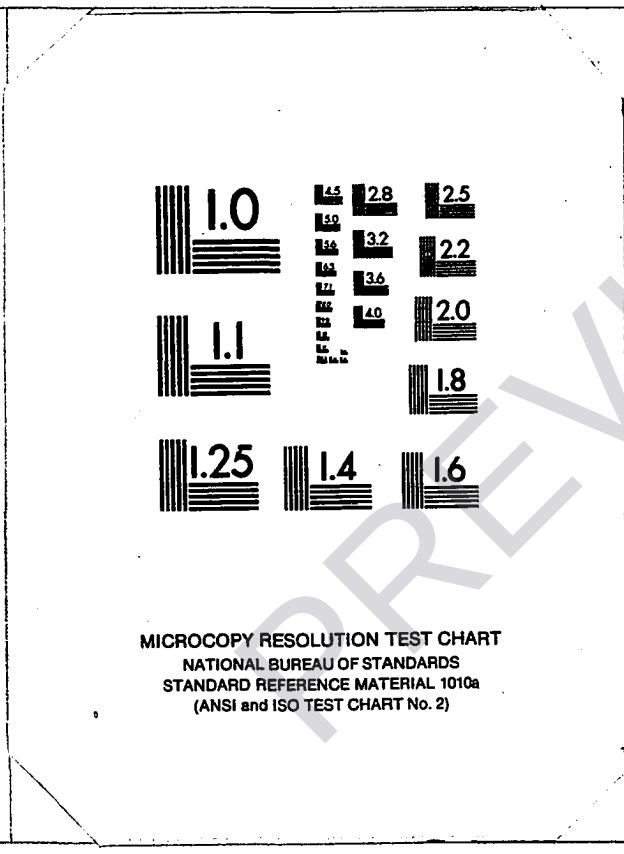

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COPING AND INTERACTION PATTERNS WITHIN FAMILIES OF ADULTS WITH THE CHRONIC DISEASE RHEUMATOID ARTHRITIS

The University of Nebraska - Lincoln PH.D. 1986

COPING AND INTERACTION PATTERNS WITHIN FAMILIES OF ADULTS WITH THE CHRONIC DISEASE RHEUMATOID ARTHRITIS

by

Gloria Jean Gross

A DISSERTATION

Presented to the Faculty of

The Graduate College in the University of Nebraska

In Partial Fulfillment of the Requirements

For the Degree Doctor of Philosophy

Major: Interdepartmental Area of

Administration, Curriculum and Instruction

Under the Supervision of Professor Robert O'Reilly

Lincoln, Nebraska

December, 1986

TITLE

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BY

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APPROVED	DATE
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SUPERVISORY COMMITTEE

GRADUATE COLLEGE **UNIVERSITY OF NEBRASKA**

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COPING AND INTERACTION PATTERNS WITHIN FAMILIES OF ADULTS WITH THE CHRONIC DISEASE RHEUMATOID ARTHRITIS

Gloria Jean Gross, Ph.D.

University of Nebraska, 1986

Adviser: Robert O'Reilly

The purpose of this study was to identify, through intensive case study, explanatory patterns that express modes of adapting and family interaction within families of adults with the chronic disease, rheumatoid arthritis (RA).

Four adults with RA were selected to represent each of the four functional categories of RA outlined by the American Rheumatism Association. The adults with RA and all family members living in the same households constituted the sample. Three families were Caucasian, one Black. One adult with RA was male.

Each family member was interviewed separately and as a member of a family group to obtain demographic data and determine the effects of living with someone with RA as well as to ask about family interactions and ways of coping with stress. Each member recorded daily hassles and ways of coping from the Ways of Coping (Revised) Checklist devised by Lazarus and Folkman (1984). Each family was observed on two different occasions to detect communication and interaction patterns.

The degree of functional ability of the individual with RA was the factor that determined the presence and types of effects on family members for these sample families. There were no or slight effects reported in Families One and Two while there were a number of effects in both Families Three and Four. Both marriages had dissolved and both women attributed this to their inability to fulfill role expectations. Both reported that they were unable to adequately parent their young children. Children became "parentified" to the extent that they needed to prepare meals, keep house, and care for other children. The child in Family Three didn't perceive this as a problem.

Ways of coping for all individuals included more-emotion focused than problem-focused means. The most frequently reported way of coping for adults was "I prayed" and for adolescents/children, it was "Slept more than usual."

