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THE UNIVERSITY OF ALBERTA

# A THEORETICAL MODEL OF LONG TERM CARE AND CAREGIVER BURDEN

BY

GAIL B. GILEWICH

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled A THEORETICAL MODEL OF LONG TERM CARE AND CAREGIVER BURDEN submitted by GAIL B. GILEWICH in partial fulfilment of the requirements for the degree of Master of Science.

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(Supervisor)

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Date: April 7 .......................... 1987

To my husband, Lawrence, and our children, Bradley and Weylin, who provided me with valuable encouragement and support throughout my studies.

# Abstract

The purpose of this thesis was to clarify the conceptualization of burden in relation to care provision within the context of long term care. The concept of burden was reviewed through an analysis of the empirical literature. Through a systematic procedure of theory reworking, a theoretical model was proposed. Based on the similarities between the operational definitions of burden in the empirical literature and the components of the psychological and family theories of stress, the term "burden" was discarded. A psychological theory of stress was expanded to include the caregiver's environment: the family and society. From the theoretical model, variables were identified, defined, and included in propositional statements reflective of the context of care provision in long term care situations. The theoretical model was validated through an evaluation of theory standards. The propositional model was validated by examining caregiver burden research.

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# CHAPTER I

In Britain, during the late 1950's and early 1960's, there was a major shift in the conceptualization of treatment for the emotionally disturbed or mentally ill individual. The shift was from provision of treatment services within an institution to provision of treatment through community health services (Grad & Sainsbury, 1963). With the introduction of community health services, including home care, the patient's family assumed a large part of the responsibility for care of the mentally ill relative as the patient was discharged to the relatives' home (Hoenig & Hamilton, 1967).

In an attempt to understand the consequences of the change in service delivery, early investigations of the problems of the family focused on the effects that mentally ill individuals had on their families. The term "burden" was initially used by Grad and Sainsbury (1963) to describe these effects. Since this initial investigation was reported, home care has continued to be a method of service delivery throughout Britain and North America. Numerous researchers have investigated the burden experienced by families, family members or caregivers in caring for the mentally ill. In more recent years, the relationship between caregiving and burden has been addressed in the gerontological literature.

The research on families caring for adult ill relatives has provided insight into the problems that families experience in provision of long term care. The empirical research identifies burden as a phenomenon that exists; however, there is little consensus among researchers as to the definition of burden, the conceptualization of burden, the measurement of burden and the identification of variables that influence variation in burden.

Thompson and Doll (1982) reported that the earliest conceptualization of burden was related to the mentally ill who were discharged from hospitals to the care of their families. The literature primarily addressed the social costs to the families in these situations. The assumption made in the early research was "that any individual whose presence and performance aroused either fear or shame must be burdensome and could not be living within a supportive environment" (p. 380). The social costs to families were inferred from attitude measures of social distance or stigma. Grad and Sainsbury (1963) initially introduced the concept of burden to refer to the hardships or effects that mentally ill individuals have on the lives of family members. Since this initial investigation, burden has been investigated in families caring for mentally ill relatives (Herz, Endicott & Spitzer, 1976; Platt & Hirsch, 1981; Thompson & Doll, 1982), the ill elderly (Montgomery, Gonyea & Hooyman, 1985; Poulshock & Deimling, 1984; Ross & Kedward, 1977) and individuals with a dementing illness (Kahan, Kemp, Staples & Brummel-Smith, 1985; Pratt, Schmall, Wright & Cleland, 1985; Zarit, Reever & Bach-Peterson, 1980).

The conceptualization of burden has varied among researchers. However, there are two distinct conceptualizations that have been formulated and advanced by researchers; one by Hoening and Hamilton (1966) and the other by Zarit, Reever and Bach-Peterson (1980). Hoenig and Hamilton (1966) viewed burden as a dichotomous variable and separated the concept into objective and subjective components. "Objective burden" (p. 614) is defined as the effects on the life of the household and the occurrence of abnormal behavioral traits in the patient. "Subjective burden" (p. 614) is defined as the available informants' report of carrying any burden, in a subjective sense over a four year period. With this conceptualization, burden is a concept that reflects a perception or feeling state of a family member and a concept that reflects the problems of caregiving experienced by family members.

Zarit et al. (1980) conceptualize burden as a unidimensional construct. The degree of burden is operationally defined as the feelings of discomfort that the caregiver experiences in relation to the problems of caregiving. With this conceptualization, burden is a construct that incorporates both subjective and objective components into one concept.

Researchers in the area of burden tend towards using either the conceptualization of Hoenig and Hamilton (1966) or Zarit et al. (1980). Although researchers identify with one particular conceptualization, there is little consensus as to operational definitions and measurement of burden. Several terms are used in the literature to conceptualize and operationally define the effects of caregiving on family members who are providing care for physically and/or mentally impaired relatives. The terms distress, anger, frustration and strain tend to be used interchangeably with the term "burden" being identified as the concept being measured.

Researchers also vary in the unit of analysis of measurement. Burden is an attribute that is assigned to the individual, the family or the household. In most instances the respondent is an individual family member, although the term "family burden" is the construct that is identified as the concept being measured.

Montgomery, Gonyea and Hooyman (1985) concluded that the inconsistent findings of researchers in the area of burden can partially be attributed to the variation in definitions and measurement of both caregiving and its consequences. In reviewing the literature on burden, it is apparent to me that the research addressing the phenomenon of burden generally tends to lack a clearly articulated framework. I view the absence of theoretical development as contributing to the inconsistent findings and the conceptual and methodological ambiguity that presently exists.

To summarize, the problem identified for this investigation is the absence of clarity in the conceptualization of burden. Burden is conceptualized as both a dichotomous concept and a unidimensional concept. While several terms are used interchangeably to conceptualize and operationally define the effects of caregiving on family members who are providing care for physically and/or mentally impaired relatives, the term "burden" is identified as the concept being measured. There is variance in the unit of analysis of measurement. In most instances the respondent is an individual family member, and the term "family burden" is the construct that is identified as the concept being measured. I believe that clarity could be obtained through development of a theoretical model which would give direction to conceptualization and measurement of burden.

## Purpose and Justification

The purpose of this investigation is to clarify the concept of burden. Following the clarification of the concept, a theoretical model is presented that identifies the circumstances that are thought to influence the variation of burden that is experienced by family members who are providing long term care for their adult relative.

This investigation has both theoretical and practical significance. The theoretical significance relates to the investigation of conceptual issues and the minimization of inconsistencies in the conceptualization of burden. I view improving conceptualization as a necessary process in the scientific study of the family and as Burr (1973) states: "one of the biggest obstacles to the scientific study of the family is conceptual ambiguity" (p. 272).

Family research has been criticized for the failure of researchers to develop a theoretical framework for their research (Broderick, 1971; Burr, Hill, Nye & Reiss, 1979; McCullers, 1984). As McCullers cautions, embarking on research questions without theoretical guidance means that the right questions may not be asked, and we may not know how to interpret the answers we get. Theories help us organize facts and formulate research questions.

I believe that to advance knowledge in the area of burden as related to the provision of care to adult relatives, priority now should be given to the conceptual clarification of the phenomenon of burden. This clarification is required prior to the explanation of circumstances that may influence variation in burden.

The practical significance of developing a theoretical model relates to the families of ill relatives and to those who are responsible for provision of programs to mediate burden. The literature, implicitly or explicitly, indicates that caregivers of ill relatives do experience burden and that programs are required to assist families in moderating burden. A more thorough understanding of burden may assist both families and individuals who are designing and evaluating the efficacy of their intervention programs. It is logical to assume that if program efficacy is determined by the measurement of burden and indicators of burden are conceptually ambiguous, the interpretation of program efficacy may be in error. As Hoenig and Hamilton cautioned in 1967, the term burden requires care in its usage as the investigator and the investigated may have different conceptions of the term.

## Thesis Objectives

The objectives relate to the purpose of the thesis: to attain conceptual clarity of the phenomenon of burden and to develop a family oriented theoretical model that will identify the circumstances that may influence variation in burden. The objectives are as follows:

1. To establish a methodology that provides systematic inquiry.
2. To define the concept of burden.

3. To specify a unit of analysis of the concept of burden.
4. To attain conceptual clarity of the phenomenon of burden as a family process variable.
5. To identify and define the factors that influence variation in burden.
6. To develop a set of propositions that state the relationship between specifically identified variables and the variable of burden.
7. To state the propositions in verbal and diagrammatical form.
8. To make recommendations for integration of the model into future research.

The objectives have been documented in a sequence that will be followed in all stages of model development. The eight objectives are considered to be prerequistes to systematic inquiry.

## Limitations

There are three limitations that require stating in order to establish the domain of this theoretical model. First, this exploration is limited to the family where one or more family members are providing long term care to another family member. This limitation is based on the assumption that the provision of care is being provided over an extended period of time (Koff, 1982).

The second limitation is that the individual requiring the care is a family member who, due to deterioration in functioning, requires prolonged care from another individual. This limitation is based on the assumption that care provision on a long term basis involves different family dynamics than short term care.

Thirdly, it is an exploration of burden in families where the individuals receiving and providing the care are elderly spouses. Although it is recognized that providing care to a relative of any age can be burdensome, there may be factors that influence the presence of burden that are specific to the elderly adult in a marital relationship. This limitation is based on the assumption that family dynamics may differ in this stage of the life span from family dynamics in earlier stages.

The intent of this chapter was to provide an introduction to the conceptualization of burden and the purpose, objectives and limitations of this investigation. The problem identified was the conceptual abiguity documented in the burden literature. The purpose of the investigation was identified as clarification of the concept through development of a theoretical model. Eight objectives were documented and three limitations stated.

As this investigation will be exclusively oriented towards theory construction, the next chapter contains a review of theory construction literature. Four metatheoretical issues of theory construction are addressed.

# CHAPTER II

## Theoretical Issues: Literature Review

In a review of a workshop on family theory construction, Burr, Hill and Klein (1973) noted that researchers seeking to explain family phenomena were giving considerably more attention to theory building than in previous years. In analyzing their workshop structure, they recounted that very little had been written about the process or methodology of building theories.

Blalock (1969), in his book on theory construction, points out that most social scientists concede that there is a need for more adequate theories, but there is less consensus as to the process of theory construction. Because of the continued lack of consensus and the dearth of writing in this area, the metatheoretical issues of theory construction are addressed in this review.

Discussion of metatheoretical issues is viewed as a necessary starting point in constructing theory as metatheoretical issues are addressed by Burr et al. (1973) in their first phase of socialization of students to this process. The purpose of reviewing the metatheoretical issues is to provide the information necessary to initiate theory construction in a systematic way, to provide direction for my choice of methodology and to provide a standard by which to judge the validity of the developed model.

### Metatheoretical Issues

The metatheoretical issues addressed by Burr et al. and included in this review are: the nature and types of theory, the components and essential elements of theory structure, the informal and formal modes of expression utilized in presenting theory, and the criteria by which theories can be evaluated.

The nature and types of theory. Issues related to theory development have been addressed by Aldous (1970), Burr (1973), Burr, Hill, Nye and Reiss (1979), Gibbs (1972), Kerlinger (1973) and Kidder (1981).

The first issue to be addressed is how theory is defined. Definitions range from being relatively abstract (Kidder) to being more specific (Burr, Hill, Nye & Reiss; Kerlinger). Kidder defines theory as "a large body of interconnected propositions about how some portion of the social world operates" (p. 9). Burr et al. define theory as a "set of logically interrelated propositional statements that identify how variables are covariationally related to each other" (p. 17). Kerlinger's definition includes the purpose of theory. Theory is "a set of interrelated constructs (concepts), definitions, and propositions that present a systematic view of phenomena by specifying relations among variables with the purpose of explaining and predicting the phenomena" (p. 9). The latter two definitions would meet the criteria of a theory as outlined by Homans (cited in Burr, Hill, Nye & Reiss, 1979). One does not have a theory until one has properties, propositions stating the relationship between the properties and the properties form a deductive system.

The second issue to be addressed is the purpose of theory. In addition to the purpose provided by Kerlinger, that is, explaining and predicting phenomena, Burr (1973) states that the purpose is to increase our understanding. Aldous (1970) explains that theories have a generative capacity in that theories suggest new areas of systematic investigation. Gibbs (1972) suggests that the way in which a theorist constructs a theory reflects his conception of its purpose. Some theorists demand that a theory identify the cause of a phenomenon. Methodologists who support this view would believe that a theory's purpose is to identify causes of social situations and human behavior. Other theorists maintain that a theory must only offer an explanation of observed phenomena. Offering an explanation differs from the demand of identifying causes. Counterarguments for both demands are found in Burr (1973) and Gibbs (1972).

The third issue to be addressed is the types of theory. Burr (1973) specifies three types of theory: general, middle range and partial. General theories are those that have a large scope, high informative value and are not specifically tied to any social context. Middle range theories are less context-free and less generalizable than general theories. Partial theories are those that are more fragmented and not developed to the scope of middle or general theories.

The components and essential elements of theory structure. The components of theory structure are differentiated from the definition of theory. These components include concepts, variables, and propositions and are defined and described as to the way that the components are related.

Concepts are basic to theory. Concepts are defined as terms or words that symbolize some aspect of reality (Burr et al., 1979; Mullins, 1971). Burr (1973) emphasizes that a concept is a single term rather than an abstract or complex idea. Burr also emphasizes that when concepts are used, conceptual clarity is essential. It is important that concepts be "free from obscurity, ambiguity, or multiple meanings and...they are communicable to others" (p. 7). Stinchcombe (1968) relates conceptual clarity to the purpose of theory. The reason for having theories is to explain the pattern of observations in the world. If the concepts are vague, it is difficult to find corresponding observations. A theory must be specific enough that its accuracy can be challenged through research. Conceptual clarity is a prerequisite of the process of deriving explanations.

The way in which conceptual clarity is attained is by defining concepts. Burr offers two methods by which definitions can be applied to concepts. The first method is the constitutive method described by Kerlinger (1973). This method defines a concept with another concept. Such definitions use one concept in lieu of another or substitute one concept for another. Hage (1972) refers to concepts defined in this way as theoretical concepts.

The second approach to defining concepts employs an operational definition of the concept. An operational definition assigns meaning to a concept by specifying the technique that is used to measure the concept. Hage(1972) and Burr (1973) refer to the advantages of both techniques.

The constitutive method maximizes the meaning of a concept, whereas the operational definition assignment limits the meaning of the concept. Burr views the operational definition method as an attempt to measure rather than define a concept.

Hage (1972) specifies that a theory requires concepts that are both theoretically defined and operationally defined. The two kinds of definitions provide two ways of perceiving one concept. The operational definition allows us to measure. Using only an operational definition may mean that we are limiting our meaning of the concept and giving up a source of valuable insight (McCullers, 1984). On the other hand, theory without operational definitions limits our ability to empirically measure a concept.

Reynolds (1971) differentiates between abstract and concrete concepts and relates the importance of this differentiation in theory. Abstract concepts are those concepts that are relatively universal and independent of a specific time or place. In addition to time or place, one concept can be conceptually considered to be more abstract than another. For example, consider the concepts of "liking" and "sentiment". Sentiment may be defined as an emotional disposition directed toward another and liking is a positive feeling toward another. The concept "sentiment" may be considered as including "liking" and would be conceptualized as the more abstract concept of the two. A concrete concept is related to a unique spatial or temporal setting. Reynolds concludes that a theoretical concept should not be concrete, but at the same time, not so "abstract that there is confusion in identifying instances of the concept" (p. 51).

The second component of a theory is that of variables. Burr (1973), Kerlinger (1973) and Stinchcombe (1968) define a variable as a concept that varies along a dimension of its properties. The reason is that many concepts are not static references to reality, but phenomena that can vary in some way. The importance of variables is considered by Burr. One of the purposes of theory is to explain the circumstances under which variation in one variable influences variation in other variables. Some theorists who support a causal approach to theory differentiate between independent variables and dependent variables. The independent variable is recognized as a cause, whereas the dependent variable is the effect.

There are two ways that variables can vary (Burr, Kerlinger & Stinchcombe). Categorical variables have only two values. Such a variable is often called a dichotomous variable. The values of the variable are discrete, separate parts. On the other hand, continuous variables are variables that range continuously from one extreme to another. Burr emphasizes that in theory construction, all concepts should be clearly defined and the range of variation and categories should be identified.

The third component of a theory is a proposition. Burr, Hill, Nye, and Reiss (1979) define propositions as "declarative statements that assert, or at least attempt to assert, a truth" (p. 19). The declarative statements assert something about the relationship between concepts and/or variables. When considering propositions, one cannot consider the statement without considering the relationship between variables.

Relationships between variables consist of systematic patterns of covariation between variables (Burr, 1973). These relationships exist whenever variation in one variable tends to be accompanied by a systematic variation in another variable (Burr, 1973; Burr et al., 1979). Burr emphasizes that there are various types of assertions that can be made about relationships. These include the following: assertions that a relationship does exist; assertions about the direction of the relationship; assertions about the shape of the relationship; assertions about time lag; assertions about causality (dependent upon a theorist's approach to causality).

Propositions in theory do not exist independently of each other. A theorist could have a large number of declarative statements identifying the relationship between concepts and have no theory. What is required for theory is a component that establishes a logical relationship between propositions that has the purpose of providing explanation or understanding (Burr et al., 1979). This part of establishing theory is achieved through the process of generating logical explanation by induction and deduction. It is this process that groups interrelated propositions to attain multiple levels of generality. Deductive and inductive processes relate to strategies of theory construction and are described later in this chapter.

