic group admitted during a four week period (November 16 - December 14, 1988) were approached by the researcher. Out of the 71 patients admitted with an affective disorder during this time, 43 patients identified primary caregivers and gave written informed consent (Appendix 1) to have that person contacted for the study. Thus, the sample included 43 patient - primary caregiver pairs.

Although all patients admitted during the specified period were approached, there may have been some selection factors that occurred prior to the hospitalization that may threaten the external validity of the study. These selection factors may include limitation to only patients who are treated by psychiatrists with admitting privileges to that particular hospital or to those patients who live within proximity of the hospital who were admitted through the emergency department. An additional selection factor may have been that only those patients (or caregivers) who had the ability to seek out and ask for help received assistance in the form of hospital admission. As well, the external validity of this study has limitations in that 28 primary caregivers who were approached did not participate.

Procedure for Data Collection

Once written informed consent to contact the primary caregiver was obtained from each patient (Appendix 1), the researcher requested the name and telephone number of the family member who was most supportive to the patient. If the patient could not identify a family as primary caregiver, they were then asked if they had a nonfamilial relationship with any other person who they felt played a supportive, caregiving role. Initial telephone contact with each primary caregiver allowed the researcher to make arrangements to meet at the primary caregiver's convenience, usually on the next occasion that the caregiver would be at the hospital to visit the patient.

The researcher met with each primary caregiver individually in a private room adjacent to the psychiatric unit where the patient was hospitalized. After being given a full explanation of the project, including the assurance of confidentiality of responses from both the patient and the mental health professionals on the treatment team, a written consent was obtained from each primary caregiver (Appendix 1).

A five-part structured questionnaire which was developed for this study (and which will be described in the section on instrumentation) was completed by the primary caregiver in all but three cases. In three cases, the researcher recorded the caregiver's verbal responses to questions due to the caregiver's difficulty in reading and writing English. The researcher remained in the interview room with each of the caregivers and was available to answer any questions related to the questionnaire. The caregivers were directed to refer any questions that were unrelated to the questionnaire back to the attention of the patient's psychiatrist or nurse. The questionnaire took 30-45 minutes, on average, for the caregiver to complete. The data collected for the primary study were utilized for a needs assessment of the primary caregivers of psychiatric patients and have been reported previously (Damberger, 1988).

The remainder of the data were collected through retrospective analysis of the health records of the psychiatric patients within six months of the original data collection. The protocol for the needs assessment project as well as the additional retrospective analysis were assessed and approved by the Research Assessment and Priorities Committee at the participating hospital.

Instrumentation

A five-part structured questionnaire was developed and pretested for use for the needs assessment project (Damberger, 1988). Although the full instrument was was utilized in the first stage of the data collection for this research, only those measures that relate directly to this portion of the study will be described.

Demographic Information about the Primary Caregiver.

This section included a series of seven questions regarding the characteristics of the primary caregiver (sex, age, marital status, current employment status, level of education, relationship to patient, and whether they were currently living with the patient) (Appendix 1).

Patient Rejection Scale (PRS).

This instrument was comprised of an 11-item self-report scale developed by Kreisman, Simmons, and Joy (1979) which has been used to measure the primary caregiver´s expressed acceptance/rejection of the patient and/or the illness. The responses to the questions range from 1 "least rejecting", 2 "moderately rejecting", and 3 "highly rejecting". Responses on the 11 items are summed into a total rejection score. A high score reflects a highly rejecting response. The scale demonstrates a moderately high reliability, with coefficient alpha of .78 (Kreisman et al., 1979). The test-retest correlation is .72. The construct validity has been evaluated favorably in terms of correlation with other scales and indices of expressed emotion such as the Camberwell Family Interview (Vaughn & Leff, 1976). (Appendix 1).

Social Support Inventory.

McCubbin et al. (1982) developed this 60-item scale to measure the amounts, kinds, and sources of social support that individuals perceive themselves to be receiving. Cooke et al. (1988) define the five kinds and twelve sources of social support that this scale measures. The five kinds of social support are:

1. Emotional Support - information which leads you to believe that you are cared for and loved as a person.
2. Esteem Support - information that leads you to believe that you are valued and respected for who you are and what you do.
3. Network Support - information which leads you to believe that you receive a sense of trust and security for belonging to a group to whom you are also obligated.
4. Appraisal Support - information which provides you with feedback about how you are doing and ideas for resolving difficulties.
5. Altruistic Support - information which leads you to believe that you are worthwhile because of what you have done with and for others.

(Cooke et al., 1988, p.213).

The twelve potential sources of social support, as identified by Cooke et al. (1988) are:

1. Spouse/Partner
2. Children
3. Other Relatives
4. Close Friends
5. Co-Workers
6. Church/Synagogue Groups
7. Spiritual Faith
8. Community or Neighborhood Groups
9. Professionals or Service Providers
10. Special Groups
11. T.V., Radio, Newspapers, Magazines, Pamphlets, and Books
12. Other

(p.214).

The operationalization of the amounts, kinds, and and sources of social support perceived by the primary caregivers was obtained both through the total score and individual scores on kinds and sources of social support reported on the Social Support Inventory. Scores are calculated by weighting the answers such that a "no" is 0, a "yes" is 1, and "yes, a lot" is 2. Although the scale gives a total support score, it is also possible to examine what amounts of each of the 5 kinds and 12 sources of social support are being used by the primary caregivers. The test-retest reliability (stability) for the total scale is .81. The coefficient of equivalence is .79, computed by correlating the scores from two parallel forms of the test (Appendix 1). Permission was obtained from Drs. Kreisman and McCubbin to use and reproduce their instruments.

Chronicity and Severity

Additional data were collected through retrospective analysis of the patients' health records within six months of the study timeframe. Three indicators of chronicity were utilized and an index of severity was constructed using three indicators documented on the health records.

Chronicity.

This variable actually consists of three sub-variables, each measuring a different aspect of chronicity:

1) Length of Stay - the total number of days the patient was hospitalized (using the admission that occurred during the study timeframe.) It was measured by counting the number of days from admission date to discharge date.
2) Frequency of Treatment - the number of occasions that the patient has received inpatient treatment for affective disorder. This was measured by counting the number of inpatient admissions to any hospital as recorded on the patient´s health records.
3) Length of Illness - the duration of the illness. It was measured by counting the number of years from the recorded date that the patient had been diagnosed with an affective disorder to the present year.

<u>Severity</u>.

A score of severity was obtained by assessing and summing three commonly used indices of severity that are routinely recorded in the patient´s admission history:

1) Presence of suicidal thought/behavior
2) Presence of delusional/psychotic symptoms

3) Whether patient has been hospitalized on the Psychiatric Special Care Unit (PSCU) - a secure, 10 bed unit which allows for a more intensive level of observation and treatment (admission generally restricted to individuals with an illness at high levels of severity).

The reliability and validity of retrospective data collection and analysis has been challenged (Kerlinger, 1986). The scores were all determined by the researcher so there would be some internal consistency in the accuracy of scores across records based upon the researcher's judgement. In spite of this, the overall reliability of information documented in the health records could easily be challenged due to the variety of individuals who collect and document information and the extreme variability in the skill with which this information is documented. Although there is a definite consistency in the format and types of information to be collected at admission, the knowledge, skill, and accuracy with which the information is recorded depends upon which student intern, intern, resident, or psychiatrist completed the admission history. As well, much of the history is collected from the psychiatric patient. One of the symptoms which is often present with affective disorders is loss of concentration and memory. Therefore, reports of the length of illness and frequency of admission may be subject to these memory loss effects.

Analysis of Results

The statistical analysis which was planned for each research question were as follows:

Research Question 1

What is the chronicity and severity of the illness in the patients in this sample?

In order to describe the patient sample in terms of the independent variables of chronicity and severity, descriptive statistics were used. These descriptive statistics included the range, mean, median, standard deviation, and frequency distribution for each of the variables.

Research Question 2

What is the nature of the acceptance/rejection coping response of the primary caregiver and how does this vary by diagnosis, relationship to patient, and living arrangement?

Descriptive statistics were utilized to answer the first part of this question. Analysis of variance was chosen as the best method for determining whether there were significant differences between the means on each variable tested. Multiple regression could also have been utilized but due to the small sample size and number of variables involved (n=43, 5 independent variables), the researcher believed that the power of the effects measured would be compromised. Tabachnick and Fidell (1983) suggest that creating one independent variable that is a composite of others may help to improve the case-to-variable ratio, but the researcher believed it was imperative to keep the variables as single, independent variables. A one-way analysis of variance was used to test the significance of differences between the mean coping response based upon the patient diagnosis. As well, a two-way analysis of variance was used to analyze whether the caregivers' coping response was effected by their relationship to the patient and whether they were currently living with the patient.

Research Question 3

What is the relationship of chronicity and severity of the patient's illness with the primary caregivers' acceptance/rejection coping response?

This question related to the measure of stressor pile-up. Although pile-up may imply that the variables are combined to measure the additive effects, a decision was made to examine these variables for their individual effects in order to preserve the perceived qualitative differences these variables may have. In order to determine if there are any relationships and the strength of those relationships between the various chronicity and severity factors, Pearson product moment correlations were computed.

Research Question 4

What is the nature of the perceived social support available to the primary caregiver?

Descriptive statistics were utilized in order to describe the patterns of the primary caregivers' perceived social support.

Research Question 5

Are there any aspects of social support that influence the relationships of the primary caregiver's coping response to the variables of chronicity and severity of the patient's illness?

Correlational analysis, using Pearson product moment correlations were used in order to determine whether there were any relationships between the independent variables of chronicity, severity, and perceived social support with the dependent variable of caregiver's coping response. It was hoped that the correlational analysis would tease out specific groups of social support variables that could be tested by using multiple regression analysis.

CHAPTER V - RESULTS

This chapter contains a description of the results obtained from the analysis of data that were collected for this thesis. The demographics of the sampled patient - caregiver pairs will be described and contrasted with that of the patients who were not included in the research. The results will be organized and reported by the research questions.

Description of Sample

The purposive sample used for this analysis consisted of 43 primary caregivers. Of the 71 patients admitted with an affective disorder during the four week data collection period, 43 patients identified primary caregivers and consented to having that person contacted for the study. Three of these 43 patients reported that they did not have a familial caregiver, but the person identified as the individual with whom they had a close relationship was a boyfriend in two cases and a same gender friend in one case. These patients stated that this person fulfilled the role of primary caregiver in their life. For this reason, the three nonfamilial caregivers were included in the primary caregiver sample.

