This is to certify that the

dissertation entitled

Clarifying The Meaning Of Caregiver Burden:
An Examination Of The Relationship Between
Caregiver Burden and Caregiver Well-Being

presented by

Denise Marie Montcalm

has been accepted towards fulfillment
of the requirements for

Ph.D degree in Social Science

Victor L. Whitemore
Major professor

Date 6-28-91

CLARIFYING THE MEANING OF CAREGIVER BURDEN: AN EXAMINATION OF THE RELATIONSHIP BETWEEN CAREGIVER BURDEN AND CAREGIVER WELL-BEING

By

Denise Marie Montcalm

A DISSERTATION

Submitted To
Michigan State University
In Partial Fulfillment Of The Requirements
For The Degree Of

DOCTOR OF PHILOSOPHY

College Of Social Science

1991

ABSTRACT

CLARIFYING THE MEANING OF CAREGIVER BURDEN:
AN EXAMINATION OF THE RELATIONSHIP BETWEEN
CAREGIVER BURDEN AND CAREGIVER WELL-BEING

By

Denise Marie Montcalm

Recognizing the important role being played by families in caring for their aging members, policy makers, interventionists and researchers alike have been striving to better understand the caregiving experience. Early investigative efforts generated information concerning "who" the caregivers are, and "what" tasks they typically complete. These early interactions also promoted an increased appreciation for the toll that can be extracted in providing elder care. As a result, the notion of caregiver burden has come to command a great deal of attention within the gerontological literature.

Attempts to identify caregiver, care receiver, and/or situational factors that might be associated with caregiver burden appear to have been thwarted by a preponderance of inconsistent conceptualizations, and a series of correspondingly non-equivalent operationalizations. Among the questions that have emerged are those which ask whether caregiver burden is a unique construct--or merely a special variant of select alternative constructs such as, morale, depression, or well-being. The relationship between caregiver burden and caregiver well-being is the focus of this study.

First, the relationship between burden and well-being is examined from a variety of theoretical perspectives, including: symbolic interactionism, stress, role, and small group theories. An interactive model of the caregiving experience results.

Subsequently, an empirical examination of the relationship between these two constructs is undertaken. This secondary analysis uses data gathered from a sample of 307 caregivers who participated in the first wave of The Family Care Study. Exploratory factor analyses are used to evaluate the extent to which a measure of Caregiver (Burden) Reactions and a measure of well-being tap the same caregiver outcome constructs.

The data suggest that the conceptual terrain being covered by the burden and well-being instruments are distinct enough to warrant continued efforts to clarify/refine the caregiver burden construct. That is, abandoning the construct seems premature. The topical nature of the items contained within the factors derived prompted an elaboration of the interactive model. A test of the appraisal-oriented theoretical framework which resulted is recommended.

Dedicated

to

my parents

Mary and John Montcalm

ACKNOWLEDGMENTS

I wish to express my sincere gratitude to Dr. Victor Whiteman for the consistent and insightful guidance and support he has provided throughout my graduate program.

I also wish to thank the members of my guidance committee for the hours of discussion and the many helpful suggestions they each provided: Dr. Barbara Ames, Dr. William Faunce, and Dr. Margaret Nielsen.

This research was supported in part by National Institute on Aging Grant #1 R01 AG06584-01; "Caregiver Responses to Managing Elderly Patients at Home". Special thanks is extended to Dr. Charles W. Given and Dr. Barbara A. Given, the grant's primary investigators, for providing--in addition to access to this data--my first exposure to the exciting and creative interchanges that can be fostered by the interdisciplinary research process.

Grateful recognition is extended to Dr. Diane LeVande for the interest and assistance she so generously provided in the conceptualization of this project.

Appreciation is also due Michael Keefe and Dr. Arnold Greenfield for the technical assistance they provided.

I also wish to thank Mary Mareck who has shared my interest in a subject that is special to both of us.

I hold a very special debt of gratitude to Dr. Mary Jane Keller who detected and nurtured my potential as a "scholar" long before I was able to recognize it.

Very special thanks goes to Dr. Margaret Palmiter who blazed the trail of the School of Social Work's "reconstituted" doctoral program. I especially appreciate the friendship that has resulted from our shared experiences.

I also want to thank my sister, Kathy Hetrick, along with her husband, Kent, and son, Scott, for their unyielding caring and support.

I am most grateful to my "ABD Assistant", Johanna S. Hove, for being there for me in good times and bad. Without her ongoing encouragement this project may never have been completed.

TABLE OF CONTENTS

LIST OF TABLES x

LIST OF FIGURES. xii

CHAPTER I. 1

Introduction 1

CHAPTER II 8

Literature Review 8

Background Information 8
Defining Caregiver Burden. 12
Operationalizing Caregiver Burden. 21
Toward The Development Of A Theoretical Framework. 29

A Normative Perspective: Resolving The "Filial Crisis" 30
Generalized Stress Theory 33
Transactional Stress Theories 36
Symbolic Interactionism 40

CHAPTER III. 46

Methodology 46

Developing A Theoretical Framework. 46

Caregiving: An Interactive Process . . 46
Entering The Subjective Side Of Caregiving:
Stryker's Concept Of "Self" 51

Statement Of The Problem 55
Points Of Inquiry. 60
Hypotheses 60
Research Design. 63

TABLE OF CONTENTS (Continued)

The Sample. 63
Instrumentation 66

Caregiver Burden 66
Caregiver Well-Being 67

Analytic Procedures 71

Factor Analysis. 71
Studying The Measures Independently. 72
The "Grand" Analysis 75

CHAPTER IV 77

Findings. 77

The Caregiving (Burden) Inventory: A Nine Factor Model. 77
The Caregiver Well-Being Measure: A Seven Factor Model 82
The Combined Analyses -- An Eleven Factor Event 87

Discussion. 95

Clarifying The Content Of Typical Burden & Well-Being Measures 95
Identifying The Common Conceptual Ground . . 102

CHAPTER V. 112

Conclusions 112

Implications Of The Study. 112
Limitations Of The Study 114
Suggestions For Future Research. 117
Summary: The Importance Of Clarifying The Meaning Of A Word. 119

LIST OF REFERENCES 122

APPENDIX A 132

APPENDIX B 135

APPENDIX C 139

LIST OF TABLES

Table		Page
1	Sociodemographic Data For Spouse And Non-Spouse Caregivers	65
2	"Pressed" Into Service.	78
3	Role-Related Reinforcers.	78
4	Financial Issues.	79
5	Caregiver's Physical Health Status.	79
6	Family Responsiveness	79
7	Scheduling & Social Consequences.	80
8	Caregiver's Self-Appraisal.	81
9	Caregiver-Care Receiver Relationship Issues	81
10	Caregiver's Sense Of Responsibility	82
11	Positive Affect	83
12	Negative Affect (Depression).	84
13	Financial Issues.	84
14	Caregiver's Physical Health Status.	85
15	Social Affirmation.	85
16	Social Support (Mutual Aid, Companionship & Affection	86
17	Feeling Needed.	87
18	Positive Affect	88
19	Role-Related Reinforcers.	88

LIST OF TABLES (Continued)

Table		Page
20	Overall Characteristics of the Two 11 Factor Models.	89
21	Pressed Into Service.	90
22	Caregiver's Sense Of Responsibility	90
23	Financial Issues.	90
24	Social Support.	91
25	Family Responsiveness	91
26	Negative Affect (Depression).	91
27	Caregiver Role Appraisal.	92
28	Caregiver's Physical Health Status.	92
29	Schedule and Social Consequences.	92
30	Caregiver-Care Receiver Relationship Issues .	93
31	Correlation Coefficients For Unweighted Factor Clusters	94

LIST OF FIGURES

Figure		Page
1	The Caregiving Experience: An Interactive Model	48
2	Burden and Well-Being Factors Identified. . .	96
3	The Caregiver Appraisal Process: Cognitively Mediating An Emergent Person-In-Environment Event	99
4	Depicting The Burden & Well-Being Factor Solutions Derived Within The Framework Of The Proposed Appraisal Process.	101
5	Depicting The 11 Factor Composite Solution Within The Framework Of The Proposed Caregiver Appraisal Process	108
6	Potential Variables To Be Included In Testing The Usefulness Of The Proposed Interactive Theoretical Model	116
7	Hypothesized Item Overlapping In Light Of The 9-Factor Burden And 7-Factor Well-Being Solutions Proposed.	141

CHAPTER I

Introduction

Like other industrialized countries, the United States is realizing "unprecedented growth in its elderly population" (Select Committee on Aging, 1987 p.1). In fact, the elderly constitute the fastest growing segment of the population -- with the largest percentage of growth occurring within the upper age categories, i.e., 75-84, 85+ (Cockerham, 1991). Changes in life-style, as well as advances in technology and health care, have fostered significant improvements in the overall health status of our nation's elderly. Nevertheless, advanced age continues to be accompanied by an increased susceptibility to chronic physical, mental, and financial problems which prompt the need for assistance from others (Schick, 1986; Shanas and Sussman, 1981).

Contrary to the myth that persists in this country concerning family abandonment, the critical role of the "family and other informal supports in the care of the frail and chronically ill elderly" (Cantor, 1983, p.597) is well documented in the literature (Shanas, 1979; Stone, Cafferata and Sangl, 1987). Not only are family and friends identified as the primary source of social support, they also "provide between 80 and 90 percent of the medically related care, personal care, household maintenance, transportation and shopping needed by older persons" (Select Committee on Aging,

1987, p.vii; Kaye, 1986; Archbold, 1982). Furthermore, the assistance given by this informal network has been identified as a key variable in preventing inappropriate, not to mention costly, institutionalization (Robinson, 1983; Shanas, 1979; Arling and McAuley, 1983; Zarit, Orr and Zarit, 1985; Stone, et al., 1987).

While the evidence indicates that families have been responsive to the care needs presented by their older members, several demographic trends have been identified as potentially jeopardizing the ongoing availability of intergenerational caregivers. Included among these are the tendencies toward later marriage and smaller families, rising divorce rates, and the increased incidence of women working outside the home (Pett, Caserta, Hutton and Lund, 1988; Brody, 1981; Horowitz, 1985).

Concern regarding the potential implications of these changes for care recipients, as well as their families, has prompted a number of reactions including calls for a more responsive formal service system. What is being sought, specifically, is a service system which offers a "continuum of care" that is able to meet the diverse array of care-receiver needs that exist -- in a way that complements, rather than undercuts, the caregiving capacity of the informal care network. However, a simultaneous emphasis on cost containment has fostered policy decisions (e.g., prospective

insurance payments and restricted Medicare coverage for home health care services) which have severely compromised developments in this regard. The resulting preponderance of programmatic glitches and corresponding service gaps forebodes continued, if not expanded, reliance on the shrinking pool of available family caregivers (Huttman, 1985, pp.25-26,29; Foster-Alter, 1988; Select Committee on Aging, 1987).

Recognizing the importance of this informal service network, policy makers, gerontological practitioners, and researchers alike have been striving to better understand the caregiving experience. Early investigative efforts generated information concerning "who" the caregivers are, and "what" tasks they typically complete. These early interactions also promoted an increased appreciation for the toll being extracted from family, friends, and neighbors involved in the provision of elder care. Examples of the caregiving costs identified through such efforts include: compromised physical and/or emotional health; social isolation; reduced privacy; loss of free time; conflicts associated with the frequently competing roles of parent, spouse, caregiver, and employee; the emergence (or exacerbation) of sibling conflicts; career interruptions; and financial strain (Archbold, 1982; Cantor, 1983; Kosberg and Cairl, 1986; Horowitz and Dobrof, 1982).

Of course, not all caregivers find the experience of caring for an older person burdensome. Quite the contrary,

many have reported that they derive a great deal of "self-satisfaction from the caregiving experience" (Montgomery, Gonyea, and Hooyman, 1985a, p.19; Robinson and Thurnher, 1979; Silliman, Earp, Fletcher and Wagner, 1987). Nonetheless, the emphasis has been on the negative consequences of caregiving. In large part, this focus seems to have resulted from the widely held assumption that the burdens or costs involved in providing such care will "eventually wear down or erode the informal caregiving network" (Select Committee on Aging, 1987, p.24). The concern sparked by this "wear and tear" hypothesis has spawned a series of investigative efforts which have attempted to identify particular care-receiver, caregiver, and/or situational characteristics that may be influencing the occurrence caregiver burden (Townsend, Noelker, Deimling and Bass, 1989, pp. 393-94; Haley and Pardo, 1989).

As the literature discussed below will illustrate, the findings generated by these correlational studies have been equivocal, at best. Faced with a plethora of seemingly contradictory results, the challenge becomes one of ascertaining why.

Those who have addressed this question point to the following factors as possibly accounting for the disparate findings which have been observed: a) the limitations which invariably accompany the use of small, self-selected, non-representative, samples; b) the normally static viewpoint

generated by cross-sectional data; and, c) the lack of conceptual clarity and corresponding inconsistency in measurement that tends to surround the concept of caregiving, as well as its consequences (Blieszner, 1986; Pearson, Verma and Nellett, 1988, Thompson and Doll, 1982; Montgomery, Stull and Borgatta, 1985b).

Among the questions that have emerged in regard to the conceptual and operational aspects of this situation are those which ask whether "caregiver burden" is a unique construct -- or merely a special variant of select alternative constructs such as "morale", "depression", or "well-being" (Montgomery, et al., 1985b, p.150; George and Gwyther, 1986, p.253-254; Becker and Morrissey, p.300). It is the relationship between **caregiver burden** and selected elements of **caregiver well-being** that constitutes the focus of this study.

Specifically, this effort attempts to test George and Gwyther's assertion that caregiver burden and caregiver well-being are simply different sides of the same conceptual coin. As they express it, **"to anticipate caregiver burden...is synonymous with the expectation that caregivers will experience decrements in selected areas of well-being..."** (George and Gwyther, 1986, p.253). While their posited relationship may be intuitively appealing, it has yet to be theoretically grounded or empirically demonstrated.

This project explores the theoretical relationship between **caregiver burden** and **caregiver well-being** by extrapolating from the works of others who have applied stress, role, or small group interaction theories to the definitional and conceptual dilemmas involved. Moreover, by incorporating a symbolic interactionist perspective into the proposed theoretical framework, an attempt is made to illustrate the processes through which phenomena such as caregiver burden and caregiver well-being come to be socially and individually constructed.

The investigator also attempts to assess the degree of conceptual correspondence that exists between these two constructs by systematically comparing the results generated by a measure of Caregiver (Burden) Reactions with those produced by an instrument designed to measure select dimensions of caregiver well-being. In particular, factor analytic strategies are used to evaluate the extent to which these devices reliably measure the same caregiver outcome constructs. Finally, the conceptual dimensions identified through this statistical process are examined in light of the logical patterns, topical themes, and theoretically informative relationships that emerge.

It might be noted that, as a result of the aforementioned efforts to analyze and synthesize a variety of relevant theoretical perspectives, an interactive model of the caregiving

experience was developed (Please see Figure 1, p. 48). This model proved helpful in generating hypotheses regarding the relationships expected to exist between the constructs of "burden" and "well-being". It also facilitated efforts to interpret the rather complex relationships uncovered through the factor analytic studies.

Importantly, though, the model's substantive elements emanated from existing theories **not the empirical data examined** in this study. As a consequence, the data emerging from the analyses of the burden and well-being instruments do not exhibit a direct conceptual correspondence with the theoretical framework that is developed/proposed. The tenuousness of this linkage becomes increasingly apparent as the project unfolds. Among the implications of this conceptual distinctiveness is the fact that the instrument comparison data fails to provide a "test" of the theoretical model. This does not negate, however, the fact that information from both sources can shed light on how the constructs of burden and well-being relate. Nevertheless, the reader will find that the study tends to follow two related, yet independent paths.

CHAPTER II

Literature Review

Background Information

As noted earlier, policy makers, interventionists, and researchers involved in the area of gerontology have become increasingly aware of various demographic and social trends that combine to predict a demand for care that is likely to exceed the supply of available informal caregivers. Given this concern, along with those pertaining to the rising costs of formalized long term care, it is not surprising that the informal care network has commanded a great deal of attention within the gerontological literature.

Many of the studies undertaken to date have been descriptive in nature, addressing such questions as: "Who are the caregivers?", "What tasks do they typically perform?", and so on. Among the findings generated by these investigations is the aforementioned observation that informal care networks, especially families, provide the lion's share of assistance to our elderly population. Furthermore, while caregiving is generally characterized as a "family endeavor which affects all members, one family member is usually identified as **the** [emphasis in original] caregiver" (Archbold, 1982, p.12; Caserta, Lund, Wright and Redburn, 1987).

Despite the fact that these primary caregivers constitute a heterogeneous group, certain patterns have been detected. For example, it has been found that, "in general ...caregivers tend to be female, about 57 years of age, and live in the same household as the care recipient" (Select Committee on Aging, pp.17-18). Furthermore, in comparison to the general population, "caregivers are less likely to be employed, are more likely to be poor...and are more likely to report fair to poor health" (Select Committee on Aging, 1987, p.18).

It also has been learned that there is a hierarchical nature to the caregiving network. That is, older persons tend to turn first to their spouses for help -- then, in declining order, to adult children, other relatives (i.e., siblings, grandchildren, nieces/nephews, etc.), friends, neighbors, and "finally, to the bureaucratic replacements for families ...social workers, ministers, [and] community agencies..." (Shanas, 1979, p.174; Archbold, 1982; Cantor, 1983; Cantor, 1980).

As the litany of caregiving costs presented earlier indicates, these initial investigations also unearthed a good deal of information pertaining to the negative "consequences of family caregiving" (Archbold, 1982, p.13; Cantor, 1983; Robinson and Thurnher, 1979; Deimling, Bass, Townsend, Noelker, 1989). Subsequent concern about the potentially erosive nature of these "costs" prompted a series of studies

on "the problem of 'caregiver burden'" (Stone, et al., 1987, p.1; Montgomery, et al., 1985a; Gubrium and Lynnott, 1987; Poulshock and Deimling, 1984; Pratt, Schmall, Wright, and Cleland, 1985; Pruchno and Resch, 1989). In particular, researchers have sought to identify care-receiver, caregiver, and/or situational factors that correlate with reported feelings of burden (Select Committee on Aging, 1987). As already noted, the findings generated by these correlational studies typically have spawned more questions than answers. A brief discussion of the results of various studies which explored the relationship between select **caregiver characteristics** (i.e., age, health status, financial resources, relationship to caregiver, etc.) **and perceived burden** is offered as a means of illustrating the problem.

Utilizing a sample (N=80) of chore services recipients and their primary caregivers, Montgomery, et al. found "age and income to be the best predictors of subjective burden" (1985a, p.19). Specifically, they found that younger and wealthier caregivers were more likely to feel burdened. Meanwhile, Pratt, et al. (1985) completed a similarly focused study with 240 Alzheimer's patients and their caregivers. In direct contrast to the findings of Montgomery and company, Pratt's group found no significant association between caregivers' age or income and their "subjective sense of burden". In fact, compromised caregiver health status was the only

caregiver characteristic they found to correlate significantly with feelings of burden (Pratt, et al., 1985, p.27)

Interestingly, Cantor's study (1983) of 136 elderly homemaker clients and their informal caregivers appears to simultaneously support and contradict the studies just described. Among other observations, she found spouses to be "the highest risk group among caregivers" for feeling stress and strain -- because of their advanced age, lower incomes and generally poorer health status (Cantor, 1983, pp.600-603).

Such perplexing inconsistencies by no means end here. Similar variations in findings permeate studies which have examined the relationship between **care-receiver characteristics** (e.g., functional capacities, cognitive impairments, etc.) **and burden**, as well as those which have addressed **situational features** (e.g., number of helpers available, care-receiver and caregiver housing arrangements, etc.) **and feelings of burden** (See, for example, Zarit, Reever, Bach-Peterson, 1980; Deimling and Bass, 1986; Pearson, Verma, and Nellett, 1988; Deimling, Bass, Townsend, and Noelker, 1989; Williamson and Schulz, 1990).

There are a number of design factors that are commonly cited as likely accounting for the discrepancies that typify this literature. Included among these are limitations associated with the sampling procedures that typically have

been employed, variations in the analytic strategies which have been involved, and a tendency to rely on cross-sectional designs (Barer and Johnson, 1990; Matthews, 1988; Montgomery, et al, 1985b; Montgomery, 1989).