The components of a theory have been identified. Hage (1972) summarizes the components and indicates the contribution of each component part to the whole theory. By developing propositional statements, the theorist has moved from description to analysis. Definitions of concepts add to the description by providing meaning and measurement. This allows the theoretical concepts to be explicit. Linkages or interrelationships add to the analysis by providing plausability and testability. This eliminates tautology. The ordering of statements and linkages into some inductive-deductive arrangement eliminates inconsistency.

The expression of theory. This issue has been addressed by Blalock (1969), Burr et al. (1979), Gibbs (1972), Mullins (1971), Reed (1984) and Reynolds (1971). There are three ways in which theory can be expressed: verbally, graphically and quantitatively through mathematical symbols. These methods constitute the use of a model. A model, defined by Reed, is a device used to represent an idea through the use of a physical or symbolic form. DiRenzo (cited in Reed, 1984) stresses that theories are not models. The function of a theory is to provide an explanation. A theorist uses a model as a basis for explanation by providing a structure that is helpful for organizing knowledge into a logical pattern and specifying relationships between variables. As such, concepts and the relationship between concepts are the prime material of a model.

In practice, theorists employ the use of verbal statements and graphic or symbolic representation of the verbal statements. Burr et al.(1979) caution that although language is more expressive and more easily understood than other expression modes, it can be imprecise. Diagrammatic modes of expression have the advantage of being concise and precise when they are understood.

Evaluation of theory. The documentation addressing the first three metatheoretical issues emphasizes that theory has a definition and purpose. In addition, theory consists of specific components and methodologies exist by which to document theory. Theory construction must also include a methodology for evaluation. My review of the relevant literature on theory construction indicates that specific methodologies are not explicity addressed in the literature. An exception is the insight provided by Hage (1972) in his analysis of criteria for evaluating theories.

The first criterion to be considered relates to the completeness of the theory. The theoretical definition provides a yardstick by which theoretical components can be measured. Hage points out that a theory can be considered as fairly complete if it contains the following components: concepts, definitions, statements and linkages (interrelationships). However, in order to answer questions related to whether a work is a theory or how much of a theory it is, evaluation must specifically consider whether all components of theory exist and the extent to which they exist. For example, definitions and linkages must be theoretical and operational. If a theory fragment does not include theoretical definition, one "can say that the meaning of the terms has not been specified" (p. 177). If a concept is not operationally defined, one can say that the concept cannot be measured.

The second criterion is that theory construction should be evaluated according to theory standards. There are four standards which should be considered: scope, parsimony, precision of prediction and accuracy of explanation.

The scope of a theory is the generality of the theory. It is a measure of how many of the basic issues in a discipline are taken into consideration by the theory. The importance of the scope of theory is that as theories become more general, they tend to stand without revision for a longer time. However, this does not imply that theories of the middle range (medium scope) or partial theories should not be constructed as these theories also contribute to knowledge and understanding.

Parsimony, as a standard, is a property of theoretical statements. Theories must be stated in simple terms. The objective is to explain as much as we can in as simple a way as possible. McCullers (1984) explains that this principle can be expressed in several forms. Lower-order phenomena should not be explained in terms of higher-order processes. As an example, the behavior of non-humans should not be explained in terms of human qualities. Simple explanations are favored over more complex, abstract explanations. For example, explanations requiring fewer assumptions are favored. The intent is to keep theorizing as simple as possible.

Hage believes that the precision of a prediction is a standard of a theory. By precision, he is explicit that prediction is provided through sets of equations. One equation will supply us with some predictions; however, sets of equations are required to be precise.

The last standard is the accuracy of explanation or the validity of theory. The explanation of any theory lies in its set of premises or theoretical linkages. The set of premises serves to identify a chain of events that assist us in deciding whether the phenomenon is explained accurately. In practice, empirical research, based on the premises, plays an essential role in judging the accuracy of explanation.

Burr (1973) maintains that generating theoretical propositions is not sufficient in theory construction. This process must be accompanied by a validation process. This involves systematically assessing the empirical literature for support of the propositions. This process, as a part of theory construction, would meet Hage's expectation of accuracy of explanation.

In summary, the four metatheoretical issues raised by Burr et al. have been addressed. These issues need to be addressed in theory construction, regardless of the specific methodology used in theory construction. It is my intent to elaborate on these issues in the chapter on methodology and throughout the development of my model.

# CHAPTER III

## Methodology

Theory construction begins with an idea (Reynolds, 1971). Before developing definitions, propositions and more formal theory, a theorist usually has a conceptualization or an orientation toward a phenomenon. It is this idea that forms the basis for the written theory. It is also the idea that partially identifies the purpose for developing theory.

My perspective of the research into family burden has basically been outlined in the introduction. It was a review of the literature on burden that initially formed the idea that conceptual ambiguity existed and ultimately led to the purpose of the thesis. However, there is another factor that influenced my perspective of family burden.

My conceptualization of burden has been influenced by the theoretical orientations of psychological theories, family systems theory, family crisis theory and developmental theory. This influence has an impact on my conceptualization of burden. This influence is also reflected in my methods of dealing with metatheoretical issues and choice of strategy. This will be further explained as methodology is established.

Burr (1973) states that theory construction can be viewed with varying degrees of breadth. When viewed in a very narrow sense, theory construction consists of inventing new theories, extending existing theories, integrating theories that have not previously been combined and modifying existing theories in light of new information that is available. When viewed from a broader perspective, theory construction includes conceptual development, gathering empirical data to generate, test, and/or modify theory, improving data retrieval systems and improving measurement instruments.

Strategies of theory construction can be inductive and/or deductive (Aldous, 1970; Burr, 1973). Inductive strategies are those that use relatively specific and concrete ideas to generate new ideas of a more general and abstract nature. The grounded strategy and codification strategy are examples of an inductive strategy. The theory construction process starts with data to generate new theoretical insights.

Deductive strategies are those that identify relatively abstract, general propositions, and proceed by deducing from the general ideas new propositions that have not been identified. Borrowed theory is an example of deductive theory construction. Both Aldous and Burr describe this strategy as borrowing concepts from other areas within the discipline as well as other disciplines. When the initial borrowed propositions are sufficiently general to make deductions about phenomena in the new area, this method can be described as a deductive strategy.

## Model Strategy

The strategy that is used in the development of my model is the theory reworking strategy used by Burr (1973). Burr defines this strategy as a process of modifying or remodelling an existing theory with the purpose of improving upon it. It may not build a theory, in the strict sense of increasing the amount of theory, but it can build theory in the sense of improving clarity, testability, communicability, parsimony and heuristic value. Burr elaborates on the usefulness of this method. At the time of his work (1973), there were vast amounts of theory that had been advanced, but poorly written. He advocates that using this approach of systematizing present theory in the field will advance knowledge. This strategy is both inductive and deductive and has been described by Burr, Hill, Nye and Reiss (1979) as a theory-repairing program. The procedures are outlined as follows:

1. Start with conceptual clarification of the major dependent variable to be explained or the major determinant variable whose consequences are to be discussed.
2. Review theories that are context-free that pertain to the phenomenon of interest.
3. Formulate a limited number of general context-free propositions, using formal language.
4. For each proposition, deduce context-specific propositions that would follow by subsumption at lower levels of abstraction.
5. Scan the research literature for empirical support. Include the direction and shape of the relationships.
6. Incorporate all these propositions into a model.

My reasons for using Burr's approach are based on the following rationale: this approach includes the domain of conceptual clarification; psychological and family theories have been developed sufficiently in recent years to the point that assumptions have been established; both a theoretical orientation and an operational definition orientation can be utilized; the existing empirical literature can be integrated into the process; the approach is consistent with the objectives outlined in the introduction; and I believe that upon completion of this process, I could feel assured that the majority of the metatheoretical issues would have been addressed.

### Specific Methodology

The first step of the process will be to review the literature to identify conceptual ambiguity and to indicate documented evidence of the need for clarification. This methodology will provide validation for my purpose in developing a theoretical model and serve as a basis for obtaining clarity in the conceptualization of burden. The literature will be analyzed for variance in conceptualization and measurement of burden. Upon completion of this step, the methodology will follow Burr's(1973) procedures. The sequence of procedures is altered in that the sixth procedure will precede the fifth procedure.

Conceptual clarification of burden. The concept of burden will be defined, such that it meets the standard of conceptual clarity. The concept will be defined theoretically to derive meaning and operationally to provide measurement. In addition to providing definition of the concept of burden, all other variables that may influence variation in burden will be defined. This will occur throughout all stages of the process of theory construction. It should be noted that conceptual clarification of burden will not be achieved independently of the theory review phase of the process as my perspective is already influenced to a degree by specific theories.

Theory review. In the last two decades, theorists in the disciplines of psychology, sociology and family studies have searched for theories developed in other disciplines or contexts (borrowed theory) and translated these theories to generate theory in their particular area of interest. Examples of borrowed theory applied to the family area include structure-function, interaction, development, exchange and systems theory (Aldous, 1970; Hill & Hansen, 1960). In addition to psychological theory, three existing theories of family study will be reviewed and the basic assumption and premise of each theory stated: systems, development and family crisis. I feel that these theories will provide insight into the nature of the burden and long term care. It provides delineation of a way of thinking of a particular orientation. This will also serve as a method of identifying variables (Hage, 1972) and formulating a theoretical model from which to develop propositions.

Formulate propositions. The variables and propositions will be derived from the theory review. A search for context-free propositions will be carried out. Context-free propositions are those propositions that hold for individuals and/or families regardless of culture, subculture, role or situation. It is recognized that context-free propositions cannot be obtained exclusively. This is because the nature of burden is bound to a context of families that are providing long term care to a family member and to a particular time in life. The objective would be to obtain a partial or middle range theory that is gleaned from using some context-free propositions of a general theory as a basis for generating context-specific propositions. Due to the nature of the theoretical context, Burr's third and fourth procedures are combined.

The propositions will be statements that assert a relationship between concepts and/or variables. No reference will be made as to causality (Burr, 1973). The propositions will only be covariational statements. This method is influenced by the orientation of family systems theory and causal statements are counter to the basic premises of systems theory. Montgomery and Fewer (1986) point out that the notion of cause has been borrowed from the physical sciences and should not be applied to the study of human interaction. People who assert causality believe "that one person can determine how another person will behave and that this causality is usual in normal human interaction" (p. 8). Montgomery and Fewer recommend using the word "affect" in place of "cause". In this way, a person would hold the belief that one cannot cause another's behavior, but one person can affect another's behavior.

<u>Model format</u>. A propositional model will be developed that will link all the propositions into a whole structure. The model will organize the propositions into a logical pattern. This will be achieved through verbal statements of propositions and a graphic representation of the verbal statements.

<u>Theory validation.</u> The theoretical model and propositional model will be validated. The theoretical model will be validated subjectively by judging my model against the standards of theory outlined in the

second chapter. In addition, the explanatory power of the propositional model will be validated by examining the literature on burden relative to the developed model.

This process will involve an in depth analysis of the operational definition of burden and the inconsistencies in the research findings. My model will be used to indicate how conceptual clarity could be achieved and how differences in the research findings may be explained.

This process, with its purpose of indicating the explanatory power for my model, differs somewhat from scanning the research literature for empirical support, as described in Burr's sixth step. Burr (1973) points out that it is difficult to identify the criteria that can be used to evaluate the research data as evidence for or against the propositions or for deciding how much confidence can be placed in the evidence. However, Burr also states that empirical data should be used as it is an important part of the process of construction to provide a measure of the validity of theoretical ideas.

To scan the literature for empirical support, as the only method of theory validation, is not appropriate when the research findings are derived from concepts that are ambiguous. Therefore, the literature will be reviewed with the purpose of gaining validity for my model.

In summary, the process to be followed in construction of a theory of burden is as follows: conceptually clarify the concept of burden, review existing family theories and generate assumptions and variables to form a theortical model, formulate propositions, link all propositions into a whole, and review the existing literature on burden.

Throughout the process, all concepts will be defined.

# CHAPTER IV

## Model Development

The initial step in formulating my model is to review the literature on burden for evidence of conceptual ambiguity. The purpose of this stage of model development is to provide insight into the conceptual problems that presently exist. From this review of the literature, the problems of conceptualization will be identified. These problems will serve as a basis for initiating my model and proceeding to the second stage of analysis - conceptual clarification of the phenomenon of burden.

### Conceptualization of Burden (1963-1986)

Thompson and Doll (1982) report that the earliest conceptualization of burden was related to the mentally ill who were discharged from hospitals to the care of their families. The literature primarily addresses the social costs to the families in these situations. The assumption made in the early research is "that any individual whose presence and performance aroused either fear or shame must be burdensome and could not be living within a supportive environment" (p. 380). The social costs to families are inferred from attitude measures of social distance or stigma. Grad and Sainsbury (1963) initially introduced the concept of burden to refer to the hardships or effects that mentally ill people have on these families. They view these effects as costs to the family. Burden is operationally defined as the relatives' report of the patient's affect on the relatives' health, the social and leisure activities of the family, the children in the home, the domestic routine, the income of the family and the employment of members of the family. A three point scale is used to rate these variables: "not affected by the patient", "affected", or "severely affected". Burden is inferred from these ratings.

Hoenig and Hamilton (1966, 1967), in an effort to assess the way in which mentally ill patients affected their household and the extent to which they did so, separate the concept of burden into objective and subjective components. This conceptualization has been advanced by other researchers investigating the effect of home care or caregiving on relatives of the mentally ill (Herz, Endicott & Spitzer, 1976; Platt & Hirsch, 1981; Thompson & Doll, 1982) and the ill elderly (Montgomery, Gonyea & Hooyman, 1985; Poulshock & Deimling, 1984; Ross & Kedward, 1977).

Hoenig and Hamilton (1966) define "objective burden" (p. 614) as the effects on the life of the household and the occurrence of abnormal behavioral traits in the patient. The specific effects on the household are financial effects, effects on the health of any household member, effects on the children and effects on family routines. The abnormal behavioral traits consist of such traits as wandering at night, unacceptable sexual behavior, unresponsiveness, requiring physical nursing care and hypochondriasis. They assume that any of the behaviors, displayed more than occasionally, must constitute a form of burden to the patient's family.

These researchers define "subjective burden" (p. 614) as the available informants' report of carrying any burden, in a subjective sense, over a four-year period. The subjective burden is rated as being none, some or severe. The subjective burden is directed at attitudes rather than specific events. The authors report that the expected subjective attitudes of the informants do not necessarily coincide with the objective burden reported. For example, the illness could have a large impact on the family's daily routine, but this does not imply that the family subjectively experiences burden.

The other researchers who have used the objective-subjective dichotomy in conceptualizing burden differ in their operational definitions. Herz, Endicott and Spitzer (1976) conceptualize subjective burden as the subjective distress experienced by one or more family members. The subjective distress items include symptoms in the family such as having trouble sleeping, being afraid of being harmed, feeling nervous, tense and afraid. Their objective burden is operationally defined as the specific problems experienced by the family. These problems include such factors as the family being inconvenienced, the family assuming the patient's responsibilities, the family missing work, the patient being noisy at night and interfering with others' activities.

Platt and Hirsch (1981) conceptualize the objective burden as being the adverse effects of the patient's conduct upon children, adults and upon all household members. Rather than using the term "subjective burden", the term "subjective distress" is used to reflect the distress to the family member arising from the patient's behavior, the patient's limited social performance and the objective burden to all household members. Subjective distress is interpreted as the feelings, attitudes and emotions about the objective events.

Thompson and Doll (1982), in studies of the families of the mentally ill, further define objective and subjective burden. They define subjective burden as the "emotional costs the patient's presence and behavior had on his or her family" (p. 381). The four indicators of subjective burden that are specifically delineated by these researchers are the presence of feelings of overload, being trapped, resentment and exclusion. From these four indicators, a summary scale is constructed of the families' sense of burden. Objective burden is defined in terms of the disruptions to family life. As in other studies, an additive summary score is constructed to reflect the severity of the burden.

In the gerontological literature, Ross and Kedward (1977) operationally define objective burden as the effects of caregiving. Their subjective burden is defined as " subjective bother caused by sacrifice in work and social activities, feelings of neglect among other family members, feelings of depression, anxiety, anger, and concern over the patient's odd behavior, and psychiatric vulnerability of other family members" (p.423). The social interviewer assigns a rating of burden based upon the combination of subjective and objective items.

Montgomery, Gonyea and Hooyman (1985) incorporate the aspect of change into their definition of objective burden. The definition includes the extent to which providing care has changed various aspects of the caregivers' life and household. The difference between this conceptualization and the literature on mental illness is that Montgomery et al. incorporate change as a function of caregiving rather than the presence of the ill person. The caregiving experience is incorporated into their definition of subjective burden. Subjective burden is defined as "the respondents' attitudes towards or emotional reactions to the caregiving experience" (p. 21). Using a 5-point, 13-item inventory, respondents are asked how often they have experienced the feelings identified on the inventory. Objective burden is measured using a 5-point, 9-item inventory reflecting aspects of the caregiver's life that may have been affected by caregiving. Respondents are requested to indicate the extent to which caregiving behaviors had changed identified areas of their lives.