Patient Sample

Seventy five percent of the patients who were sampled were female. Their ages ranged from 13-86 years, with the mean age being 36.6 years. Slightly more than half (51%) were married, thirty five percent were single, and only fourteen percent of the sample were either separated, divorced, or widowed. Major Depression was the affective disorder diagnosed in two-thirds (67%) of the patients, whereas Bipolar Disorder was the diagnosis for twenty three percent of the patients. The remaining four patients had been diagnosed with one of the other types of affective disorder. These rates of diagnostic frequency for the Bipolar Disorder group are higher than the incidence rates found within Edmonton by Bland et al. (1988).

There was a wide variation in the patients' illness-related measures of chronicity (length of stay, treatment frequency, and length of illness) as well as a full range of variation on the severity of illness measures. A full description of these variables will be reported as results to the specific research questions posed in this study.

Caregiver Sample

The caregivers sampled consisted of an almost equal representation by gender (51% female, 49% male). Caregiver ages ranged from 20-74 years and the mean age was 44.6 years. More than three-quarters (76.7%) of the caregiver sample were married. Forty four percent of the caregivers were spouses of the patient, twenty one percent were parents, whereas children and siblings represented an additional twenty five percent. Only one grandparent was identified as a caregiver. Two of the remaining caregivers were boyfriends (4.7%) and one was same gender friend (2.6%). Two-thirds of the givers lived with the patient.

Approximately one quarter of the caregivers sampled %) had not completed high school but another (25.6%) were high school graduates. Almost half of the sample (48.8%) had been educated beyond high school. Fifty six percent of the caregivers were employed full-time, fourteen percent worked part-time and the remainder were unemployed (30%).

Patient - Caregiver Pairs Not Sampled

Since more than one third of the patients and their caregivers did not choose to participate (28 out of 71 possible), it was important to determine whether there were any differences between the patients whose caregivers were contacted compared with those patients whose caregivers were not contacted. This analysis will assist in the determination as to whether the results, using this particular sample, are generalizable to the population from which it was drawn.

The nonsampled patients had a slightly higher representation of females (82%) as well as a slightly higher average age (42.3 years). The nonsampled group had a lower rate of marriage (42.9%) and twenty five percent were either separated, divorced, or widowed. There was little difference in the diagnostic frequency across the nonsampled group as compared to the sampled patients. Although the ranges on the chronicity variables appeared to be as variable as the sampled patients, the severity of illness indicators appeared to be slightly higher for the nonsampled patients, indicating that these patients may have a more severe illness.

Of the 28 patient - caregiver pairs who did not take part in the study, the reason for their noninclusion in the sample were as follows:

1) unable to meet with the researcher during the specified time period (50%);

2) unavailable for contact due to distance or absence (21.4%);

3) refused to meet with the researcher (10.7%);

4) psychiatric patient refused to have their primary caregiver contacted (14.3%); and

5) primary caregiver not contacted due to death of the psychiatric patient (3.6%).

In order to determine if any of the differences noted between the sampled and nonsampled patient groups were statistically significant, a series of t-tests for independent groups were calculated (Table 1). There were no statistically significant differences at the p=.05 level between the two patient groups on the demographic measures or chronicity variables. Only the severity index was significant at the p=.10 level. Therefore, the assumption is made that the sampled patients are representative of the population from which it was drawn, particularly with respect to the demographic measures and chronicity variables. What is unknown though, is whether the sampled primary caregivers are representative of the total population of caregivers. This comparison was not possible to complete since the nonsampled caregivers were either not available or not willing to participate.

TABLE 1

Comparison of Means of Sampled vs Nonsampled Patients on Demographics, Chronicity, and Severity

(t-tests for independent groups, p=.05)

	Sampled $\bar{X}$	Nonsampled $\bar{X}$	t-value	sig.
SEX OF PATIENT	0.26	0.18	0.75	NS
AGE OF PATIENT	38.6	42.29	- 0.8	NS
MARITAL STATUS	2.07	2.39	- 0.93	NS
DIAGNOSIS	4.37	4.36	0.04	NS
LENGTH OF STAY	61.70	55.18	0.49	NS
FREQUENCY OF TREATMENT	3.65	4.86	- 1.03	NS
LENGTH OF ILLNESS	9.70	9.86	- 0.0	NS
SEVERITY OF ILLNESS	1.00	1.32	- 1.46	NS (sig.@ p=0.10)

Results

The presentation of results will be reported in terms of the specific data obtained in order to answer each of the five research questions.

Research Question 1

What is the nature of the chronicity and severity of the illness in the patients in this sample?

Chronicity.

As it is believed that chronicity may be measured by symptoms that are relatively unremitting for a length of time of two years or more as well as by well as by recurring episodes of illness (Billings & Moos, 1984), chronicity was measured with three separate indicators. Because it is not known if these indicators may have a potentially different effect on the coping responses of primary caregivers, the indicators were kept as separate scores rather than combined into a composite index of chronicity.

The unremitting nature of the symptoms, believed to be indicative of chronicity, was measured by two separate indicators: the length of the patient's stay in hospital and the overall length of illness. The patient's length of stay during the current hospitalization was extremely variable in this sample, ranging from 7 - 207 days. The mean was 61.7 days and the standard deviation was 51.6 (Table 2). When these results were recoded into number of weeks of hospitalization, percentage frequencies show that greater than 50% of the sampled patients were hospitalized for over 6 weeks (Table 3).

In addition to chronicity being indicated by symptomatic nonrecovery for a period of two or more years, chronicity may also be a sequel to one or more episodes of depression from which the patient does not recover (Cassano et al., 1983). It was assumed that the length of the patient's illness from the time of first diagnosis may be indicative of a sequence of unresolved and/or recurring episodes of illness. Although arguments may be made that the length of illness is a factor of the patient's age, Keller et al. (1984) have not found that age was a predictor of the course of illness. Therefore, in the current study, the length of illness since first diagnosis was used as an indicator of chronicity. In this study, the range of the length of illness measure varied from 1-35 years. The sample mean was 9.7 years and the standard deviation was 8.9. When using the median split of 6

TABLE 2

Descriptive Statistics for Chronicity and Severity
(range, measures of central tendency, variance)

	Range	Mean	Median	Standard Deviation
LENGTH OF STAY (days)	7 - 207	61.70	54.00	51.62
FREQUENCY OF TREATMENT (occasions)	0 - 19	3.65	2.00	4.27
LENGTH OF ILLNESS (years)	1 - 35	9.70	6.00	8.94
SEVERITY OF ILLNESS	0 - 3	1.00	1.00	0.93

TABLE 3

Frequency and Percentage Distribution of Patient´s Length of Hospitalization by Weeks

Number of weeks	Number of Patients	Percentage
0-3 weeks (7-21 days)	13	30.2
3-6 weeks (22-42 days)	7	16.3
7-12 weeks (43-84 days)	9	20.9
13-15 weeks (85-105 days)	6	14.0
16-29 weeks (106-207 days)	8	18.6

years, 51.2% of the patients sampled had been diagnosed with an affective disorder for up to 6 years whereas 48.8% had this diagnosis from 7-35 years.

Chronicity, as indicated by the recurring nature of the illness, was measured by the frequency of inpatient treatment (admissions) each patient in the sample. This ranged from 0 - 19 previous admissions. The sample mean was 3.6 admissions and the standard deviation was 4.3. Almost 21% of the sampled patients had no previous admissions whereas slightly more than 32% had at least 1 or 2 previous admissions. Approximately 37% of the patients had been hospitalized between 2 to 9 previous occasions whereas only slightly more than 9% had 10 or more previous admissions.

Severity.

The severity of illness scores were obtained through the use of three indicators (1) suicidal ideation/behavior, (2) delusional or psychotic symptoms, and (3) requirement of secure admission for treatment. These three indicators were equally weighted and summed to create a composite index score of severity. The severity scores in this sample varied from 0 to 3. The mean score was 1.00 with a standard deviation of 0.9. Only 7% of the sample scored in the most severe range whereas almost 21% scored in the moderately severe range. The remaining 72% of the sample were almost equally distributed between the not severe (35%) and less severe (37%) categories.

In summary, this sample represents a moderately chronic group of patients in which almost 50% have been first diagnosed with an affective disorder more than 6 years ago. Chronicity in terms of the length of of current hospitalization has a slightly positive skew. That is, 46.5% of the patients were hospitalized for under a 6 week period of time (< 42 days) whereas the remaining 53.5% patients had hospitalizations varying in length from 6 weeks up to 29 weeks (from 43 to 207 days). Considering that the average length of stay for patients in this particular hospital is approximately 28 days, this sample represents a group with a definitely longer period of hospitalization. In terms of frequency of relapse (recurrence or readmission), the majority of these patients (53.5%) had between 0 to 2 previous admissions for treatment which indicates lower chronicity than the other two indicators. The sample shows a positive skew in terms of the severity of illness, with the majority of scores (72%) falling in the not severe or less severe categories.

Research Question 2

What is the nature of the acceptance/ rejection coping response of the primary caregiver and how does this vary by diagnosis, relationship to patient, and living arrangement?

The coping response of the primary caregiver was obtained through the caregiver scores on the Patient Rejection Scale (PRS). The responses on the 11 items of the PRS are scored from 1 - 3. One is indicative of a less rejecting response and three is most rejecting. Scores on the 11 items were summed for a composite score. The total scores in this sample ranged from 11 to 26 with a mean of 16.5 and standard deviation of 3.6. Individual item scores and distribution of the sample by mean, standard deviation, and percentage can be found in Table 4. The response pattern and score means are similar to the group of parents of schizophrenic patients upon which the PRS was normed (Mean = 16.5, SD = 3.8).