Increasingly it has been suggested, however, that the confusion described here may be the result of an even more fundamental problem. That is, a large part of this apparent intellectual quagmire may well stem from a preponderance of inadequate conceptualizations and a series of correspondingly inconsistent, non-equivalent, operationalizations (Poulshock and Deimling, 1984; Montgomery, 1989; Stephens and Kinney, 1989; George, 1990).

As already noted, it is precisely the conceptual and operational aspects of the caregiver burden phenomenon that constitute the focus of this effort. At this point, the reader's attention is directed toward the definitional elements of this topic.

Defining Caregiver Burden

Literally, "burden refers to the load borne, the responsibilities carried, or the time and effort required for one person to attend to the needs of another" (Montgomery, et al., 1985b, p.138). Accordingly, any interpersonal assistance that

involves the investment of a person's time, energy, or material goods can be considered, "by definition a burden or cost" (Montgomery, et al., 1985b, p.141). It is interesting to note that portrayed in this fashion burden, itself, appears to be a rather neutral phenomenon.

Conceptualizing caregiver burden as the investments or "costs" associated with the provision of informal, interpersonal assistance, however, is not terribly informative. Typically gerontologists have responded to this definitional ambiguity by delineating the costs involved in categorical terms. Stone, Cafferata, and Sangl, for example, define burden as "the social, emotional, and financial costs associated with the caregiving experience" (1987, pp.1-2). In a similar vein, George and Gwyther depict caregiver burden as "the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (1986, p.253). Despite their clarifying intent, however, such definitions also lack specificity. Unfortunately, their meaning is even further obscured by the tendency for gerontologists to use the term "caregiver burden" interchangeably with phrases like: "caregiver strain", "the consequences of caregiving", "caregiver stress, problems, ...adverse effects", and so on (Montgomery, et al., 1985a, p.20).

The negative tenor conveyed by these alternate descriptors (i.e., "caregiver stress", "problems", "strain", and "adverse effects") seems to reflect what Montgomery, Stull, and Borgatta describe as the "social problem approach" (1985b, p.138) that has typified responses to the caregiving phenomenon. According to this perspective, the outcomes associated with caregiving are automatically presumed to be bad. Given this assumption, the primary agenda logically becomes one of carefully examining the costs or burdens involved "...so that they can be prevented or controlled, and their consequences mitigated" (Montgomery, et al., 1985b, p.138).

Although the "applied" focus of the social problem perspective typically fosters the development of very useful descriptive data, the atheoretical nature of the approach tends to limit its capacity to link the key variables uncovered in any systematic way (Montgomery, 1985b, pp. 138, 141). Perhaps this explains why many of the caregiver studies undertaken thus far have been able to produce important insights regarding such topics as **the typical caregiver**, the composition of **the caregiving network**, and **the kinds of tasks generally undertaken** by caregivers, while descriptions of the variables involved in producing such "averages" yield results which seem to beg further explanation. Why is it, for example, that the financial, social, physical, and emotional toll experienced by caregivers can vary so dramatically, even when similar care-receiver, caregiver, and/or situational

circumstances are involved? As later discussions will exemplify, researchers are beginning to reexamine the inconsistent patterns being detected from a variety of theoretical perspectives.

According to the social problem perspective, then, caregiver burden is by no means a neutral phenomenon, but a formidable opponent that needs to be reckoned with. Characterized in this fashion, it is no wonder that reactive, problem solving perspectives, such as the one reflected in the earlier noted "wear and tear" hypothesis, have dominated the research agenda to date.

It is also important to point out that when caregiver burden is cast in terms of a social problem, the focus subtly shifts from the caregiving investments or "load borne" aspects of the equation, to the negative outcomes associated with having assumed such responsibilities. As a result, the lines between process, and product, cause and effect, become increasingly blurred (Montgomery, 1985b). Does caregiver burden, by definition, refer simply to the process of undertaking certain care providing responsibilities? Or, do the investments of time, energy, and material goods involved in the provision of such care cause subsequent burdens to emerge? As will become evident shortly, questions like these are not easily resolved. Moreover, the pertinent dimensions involved in the dilemma do not seem to end here.

Specifically, by characterizing burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative", Zarit, Todd, and Zarit (1986, p.261) introduce yet another way of conceptualizing caregiver burden. Like proponents of the social problem perspective, Zarit, et al, focus on the negative consequences of providing care. However, their emphasis is clearly on the caregiver's subjective perception that the caregiving interchange is accountable for specific types of discomforting outcomes (Zarit, et al., 1980). Thus, in contrast to the views depicted above, caregiver burden is <u>not necessarily</u> perceived as an unavoidable, negative, consequence of providing care, nor is it characterized as a definitionally determined construct. Rather, Zarit and company portray caregiver burden as the product of a specific, subjective interpretive process.

Interestingly, the objective/subjective categorical division has been used by several researchers in an effort to clarify components of the caregiver burden construct. Montgomery, Gonyea, and Hooyman (1985a) were among the first to conceptually and operationally define caregiver burden in terms of its objective and subjective dimensions. Specifically, drawing from the literature on families caring for "mentally ill kin", Montgomery, et al., defined subjective burden as "the caregiver's attitudes toward or emotional reactions to the caregiving experience" (1985a, p.21). In contrast,

objective burden "was defined as the extent of disruptions or changes in various aspects of the caregiver's life and household" (Montgomery, et al., 1985a, p.21). In support of the conceptual independence they had posited, Montgomery and company's subsequent investigations found subjective and objective burden to display distinct sets of correlates (1985a, p.22). In particular, they found age and income to be related to subjective burden; whereas, tasks which "temporally or geographically [confine the caregiver surfaced as] the best predictors of objective burden" (Montgomery, et al., 1985a, p.19).

It is important to note that merely dividing burden into its objective and subjective components has not proved to solve the definitional dilemma described here. Unfortunately, the vague manner in which objective and subjective burden have been defined has allowed "a potpourri of items [to be] subsumed within each category" (Poulshock and Deimling, 1984, p.230). Consequently, the level of conceptual and operational continuity that exists between studies employing these constructs tends to vary considerably.

In the face of such definitional ambiguity, it is not surprising that the theoretical relationship between objective and subjective burden has been portrayed in different, if not inconsistent, ways. As already noted, Montgomery, et al., depict objective and subjective burden in relatively

independent terms with "only modest correlations between the two aspects of burden" being detected (Stephens and Kinney, 1989, p.41). Even greater conceptual independence was reported by Cox, Parsons, and Kimboko, as they found "no significant relationship...between perceived burden and objective burden" (1988, p.433) in their study of 54 inter-generational caregivers.

According to the analytic model developed by Poulshock and Deimling, however, objective and subjective burden are by no means independent. In fact, subjective burden is portrayed as "the mediating force" that exists between the care receivers' presenting needs and the observable "impact" (read: objective burden) caregiving subsequently exerts on various aspects of a caregiver's life -- including areas such as: "family relationships, social activities, health, or employment changes" (Poulshock and Deimling, 1984, p.231). Observing that not all caregivers respond to similar tasks or patient behaviors in the same way, Poulshock and Deimling assert that variations in the type and intensity of objective burden exhibited are indicative of each caregiver's "highly personal and individualized response" (1984, p. 231) to the challenges presented by the care providing situation.

In direct contrast to Poulshock and Deimling, Stull cites a series of analyses involving structural equation models to support his contention that "objective burden *causes* [emphasis

in original] subjective burden" (1989, p.2). Specifically, the data generated through Stull's analytic efforts suggest that it is the physical, social, financial, and time investments involved, which determine the caregiver's subjective assessments of the care receiver and the demands he/she poses, as well as the quality of the care receiver-caregiver relationship (1989, pp.1-3).

As Gubrium and Lynott (1987) note, a body of literature also exists where objective burden is defined in terms of the care receiver's presenting level of impairment. According to this viewpoint, the objective facts pertaining to the care receiver's level of impairment are not only conceptually separate from the caregiver's response to the care providing situation but, "are hypothesized to have a causal impact, usually negative, on the caregiver's feelings and perceptions" (Gubrium and Lynott, 1987, p. 268).

Proponents of this perspective also distinguish the impact of the care receiver's impairment on the caregiver's subjective response from "the impairment's impact on the caregiver's quality of life", (Gubrium and Lynott, 1987, p. 274), i.e., sleep difficulties, social isolation, etc. Thus, this conceptual scheme posits independent causal linkages between: 1) **objective** and subjective or **felt burden**; and, 2) **objective** burden and the way caregiving impacts on various indices of the **caregiver's quality of life**.

In contrast to the two dimensional, subjective/objective portrayal presented above, several researchers have found caregiver burden to exhibit a multidimensional character when applying select statistical (factor analyses) and/or measurement (multiple measures) strategies to studies of the phenomenon. Deimling and Bass (1986), by way of example, discerned a number of interesting correlational patterns when employing four measures of "caregiver stress effects" -- two of which were drawn from a factor analysis of items contained within a caregiver burden scale. Included among the latter were: a) "negative changes in elder, caregiver, and family relationships", and b) "restrictions in caregivers' activities resulting from caregiving" (Deimling and Bass, 1986, p.781). A single item asking about negative changes in the caregiver's health status and the Zung Depression Scale constituted the other two measures.

While the care-receiver's "level of impairment" correlated with all four measures of stress, the amount of variance explained in the area of elder, caregiver and family relationships was significantly greater than that accounted for in the other three areas (Deimling and Bass, 1986). Given this result, Deimling and Bass concluded that "future research would benefit by conceptualizing...caregiver stress effects as a multidimensional construct" (1986, p.784).

In a similarly focused study Pearson, Verma, and Nellett found caregiver burden -- as measured by Greene's factor analytically derived, 20 item, Relative's Stress Scale -- and "caregiver's distress regarding discrepancies between patient abilities and behaviors" to exhibit similar, yet unique, relationships to various measures of "patient functional status" (1988, pp.81-82). Like Deimling and Bass, Pearson, et al., closed by underscoring "the need for further refinement of the dimensions of caregiver burden" (1988, p.82).

To summarize briefly, **caregiver burden** has been conceptually, or nominally, defined by gerontological investigators in rather imprecise terms. Despite the lack of agreement that exists concerning the conceptual components believed to be encompassed under the rubric of caregiver burden, a growing appreciation for the complexity of the phenomenon, nevertheless, has emerged. In instances like these where conceptual definitions are vague, at best, a review of the operational definitions that typically have been employed can help clarify the meanings that have come to be associated with the construct of interest (LeVande and Montcalm, 1988).

Operationalizing Caregiver Burden

Researchers have attempted to operationalize this conceptually illusive phenomenon by drawing upon insights emanating

from such diverse sources as "open-ended interviews" (Robinson, 1983, p.344), "clinical experience" (Zarit, et al., 1980, p.651), and, the observations of colleagues (Greene, Smith, Gardiner, and Timbury, 1982). The resulting operational formats have consisted of everything from a series of open-ended single item questions (Cantor, 1983) to fairly complex, multi-item instruments such as, Robinson's (1983) "Caregiver Strain Index"; Greene, Smith, Gardiner and Timbury's (1982) "Relatives Stress Scale"; and Zarit's (1980) "Caregiver Burden Interview".

Perhaps more germane to this analysis are the content variations which seem to abound. While an elaborate item analysis is beyond the scope of this particular discussion, a comparative review of instruments typically used to measure caregiver burden does seem warranted.

It might be noted that all of the instruments targeted here contain items designed to measure the social, psychological, fiscal, and physical dimensions commonly referenced in conceptual definitions of caregiver burden. At least in this regard, then, the instruments appear to cover comparable conceptual domains. The question that quickly surfaces is: Do these instruments tap the same conceptual dimensions equally? Said differently, are they equivalent measures of caregiver burden?

Greene, et al.'s (1982, p.123) "Relative's Stress Scale"

1. Is your sleep disrupted by _____?	Never (0)	Always (4)
2. Has your health suffered at all?	Not at all (0)	Quite a lot (4)

Although the identified indicants are by no means mutually exclusive, they still seem to possess a degree of conceptual independence. After all, a caregiver conceivably could experience difficulties in any one area without perceiving the others as problematic. For example, a caregiver could find the tasks of lifting and turning the care-receiver to be quite taxing, yet, those demands might not be viewed as threatening the caregiver's overall health nor disruptive of his/her sleep. Therefore, on the face of it, it seems these instruments may be tapping distinctive aspects of the physical component of caregiver burden.

Not unexpectedly, the variations observed among these instruments are even greater in domains that typically exhibit less definitional consensus (i.e., the psychological and social arenas). Robinson (1983, p.345), for instance, while not appearing to address caregivers' perceptions of the caregiver-care receiver relationship directly, does include two questions which ask how upsetting caregivers find select care receiver personality changes (e.g., appear not to be themselves) and behaviors (e.g., incontinence, verbal

To begin addressing this question it may be helpful to consider how the "physical" dimension of caregiver burden is typically operationalized. The physical domain was selected for illustrative purposes because it is generally viewed as a rather straightforward, commonly understood concept. However, as the questionnaire items cited below demonstrate, each of these researchers perceived the physical demands posed by caregiving in somewhat unique terms (i.e., lifting, concentrated efforts, sleep disruption, health status decline).

OPERATIONALIZING THE "PHYSICAL" DIMENSION OF CAREGIVER BURDEN

J. M. Zarit's (1980, p.651) " Caregiver Burden Interview"

1. I feel my health has suffered because of my involvement with _____.	Not at all (1)	Extremely (4)

Robinson's (1983, p.345) "Caregiver Strain Index"

1. It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)	Yes (1)	No (0)
2. Sleep is disrupted (e.g., because _____ is in and out of bed or wanders around at night)	Yes (1)	No (0)

hostility). Zarit (1980, p.651), in contrast, uses eight separate items to measure caregivers' perceptions of their interactions with care receivers. Specifically, Zarit asks whether caregivers find the caregiving interchange to engender feelings of guilt, anger, depression, resentment, usefulness, pleasure, or strain.

In their review of "eight different procedures for assessing caregiving stress", Stephens and Kinney (1989, p.42) also found several inequalities to exist in regard to instrument format, as well as measurement quality, and content. In terms of content, for example, they found three instruments to focus on care-receiver characteristics as the sole source of potential caregiver burden/stress/strain. In contrast, the remaining five instruments were found to broaden the range of potential stressors by incorporating situational factors -- e.g., "the amount of understanding received from family and friends about caregiving" (Stephens and Kinney, 1989, pp.50, 47,48) -- into the assessment process.

Stephens and Kinney (1989) also cited the differential use of time frames as another dimension of instrument variance. Coming from a "transactional stress" perspective, these researchers maintain that data regarding recent events serve as better predictors of caregiver burden/stress/strain than more distant occurrences (Stephens and Kinney, 1989). In conducting their review, they found three instances where "no

time anchor [was] specified for any of the items" employed. Several other instruments contained items that asked the respondent to address the question in relation to the time "since caregiving began" (Stephens and Kinney, 1989, pp.49-50). Still others asked the respondent to think about select items in terms of more finite time intervals such as, the past week or the previous month.

With respect to measurement quality, Stephens and Kinney (1989) found reliability data to be available for all but two of the eight instruments reviewed. Test-retest reliability was evaluated in three instances, with subscale coefficients ranging from .56 to .85. Similar variability was observed among the measures of internal consistency available for five of the eight targeted instruments. The specific reliability coefficients obtained in this regard ranged from a rather modest rating of .60 to a more substantial one of .92. (Stephens and Kinney, 1989, p.45).

Interestingly, information concerning construct validity was available for seven of the eight instruments examined. Unfortunately, however, it is not possible to assess the relative adequacy of these particular caregiving stress instruments because "different researchers have validated their measures against different criteria" (Stephens and Kinney, 1989, p.51). Consequently, while a number of significant validity coefficients have been reported by scale

developers within, for example, the affective or emotional domain, the value of these findings has been compromised by the fact that the comparisons undertaken involved such varied constructs as: depression, hostility, anxiety, distress, morale, positive affect, psychiatric symptoms, etc. (Stephens and Kinney, 1989, pp.43-45).

Given this circumstance, it is not surprising that questions concerning the conceptual equivalence of current caregiver burden measures continue to abound. Furthermore, given the uniform lack of information concerning the discriminant validity of the instruments involved, it is no wonder that Stephens and Kinney, (1989) Montgomery, Borgatta, and Stull (1985), George and Gwyther (1986) and others have begun raising questions about the conceptual distinctiveness that likely exists among the constructs of caregiver burden, depression, morale, and well-being. Clearly, this is a topic which shall be revisited throughout the course of this effort.

Another generic issue pertaining to the operationalization of caregiver burden is the concern that has emerged regarding the sensitivity level of the instruments which have been developed. Specifically, it is not uncommon for researchers to observe that caregivers tend to report low levels of burden on self-report measures (Zarit, et al., 1980; Pearson, et al., 1988). Recent efforts to examine this response pattern reveal that caregivers typically express

"high levels of stress during screening interview[s] but, ...lower amounts on self-report instruments..." (Zarit and Toseland, 1989, p.481; Toseland and Rossiter, 1989). In a recent study of depression among family caregivers, Gallagher et al., likewise discovered "significant underreporting of affective symptoms by caregivers when assessed by a self-report inventory compared to results of personal interview" (Zarit and Toseland, 1989, p.481; Gallagher, Rose, Rivera, Lovett, and Thompson, 1989).

Recognizing the "floor effects" that can accompany such reporting biases (i.e., "participants with a low initial score have little room for improvement"), Zarit and Toseland have suggested "broadening the range of responses possible for individual items in a scale" (1989, p.481). Doing so could reverse the score compression phenomenon that seems to occur with the 2, 3, and 5-point Likert scales currently employed. Said differently, broadening the range of responses could make it possible for the typical instrument to discriminate more precisely between different levels of caregiver stress/strain/burden (Zarit and Toseland, 1989).

In summary, the diversity that characterizes the conceptual portrayals of caregiver burden appears to be mirrored in the operationalizations that have evolved. As a result, gerontologists find themselves continuing to grapple with the challenge of distinguishing what, if any, aspects of

the caregiver burden phenomenon are conceptually unique and which specific dimensions are being tapped by a given instrument. It appears that resolution of this quandary will require the introduction of relevant theoretical models that prove capable of providing the analytic framework necessary to interpret the caregiving response patterns being detected.

Toward The Development Of A Theoretical Framework

While the ambiguity that surrounds the construct of caregiver burden can be viewed as impeding the prompt resolution of the caregiving challenges noted earlier, it is perhaps more useful at this juncture to consider this conceptual entanglement as having alerted caregivers, interventionists, researchers, and policy makers to the complexity of the phenomenon involved. From this vantage point, it becomes increasingly apparent that future efforts to refine definitions, as well as measures, of caregiver burden will depend on the availability of theoretical models that are capable of accommodating the diverse, dynamic nature of the caregiving experience (Montgomery, et al, 1985b). Responses to this challenge have begun to emerge. In the pages that follow, a number of these contributions are summarized and a preliminary plan for integrating the key elements of these theoretical views is proffered.

A Normative Perspective: Resolving The "Filial Crisis"

Recognizing the pervasive involvement of family caregivers in the long-term-care network, it is not surprising that early attempts to "explain" the diversity of responses engendered by the caregiving experience tended to recast the issue as a family affair. In particular, those subscribing to this perspective attempted to depict the dilemmas associated with intergenerational caregiving as one of the normal developmental tasks to be encountered during mid-life. Blenkner characterized this task as "the filial crisis"; that is, that point when "parents can no longer be looked at as the rock of support in times of emotional trouble or economic stress but may themselves need their offsprings' comfort and support" (Blenkner, 1965, referenced in Silverstone, 1979). According to this viewpoint, successful resolution of the filial crisis is attained when the adult child is able "to accept their parents' aging and to fulfill their needs for help and support" (Cicirelli, 1983, p.41; Silverstone, 1979; Brody, 1979) in ways that are compatible with their own needs, resources and capacities. At such a point, "filial maturity" is allegedly achieved.

As Silverstone notes, "implicit in the concept of filial maturity is the concept of filial responsibility -- a notion that we have a duty to the older generation to be there for them in their years of decline and need" (1979, pp.108). Above and beyond the debates that have ensued regarding the

primacy of attachment versus obligation as the potential motivating factor in caregiving relationships, the usefulness of characterizing caregiver burden as an unresolved "filial crisis" seems questionable. Not only is there a good deal of uncertainty regarding current societal expectations about responsible caregiving, but explanations that begin with an assumed set of normative motivations seem to obscure the fact that individual caregivers do not interpret or subscribe to accepted societal norms with equal vigor.