Poulshock and Deimling (1984) also conceptualize burden as having two factors. They assume that although the concrete effects that families experience are of importance, it is the individual's subjective experience that filters their reports of the effects. They report that the burdens that caregivers experience are the result of personal responses to specific caregiving contexts and that these contexts are defined largely by the types of impairment that are exhibited by the ill relative. Their thesis is that in the analysis of burden, burden as a subjective response should be placed in a mediating role between the elder's impairment and the impact on the life of the caregiver. The meaning of subjective burden arises from the caregiver's connectedness to the ill elderly person's impairment. Their measurement reflects this connectedness. They identify four indicators of impairment: dependency associated with physical impairment, lack of sociability, disruptive behavior and cognitive incapacity. The respondents are asked questions relating to the degree to which the specific impairment upset them or created a difficulty for them. Burden measures are derived from answers to these questions. For example, the burden measure associated with dependency in self care incorporates caregiver responses to questions about the difficult or tiring nature of the tasks performed by the caregiver. As a result, these researchers classify burden as activities of daily living (ADL) burden, sociability burden, disruptive behavior burden and cognitive incapacity burden. These authors do not use the term "objective burden". They use caregiving impact to describe the effects of caregiving and incorporate many of the items cited previously by other researchers as objective burden. These items include the impact caregiving has on family relationships, social activities, health or employment changes.

There are several studies investigating the burden in families caring for a relative with a dementing illness or Alzheimer's disease (Kahan, Kemp, Staples & Brummell-Smith, 1985; Pratt, Schmall, Wright & Cleland, 1985; Zarit, Reever & Bach-Peterson, 1980). These studies incorporate the conceptualization of burden outlined by Zarit, Reever and Bach-Peterson (1980).

Zarit et al. conceptualize burden as a unidimensional construct. The degree of burden is operationally defined as the feelings of discomfort that the caregiver experiences in relation to the problem of caregiving. These problems include the caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the relative with dementia. They assume that the discomfort associated with these situations would place burden upon the caregiver, A total burden score is derived from their 29-item inventory of questions pertaining to the feelings of the caregiver with respect to the problems of caregiving. The feelings include such factors as feeling resentful, stressed, embarrassed, guilty, angry, depressed, afraid, strained, and uncomfortable.

In summary, it can be concluded that the phenomenon of burden is not universally conceptualized or consistently operationalized. The term is generally used to refer to the hardships, costs or effects that ill relatives have on their families and/or the effects of caregiving on the daily lives of the families. The concept has been dichotomized into subjective and objective components, with little consensus as to the operational definitions of these components. The concept has also been viewed as a unidimensional construct that incorporates both subjective and objective components. The concept of burden has been studied as a dependent variable and proposed as a mediating variable.

The purpose of the review on the conceptualization of burden was to provide insight into the conceptual ambiguity surrounding the phonomenon of burden and to provide justification for the development of a theoretical model. Based on this review, a number of initial problems with the conceptualization can be identified. The problems are presented, followed by the derivation of the problem from the literature. These questions will serve as a starting point for the conceptual clarification of burden.

## The Problems with Conceptualization

The first problem to be identified is that of conceptual ambiguity of the term "burden". In the discussion of metatheoretical issues, it was pointed out that conceptual clarity can be attained by two methods: providing an operational definition and defining one concept with another concept (Burr, 1973; Hage, 1972; Kerlinger, 1973; McCullers, 1984). The researchers of the documented literature generally use operational definitions to define the concept of burden. They assign meaning to the concept by specifying the technique that is used to measure it.

The variance in the operational definitions, while providing an empirical measurement, communicates a lack of consistency and/or ambiguity surrounding the definition. As Poulshock and Deimling (1984) relate, "burden has been broadly defined and differentially measured" (p. 230), numerous issues have been subsumed under the term of burden and these authors question its use as a unified concept. Some researchers only view burden as a subjective concept and define it as a perception or subjective feeling of the caregiver, family or household in response to various aspects of caregiving and/or the presence of the ill relative. Other researchers regard burden as the effects or consequences of caregiving on the presence of an ill relative. Some combination of these two conceptualizations is a view expressed in measurement by other researchers. The problem exhibited by the variance in operational definitions is that the variance, rather than attaining conceptual clarity, communicates ambiguity as to the definition and presentation of the concept as a unified concept.

In analyzing the operational definitions documented in the literature, there is one common factor that links the various definitions. The common factor is that burden, either partially or completely, is viewed as a perception or subjective feeling state of the caregiver, family member or family. Although consistency in this orientation towards the phenomenon is evident, variance of measurement is observed. The measurement instruments that have been developed to measure the subjective aspect of burden are similar in content to indexes developed to measure caregiver strain (Robinson, 1983), subjective distress (Platt & Hirsch, 1981), and family stress (Greene, Smith, Gardiner & Timbury, 1982). The second problem that is identified is whether stress, strain and burden are the same concept or different concepts. This problem is derived from the identification of similar operational definitions being used and a different phenomenon being identified as the concept being measured.

The third problem is derived from the variance in the unit of analysis of measurement. Burden, as an attribute or property, is assigned to the individual, the family or the household. In most instances, the respondent is an individual family member, although the term "family burden" is the construct that is identified as the concept being measured.

These problems are addressed in the second stage of model development: conceptual clarification of the concept of burden.

## Conceptual Clarification of Burden

The first step in attaining clarity of the concept, with the purpose of viewing burden as a unified concept, is to arrive at a constitutional definition of burden and an operational definition of burden (Kerlinger, 1973). Insight may be gained and meaning maximized by using both methods (McCullers, 1984).

The initial assumption is made that burden is a subjective feeling. I agree with those researchers who raise the argument that caregiving can have an impact on various aspects of family life, but it is the subjective experience of the individual that filters the report of the effect or impact (Montgomery, Gonyea & Hooyman, 1985; Platt & Hirsch, 1981; Poulshock & Deimling, 1984; Thompson & Doll, 1982). This argument, and the idea that burden as a perception is a common factor throughout the literature, form the basis for this assumption. Based on this assumption, a unit of analysis can be assigned.

Burden is a perception of an individual and therefore is a property of an individual. The contributions of Montgomery and Fewer's (1986) view of systems theory and the maintenance of differentiation of levels is relevant to specifying a unit of analysis. They maintain that properties are specific to system levels. A family and an individual in the family are at different levels of the system and both have characteristics or properties that apply to each. For example, terms such as ideas, shame, and expectations are all characteristics of an individual; whereas consensus, communication, and interaction are family properties. Burden, as a perception, is specifically a characteristic of the individual. Based on this assumption, the term "family burden" is ambiguous and not considered appropriate. The term to be used at this point in the development of the model is "perceived burden". This term typifies a specific single unit of analysis.

The second problem to be addressed is whether the terms of burden, strain, distress and stress are synonomous terms. Providing an explanation for this problem is necessary before arriving at a constitutional definition for burden.

Having identified burden as perceived, it is appropriate to review theories of stress to determine whether burden and stress are synonymous terms. Due to the variance in the conceptualization of stress, a brief overview of the current orientation of stress is described.

Theories of stress. The way in which stress is defined varies with the interests expressed in various fields of study and within fields of study (Cox, 1982; Hoes, 1985; Monat & Lazarus, 1977; Singer, 1980). In the study of stress in humans, stress is studied as a dependent variable and an independent variable. Cox and MacKay (cited in Cox, 1982) present a third method. Stress, in their model, is an intervening variable.

Stress, as a dependent variable, has a response based orientation and definition. This approach is primarily a physiological model in orientation, based on the work of Selye (1956). In this orientation, stress is the organism's response to an external threat or demand. The response is non specific, in that any factor may cause a response. Within a physiological orientation, stress is viewed as a response and any stimulus which produces a characteristic physiological response is the stressor.

Stress, as an independent variable, has a stimulus based orientation and definition. The definition and corresponding model are oriented towards a mechanical or engineering model. Stress is conceived as an external force or pressure applied to the organism. Characteristics of the environment, which are recognized as stimuli that are disruptive to the organism are described as stress and these external stresses give rise to a stress reaction, or strain, within the individual.

Cox (1982) identifies the weakness of the response based and stimulus based models in the study of human stress. In both models, man is viewed as a passive agent in the process. Cox perceives man as an active being, with psychological processes available that mediate the outcome of the relationship between the stimulus and the response. Cox proposes that stress should be considered as an intervening variable and places stress within a transactional framework. This orientation is consistent with the psychological stress model proposed by Sarason (1980), described by Turk and Kerns (1985) in conceptualization of theories of the family in health and illness, and the model proposed by Hill (1958) in the study of social stresses on the family. A transactional model directs attention to the individual and environmental factors.

In a transactional model, stress is a process that is derived through the existence of a particular relationship between the individual and his/her environment. Psychological processes of the individual, the environment and the relationship between the individual and the environment are explicit components of stress. Conceptually, the transactional model is a psychologically oriented model that implicitly derives its orientation from systems theory. The conceptualization of the model includes characteristics of the view of man, as an open system, capable of exchanging information with the environment, exhibiting a quality of adaptation and having the property of feedback which affects the stability or instability of the system (Hall & Fagen, 1968). The model is depicted in Figure 1 and described below.

In the transactional model, stress is conceived as a perceptual phenomenon. The individual perceives an imbalance between a demand from the environment and his/her ability to cope with requirements of the demand. This definition has been proposed in the study of psychological stress (Cox, 1982; Sarason, 1980) and in the study of family stress (McCubbin & Patterson, 1983). Viewed in this way, it is the perception of discrepancy between demands and capabilities that gives rise to the emotional experience of stress and the stress response of coping. In this orientation, individual differences can be accounted for due to the fact that it is the individual perception or cognitive appraisal of

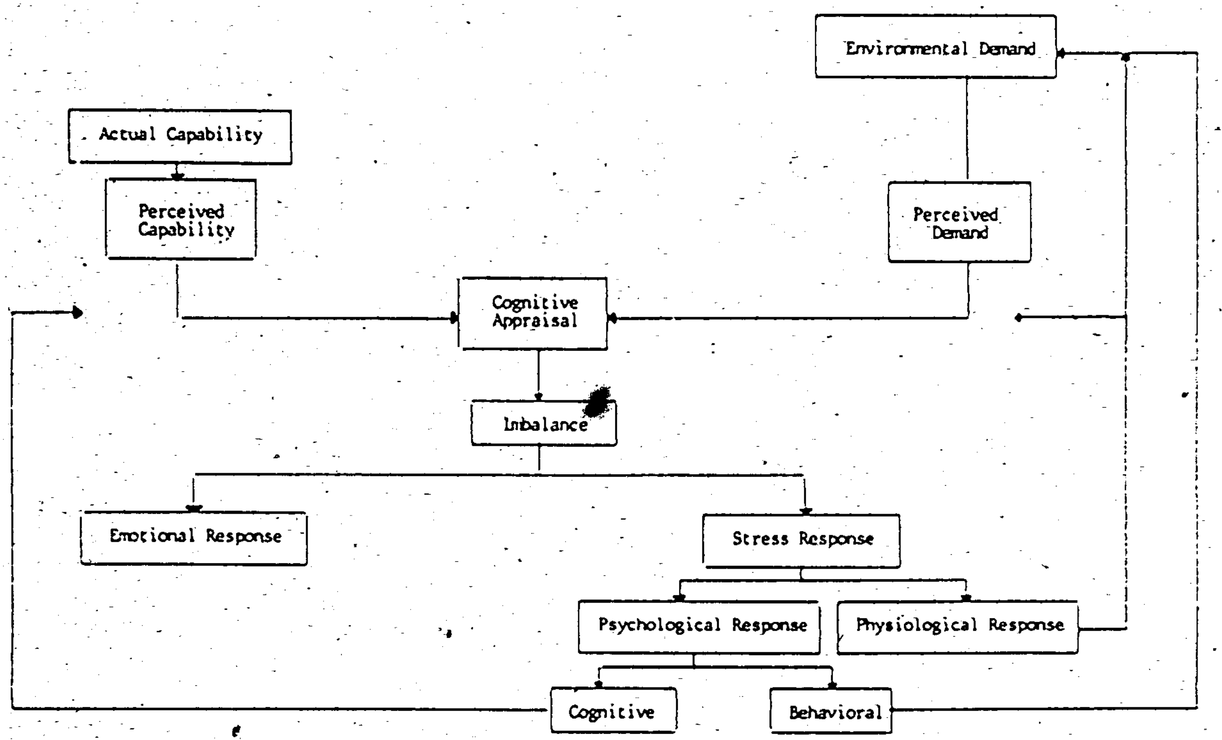


Figure 1. Cox-MacKay Transactional Model of Stress (Cox, 1982)

situations that moderate the experience.

The model is derived from both response and stimulus based theoretical orientations (Cox, 1982). It is stimulus oriented in that stimuli which are disruptive to the system are perceived and it is response based in that the individual responds to the stimulus. This response is psychological (cognitive or behavioral) and/or physiological. These psychological or physiological responses are the individual's response or coping mechanisms. The model is transactional in that the individual is perceiving and interpreting information from the environment.

The model incorporates a systems perspective in that it is oriented towards circularity rather than linearity by directing attention to the concept of feedback. Stress is a process whereby individuals, through their perception of information from the environment, perceive an imbalance between the demand(s) and their capability to cope with the requirements of that demand. Individuals respond to the perception psychologically and physiologically. These responses are fed back, through cognitive and/or task oriented processes, for alteration or continuation of the perceived imbalance of the demand and ability. Through appraisal, the experience of stress and response to stress and feedback, stress is conceptualized as a process.

In summary, some theories of stress have been presented. Stress is conceptualized and studied as a response, or as a stimulus. Another approach is an integration between the response and stimulus based models. This approach is transactional and theorists using this approach view stress as a perceptual phenomenon.

Burden and stress. The transactional model, through analyzing the conceptualization of the stress process and the component parts of stress, is relevant to conceiving the emotional response and burden as synonymous concepts. Cox (1982) points out that the experience of stress is described by individuals in ways that are associated with emotions such as anger, anxiety, fear, grief, guilt and shame. The individual does not simply report being stressed. The experience of stress is perceived cognitively and expressed in terms that describe the emotions associated with the perception. This conceptualization is similar to the view expressed by Lazarus (1977), who maintains that cognitive factors underlie emotional reaction and influence the intensity of the emotional reaction.

In the development of a theory of emotions, Kemper (1978) defines emotion as "a relatively short-term evaluative response essentially positive or negative in nature involving distinct somatic (and often cognitive) components" (p. 47). Positive emotion is gratifying and is expressed in terms of the individual feeling such states as happy, loved, glad, etc. Negative emotion is aversive and is expressed in terms such as feeling angry, mad. These expressions are the cognitive components and are labels that identify the emotion. The somatic components are physiological and include such measurable and observable events such as changes in heartbeat, pulse, rate of respiration, etc. There appears to be a conceptual link between the orientation of the transactional stress model and this theory of emotion.

Based on the assumption that the expression of stress is through terms which are descriptive of emotions, the researchers who operationally define subjective burden are essentially defining the emotional experience of the stress process. The following excerpts from various operational definitions of burden highlight this point.

The burden interview developed by Zarit, Reever and Bach-Peterson (1980) is a self-report instrument containing statements that reflect feelings of the caregivers in various aspects of their situation. Some of the feelings that are included are resentment, stressed, embarrassed, angry, nervous or depressed, afraid, useful, pleased. Feelings are also documented in the Relatives Stress Scale developed by Greene et al. (1982) to measure stress.

When anaylyzing these operational definitions and the transactional model of stress, it is apparent that the constitutional definition of emotion in the transactional model is consistent with the operational definition of burden in recent burden studies. All researchers conceive burden as an emotional response to caregiving. It is apparent that burden is the term used by some researchers to describe the emotional response of the individual. Based on this analysis, the initial assumption to be made in my model development is that stress is a process which includes perceived phenomena and subjective (perceived) burden is synonymous with the emotional experience of the stress process. Using the term burden to reflect the emotional response of the stress process contributes to ambiguity.

The transactional model of stress proposed by Cox (1982) will be used as a starting point for my theoretical model. Use of the model can be justified within the context of daily life of individuals in the family and within the specific context of chronic illness and long term care. The model directs attention to the individual, the environment (the family and society) and the interaction of individuals within their environment. The model also provides an identification of variables that are considered to be important in the experience of stress and a person's response to stressful situations. This conceptualization will allow a researcher to incorporate the aspect of individual differences. The merit of this approach is that it can provide an orientation from which to view illness and long term care at the individual level, while at the same time considering the environment.

A brief summary of my conceptualization is presented. The caregiver perceives a discrepancy between demands from the environment and his/her ability to cope with the demand requirements. This perceived discrepancy gives rise to an emotional response. Through the process of adaptation, the caregiver copes with the perceived discrepancy and the emotional response.

The second task in my model development is to extend the transactional model to include the context of the family. The individual is viewed within the context of the family. It is the individual who experiences stress. Viewing stress as a personal property is consistent with psychological theories of stress and the thesis of Montgomery (1985) in the study of stress in the family. Montgomery contends that the trend of family scholars studying stress as a family property has impeded attempts to understand the behavior of the individual and family interaction. This view is supported by Turk and Kerns (1985) who maintain that, perhaps, family theorists in directing their focus specifically to the family, have given little attention to the individual within the family.

## Interactional Model of Stress

My model is described as an interactional model for the reason that the primary area of concern is the individual's interaction with the family. A family member interacts with other family members and transacts with members of social systems (Montgomery & Fewer, 1986). In all phases of development of the model, the environment of the individual is the family and society. The interactional model has a systems theory perspective. Four assumptions can be posited which reflect the systems perspective and are considered throughout the theoretical model development. These assumptions pertain to levels of systems, information processing, change, and feedback.