In order to determine if there was any variance in

TABLE 4

Patient Rejection Scale

Response Distribution by Mean, Standard Deviation and Percentages

Item	Mean	SD	Response by Percentage (n)		
			Often	Some-times	Never
It gets easier to understand him/her.*	1.58	.59	46.7 (20)	48.8 (21)	4.7 (2)
He/she is an important part of my life.*	1.12	.32	88.4 (38)	11.6 (5)	0 (0)
I don´t expect much from him/her anymore.	1.81	.54	7.0 (3)	67.4 (29)	25.6 (11)
I´m tired of having to organize my life around him/her.	1.72	.67	11.6 (5)	48.8 (21)	39.5 (17)
I enjoy being with him/her.*	1.35	.53	67.4 (29)	30.2 (13)	2.3 (1)
I just don´t care what happens to him/her anymore.	1.23	.53	4.7 (2)	14.0 (6)	81.4 (35)
I get more and more irritated with him/her.	1.74	.69	14.0 (6)	46.5 (20)	39.5 (17)
If he/she leaves me alone, I leave him/her alone.	1.72	.73	16.3 (7)	39.5 (17)	44.2 (19)
I don´t mind doing things for him/her.*	1.44	.66	65.1 (28)	25.6 (11)	9.3 (4)
I feel that I can help him/her get better.*	1.63	.65	46.5 (20)	44.2 (19)	9.3 (4)
I wish he/she had never been born.	1.12	.32	0 (0)	11.6 (5)	88.4 (38)

*reversed

the primary caregivers´ coping response by diagnosis of patient, relationship to patient, and living arrangement, analysis of variance tests were conducted. A one-way analysis of variance was conducted with the caregivers´ mean coping response scores by diagnosis of patient. No statistically significant effect was found for the diagnosis of patient upon mean coping response (Appendix 2). The two-way analysis of variance on the caregivers´ mean coping response was also not statistically significant for effects of relationship to patient or living with the patient (Appendix 2). Recoding of the diagnosis of patient into two rather than six groups (Major Depression and Bipolar Disorder) as well as recoding of the relationship to patient into two groups (family of origin and immediate family) did not improve the results when the analysis of variance were rerun (Appendix 2).

Research Question 3

What is the relationship of chronicity and severity of the patient´s illness with the primary caregivers´ acceptance/rejection coping response?

In order to determine whether the various chronicity and severity indicators were related in any way to the coping response of the primary caregivers, Pearson product moment correlations were computed between each of the chronicity and severity indicators and the total scores on the PRS. The results of the correlational analysis are presented in Table 5. There were no significant correlations between any of the indicators and the caregivers' coping response. A scatterplot of the correlation between patient length of stay and caregivers' coping response reveals the nonlinear relationship between these variables (Appendix 2).

In order to ascertain whether the variation in mean scores on the PRS (coping response) was affected by the chronicity and severity indicators, a three-way analysis of variance was conducted. Patient's length of stay was not included in the analysis of variance due to the nonlinear dispersion of the scores. The other chronicity indicators, treatment frequency, and length of illness, were partitioned into categorical groups. Treatment frequency was transformed into three groups, with group 1 being low treatment frequency (0-2 previous occasions), group 2 representing moderate treatment frequency (3 - 9 previous occasions), and group 3 being high treatment frequency (10 - 19

TABLE 5

Pearson Correlations Between Chronicity and Severity Variables and Caregivers´ Coping Response

Chronicity/Severity Variables	Coping Response
PATIENT LENGTH OF STAY	.0000
TREATMENT FREQUENCY	-.1074
LENGTH OF ILLNESS	.1664
SEVERITY OF ILLNESS	-.1486

Note: rcrit=.3011 (p=.05); rcrit=.3890 (p=.01) two-tailed tests previous occasions). Length of illness was partitioned into two groups, those with a shorter length of illness (1-6 years) and a second group with a longer length of illness (7-35 years). The severity of illness scores remained in the four categories of not severe, less severe, moderately severe, and most severe. The three-way analysis of variance results did not yield any statistically significant effects for any of the variables tested (Appendix 2). Even with recoding of all of the variables into two groups (low and high), the three-way analysis of variance results remained nonsignificant (Appendix 2).

Research Question 4

What is the nature of the perceived social support available to the primary caregivers?

The Social Support Inventory (SSI) generated a number of scores measuring the amounts of the different kinds of social support received from different sources. The description of the entire sample (male and female) of caregivers' mean scores on the SSI are presented in Table 6. As shown in this table, the mean scores on each individual item (measuring the amount of a

TABLE 6

All Caregivers´ Mean Scores on the Social Support Inventory

Sources of Support	emo	est	net	app	alt	Total Mean Sources
	Kinds of Support					
spouse/ partner	1.442	1.488	1.279	1.047	1.535	1.358
children	1.302	1.116	1.140	0.884	1.302	1.149
relatives	1.233	1.140	1.070	0.860	1.395	1.140
friends	1.116	1.186	1.093	1.047	1.256	1.140
co-workers	0.605	0.791	0.698	0.488	0.814	0.679
church	0.605	0.605	0.628	0.535	0.698	0.614
faith	1.000	0.953	1.070	1.116	1.116	1.051
community	0.372	0.419	0.395	0.209	0.488	0.377
professionals	0.605	0.628	0.558	0.419	0.698	0.582
spec. groups	0.163	0.116	0.186	0.116	0.233	0.163
media (TV/ books)	0.674	0.558	0.791	0.767	0.628	0.684
other	0.140	0.140	0.093	0.047	0.163	0.117
Total Mean Kinds	0.771	0.762	0.750	0.628	0.860	
					Total Sources	9.054
					Total Kinds	3.768

Note: emo=emotional; est=esteem; net=network; app=appraisal; alt=altruistic

particular kind of social support from a particular source) are given as well as the mean subscores for each of the amounts of the particular kinds and sources of support (row and column totals). These mean subscores are calculated by summing the scores for each of the questions pertaining to that category and then dividing by the number of questions to get a mean score. As well, results are reported in terms of a total score for the total amount of the kinds of social support provided ($\overline{X}$=3.768) as well as a total score for the sources of support ($\overline{X}$=9.054). Tables 7 and 8 represent the results on the SSI by caregiver gender in a similar fashion.

The SSI was standardized utilizing a group of 118 parents participating in a parent education program. McCubbin et al. (1988) are currently collecting norms from other samples but this information is not yet available. Mahaffey (1989) utilized the SSI with parents of diabetic adolescents. As diabetes is a chronic illness, Mahaffey's group scores on this instrument may be appropriate for use as a comparison group to the current sample. The mean scores for total kinds and total sources for females were 4.025 and 11.055 and the males' mean scores for total kinds and

TABLE 7

Female Caregivers' Mean Scores on the Social Support Inventory

Sources of Support	Kinds of Support emo	est	net	app	alt	Total Mean Sources
spouse/ partner	1.227	1.273	1.136	0.909	1.318	1.172
children	1.500	1.182	1.364	1.000	1.500	1.291
relatives	1.182	1.136	1.045	0.727	1.364	1.090
friends	1.182	1.227	1.091	1.227	1.318	1.209
co-workers	0.636	0.773	0.682	0.545	0.773	0.681
church	0.818	0.773	0.773	0.636	0.909	0.781
faith	1.273	1.136	1.091	1.227	1.182	1.181
community	0.273	0.273	0.273	0.091	0.318	0.245
professionals	0.682	0.682	0.636	0.455	0.682	0.627
spec. groups	0.045	0.045	0.045	0.000	0.091	0.045
media (TV/ books)	0.909	0.636	0.955	0.773	0.773	0.809
other	0.182	0.182	0.091	0.091	0.182	0.145
Total Mean Kinds	0.825	0.776	0.765	0.640	0.867	
					Total Sources	9.276
					Total Kinds	3.987

Note: emo=emotional; est=esteem; net=network; app=appraisal; alt=altruistic

TABLE 8

Male Caregivers´ Mean Scores on the Social Support Inventory

	Kinds of Support					
Sources of Support	emo	est	net	app	alt	Total Mean Sources
spouse/ partner	1.667	1.714	1.429	1.190	1.762	1.552
children	1.095	1.048	0.905	0.762	1.095	0.981
relatives	1.286	1.143	1.095	1.000	1.429	1.190
friends	1.048	1.143	1.095	0.857	1.190	1.066
co-workers	0.571	0.810	0.714	0.429	0.857	0.676
church	0.381	0.429	0.476	0.429	0.476	0.438
faith	0.714	0.762	1.048	1.000	1.048	0.914
community	0.476	0.571	0.524	0.333	0.667	0.514
professionals	0.524	0.571	0.476	0.381	0.714	0.533
spec. groups	0.286	0.190	0.333	0.238	0.381	0.285
media (TV/ books)	0.429	0.476	0.619	0.762	0.476	0.552
other	0.095	0.095	0.095	0.000	0.143	0.085
Total Mean Kinds	0.714	0.746	0.734	0.615	0.853	

Total Sources 8.768

Total Kinds 3.662

Note: emo=emotional; est=esteem; net=network; app=appraisal; alt=altruistic

sources were 4.897 and 10.775.

In the current sample, the individual item that had the highest score was altruistic support from the spouse/partner of the primary caregiver (1.535). Analyzing the male and female responses separately, male caregiver responses were most influential in determining this result. That is, the male mean score on altruistic support from spouse/partner was 1.762 whereas the female mean response score was only 1.318. In fact, this particular item was not the highest scoring individual item for females, as they rated the emotional and altruistic support received from children (1.500 for each) as the highest.

The highest mean subscores for the kind and source of social support were altruistic support (0.860) and support from spouse/partner (1.358) in the overall sample. Once again, there are differences in perceived social support reported by each gender. Although both male and females had the highest mean score on altruistic support, there was some variation in the amount of other kinds of social support that was reported for each gender. Male caregivers had a much higher mean score on the amount of perceived social support from their spouse/partner (1.552) whereas female caregivers reported higher mean scores from children (1.291), close friends (1.209), and spiritual faith (1.181) over the perceived support from spouse/partner (1.172).

Comparing the results of this entire sample to the norm group shows similar trends in response patterns. Most scores in the present sample are lower than the norm group scores. The exceptions were for support from coworkers (norm group score .581); support from spiritual faith (norm group score .978); and media (norm group score .546). The most striking difference is that the mean score of this sample is much lower in terms of perceived support from special groups than the norm group (0.163 compared to 0.897).

Using Mahaffey's (1989) sample for comparison of results by gender, the primary caregiver sample for the current study has consistently lower mean support scores in almost all categories for both males and females. Although the pattern of responses for both genders are comparable between samples, specific differences can be noted when comparing the female samples. The females in Mahaffey's sample have a response pattern similar to the males in her sample whereas the female caregivers in this sample rate support from children, close friends and spiritual faith higher than support from spouse/partner. Thus, the current sample appears to show more differences between the support perceived by male versus female caregivers.