Empirical support for the latter was presented in a 1988 study completed by Finley, Roberts and Banahan. Among other findings these researchers found that their respondents' sense of filial obligation varied according to a number of individual and social factors, including: gender of the adult child, parent type (mother, father, mother-in-law, father-in-law), residential distance between parent and adult child, as well as the differential involvement of role conflicts pertaining to employment, social obligations and other family responsibilities (Finley, et al., pp.76-77).

Other writers have criticized studies which rely on the notion of filial responsibility as the key element in their explanatory scheme on somewhat different grounds. Specifically, they argue that, at best, such studies can be viewed as "documenting a norm about intergenerational relations which reflects the cultural paradigm of 'togetherness' while, at the

same time pinpointing a barely researched set of conditions where the norm may not apply" (Jarrett, 1985, p.6).

Discussing the implications of such a practice from a clinician's perspective, Jarrett argues that the widely held "set of Norman Rockwell idealizations about family ties, including some specific to the aging", belies the reality of many individuals' lives. In her estimation, societal attempts to impose a norm of family closeness where it does not exist, creates a situation where "a caregiver's lack of affection for a care-receiver" cannot help but promote a feeling of strain (Jarrett, 1985, p.7). In her words, "the problem...is that they see their caregiving behavior as self-defeating -- whatever they do or contemplate reminds them of what they should feel but do not" (Jarrett, 1985, p.9). As one caregiver expressed the dilemma: "I know that love doesn't conquer all, but if I loved her I'd feel better about myself" (Jarrett, 1985, p.8).

Jarrett's concern about the dangers of reifying societal norms was echoed recently by Gratton and Wilson in their discussion of family support systems and the minority elderly. As they observed, numerous studies of family assistance networks have identified "high attachment to filial responsibility norms...[and] greater respect and vibrant family relations" as the primary factors which account for the "extraordinary readiness of [Black and Hispanic] extended

families to assist..." (Gratton and Wilson, 1988, p.84) their aged members. Upon closer inspection of the literature describing these interactions, however, Gratton and Wilson found evidence of other factors like, care-receiver health status (as opposed to "cultural familism") determining the caregiving activities being undertaken by minority kinship networks (1988, p.86). Given this finding, Gratton and Wilson cautioned policy makers and interventionists to not overestimate the assistive capacity of the minority family because of a potentially erroneous assumption that filial norms somehow prepare minority families to "bear special burdens" (1988, p.87).

This is not to say that gerontologists should ignore cultural factors that may be influencing patterns of family caregiving. The above-noted example, however, underscores the importance of carefully examining not only the potential origins, but the ongoing utility of observed interaction patterns.

Generalized Stress Theory

Stress theory is an alternative explanation that has emerged to account for the diversity in caregiver responses that has been observed. According to this formulation, stress is viewed "as the individual's response to events in the environment...[and]...is taken as a precursor to, or instrument of, dysfunctional adaptation and disease" (Rice,

1988, p.40). In particular, it is believed that such stress reactions occur when accumulated stress starts to exceed the individual's innate level of tolerance; that is, when the individual is no longer able to adapt (Rice, 1988, p.40).

Given this portrayal, it is not surprising that proponents of stimulus-response oriented stress theories have focused their energies on identifying "those enduring problems that have the potential" (Robinson, 1983, p. 344) for evoking stress. Interestingly, there appears to be a striking similarity between this perspective and the "wear and tear hypothesis" mentioned earlier.

Romeis argues that by focusing "on the caregiver's ability or inability to adjust to the stressor", such perspectives fail to capture

> how caregiver strain (1)seriously affects some caregivers but not others in similar social situations, (2)develops over time, (3)is the product of dynamic social processes, and (4)can be abstracted to have analytical meanings that are tied to society (1989, pp. 189-90).

Therefore, in an attempt to imbue the construct with the breadth and flexibility felt necessary, Romeis redefined caregiver strain "as a bio-psycho-social reaction of a primary caregiver resulting from an imbalance of care receiver demands (CR-d) relative to caregiver resources (CG-r)" (1989, pp.191-192). Superficially the demand-resource equation proffered by Romeis seems very similar to the stimulus-response paradigm

presented above. However, the linear direction suggested by the stimulus-response format is significantly softened by casting the relationship between **demands and resources** as one of **balance.** Ever so subtly, the interdependence and changeable nature of these factors becomes emphasized. In turn, it is imbalance--its origin, magnitude, duration, and impact--that becomes the research agenda of import.

Among the challenges posed by the demand-resource dilemma is the task of discerning how the ratio between the two variables actually becomes calculated. According to Romeis, this evaluative process will remain illusive until there is an "...understanding [of] how the caregiver interprets the demands of the elder and how the caregiver organizes and selects from the available resources" (1989, p.193). While Romeis' definitional scheme does not provide a theoretical basis for addressing this issue, he does offer a way of approaching the phenomenon empirically. In particular, he suggests employing a series of longitudinal designs that would enable researchers to monitor changes in the care-providing demands presented, as well as the caregivers' capacities to identify, access, and utilize available resources (Romeis, 1989, p.199).

In several respects the definitional effort of Romeis seems to echo the early model-building work of Montgomery, Stull, and Borgatta (1985b). Specifically, these writers were

among the first to characterize the caregiving experience as an interactive event that occurs between a caregiver and a care receiver within the context of a larger "social field" (Montgomery, et al., 1985b, pp.143-46). In so doing they, too, found it necessary to abandon the traditional, linear descriptions of caregiving. Ultimately, by drawing upon rather generalized notions of small group, as well as role theorists, Montgomery, et al., produced a conceptual model that appears capable of reflecting the interactive, processual nature of caregiving endeavors (1985b, pp.148-149). Additional details of the model will be articulated later in this discussion, when the potential utility of the device is illustrated.

Transactional Stress Theories

An even greater emphasis on the interactive nature of caregiving is apparent in the writings of Stephens, Kinney, Deimling, Bass, Poulshock, and others who subscribe to what have been labeled "transactional" models of stress. Grounded in Lazarus and Folkman's "cognitive theory of psychological stress and coping", transactional perspectives view the person and environment "...as being in a dynamic, mutually reciprocal, bidirectional relationship" (Folkman, Lazarus, Gruen, and DeLongis, 1986, p.572). Stress, according to this conceptual scheme, is a "particular relationship between a person and the environment that is appraised by that person as taxing or

exceeding his or her resources and therefore threatening well-being" (Stephens and Kinney, 1989, p.40; Folkman, et al., 1986).

As the title implies, the processes of cognitive appraisal and coping constitute the active ingredients in this formulation. Cognitive appraisal encompasses two steps. The first involves determining if a "particular encounter with the environment" is relevant to the individual's "well-being and, if so, in what way" (Folkman, et al., 1986, p.572). Secondly, a determination is made concerning what, if anything, one can do to neutralize, if not profit from, the situation (Folkman, et al., 1986, p.572). In contrast, coping refers to the cognitive, behavioral and emotional activities that one undertakes "to manage the internal and external demands of the person-environment transaction that [has been] appraised as taxing or exceeding a person's resources" (Folkman, et al., 1986, p.572).

As Stephens and Kinney (1989) point out, one advantage of the transactional approaches is that they enable the researcher to analytically separate the cognitive appraisal process from the bio-psycho-social responses subsequently exhibited. It would appear that doing so is advantageous to the extent that the division "permits a better understanding of the intricate cognitive processes that intervene between the more objective caregiving events and caregivers' psycho-social

adaptation to these events" (Stephens and Kinney, 1989, p.41). The danger in dividing the process in this way is that one may find oneself left with a series of components that differ so dramatically from the reality they intend to portray that the usefulness of the exercise becomes compromised (Lazarus, 1982).

Although their terms are different, the key elements of the theoretical model developed by Poulshock and Deimling parallel those of the transactional theorists. In their scheme, Poulshock and Deimling (1984) define caregiver burden as the subjective interpretations caregivers assign to the problems that flow from the caregiving circumstance--most notably: the elder's impairment (See also: Stephens and Kinney, 1989). In other words, a caregiver's level of burden is synonymous with how problematic he/she sees the caregiving context.

Among the critical outcomes of this mediational process is the **impact** that caregiving subsequently exerts on various aspects of the caregiver's life (e.g., family relationships, health status, social ties). In making this distinction, these writers also try to separate the interpretive, or filtering process from its associated effects. More generally, Poulshock and Deimling's (1989) analytic framework involving the **caregiving context**, **burden**, and **impact** can be viewed as essentially mirroring the **potential stressor**, **appraisal**, and

coping sequence that characterizes the transactional models of stress (Stephens and Kinney, 1989).

In a 1986 study of the relative impact of symptoms associated with various cognitive/emotional impairments, Deimling and Bass attempted to augment their explanatory framework with select elements of a symbolic interactionist perspective. Specifically, citing the symbolic interactionist's assertions regarding the connections between ascribed social meanings, interpersonal expectations, and assessments of legitimacy, Deimling and Bass argued that symptoms which are expected to accompany the aging process will be more readily accepted and, hence, less likely to be perceived negatively (Deimling and Bass, 1986, p.779).

Although the specific conclusions Deimling and Bass were able to draw from the study were quite modest, they did find evidence that expectations regarding illness-related decreases in functioning seemed to render their occurrence more palatable (1986, p.783). Perhaps more important is the fact that their attempt to include this theoretical framework in their analysis sparked this author's interest in examining further how symbolic interactionism might inform efforts to understand the subjective, interpretive process that seems so critical to the caregiving interchange. It is to the explication of the basic tenets of this theoretical framework that this effort now turns.

Symbolic Interactionism

One need not dig deeply into the relevant literature to discover the rich and varied intellectual heritage of what has come to be known as "symbolic interactionism". Those thought to be "the most influential of the early interactionists" (i.e., Charles Horton Cooley, George Herbert Mead, and William I. Thomas) are said to have drawn their perspectives from such varied sources as: the Scottish Moralists, including, Adam Smith, David Hume, and Adam Fergeson; the American Pragmatists, most notably, William James, John Dewey, and Charles Pierce; the behaviorist, John B. Watson; the evolutionist, Charles Darwin; as well as, the German Idealists, e.g., Johann Fichte, Immanual Kant, and Friedrich von Schelling (Meltzer, Petras and Reynolds, 1978, p.45; Manis and Meltzer, 1978, p.2; Turner and Beeghley, 1981; Stryker, 1981).

Given the diversity of these intellectual antecedents, it is no wonder that the ideas espoused by these "founding fathers" fail to produce a single, coherent, theoretical view. It is also not surprising that theorists who have subsequently attempted to build on this foundation--Blumer, Kuhn, Turner, and McCall, to name a few--have, likewise, varied in the interpretations and theoretical formulations they have offered. As a result, many have concluded that "there is no single, symbolic interactionism whose tenets command universal acceptance..." (Stryker, 1981, p.15). Despite the internal variation that continues to characterize the content of

symbolic interactionism, there is "a core set of theoretical assumptions and concepts which most, if not all, working within the framework accept and use..." (Stryker, 1981, p.3).

Central to the perspective of symbolic interactionism is "the recognition that human beings do not typically respond directly to stimuli", but to the **meanings** they ascribe to that stimuli (Manis and Meltzer, 1978, p.6). In other words, people interpret or define stimuli and then act on the basis of those interpretations. As Blumer describes it, "this mediation is equivalent to inserting a process of interpretation between the stimulus and response in the case of human behavior" (Blumer, 1969, p.79).

According to the symbolic interactionists, the meanings employed in this mediational process "are socially derived from interaction with others, rather than inherent in the stimuli themselves or idiosyncratically assigned by the individual" (Manis and Meltzer, 1978, p.6). What enables human beings to share meanings is, of course, their capacity to use symbols, most notably language. In this conceptual scheme, a symbol is defined as "a gesture that is understood by the sender as well as the receiver" (Lauer and Handel, 1983, p.29).

Among other functions, symbols serve as cues that enable people "to predict their own and others' behavior" and,

therefore, "anticipate the future of a course of an interaction" (Stryker, 1980, p.37). This capacity to "read" others on the basis of symbolic cues--to designate their position and thus, see the situation from their point of view--is oftentimes referred to as "taking the role of the other" or "role taking", i.e., empathy (Turner and Beeghley, 1981, p.471).

Symbols also make it possible to view one's self as an object or, as Stryker suggests: "objectively" (1980, p.37). It is this capacity that symbolic interactionists see as enabling people to direct their own behavior. From this perspective, then, human behavior becomes characterized as "an elaborate process of interpreting, choosing, and rejecting possible lines of interaction" (Manis and Meltzer, 1978, p.8). Said differently, conduct is perceived as being constructed, not merely released, during the course of an interaction.

The symbolic interactionists characterize society as "consisting of people in interaction" (Blumer, 1969, p.83). This processual conceptualization intentionally contrasts with the more conventional, generally static, portrayals of society as social structure, collective representation, and so forth (Manis and Meltzer, 1978, pp.6-7). In essence, social organization is perceived as a framework in which interacting units develop there interactions, however, it is not considered to be the cause or "determinant of that action" (Blumer, 1969, p.87).

There appears to be a significant level of disagreement among symbolic interactionists regarding the degree to which this framework is likely to shape interaction. Nonetheless, they do appear to agree that patterned regularities surrounding interactions are significant to the degree that they affect "the probabilities of particular kinds of persons coming into contact in particular kinds of settings, and in affecting the probabilities that interaction will take on particular form and content" (Stryker, 1980, pp.66, 69).

Implied in several of the preceding discussions is the symbolic interactionists' assumption that "human beings are active in shaping their own behavior" (Manis and Meltzer, 1978, p.7). Critical to this proposition is the earlier noted capacity of people to use symbols to interpret rather than simply react to stimuli. This coupled with an assumed capacity to engage in internal conversation or thought, renders the individual "capable of forming new meanings or new lines of action" (Manis and Meltzer, 1978, pp.7-8).

This is not to suggest that previous experiences and situational factors do not influence an individual's interpretations of stimuli and resulting actions; rather, it introduces the notion that, once socialized, an individual possesses the ability to create alternative responses that are not entirely determined by situational factors or antecedent events. Manis and Meltzer refer to this as a form of "soft

determinism" (1978, p.8). In the interactionists' view, it is this capacity to change interaction patterns that enables people to alter the social structure in which they are enmeshed (Stryker, 1980, p.48). Significantly, what emerges is the symbolic interactionists' assumption concerning the existence of a reciprocal relationship between the individual and society via the medium of interaction (Hewitt, 1984; Stryker, 1980).

The last general item to be presented here is the symbolic interactionists' assumption that "an understanding of human conduct requires study of the actors' covert behavior" (Manis and Meltzer, 1978, pp.8-9). The foundation for this methodological principle is the perception that behavior is emergent rather than mechanistic. The specific rationale is--if conduct is indeed mediated by the interpretations/meanings employed by the actors involved, then it becomes essential to see the world from their point of view if an understanding of their behavior is to be attained (Manis and Meltzer, 1978; Stryker, 1978).

It is this undeniable focus on the subjective that has caused many researchers to discount the value of this theoretical perspective. As will become evident momentarily, several symbolic interactionists have attempted to include the objective aspects of interaction by incorporating various aspects of role theory into their formulations.

Admittedly, the general tenets of symbolic interactionism do not provide the potential user with the theoretical tools required to explain human behavior. What they do seem to offer is a perspective, a way of looking at the social world, if you will. Not unlike transactional stress theory, it is a view that emphasizes the dynamically emergent quality of social life. In the next chapter, consideration is given to how the basic principles associated with this perspective might be expanded upon and integrated with pertinent aspects of other noted theories into a revised conceptualization of the caregiving experience.

CHAPTER III

Methodology

Developing A Theoretical Framework

Caregiving: An Interactive Process

To facilitate the synthesizing of relevant theoretical views into a meaningful conceptual framework, the model presented in Figure 1 (Please see page 48) was developed. As the title suggests, the model depicts informal caregiving as an interactive entity.

Extrapolating from the earlier noted model-building work of Montgomery, et al. (1985b), Section A emphasizes the fact that caregiving occurs in the context of a relationship. A relationship that evolves between at least two people--a care receiver and a caregiver. Significantly, it is by characterizing the relationship as a series of caregiving events that the emergent nature of the phenomenon is stressed.

In addition, by stressing the evolutionary character of this relationship, the model accentuates the limits inherent in cross-sectional portrayals that capture but a slice of this unfolding process. As Montgomery, Borgatta, and Stull (1985b) observe, such a fluid presentation lends itself much more readily to questions concerning the processes involved, as opposed to the traditional tendency to fixate on aspects of

the relationship that can be discerned at a given point in time. By way of example, rather than looking at "Length of Caregiving" as a summary variable, an alternate way of asking about this aspect of the relationship might be "Has the caregiving changed?", "If so, in what ways?" (Montgomery, et al., 1985b, p.149-150).

In instances where caregiving changes have been detected, the model encourages consideration of antecedent events and how they were "mediated through the current cross-section of identifiable variables" (Montgomery, et al., 1985b, p.150). Said differently, the paradigm signifies a type of "causal inference model" that prompts consideration of "current concomitant conditions" as these affect the relationships between relevant predictor variables and their posited consequences. In so doing, the model not only emphasizes the temporal aspects of the phenomenon, but fosters an awareness of the theoretical distinctiveness of the variables involved, as well (Montgomery, et al., 1985b, p.150).

Notably, the specific connections between the interactants and potential situational/contextual factors of import remain undefined during phases A and B. They are included within the boundaries of the portrayals, however, in an attempt to underscore the fact that interpersonal interchanges do not occur in a vacuum.

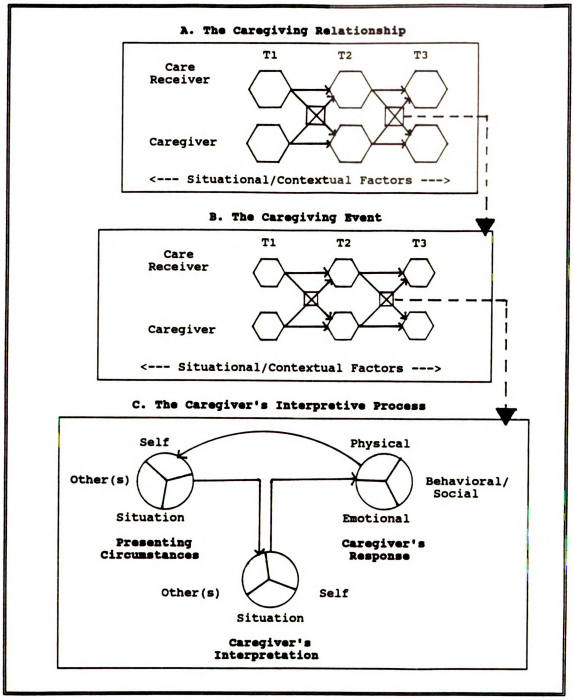

Figure 1 THE CAREGIVING EXPERIENCE: AN INTERACTIVE MODEL -- A Series Of Nested Interchanges

Expectations regarding what likely happens within Section A's boxed-in points of intersection are explicated further in Section B, entitled: "The Caregiving Event". In particular, this portrayal of "The Caregiving Event" suggests that, just as "The Caregiving Relationship" evolves over a series of caregiving interchanges, each "Caregiving Event" consists of a sequence of symbolic interactions; that is, a series of interchanges in which words and gestures are exchanged among the participants. As is the case in **The Caregiving Relationship** (Figure 1, Section A), the boxed-in points of intersection signify **the interactions** which together form **The Caregiving Event** (Figure 1, Section B). Identical portrayals of **The Caregiving Event** and **The Caregiving Relationship** were used to convey this notion of a nested series of interchanges.

A key element of this symbolic exchange is the interpretive process that is undertaken by each of the participants. Section C depicts this evaluative process from the vantage point of the caregiver. In many respects, "The Caregiver's Interpretive Process", as depicted in Section C, illustrates Blumer's description of human behavior as essentially "inserting a process of interpretation between the stimulus and the response..." (1969, p.79). It might be noted that such a perspective is not unlike Lazarus and Folkman's notion of cognitive appraisal, nor is it significantly different from Poulshock and Deimling's concept of mediation.