## Theoretical Assumptions

The first assumption is that a family system has levels (Broderick & Smith, 1979; Montgomery & Fewer, 1986). The family, coalitions of members and individual family members constitute the levels. The family system exists in a societal system. Properties can be assigned at all levels of the system. This factor is considered through all stages of model development and is depicted in Figure 2.

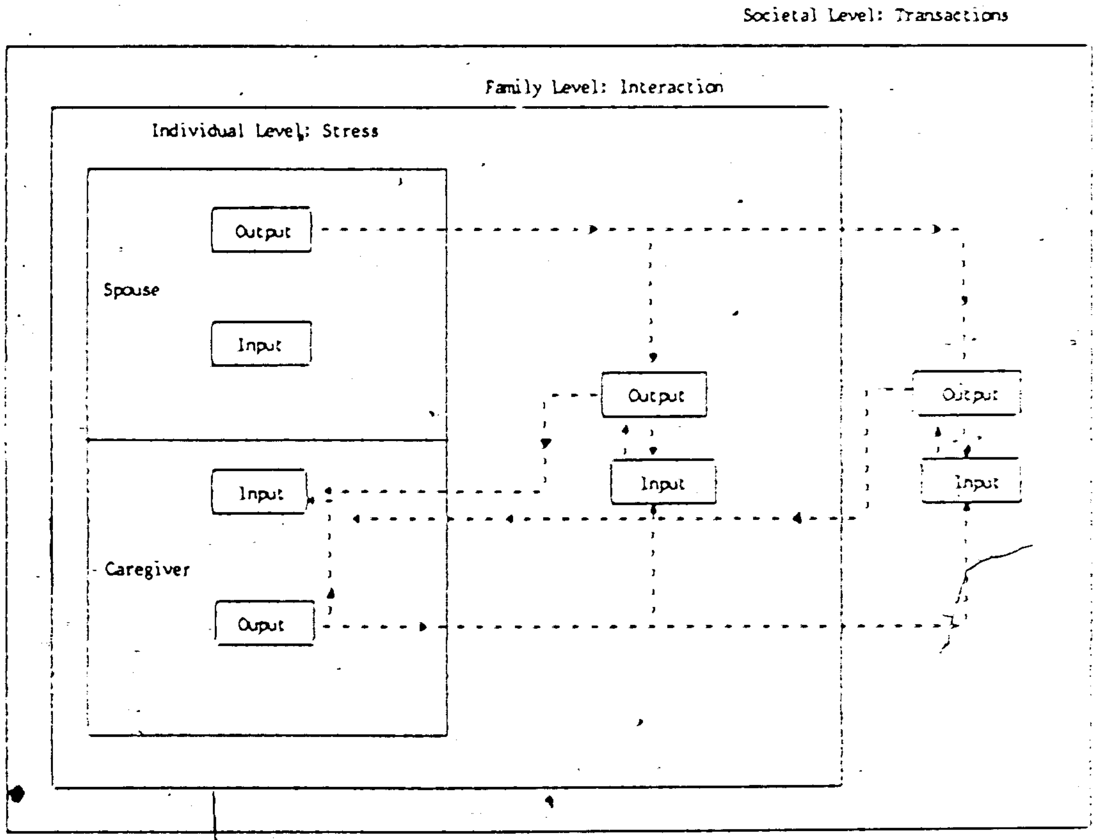


Figure 2. System Levels and Feedback

The second assumption is that living systems, at some level, manage information (Montgomery & Fewer, 1986). Information from the environment is received by an individual and the individual manages the information by sharing with others, withholding the information from others, or distorting the information. Montgomery and Fewer note that management of information includes elements of accuracy and expressiveness. Information reception and management are critical elements of a theoretical model of stress as the individual, through perception, is constantly receiving information and managing information.

The third assumption made in the interactional model is that individuals experience stress in relation to past and present experiences of life. These experiences may be psychological, physiological and/or social. These experiences trigger change in the system. It is the change that is perceived by the individual. This assumption is formulated by considering Bateson's work on information (cited by Montgomery & Fewer, 1986). Individuals can only perceive information about change.

The changes that are perceived by the caregiver may arise from three sources: within the individual subsystem, the family system and the societal system. Older individuals experience many changes in their life and individual cognitions appraise these changes. They include physiological changes, psychological changes, role changes within the family, and societal change (Burdman, 1976; Meyer & Meyer, 1983). These changes occur as a part of the normal aging process and are experienced by all individuals in the closing of the life cycle. These changes are to be considered "normative changes". This term has been borrowed from family crisis theory (McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Montgomery, 1982). These authors also refer to "nonnormative" changes. Nonnormative implies that the change is unpredictable. Individuals in the closing of the life cycle may be experiencing a deterioration in human functioning that arises from disease, illness or trauma (Meyer & Meyer, 1983). The caregivers in this model are also experiencing changes in role function associated with the illness of their spouse. These can be considered as nonnormative changes.

The fourth assumption is that systems maintain their integrity through feedback. Feedback occurs within the individual system and between the individual, family and society. The process is depicted in Figure 2 by broken lines containing arrows. Interaction and transaction occur through the process of feedback. Watzlawick, Bavelas and Jackson (1967) describe this characteristic of living systems as "part of a system's output is reintroduced into the system as information about the output" (p. 31). Feedback is a part of the process of adaptation. Individuals have the ability to perceive and manage information (Montgomery, 1982) and interpret the consequences of their actions (French, 1977).

Using these assumptions as an initial framework, the interactional model is now developed in three phases. The first phase focuses attention on the major variable in the model - the emotional response. The intent in this phase is to define the emotional response through constitutional and operational methods. The second phase will direct attention to those variables that influence variation in a person's emotional response within the context or domain in which stress is studied. The variables are derived from the theoretical model of stress. It is from the identification of variables and conceptualization of the context that the propositional statements and propositional model in the third phase are derived.

### Phase I: Emotional Response

Considering the importance of assigning properties at the appropriate level of the system (Montgomery & Fewer, 1986), stress is considered at the individual level. At this point, the model proposed by Cox (1982) is essentially unchanged. Although it is understood that a physiological response occurs concomitantly with a behavioral or cognitive stress response, it is not considered in this model.

Individual stress is considered to be a perceptual phenomenon. The individual of interest is the elderly caregiver. This person is defined as a person who identifies the care required by their spouse and provides the care (Archbold, 1983). The caregiver's emotional response is the major determinant variable in the model and conceptual clarification has been attained through the previous discussion of stress and burden. Stress has been conceptualized as a process whereby an emotional response occurs following the perception that one's capabilities fall short of the requirements to meet the demands of the situation. The individual is making a comparison between the demands and his/her capabilities to meet the requirements of the demand. An imbalance between demands and capabilities is perceived and an emotional response is experienced (Cox, 1982).

Considered in this conceptualization is that stress is constant in our daily lives (Walker, 1985) and that some stress is essential for the health of any system (French, 1977). This means that in reality, one cannot not experience stress. The level of imbalance becomes an important aspect of discussion. The individual, through coping and adaptation to change, seeks a balance in the system.

Balance, in any system, refers to the achievement of a steady state (Dell, 1982). This balance is conceptualized as an optimum level of functioning, recognizing that there is always a certain imbalance in the system that is due to the system continuously changing. Dell specifies that a balanced state is not a specific state. It is a state that is always slightly different from the former steady state, as a system "can only behave in accordance with its own organization" (p. 29).

Inferred from this conceptualization is that an optimum level of functioning is a balance between the demands and capabilities such that the person perceives that this is the best that he/she can do under the circumstances (McCubbin & Patterson, 1983). This balance is conceptualized on a continuum whereby a large discrepancy would reflect a situation where the demands exceed the capabilities, such that the emotional response is aversive and over time, suboptimal behavior and performance in the physiological and psychological subsystems will result (Hamilton, 1980; Monat & Lazarus, 1977). McGrath (cited by Cox, 1982), assumes that a minimal discrepancy between demands and capabilities will not be perceived as very stressful; whereas a large discrepancy would be perceived as very stressful.

The experience of stress is reflected operationally through evaluation of the individual's emotional state. Operationally defining stress as an emotional state is consistent with the thesis of Cox (1982). The experience of stress is described by individuals in ways that are associated with emotions. Kemper (1978) points out that emotions are always a response to a stimulus. Kemper questions whether people are always consciously aware that a specific demand or event is cueing the emotion. I view emotion as the reported experience of stress and assume that individuals are not always aware of the specific source of the emotion. Emotion can be tapped through measures of dysphoric mood (negative affect) and elation (positive affect) (Kane & Kane, 1984). Affect is described by Kemper (1978) as a longer-term emotion. Negative affect reflects the emotional response to a perceived large discrepancy and positive affect reflects a minimal discrepancy. McCubbin and Patterson (1983) report that stress becomes distress when it is perceived as unpleasant. Negative affect and distress could be used synonymously.

## Phase II: Identification of Variables

Stress is conceptualized as a process which includes a person's perception of a demand-capability imbalance, the individual's subsequent emotional response and coping response. The intent in this phase is to explore the environment in which individual stress occurs and identify and define those variables that are perceived to influence variation in individual emotional responses (affect) within the context of chronic illness and long term care. The focus of attention continues to be on the stress of the caregiver. On completion of variable identification, the theoretical model will be complete. The interactional model will then be used to develop propositional statements about caregiver stress and the factors that influence variation in caregiver stress.

## The Environment

The environment of the individual is depicted in Figure 3. The environment includes the family (depicted as the spouse) and society.

The family is the first component of the environment to be defined. The following definition of the family is derived from various sources in the literature and assists in the conceptualization of what is meant by family.

The family is a living system that can be identified as a collection of individuals whose behavior is interrelated in a particular way and the existing relationships among these individuals (Montgomery & Fewer, 1986). The family is a rule-governed system and individuals within the system are assigned, through occupation of a unique position, roles (Jackson, 1970). The family is an ongoing system characterized by complex structural relationships of communication and interaction between its components and subsystems (Speer, 1970). The family system is transformed over time and adapts to members' stress to maintain

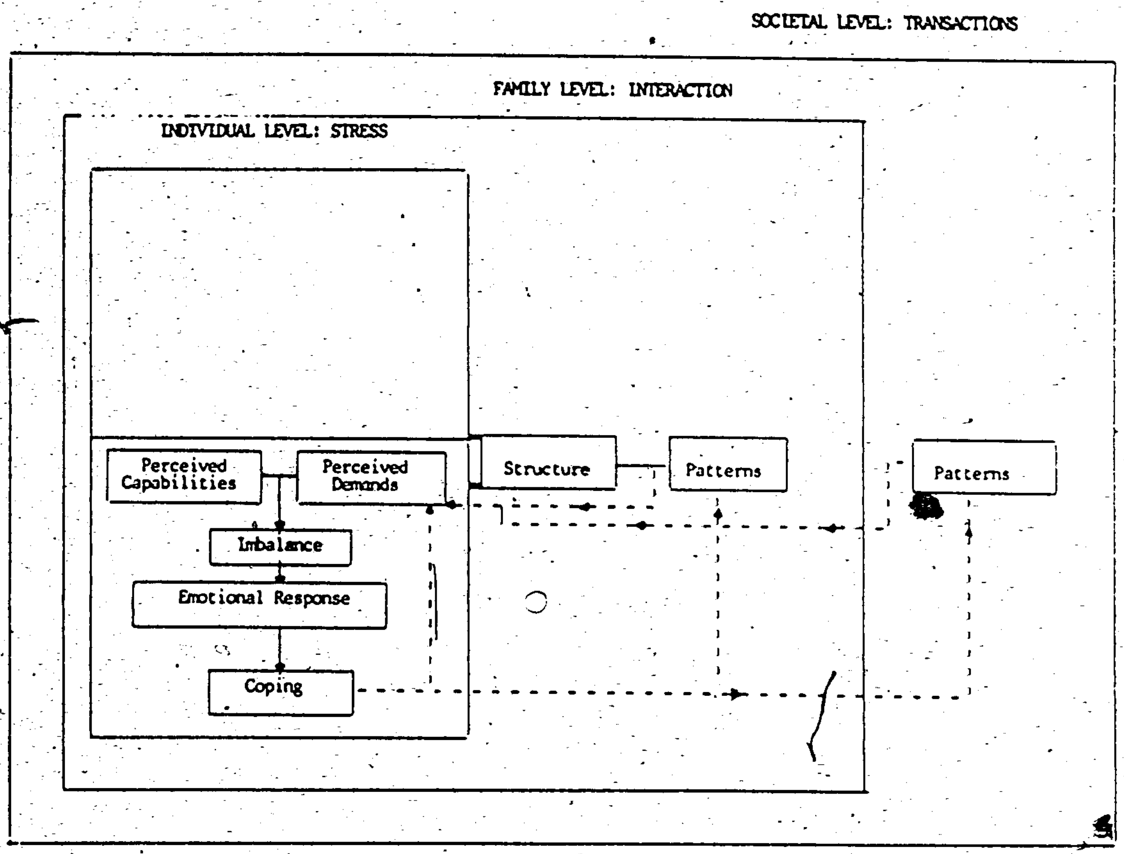


Figure 3. Interactional Model of Stress

continuity in its functions of psychosocial protection of its members, accommodation to culture and transmission of that culture (Minuchin, 1974).

From this definition, a perspective of the family and its characteristics arise. The definition synthesizes two theoretical orientations of the family; the developmental and systems approach. The importance of the developmental approach to my model is that it concerns the family and movement through time and change (Montgomery, 1982). The systems perspective focuses attention upon the designation of units in a system, interaction between the various interrelated parts of a family system, communication, boundaries and complex relationships (Broderick & Smith, 1979). The systems perspective also provides insight into family processes and adaptation (Montgomery & Fewer, 1986). All these factors are considered to be relevant to the identification of variables that influence individual stress and the variation in stress.

From the definition, it can be assumed that the family has a structure. The family is composed of a group of individuals who have characteristics that provide a family configuration. Structural characteristics include such factors as gender, age, size and age distribution (Turk & Kerns, 1985). For a group of individuals to be classified as a family, the group must be legally, socially, or internally defined as a family (Montgomery & Fewer, 1986).

Within, or being derived from the family structure, individuals interact with each other in a particular way. The interaction is specific to the family and differs from interaction (or transaction) with individuals from the societal system (Montgomery & Fewer, 1986). Interaction is continuous and through this continuity, a family develops behavioral patterns of action and interaction. The family's patterns are its particular ways of behaving and involves interdependent members of the family performing integrative, task related and problem-solving activities (Montgomery, 1982).

The individuals in the family transact with society (Montgomery & Fewer, 1986). The societal system is a social system and the social context within which families are embedded are important to explaining family phenomena (Lee, 1979). The societal system includes such components as organizations, social groups, and institutions. This system also has patterns, identified as patterns of action and transaction. These patterns have been influenced by individuals and families (Walker, 1985).

In summary, the family is composed of a group of individuals who interact in the family system and transact with the social or societal system. These systems are considered to be interdependent and the components of the model to follow reflect this interdependence.

Cox (1982) identifies those variables that are component parts of the stress process and influence the emotional response. These variables are depicted in Figure 4 and include demands, capabilities and coping responses. These variables are defined and discussed relative to the context or domain of this model.

## Demands

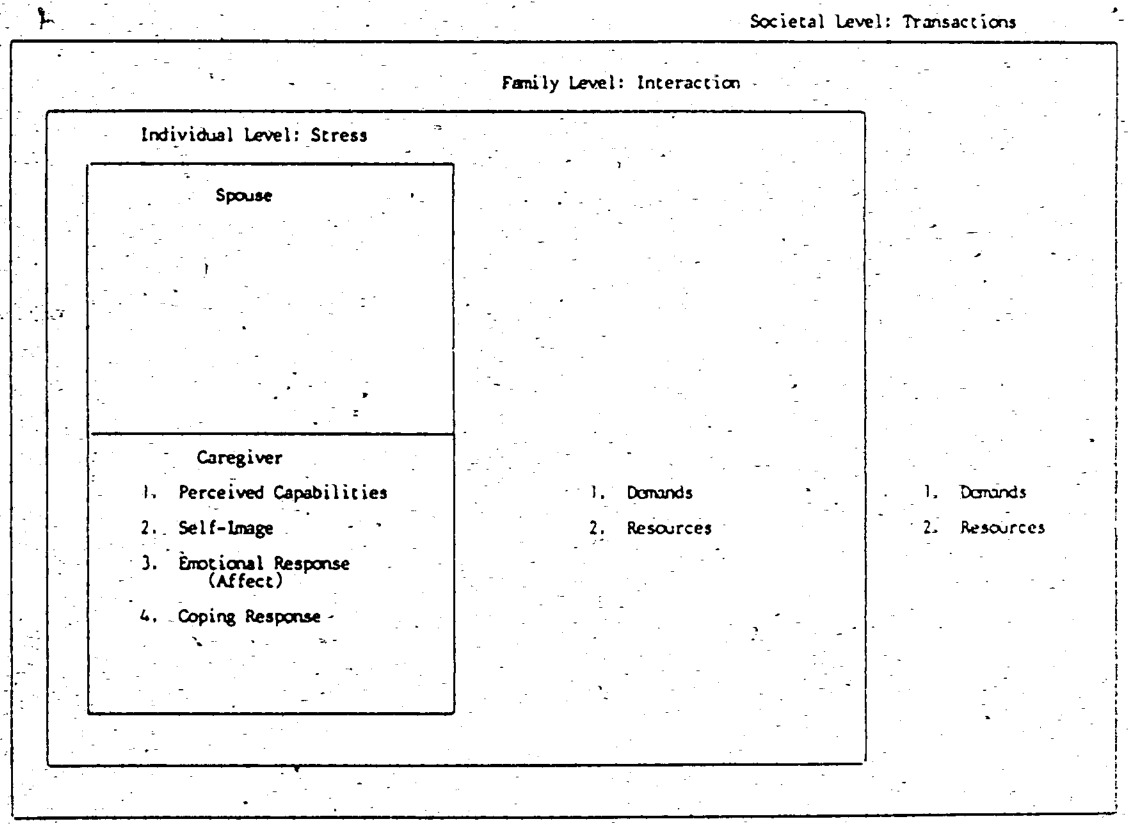


Figure 4. Interactional Model of Stress: Variable Identification

Through interaction and transaction, the caregiver perceives demands. These demands arise from the environment and can be classified as hardships associated with interactional and transactional dynamics. Defining a demand as a hardship is consistent with family crisis theory (McCubbin & Patterson, 1983) and the term "objective burden" described in the burden literature. In considering the dictionary definition of burden, the term burden and demands could be utilized synonymously. Burden, as a noun, is defined as "1. something carried; 2. something difficult to bear physically or emotionally" (Webster's II New Riverside Dictionary, 1984). This definition implies that burden is a hardship. While recognizing that these two terms could be used synonymously, I am using the term "demand" in my model. I concur with the view expressed by Poulshock & Deimling (1984) that the term "burden" should be discarded as confusion exists regarding the meaning.