In summary, the current sample reports to have lower levels of perceived support, regardless of the kind or the sources, compared with other groups. Altruistic support (information which leads you to believe that you are worthwhile because of what you have done with and for others) is clearly the kind of social support perceived by both male and female caregivers. The perceived support received from spouse/partner is reported more frequently than other sources, but when examining the results reported by gender of the caregiver, it appears that this source of support is more frequently reported by males than females.

Research Question 5

Are there any aspects of social support that influence the relationships of the primary caregivers´ coping response to the variables of chronicity and severity of the patient´s illness?

The planned analysis designed to answer this question was multiple regression. Pearson correlations were computed between each of the chronicity, severity, and social support mean scores with the coping response mean scores. The complete results of the correlational analysis are presented in Appendix 2. Due to the large number of items included on the SSI as well as the small sample size, the researcher wanted to see if certain items appeared to cluster in any way so that these items could be combined. It was hoped that statistically significant relationships between variables would be identified and then entered into multiple regression analysis. Due to the lack of relationships (or very weak relationships) found between the variables, it was decided that there was not enough statistical evidence to conduct the regression analysis.

CHAPTER VI - DISCUSSION

This chapter will include a discussion of the findings from the statistical analysis of the data and their implications. Comments on the study of caregivers and this particular sample of caregivers will be made. The findings will then be considered, with comments made on each research problem. The strengths and weaknesses of the research, including theoretical and methodological problems will be presented including suggestions for further exploration. Finally, the applications and implications of the research with regards to primary caregivers of patients with affective disorders will be put forth.

Nature of Caregiver Group

This study focused on the individuals (caregivers) who were identified by the patient as having played the most supportive role at the time of hospitalization and throughout the illness. The person identified as the primary caregiver was a family member in all but three cases. In those three cases, the patient chose a boyfriend or friend as their primary caregiver. It was assumed that these caregivers were in a "surrogate" familial role in that they were providing the emotional dimension of personal interaction thus they were included in the "familial" caregiver group.

Gaps in the research on caregivers to the mentally ill appears to be related to the sampling procedures that were used. That is, most studies sample the nearest relative or a significant other to the patient (Creer et al., 1982; Doll, 1976; Grad & Sainsbury, 1963; Gubman et al., 1987; Hatfield, 1979; Hatfield et al., 1982; Leavitt, 1975; Rose, 1983) regardless of the patient's perception of this person as a supportive caregiver or not. These studies did not define what was meant by "significant other", therefore there is little value in comparing from sample to sample when there is no differentiation of the type of nonfamilial relationships. The proportion of familial to nonfamilial relationships, parental to spousal relationships, cohabitating to noncohabitating relationships varies from study to study. Most of the samples are overrepresented by familial rather than nonfamilial relationships. The majority of these familial relationships are parental in nature, followed by spousal, sibling, children, other relative, with nonfamilial relationships being the least represented.

Gubman et al. (1987) and Leavitt (1975)

specifically sampled only those caregivers who were cohabitating with the patient whereas many of the other studies reviewed did not specify this. This sampling method yielded nonspecific results, reflecting the wide range and variety of caregiving relationships that psychiatric patients have. That is, although the primary caregiver most often is a family member, the nature of that familial relationship and living arrangements may vary. What is not very clearly defined is whether or not such factors as the types of illness, chronicity, severity, or treatment affect the patient-primary caregiver relationship. As well, it is not known what other patient characteristics (such as age, sex, marital status) may influence the involvement of certain kinds of primary caregivers. For example, it has been asserted that women are most likely to fill caregiving roles for the mentally ill (Ascher-Svanum & Sobel, 1989; Thurer, 1983). The current study sample did not confirm this finding as there were almost equal numbers of males and females identified as primary caregivers.

Research with caregivers of patients with affective disorders has focused more specifically on spousal caregivers (Fadden et al., 1987; Hafner, 1986;

Hooley et al., 1986; Targum et al., 1981). Although Fadden et al. (1987) fully intended to interview any adult with whom the patient spent most of his or her time, their sample yielded patients who were living with a spouse. This may have been a reflection of the population of patients that attended their clinics. It could also be representative in that the caregivers of depressed patients are more commonly spouses. The sample utilized for the present research did not sample only spousal caregivers.

Patient-Caregiver Pairs - Sampled vs. Nonsampled

The availability of health care records allowed for some description of the psychiatric patients whose caregivers did not participate in the study in addition to knowledge of the sampled patient-caregiver pairs. Of the 71 patients admitted with an affective disorder during the data collection period, 43 patient-caregivers consented to participate in the research. An analysis of the characteristics of the remaining 28 patients compared to the patients who were included in the sample reveals minimal differences between the two groups. What is not known, however, is whether or not the caregiver group sampled had similar characteristics to those who did not participate.

When examining the reasons for non-participation, only 10% of the caregivers directly refused to meet with the researcher. Another 14% of the caregivers were not contacted due to the patient's refusal to have their caregiver contacted. This refusal rate of approximately 25% may have biased the sampling toward those caregivers who were more positive towards the ill family member. Another source of potential bias was the fact that twenty one percent of the caregivers not sampled were either residing too far away to be contacted or were not in contact with the ill family member. One cannot be sure why they were absent or not in contact with the patient. Possibly these caregivers were absent or unavailable because of their more negative perceptions of the patient during exacerbations of the illness. It could also be possible that they could not travel to this particular hospital.

Half of the caregivers not included in the sample were unable to meet during the data collection period. In some cases this was due to their relative being discharged from hospital before the caregivers were contacted by the researcher or due to difficulties in scheduling interviews at a convenient time for the caregiver. In the remaining cases, the unavailability for interview may have been indirect refusal to participate in the study.

Whatever the reason given by the patient or caregiver for not participating in the research, the fact that one-third of the total sample available did not participate will have some significance that cannot be tested in this study. Do these nonparticipating caregivers perpetuate the "myths of mental illness" by their failure to acknowledge their relative's illness? Do they, as suggested by Yarrow et al. (1955) desire some secrecy or protection from the acknowledgement that their family member has a mental illness? Is this a group of caregivers who are reluctant to seek help? Are they afraid to seek help due to guilt that they may have played a role in the patient's illness, or that perhaps they themselves will be found to be ill? Does participation in a study mean having to acknowledge acceptance of the patient's illness? It may be that these caregivers have internalized perceived rejection of the mentally ill, whether it be their own feelings of rejection or some experience with perceived rejection from others. Are these caregivers avoiding contact with professionals because of their own rejection, or due to a fear of rejection? Have these caregivers decreased their contacts with others since the recognition of mental illness in their relative as a consequence of the illness and as a way of coping? These questions remain unanswered with the present study but poses directions for further research in this area.

Research Question 1

What is the nature of the chronicity and severity of the illness in the patients in this sample?

All patients in the sample suffered from an affective disorder. Chronicity and severity of illness were specifically examined. It had been hypothesized that these patient/illness-related factors may contribute to the pile-up of stressors for the family. Conceptually, the impact of pile-up may be additive, but the measurement and analysis utilized in the present study precluded examining these variables for their additive effects. Rather, it was decided to keep the variables separate in order to look at the qualitative differences between the variables as opposed to the additive value of concurrent events. It was assumed that the severity of the illness and current symptoms would have an impact on how the primary caregiver would react and interact with the patient. As well, it was assumed that an illness that was chronic in nature (that is, either the presence of unremitting symptoms for up to two years or recurring episodes of illness) would have an impact on other family members, especially the primary caregiver to the patient.

The first question examined the chronicity and severity of the illness in the patients included in the sample. Analyzing the results of the three chronicity indicators (length of stay, frequency of treatment, length of illness) and the severity index score, it appears that the sample represents a group of patients with moderately chronic affective disorders of a less severe nature.

Chronicity is defined by depressive symptomatology that is nonremitting for a period of two years or more (Akiskal, 1982; Cassano et al., 1983; Keller et al., 1984). Due to the unavailability of full data covering a two-year period of time, a different operational definition of chronicity was used. Chronicity was defined as being comprised of two factors: the length of stay in hospital and the duration of illness. The researcher believed that these factors would provide a reasonable indication of chronicity.

The extreme variation in length of stay in hospital necessitated collapsing the data into number of weeks in hospital rather than number of days. Less than half the sample (46.5%) remained in hospital for less than six weeks. Considering that the average length of stay for patients´ in this particular hospital is approximately four weeks, on the surface it appears that this group is considerably more chronic in terms of their length of hospitalization. But when it is realized that the hospital´s average length of stay for patients is calculated for all psychiatric illnesses and not just affective disorders, it is difficult to say whether this sample represents a group of more or less chronic patients.

Almost 50% of the patients had been diagnosed and were ill with an affective disorder for at least seven years or more. Fifty-one percent of the patients had been diagnosed and ill for less than six years. Whether or not any of these patients had been diagnosed early in their illness, or if they had been ill for a length of time prior to diagnosis could not be assessed in this study. A long prodromal period and insidious onset prior to assessment and treatment is a reliable predictor of a chronic course of illness (Hirschfield et al., 1986; Keller et al., 1986), and this would add considerable information about chronicity. Almost half of the sampled patients had been diagnosed for at least 7 years prior to this particular hospitalization which is an indication that this may be a more chronic group of patients. Keller et al. (1984) state that the longer the period of time since first diagnosis may be predictive of a more chronic illness or may indicated a sequel of unremitted or recurring episodes of illness (Cassano et al., 1983).

Billings and Moos (1984) identified that recurring episodes of illness are also indicative of a more chronic course of illness. Only twenty one percent of this sample had no previous admission to hospital whereas one-third (32%) had 1 or 2 previous admissions. Although these two groups represent more than half of the sample, more than one-third of the sample had been hospitalized from 2 to 9 occasions with an additional 9% having had 10 or more previous hospitalizations. Considering that some of these individuals may have also had recurring episodes of illness that may not have required hospital-based treatment, this is a conservative measure of chronicity.

In summary, using illness length, length of hospitalization, and number of hospitalizations as indicators of high chronicity, this sample represents a moderately chronic group of patients who had a relatively low severity of illness. The choice of a hospitalized population may have skewed the chronicity of the sample in that more chronically ill individuals are likely to be hospitalized (Billings & Moos, 1984) either due to having a treatment resistant illness (Freyhan, 1978), or having greater knowledge and accessibility to hospital-based treatment with increased experience with being ill and a greater tendency to seek help from professionals (Roberts, 1988). Keller et al. (1984) even go so far as to say that persons with an affective disorder who never seek treatment or hospital-based treatment may have less risk of developing a chronic form of the illness or may have a less severe form of the illness.