It is during the interpretive phase of this interactive process that the caregiver ascribes meaning to the care receiver (and other key parties) involved, the situational factors presented, and the "self" the caregiver has brought to the event. In identifying significant characteristics of the care receiver, for example, the caregiver will likely take note of the care receiver's overall level of functioning. In turn, these data may be translated into current care receiver needs. Conclusions about key others might include an assessment of their capacity to provide assistance, or perhaps support. Situational factors of import might include items like the geographical proximity of the caregiver to the care receiver, the availability of assistive devices (i.e., lifts or handrails), and so forth. The evaluation of self might well encompass an assessment of one's ability to address the caregiving demands presented--either independently, or by marshalling the resources of others.

The tentativeness surrounding these various evaluative remarks reflects the fact that, despite widespread agreement concerning the occurrence and significance of covert symbolic exchanges, there is a strong lack of agreement regarding the substance and format of these "internal conversations" or "thoughts". In large part, the dispute seems to be reflective of the differences which exist concerning the structure of the "self"; for example: Mead's "I" - "Me", Turner's "ideal self" - "real self", and, Stryker's "hierarchy of identities".

An elaboration of Stryker's model is provided to illustrate more specifically how current developments occurring within symbolic interactionism may ultimately facilitate a more thorough understanding of the caregiving experience.

Entering The Subjective Side Of Caregiving: Stryker's Concept Of "SELF"

In brief, Stryker's identity theory posits that a self which emanates from a "complex and differentiated" society must itself be "complex and differentiated" (Stryker, 1980, p.59). Yet, just as society exhibits a degree of orderliness (e.g., patterned interactions) so does the self. The major elements of this conceptual scheme include: "identity (or role identity), identity salience, and commitment" (Stryker, 1980, pp.60-61).

Structurally Stryker (1980 and 1982) perceives the self as being composed of a number of discrete parts, which he refers to as "identities". These identities, signify the positions one holds within organized social structures. In that positions carry shared expectations regarding behavior, they are equivalent to the conventional notion of role. Hence, the alternative referent: role identity.

Within the self, these identities are organized according to a hierarchy of salience. Stryker defined salience as

the likelihood "of a given identity being invoked...in either a variety of situations..." (1982, p.203) or a selected one. The idea of ranking identities probabilistically is not unique. As Hoelter remarks, the concept "has its roots in James' notion of multiple selves and the varying degree of value placed in each" (1983, p.140). More recently, "the relative importance of identities for self-definition has been approached using various labels including identity prominence, role-person merger [and the] psychological centrality of self components..." (Hoelter, 1983, pp. 140-141).

It is important to note that while Stryker sees the process of naming, or positionally designating oneself, as equivalent to internalizing the social expectations which accompany that role, he does not perceive behavior to be determined by these meanings. He sees social meanings as constraining but not controlling. Following the "role making" idea put forth by Turner, Stryker maintains that "people do not simply take roles; rather, they take an active, creative orientation to their roles" (Ritzer, 1983, p.183) He does, however, acknowledge that "some social structures permit less creativity than others" and thus, "limit the degree to which roles are 'made' rather than 'taken'" (Ritzer, 1983, p.183).

Commitment refers to the degree to which "one's relationships to specific others depend on being a particular kind of person" (Stryker, 1980, p.61). One's level of commitment,

then, "is measured by the 'costs' of giving up meaningful relationships" (Hoelter, 1983, p.141). Stryker conceptualizes commitment in two dimensions: 1) the depth or intensity of the relationships involved; and, 2) the sheer number or "extensivity" of the connections associated with a given identity (Stryker, 1982, p.204).

In offering this specification of the concept of self, Stryker has laid the ground work for exploring further the complex and likely reciprocal "relationship between identity (self) and behavior" (Stryker, 1981, p.24; Burke and Reitzes, 1981, p.83). The key proposition Stryker offers with regard to these variables "is that commitment affects identity salience which, in turn, affects behavioral choices" (Stryker, 1981, p.24). Like the transactional stress model, Stryker's perspective fosters a conceptual distinction between the subjective appraisals that a caregiver makes concerning his/her caregiver identity and the behavioral, social, physical and emotional responses that follow. It also underscores the importance of the social context within which the role unfolds.

With regard to the latter, Hoelter maintains that while "commitment to a role [and, by extension a social network] might be central to understanding the process of self-definition," (1983, p.141) it must be tempered by performance and subsequent evaluation of the role in question. Building

on Rosenberg's notion of self-enhancement, Hoelter posits that the salience of an identity will be positively influenced to the extent that activities and attributes associated with it enable the individual "to think well" of him/herself (1983, p.141).

Considering both Stryker's and Hoelter's observations, a more complete understanding of the self-defining aspects of the caregiver's interpretive process might be achieved if, in addition to the questions posed earlier, data were collected on items such as: a) the size of the helping network; b) the intensity of the caregiver's attachment to the care-receiver, as well as other individuals comprising the helping network; and, c) the caregiver's perception of the quality of his/her performance. With respect to the last item, an indication of the content and frequency of evaluative remarks heard by the caregiver concerning his/her performance would be germane.

Tallied together, such evaluative information would appear to provide a sense of the caregiver's overall assessment of the presenting care-providing circumstances. Incorporating Romeis' formula regarding the care-receiver demand/ caregiver resource ratio, it seems logical to assert that **the caregiver will feel burdened to the extent that he/she perceives the care-receiver's needs as outstripping available resources.**

The theoretical views presented by Stryker and Romeis complement the interactive theoretical framework presented here by attempting to unravel the mysteries of the subjective domain. Despite the insights they offer, much remains unknown about the relationship between one's interpretations of a given caregiving event and the bio-psycho-social responses subsequently engendered.

Among the questions that persist are those concerning the conceptual ties between caregiver burden and caregiver well-being. In the following section, this dilemma is reconsidered in light of the theoretical model presented above.

Statement Of The Problem

The confusion that has come to characterize the conceptual and operational definitions of caregiver burden has not only compromised attempts to understand and ameliorate the phenomenon, it also has prompted its usefulness as a unique construct to be called into question. Given the inconsistent data that have emanated from empirically directed studies, it seems wise to begin examining the entity with an eye toward the theoretical domain. This project attempts to accomplish this by examining the relationship between indices of caregiver burden and caregiver well-being from the vantage point of the interactive theoretical model described in the previous section.

In order to articulate the specific problem of interest here, it is necessary to return to George and Gwyther's assertions concerning the relationship between these constructs. Specifically, characterizing **caregiver burden** as "the physical, psychological or emotional, social, and financial problems..." that can accompany caring for an impaired older family member and, **caregiver well-being** as "physical health, mental health, social participation and financial resources...", George and Gwyther concluded that the two constructs "are but opposite sides of the same coin" (1986, p.253).

Given the particular definitions chosen, there is a distinctively logical appeal to the conceptual congruence George and Gwyther proffer. This is not to suggest that their definitional choices are somehow peculiar. Quite the contrary, as previous discussions indicate, it is not uncommon to define caregiver burden in terms of the "costs" associated with the caregiving experience. Likewise, there is substantial precedence within the literature on well-being to define the construct "in terms of adjustment within specified domains of a person's life..." (Larson, 1978, p.110) --including areas such as: physical health, socioeconomic status, social connectedness, and emotional health (See for example Andrews and Withey, 1976, pp.11-12; George, 1981, p.357-358). These characterizations, however, introduce restrictions which must be explicated before the nature of the relationship between these two terms can begin to be unravelled.

First, by focusing on the biological, psychological and social consequences of caregiving, George and Gwyther appear to completely by-pass the interpretive process undertaken by the caregiver. If, as has been posited, burden is indeed a function of the caregiver's evaluation of the presenting caregiving circumstances, the implications of this oversight become obvious.

Secondly, it becomes crucial to note that the concept of well-being sports as many, if not more, definitional and operational variants as burden. As Lawton laments, "one emerges from this literature...with bewilderment over the variety of constructs that fall easily into [the] category..." of psychological well-being (1982, p.617). There are, by way of example, substantially diverse views regarding the degree of conceptual correspondence that exists among typical characterizations of "global" well-being, such as: positive affect, life satisfaction, psychological distress, morale, and happiness, to name a few (Lawton, 1982, pp.621-623; George, 1981, pp.351-353; Veit and Ware, 1983, p.741). There also is considerable debate over the relationship between these global indicators and more "domain specific measures...e.g., 'your work' 'your family life'...", etc. (George, 1981, 356). While predictable relationships between "life concerns" (i.e., domains/values) and global psychological well-being are typically uncovered (Andrews and Withey, 1976), the evidence

does not suggest that one necessarily serves as an adequate proxy for the other.

George and Bearon wisely advise that until this relationship is better understood, "the choice of a global or domain-specific measurement approach should be guided..." (1980, p.42) by the study question, as well as, the theoretical considerations involved (See also, George, 1979, 215). In this instance, George and Gwyther's focus on select domain-specific dimensions of well-being seems to reflect their decision to cast "burden" in terms of the impact caregiving can exert on one's physical, mental, fiscal, and social status. Again, viewed from this vantage point, the conceptual overlap posited by George and Gwyther seems quite logical--if not definitionally imposed.

In practice, unfortunately, the delimited focus of their "burden" and "well-being" constructs tends to be easily obscured. The prevailing tendency to describe, define, and measure these constructs in rather imprecise terms seems to be partially responsible for this. In addition, however, George and Gwyther (1986) seem to have clouded the issue themselves by including Bradburn's Affect Balance Scale (1969) among their operationalizations of caregiver mental health. Consequently, it is not surprising that those who have followed their practice of substituting generic well-being indicators for traditional measures of burden, also have followed their

example of using conceptually mixed (global and domain specific) operationalizations of mental health (See, for example, Noelker, Deimling and Bass, 1989, p.396).

The precise discriminations suggested by a careful reading of George and Gwyther's initial arguments seem to have become blurred. In turn, the logic of burden being subsumed under the conceptual umbrella of well-being has become increasingly precarious. Consider, for example, Montgomery's recent critique of the matter:

> "While it is plausible ...that there is an inverse relationship between well-being and caregiver burden, it does not follow that this relationship is one of unity...[after all,] many factors and situations...other than caregiving...can influence well-being" (1989, p.208).

By concurrently referring to the literature that points to "...health, income, and social support as predictors of well-being", Montgomery (1989, p.208), alludes to the fact that she has interpreted well-being in much more global terms than the dimensional (i.e., domain specific) approach originally described by George and Gwyther. Otherwise her arguments become tautological. Montgomery's suggestion that this conceptual quandary could benefit from further empirical investigation (1989, p.208-209) is well taken. In fact, it is precisely to such an endeavor that our focus now turns.

Points of Inquiry

The relationship between caregiver burden and caregiver well-being is a rather complex one indeed. Clearly it varies with, among other things, the definitions and measures involved. Consequently, in considering the degree of conceptual correspondence that exists between these two concepts, one of the key questions that surfaced was:

Exactly what dimensions of caregiver burden and caregiver well-being are tapped by typical measures of these constructs?

In light of George and Gwyther's assertions, another critical question became:

To what extent do typical measures of caregiver burden and caregiver well-being tap the same underlying constructs?

Hypotheses

In separating the caregiver's cognitive evaluations of the caregiving experience from his/her emotional, social and biological reactions, the theoretical framework presented here prompts one to question George and Gwyther's assertion that burden and well-being are synonymous. Acting on the assumption that the measures selected would adequately tap the

various dimensions of caregiving believed to be critical to an interactive perspective, it was hypothesized that:

Systematic analyses of responses obtained to items contained within a caregiver burden instrument and an "instrument" of caregiver well-being would reveal **The greatest amount of overlap to occur between burden and well-being items that measure the caregivers' bio-psycho-social responses to caregiving.**

In part, the conceptual overlap predicted here reflects the anticipated presence of the "definitional confound" that seems to be highlighted in the work of George and Gwyther. Such a phenomenon occurs when predictor and criterion measures contain items which lack conceptual independence. In evaluating the problem with respect to caregiver stress/strain/burden, Stephens and Kinney caution that, "predicting social functioning (or morale or somatic health) from stress measures that contain elements of that domain could produce spuriously high associations between stress and outcomes" (Stephens and Kinney, 1989, p.51).

It was also hypothesized that:

There would be less overlap between burden items that address the caregivers' appraisals of the caregiving circumstance and burden/well-being items designed to tap the caregivers' bio-psycho-social responses to the event.

It was expected that the amount of overlap uncovered in this regard would reflect the degree to which items within the well-being measure contained elements of cognitive appraisal. The evaluative nature of well-being items like the one addressing income adequacy would be relevant here (i.e., "Do you feel that your total income for 1986 was enough to meet your usual monthly expenses and bills?"). The more subtle evaluative focus suggested by questions concerning the availability of and/or caregiver satisfaction with the amount of social support received--would also apply. As this hypothesis suggests, it was anticipated that well-being items of this nature would likely load with appraisal-oriented burden items, such as: "My financial resources are adequate to pay for things that are required for caregiving."; "My family understands how difficult caring is for me.", and so forth.

Finally, it was believed that:

The least amount of overlap would occur between well-being items which tap the "global" aspects of the construct and burden or well-being items that focus on more situation/domain-specific phenomena.

For example, despite their shared focus on "enjoyment", the situationally focused burden item "I enjoy caring for ___." was not expected to load with the more globally directed well-being item that asked: "During the past month how much of the time have you enjoyed life?".

Research Design

In order to address the questions that have been posed concerning typical measures of caregiver burden and caregiver well-being, **a secondary analysis of the data set generated by the initial wave of the Family Care Study--conducted by Michigan State University's College of Nursing and College of Human Medicine, Department of Family Practice--was undertaken.** This data set was selected because of the conceptual comprehensiveness that characterizes the burden and well-being measures the researchers chose to incorporate in their study.

The Sample

The sample employed consisted of 307, self-selected, primary caregivers who lived in the Midwest at the time of the original study. The researchers recruited participants by networking with over 250 community agencies and groups who helped in locating individuals who were providing family members with in-home care. Specific recruitment strategies involved an innovative "card back system" and an extensive public relations effort, e.g., press releases, television interviews, and organizational newsletters (Given, C., 1989, p.2; Stommel, M., Given, C., and Given, B., Undated). The card back system essentially entailed providing potential participants with information about the study along with a post card to return if they were interested in hearing more about and/or participating in the Caregiver project.

To be eligible for inclusion in the study, care-receivers "had to be at least 64 years of age" and dependent "in at least one Activity of Daily Living or Instrumental Activity of Daily Living" (Ogle, K., Stommel, M., Given, C., and Given, B., Undated, p.7). In addition, the caregiver had to be a family member of the care receiver "and self acknowledged as the primary caregiver for that person" (Ogle, et al., Undated, p.7). The key sociodemographic characteristics of the sample are presented in Table 1 which is located on page 66.

In comparison to the national profile presented by Stone, et al. (1987), this sample consists of rather seasoned caregivers who have maintained "relatively good health" (Given, 1989, p.2). Such uniqueness was not viewed as posing any particular analytic problem, however, as "representativeness" is not as important as item-response variance in investigative efforts of this nature (Comrey ,1973, p.202).

Table 1
Sociodemographic Data For Spouse & Non-Spouse Caregivers

	Spouse Caregivers		Non-Spouse Caregivers	
	Number	Percent	Number	Percent
Subsample Size	159	52%	148	48%
Gender				
Females	120	75%	137	93%
Males	39	25%	11	7%
Race				
Caucasian	151	95%	132	89%
Black	7	4%	15	10%
Marital Status				
Single			25	17%
Married			82	55%
Widowed			20	14%
Separated			2	1%
Missing			19	13%
Overall Health				
Excellent	20	11%	28	19%
Good	84	53%	91	61%
Fair	47	30%	26	18%
Poor	8	5%	3	2%
Employed				
Yes	14	9%	62	42%
No	145	91%	86	58%
Mean Age	69 Years		53 Years	
Mean Duration Of Caregiving	5.58 Years		5.08 Years	

Data Adapted From Given, 1989, Table 1

Instrumentation

Caregiver Burden

If a test of the conceptual correspondence between the constructs of caregiver burden and well-being is to be meaningful to gerontologists, the measures employed in such an analysis need to be reflective of the genre of instruments currently in use. The caregiver burden measure developed for the Family Care Study certainly meets this criterion. In particular, the measure successfully incorporates the "core set of perceived impacts and/or reactions" that have come to be associated with "the processes and situations of caregiving" (Stommel, et al., Undated, p.10). What emerges is a multi-dimensional conceptualization that encompasses subjective and objective, as well as positive and negative reactions to the caregiving experience.

The instrument's developmental process began with an extensive literature review and a series of in-depth caregiver interviews which produced an initial pool of 111 items. These questions were administered to a pilot sample of 99 caregivers who were providing in-home care for family members experiencing physical and/or cognitive difficulties. In turn, the data "were submitted to a confirmatory factor analysis ...and the item pool was reduced to 77 statements representing 9 dimensions of caregiving" (Given, 1989, p.3; Stommel, et al., Undated).

Subsequently, these 77 items were administered to two independent samples, one involving the 307 caregivers of patients with physical impairments being studied here, and the other was made up of 120 caregivers of patients with Alzheimer's disease. Independent confirmatory factor analyses were then conducted which resulted in the identification of six factors, with 35 items loading identically in both samples. (Given, C., Given, B., Stommel, M., Collins, C. and King, S., Undated, p.2).

While the 35-item, six factor burden instrument has exhibited good psychometric properties (Given, C., et al., Undated), a decision was made to capitalize on the more diverse conceptual terrain made available by the 77 item version of the caregiver burden questionnaire. The specific goal was to increase the likelihood of tapping the significant dimensions of this effort's interactive model of caregiving. Items encompassed within that instrument can be located in Appendix A.

Caregiver Well-Being

As Larson's article, entitled, "Thirty Years of Research on the Subjective Well-Being of Older Americans" (1978) suggests, the concept of psychological well-being is no stranger to the gerontological literature. As noted earlier, there is a degree of uncertainty regarding what the construct actually entails. It is, however, generally assumed that

indicators of well-being should tap the following dimensions: "...positive affect, negative affect, happiness, and generalized life satisfaction" (Lawton, 1982, p.623).

In addition to the elements denoted above, operationalizations of subjective well-being often encompass an indication of one's "perceived quality of life" (Lawton, 1982, p.623). That is, some measure (or constellation of measures) that conveys the "set of evaluations a person makes about each major domain of [his/her] current life" (Lawton, 1982, p.623). Little definitive information exists concerning "the number and identity of such domains" (Lawton, 1983, p.65). Nevertheless, "good health, an adequate income, and social interaction have been associated with a sense of well-being about one's life" (Given, B., Given, C., Ellis, B. and Stommel, M., Undated, p.12). The similarities between this portrayal of subjective well-being and the definition of well-being provided by George and Gwyther are noteworthy.

In an effort to capture the multi-dimensional aspects of this construct, several items from the various measures contained in the Family Care Study's data set were brought together to form a **caregiver well-being** "instrument". These items are presented in their entirety in APPENDIX B.

Briefly, this measure consists of items designed to tap

1. The Caregiver's **Physical Health**, including:
   a) Self-rated health;
   b) Number of days sick (past 3 months);
   c) Changes in health (past 3 months); and,
   d) Three indicators of health care service utilization: 1) # of doctor visits,
      2) # of emergency room/urgent care clinic visits,
      3) # of days hospitalized.

2. The Caregiver's **Financial Status**
   --as reflected by:

   a) Level of income; and,
   b) Adequacy of income.

3. The Caregiver's **Mental Health**
   --as assessed by the following multi-item indexes:

   a) Rand Corporation's Positive Well-Being Scale;

[It might be noted that this instrument has been tested on nationwide samples of varying sociodemographic compositions. The factor analytic studies employed by Veit and Ware yielded support for a hierarchical model of mental health consisting of two higher order constructs (psychological distress and well-being) and 5 subscales, i.e., anxiety, depression, loss of emotional control, general positive affect and emotional ties (Veit, C. and Ware, J., 1983, 730, 748, 741; Ware, J., Davies-Avery, A., and Brook, R., 1980; Ware, J., Johnston, S., Davies-Avery, A., and Brook, R., 1979). The 10 items comprising the positive mental health scale used here specifically

"tap the extent to which people are happy, satisfied, and pleased with their personal lives" (Given, B., et al, Undated, p.13).]

and, b) The Center For Epidemiological Studies Depression Scale (CES-D)

[CES-D is an instrument which was designed specifically to measure "the degree of depressive symptoms in the population at large" (Hertzog, 1989, p.284; Radloff, L., 1977, p.385). Significantly, Radloff's initial validation studies and "subsequent work by Aeneshensel suggest that there may be 4 factors contained in the CES-D: (depressive) Affect, (lack of) Well-Being, Somatic Symptoms...and Interpersonal Problems" (Hertzog, 1989, p.284). Again, information pertaining to the alpha, mean, and standard deviation obtained for wave 1 of the Family Care Study can be found in Appendix B.]

and finally,

4. The Caregiver's Level of **Social Participation** --as measured by a modified version of Russell and Cutrona's (1984) Social Provisions Scale.