Individuals perceive demands constantly in that, as a facet of daily experiences in interaction and transaction, change is always experienced (Walker, 1985). Individuals are perceiving the hardships associated with change. The perception of demands is considered by Lazarus (1977) to be a cognitive appraisal. These demands have the potential to strain the adaptive system and contribute to information overload (Hamilton, 1980). The demands that are relative to the context of the model are further explored. Perception of these demands may arise from two sources: within the family system and the social system.

Demands: Family interaction. The primary source of demands for the caregiver arises from family interaction. From the definition of the family, used in this thesis, it is assumed that the individual is part of an interacting group of individuals, has a relationship to other family members and has a responsibility, through occupation of various roles, to provide for the physical and psychosocial needs of the members of the family. The demands arising from the family include normative and nonnormative demands.

The demands are associated with the family's interaction patterns and arise from the family's execution and correction patterns. Execution patterns are task oriented and are associated with the performance of essential daily activities (Montgomery, 1982). Correction patterns are problem-solving patterns and are concerned with adjustment of inappropriate execution patterns (Montgomery, 1982).

Normative execution patterns can be described as those patterns that are associated with getting things done in providing for the needs of the members in a particular life cycle stage. Each person assumes responsibility associated with designated roles. Roles are not mutually exclusive or static. The individuals in the family establish roles, which, in a particular way, fit together in a specific family (Jackson, 1970; Montgomery & Fewer, 1986).

Execution patterns are considered at the family level of analysis as they are derived through interaction. The caregiver may have responsibilities associated with various roles. The expectations for behavior in these roles are supplied in part by the caregiver's relationship to other family members (Eshleman, 1974) and are considered unique to a specific family. Roles in the closing of the life cycle may include the grandparent role, the husband or wife role (Eshleman, 1974). The responsibilities associated with these roles may follow a traditional pattern in that the individuals are of an age where traditional role patterns were the norm throughout the early stages of the life cycle. Based on this assumption, the wife would assume such responsibilities as those associated with household tasks and the husband would assume responsiblities such as financial management. However, as family patterns are unique, it is more appropriate to examine the actual responsibilities that arise from roles. These responsibilities can be viewed as role demands.

Nonnormative demands [illegible]e from the context of long term care. The individual who requires care is experiencing a change in the bodily subsystems that manifests itself in physical and/or cognitive dependency on others for assistance in meeting daily needs. Due to illness of the member, the caregiver may have new responsibilities that were formerly part of the ill person's role activities. In addition, care provision is a role activity that arises from the role of care provider.

The nature of the care provision and assumption of new role activities is specific to the characteristics of the disease and the needs of the spouse. However, in all instances, problem-solving is a major portion of the caregiver's responsibilities as the disease manifests itself in decreased abilities to function in daily life. Two conditions are described that reflect the individual differences in functional ability, provision of care and problem solving requirements.

An elderly person with Alzheimer's disease is suffering from a progressive decline in their intellectual ability, cognitive ability and perceptual-motor integrity (Kerns & Curley, 1985). These deficits contribute to a decreased ability to function adequately in activities of daily living, social and occupational activities (American Psychiatric Association, 1982). The disease is generally insidious and progressive and culminates in complete dependency and death of the individual within a six year period (Pratt, Schmall, Wright & Cleland, 1985).

The demands associated with caring for a person with Alzheimer's disease are immense. They include the responsiblities of assisting the impaired person in doing activities of daily living, and assuming additional various household or financial tasks (Mace & Rabins, 1981). These tasks are practically oriented tasks that involve complex problem-solving in association with daily life and occur daily over a long period of time.

These demands associated with caregiving of a person with Alzheimer's disease are quite different from the actual demands associated with caring for a person with a limb amputation. A limb amputation refers to total or partial loss of an extremity from trauma, surgery or disease (Okamoto, 1984). Dependent on the level of amputation and the limb involved, the individual may require minimal assistance in daily activities such as cutting meat, dressing, walking or driving a car. The caregiver would provide assistance in these areas. In contrast, the caregiver of a person with Alzheimer's disease would be providing assistance for cognitive deficits as the person with the disease does not remember to do daily activities or cannot initiate these activities.

Nonnormative psychological demands are also a facet of family dynamics. Caregivers deal with the psychological aspects of chronic illness in their spouse. These include such psychological demands as the impact of a diagnosis to their spouse and the marital relationship, the possible outcome of a diagnosis, their own feelings about disability and dependency and feeling a sense of loss as their relative is no longer the same person (Barnes, Raskind, Scott & Murphy, 1981; Rabins, Mace & Lucas, 1982; Power & Dell Orto, 1980).

With the advent of a disorder, there is a change in the body subsystems which places nonnormative demands on the individual with the disorder. When dependency exists in one individual, the demands for care must be met by another individual. The individuals providing the care have nonnormative demands of daily living placed upon them.

Family demands have been described as role activities that arise from the role of the caregiver in executing task-oriented family patterns. They include the role activities associated with everyday life, including the activities and problem-solving demands associated with care provision as well as the psychological demands associated with care provision.

<u>Demands: Societal system.</u> The second source of demands on individuals is the societal system. Individuals, in their transactions with society, have demands placed upon them by the social system. As with family demands, the caregiver has a social role with expectations

that arise out of transaction. The demands from society can be classified as role activities that accrue from individual transaction with society to meet individual and family needs. Social role activities are those activities that the caregivers perform in association with social roles. Examples of social role activities include employment, volunteer service, visiting friends, participation in social organizations (Kielhofner & Burke, 1985).

While many role activities may be associated with friend and social networks, the caregiver and the family are associated with the health care system. This transaction and its associated role activities are considered nonnormative in that the demands may be unpredictable. The demands arise from the expectations of society regarding caring for ill family members. These expectations are derived from the patterns of society associated with social policy.

One policy that affects the caregiver is provided by Kane and Kane (cited by Koff, 1982). In six countries evaluated, social policy is directed towards developing services that would enable the elderly family member to remain in their own homes. Inherent in this policy is the societal expectation that families are expected to care for their members within the context of the home environment.

Demands: Coping response. Individuals, through the process of feedback, perceive demands from their particular coping response (Montgomery, 1985). Coping responses induce change in the system. Through change, the individual is confronted with new demands. The way in which the individual copes with the experience of stress associated with these demands can also be a form of additional hardship. McCubbin, Joy, Cauble, Comeau, Patterson and Needle (1980) point out that ineffective coping responses can be an additional hardship at the family level. Coping methods such as drinking alcohol affect family interaction. Cognitive defense mechanisms retard the natural process of getting on with solving problems. A coping response that minimizes personal stress may transmit the demand to others in the family, which leads to family strain (Montgomery, 1985). Due to the many demands associated with care provision, the caregiver may decide to give up social activities to meet the needs of his/her spouse. If the social activity is particularly meaningful to the caregiver, he/she may experience psychological demands associated with giving up the activity.

The demands perceived by the caregiver are many and varied. They include normative demands arising from family interaction and social transactions. They also include nonnormative demands arising from secondary age changes of the spouse, family interaction and social transaction within the context of care provision. All demands have the potential to contribute to information overload (Hamilton, 1980) or "pile up" (p. 11) of demands (McCubbin & Patterson, 1983) and influence the perception of caregiver stress.

## Capabilities

The primary appraisal of a demand is followed by an appraisal of one's ability to cope with the requirements of the demand. Individuals, as active beings, have the ability, through perception, to evaluate their capabilities. Perception is covert behavior. Larson (1972) describes covert behavior as representing the "internal thought processes utilized by the individual in initiating or responding to action in an interactional context" (p. 16). As covert behavior is a response, it is considered to be a secondary appraisal in this model. The caregivers' perceptions of their ability to cope with the requirements of the demand is conceptualized as the critical factor in the perception of stress and experience of emotion associated with the perception of stress. Emotional experiences are, in part, a function of the perceptions or cognitive appraisal which the individual makes of the situation (McGrath, 1977).

Capabilities are defined as having the ability or capacity to cope (Webster's II New Riverside Dictionary, 1984). Within this model, the caregivers perceives their ability (mental or physical power) or capacity to cope with the requirements of the demand. Capabilities include physical, mental, psychological and emotional facets of the individual. These perceived capabilities are part of the continuity of the individual through time. It has been observed by Zube (1982) that older people have considerable continuity in their personality and behaviors across the life span.

Capabilities: Primary aging. At the individual subsystem level, changes occur in the biological, psychological or emotional subsystem. The individual caregiver in this model is elderly. Within this particular stage of the life cycle, individuals experience physiological changes in their bodily systems (Burdman, 1986). These changes are part of a cumulative process that can be conceived of as primary age changes (Meyer & Meyer, 1983). These changes, although occurring at varying rates among individuals, are cellular changes that are characteristic of normal aging and progress with age.

The psychological changes that coincide with a particular life cycle are also important in the discussion of stress. There are certain developmental tasks associated with aging that accompany these changes. These include dealing with loss, dealing with the future and death, contemplation of the meaning of one's life, reaction to assumption of different roles and assumption of greater intellectual, rather than physical mastery of the environment (Meyer & Meyer, 1983).

These changes take place as part of the process of aging. Individuals don't actually perceive physiological or cognitive changes at the cellular level but perceive such changes as decreased strength, slowing of reflexes, poor vision and diminished hearing. As individuals vary in the rate of change, minimal change can be identified as a capability.

Capabilities: Secondary aging. Within the life span cycle, the caregiver could also be experiencing changes that can be classified as "nonnormative" changes. Nonnormative change includes the experience of a deterioration in human behavioral functioning. The deterioration arises from illness, disease, or trauma and is manifested in the biological, cognitive, emotional and/or social functioning of the individual. Meyer & Meyer (1983) refer to these processes as secondary aging processes. Such changes can be operationally defined as the existence of such pathological states as cardiovascular disease, arthritis, respiratory disease (Burdman, 1986). Difficulties in physical performance can be inferred from these states.

Physical performance will depend on the manifestation of the disease process. The individual with arthritis may experience the perception of pain and decreased strength. The individual with cardiovascular or respiratory disease may experience difficulty in breathing and tire easily. These difficulties are experienced in the daily life of the individual.

Although the primary changes occur in all individuals, as the person chronologically ages, secondary age changes may be more evident. However, not all individuals experience secondary age changes and secondary age changes vary with each individual. Absence of secondary age changes is identified as a capability; whereas, secondary changes are identified as a capability limitation.

Primary and secondary age changes diminish one's physical capabilities over time; however, individuals can still remain remarkably independent in self-care, instrumental and social activities (Kane & Kane, 1984). This capacity is a capability which partially reflects physical and cognitive system integrity. Problem solving abilities may also be less effective with age (Rogers & Snow, 1985). The ramification of the ineffectiveness of problem-solving abilities, such as intelligence, capacity to learn and memory, are probably negligible because of the following: the declines are small; intelligence scores are not positively correlated with occupational tasks of later life;

life experience can substitute for lost function; older people can retrieve items from long term memory with ease and older people can learn (Rogers & Snow, 1985). These capabilities will be further explored and defined in the development of propositions.

## Self-Image

Individuals have an image of self. This variable is added to the model, as depicted in Figure 4. I consider the self-image to be a powerful factor in influencing the appraisal of one's capabilities to cope with the requirements of the demands. Individuals, through past thoughts, attitudes and interaction with others, have a self-image (Larson, 1972). This self-image is associated with self-esteem or self-denigration. Pearlin and Schooler (1978) define self-esteem as "the positiveness of one's attitude towards oneself" (p. 5). They define self-denigration as the extent to which one holds negative attitudes towards oneself" (p. 5). This variable is continuous in that one's self-image could range from self-denigration or low self-esteem to high self-esteem.

A person's self-image is conceptualized as a contingent variable. This assumption is based on the thesis of Burdman (1986). Burdman relates that when individuals hold a negative self-image, they are vulnerable to high levels of tension or stress. Martin (1973) reports that a depressed individual frequently has low self-esteem. A person with depression believes that he/she is unworthy and incompetent. Martin points out that this cognition appears to be very resistant to change and therefore can be classified a powerful variable. As a high level of stress over a long period of time is correlated with extreme negative affect or depression (Burdman, 1986), it can be assumed that a person's self-image will influence the appraisal of one's capabilities to meet the requirements of the demands.

Tallman (1970) offers an explanation of the importance of self-esteem. Positive self-esteem encourages open channels of communication and individuals possessing self-esteem utilize a broad range of ideas in seeking solutions. The caregiver, through the demands of providing care, is required to solve complex problems in unique situations. The assumption is made that a person with a high level of self-esteem, due to his/her problem-solving repertoire, would feel capable of meeting the requirements of the demand.

In summary, the caregiver initially perceives demands from changes in family interaction or societal transactions. The perception of the demand is followed by an appraisal of his/her ability to meet the requirements of the demand. A comparison is made, through cognitive processes, between the perceived demand and the perceived capability. The caregivers' perception of their ability to cope with the demands and caregivers' self-esteem are considered critical variables in the appraisal of the discrepancy between demands and capabilities. A perceived minimal discrepancy is not considered very stressful; whereas, a large discrepancy can be perceived as very stressful. Having perceived this discrepancy, the individual emotionally responds. Following the emotional response, the caregiver copes with the appraisal process and the emotional response.

## Coping Response

Coping responses are what a person does in response to stress and are conceptualized as being action-oriented (Kane & Kane, 1984; Pearlin & Schooler, 1978). The function of coping responses is to regulate emotions (Lazarus, 1977). Emotional experiences are, in part, a function of cognitive appraisal (McGrath, 1977). Emotional experiences are also a function of coping responses (Lazarus, 1977). Coping reponses include the behaviors, cognitions and perceptions that individuals engage in when contending with stressful situations (Cox, 1982; Monat & Lazarus, 1977; Pearlin & Schooler, 1978). Pearlin and Schooler document that there are three types of coping responses: responses that change the situation or alter the demand, responses that change the meaning, and responses that function to control stress itself. I would suggest that the latter response is conceptually ambiguous. As stress is a process, the individual is actually seeking to control the emotional response. The specific behaviors associated with these responses are discussed in association with the propositional statements in the next phase of model development.

Resources. Another variable has been added to the interactional model of stress. Individuals draw on their resources or resources are available to the individuals in their coping repertoires (McCubbin & Patterson, 1983; Pearlin & Schooler, 1978). Viewed from this perspective, resources are critical variables to be considered in a person's adaptation to stressful situations. Whether a person uses a resource is contingent on the availability of the resource and the perceived value of the resource to the individual. These factors will be considered in more depth with proposition development. At this point, resources are considered to be a critical factor in the individual's coping response and should be included in the theoretical model and defined.

A resource is defined as as source of support of aid (Webster's II New Riverside Dictionary, 1984). The resource may be in the form of physical, psychological or emotional support. The individual perceives resources from all three levels of analysis as perception occurs in interaction with family and society. ~~Resources~~ include a broad range of support or aid which are potentially available to any member of the family in time of need (McCubbin et al., 1980).

In summary of this phase, the variables that give rise to the perception of stress and influence a person's adaptation to stress have been identified and defined. The variables include demands, capabilities, self-image, coping responses and resources. The relationship of these variables to the caregiver's emotional response(affect) are explored in the next phase of model development.

## Phase III: Propositions

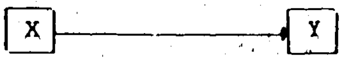
The development of propositions is an important part of theoretical development (Burr, 1973). The significance of the propositions relates to the purpose of developing this model. What is required is a model that will assist individuals providing intervention programs. To achieve this purpose, this model must assist researchers in designing empirical studies to evaluate individual differences. Over time, the individual assisting caregivers would benefit by a more thorough understanding of why some caregivers respond differentially to stressful situations and what coping responses may be effective in moderating the emotional response. In order to understand the variance in individual differences, propositions need to be developed that incorporate the variables identified in the previous phase.