It seems surprising that the majority of patients in the sample had a nonsevere or less severe illness (as measured by the severity indicators chosen). The common assumption is that the more severe affective illnesses require hospital-based treatment (Wing & Bebbington, 1982). Perhaps it is not so much the severity of the illness as much as the response of the illness to treatment along with the availability of supportive resources to the patient and caregiver that determine hospitalization. It may also be that some patients and/or their families are better able or more willing to seek help for the illness regardless of the severity of the illness (Roberts, 1988).

Research Question 2

> What is the nature of the acceptance/rejection coping response of the primary caregiver and how does this vary by diagnosis, relationship to patient, and living arrangement?

Expressed emotion by the family/significant others of psychiatric patients diagnosed with affective disorders has only been minimally explored (Coyne et al., 1987; Hooley et al., 1986; Vaughn & Leff, 1976). This research attempted to look at the primary caregivers´ expressed emotion as a central coping response in the process of adapting to the family member´s illness rather than as a contributing factor in the illness (Chelsa, 1989). Although looking at expressed emotion in this manner will not truly reflect the systemic changes and adaptation in the primary response to illness/patient, it examines EE as a dependent variable rather than as an independent variable.

The coping response of acceptance/rejection (one type of EE) for this sample was similar to the accepting/rejecting responses of family members who had a relative ill with schizophrenia. When comparing individual items (Table 4, previous chapter), the items with the most highly rejecting responses for this group of primary caregivers appear to be related to expectations (item #3), organizing life around the patient and their illness (item #4), irritation with the patient (item #7), and mutual withdrawal (item #8). The degree of irritation with the patient appeared to be higher in this sample than the irritation expressed by families of schizophrenic patients. Perhaps this is a reflection of Anderson et al.'s (1986) suggestion that symptoms of depressive illnesses are more likely to be viewed as willful or within the control of the patient than symptoms of some of the other psychiatric illnesses such as schizophrenia, Alzheimer's disease, or drug-induced psychosis. Jacob et al. (1987) also comment that caregivers are often more irritated and frustrated with the patient because they feel that the patient could demonstrate a better degree of control over their depressive symptoms.

The item regarding withdrawal of the patient and from the patient appears to be more relevant to primary caregivers of this sample than to relatives of schizophrenic patients. Although schizophrenic patients also demonstrate symptoms of withdrawal, perhaps their families are more aware of this as a symptom that must be recognized and dealt with than are the familial caregivers of depressed patients.

Whether the same range and degree of acceptance/rejection would have been present in the nonparticipant caregivers would be interesting to know. Although it could be hypothesized that the 28 caregivers who did not participate are more highly rejecting because they either refused, weren´t available, or didn´t live within the proximity of the patient, it is not known whether these caregivers were actually accepting or rejecting in their coping response.

There was no statistically significant variation in the caregiver´s acceptance/rejection responses when examining the mean scores for the various diagnoses, (using DSM-III-R criteria), relationship of the caregiver to the patient, or living arrangement. The specific diagnosis of the patient would be indicative of the symptoms and behaviors that the patient and primary caregiver would have to cope with and it was felt that this may relate to the amount of acceptance/rejection expressed. For example, the burden research indicates that relatives of patients with a bipolar illness reported more burden than relatives of patients with other affective disorders (Targum et al., 1981). The wide variety of diagnoses and the small numbers of patients in each diagnostic category (except for Major Depression) may have made it difficult to find statistically significant variation by diagnosis. Even recoding of the data into two groups (Major Depression and Bipolar Disorder) did not improve the statistical analysis results.

It was assumed that the primary caregiver relationships with the patient would be a relationship of intimacy. The level of intimacy was not measured specifically in this study. Differentiating the closeness of the relationship might have helped discern whether certain types of caregivers are more accepting/rejecting than others. Hooley et al. (1986) speculated that depressed patients' increased sensitivity to criticism by a spouse opposed to criticism from other family members was related to the threat of termination of marital relationships whereas other family relationships are rarely terminated. However, there were no statistically significant differences in the acceptance/rejection response of the caregivers when examining these responses by relationship to patient in the current research.

The lack of differences in the coping response of cohabitating versus non-cohabitating caregivers was also surprising. The burden research with families of depressed patients indicated that the caregivers living with their ill relatives reported more burden than noncohabitating relatives (Coyne et al., 1987; Fadden et al., 1987b; Jacob et al., 1987). This finding however does not correlate with the degree of rejection expressed by the caregivers in this study. Perhaps it is not the living arrangement that has an impact on the family member's acceptance/rejection coping response but the quality of living within the living arrangement. This was not measured in this study.

Reviewing this finding leads to a methodological question: is the measure of patient acceptance/

rejection an indicator of the coping ability or is it a coping result? Rejection or expressed emotion may be a result of coping rather than coping itself.

Even if rejection (EE) is an accurate measure of coping response, variables other than chronicity and severity of the patient´s illness may have influence upon the pattern of coping. In fact, illness or patient variables may be entirely unrelated to the process of adaptation. The key variables that impact upon adaptation may not have been measured. Some of the variables that merit future investigation in terms of their impact on the coping response to the patient´s patient´s illness include: (a) the quality of the relationship of the patient with the primary caregiver, pre- and post-illness; (b) the quality and satisfaction with the living arrangements: (c) the the previous perception and utilization of the resources of social support. These are just a few of the possible variables.

Research Question 3

What is the relationship of chronicity and severity of the patient´s illness with the primary caregivers´ acceptance/rejection coping response?

The illness related variables of chronicity and severity were chosen for this study as pile-up variables in the primary caregiver's response to the crisis of mental illness in their family member. It was believed that these variables would create more disruption in the lives of both the patients and their primary caregivers. That is, the degree of chronicity in terms of time since first diagnosis, length of hospitalization, and frequency of hospitalization may impact upon the primary caregiver's ability to cope as well as the type of coping response. Likewise, the severity of illness may also have an influence upon the amount of disruption and adjustment that must be made by both patients and their primary caregivers.

The results indicate that this sample represents a moderately chronic group of patients with a lower severity of illness. The lack of relationship between these variables and the acceptance/rejection response of the primary caregivers was somewhat surprising in view of the intuitive appeal of the "disruption-to-the-family" explanation. The lack of significant relationship between the chronicity and severity and the coping of the caregivers may be due to the static nature of the independent variables measured. That is, chronicity and severity of the patient's illness at the particular point in time do not reflect any dynamic process in the response by family members but are merely static indicators at a point in time. As pointed out by Keitner et al. (1985), family disruption and dysfunctional communication generally improves with with the hospitalization of the ill relative. In order to better examine the relationship between the illness-related variables and the coping response of caregivers, it may be necessary to examine the response of the caregiver over a period of time rather than at only one point in time.

Research Question 4

What is the nature of the perceived social support available to the primary caregivers?

The resources available, perceived and utilized by the primary caregivers are believed to assist in the process of adaptation to the crisis (McCubbin et al., 1980). Social support as a resource to caregivers in the current study appears on the whole to be most beneficial when perceived as being received from spouse/partner and in the form of support termed by Cooke et al. (1988) as "altruistic support".

The male caregivers' reports were more influential in the high scores on altruistic support. They reported that perceived social support from their spouse/partner was most beneficial whereas females perceived support from children, close friends, or faith rather than the perceived support from spouse/partner. This may be a reflection of the findings by Flaherty and Richman (1989) that males rely on fewer sources of support than females and that within intimate relationships males tend to invest more in a single relationship than females. In 44% of the cases in the current sample, the perceived spouse/partner support was being received from the patient. As chronically ill individuals frequently are unable to return support to others (Tilden & Weinert, 1987) caregivers who are relying on their ill spouse/partner for support may find that support is not there when they need it. These same authors state that reciprocity of support is important for balanced and healthy relationships. Chronically ill individuals may not be capable of reciprocating support to others, [illegible] their spouses.

The female caregivers' perception of support from children and close friends may be related to the stage of development that the family is going through. That is, during the period of parenting, women may tend to focus their attention more on their children than on their spousal relationships (Coleman, 1984; Ehrensaft, 1987). As well, female relationships often extend outside of the spousal/marital relationship (Buhrke & Fuqua, 1987). Female caregivers may often be misled in terms of perceived support according to Belle (1982). She identifies that females often give more support than they receive. It may be that the perception of altruistic support as an important source of support is actually an indication that giving to others is as supportive as receiving support from others.

The comparison made in the previous chapter with results from caregivers´ of diabetic youth (Mahaffey, 1989) should be reviewed cautiously. Her sample of caregivers included only parents of diabetic youth whereas this sample of caregivers and patients was more heterogeneous. Although Mahaffey´s (1989) caregivers were also dealing with a chronic illness, the perception of support may have been influenced by the presence within the family of potentially supportive individuals, such as a spouse and children. The caregivers in the current research sample may not have had as many potentially supportive individuals available from which to receive support.

The sample overall reports lower perceived support, regardless of the kind or the source of support when compared to other groups. It is not known whether the perception of support has previously been low in these caregivers (are they "underutilizers" as discussed by Roberts (1988)) or if this is directly related to having had a family member diagnosed and treated for a depressive illness. From the earlier research on support and help-seeking by families of the mentally ill, there is some evidence that relatives/caregivers reduce the number of relationships they have after the recognition of illness in a family member (Kreisman & Joy, 1974). This raises another research question: Do family members actively withdraw in times of difficulty rather than increase their contact with others as a means of coping? That is, rather than seeking more resources, such as more sources and kinds of social support, do these family members try to cope by avoiding contact with others?

Altruistic support is clearly the kind of social support perceived as being most frequently received by caregivers of both sexes. Although altruistic support is defined by Cooke et al. (1988) as "information which leads you to believe that you are worthwhile because of what you have done with and for others" (p. 213), it is debatable as to whether this is, in actuality, true altruism. Altruism is commonly understood as an unselfish concern for others and activities that are done in a very selfless manner. It is apparent that altruistic support is not selfless in that these individuals perceive that they receive some recognition or feeling that they are worthwhile from having done something with and for others. The concept of altruistic support, as defined by Cooke et al. (1988) may be more akin to what Rubin (1974) identifies as an opportunity for nurturance. That is, that social relationships provide the opportunity for an individual to have a sense of being needed and gives meaning to one's life. Rubin (1974) often associates this opportunity for nurturance with responsibility for children.