[The format employed here encompasses 18 of the 24 items contained within the original measure. Although data concerning the psychometric properties of this particular version is lacking, recent studies have revealed the instrument on which it is based to be a "reliable and valid measure of social support" (Cutrona and Russell, 1987, p.39).]

Analytic Procedures

Factor Analysis

It is not uncommon for social scientists to disagree on the meaning and structure of the complex variables that tend to spark investigative interest. Any movement beyond this state of uncertainty, however, requires continual examination of "what is related to what and how" (Comrey, 1973, p.1). Factor analysis emerges as one means of beginning to confront this challenge. Among other contributions, the strategy can be used to investigate what items or "measures belong together --which one's virtually measure the same thing...and how much they do so" (Kerlinger, 1989, p.569).

Specifically, factor analysis provides a means of reducing "a set of intercorrelated responses to a smaller set of unobserved 'factors' which presumably give rise to the observed data" (Rossi, Wright, and Anderson, 1983, pp.270-271). It accomplishes this by considering each item a variable and then computing a matrix of correlations among them. These interrelationships, in turn, are analyzed "in such a way that [they] can be described adequately by a group of categories called factors." (Rossi, et al., 1983, 270-271). These analytic dimensions are then defined according to the researcher's evaluation regarding what the items loading on a particular factor share, and how this group of indicants differs from the other factors that have been identified (Kim

and Mueller, 1978, p.56). It is in this way that the empirical data are imbued with theoretical meaning.

In addition to this data reduction function, factor analysis has been used by social scientists as a means of analyzing and refining their measures (Comrey, 1973, pp.242-243). Exploratory factor analysis, in particular, has proven to be a useful mechanism for "dimensionalizing" an array of conceptually diverse domains (Lawton, 1982, p.621). When meaningful thematic clusters are identified they provide the researcher with a rich conceptual backdrop against which to check "the meaning of a particular variable or variables" (Kim and Mueller, 1978a, p.10). It is precisely its value as a heuristic device that prompted the selection of factor analysis for this study.

Studying The Measures Independently

After reviewing pertinent descriptive data for the items incorporated in the study (i.e., frequency counts, measures of central tendency, and measures of dispersion), each instrument underwent a series of independent exploratory factor analyses. The purpose of this step was to determine what dimensions of caregiver burden and caregiver well-being were actually being tapped by the measures selected.

Following the advice of Kim and Mueller (1978a), initial decisions concerning data input formats, factor extraction methods, missing variables, and rotational solutions were made in accordance with the default options contained within the computerized statistical package used, i.e., SPSS, Version 4.0 (Kim and Mueller, 1978a, p.60). It should be noted that nothing occurred during the course of the investigation to warrant a change in the data input method used (i.e., correlation matrix). Likewise, pairwise deletion of missing cases, (i.e., the practice of retaining "cases with complete data on each pair of variables correlated" -- Norusis, 1988, p.151) proved to be a most satisfactory approach.

Although maximum likelihood and alpha extraction methods were tried at various points throughout the analyses, the principal components (default option) alternative was found to consistently produce superior results. That is, the solutions generated through the principal components method typically "explained" more of the variance in the matrices than the other strategies tried. Also, the solutions produced through this extraction method appeared to be slightly clearer -- conceptually.

Ultimately the default-directed orthogonal rotation method (Varimax) was set aside in favor of an oblique (Direct Oblimin) approach. This decision was based on both conceptual and logistical grounds. Given the substance of the factors

that were consistently emerging (e.g., caregiver health status, caregiver financial status, social affirmation, etc.) there were no grounds to assume that they would not be related (i.e., orthogonal). Corroborative evidence for this assertion emanated from the correlation matrices which exhibited a great deal of inter-item relatedness. In addition, solutions produced with the oblique rotation method appeared to most closely approximate the ideal of "simple factor structure" (Kim and Mueller, 1978b, pp.30-32).

A development which plagued these analyses was the on-going presence of an "ill-conditioned matrix" warning. This characteristic is parallel to the problem of multicollinearity in regression analysis (Hull and Nie, 1981, p.293). In this instance the message signifies "global instability" within the matrix; a condition which means that even minor changes in the items' values (e.g., rounding) can cause dramatic fluctuations in the resulting factor loadings (A. Greenfield, personal communication, April 3, 1991). To alleviate the problem it was necessary to systematically eliminate several items due to the apparent magnitude of their relatedness with other items in the study.

Determining the number of factors to be extracted proved to be an interesting challenge, as well. As Comrey suggests, determining when to stop extracting factors, that is, deciding when "the remaining factors are too small to be retained, is

somewhat like trying to decide how short someone must be to be called short" (Comrey, 1978, p.101). Several indicators were used to guide decisions made in this regard. The scree patterns often provided clues as to where meaningful cut-off points may be for the different data sets. Simple structure was another cue. Ultimately, however, factors were retained when substantive meaning was found to be shared by 3 or more variables loading at an absolute value of .300 or higher. There were two exceptions to this acceptance formula: the well-being health and financial status clusters. These factors were retained with only 2 items because of their conceptual clarity and the valuable role they have played historically in caregiving research.

The "Grand" Analysis

Once factor solutions had been derived for the caregiver burden and well-being measures, a series of factor analyses involving the remaining items of both instruments was undertaken. The purpose of these analyses, of course, was to determine the degree to which these two measures are in fact tapping the same conceptual domains. Again, employing SPSS, Version 4.0, a principal components extraction method with oblique rotation was used to achieve what was believed to be the most conceptually meaningful and statistically sound solution.

It might be noted that the factor solutions derived through the initial (independent) analyses were used to make predictions regarding the number of factors expected to emerge in the composite analysis (Please see Appendix C). This approach, however, was quickly abandoned due to the number of uninterpretable factors produced by this prescriptive procedure. A return to the exploratory format ensued. The factor solutions which emanated from these efforts are described in Chapter IV.

CHAPTER IV

Findings

The Caregiving (Burden) Inventory: A Nine Factor Model

Exploratory factor analyses of the caregiver burden measure resulted in a solution consisting of 9 conceptually meaningful factors. Forty of the seventy-seven Caregiving Inventory items were retained in this nine factor model, which explained 58% of the variance in the matrix. A test of inter-item consistency produced an overall alpha of .82.

A description of these nine factors can be found in Tables 2 through 10 below. Specific information concerning the variables which form each factor, along with their respective factor loadings has been included. In presenting these data, remarks regarding the themes detected and the factor titles selected were interjected where appropriate. It might be noted that although no attempt to scale these factors was undertaken, reliability tests (Cronbach's alpha) were computed in an attempt to gain an indication of scaling potential.

The items which form the factor presented in Table 2 join together to convey a sense of having become entrapped in the caregiver role. The social pressure suggested here seems to go beyond a perception of being picked or even drafted for

Table 2
Pressed Into Service

Variable	Description	Loading
Burd48	Family made me the caregiver	.801
Burd12	Make me feel it's my job	.666
Burd55	Feel I was forced into caring	.603
Burd20	Care because I have to	.596
Burd6	No where else to go	.436
5 items		alpha .75

this role, hence the title **"Pressed Into Service"**. Pearlin, et al.'s (1990) notion of "role captivity" conveys a similar message.

Table 3
Role-Related Reinforcers

Variable	Description	Loading
Burd5	Feeling needed important	-.666
Burd25	Enjoy caregiving	-.591
Burd35	Pleased when __ remembers me	-.412
Burd74	Expected an easier time	-.395
4 items		alpha .65

As evident in Table 3, the top loading items comprising the **Role-Related Reinforcers** factor clearly speak to the potential positive aspects of providing care. Keeping in mind that items are scored in a negative direction, "expectations of an easier time" can be seen as fitting in, thematically, with <u>not</u> enjoying the caregiving experience and <u>not</u> feeling good about others remembering things that we find special.

The items composing the **Financial Issues** (Table 4) and **Caregiver's Physical Health Status** (Table 5) factors seem to reflect their respective labels rather directly. Consequently no additional comments seem warranted.

Table 4
Financial Issues

Variable	Description	Loading
Burd3	Financial resources adequate	.814
Burd38	Worried about money	.704
Burd23	Can afford home health care	.688
Burd16	Family strained financially	.677
4 items		alpha .74

Table 5
Caregiver's Physical Health Status

Variable	Description	Loading
Burd14	Healthy enough	.697
Burd36	Health has declined since CG	.613
Burd29	Takes all my strength	.525
3 items		alpha .75

Table 6
Family Responsiveness

Variable	Description	Loading
Burd51	Family understands	-.789
Burd69	Family admires me	-.626
Burd2	Family works together	-.613
Burd41	Family left me alone	-.504
Burd30	Wish family would understand	-.475
5 items		alpha .71

The items in Table 6 portray a variety of positive as well as negative responses that can be offered by a caregiver's family members. Because of the balanced characterization conveyed by this constellation of questions, it seemed appropriate to use a more neutral label than those historically used to describe the impact other family members can exert on caregivers e.g., Given's "Family Abandonment" (1989) scale, Pearlin, et al.'s (1990) "Family Conflict" measure.

Table 7
Scheduling & Social Consequences

Variable	Description	Loading
Burd4	Daily schedule changes a lot	.762
Burd46	Visit family & friends less	.730
Burd39	Social activities unaffected	.688
Burd18	Activities/work interrupted	.624
Burd11	Activities center around CG	.602
Burd52	Friendships are the same	.525
6 items		alpha .79

At first glance the items contained within the **Scheduling and Social Consequences** factor may appear to be rather odd bedfellows. Closer inspection, however, reveals a common theme: time. Caregiving can be confining and/or unpredictable in its demands. In either case, a typical response involves adjusting one's schedule and/or altering discretionary activities. These are the precise issues being tapped by this factor.

Table 8
Caregiver's Self-Appraisal

Variable	Description	Loading
Burd53	I care better	.718
Burd40	I'm doing a good job	.686
Burd47	I'm best suited	.655
Burd71	I've done all one can expect	.603
4 items		alpha .65

Outside of Lawton's materials on "Caregiving Mastery" (1989), the focus of the items presented in Table 8 seems to be a rather unique one amidst the caregiver burden literature. Thus, its appearance--while certainly welcomed, given the theoretical framework informing this effort--was somewhat surprising. Thematically, the items address the caregiver's assessment of his/her role performance, as well as the role fit felt to exist. **Caregiver's Self-Appraisal** was the phrase selected to reflect these different dimensions.

Table 9
Caregiver-Care Receiver Relationship Issues

Variable	Description	Loading
Burd13	Embarrassed by __'s behavior	-.656
Burd54	__ can't tell past/present	-.651
Burd44	__ sometimes disrupts meals	-.583
Burd72	__ really appreciates me	-.560
Burd9	Frustrated with __'s memory	-.440
Burd73	I do more than __ did for me	-.323
6 items		alpha .72

The next factor identified through this analysis of the Caregiving Inventory consists of items pertaining to the care receiver's functional capacities as well as the caregiver's reactions to those characteristics. In addition, the category encompasses 2 questions which speak to the level of reciprocity the caregiver perceives to exist in his/her relationship with the care recipient. The generic title **Caregiver-Care Receiver Relationship Issues** was selected in an effort to incorporate these rather varied themes.

Table 10
Caregiver's Sense of Responsibility

Variable	Description	Loading
Burd67	My responsibility to care	.798
Burd70	Can't quit	.699
Burd77	Can't do enough to repay	.486
3 items		alpha .71

A sense of filial obligation or family responsibility emanated from the items described in Table 10. **Caregiver's Sense of Responsibility** was chosen as a title as it seemed to capture that focus in a rather "neutral" manner.

The Caregiver Well-Being Measure: A Seven Factor Model

Exploratory factor analyses involving the caregiver well-being measure produced a seven factor solution. Specifically, the model selected retained 34 of the 59 items contained

within the original instrument. Approximately 55% of the variance in the matrix was "explained". A Cronbach's alpha of .89 was obtained for the overall measure.

The specific factors derived through this analytic process are described in Tables 11 through 17. The reporting format used is similar to that employed in the previous section.

Table 11
Positive Affect

Variable	Description	Loading
Feel8	Satisfied with personal life	.820
Feel7	Happy	.809
Feel4	Enjoyed things	.629
Feel1	Future hopeful	.535
Feel2	Daily life full/interesting	.522
Feel3	Felt relaxed/tension free	.517
6 items		alpha .86

As suggested in earlier discussions, constructs like happiness and life satisfaction emerge as key themes in the literature concerning global well-being. Consistent with those works, the title **Positive Affect** was selected to reflect the cluster of positive life perspectives presented here.

Negative Affect is another theme that surfaces as significant to overall well-being (Bradburn, 1969; Andrews and Withey, 1976). As the parenthetic subtitle indicates, all of

Table 12
Negative Affect (Depression)

Variable	Description	Loading
Feel15	Trouble concentrating	-.730
Feel13	Couldn't shake blues	-.656
Feel17	Everything an effort	-.616
Feel30	Couldn't get going	-.584
Feel21	Sleep restless	-.578
Feel11	Bothered more	-.529
Feel12	Poor appetite	-.506
Feel20	Felt tearful	-.503
Feel10	Awaken refreshed	-.441
9 items		alpha .82

the items associated with this factor (except Feel10) were initially part of the CES-Depression scale. The items retained, however, are only a fraction of those contained within the original scale. How these changes may have attenuated the instruments's capacity to tap the construct it was designed to measure remains unclear. Nevertheless, the items comprising this factor join together in conveying the presence of a rather negative state of being.

Table 13
Financial Issues

Variable	Description	Loading
Income	Total Gross Income (1986)	.797
Suffinc	Sufficient to cover expenses	.787
2 items		alpha .56

Table 14
Caregiver's Physical Health Status

Variable	Description	Loading
Chlth3	Health compared to 3 mos. ago	.603
Chlth	Self-Rated health	.451
2 items		alpha .32

Again, there seems to be a clear correspondence between the financial and health status items and their respective factors. It is the limited number of items which comprise these factors that surfaces as problematic. Consisting of only 2 intercorrelated items, the **Financial Issues** and **Caregiver Physical Health Status** factors obviously would enter the "hierarchy of factors" (Comrey, 1976, p.210) at the lowest level. However, because of the significant role each historically has played within caregiving research, it was not felt that they could be eliminated.

Table 15
Social Affirmation

Variable	Description	Loading
Socpv16	People admire my talents	.754
Socpv11	Competence is recognized	.616
Socpv7	Skills not respected	.569
Socpv5	Others enjoy similar things	.480
4 items		alpha .72

Recognizing that people serve a variety of functions for one another, social support increasingly has been depicted as

a multidimensional phenomenon (Holahan and Moos, 1981; Moos and Mitchell, 1982; George, 1989; Fiore, Coppel, Becker and Cox, 1986; Cutrona, Russell, and Rose, 1986). The factors described in Tables 15 through 17 attest to such a characterization. The items in Table 15, by way of example, reflect what Cutrona and Russell describe as "reassurance of worth", as well as, a "sense of belonging" (1987, pp.41-42). The term **Social Affirmation** seemed to capture both of these themes.

Table 16
Social Support (Mutual Aid, Companionship & Affection)

Variable	Description	Loading
Socpv3	No one to provide guidance	.741
Socpv8	No one would help	.727
Socpv1	People I can depend on	.661
Socpv2	No close personal ties	.588
Socpv12	No one shares my concerns	.492
Socpv9	Have close ties	.456
Socpv15	No one to talk to re problems	.382
7 items		alpha .81

The items in Table 16 address the extent to which "others can be counted on for tangible assistance" and/or guidance (Cutrona and Russell, 1987, pp.41-42). There also are questions which tap how attached or close one feels to others. The generic term **Social Support** seemed capable of conceptually covering these different dimensions.

Table 17
Feeling Needed

Variable	Description	Loading
Socpv18	No one needs my care	.763
Socpv13	No one relies on me	.693
Socpv6	Personally responsible for __	.623
Socpv4	People depend on my help	.477
4 items		alpha .62

The last factor to be described in this set consists of a rather unique constellation of items which speak to the very human need to be needed. It is what Cutrona, Russell, and others have termed "the opportunity for nurturance" (1987. p.42). Admittedly **Feeling Needed** is technically not an indicator of social support. After all, the items portray the caregiver as "the provider rather than the recipient of assistance" (Cutrona and Russell, 1987, p.42). Nonetheless, it is a major element of interpersonal interaction and, therefore, seems to fit within this general conceptual arena.

The Combined Analyses -- An Eleven Factor Event

Utilizing the items contained within the factor solutions derived independently for the Caregiving Inventory (n=40) and the caregiver well-being instrument (n=34), a series of combined exploratory factor analyses were undertaken. The purpose of this analytic expedition was to determine where

these different measures may be covering the same conceptual terrain.

In working toward a meaningful solution, it was discovered that **Positive Affect** items and those associated with the **Role-Related Reinforcers** factor could not be entered into the analysis simultaneously--without engendering an "ill-conditioned matrix" warning. The specific elements contained within each of these factors are described in Tables 18 & 19.

Table 18
Positive Affect

Variable	Description	Loading
Feel7	Happy	.783
Feel8	Satisfied with personal life	.691
Feel4	Enjoy things	.644
Feel10	Awaken refreshed	.561
Feel1	Future hopeful	.412
-------		
5 items		alpha .81

Table 19
Role-Related Reinforcers

Variable	Description	Loading
Burd35	Pleased when __ remembers me	-.715
Burd5	Feeling needed important	-.672
Burd25	Enjoy caregiving	-.605
Burd72	__ really appreciates me	-.506
-------		
4 items		alpha .70

Significantly, regardless of whether the items which constitute the **Positive Affect** or **Role-Related Reinforcers** factor are retained in the analytic process, the eleven factor model emerges as the most satisfactory solution. As the data in Table 20 reflect, the different versions of this 11 factor solution are, by and large, equivalent. Furthermore, the data provided within Tables 21-30 reveal that, beyond the inclusion of **Positive Affect** or **Role-Related Reinforcers**, the remaining components of the 11 factor solution are essentially the same as well.

Table 20
Overall Characteristics of the Two 11 Factor Models

Positive Affect	Role-Related Reinforcers
-- Retains 48 of the 74 original items -- Explains 57% of the variance in the matrix -- Overall alpha .85	-- Retains 47 of the 74 original items -- Explains 57.7% of the variance in the matrix -- Overall alpha .83

While some merging occurred, no new factors emerged as a result of the composite analysis. Therefore, the factor-related data are presented in Tables 21 through 30 without additional commentary.