Propositions will be developed in two parts. The first part will focus on the relationship of demands, capabilities and self-image to the emotional response. The second part will focus on the relationship of coping responses and resources to the emotional response.

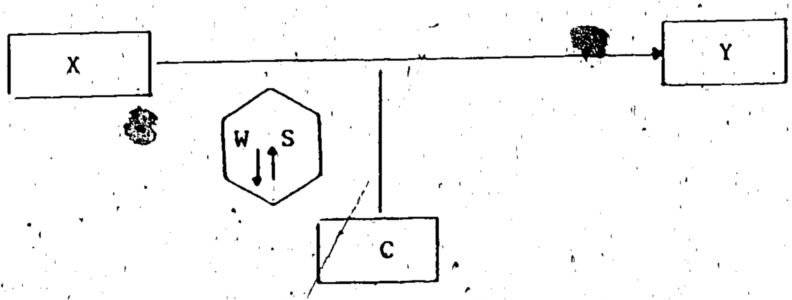
The caregiver is perceiving his/her capabilities in relation to the requirements of the demand. Drawing from the description of capabilities and demands outlined in the previous phase, potential capabilities can be identified that should influence whether individuals perceive they have the capability to meet the requirements of various demands. The assumption is made that a caregiver who possesses these capabilities would perceive the demand and perceive they are capable to meet the requirements of the demand. This individual would likely present with a more positive affect than individuals who perceive the demand and perceive they are not capable to meet the requirements of the demand. Capabilities, in association with perception of the demands, is identified as a determinant variable.

Potential capabilities are initially identified and defined. Support for inclusion of the variable is documented and propositional statements are derived from this documentation. A schematic representation of the propositions is depicted in Figure 5. The diagramming convention used for the schematic representation is derived from Burr, Hill, Nye & Reiss (1979).

Relationships between the variables are considered as covariational. Relationships are classified as positive (+) or (-). This covariational relationship is expressed as follows:



. Where one variable appears to influence the relationship between two variables, rather than directly influencing either of the variables, a contingent variable is identified. A contingency variable is synonymous with an interacting variable as it specifies conditions under which the relationship between two variables is altered. A contingency variable is represented as follows:



Contingency or Interacting Relationship: C influences the direction of the relationship between X and Y. Increases in C strengthen the

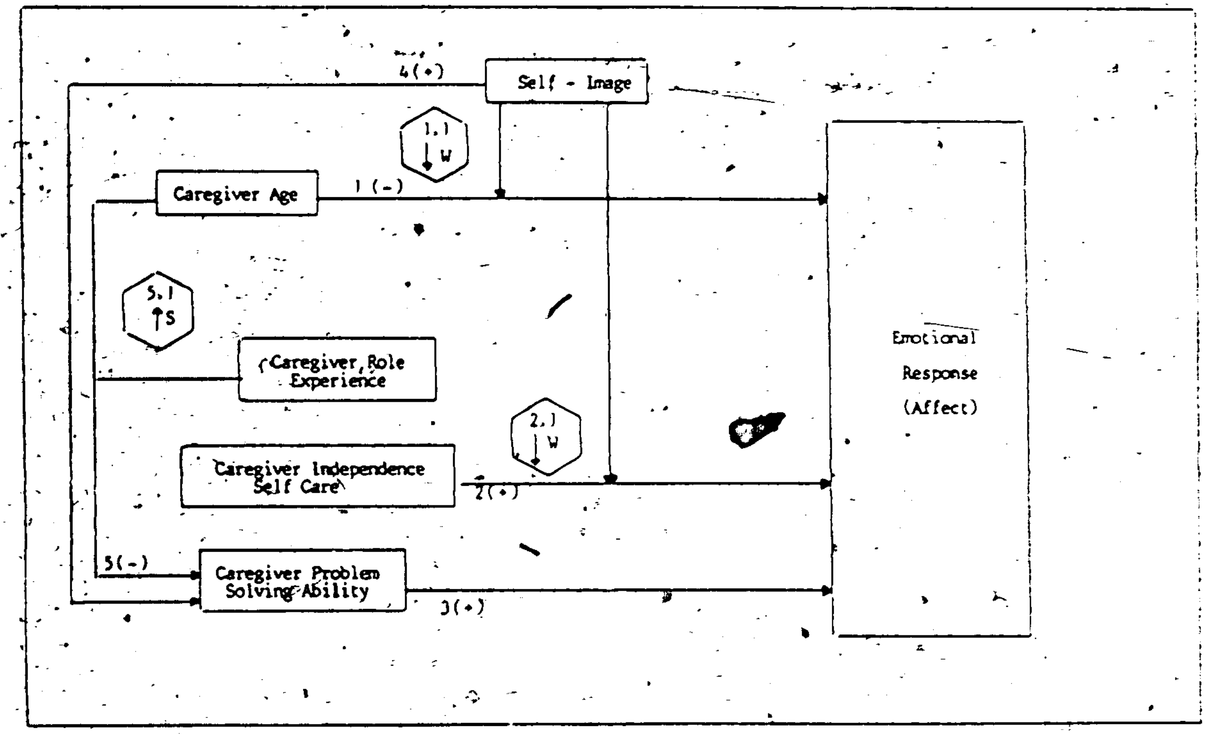


Figure 5. Schematic Representation of Propositional Statements: Part I

relationship (S) and decreases in C weaken (W) the relationship.

Propositions: Part I

Age. Primary aging changes are characteristic of the cumulative process of aging (Burdman, 1986; Meyer & Meyer, 1983) and all older people experience the changes associated with aging. As the aging changes are progressive, a person whose chronological age is lower would not be experiencing the extent of impairment as a person whose chronological age is higher. A caregiver with a lower chronological age may be better able to perform his/her personal self care activities and caregiving functions with greater physical ease.

Elderly people are at risk for developing secondary aging changes (Burdman, 1986). For example, 40% of Caucasian individuals over the age of 65 suffer from some form of hypertension, which predisposes the individual to heart disease and stroke (Burdman, 1986). Although many diseases can be correlated to other vulnerabilities of the individual, older people, as they age, tend to become more vulnerable to disease (Burdman, 1986). A caregiver who has any form of disease and associated impairments would find the tasks of personal care and caregiving difficult. The assumption is made that a person's age can be conceptualized as a capability and the following proposition is formed:

> Proposition 1. The lower the caregiver's chronological age, the more positive the caregiver's affect. This is a negative relationship.

Self-Image. The caregiver's self-image is conceptualized as a contingent variable that will influence the relationship between age and perceived discrepancy. Irrespective of chronological age, the caregiver who holds a relatively negative self-image may not perceive he/she has the capabilities to meet the requirements of the demands of interaction and transaction. As a person's physical status changes, this individual may perceive himself/herself as helpless and worthless. The loss in physical and cognitive abilities may represent a loss of general well-being and autonomy (Burdman, 1986). A person who holds a relatively positive self-image may perceive that he/she has the capabilities to meet the demands in that the changes do not represent a loss of general well-being or autonomy. Based on this assumption, a younger caregiver with a negative self-image will be more likely to present with negative affect. The following proposition results from this assumption.

> Proposition 1.1. The caregiver's self-image will influence the relationship between chronological age and caregiver affect. This is a contingent relationship.

Absence of Secondary Aging Changes. Good health is a resource (French, 1977) and, within my description of a capability, can be described as a capability. As Burdman (1986) points out, the elderly are at risk for secondary age changes. Eighty-one percent of persons over sixty-five have some chronic illness (Landreth & Berg, 1980). The most commonly encountered disease conditions are: cardiovascular conditions, cancer, musculoskeletal problems such as arthritis and gout, cerebrovascular accidents (stroke), diabetes and respiratory conditions. Each of these conditions will produce different functional limitations (Burdman, 1986). For example, a caregiver with osteoarthritis has a slowly progressive disorder of the joints where the articular cartilage deteriorates (Melvin, 1980). The person with this condition experiences pain and would have pain and difficulty in performing his/her own and his/her spouse's self care. Diabetes is a condition where the glucose metabolism is upset (Walter, 1982). Although the glucose metabolism upset can be balanced by drugs, activity and diet, the disease is accompanied by complications such as vascular disease, renal disease and degeneration of nerves. This individual would also have difficulty with self care tasks and caregiving as the requirements of glucose balance are stringent and sensory loss (nerve degeneration) impairs function.

The assumption is made that absence of secondary aging changes is a capability, as these changes impair the ability to function in daily life. The ability to perform these activities is also meaningful to the majority of individuals (Kielhofner & Burke, 1985). It is assumed that, as activities are meaningful, caregivers with absence of secondary changes would perceive a minimal discrepancy between demands and capabilities in that they should perceive they have the capability to meet the demand requirements.

The absence (or presence) of the cognitive and physiological status of individuals can be achieved through evaluation of health status (Kane & Kane, 1984). Operational measures include such items as pain or discomfort, signs on physical examination, physiological and cognitive indicators. These indicators, if used, would not be sufficient to ascertain the functional level of the caregiver. Despite the presence of secondary aging changes, individuals can still be relatively independent in performing self care and household tasks (Kane & Kane, 1984; Landreth & Berg, 1980). As it is probable that the caregiver has secondary changes and that daily functioning involves many of these tasks, the functional ability of the caregiver may be a more appropriate indicator of health status. Independence in daily activity can be operationally defined as the degree of independence in such activities as dressing, feeding, mobility and instrumental tasks (Kane & Kane, 1984). The degree of independence is reflected on a continuum from being completely dependent on another individual for assistance to being completely independent.

> Proposition 2. The higher the caregiver's level of independence in self care and instrumental tasks, the more positive the caregiver's affect. This is a positive relationship.

Self-Image. The caregiver's self-image is conceptualized as a contingent variable which influences the relationship between independence in self care and caregiver affect. Irrespective of a higher level of independence as a potential capability, the individual with a negative self-image may not value the capability of independence and may not perceive that he/she has the capability to meet the requirements of the demands of interaction and transaction. In a study by Abrahams & Patterson (1980), it was found that the psychologically impaired individual was more likely to report limitations because of health problems, worry about his/her health and rate himself/herself in poor health. The psychologically healthy individual was more likely to rate himself/herself as physically healthy, regardless of the actual physical condition. Based on the empirical evidence of this study, the following proposition is stated.

Proposition 2.1 The caregiver's self-image will influence the relationship between independence in self care and caregiver affect. This is a contingent relationship.

Problem-Solving Behavior. Tallman (1970) defines problem solving as referring to "those behaviors which individuals or groups choose and implement in order to achieve desired ends" (p. 95). Tallman points out that a problem is confronted in all situations people encounter. Once having learned, through coping, which responses are effective, the behaviors become patterned or habitual and, when the situation changes, the individual confronts a new or modified problem. The concern of this model is information about change. Accordingly, attention is drawn to the new or modified problems of the caregiver. These problems require "new solutions through the production of innovative or creative ideas" (p. 95).

The caregiver, in providing care, has many demands that involve the production of innovative and creative ideas. Although the nature of the demands vary with the diagnosis and functional limitation of the spouse, problem-solving is a requirement of the demand. As an example of problems faced by the caregiver, the problems presented to the caregiver of a spouse with Alzheimer's disease are briefly presented. The difficulties faced by the family are well documented in the literature by Barnes, Raskind, Scott and Murphy (1981); Mace and Rabins (1981); Rabins, Mace and Lucas (1982). The caregiver faces a number of problems relating to the behavior and memory deficits and mood changes of the spouse. These include problems such as the spouse night wandering and wandering out of the house, being physically and/or verbally aggressive, being incontinent and exercising poor safety judgment. These behavioral changes can be difficult to define as they are usually insidious. The caregiver may find that his/her spouse violently resists the care provided.

While some caregivers experience only some of these problems, other caregivers will experience many of the problems (Mace and Rabins, 1981). However, as new demands, these problems require effective problem-solving behavior. The assumption made is that effective problem-solving behavior is a capability that, if possessed by the caregiver, will minimize the perceived discrepancy between demands and capabilities.

Problem solving can be operationally defined as the methodology one would use when confronted with demands. The demands should be specific to the elderly within the context of caregiving. Problem solving is conceptualized as a continuous variable with a range of minimal ability to high ability.

Proposition 3. The higher the caregiver's problem-solving ability, the more positive the caregiver's affect. This is a positive relationship.

In summary of these propositions, the variables of age, independence in self care and problem-solving are related to the perceived discrepancy between demands and capabilities and subsequent emotional response. It is predicted that capabilities such as lower age, higher independence in self care and creative problem-solving abilities in the caregiver will minimize the discrepancy between perceived demand and capabilities and these caregivers will have a positive affect. Self-image is conceptualized as a contingent variable, influencing the relationship between age, independence in self care and caregiver affect.

Self-image is not a contingent variable between problem solving and caregiver affect as individuals with a negative self-image are not deemed capable of innovative problem-solving (Tallman, 1970). Therefore, the following relationship is established.

Proposition 4: Self-image is related to problem-solving capabilities. This is a positive relationship.

Additional relationships can be identified from the propositional statements made. The first relationship is between age and problem-solving. It was pointed out previously that the problem-solving ineffectiveness is a characteristic of aging (Rogers & Snow, 1985). The ramifications are perceived as being small. Two of the reasons provided by Rogers and Snow (1985) are relevant to the discussion. Firstly, the declines are small; and secondly, life experience can substitute for lost function. The declines may be small, but what is required of the caregiver is new learning associated with creative problem-solving. Life experience may or may not substitute for lack of problem-solving ineffectiveness in these situations.

It could be assumed that caregiver functions may be more easily adapted to by women than men. The reason provided for this is that many of the caregiving functions are associated with caring functions performed with children in an earlier stage of the life cycle. As the risk of secondary aging changes increases with age, the caregiver may have experienced caregiving and accessing the health care system more recently than previous life cycle stages (Turk & Kerns, 1985). Regardless of age or gender, a caregiver who has provided this type of care in previous situations may be more effective with problem-solving as new learning is not as highly involved and perceive he/she has the capabilities to meet the demand requirement. This situation becomes a modified demand as there may be more ease of transition into the role (Burr, 1973).

Two propositions can be formed from this observation. These are propositions that reflect the impact of age on problem solving and the caregiver's previous experience with caregiving functions. The caregiver's previous experience is reflected on a continuum from little or no experience to a lot of experience.

Proposition 5. The lower the caregiver's age, the higher the level of problem-solving ability. This is a negative relationship.

Proposition 5.1. The caregiver's previous experience with care provision will influence the relationship between age and problem-solving ability. This is a contingent relationship.

## Propositions: Part II

Throughout this model, stress is conceptualized as a process. The demands are constantly perceived and caregivers are constantly perceiving their capabilities in relation to the requirements of the demands. Having perceived a discrepancy between demands and capabilities, the caregiver emotionally responds to the discrepancy and subsequently adapts through the coping process. The variables of importance to the coping process are coping responses and resources. Propositional statements are depicted in Figure 6.

In their coping responses, caregivers alter the demand itself, change the meaning of the demand, increase their capabilities and/or deal with the emotions associated with stress. In coping, the caregiver draws upon available resources (Pearlin & Schooler, 1978). The intent in this phase is to explore the various coping strategies that have been identified in the literature as methodologies used by individuals as they cope with demands and stress.

Altering Demands: Increasing Capabilities

Altering the nature of the demand, by changing the meaning of the demand or eliminating or modifying the demand, is a coping response (Monat & Lazarus, 1977; McCubbin & Patterson, 1983; Pearlin & Schooler, 1978). The assumption is made that altering the demand minimizes the discrepancy between demands and capabilities through the reduction of information overload. This reduction places less strain on the adaptive system (Hamilton, 1980). There are many ways an individual can alter the demands associated with family interaction and societal transactions. Some of these strategies are identified. The strategy

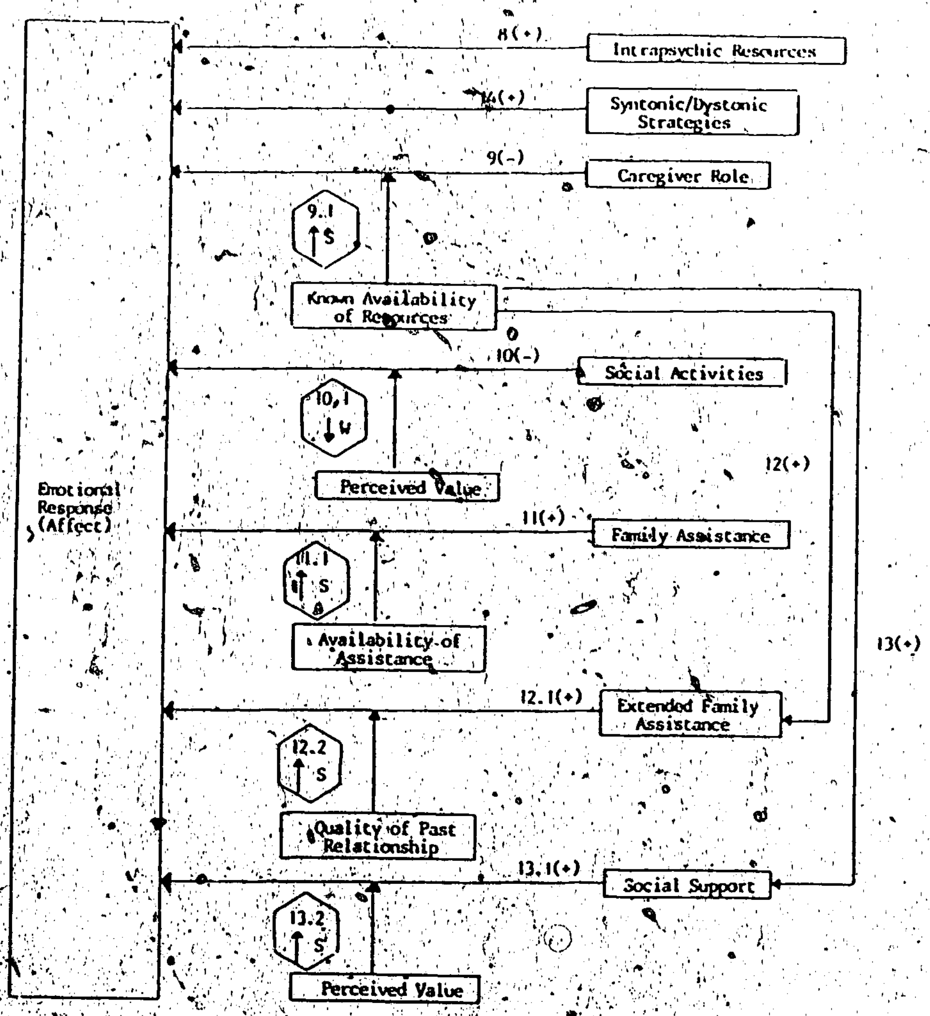


Figure 6. Schematic Representation of Propositional Statements: Part II

may increase the perceived discrepancy or decrease the discrepancy between demands and capabilities and influence the emotional response. An increase in perceived discrepancy and occurrence of negative affect is considered to be an ineffective adaptation over time; whereas, a decrease in perceived discrepancy and occurrence of positive affect is considered to be an effective adaptation. The way in which a caregiver ch[illegible]es to alter the demand will always place new demands on the caregiver as the action feeds back as input to the individual.