Research Question 5

Are there any aspects of social support that influence the relationships of the primary caregivers' coping response to the variables of chronicity and severity of the patient´s illness?

Due to the lack of statistically significant relationships between the various variables of the study, it was not possible to answer this particular question. Whether the lack of significance is a reflection of the existence of little relationship between these variables, due to some theoretical or methodological problems, or a combination of the two is unknown. The next section will discuss these possible weaknesses.

Theoretical Strengths and Weaknesses of This Research

The lack of significant results may indicate weaknesses in the conceptualization of this research. The choice of the Double ABCX Model as the conceptual framework may best represent the crisis of the identification of affective illness in one family member and the response of the primary caregiver in this crisis. What may have been incorrect in the conceptualization are the specific components of the model chosen for the research, the pile-up variables and coping variable of acceptance/rejection response.

Although chronicity and severity of the illness may be `pile-up´ variables in the family crisis, there is no evidence from this research that indicates the influence of this upon the coping response of the caregiver. Whether these variables have no effect or that some other variables such as symptoms or behaviors augment the effects of these variables in unknown. It may be possible that the acceptance/rejection response as a means of coping by the primary caregiver is inappropriate. That is, that the primary caregiver´s expressed acceptance/rejection is not coping per se, but that the acceptance/rejection response is merely a symptom of coping.

Previous research clearly indicates that social support is a resource to individuals and families during times of crisis. Although it must be acknowledged that there is some evidence that social support may have negative or detrimental effects on coping (Roberts, 1988), it is likely that the lack of statistically significant results in the area of social support in this research is due to a methodological flaw rather than a theoretical weakness. This assumption is made due to the lack of significant results using any of the variables in this research.

Of course, it must be kept in mind that the lack of statistically significant results may be due to an error in the assumptions made in formulating the research questions. Although the current research was not testing scientific hypotheses, the research questions and the relationships which were being examined are also subject to Type I and Type II errors. The possibility of these methodological errors as well as others will be discussed in the next section.

Methodological Strengths and Weaknesses in this Research

The methodology of this research produced strong results in that all variables had a full range of variation and there was no missing data. Also, the use of patients´ health records allowed for some information to be available for patients who did not participate in the study. This is helpful in determining whether the patients sampled differed significantly from the remainder of the population. The representativeness of the sample is still limited though by the primary caregivers who were not contacted.

Although the purposiveness of the sampling had some positive benefits, this "one-shot" design does not allow for the examination of the relationships in the fluid and dynamic manner in which they exist. Kerlinger´s (1986) assumption that such a design is scientifically worthless may be a little harsh, but his point that the lack of control and comparison afforded by this design is well taken. As pointed out in Chapter 1 of this thesis, the crisis of affective illness in the family is a dynamic, reciprocal and systemic process. Capturing the action, reaction, and interaction of the relationships involved is difficult. Although one-shot designs cannot capture this complexity, there is some descriptive and exploratory value in examining a particular sample at a particular point in time.

The use of existing measures, the Social Support Inventory (SSI) for the social support, and the Patient Rejection Scale (PRS) for the acceptance/rejection response, assisted in the reduction of measurement error as both instruments had reliability values greater than .70. Unfortunately, all of the chronicity and severity measures were subject to a greater degree of measurement error as these measures are only as reliable as the variety of individuals who recorded the information on the patient´s health records.

The choice of McCubbin et al. (1982) Social Support Inventory may have contributed to the methodological weaknesses of this research. Intuitively, the SSI appeals to the researcher as a thorough and comprehensive instrument that examines types, sources, and the total amount of social support. Unfortunately, the results from the instrument are unwieldly and an extremely large sample is required to utilize the inventory effectively. Additionally, the norms currently available for the instrument are tentative and restricted to a fairly small sample. Also, as Mahaffey (1989) points out, the combination of support types could be improved upon, with a critical examination of the support type currently classified as "altruistic support".

The small sample size does increase the probability of having made a Type II error in this research. In other words, the lack of significant results may not be due to the fact that there are no significant relationships between the variables tested, but due to the decreased power to differentiate the real effects of the independent variables.

In spite of the difficulties of using purposive samples, some measures that may have been unreliable, and standardized measures that do not yield data that can be easily interpreted and utilized, this research does raise some interesting questions for further investigation. Such future investigations will now be discussed.

Further Exploration

The research questions that this study set out to answer have not all been fully answered. Several additional questions that require further investigation have been raised. These include further exploration of coping responses, the reasons for nonparticipation by familial caregivers, patient/illness related variables of chronicity and severity, the quality of relationships and living arrangements in these families, as well as specific investigation into the perceived social support of familial caregivers. Each of these areas of concern will be presented.

The first question raised is whether the emotional expression of acceptance/rejection by the familial caregiver is a central coping response to having an affectively disordered relative? Although this particular response has been previously linked as contributory to the course of illness, there is no evidence from this research that the coping response of acceptance/rejection is influenced by the patient/illness related variables that were studied or by the perceived social support. As suggested earlier, perhaps the expression of acceptance/rejection is merely a symptom of another coping response. Future qualitative research could explore what the usual coping responses of family members are and then follow with quantitative research that could test the significance of the response described by the earlier research.

With regard to the second question, there was a large proportion of the familial caregivers who did not participate in the study. Is this nonparticipation, unavailability, or uncooperativeness "usual" for family members of the affectively disordered? Primary caregivers´ nonparticipation in the study may reflect their nonparticipation with treatment and could have possible ramifications for patient/illness outcomes and reflect the caregivers´ own abilities to accept and manage the illness of the relative.

The third question involves the patient/illness variables of chronicity and severity. Ideally, long-term prospective studies of first-time diagnosed patients could assist in a better understanding of the chronicity and severity of the illness and the family member´s responses to these illness variables over time. What constitutes chronicity and severity for the professionals and how does this differ from what family members´ perceive chronicity and severity to be? Using professionals´ definitions of these variables may not capture what has the most impact on the family members and their adaptation to the illness of their relative.

Future research with caregivers should not only look at the quality of intimacy in the relationship between the patient and the caregiver (rather than the structure of the relationship such as whether they are a spouse, sibling, child, etc.) and should also examine the quality and satisfaction of the patient and the familial caregiver with the living arrangement. How does the fact that the caregiver lives with the patient and their satisfaction or dissatisfaction with that living arrangement and daily life impact upon the adaptation to illness of a relative?

Finally, further investigation of the social support perceived by the familial caregiver of patients with affective disorders is warranted. Of particular interest are the decreased levels of perceived social support found in these particular caregivers when compared to other groups. Is the reduced perception of social support in these caregivers directly related to having a relative with an affective disorder or related to other factors in combination with the relative's illness. Specific forms of perceived support, such as altruistic support, need to be examined more closely in future research. As well, what appears to be minimal resources of support for men (often restricted to spousal support) may have implications for further study.

Application and Interventions with Primary Caregivers

The ultimate goal of any research is to add to the body of scientific knowledge such that there is an impact on theory, further research, or on clinical practice (Miller, 1986). Although there were no statistically significant results in this research, negative results play an important role in planning for the future.

Implications for future research has been outlined in the previous section. With regards to the implication on theory, this study does not produce evidence that will support or refute the well-established Double ABCX Model. A theoretical contribution of this research is the identification of altruistic support as the central kind of social support perceived by these familial caregivers. Although the reciprocal nature of social support has been documented (Stewart, 1989), altruistic support as defined by Cooke et al. (1988) is not well-defined or investigated.

Implications for clinical practice involve both the recognition of the variation of the familial caregiver group as well as the type of support that they perceive as being available and helpful. It is evident from this study that the familial caregiver of patients with an affective disorder could involve a wide variety of individuals. It may be important for clinicians to be aware of the variety of individuals that patients identify as being most supportive to them. Rather than automatically asking to see the spouse, it may be more important for the clinician to ask the patient for the name of their familial caregiver.

The identification of altruism as the most frequently reported source of perceived support may be something that can be utilized by clinicians. That is, if this form of support is perceived as helpful by familial caregivers, provision of self-help or mutual help groups is warranted. The familial caregivers can receive support through giving of support to other familial caregivers. Stewart (1989) identifies that other forms of support such as informational, emotional, and esteem support can also be provided through self-help groups.

Summary

There is no doubt that the mental illness of one member of the family is a potential stressor to both the patient and their familial caregiver. Although the current research did not find statistically significant results to the research questions posed at the outset, several interesting areas for further investigation were raised and discussed earlier within this chapter.

What is most apparent to the author in this research as well as in other family stress research, is the complexity of describing and understanding the impact of stressors on familial relationships. The process of coping with stressors is a very complex one, involving an interaction of perceptions, resources, and behaviors for each individual involved. When the process of coping is examined within the context of one or more familial relationships, the ability to study this process becomes even more complicated. Not only must researchers be aware of the many different variables involved in the process of coping for one individual, these must be looked at in combination with the other family members´ individual and collective coping responses.

At this point in time, it appears that the ability to fully examine the family stress process is limited to some extent by the difficulty in empirically testing theoretical models with the available methods. An example of deficits of current methods was evident in this research through the use of the elaborate yet unwieldly Social Support Inventory. Although this particular instrument may be useful in research with extremely large samples, the further constraint and realities of research timeframes and budgets limits setting up ideal research conditions. In spite of these difficulties, family researchers should continue to search for meaning, understanding, and knowledge of the family stress process. This can be accomplished not only through theory conceptualization, but also through the critical use and development of a vast array of research methods.

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APPENDICES

APPENDIX 1 - Instrumentation

- Patient Consent to Contact Family Member
- Patient Demographic Information
- Primary Caregiver Consent to Participate
- Primary Caregiver Demographic Information
- Patient Rejection Scale (PRS)
- Social Support Inventory (SSI)

APPENDIX 2 - Additional Tables of Statistical Analysis

APPENDIX 1

NEEDS ASSESSMENT PROJECT

PATIENT CONSENT TO CONTACT FAMILY MEMBER

I consent to have researcher Lynn Damberger contact my family member for the Needs Assessment Project. I understand that no information will be given to my family about my condition or treatment nor will information given by my family affect the care that I am receiving.