Table 21
Pressed Into Service

Variable	Description	+ Affect	Role +
Burd48	Family made me caregiver	-.757	.794
Burd55	Forced into caring	-.667	.625
Burd20	Care because I have to	-.661	.593
Burd12	Made to feel it's my job	-.576	.563
Burd6	No where else to go	-.554	.503
---			
5 items	(alpha .75)		

Table 22
Caregiver's Sense of Responsibility

Variable	Description	+ Affect	Role +
Burd67	My responsibility	.802	.785
Burd70	Can't quit	.703	.590
Socpv6	Feel responsible for __	.524	.525
---			
3 items	(alpha .61)		

Table 23
Financial Issues

Variable	Description	+ Affect	Role +
Burd3	Financial resources OK	.767	.761
Suffinc	Income covers expenses	.752	.754
Burd16	Family strained fiscally	.648	.658
Burd38	Worried about money	.636	.638
Burd23	Can afford home health	.599	.592
Income	1986 gross income	.553	.557
---			
6 items	(alpha .78)		

Table 24
Social Support

Variable	Description	+ Affect	Role +
Socpv3	No one provides guidance	.704	.739
Socpv8	No one would help	.659	.674
Socpv2	No close personal ties	.638	.661
Socpv9	Have close ties	.585	.647
4 items	(alpha .71)		

Table 25
Family Responsiveness

Variable	Description	+ Affect	Role +
Burd51	Family understands	.759	-.745
Burd69	Family admires me	.665	-.633
Burd41	Family left me alone	.472	-.511
Burd2	Family works together	.489	-.506
Burd30	Wish family understood	.523	-.497
5 items	(alpha .72)		

Table 26
Negative Affect (Depression)

Variable	Description	+ Affect	Role +
Feel15	Trouble Concentrating	.616	.727
Feel13	Couldn't shake blues	.614	.723
Feel12	Poor appetite	.580	.525
Feel20	Felt tearful	.531	.499
Feel10	Awaken refreshed		.410
Socpv13	No one relies on me	.403	.351
6 items	(alpha .62 & .65)		

Table 27
Caregiver Role Appraisal

Variable	Description	+ Affect	Role +
Burd40	I'm doing a good job	.781	.791
Burd71	Done all expected	.705	.726
Socpv11	Others see my competence	.422	.420
Burd47	I'm best suited for CG	.353	.311
4 items	(alpha .54)		

Table 28
Caregiver's Physical Health Status

Variable	Description	+ Affect	Role +
Chlth	Self-Rated health	.708	-.681
Burd14	Healthy enough	.727	-.665
Burd36	Health had declined	.593	-.580
3 items	(alpha .74)		

Table 29
Schedule and Social Consequences

Variable	Description	+ Affect	Role +
Burd4	Daily schedule changes	.743	-.744
Burd46	Visit less	.727	-.721
Burd39	Social activities same	.662	-.694
Burd11	CG center of activities	.672	-.684
4 items	(alpha .75)		

Table 30
Caregiver-Care Receiver Relationship Issues

Variable	Description	+ Affect	Role +
Burd9	__'s memory frustrating	-.641	-.702
Burd13	Embarrassing behavior	-.619	-.571
Burd54	Can't tell past/present	-.504	-.529
Burd72	__ really appreciates me	-.585	*-.467
-------			
4 items	(alpha .63)		

* Duplicate item: also loads on "Role-Related Reinforcer"

Notably, factors derived from both the burden and the well-being measures were retained in the final solution. To examine the possibility of a second order, or general well-being/burden factor, correlation studies involving the 12 substantively meaningful clusters derived through the composite analysis were completed. The results can be found in Table 31.
(Please see page 94)

Table 31
CORRELATION COEFFICIENTS FOR UNWEIGHTED FACTOR CLUSTERS

	Positive Affect	Role-Reinforcers	Pressed	CG Sense of Responsibility	Financial Issues	Social Support	Family Response	Negative Affect	Health	Schedule & Social	CG-CR Relations	CG Role Appraisal
Positive Affect	1.00											
Role Reinforcers	.40	1.00										
Pressed	.34	.41	1.00									
CG Sense of Responsibility	-.12	-.36	-.16	1.00								
Financial Issues	.17	.01	.06	-.09	1.00							
Social Support	.45	.21	.34	-.10	.19	1.00						
Family Responsiveness	.38	.32	.40	-.29	.09	.49	1.00					
Negative Affect	.58	.15	.25	-.05	.21	.30	.20	1.00				
Health	.44	.10	.25	-.04	.32	.31	.22	.45	1.00			
Schedule & Social	.37	.11	.21	.14	.13	.14	.16	.28	.31	1.00		
CG-CR Relationship	.38	.46	.42	-.16	.06	.29	.26	.28	.18	.22	1.00	
Role Appraisal	.01	.15	.07	-.26	.006	.10	.11	-.06	-.008	-.21	.06	1.00

Note: In interpreting these correlations keep in mind that all items were scored in a negative direction. Consequently, higher burden scores indicate higher burden and higher well-being scores suggest more compromised levels of well-being.

Discussion

Clarifying The Content Of Typical Burden & Well-Being Measures

The objective of the initial analyses was to develop as clear a picture as possible concerning what dimensions of caregiver burden and caregiver well-being were being tapped by typical measures of these constructs. The specific factors uncovered through these analyses are presented in Figure 2.

Not unexpectedly, both measures exhibited a multidimensional character. While obvious thematic overlap surfaced in the health and financial arenas, a number of unique dimensions were suggested by each instrument, as well. Closer inspection of the content of these various factors revealed that many of the clusters contained both appraisal and response variables. Consequently, early attempts to examine the factors from the vantage point of the study's theoretical framework proved unproductive.

Emphasis then shifted to the topical makeup of the items contained within the various factors (e.g., family, financial matters, caregiver competence, and so on.). Using these data, areas of topical similarity between burden and well-being items were identified. In turn, a 13 factor solution was predicted for the "grand" analysis (Please see Appendix C).

Caregiver Burden	Caregiver Well-Being
-- Pressed Into Service	-- Positive Affect
-- Role-Related Reinforcers	-- Negative Affect (Depression)
-- Financial Issues	-- Financial Issues
-- Caregiver Physical Health Status	-- Caregiver's Physical Health Status
-- Family Responsiveness	-- Social Affirmation
-- Schedule & Social Consequences	-- Social Support
-- Caregiver's Self-Appraisal	-- Feeling Needed
-- Caregiver's Sense of Responsibility	
-- Caregiver-Care Receiver Relationship Issues	

Figure 2 Burden and Well-Being Factors Identified

As mentioned earlier, the results generated through this prescribed solution proved to be marginally informative.

Continued attempts to use the study's interactive analytic scheme to interpret the "within instrument" patterns at the "item" level only served to accentuate the conceptual challenge posed by nonrecursive theoretical models. Not only were factors mixed with caregiver appraisal and response items, but arguments could be made for logically placing a number of the different individual items in either category. This held true even for select items within the seemingly more tangible domains, i.e., somatic health and finances. This point is perhaps best illustrated with a series of examples.

Do, for instance, statements regarding compromised family finances or declining health reflect appraisals of the current resources available to the caregiver (inputs)? Or are they indicators of the costs that have been incurred as a result of having provided care (outcomes)?

What about a caregiver's reported frustration with a care recipient's memory? Is that an indication of the caregiver's current emotional resources? Or is it an indication of his/her reaction to a critical element of the caregiving circumstance?

Faced with such puzzling questions, it was decided that further elaboration of the appraisal-reaction component of the caregiving event was essential. A return to the theoretical literature ensued.

Drawing upon the work of Lazarus and Folkman (1986), in addition to Pearlin, et al. (1990), the model presented in Figure 3 was developed. Briefly, this portrayal adds two critical pieces to the study's interactive analytic scheme. First, it incorporates Lazarus and Folkman's assertion that the appraisal process involves more than simply calculating the resource to demand ratio. The caregiver also makes decisions regarding the meaning of any calculated findings.

The importance of this observation for those seeking to understand the caregiving experience is that it underscores the significance of going beyond merely identifying the presence of a resource/demand imbalance (e.g., a financial short fall). It also becomes essential to determine the extent to which an identified deficit is perceived by the caregiver as being potentially harmful or beneficial (e.g., an opportunity to demonstrate one's creative problem solving skills). Certainly, the explicit inclusion of this element in the theoretical model is a welcomed addition from the symbolic interactionists' perspective.

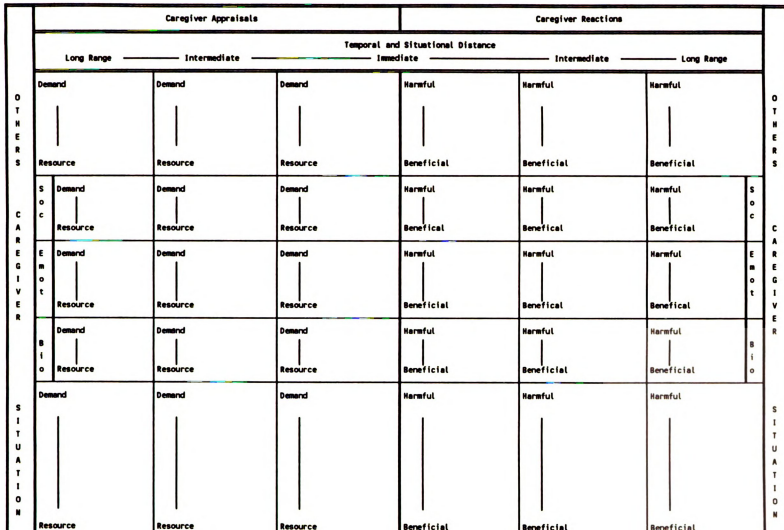

Figure 3 THE CAREGIVER APPRAISAL PROCESS: COGNITIVELY MEDIATING AN EMERGENT PERSON-IN-ENVIRONMENT EVENT

A second important feature of this model is the emphasis it places on the element of distance--both situational and temporal. As the examples noted above illustrate, it is difficult to assess the impact a variable is likely to exert on the caregiving experience unless one is able to specify the relevance the caregiver has assigned that item. Distinguishing pertinent elements, in terms of their respective time and situational referents, surfaces as a means of beginning to identify such specifications.

The grid presented in Figure 3 also emphasizes the contextual nature of the appraisal process by allowing one to designate "environmental" as well as caregiver inputs and reactions. Though not explicitly indicated, the model is nonrecursive/reciprocal.

Figure 4 illustrates how the author views the sixteen factors derived through the independent analyses in light of the elaborated conceptual model. The location of each factor was determined on the basis of the primary "tenor" conveyed by the items involved--in terms of time, situation, source, and evaluative focus. The potential relevance of instances where factors fall between cells is a topic that shall be revisited.

In looking at the patterns suggested by this portrayal the tendency for burden factors to cluster within the immediate caregiving framework becomes readily apparent. In

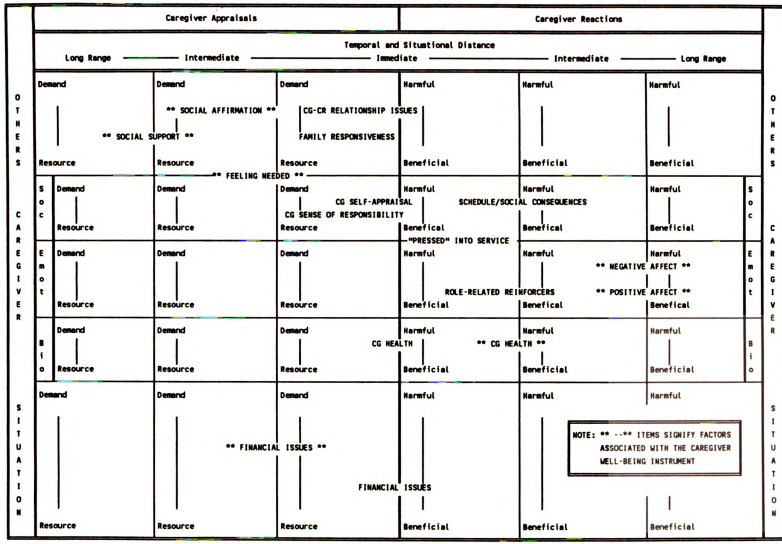

Figure 4 DEPICTING THE BURDEN AND WELL-BEING FACTOR SOLUTIONS DERIVED WITHIN THE FRAMEWORK OF THE PROPOSED APPRAISAL PROCESS

contrast, well-being factors tend to occupy the more intermediate and global domains. These patterns will be reconsidered momentarily, also, as the results of the "grand" analysis are addressed.

Identifying The Common Conceptual Ground

Determining the extent to which typical measures of caregiver burden and caregiver well-being tap the same underlying constructs was the other major question to be addressed by this study. As the hypotheses articulated in Chapter III indicate, the prospect of total overlap between the selected instruments was never given serious consideration. A select pattern of conceptual similarity, however, was expected on the basis of the theoretical framework that had been offered.

Importantly, these predictions targeted process, rather than content/topic domains. That is, items were expected to load together to the extent that they mutually addressed: 1) the caregiver's appraisals of presenting resources and demands; 2) the caregiver's subsequent social, biological, or emotional reactions; or 3) the global consequences/changes experienced by the caregiver. As relayed previously, the factors derived through this exploratory effort reflected topical distinctions (e.g., family, feeling positive), as

opposed to elements of process. As a result, the hypothesized relationships could not be addressed directly.

The caregiver appraisal framework surfaced, however, as a means of indirectly evaluating the usefulness of these predictions by providing a vehicle for examining the relationships which emerged between factors--while still accounting for select within factor variations. Figure 5 illustrates the author's interpretation of the source, time, situation, and evaluative elements associated with each of the 12 factors that emanated from the composite analysis. Before addressing the relationships exhibited among these different factors, an elaboration of the process followed in determining their respective placements seems warranted.

In deciding where to place a given factor within the theoretical framework, a number of assessments were made with respect to each of the items included in the cluster. First, a choice was made as to whether the items involved addressed characteristics of the situation, other people, or the caregiver. For example, **Financial Issues** was identified as the only non-social contextual factor to be tapped by these instruments. The **Social Support, Caregiver-Care Receiver Relationship Issues,** and **Family Responsiveness** factors all seemed to convey information concerning other people, primarily.

Not unexpectedly, most of the elements contained within these measures focused on various attributes of the caregiver, e.g., the caregiver's **Sense of Responsibility, Health Status, Positive Affect**, etc. In these instances, an additional decision had to be made regarding the actual caregiver dimension(s) being emphasized, i.e., biological, emotional, or social.

Most of these categorizations seemed rather straightforward, such as characterizing the caregiver's physical health status as a biological factor. There were, however, a few more challenging placements. **Pressed Into Service**, by way of example, was classified as a social/emotional characteristic because the items involved appeared to simultaneously tap the caregiver's emotional reactions (Burd55) and the sense of social pressure (Burd48 & Burd6) he/she felt with regard to the "decision" to undertake/sustain the caregiving role. The **Role-Appraisal** factor was placed between the "others" and "caregiver-social" cells as there were items which seemed to reflect both the caregiver's (Burd40) and other people's (Socpv11) assessments of the caregiver's role performance.

Once these divisions were made a determination concerning the "evaluative" aspects of the item ensued. Specifically when the content addressed by a given item was best characterized as a demand, a resource, or a ratio of demands to

resources (i.e., an "adequacy" rating), the item was classified as falling within the **caregiver appraisal** domain. In contrast, when the item suggested an indication of a harmful or beneficial outcome or response, it was placed within the **caregiver reaction** domain. The items which constitute the **Caregiver Physical Health Status** surface as means of illustrating these differences.

Burd14, which reads: "I am healthy enough to care for ____", suggests an "adequacy" estimate. The question concerning current health status (i.e., How would you rate your overall health at the present time) serves to identify a potential "resource". Conversely, Burd36, which states: My health has gotten worse since I've been caring for ____", definitely highlights a potentially "harmful" consequence of caregiving. Since the factor **Caregiver Physical Health Status** seems to reflect both evaluative domains, it was placed between the **appraisal--reaction** division.

The third and final dimension considered in this placement process was "distance". Given the interactionist perspective that informs the study's theoretical view, "immediacy" or currency reflects more than mere time. It applies to other elements which are relevant for the (caregiving) interactive event, as well. In other words, since caregiving constitutes the event of interest, items relating directly to that interactive experience are considered more

immediate--less distant. Alternatively, items with no reference to the caregiving event, per se, are classified as being more distant, conceptually.

Frequently, time/situation referents were introduced by actually mentioning caregiving time and/or situation anchors within the questions posed. This was generally achieved by including a statement such as, "since I began caring for ___"..., or by simply incorporating the term "caring" within the question. Sometimes additional distance was imposed by introducing a time frame stimulant that clearly went beyond any particular caregiving event. Consider, for example, the reference to 1986 income, or queries concerning the incidence of positive/negative feelings occurring "during the <u>past month</u>". Perhaps taking a look at the items which comprise the **Social Support** factor might help to clarify the time/distance issue even further.

Socpv3	There is no one I can turn to for guidance (for help) in times of stress.
Socpv8	If something went wrong, no one would come to my assistance.
Socpv2	I feel that I do not have close personal relationships with other people.
Socpv9	I have close relationships which provide me with a sense of security and well-being.

The first two items (Socpv3 & Socpv8) seem to convey a "generic" time/situation focus. While the availability of such help certainly may have relevance for any caregiving event, the permanency suggested by the overall tone signifies the presence of a more intermediate "pattern", rather than an appraisal of current circumstances. The latter two items, on the other hand, appear to completely omit reference to time and event. Instead they seem to speak to the more general/ global characteristics that surround the structure of a caregiver's social network. In light of this perceived dual focus, the **Social Support** factor was placed between the **long range--intermediate** divider.

With that explanatory backdrop, an examination of the relationships exhibited among the factors uncovered through the combined analyses becomes more meaningful. It seems particularly helpful to consider the patterns presented in Figure 5 in contrast to those shown in Figure 4.

It is interesting to note, for example, that well-being and burden factors which share a "substantial" area of a common cell in Figure 4 end up merging (i.e., health and finances), or clashing (i.e., **Role-Related Reinforcers** and **Positive Affect**), in the composite analysis. With regard to the pair of clashing factors, it seems that the two occupy enough of the same conceptual territory to cause the matrix to become ill-conditioned. Yet, a test of intercorrelation

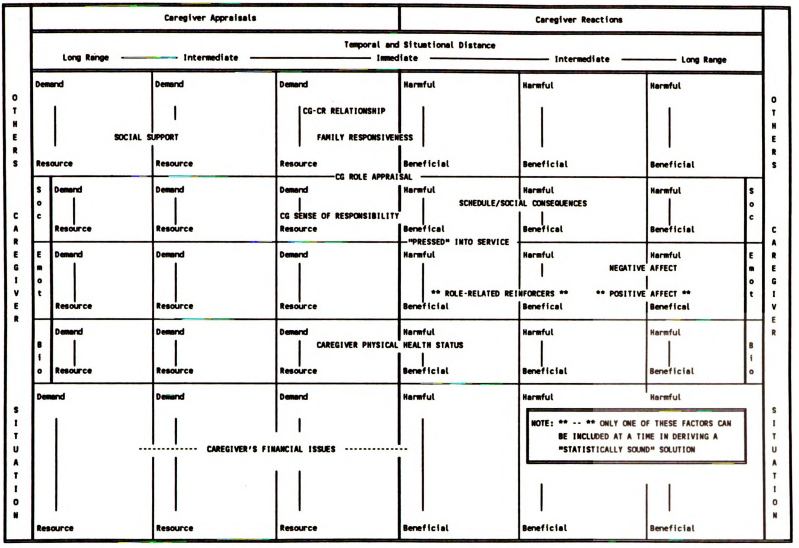

Figure 5 DEPICTING THE 11 FACTOR COMPOSITE SOLUTION WITHIN THE FRAMEWORK OF THE PROPOSED CAREGIVER APPRAISAL PROCESS

suggests that they also cover enough independent terrain to retain their conceptual integrity (See Table 31, r=.40). The merging that occurred with the health and financial factors may reflect a procedural artifact prompted by the weakness of the well-being factors entered into the study. Alternatively, it might reflect the strength of "money" and "health" as response referents. That is, perhaps people's responses to these cues are so centered in assessments of their current (overall) status that alternative situational or context cues are readily overlooked.

Feeling Needed and **Social Affirmation** are two factors which were eliminated during the composite analysis. Consideration of the many cells simultaneously occupied by the **Feeling Needed** factor seems to provide a clue as to why it was omitted. Its position suggests a high degree of conceptual interrelatedness with a number of other well-being and burden factors. The redundancy involved apparently exceeded the tolerance level of the factor analysis procedure. The situation encountered by **Social Affirmation** was likely similar. Specifically, a high degree of conceptual overlap with the **Social Support** factor prompted the elimination of select social affirmation items in order to restore the stability of the matrix. Surgery of this nature tends to weaken the overall strength of the factor. As indicated in this case, when the cuts are severe enough the result can be fatal.

An examination of the original hypotheses in light of the available findings reveals:

1. In contrast to the hypothesized relationship concerning caregiver bio-psycho-social response items, the greatest amount of overlap occurred between burden and well-being items that shared temporal, source, situation, and/or evaluative referents.

2. The appraisal-response distinction did not appear to direct the loading patterns discerned through these analyses. Rather, topical similarities (i.e., finances, social support, family, etc.) seemed to provide the conceptual organizing themes.