<u>Intrapsychic Strategies.</u> The individual can alter a demand by using his/her intrapsychic resources or cognitive defense mechanisms (Lazarus, 1977). Intrapsychic resources are part of the cognitive processes of humans that allow people, through interpretation of the environment, to manipulate the environment (Lazarus, 1977). The ultimate function of these mechanisms is to regulate stress related emotions (Lazarus, 1977). Defense mechanisms do not function to actually eliminate the demand or alter the demand, but function to control the impact of the demand (Monat & Lazarus, 1977). The use of intrapsychic resources as a coping response is well documented in the literature (Monat & Lazarus, 1977; McCubbin & Patterson, 1983; Montgomery, 1985; Pearlin & Schooler, 1978). Intrapsychic resources include such mechanisms as cognitive denial, detachment and redefining the situation as a challenge.

For an intrapsychic resource to be effective in minimizing the discrepancy, the caregiver has to perceive the situation as a source of his/her problem (Pearlin & Schooler, 1978). This may be difficult in the complex situations confronting the caregiver. However, cognitive defenses are used in association with stress experience. For example, Teusnik and Mahler (1984) discuss cognitive defense mechanisms of caregivers in relation to their spouse's memory loss. The caregiver notices memory loss in his/her spouse. The caregiver's response to the demand is to minimize it by offering rational explanations for it or deny that he/she is perceiving the information. The function of the defense is to control the emotion. These defenses serve to control emotion for a short period of time (Lazarus, 1977; McCubbin, Joy, et al., 1980; Montgomery, 1985). Eventually, the caregiver will have to deal with the demands. These responses are temporarily effective in reducing stress, but may be maladaptive if they continue too long.

Proposition 8: The use of intrapsychic resources by the caregiver is related to caregiver affect. This is a positive relationship.

Change Caregiver Function. To decrease the demands of caregiving, the care provider could alter their responsibilities for care. The caregiver has been described as a person who actually provides or performs the care personally. The caregiver could become a care manager. The tasks associated in care managing are less demanding in a physical sense in that caregiving involves management of care provided by others (Archbold, 1983). A second type of change would involve transfer of the care to another caregiving agent, such as an institution (Archbold, 1983).

The types of caregiver roles are defined by the specific function of the roles and are discrete variables. This type of change, while modifying the demand by reducing the physical and rigid scheduling aspects of caring, presents the caregiver with new demands in that he/she is giving up an activity that may have been meaningful and now must deal with the psychological demands. Alternate caring roles also involves transition out of roles, management of other individual's and transactions with more people. However, the care manager is able to spend more time engaging in spousal social and psychological support. While demanding, these activities may provide more meaning to the caregiver's experience (Archbold, 1983).

Proposition 9. Changing the function of the caregiver to roles involving less physical demands is related to caregiver affect. This is a negative relationship.

The resources of the caregiver are critical to the relationship expressed in this proposition as individuals draw on their resources in their coping strategies. A caregiver can only change functions if economic and social resources, through the family and society, are available and known to be available. The services of care provision by another person or agency may have to be purchased by the caregiver or be available in society to the caregiver.

Although long term care social policy is gradually adap[illegible] family needs over time, services are not necessarily available (Koff, 1982). Services are required to assist caregivers in changing their function. Such services include day centers, day hospitals and short term extended care admissions (MacMillan, 1969); services to meet household and caregiving needs (Harel & Deimling, 1984; Treas, 1977) and financial support (Shanas, 1979). The availability of these, or similar resources, is conceptualized as a contingent variable. The following proposition is stated.

> Proposition 9.1. The known availability of family and social resources will influence the relationship between changing the caregiving role and caregiver affect. This is a contingent relationship.

Decreasing Social Role Activities. As part of the social transaction with extended family and society, the caregiver may be involved in social role activities. To decrease the number of demands, the caregiver can decide to give up social role activities. Caregivers may perceive that giving up these activities, in order to meet the demands of caregiving, may decrease the number of demands and increase their capabilities to meet the requirements of other demands. Essentially, the caregiver would be dealing with less information.

This action on the part of the caregiver is conceptualized as having the potential to decrease the discrepancy between demands and capabilities. As with any action that involves altering demands, this action will eventually give rise to new demands. The caregiver may have to deal with the psychological aspect of giving up activities. This may represent another loss to the caregiver and eventually affect family interaction. The meaning or value of the activity may be an important variable to consider in the relationship of this coping response and stress.

A family system involves many different activities (Montgomery, 1982). The activities reflect the values and goals of the individuals. Montgomery (1982) defines values as the "criteria which are used to judge the worth of some behavior or thought" (p. 75). He points out that values are called upon when people make comparisons and decisions. As the caregiver is making a decision to give up social activities, the perceived discrepancy may be decreased if the activity is not valued or is not particularly meaningful to the individual. The meaning of the activity can be reflected on a continuum from no value to high value. Should the activity be highly meaningful to the caregiver, the psychological response of the caregiver may influence family interaction and create new demands. Blau (cited in Cobb, 1976) points out that, in the elderly, participating in social activities is protective against low morale. It is probable that the caregiver would perceive some activities as psychologically meaningful. Based on the documentation about the action and the influences of values, two propositions are asserted.

Proposition 10. Decreasing or eliminating social role activities is related to caregiver affect. This is a negative relationship.

Proposition 10.1. The perceived value of the activities will influence the relationship between decreasing the social role activities and caregiver affect. This is a contingent relationship.

Seeking Family Assistance. ~~In~~ the interactional model the caregiver's family consists of the caregiver's spouse. The caregiver may be able to receive support from his/her spouse. Individuals usually try and solve problems within the family before seeking the assistance or support of extended family or social support (Johnson & Johnson, 1983).

The caregiver exists in a family situation where the spouse, despite requiring care, may be able to assist the caregiver in meeting the requirements of physical demands and psychological demands. In the aging life cycle, the elderly couple develops routines that function to assist each other in meeting such demands as self care and the psychological demands of aging. The caregiver may require physical assistance in such areas as personal self care, household tasks and social tasks. The spouse, in interaction with the caregiver, may be able to assist the caregiver in these functions.

Not all spouses will be able to give this support. For example, a spouse with the late stages of Alzheimer's disease would not be able to provide this assistance to the caregiver as the spouse requires complex care himself/herself. On the other hand, a spouse with only dysfunction from amputation may be able to provide some physical assistance to the caregiver.

Seeking the support of the spouse to help solve problems is an action that has the potential to reduce the complexity of the demands. The family problem-solves through its correction patterns (Montgomery, 1982). The caregiver is confronted with demands that require creative problem-solving. Effective communication is required for creative problem-solving (Montgomery, 1982; Tallman, 1970). An optimal family structure for effective communication is where one member of the family is designated as a sponsor or has the authority to act on behalf of the family and open channels of communication exist (Montgomery, 1982; Tallman, 1970). Communication, at a family level, includes such factors as the ways family members respond to each other's emotional expressions of love, anger, sorrow and the ways family members work together to solve problems (Montgomery, 1982; Kane & Kane, 1984).

The assumption is made that the spouse's specific dysfunction may interfere with the effectiveness of communication and problem- solving. A person with a cognitive deficit may not be able to provide the psychological support or assist with problem-solving. Despite the absence of cognitive deficit, a spouse may not be willing to provide the support. The past pattern of the marital relationship may influence the ability of the spouse to provide spousal support. Qualitative family patterns are important to the morale of older people (Mancini, 1979) and past relationships are considered to be an important factor in spousal support.

Through deterioration in human behavioral functioning or the past marital relationship, the support may not be perceived to be available. While seeking family support has the potential to reduce demands, the perceived unavailability of spousal support moderates this relationship. Based on this assumption, the following propositions are stated:

Proposition 11. The amount of family assistance is related to caregiver affect. This is a positive relationship.

Proposition 11.1. The amount of perceived availability of spousal support will influence the relationship between spousal support and caregiver affect. This is a contingent relationship.

Seeking Extended Family Assistance. The extended family of the caregiver includes children and grandchildren. Children of the caregiver are a major support of families in times of illness (Horowitz, 1978; Johnson & Johnson, 1983; Shanas, 1979). Adult children can provide psychological, physical and financial support. It is not uncommon that families seek the assistance of extended family for support as the extended family is part of the elderly person's continuity from the past. When this resource is available, it has the potential to alter demands through the provision of support.

The caregiver may have access to family support and not value the support. ~~As~~ Butler and Lewis (1973) point out, the numbers and proximity of kin give no clear indication of the value of the contact. In the elderly population, the maintenance of a parent-child bond is based on the willingness of both parties to engage in supportive behaviors. The willingness depends on the quality of the relationship over the previous decades (Hess & Waring, 1978). Hess and Waring assert that the quality of the relationship reflects such variables as basic trust, respect, shared values and genuine affection. Viewed from this perspective, the quality of parent-child relationship will influence the relationship between availability of family support and caregiver affect as the perceived value of the support becomes a key factor in seeking family support.

Proposition 12. The amount of extended family assistance is related to the availability of extended family. This is a positive relationship.

Proposition 12.1. The amount of extended family support is related to caregiver affect. This is a positive relationship.

Proposition 12.2. The perceived quality of the parent-child relationship will influence the relationship between the accessibility to extended family support and caregiver affect. This is a contingent relationship.

Seeking Social Support. When individuals are not able to solve problems within the family and extended family, they turn to society for assistance (Shanas, 1979). Societal resources are represented in the transactional network of which the individual is a part (Pearlin & Schooler, 1978). The existence of these supports, outside the family, means that the caregiver has access to nonmarital sources for the satisfaction of individual and family needs (Lee, 1979). These social networks include voluntary organizations, friend networks, government agencies, religious organizations and health care systems. It is probable that the friend network becomes diminished over time as the pool of friends diminishes (Zube, 1982). The social organizations may be available and have the potential to support the caregiver, but be unknown to the caregiver. If a resource is unknown to the caregiver, it is not accessible or available.

Proposition 13. The amount of social support is related to the known availability of the resource. This is a positive relationship.

There are many resources available to the caregiver that can assist with decreasing the demands of the caregiver and ultimately decreasing the perceived discrepancy between demands and capabilities. These include some of those already mentioned, such as assistance with housekeeping tasks and provision of day care services. They also include services that meet the health needs of the caregiver and the spouse. In chronic mental illness, for example, psychoactive drugs can be helpful in blunting the spouse's aversive behaviors (Eisdorfer & Cohen, 1981; Mechanic, 1986). An individual with a physical and/or cognitive condition can be assisted by provision of methodologies and assistance that will assist him/her in being more independent. The health care system can provide aids to assist in easier mobility on stairs and easier performance of daily activities (Morycz, 1980; Trombly, 1983). As retirement can negatively affect the family economy (Zube, 1982), societal agencies can be supportive in augmenting family economic resources (Treas, 1977). These resources are forms of tangible assistance and provide the caregiver with sources of support that can decrease the demand and/or increase the capabilities.

Harel and Deimling (1984) point out that the literature generally equates social networks with supportive functions. Social networks are not always perceived by caregivers as supportive. The caregiver may perceive the resources negatively, in that the support does not meet the caregiver's expectations (Fiore, Becker & Coppel, 1983). Should the expectations not be met, the caregiver continues to experience negative affect and depression can occur. The individual's subjective interpretation of the social resource's role function is important. The caregiver has to perceive that the resource is meeting his/her particular needs. For example, a person with Alzheimer's disease progresses through phases of change. The support offered by the health care system to the caregiver should vary with the phases of change (Cohen, Kennedy & Eisdorfer, 1984). A caregiver who has just learned a diagnosis may perceive the need for education about the disease process or education about resources. Should the individual be provided with neither of these, the support may not be valued by the caregiver. An individual providing the support needs to be perceptive of the needs of the caregiver for the ultimate reduction of negative affect. The caregiver's affect is indirectly influenced by the ability of the social support network to meet the caregiver's specific needs, such that the support is valued by the caregiver. The additional propositions are formed from the diaglogue on social support.

Proposition 13.1. The amount of available social support is related to caregiver affect. This is a positive relationship.

Proposition 13.2. The perceived value of the social support influences the relationship between the available social support and caregiver affect. This is a contingent relationship.

Dealing With The Emotional Response

The caregiver may use different methods to deal with the emotions of stress (Lazarus, 1977; McCubbin & Patterson, 1983; Montgomery, 1985). These include behaviors that are unique to each individual and represent a continuity from previous handling with stressful situations. Such behaviors include drinking alcohol, watching television, avoiding confrontation, and relaxation. Lazarus (1977) describes these methodologies as strategies that reduce the visceral or motor reactions associated with the stress emotion.

The methods described above are action-oriented strategies that the caregiver might use to decrease the visceral motor reaction that accompanies stress. However, not all strategies are effective in reducing negative affect over time. The use of alcohol may be perceived as an action that will moderate emotion. Methods such as this only have short term benefit. French (1977) describes these methods as dystonic symptoms. They are actions that either push the family apart or delay the impact of the demand. Relaxation can be classified as a syntonic methodology in that it is a stress management technique that may serve to pull the family together and has longer term benefits (Montgomery, 1985).

Proposition 14: The use of syntonic and dystonic stress reducing methodologies is related to caregiver affect. Syntonic methodologies and stress is a positive relationship. Dystonic methodologies and stress is a negative relationship.

In this phase of model development, propositions have been developed in two parts. The first part identified variables that are related to the appraisal process of stress. The second part identified variables that are related to the coping process of stress.

As stress is a process, the perception and management occur over time as situations change. The time aspect has been implicitly examined through the coping response relationships. Coping responses, through feedback, result in new or modified demands. No specific propositions are formulated for this part of the process. The time factor is presented as a constant in this model.

The model would not be complete without focusing attention on the caregiver's affect as depression in a relatively common occurrence in the elderly (Burdman, 1986). Affect is conceptualized as influencing both the perception of demands and capabilities and the individual's response to stressful situations. The importance of affect is recognized when attention is drawn to the person who has negative affect. As negative affect is a part of depression; the depressed person's perception of stress and response to stress is examined.

Beck (cited in Neufeld & Mothershill, 1980) proposes that the depressed individual is predisposed to viewing the self, the environment and the future in a negative manner. He proposes that the depressed person's inaccurate perceptions of reality are developed through previous life experiences. In the first part of the propositional statements, the variable of self-esteem was considered to have a direct influence on other capabilities. Extreme negative self-image is a classic symptom of depression (Burdman, 1986; Charatan, 1980; Kane &

Kane, 1984). As negative affect is a precursor to depression, the elderly caregiver with a negative self-image may be at risk for depression. This, while not included in the model in propositional form, has clinical significance.

Depressed people may not cope effectively with the demands or their emotional response. They can neither alter the demands nor increase their capabilities (Burdman, 1986; Montgomery, 1985; Neufeld & Mothershill, 1980). They lack the skill to elicit support and maintain the support. As they do not cope effectively with stressful situations, they have repeated failures and this failure is additional information to be processed. In summary, the person who holds a negative self-image is at risk for negative affect and, over time, depression.

## Summary of Development of the Interactional Model

Evidence of conceptual ambiguity was gained through an analysis of the burden literature. Conceptual clarity of burden was attained through an analysis of the operationalization of burden and correlation with psychological and family theories of stress. As a result of this analysis, the assumption was posited that "subjective burden" and "caregiver affect" are synonymous terms and these concepts are component parts or elements of the process of stress. Stress was conceptualized at the individual level of analysis.

The transactional model of stress proposed by Cox and MacKay (cited in Cox, 1982) was used as an initial starting point for a theoretical model. This model was expanded to include the environment of the individual, resulting in an interactional model.