Signature ____

Date ____________________

Witness ____

Needs Assessment Project

Patient Demographic Information

Sex ___________

Age ___________

Marital Status ___________

Diagnosis ___________

Relationship of primary caregiver to patient ___________

Needs Assessment Project

Primary Caregiver Consent for Participation

In order to examine the needs of family members of patients admitted to the Department of Psychiatry, we are interested in learning about what kinds of assistance you would like to have in order to live with your relative's illness. You will be asked questions about your relative's illness and treatment, your feelings about your relative, as well as questions about your support systems. You may choose not to answer questions and you may cease to participate at any time.

All of your responses will be strictly confidential and only used for the research purposes. No information will be given to your ill family member nor to the members of the treatment team providing care for your family member, including the psychiatrist. Nor will your responses affect the nature of the care that your relative is receiving. The responses that you provide will be used by the researcher to assess the needs of families, to evaluate and make recommendations for future programming to meet the needs of family members of psychiatric patients.

I consent to provide information for the Needs Assessment Project and fully understand that my responses will be strictly confidential and only used for the purposes outlined above.

Signature ______________________________

Relationship to Patient ____________________

Witness ____________________ Date ____________

Needs Assessment Project

Caregiver Questionnaire

Please place a check mark or write in your answer in the spaces provided. Try to answer all the questions. You may ask the researcher any questions you may have related to the questionnaire.

A. Demographic Information of Primary Caregiver

1. Sex

_____ Female

_____ Male

2. Age

_____

3. Marital Status

_____ single

_____ married

_____ common-law

_____ separated

_____ divorced

_____ widowed

4. Occupation

____

5. Current Employment Status

_____ full-time

_____ part-time

_____ not employed at present

6. Level of Education (place check mark beside highest level attained.)

_____ elementary school

_____ junior high school

_____ some high school

_____ completed high school

_____ some post-secondary education

_____ completed post-secondary education

_____ baccalaureate degree

_____ masters degree

_____ post-graduate education

7. Relationship to Patient

_____ Parent

_____ Spouse

_____ Common-law spouse

_____ Boy/Girlfriend

_____ Sibling

_____ Grandparent

_____ Child

_____ Friend

_____ Other Relationship (please specify ________ ________________________)

8. Currently Living with Patient

_____ Yes

_____ No

PATIENT REJECTION SCALE (PRS)

(Kreisman, Simmons & Joy, 1979)

Please circle the response that best describes your feelings about the patient, as indicated by the statements.

It gets easier to understand him/her.	often	sometimes	never
He/she is an important part of my life.	often	sometimes	never
I don't expect much from him/her anymore.	often	sometimes	never
I'm tired of having to organize my life around him/her.	often	sometimes	never
I enjoy being around him/her.	often	sometimes	never
I just don't care what happens to him/her anymore.	often	sometimes	never
I get more and more irritated with him/her as time goes on.	often	sometimes	never
If he/she leaves me alone, I leave him/her alone.	often	sometimes	never
I don't mind doing things for him/her.	often	sometimes	never
I feel that I can help him/her get better.	often	sometimes	never
I wish he/she had never been born.	often	sometimes	never

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SOCIAL SUPPORT INVENTORY

The questionnaire on the next page asks questions regarding the people that you currently receive support from. Please answer each question by filling in the circle of the response that best describes your answer to the question.

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SOCIAL SUPPORT INVENTORY

Please read each statement and then indicate how much support you receive from each of the sources listed by marking: NO (N), YES (Y), or YES A LOT (Y+).

I. I have a feeling of being loved or cared about from:

	NO	YES	YES A LOT
My spouse or partner	Ⓝ	Ⓨ	(Y+)
My children	Ⓝ	Ⓨ	(Y+)
Other relatives	Ⓝ	Ⓨ	(Y+)
Close friends	Ⓝ	Ⓨ	(Y+)
Co-workers	Ⓝ	Ⓨ	(Y+)
Church/Synagogue groups	Ⓝ	Ⓨ	(Y+)
My spiritual faith	Ⓝ	Ⓨ	(Y+)
Community or neighborhood groups	Ⓝ	Ⓨ	(Y+)
Professionals or Service Providers	Ⓝ	Ⓨ	(Y+)
Special groups I belong to	Ⓝ	Ⓨ	(Y+)
Reading certain books or watching T.V.	Ⓝ	Ⓨ	(Y+)
Other:	Ⓝ	Ⓨ	(Y+)

II. I feel I am valued or respected for who I am and what I can do by:

	NO	YES	YES A LOT
My spouse or partner	Ⓝ	Ⓨ	(Y+)
My children	Ⓝ	Ⓨ	(Y+)
Other relatives	Ⓝ	Ⓨ	(Y+)
Close friends	Ⓝ	Ⓨ	(Y+)
Co-workers	Ⓝ	Ⓨ	(Y+)
Church/Synagogue groups	Ⓝ	Ⓨ	(Y+)
My spiritual faith	Ⓝ	Ⓨ	(Y+)
Community or neighborhood groups	Ⓝ	Ⓨ	(Y+)
Professionals or Service Providers	Ⓝ	Ⓨ	(Y+)
Special groups I belong to	Ⓝ	Ⓨ	(Y+)
Reading certain books or watching T.V.	Ⓝ	Ⓨ	(Y+)
Other:	Ⓝ	Ⓨ	(Y+)

III. I have a sense of trust or security from the "give-and-take" of being involved with:

	NO	YES	YES A LOT
My spouse or partner	Ⓝ	Ⓨ	(Y+)
My children	Ⓝ	Ⓨ	(Y+)
Other relatives	Ⓝ	Ⓨ	(Y+)
Close friends	Ⓝ	Ⓨ	(Y+)
Co-workers	Ⓝ	Ⓨ	(Y+)
Church/Synagogue groups	Ⓝ	Ⓨ	(Y+)
People who share my beliefs and values	Ⓝ	Ⓨ	(Y+)
Community or neighborhood groups	Ⓝ	Ⓨ	(Y+)
Professionals or Service Providers	Ⓝ	Ⓨ	(Y+)
Special groups I belong to	Ⓝ	Ⓨ	(Y+)
Ideas I get from books, T.V., etc.	Ⓝ	Ⓨ	(Y+)
Other:	Ⓝ	Ⓨ	(Y+)

SOCIAL SUPPORT INVENTORY (cont.)

Please read each statement and then indicate how much support you receive from each of the sources listed by marking: NO (N), YES (Y), or YES A LOT (Y+).

When I need to talk or think about how I'm doing with my life, I feel understood and get help from:

	NO	YES	YES A LOT
My spouse or partner	N	Y	Y+
My children	N	Y	Y+
Other relatives	N	Y	Y+
Close friends	N	Y	Y+
Co-workers	N	Y	Y+
Church/Synagogue groups	N	Y	Y+
My spiritual faith	N	Y	Y+
Community or neighborhood groups	N	Y	Y+
Professionals or Service Providers	N	Y	Y+
Special groups I belong to	N	Y	Y+
Reading certain books or watching T.V.	N	Y	Y+
Other:	N	Y	Y+

V. I feel good about myself when I am able to do things for and help:

	NO	YES	YES A LOT
My spouse or partner	N	Y	Y+
My children	N	Y	Y+
Other relatives	N	Y	Y+
Close friends	N	Y	Y+
Co-workers	N	Y	Y+
Church/Synagogue groups	N	Y	Y+
People who share my beliefs and values	N	Y	Y+
Community or neighborhood groups	N	Y	Y+
Professionals or Service Providers	N	Y	Y+
Special groups I belong to	N	Y	Y+
Causes that are promoted in books or on T.V.	N	Y	Y+
Other:	N	Y	Y+

APPENDIX 2

Additional Tables of Statistical Analysis Page

One-Way Analysis of Variance
Patient Diagnosis with Caregiver´s Coping

Source	SS	DF	MEAN SQUARE	F	SIG. OF F
Main effects	44.405	5	8.881	.664	.668
pt. diagnosis	44.405	5	8.881	.664	.668
Explained	44.405	5	8.881	.664	.668
Residual	510.293	37	13.792		
Total	554.698	42	13.207		

Two-Way Analysis of Variance
Caregiver´s Relationship to Patient and Living Arrangement with Coping

Source	SS	DF	MEAN SQUARE	F	SIG OF F
Main Effects	90.811	7	12.973	1.025	.432
RELATIONSHIP	64.677	6	10.780	.852	.540
LIVING WITH	7.488	1	7.488	.592	.447
2 way interactions	46.381	2	23.191	1.833	.176
RELPT LIVPT	46.381	2	23.191	1.833	.176
Explained	137.192	9	15.244	1.205	.325
Residual	417.506	33	12.652		
Total	554.698	42	13.207		

One-Way Analysis of Variance
Patient Diagnosis with Caregiver´s Coping
(Recoded Variables)

Source	SS	DF	MEAN SQUARE	F	SIG. OF F
Main effects	4.762	1	4.762	.355	.555
Pt. Diagnosis	4.762	1	4.762	.355	.555
Explained	4.762	1	4.762	.355	.555
Residual	549.935	41	13.413		
Total	554.698	42	13.207		