3. With the exception of the conceptual entanglement encountered by **Positive Affect**, the more global indicants of well-being (i.e., **Negative Affect** and **Social Support**) did exhibit the least amount of overlap with caregiver burden factors.

In addition to analyzing the relationships among the factors derived through the "grand" analysis on conceptual grounds, unweighted, inter-cluster correlations were computed using SPSS, Version 4.0. Among other considerations was the

potential presence of a second-order, or general well-being/ burden factor. In particular, if such a factor were underlying the different components, one would expect the factors identified to demonstrate a high degree of correlation. As the data in Table 31, page 94, illustrate, this was not the case. The potential implications of this, as well as the study's other findings, are addressed in the next chapter.

CHAPTER V

Conclusions

Implications Of The Study

The caregiver burden and well-being measures examined in this study were both found to consist of several different conceptual components. It follows that, if the measures involved are themselves complex and multidimensional, then the relationship between them, likewise, will be complex and multidimensional.

There were, for example, areas where these measures seemed to overlap considerably; the most notable occurrences surfacing in the fiscal and health arenas. There also were a number of categories within each instrument that exhibited stark independence with respect to the conceptual terrain covered. Given the latter, the wisdom of categorically substituting one measure for the other in studies concerning the caregiving experience is highly suspect.

George and Gwyther (1986) are certainly correct in their assertion that the use of generic measures of well-being would facilitate comparisons between caregiver and non-caregiver groups. If such comparisons are imperative to the questions of import for one's study, the advantage of using standardized, generic measures of well-being seems self-evident. The

danger emerges in alluding to the possibility that well-being instruments are capable of serving as proxies for measures of caregiver burden.

Among other distinctions, the data examined here clearly supports the situation specific nature of caregiver burden items. To the extent that one's study focuses on topics, such as: the impact caregiving exerts on the caregiver, differences in coping strategies employed by caregivers, and so on, such situation specific data would seem preferable (Montgomery, 1989, p.209).

Support for the inclusion of both well-being and burden measures in studies involving caregivers emerges from the study's theoretical model. Adapted for this investigative effort, the model posits a rather complex, yet significant relationship between a caregiver's experience of burden and the impact this poses for his/her subsequent well-being. Although much needs to be done before the usefulness of this theoretical framework is determined, there would seem to be little to lose and much to gain by incorporating indicators of both constructs in future studies of caregiving.

A methodological matter highlighted by the measurement overlap detected pertains to the presence of definitional redundancy. What is being referenced, in particular, is the conceptual confounding that appears to characterize burden and

well-being financial and health items, especially. The finding accentuates the need for caution when considering statements concerning the relationship between burden and well-being when those assertions are based on measures of this nature. A procedural "factor" may be at work.

Limitations Of The Study

In considering the limits of this study it seems important to comment on the restrictions associated with the analytic strategy employed. Among other considerations is the fact that each of the factor solutions selected represents but "one interpretation of the data" (Comrey, 1973, p.162). In addition to the various procedural decisions that must be made, choices regarding which items to retain, what labels to use in describing the different factors, etc., create the possibility of researcher bias entering into the process. The usefulness and accuracy of these analytically derived "hypotheses about nature" (Comrey, 1973, p. 167), must be tested against criteria collected outside the confines of the factor analytic study.

Another limitation is the fact that the theoretical model adapted for this study has not been "tested". Doing so will require, at minimum, the identification/development of measures that are capable of tapping the critical dimensions of the theory -- with sufficient precision to detect changes/

differences in the variables targeted. In other words, measures will need to be selected/devised for each of the conceptual "cells" contained within the Caregiver Appraisal model. Figure 6 illustrates the kinds of variables one might include in undertaking such an effort.

In this study, judgments regarding the most fitting cell(s) for each factor were admittedly clouded by the inclusion of multiple processual (if not thematic) perspectives within a single factor. Once again, an illustration may prove helpful. Consider, for a moment, the items contained within the burden instrument's **Financial Issues** factor. Using the study's process-oriented theoretical framework, the author sorted these items in the following manner:

Resource/Demand ----->	Appraisal ----->	Reactions
Worried About Money	Financial Resources Adequate	Caregiving has Put A Strain On Family Finances
Can Afford Home Health Care		

In light of this categorical breakdown, the burden **Financial Issues** factor was placed so it "tapped" immediate, situational appraisal <u>and</u> reaction cells. Given the potential for bias, future efforts of this nature would benefit from the inclusion of multiple, independent raters.

	Caregiver Appraisals			Caregiver Reactions			
	Temporal and Situational Distance						
	Long Range ——— Intermediate	Immediate		Immediate ——— Intermediate		Long Range	
OTHERS	FAMILY & SOCIAL NETWORK COMPOSITION CAREGIVER-CARE RECEIVER RELATIONSHIP TYPE	AVAILABLE FAMILY CAREGIVER-CARE RECEIVER --RELATIONSHIP QUALITY --LIVING ARRANGEMENT	PERCEIVED SOCIAL SUPPORT --INFORMATIONAL --EMOTIONAL --TANGIBLE CARE RECEIVER --ADL & IADL NEEDS --CARE EXPECTATIONS	FAMILY REACTIONS CONSTRICTION OF SOCIAL LIFE CARE RECEIVER REACTION TO HELP PROVIDED	RELATIONAL DEPRIVATION FAMILY CONFLICT	ISOLATION FAMILY ABANDONMENT	OTHERS
CAREGIVER	Soc CAREGIVER -- OCCUPATION -- EDUCATION -- CULTURAL TEMPLATE	DURATION CAREGIVING ROLE CG'S VALUES/BELIEFS (e.g., FILIAL OBLIGATION)	WORK SCHEDULE FLEXIBILITY PREDICTABILITY OF TASKS	ROLE CAPTIVITY	SOCIAL/RECREATIONAL CHANGES JOB-CAREGIVING CONFLICT	SOCIAL FUNCTIONING ABDICATE CAREGIVER ROLE	Soc	CAREGIVER
	Emot PERSONALITY FACTORS	COPING STYLES	COMMITMENT TO CAREGIVER ROLE IDENTITY (INTENSITY)	ANTICIPATED "GAIN" CG ROLE APPRAISAL	COMPETENCE POSITIVE FEELINGS NEGATIVE FEELINGS ANXIETY	PSYCHOPATHOLOGY WELL-BEING SELF-ESTEEM MORALE	Emot	
	Bio GENDER AGE GENETIC PACKAGE ILLNESS RISK FACTORS	IMMUNITIES TEMPORARY VULNERABILITIES	PHYSICAL DEMANDS (e.g., LIFTING) VIGILANCE REQUIRED	SOMATIC CHANGES (PRECURSERS TO ILLNESS) FATIGUE	ACUTE ILLNESS DECREASED EXERCISE	CHRONIC ILLNESS LONGEVITY	Bio	
SITUATION	POLICIES/LAWS GOVERNING RESOURCES & THE RESULTING FORMAL SERVICE NETWORK	LOCAL SERVICE NETWORK (AVAILABLE SERVICES) INCOME	SERVICE ACCESSIBLITY --AFFORDABLE --PROXIMITY SERVICE UTILITY --ACCEPTABLE TO CG & CR	IMPACT OF SERVICES USED (CG) FINANCIAL WORRIES	FORMAL/INFORMAL CARE NETWORK CONFLICT ECONOMIC PROBLEMS	FORMAL/INFORMAL CARE NETWORK INCOMPATABILITY	SITUATION	

Figure 6 POTENTIAL VARIABLES TO BE INCLUDED IN TESTING THE USEFULNESS OF THE PROPOSED INTERACTIVE THEORETICAL MODEL

Suggestions For Future Research

One of the most compelling questions sparked by this investigation pertains to the analytic utility of the theoretical model presented. As noted in the previous section, it will be impossible to test the relationships that exist among the appraisal-reaction components without establishing conceptually distinct operationalizations for the various elements involved. Once the measurement issue is resolved, it would seem possible to test the temporally ordered relationships suggested by the Caregiver Appraisal model. Path analysis and structural equation modeling surface as particularly promising analytic strategies in this regard.

Should the measurement issues delay/impede the use of the sophisticated analytic strategies suggested, it may be informative to use the model in a manner similar to that employed here. That is, to "interpret" what aspects of the caregiving process are being tapped by measures in use. This is not to suggest that the model will be able to resolve the definitional and operational dilemmas which have plagued caregiver burden. The model may, however, provide fresh insight into how previous findings might be viewed or reinterpreted.

In many respects this study joins the efforts of Rice (1988), Kinney and Stephens (1989), Pearlin, et. al., (1990)

and others, in demonstrating support for the apparent usefulness of ideas associated with the transactional stress theories, especially the work of Lazarus and Folkman (1986). Following their model, the limitations imposed by discerning only the presence or absence of demands/resources, deficits/surpluses, become strikingly apparent. Even indicators of adequacy come up short -- lacking the precision required to discern the meaning the caregiver actually ascribed to that appraisal.

Adapting Lazarus and Folkman's thinking on stress to the caregiving experience, the Caregiver Appraisal process was characterized as an emergent, cognitively mediated, person-in-environment event (1986, p.77). Cast in this framework, efforts to understand the caregiving experience seem predicated on determining: What is it about the caregiver and the caregiving context he/she faces "that produces appraisals of harm and threat or appraisals that some benefit is possible or probable" (1986, p.77). Addressing this question will require studying caregivers in different caregiving circumstances over time.

Studying caregivers in context suggests the need for incorporating more qualitative strategies (e.g., panel studies with open-ended interview questions and in-depth interviewing) into the caregiving research agenda. The literature suggests a movement toward longitudinal studies (e.g., Pearlin, et al,

1990). A few examples of qualitative approaches have begun to surface, as well (e.g., Hasselkus, 1988). What is being suggested here are studies incorporating the two. Interestingly this is the same methodological maxim espoused by the symbolic interactionists.

Summary: The Importance Of Clarifying The Meaning Of A Word

One of the most significant issues this study highlights is the cost of using imprecise words in attempting to identify, quantify, or describe phenomena. The well documented practice of using the term caregiver burden in inconsistent, if not contradictory, ways has served to undermine attempts to understand the phenomenon. Without this understanding it becomes difficult, if not impossible, to develop and evaluate responsive interventions. This quandary plagues the interventionist whether he/she is attempting to provide individual treatment, family or group intervention, or working toward the establishment of meaningful policies.

Further study may reveal that the term needs to be modified or perhaps even abandoned on substantive grounds. However, it seems premature to do so without at least reaching agreement about what the phenomenon is that is being given up/changed.

The complexity of the caregiving experience is gradually becoming acknowledged. Recognition of the need to move beyond characterizations of the normative experience has emerged. This study joins those which have promulgated a processual vision of caregiving. In particular, this study emphasizes the illusive nature of burden; portraying it as the result of having assembled select caregiving-related variables in particular constellations. Said differently, **burden occurs when a caregiver perceives the presenting demands of caregiving as outstripping available resources, thereby creating a deficit -- a deficit which the caregiver has interpreted as harmful.** Characterized in this fashion, it becomes readily apparent that none of the cells in the model will directly illustrate the presence or absence of burden. Only by identifying how the caregiver puts these items together can the process of burden be understood.

Beyond the methodological implications, this elaborated characterization of the caregiving experience may help policy makers and interventionists to understand the challenges and dilemmas being encountered by our nation's caregivers. In particular, by providing a framework that is capable of incorporating the various individual, situational, and interpersonal variables of import--along with their varied and complex relationships--the model may help efforts to identify critical elements which enter into caregiving decisions and facilitate the tracking of related consequences. In so doing, the model

may ultimately contribute to the establishment of policies and/or the development of actual intervention strategies.

With respect to the question of conceptual integrity, this study presents evidence which suggests that certain ingredients associated with the burden-determining process interact, even overlap, with select elements of well-being. Identifying these types of conceptual overlays may help clarify the meaning of caregiver burden. Care must be taken to insure, however, that insights regarding such similarities do not obscure the unique dimensions of the concept. It is hoped that this modest effort will contribute to the avoidance of such an oversight.

LIST OF REFERENCES

LIST OF REFERENCES

Andrews, F. & Withey, S. (1976). Social Indicators of Well-Being: Americans' Perceptions of Life Quality. New York, NY: Plenum Press.

Archbold, P. (1982). All-Consuming Activity: The Family As Caregiver. Generations, Winter, 12-13,40.

Arling, G. & McAuley W. (1983). The Feasibility of Public Payments for Family Caregiving. The Gerontologist, 23(3), 300-306.

Barer, B. & Johnson, C. (1990). A Critique of the Caregiving Literature. The Gerontologist, 30(1), 26-29.

Becker, J. & Morrissey, E. (1988). Difficulties in Assessing Depressive-Like Reactions to Chronic Severe External Stress as Exemplified by Spouse Caregivers of Alzheimer's Patients. Psychology and Aging, 3(3), 300-306.

Blenkner, M. (1965). Social Work and Family Relationships in Later Life, With Some Thoughts on Filial Maturity. In E. Shanas and G. Streib (Eds,), Social Structure and the Family: Generational Relations. New York, NY: Prentice Hall.

Blieszner, R. (1986). Trends in Family Gerontology Research. Family Relations, 35(October), 555-562.

Blumer, H. (1969). Symbolic Interactionism: Perspective and Method. Los Angeles, CA: University of California Press.

Bradburn, N. (1969). The Structure of Psychological Well-Being. Chicago, IL: Aldine Publishing Company.

Brody, E. (1979). Aged Parents and Aging Children. In P. Kagan (Ed.), Aging Parents (pp. 267-287). Los Angeles, CA: University of Southern California Press.

Brody, E. (1981). 'Women in the Middle' and Family Help to Older People. The Gerontologist, 21(5), 471-480.

Cantor, M. (1980, November). Caring For The Frail Elderly: Impact On Family, Friends, and Neighbors. Paper presented at the 33rd Annual Scientific Meeting of the Gerontological Society of America, San Diego, CA. Cited in Cantor, 1983.

Cantor, M. (1983). Strain Among Caregivers: A Study of Experience in the United States. The Gerontologist, 23(6), 597-604.

Caserta, M., Lund, D., Wright, S. & Redburn, D. (1987). Caregivers to Dementia Patients: The Utilization of Community Services. The Gerontologist, 27(2), 209-214.

Cicirelli, V. (1983). Adult Children and Their Parents. In T. Brubaker (Ed.), Family Relationships in Later Life (pp. 31-46). Beverly Hills, CA: Sage Publications.

Cockerham, W. (1991). The Demography of Aging. This Aging Society (pp. 15-47). Englewood Cliffs, NJ: Prentice Hall.

Comery, A. (1973). A First Course in Factor Analysis. New York, NY: Academic Press.

Cox, E., Parsons, R., & Kimboko, P. (1988). Social Services and Intergenerational Caregivers: Issues For Social Work. Social Work, 33(5), 430-434.

Cutrona, C., Russell, D., & Rose, J. (1986). Social Support and Adaptation to Stress by the Elderly. Journal of Psychology and Aging, 1(1), 47-54.

Cutrona, C. & Russell, D. (1987). The Provisions of Social Relationships and Adaptation to Stress. Advances in Personal Relationships, 1, 37-67.

Deimling, G. & Bass, D. (1986). Symptoms of Mental Impairment Among Elderly Adults and Their Effects on Family Caregivers. Journal of Gerontology, 41(6), 778-784.

Deimling, G., Bass, D., Townsend, A., & Noelker, L. (1989). Care-Related Stress: A Comparison of Spouse and Adult-Child Caregivers in Shared and Separate Households. Journal of Aging and Health, 1(1), 67-82.

Finley, N., Roberts, D., & Banahan, B. (1988). Motivators and Inhibitors of Attitudes of Filial Obligation Toward Aging Parents. The Gerontologist, 28(1), 73-78.

Fiore, J., Coppel, D., Becker, J., and Cox, G. (1986). Social Support as a Multifaceted Concept: Examination of Important Dimensions for Adjustment. American Journal of Community Psychology, 14(1), 93-111.

Folkman, S., Lazarus, R., Gruen, R., and DeLongis, A. (1986). Appraisal, Coping, Health Status, and Psychological Symptoms. Journal of Personality and Social Psychology, 50(3), 571-579.

Foster-Alter, C. (1988). The Changing Structure of Elderly Service Delivery Systems. The Gerontologist, 28(1), 91-98.

Gallagher, D., Rose, J., Rivera, P., Lovett, S. & Thompson, L. (1989). Prevalence of Depression in Family Caregivers. The Gerontologist, 29(4), 449-456.

George, L. (1979). The Happiness Syndrome: Methodological and Substantive Issues in the Study of Social-Psychological Well-Being in Adulthood. The Gerontologist, 19(2), 210-216.

George, L. (1981). Subjective Well-Being: Conceptual and Methodological Issues. In C. Eisdorfer (Ed.). Annual Review of Gerontology and Geriatrics (pp.345-382). New York, NY: Springer Publishing Company.

George, L. (1989). Stress, Social Support, and Depression Over the Life Course. In K.S. Markides and C.L. Cooper (Eds.), Aging, Stress, and Health pp. 241-267. New York, NY: John Wiley and Sons.

George, L. (1990). Caregiver Stress Studies -- There Really Is More To Learn. The Gerontologist, 30(5), 580-581.

George, L. & Bearon, L. (1980). Quality of Life in Older Persons: Meaning and Measurement. New York, NY: Human Sciences Press.

George, L. & Gwyther, L. (1986). Caregiver Well-Being: A Multidimensional Examination of Family Caregivers of Demented Adults. The Gerontologist, 26(3), 253-259.

Given, B., Given, C., Ellis, B., & Stommel, M. (Undated). Prediction of Caregiver Well-Being: A Comparison of Caregivers of the Physically Impaired and Caregivers of Patients with Alzheimer's Disease. Manuscript Submitted for Publication.

Given, C. (1989). Caregiver Responses to Managing Elderly Patients at Home (Final Report For Grant Number 1 RO1-AGO6584). East Lansing: Michigan State University.

Given, C., Given, B., Stommel, M., Collins, C., and King, S. (Undated). Development of Scales to Assess the Reactions of Caregivers of Patients with Physical Impairments and Alzheimer's Disease. Manuscript Submitted for Publication.

Gratton, B. & Wilson, V. (1988). Family Support Systems and the Minority Elderly: A Cautionary Analysis. Journal of Gerontological Social Work, 13(1/2), 81-93.

Greene, J., Smith, R., Gardiner, M., & Timbury, G. (1982). Measuring Behavioural Disturbance of Elderly Demented Patients in the Community and its Effects on Relatives: A Factor Analytic Study. Age and Ageing, 11, 121-126.

Gubrium, J. & Lynott, R. (1987). Measurement and the Interpretation of Burden in the Alzheimer's Disease Experience. Journal of Aging Studies, 1(3), 265-285.

Haley, W. & Pardo, K. (1989). Relationship of Severity of Dementia to Caregiver Stressors. Psychology and Aging, 4(4), 389-392.

Hasselkus, B. (1988). Meaning in Family Caregiving: Perspectives on Caregiver/Professional Relationships. The Gerontologist, 28(5), 686-691.

Hertzog, C. (1989). Using Confirmatory Factor Analysis for Scale Development and Validation. In M.P. Lawton & R. Herzog (Eds.). Special Research Methods for Gerontology (pp. 281-306). Amityville, NY: Baywood Publishing Company, Inc.

Hewitt, J. (1984). Self and Society: A Symbolic Interactionist Social Psychology (3rd ed.). Boston, MA: Allyn and Bacon, Inc.

Hoelter, J. (1983). The Effects of Role Evaluation and Commitment on Identity Salience. Social Psychology Quarterly, 46(2), 140-147.

Holahan, C. & Moos, R. (1981). Social Support and Psychological Distress: A Longitudinal Analysis. Journal of Abnormal Psychology, 90(4), 365-370.

Horowitz, A. (1985). Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences. The Gerontologist, 25(6), 612-617.

Horowitz, A. & Dobrof, R. (1982). The Role of Families in Providing Long-Term Care to the Frail and Chronically Ill Elderly (Final Report Submitted to the Health Care Financing Administration, Department of Health and Human Services). Cited in Matthews, S. (1988). The Burdens of Parent Care: A Critical Evaluation of Recent Findings. Journal of Aging Studies, 2(2), 157-165.

Hull, C. & Nie, N. (1981). SPSS Update 7-9: New Procedures and Facilities for Releases 7-9. New York, NY: McGraw-Hill Book Company.