The tools (resources) reported as needed for successful coping were any treatments or devices that would allow the afflicted individual to maintain role function. Failure in role function was associated with ineffective coping. The family of origin served as an important source of coping strength for all subjects by providing both material and emotional support.

Acknowledgments

I wish to express my appreciation to Dr. Robert O'Reilly for his guidance and assistance throughout the development of this dissertation. Dr. Jeannene Boosinger has, for a number of years, been my role model and mentor in the fullest sense of that overused word. She has consistently forced me to "do it a little better" and I am grateful for that. I thank Dr. Robert Brown and Dr. R. McLaran Sawyer who have been both excellent teachers and advisors throughout my doctoral program and the writing of the dissertation.

The members of my nuclear and extended families have never wavered in their support, encouragement and prayers. I quite simply could not have finished without the help of my husband--Charles, my children--David, Michele, Bill, and Cindy and that of my parents, Ralph and Betty Brunt.

My colleagues at Bishop Clarkson College of Nursing have offered encouragement and helped in the problem-solving process.

A special thanks goes to my typist, Karen, who took phone calls at odd hours, worked at my whim, and produced a beautiful document.

It is the members of the families who must have the most recognition, however. They allowed a stranger into their lives and homes and were willing to be studied. Their courage was an inspiration.

Finally, thanks to Dr. Clifford Hardin, whose telegram so many years ago started it all!

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CHAPTER I

INTRODUCTION

Context of the Problem

Chronic illness is the number one health problem in the United States. The mortality rate from chronic diseases such as heart disease, cancer, and stroke increased more than 250% from 1900 to 1975 (Califano, 1979). The term "chronic disease" implies, however, that most people with these diseases do not die, but live for long periods of time with the disorder. The National Center for Health Statistics (Califano, 1979) reported that 14.1% of the general population and 46% of those over age 65 experience limitations in their activities caused by one or more chronic diseases. Each person afflicted with such a disease is also a member of a social structure whose members are also affected by the disorder by virtue of the changes in the ill member. The family unit is the most frequently affected social structure.

There has been a dramatic change in the delivery and use of health care in the past five years due to several events. First, there was an economic recession during which many workers were laid off and as a consequence, had no health insurance. This was followed by the federal government changing the method of payment for Medicare reimbursement to make the system more cost-efficient. This new system had the effect of shortening hospital stays and

for many, meant that no health care was provided within the hospital/acute care setting. Those who were hospitalized were more acutely ill. Advances in medicine and technology made it possible to maintain and prolong life in those who quite probably would have died from that same condition even 15 years ago. At the same time, those with less severe conditions were now being cared for in extended care facilities and in their own homes. The professional nurse is the member of the health care team most likely to provide care in these two settings. For this reason, nurses are interested in information that will enhance positive adaptation by both the client and the family.

The health care providers are peripheral to the family most of the time however, since it is the person with a chronic illness and members of his/her family who are primarily responsible for maintaining function and preventing further disability. Investigators from medicine, sociology, and medical psychology have examined the impact of this responsibility on the afflicted individuals and their coping strategies. A recent text edited by Burish and Bradley (1983) contains chapters on coping with chronic illness including specific disease states, such as spinal cord injuries, as well as conceptual issues and discussions related to research in this particular area. There is a fairly large body of knowledge about the individual with such a disorder.

This is in contrast to the amount of research which has been done on the effects on and coping strategies used by the family members. A chronic illness that affects one member in a family has implications for all family members and requires a variety of adaptive moves for the family to remain functional. Family systems theory as explicated by Minuchin (1974), Bowen (1978), and others postulates that a change in any part of the family system creates a change in all the other subsystems. The majority of studies done on family members is concentrated in the field of pediatrics with studies done on the effects seen on parents and patterns of parental coping when children have chronic disease. Taylor (1980) examined the effects on siblings of children with chronic disease.

Paradoxically, given that most people with chronic diseases are adults, there is a dearth of information available on the effects of living with an adult with a chronic disease and coping strategies used by family members. Most early studies were done to determine the effects of family support on patient compliance with medical regimes, but did not examine the actual needs or coping methods used by family members. Recent reports (Bruhn, 1977; Craven & Sharp, 1972; Croog & Fitzgerald, 1978; Fengler & Goodrich, 1979; and Sexton & Munro, 1985) have shown a shift to emphasis on family members, typically the spouse. Most studies used the survey method to obtain

data. An intensive examination of a case family's interaction and patterns of coping was not found.