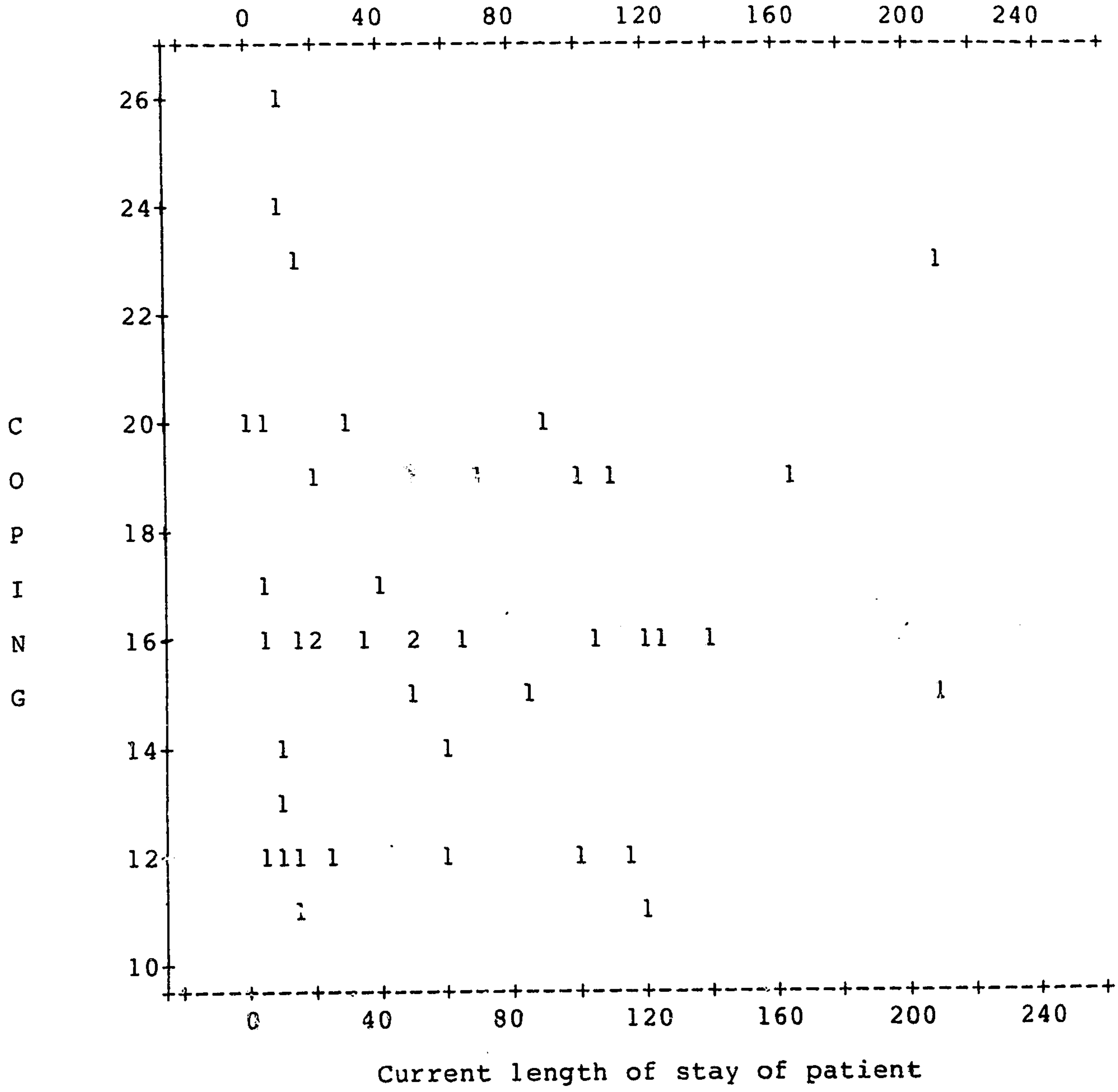
Two-Way Analysis of Variance
Caregiver´s Relationship to Patient and Living Arrangement with Coping
(Recoded Variables)

SOURCE	SS	DF	MEAN SQUARE	F	SIG. OF F
Main effects	26.184	2	13.092	.970	.388
RELATIONSHIP	.050	1	.050	.004	.952
LIVING WITH	25.516	1	25.516	1.890	.177
2-Way Interactions	2.064	1	2.064	.153	.698
RELPT LIVPT	2.064	1	2.064	.153	.698
Explained	28.248	3	9.416	.698	.559
Residual	526.450	39	13.499		
Total	554.698	42	13.207		

Scatterplot

Caregivers' Acceptance/Rejection Coping Response

with Patient Length of Stay



Three-Way Analysis of Variance
Patient's Treatment Frequency, Length of Illness, and Severity of Illness by Caregiver's Coping

Source	SS	DF	MEAN SQUARE	F	SIG OF F
Main Effects	67.167	6	11.195	.827	.557
TREATMENT FREQUENCY	36.270	2	18.135	1.339	.275
LENGTH OF ILLNESS	18.358	1	18.358	1.356	.252
SEVERITY OF ILLNESS	10.891	3	3.630	.268	.848
Explained	67.167	6	11.195	.827	.557
Residual	487.530	36	13.543		
Total	554.698	42	13.207		

Three-Way Analysis of Variance
Patient´s Treatment Frequency, Length of Illness, and Severity of Illness by Caregiver´s Coping
(Recoded Variables)

SOURCE	SS	DF	MEAN SQUARE	F	SIG. OF F
Main effects	25.931	3	8.644	.623	.605
TREATMENT FREQUENCY	2.243	1	2.243	.162	.690
LENGTH OF ILLNESS	9.845	1	9.845	.710	.405
SEVERITY	6.020	1	6.020	.434	.514
Two-way Interactions	11.757	3	3.919	.283	.838
TXFREQ LENGILL	3.161	1	3.161	.228	.636
TXFREQ SEVILL	5.318	1	5.318	.383	.540
LENGILL SEVILL	1.095	1	1.095	.079	.780
Three-Way Interact.	31.592	1	31.592	2.278	.140
TXFREQ LENGILL SEVILL	31.592	1	31.592	2.278	.140
Explained	69.281	7	9.897	.714	.661
Residual	485.417	35	13.869		
Total	554.698	42	13.207		

Pearson Correlations Between the Composite Indices of Social Support, Chronicity and Severity and the Coping Response of Acceptance/Rejection by the Primary Caregiver

- Social Support with Patient´s Length of Stay (Chronicity)
- Social Support with Patient´s Frequency of Treatment (Chronicity)
- Social Support with Patient´s Length of Illness (Chronicity)
- Social Support with Severity of Illness
- Social Support with Caregivers´ Acceptance/Rejection Coping Response

Caregivers´ Pearson Correlations between Social Support and Patient´s Length of Stay (Chronicity)

	Kinds of Support				
Sources of Support	emotional	esteem	network	appraisal	altruistic
spouse/ partner	.1697	.0422	.0708	-.0437	.0617
children	-.0259	-.1537	-.0633	-.0498	-.1764
relatives	-.0708	.0795	.0523	-.1153	-.1679
friends	.0700	.0866	.0932	.1530	.2209
co-workers	.2235	.2806*	.2011	.0651	.0949
church	-.0128	-.1449	-.0111	.1009	-.0020
faith	.0605	.0384	.1422	.3002*	.2358
community	.1170	.1764	.1069	.0522	.0916
professionals	-.2010	-.0748	-.1303	-.1089	-.1516
spec. groups	.1099	.0036	.0511	.1344	.0558
media (TV/ books)	.2087	.1105	.1389	.2457	.0733
other	.1537	-.0556	.0533	.1128	.0172

Note: $*p < .05$

Caregivers´ Pearson Correlations between Social Support and Patient´s Frequency of Treatment (Chronicity)

	Kinds of Support				
Sources of Support	emotional	esteem	network	appraisal	altruistic
spouse/ partner	-.1701	-.2672*	-.2243	-.1648	-.3175*
children	-.0518	-.1775	-.0065	.0948	-.1560
relatives	.0369	-.2802*	.0249	.1561	-.1142
friends	.1204	-.0399	.1407	.2280	-.0303
co-workers	-.0760	-.2190	-.1470	.0027	-.1355
church	.1441	.1154	.1481	.2390	.1942
faith	.2620*	.1563	.2032	.1583	.1308
community	.2455	.1628	.1906	.3966**	.1000
professionals	.0102	.0137	.0852	.0502	.0043
spec. groups	.2377	.1503	.1871	.2879*	.2589*
media (TV/ books)	.0091	-.1761	.2259	.2200	.2230
other	.4985**	.3471*	.2014	-.1335	.0971

Note: *p < .05 , **p < .01

Caregivers´ Pearson Correlations between Social Support and Patient´s Length of Illness (Chronicity)

	Kinds of Support				
Sources of Support	emotional	esteem	network	appraisal	altruistic
spouse/ partner	-.1074	-.0176	-.2203	.1927	-.2316
children	-.1130	-.1767	-.1761	.0623	-.1827
relatives	.1011	.1075	.1683	.0796	.0598
friends	.1005	-.0253	.0839	.1697	.1344
co-workers	-.0298	.0082	.0721	-.0464	.1331
church	-.1240	-.1651	-.0251	-.1016	.0358
faith	.0221	.0302	.1512	.0164	.1569
community	.2826*	.2401	.2381	.3128*	.3009*
professionals	.0542	.0284	.0742	-.0025	.1204
spec. groups	.2100	.1274	.1779	.2423	.2148
media (TV/ books)	-.3062*	-.4008**	-.1740	-.0001	-.1633
other	.4330**	.1024	.4200**	.2323	.2974*

Note: $*p < .05$, $**p < .01$

Caregivers´ Pearson Correlations between Social Support and Severity of Patient´s Illness

	Kinds of Support				
Sources of Support	emotional	esteem	network	appraisal	altruistic
spouse/ partner	.0367	-.0366	.0366	.0682	-.0366
children	.0320	-.0352	.0000	.0388	-.0961
relatives	-.1951	-.1995	-.0562	-.1142	-.1903
friends	-.0946	.0000	-.0422	-.0788	.0443
co-workers	.0353	.0347	.0347	.0770	-.0351
church	.0000	.0441	.0416	.0816	.0000
faith	-.0711	.0000	.1220	.1056	.1317
community	.1441	.1232	.0882	.0552	.1629
professionals	-.0882	-.0445	.0000	-.0438	-.0859
spec. groups	.1783	.0793	.1542	.2379	.1352
media (TV/ books)	-.0756	-.0872	.0000	.0000	.1921
other	.0000	.1995	.0000	.0000	.0000

Caregivers´ Pearson Correlations between Social Support and Acceptance/Rejection Coping Response

	Kinds of Support				
Sources of Support	emotional	esteem	network	appraisal	altruistic
spouse/ partner	-.2323	-.0911	-.2273	-.0428	-.1372
children	-.0412	.1226	.0187	.1022	.0731
relatives	-.1198	.0408	-.1059	-.0505	-.0716
friends	.0202	.1146	.1089	.1412	.0889
co-workers	.1341	.2048	.1772	.2082	.2928
church	-.2482	-.1134	-.1119	-.1735	-.1162
faith	-.1810	-.1713	-.0663	-.0298	-.1714
community	-.0421	-.0144	-.0439	-.1714	.0439
professionals	.0102	-.0063	.0220	.0070	-.0323
spec. groups	-.2916	-.2894	-.3106*	-.2894	-.2830
media (TV/	-.1203	.0315	.0532	.0419	-.3738*
other	-.1117	.0154	-.1208	-.1918	-.1792

Note: *p < .05

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