Stress is conceptualized as a process whereby individuals, upon receiving information about change, cognitively appraise the demands confronting them and their capabilities to meet the requirements of the demands. Demands and capabilities specific to the context of the aging life cycle, long term care and illness were identified as variables that influence the perception of the discrepancy between demands and capabilities and subsequent emotional response. These variables were derived from the Cox and MacKay model. The variable of self-image was included in the interactional model. Two variables were identified as being critical to the evaluation of individual differences in the caregivers' emotional responses: the caregiver's perception of his/her capabilities to meet the requirements of the demand and the caregiver's self-image.

Following the appraisal of a demand-capability imbalance the individual adapts to the imbalance and emotional response through coping. Coping responses are actions in which a person engages in adaptation to the imbalance and emotional response. An individual draws upon his/her resources in order to adapt to stressful situations. Resources arise from three levels of analysis: individual, family and society. Resources are potentially available to the individual in time of need. This variable has been added to the model.

Based on the theoretical model, propositional statements were formulated in two parts. The first part focused on the relationship of perception of capabilities to meet the requirements of the demands and self-image to caregiver affect (the emotional response). The second part focused on the relationship of coping responses and resources to caregiver affect. The interactional model was used to advance theoretical propositions. This process resulted in a propositional model. Subjective validity of the interactional model and propositional model will be explored in the next chapter. Objective validity can be gained only through the measurement process.

# CHAPTER V

## Model Validation

As outlined in the model strategy, the validation of the model involves two procedures. The first procedure is to validate the theoretical model by determining if the model meets the criteria and standards of a theory. The second procedure is to validate the propositional model derived from the theoretical model. The purpose of this procedure is to judge if the model has explanatory power.

### Theoretical Model Validation

In order for a theory to be complete, the theory must contain: constructs, propositions stating the relationship between variables and propositions that are logically related. These propositions must form a deductive system (Burr, 1973; Burr, Hill, Nye & Reiss, 1979; Hage, 1972; Kerlinger, 1973). The interactional model contains all these components of a complete theory. Constructs were identified in a systematic way. Theoretical assumptions from existing theories were used to generate a theoretical framework of stress. Assumptions were derived from psychological, developmental, systems and family crisis theory. These assumptions meet the standard of parsimony and formed the basis for establishing a theoretical model from which to identify and define variables and formulate propositions.

While the theory is complete, the scope of the theory is limited to Burr's (1973) description of a middle-range theory. The developed model does not meet the criteria of a general theory as the scope is limited and the social context is specific to the elderly and long term care. The interactional model can be justified by considering the way in which the model can be generalized beyond the limited scope presented. The interactional model of stress can be generalized to caregivers of family members within any family structure or individuals within any life cycle. The theoretical model utilizes variables that are relatively context-free. The theoretical definitions of variables such as affect, capabilities, self-image, coping responses, resources and the linkages between these variables, can be applied to any context of long term care in the family. The interactional model includes operational definitions of these variables and propositions relative to the elderly person. This model could be applied to other situations by altering the operational definitions of context-specific variables.

Throughout the development of the theoretical model, concepts were defined. The concepts were defined through theoretical or constitutive methods and operational methods. By using both methods, the criteria for defining concepts as outlined by Burr (1973), Hage (1972) and Kerlinger (1973) were met. The operational definitions do not actually specify a measuring instrument or technique. This remains to be developed with empirical testing of the model. Sufficient definition is provided to make measurement possible as conceptual clarity is achieved and the meaning of the construct is maximized. All variables are defined and categories identified and/or range of variation established.

While measurement could be derived from the model, the methodology of measurement was not established. Although beyond the scope of the model, the time factor needs to be considered in future empirical validations of the model. As stress is a process, I feel that longitudinal data collection is required to test the validity of the model. I would concur with Lazarus (1977) who points out that researchers need to study individuals over a long period of time, as they experience stress and cope with stress from one situational context to another. This process would increase our understanding of the various individual response systems of emotion and the cognitive appraisal processes that regulate the individual's interaction with his/her environment.

The interactional model and subsequent propositional model are expressed verbally and through diagrammatical representation of verbal description. Both methods represent a standard of expression (Blalock, 1969; Burr, 1973; Burr et al., 1979; Gibbs, 1972; Mullins, 1972; Reed, 1984; Reynolds, 1971). The process of diagrammatical expression was particularly helpful in organizing the presentations of verbal description and keeping the framework systematic.

## Propositional Model Validation

Theories are developed to increase our understanding (Burr, 1973) and suggest new areas of systematic inquiry (Aldous, 1970). As outlined previously, the propositional model needs to be evaluated for evidence of explanatory power. The procedure to be followed is to analyze existing studies on burden relative to the interactional model.

Comparisons of the findings between studies are not made as each researcher uses different measurement techniques. Attention will be focused on their conceptualization and specific findings. Support for the interactional model will be documented and the model will be used to offer alternate explanations where indicated. As indicated in the introduction, many studies on burden exist. Only three studies will be reviewed. These studies use different approaches to burden but are all studying the phenomenon of burden in the elderly population.

The conceptualization of burden by Zarit, Reever and Bach-Peterson (1980) and Pratt, Schmall, Wright and Cleland (1985) is initially reviewed. A burden scale was developed by Zarit et al. and is used in studies of burden by Zarit et al. and Pratt et al.

Zarit et al. (1980) researched the factors contributing to feelings of burden of caregivers of elderly individuals with senile dementia. The purpose of their research was to investigate factors related to the amount of burden experienced by caregivers and to identify sources of burden.

The measurement of subjective burden is gained through a 29 item burden scale. The scale is a self-report instrument that includes statements about how the caregiver feels about various aspects of caregiving. Examples of statements used are: "I feel strained in my interactions with my spouse", "I feel that my social life has suffered because of my involvement with my spouse", "I feel that I don't have enough money to support my spouse in addition to the rest of our expenses" (p. 651). All statements reflect potential concerns of caregivers in such areas as caregiver's health, psychological well-being, finances, social life and the marital relationship. Twenty-nine caregivers were asked to indicate how much discomfort the concern caused by indicating discomfort on a scale from "not at all" to "extremely". The researchers make the assumption that the "discomfort caused by these situations places burden upon the caregiver" (p. 651). A total burden score is calculated from a possible score of 84.

Zarit et al. do not offer a theoretical base for their development of the scale. However, they scanned the literature for problems frequently cited by caregivers. This accounts for face validity. Using my model to provide a theoretical base, the scale can be analysed for content and problem's generated.

By using the feelings of discomfort as an indicator, these researchers are including the perception of the caregiver's existing emotional state to a certain degree. The scale incorporates feelings such as feeling nervous, strained, angry, resentful in thirteen of the it~~ems. In th~~e statements, these feelings are associated with nonnormative demands of caregiving and psychological demands of interaction. The remaining sixteen items are discomfort about specific caregiving demands. The researchers do not differentiate between "stressor" and "emotional state" and make the assumption that the statements about caregiving reflect the source of burden.

Contrary to the expectations of the researchers, the level of burden reported by the caregivers is low. The mean score is 31 out of a possible 84 on the interview. Pratt et al. used the same burden interview in a similar study. It is noted that the scale used by these authors differs slightly from the original scale. Pratt et al. used the burden interview described by Zarit and Zarit (1982). Rather than listing statements and asking the respondent to state the degree of discomfort, the items are in the form of questions to which respondents indicate how often (on a five-point scale) they feel that way. This may elicit a longer term emotional state. The caregiver burden score ranges from 0 to 88 and in a study of 240 caregivers, the mean burden score is 40.08. Through combining emotions associated with demands, Zarit et al. are assuming that the demand is the source of burden. The advantage of this approach is that researchers are able to study a group of individuals who are confronting similar situations. The results of the burden interview are compatible with the findings of other stress studies of different situational contexts and the theories of psychological stress. The way in which the findings are compatible is that when confronted with similar situations, people vary in their level of stress (Appleby & Trumbull, 1977; Cox, 1982; Lazarus, 1977; McGrath, 1977; McCubbin & Patterson, 1983; Sarason, 1980).

There are two disadvantages to the multidimensional measurement of burden. The first disadvantage is that it is not clearly understood what is being measured. The second disadvantage is that the source of burden is considered to be only caregiving. These disadvantages are further explored ~~relative~~ to the interactional model and validity of the scale.

In the interactional model, I make the assumption that it is not the stressor or caregiving alone that influences the emotional response. I assume that the emotional response is a function of the caregiver's perception of the discrepancy between his/her capabilities to handle the demands of caregiving and his/her capabilities. Should people lack these capabilities, they would be more vulnerable to negative affect. As people are not always aware of the source of their emotional response, the emotional response and capabilities in relation to the demands are separated.

The conceptualization in the interactional model may provide the researcher with an avenue to define the sources of burden or negative affect and a methodology with which to identify those people who may be at risk for negative affect and ultimate depression. The validity of my conceptualization can only be gained through construction of scales that reflect this conceptualization and empirical research. At this point, validity for my conceptualization is offered through a critique of the scale construction by Zarit et al. and the findings of both Zarit et al. and Pratt et al.

In using the scale developed by Zarit et al., the theoretical orientation of Pearlin and Schooler (1978) is being followed. This orientation provides the researcher with the assumption that the stressor and emotional response are interchangeable concepts. The researchers define the stressor and emotional response for the caregiver and limit the scale to caregiving stress. The scale includes many statements that force the caregiver to consider the idea that caregiving functions or effects cause distress. Referencing the interview by Zarit and Zarit (1982), consider the following questions or combinations of questions as an example of causal statement. How frequently "do you feel that your health (social life) has suffered because of (your involvement with your relative) (caring for your relative)" and "do you feel uncomfortable about having friends over, because of your relative" (p. 28). In addition to specifying "cause", the disadvantage of this context-specific approach is that other sources of stress are not considered as influencing the caregiver's emotional response.

The interpretation of the findings from use of the scale are also subject to debate. The last question on the scale is relatively context-free. The caregiver is asked to respond, on a scale from not at all to extremely, "overall, how burdened do you feel in caring for your relative?" (p. 28). This question is included in the additive score (Zarit et. al., 1980). This procedure may be a threat to the internal validity of the scale. Kerlinger (1973) specifies that summated scales should reflect a set of items that are relatively equal in value. As no validation of scale construction is reported by the researchers, it is not known whether a validation process occurred. Through examination of scale content, I feel that a summation of scores is inappropriate in that: a) the last question is not of equal value to the remaining questions, and b) feelings about caregiving and effects of caregiving are different constructs.

Montgomery, Hooyman and Gonyea (1985) address the issue of separating the effects from the feelings about caregiving. Although there is not a complete separation of feelings and the context of caregiving, partial support for my conceptualization is gained. They studied the relationship between subjective burden and objective burden. Their sample includes 80 caregivers of elderly relatives. These caregivers are identified as the primary people providing assistance to their elderly relatives and live within an hour's driving distance of their relatives. The extent of their caregiving tasks vary, as does the amount of time spent on these tasks. The researchers use correlational analysis between the measures of objective burden, subjective burden and measures of the independent variables of caregiver's age, relationship to elder, caregiver's employment status, family income, number of others who assist in care, and the types of tasks involved in caretaking.

Objective burden is defined as the extent of disruption or change in particular aspects of the caregiver's life and household. The researchers constructed a 9 point inventory reflecting the amount of changes such as privacy, time, money and personal freedom. Respondents were asked to indicate, on a 5 point scale, the amount of change. In the interactional model, these changes would be expressed as demands. Montgomery et al. (1985) define subjective burden as the caregiver's attitude toward the caregiving experience or emotional reaction to the caregiving experience. The researchers use the 13 items about feelings that Zarit et al. included in their scale. They exclude the context-free question about overall burden. Using multiple regression analysis to explore the relationship between objective burden, subjective burden and the independent variables, they determined that each type of burden has different correlates and the two types of burden share only 12%

common variance.

The correlates of objective burden include the presence of other family members to assist with caregiving (r=-.19, p<.05). Subjective burden was significantly related to age (r=-.28). Montgomery et al. conclude that a given family may experience a high level of objective burden (demands) and a low level of subjective burden (stress about caregiving) or vice versa. This is consistent with stress studies and theoretical orientations of stress. Of particular interest to me is that age (as a capability) is an important variable. This finding underscores the need to include capabilites as a variable in measurement of stress. Identification of capabilities may assist in identifying those at risk for negative affect.

Despite the problems identified with the Zarit et al. burden scale, the findings are of interest and are used to provide partial validation for my conceptualization. The researchers using this scale correlate the burden scale with other variables to determine those factors that moderate caregiving burden. Zarit et al. (1980) use correlational analysis between the burden score and the duration of illness, various measures of functioning of the relative, and frequency of family visits. Only the latter is reported to be significantly related to the level of burden (r=-0.48, p<.01). Their interpretation of this finding is that informal support may be an important factor in assisting caregivers who report excessive feelings of burden. Family support is not related to the other variables and from this analysis, they conclude that such factors as severe memory loss and the problems associated with it are distressing to family members, but the coping ability of the caregiver may depend on other supports available to them.

Zarit et al. point out that no information was elicited on the quality of the visits and posit that this information would probably affect the degree of relief. I concur with this statement, as indicated in the development of propositional statements. As the validity of the burden scale and the measurement of support are questioned, I would question the degree of generalization that can be inferred from the results.

Pratt et al. (1985) concentrate on identifying coping strategies that mediate the sense of burden. Their sample consists of 240 caregivers of relatives of institutionalized and noninstitutionalized relatives. It can be assumed from this that caregivers differ in their caretaking function. Correlation procedures are used to examine the relationships between burden and coping strategies. Coping strategies reflect family and social supports, and intrafamily processes commonly used by families in response to difficulties. The measure used to determine coping strategies is the Family Crisis-Oriented Personal Evaluation Scales (F-COPES) designed by McCubbin, Larsen and Olson (1982). Internal coping strategies include reframing, confidence in problem-solving and passivity. External coping strategies include spiritual support, extended family support, support of friends, neighbors and community services. Identified by Pratt et al. as potential mediators of burden are the internal coping strategies used by the caregiver, spiritual support and extended family support. Caregiver burden was not found to be related to the support of friends, neighbors or the use of community services.

Despite the limitations of the burden scale, confidence in family problem-solving is included in correlational analysis. They define problem-solving as a coping strategy. Their definition of problem-solving meets my criterion of a capability as the respondent's confidence in problem-solving is being measured as opposed to the specific action taken. In other words, caregivers who report less burden, feel they are capable of handling problems in caregiving (r=-.18).

The internal coping strategies of reframing (redefining experiences) and passivity (avoidance responses) can be equated with cognitive defense mechanisms and dystonic methodology in the interactional model. These coping strategies correlated in the direction predicted in the interactional model: reframing (r=-.15) and passivity (r=.26). Burden scores are also significantly related to spiritual support (r=-.25) and extended family support (r=-.16). Caregiver burden is not significantly related to calling upon friends (r=.02), neighbors (r=-.07) or to the use of community services (r=.10).

Pratt et al.⁹ did not expect to find that there was no significant relationship between burden and the presence of friends or membership in a support group. They explain this finding by pointing out that the sense of burden may be difficult to abate and the short length of stay may be insufficient to affect moderation of burden. Extending their explanation to incorporate the propositions in the interactional model, the support group or friends may not have been meeting the caregiver's specific needs.

Pratt et al. note that the level of burden is no different between caregivers whose relatives are institutionalized or non-institutionalized. They report that this seems inconsistent with the belief that institutionalization moderates the stress of caregiving. They recognize that burden is subjective and may be influenced by factors other than caregiving functions. This recognition lends support to the interactional model in that to identify the source of burden, researchers should separate the emotional response from the other variables. Separation of these variables may assist in explaining the source of negative affect and assist individuals in planning intervention programs.

The three studies of caregiving burden have been presented to validate my model. To my knowledge, there are no studies that completely separate the emotional response from the demands and coping response. The studies presented to validate the propositional model and the theoretical model validation ~~provide a~~ subjective evaluation of the validity of the model. An objective evaluation can be gained only through empirical research.

# CHAPTER VI

## Conclusions and Recommendations

The purpose of developing a theoretical model was to clarify the concept of burden and to identify the circumstances that may influence variation in burden experienced by elderly caregivers of dependent spouses. Through an analysis of psychological theories of stress, the systems perspective and researchers' operational definitions of burden, the concepts of burden and affect were conceptualized as being synonymous and component parts of the stress process. Through the utilization of assumptions from various theories, a theoretical model was developed and propositions formed.

Through a synthesis of various theories and application of these theories to the context of discussion, I became aware of the unique contributions of each theoretical perspective. It has been posited that researchers and clinical personnel require a sound theoretical foundation for planning and implementation of research and intervention programs. In my view, the complexity of caregiver stress is such that one theoretical framework is insufficient to provide understanding to the required degree. The synthesis of theoretical perspectives enhances the theoretical conceptualization of stress. At the same time, complexity is increased and methodological issues become apparent.

Due to the complexity of the stress process, I have suggested that longitudinal research may be the most appropriate method to rigorously test the ideas in the model. In addition to longitudinal data collection, methodologies are required that reflect the multivariate complexity of the stress process. The design of instrumentation for such procedures is a substantive issue and challenge for future investigation.

The adequacy of the interactional model, to meet the needs of researchers and clinical personnel, cannot be ascertained until specific operational measures have been developed and empirical testing completed. It is my hope that the work on the model will be conceptually refined further and stimulate continued, required research in the area of caregiving within the context of long term care. The future endeavors of researchers in the area will provide objective validation or invalidation of the theoretical model.

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