Purpose of the Study

The purpose of this study was to explore, through intensive case study, possible explanatory patterns that express modes of adapting and family interaction within families of adults with the chronic disease, rheumatoid arthritis (RA). The specific questions to be answered were:

1. What are the effects on family members of living with an adult with chronic disease, rheumatoid arthritis?
2. How is family functioning affected by the presence of chronic illness in an adult member?
3. What are the adaptive modes (ways of coping) expressed by various family members?
4. What are the tools (resources) identified as essential for successful functioning by each member of the family?
5. To what extent do the concepts of Bowen's Family Systems Theory apply to families with a member who has a chronic disease (RA)?
6. What are the differences, if any, in the adaptive modes (ways of coping) expressed by families adapting positively and those whose adaptation is dysfunctional?

7. What are the differences, if any, in the tools (resources) identified as necessary for successful functioning by families adapting positively and those whose adaptation dysfunctional?

Definition of Terms

Chronic Disease: Any impairment or deviation from normal that has one or more of the following characteristics: it is permanent; leaves residual disability; is caused by nonreversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care (Anderson & Bauwens 1981, p. 3).

Family Members: Those individuals living in the same household with an adult with the chronic disease rheumatoid arthritis whether related by blood, marriage, adoption, or common law arrangement.

Mode: A manner or way of acting, doing or being that serves the function of assisting an individual to respond to a need for change; classification includes physiologic, self-concept, role function, and interdependence.

Positive Adaptation: A response to the need for change that promotes functioning and health; response that decreases the amount of energy needed to cope with the given situation and increases energy for other human processes (Roy, 1984).

Negative Adaptation: A response to the need for change that results in dysfunction and/or illness.

Coping: Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984).

Theoretical Framework

The theoretical framework for this study was provided by the works of Salvador Minuchin (1974) and Murray Bowen (1978) in family systems theory, Sr. Callista Roy (1984) in adaptation and nursing, Lazarus and associates (1966, 1974, 1984) on coping and Wright and Leahey (1984) on family assessment.

Minuchin's model of the family is based on the belief that a family serves two purposes, the internal one of psychosocial protection of its members and the external one of accommodations to a culture. He views the family as a system that maintains itself by resisting change beyond a certain range. The family must adapt when circumstances change because the continued existence of the family as a system depends on a sufficient range of patterns and the flexibility to mobilize them when necessary. Family adaptation must take place in response to both internal stresses and extrafamilial forces. The four forces detailed by Minuchin are: 1) stressful contact of one member with extrafamilial forces; 2) stressful contact of the whole family with extrafamilial forces; 3) stress at

transitional points in the family; and 4) stress around idiosyncratic problems.

A final concept of the model is that of boundaries for each subsystem. Families form boundaries both as a family and for each member of the family. The boundaries are the rules defining who participates, and how in each subsystem. The function of boundaries is to protect the differentiation of the system. "Every family subsystem has specific functions and makes specific demands on its members; and the development of the interpersonal skills achieved in these subsystems is predicated on the subsystem's freedom from interference by other subsystems" (p. 54). Boundaries are seen as being on a continuum from enmeshed (very blurred boundaries) to disengaged (with inappropriately rigid boundaries). The boundaries of a subsystem must be firm, yet flexible enough to allow realignment when circumstances change. If a family responds to stress with rigidity, dysfunctional patterns occur.

Bowen expanded on these concepts and developed his Family System Theory. There are eight components to the theory:

1. Differentiation of self-the cornerstone of this theory which defines people according to the degree of fusion or differentiation between emotional and intellectual functioning. Those on the fused end of the continuum are so controlled

by emotional process that beliefs or opinions rarely figure in decision-making. The more differentiated person "...can participate freely in the emotional sphere [and] is also free to shift to calm, logical reasoning for decisions that govern his life" (p. 364).

2. Triangles-a three-person emotional configuration that is the molecule or the basic building block of any emotional system. The triangle is the smallest stable relationship system. "In periods of calm, the triangle is made up of a comfortably close twosome and a less comfortable outsider. The twosome works to preserve the togetherness, lest one become uncomfortable and form a better togetherness elsewhere. The outsider seeks to form a togetherness with one of the twosome, and there are well-known moves to accomplish this...In periods of stress, the outside position is the most comfortable and most desired position. In stress, each works to get the outside position to escape tension. When it is not possible to shift forces in a triangle, one of the involved twosome will set a third person aside for reinvolvement later" (p. 374).

3. Nuclear family emotional system-patterns of generation. "Certain basic patterns between the father, mother, and children are replicas of the