Huttman, E. (1985). Social Services for the Elderly. New York, NY: The Free Press.

Jarrett, W. (1985). Caregiving Within Kinship Systems: Is Affection Really Necessary? The Gerontologist, 25(1), 5-10.

Kaye, L. (1986). Home Care for the Aged: A Fragile Partnership. In C. Meyer (Ed.), Social Work With the Aging (pp. 210-215). Silver Spring, MD: National Association of Social Workers, Inc.

Kerlinger, F. (1989). Foundations of Behavioral Research (3rd Edition). New York, NY: Holt, Rinehart, and Winston.

Kim, J. & Mueller, C. (1978a). Introduction to Factor Analysis: What It IS And How To Do It. Beverly Hills, CA: Sage Publications.

Kim, J. & Mueller, C. (1978b). Factor Analysis: Statistical Methods and Practical Issues. Beverly Hills, CA: Sage Publications.

Kinney, J. and Stephens, M.A. (1989). Caregiving Hassles Scale: Assessing the Daily Hassles of Caring For A Family Member With Dementia. The Gerontologist, 29(3), 328-332.

Kosberg, J. & Cairl, R. (1986). The Cost of Care Index: A Case Management Tool for Screening Informal Care Providers. The Gerontologist, 26(3), 273-278.

Larson, R. (1978). Thirty Years of Research on the Subjective Well-Being of Older Americans. Journal of Gerontology, 33(1), 109-125.

Lauer, R. & Handel, W. (1983). Social Psychology: Theory and Application of Symbolic Interactionism (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall, Inc.

Lawton, M. P. (1982). The Well-Being and Mental Health of the Aged. In T. Field, A. Huston, H. Quay, L. Troll, and G. Finley (Eds.). Review of Human Development (pp.. 614-628). New York, NY: John Wiley & Sons.

Lawton, M. P. (1983). The Varieties of Wellbeing. Experimental Aging Research, 9(2), 65-72.

Lawton, M. P., Kleban, M., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring Caregiving Appraisal. Journal of Gerontology, 44(3), P61-P71.

Lazarus, R. (1982). Thoughts on the Relations Between Emotion and Cognition. American Psychologist, 37(9), 1019-1023.

Lazarus, R. & Folkman, S. (1986). Cognitive Theories of Stress and the Issue of Circularity. In M. H. Appley & R. Trumbull (Eds.), Dynamics of Stress: Physiological, Psychological and Social Perspectives (pp. 63-80). New York, NY: Plenum Press.

LeVande, D. & Montcalm, D. (1988, October). Defining Caregiver Burden: Issues in Conceptualization and Measurement. A paper presented at the University-Based Research on Aging Conference at Michigan State University, East Lansing, MI.

Manis, J. and Meltzer, B. (1978). Introduction: Intellectual Antecedents and Basic Propositions of Symbolic Interactionism. In J. Manis and B. Meltzer (Eds.), Symbolic Interaction: A Reader in Social Psychology, 3rd Edition (pp. 1-10). Boston, MA: Allyn and Bacon, Inc.

Matthews, S. (1988). The Burdens of Parent Care: A Critical Evaluation of Recent Findings. Journal of Aging Studies, 2(2), 157-165.

Matthews, S. & Tarler-Rosner, T. (1988). Shared Filial Responsibility: The Family as the Primary Caregiver. Journal of Marriage and the Family, 50(February), 185-195.

Meltzer, B., Petras, J., & Reynolds (1978). Varieties of Symbolic Interactionism. In J. Manis & B. Meltzer (Eds.), Symbolic Interaction: A Reader in Social Psychology, 3rd Edition (pp. 41-57). Boston, MA: Allyn and Bacon, Inc.

Montgomery, R. (1989). Investigating Caregiver Burden. In K. Markides & C. Cooper (Eds.), Aging, Stress and Health (pp.201-218). New York, NY: John Wiley & Sons.

Montgomery, R., Gonyea, J. & Hooyman, N. (1985a). Caregiving and the Experience of Subjective and Objective Burden. Family Relations, 34(January), 19-26.

Montgomery, R., Stull, D., & Borgatta, E. (1985b). Measurement and the Analysis of Burden. Research on Aging, 7(1), 137-52.

Moos, R. & Mitchell, R. (1982). Social Network Resources and Adaptation: A Conceptual Framework. In T.A. Wills (Ed). Basic Processes in Helping Relationships, pp. 213-232. New York, NY: Academic Press.

Norusis, M. (1988). SPSS-X Advanced Statistics Guide (2nd edition). Chicago, IL: SPSS, Inc.

Ogle, K., Stommel, M., Given, C., & Given, B. (Undated). Reactions to the Caregiving Role: A Comparison of Husbands and Wives. Manuscript Submitted for Publication.

Pearson, J., Verma, S., & Nellett, C. (1988). Elderly Psychiatric Patient Status and Caregiver Perceptions as Predictors of Caregiver Burden. The Gerontologist, 28(1), 79-83.

Pearlin, L., Mullan, J., Semple, S. & Skaff, M. (1990). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. The Gerontologist, 30(5), 583-594.

Pett, M., Caserta, M., Hutton, A., & Lund, D. (1988). Intergenerational Conflict: Middle-Aged Women Caring for Demented Older Relatives. American Journal of Orthopsychiatry, 58(3), 405-417.

Poulshock, S. & Deimling, G. (1984). Families Caring for Elders in Residence: Issues in the Measurement of Burden. Journal of Gerontology, 39(2) 230-239.

Pratt, C., Schmall, V., Wright, S. & Cleland, M. (1985). Burden and Coping Strategies of Caregivers to Alzheimer's Patients. Family Relations, 34(January), 27-33.

Pruchno, R. & Resch, N. (1989). Aberrant Behaviors and Alzheimer's Disease: Mental Health Effects of Spouse Caregivers. Journal of Gerontology, 44, S177-S182.

Radloff, L. (1977). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. Applied Psychological Measurement, 1(3), 385-401.

Rice, C. (1988). Caregiver Strain: A Structural Equation Model. Unpublished Doctoral Dissertation, Washington University.

Ritzer, G. (1983) Contemporary Sociological Theory. New York, NY: Alfred A. Knopf.

Robinson, B. (1983). Validation of a Caregiver Strain Index. Journal of Gerontology, 38(3), 344-348.

Robinson, B. & Thurnher, M. (1979). Taking Care of Aged Parents: A Family Cycle Transition. The Gerontologist, 19(6), 586-593.

Romeis, J. (1989). Caregiver Strain: Toward An Enlarged Perspective. Journal of Aging and Health, 1(2), 188-208.

Rossi, P., Wright, J., Anderson, A. (1983). Handbook of Survey Research. Orlando, FL: Academic Press.

Russell, D. & Cutrona, C. (1984). The Social Provisions Scale Unpublished Instrument.

Schick, F. L. (Ed.). (1986). Statistical Handbook on Aging Americans. Phoenix, AZ: Oryx Press.

Select Committee on Aging, House of Representatives, Subcommittee on Human Services. (1987). Exploding the Myths: Caregiving in America (Publication No. 99-611). Washington, DC: U.S. Government Printing Office.

Shanas, E. (1979). The Family as a Social Support System in Old Age. The Gerontologist, 19(2), 169-174.

Shanas, E. & Sussman, M. (1981). The Family in Later Life: Social Structure and Social Policy. In J. G. March (Ed.), Aging: Stability and Change in the Family (pp.211-231). New York, NY: Academic Press.

Silliman, R., Earp, J., Fletcher, R., Wagner, E. (1987). Stroke: The Perspectives of Family Caregivers. The Journal of Applied Gerontology, 6(4), 363-371.

Silverstone, B. (1979). Issues for the Middle Generation: Responsibility, Adjustment, and Growth. In P. Kagan (Ed.), Aging Parents (pp. 107-115). Los Angeles, CA: University of Southern California Press.

Stephens, M.A. & Kinney, J. (1989). Caregiving Stress Instruments: Assessment of Content and Measurement Quality. Gerontology Review, 2(1), 40-54.

Stommel, M., Given, C., & Given, B. (Undated). Depression as an Overriding Variable Explaining Caregiver Burdens. Manuscript Submitted for Publication.

Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the Frail Elderly: A National Profile (U.S. Department of Health and Human Services Public Information Series: Health Care for the Aging). Washington, DC: U.S. Government Printing Office.

Stryker, S. (1980). Symbolic Interactionism: A Social Structural Version. Reading, MA: The Benjamin Cummings Publishing Company.

Stryker, S. (1981). Symbolic Interactionism: Themes and Variations. In M. Rosenberg & R. Turner (Eds.), Social Psychology: Sociological Perspectives (pp. 3-29). New York, NY: Basic Books, Inc. Publishers.

Stryker, S. (1982). Identity Salience and Role Performance: The Relevance of Symbolic Interaction Theory For Family Research. In M. Rosenberg & H. Kaplan (Eds.), Social Psychology of the Self-Concept (pp. 200-223). Arlington Heights, IL: Harlan Davidson, Inc.

Stull, D. (1989, November). The Concept of Caregiver Burden: Its History, Measurement, and Structure. A paper presented at the 42nd Annual Scientific Meeting of the Gerontological Society of America, Minneapolis, MN.

Thompson, E. & Doll, W. (1982). The Burden of Families Coping with the Mentally Ill: An Invisible Crisis. Family Relations 31(July), 379-388.

Townsend, A., Noelker, L., Deimling, G. and Bass, D. (1989). Longitudinal Impact of Interhousehold Caregiving on Adult Children's Mental Health. Psychology and Aging, 4(4), 393-401.

Turner, J. & Beeghley, L. (1981). The Emergence of Sociological Theory. Homewood, IL: The Dorsey Press.

Veit, C. & Ware, J. (1983). The Structure of Psychological Distress and Well-Being in General Populations. Journal of Consulting and Clinical Psychology, 51(5), 730-742.

Ware, J., Davies-Avery, A., & Brook, R. (1980). Conceptualization and Measurement of Health for Adults in the Health Insurance Study: Volume VI, Analysis of Relationships Among Health Status Measures (R-1987/6-HEW). Santa Monica, CA: The Rand Corporation.

Ware, J., Johnston, S., Davies-Avery, A., & Brook, R. (1979). Conceptualization and Measurement of Health for Adults in the Health Insurance Study: Volume III, Mental Health (R-1987/3-HEW). Santa Monica, CA: The Rand Corporation.

Williamson, G. & Schulz, R. (1990). Relationship Orientation, Quality of Prior Relationship, and Distress Among Caregivers of Alzheimer's Patients. Psychology and Aging, 3(4), 502-509.

Zarit, S., Orr, K., & Zarit, J. (1985). The Hidden Victims of Alzheimer's Disease: Families Under Stress. New York, NY: New York University Press.

Zarit, S., Reever, K., Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden. The Gerontologist, 20(6), 649-655.

Zarit, S. Todd, P. & Zarit, J. (1986). Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study. The Gerontologist, 26(3), 260-266.

Zarit, S. & Toseland, R. (1989). Current and Future Direction in Family Caregiving Research. The Gerontologist, 29(4), 481-483.

APPENDICES

APPENDIX A

APPENDIX A

CAREGIVING INVENTORY

Response Options
(5) Strongly Agree
(4) Agree
(3) Neither Agree nor Disagree
(2) Disagree
(1) Strongly Disagree

1. Caring for my relative is a very lonely task.
2. My family works together at caring for____. (R)*
3. My financial resources are adequate to pay for things that are required for caregiving.(R)
4. Since I began caring for ____, my day-to-day schedule has changed a lot.
5. Feeling needed by ____ is important to me.(R)
6. I care for ____ because I have nowhere else to go.
7. I feel overwhelmed by the problems I have caring for ____.
8. I wish the family depended less on me to care for ____.
9. Sometimes I feel very frustrated when ____ can't remember recent events.
10. It's difficult to pay for ____ 's health needs and services.
11. My activities are centered around care for ____.
12. People make me feel it is my job to care for ____.
13. I am embarrassed by ____'s behavior.
14. I am healthy enough to care for ____.(R)
15. Since caring for ____, I feel that my family has abandoned me.
16. Caring for ____ has put a financial strain on the family.
17. I get very frustrated at having to constantly re-explain things to ____.
18. I have to stop in the middle of my work or activities to provide care.
19. Caring for ____ is important to me.(R)
20. I take care of ____ only because I have to.
21. I resent having to take care of ____.
22. It is very difficult to get help from my family in taking care of ____.
23. ____ and I can afford help from home care agencies.(R)

CAREGIVING INVENTORY (continued)

Response Options
(5) Strongly Agree
(4) Agree
(3) Neither Agree Nor Disagree
(2) Disagree
(1) Strongly Disagree

24. I have eliminated things from my schedule since caring for ____.
25. I enjoy caring for ____.(R)
26. I feel frustrated when ____ seems out of touch with the world.
27. Others have dumped caring for ____ on to me.
28. I get very discouraged with caring for ____.
29. It takes all my strength to care for ____.
30. I wish that my family would understand my feelings about caring for ____.
31. If I could afford it, I would find some other way to care for ____.
32. The constant interruptions make it difficult to find time for relaxation.
33. Caring for ____ makes me feel good.(R)
34. Since caring for ____, sometimes I wish I were dead.
35. I feel very pleased when ____ remembers special things that are important to me.(R)
36. My health has gotten worse since I've been caring for ____.
37. My family has done all they can do to help with caring for ____.
38. I'm worried that I won't have enough money to care for ____.
39. Caring for ____ does not affect my social activities.(R)
40. Given the situation, I think I'm doing a good job caring for ____.(R)
41. My family (brothers, sisters, children) left me alone to care for ____.
42. ____ depends too much on me.
43. Caring for ____ puts a strain on family relationships.
44. ____ sometimes disrupts meals or makes them unpleasant.
45. Since I began taking care of ____, I worry about finances a lot.
46. I visit family and friends less since I have been caring for ____.
47. Of all my family members, I am best suited to care for ____.(R)
48. My family made me the caregiver for ____.

CAREGIVING INVENTORY (continued)

Response Options
(5) Strongly Agree
(4) Agree
(3) Neither Agree Nor Disagree
(2) Disagree
(1) Strongly Disagree

49. Since caring for ____, sometimes I hate the way my life has turned out.
50. I have enough physical strength to care for ____.(R)
51. My family understands how difficult caring is for me.(R)
52. Caring for ____ hasn't changed my relationship with my friends.(R)
53. I take care of ____ better than anyone else.(R)
54. ____ is unable to distinguish past events from present events.
55. I feel I was forced into caring for ____.
56. I feel trapped by my caregiving role.
57. Caregiving has worn me out.
58. My family helps me when I have problems in caregiving.(R)
59. Since caring for ____, it seems like I'm tired all of the time.
60. I miss the companionship of friends since becoming a caregiver.
61. At this time in my life, I don't think I should have to be caring for ____.
62. I feel privileged to care for ____.(R)
63. Caring for ____ has made me miserable.
64. Since being a caregiver, I don't get proper exercise.
65. My family helps me take breaks from caregiving.(R)
66. I should care for ____ because of all that he/she has done for me.
67. I believe it is my responsibility to care for ____.
68. It seems like caregiving has always been part of my life.
69. My family admires me for being a caregiver.(R)
70. I could not live with myself if I just quit caring for ____.
71. I have done all for ____ that anyone can expect.(R)
72. ____ really appreciates what I do for him/her.(R)
73. I am doing more for ____ than he/she ever did for me.
74. Just when I thought times were going to be easier for me, I have to be a caregiver.
75. I used to think that this would be a good time in my life, but now I care for ____.
76. I really want to care for ____.(R)
77. I will never be able to do enough caregiving to repay ____.

* "(R)" signifies items which have been reversed.

APPENDIX B

APPENDIX B

CAREGIVER WELL-BEING

Caregiver's Physical Health

1. During the past three months, how many days were you so sick that you were unable to carry on your usual activities (like going to work, working around the house, caring for family member)?

   Number of days _____

7. How would you rate your overall physical health at the present time? Would you say it is:

   Excellent (1) Good (2) Fair (3) Poor (4)

8. How is your physical health now compared with three months ago? Would you say it is:

   Better (1) About the same (2) Worse (3)

2. In the past 3 months, how many times have you seen a doctor in his/her office?

   Number of times _____

4. In the past 3 months, how many times have you gone to an Emergency Room or Urgent Care Clinic for yourself?

   Number of times _____

6. In the past 3 months, how many days have you been hospitalized for physical illness?

   Number of days _____

Caregiver's Financial Status

2. Considering all of these sources of income, what was the total income before deducting for taxes for your household in 1986? Was it:

$ 0 - $1,999 (1)	$ 8,000 - $ 8,999 (8)
$2,000 - $2,999 (2)	$ 9,000 - $ 9,999 (9)
$3,000 - $3,999 (3)	$10,000 - $14,999 (10)
$4,000 - $4,999 (4)	$15,000 - $19,999 (11)
$5,000 - $5,999 (5)	$20,000 - $24,999 (12)
$6,000 - $6,999 (6)	$25,000 - $29,999 (13)
$7,000 - $7,999 (7)	$30,000 or above (14)

4. Do you feel that your total income for 1986 was enough to meet your usual monthly expenses and bills?

Yes (1) No (2)

Caregiver's Mental Health

A. Rand Corporation's Positive Well-Being Scale

Response Options
(4) Almost All Of The Time
(3) Most Of The Time
(2) Some Of The Time
(1) Rarely Or None Of The Time

DURING THE PAST MONTH HOW MUCH OF THE TIME ...

1. Have you felt that the future looks hopeful and promising?(R)*
2. Has your daily life been full of things that were interesting?(R)
3. Did you feel relaxed and free of tension?(R)
4. Have you generally enjoyed the things you do?(R)
5. Have you felt calm and peaceful?(R)
6. Have you felt cheerful or light hearted?(R)
7. Were you a happy person?(R)
8. Have you been satisfied or pleased with your personal life?(R)
9. Have you expected to have an interesting day?(R)
10. Have you been waking up feeling fresh and rested?(R)

(Alpha=.92; N=301; x=2.37; sd=.64)

B. Center For Epidemiological Studies Depression Scale (CES-D)

Response Options
(4) Almost All Of The Time
(3) Most Of The Time
(2) Some Of The Time
(1) Rarely Or None Of The Time

DURING THE PAST MONTH HOW MUCH OF THE TIME ...

11. Were you bothered by things that usually don't bother you?
12. Have you not felt like eating; had a poor appetite?
13. Have you felt that you could not shake off the blues, even with the help of family and friends?
14. Have you felt that you were just as good as other people? (R)
15. Have you had trouble keeping your mind on what you were doing?
16. Have you felt depressed?
17. Have you felt that everything you did was an effort?
18. Have you felt hopeful about the future? (R)
19. Have you thought your life has been a failure?
20. Have you felt tearful?
21. Has your sleep been restless?
22. Were you happy? (R)
23. Have you talked less than usual?
24. Have you felt lonely?
25. Were people unfriendly?
26. Have you enjoyed life? (R)
27. Have you had crying spells?
28. Have you felt sad?
29. Have you felt people disliked you?
30. Have you felt you could not get going?

(Alpha=.70; N=301; x=1.79; sd=.44)

Caregiver's Social Relationships

A. Social Support Scale

Response Options
(1) Strongly Disagree
(2) Disagree
(3) Agree
(4) Strongly Agree

1. There are people I can depend on to help me if I really need it.(R)
2. I feel that I do not have close personal relationships with other people.

Social Support Scale (Continued)

Response Options
(1) Strongly Disagree
(2) Disagree
(3) Agree
(4) Strongly Agree

3. There is no one I can turn to for guidance (for help) in times of stress.
4. There are people who depend on me for help.(R)
5. There are people who enjoy the same social activities I do.(R)
6. I feel personally responsible for the "well-being" of my relative.
7. I do not think other people respect my skills and abilities.
8. If something went wrong, no one would come to my assistance.
9. I have close relationships that provide me with a sense of security and well-being.(R)
10. There is someone I could talk to about important decisions in my life.(R)
11. I have relationships where my competence and skills are recognized.(R)
12. There is no one who shares my interests and concerns.
13. There is no one who really relies on me for their well-being.
14. There is no one I can depend on for aid if I really need it.
15. There is no one with whom I feel comfortable talking about problems.
16. There are people who admire my talents and abilities.(R)
17. There are people I can count on in an emergency.(R)
18. No one needs me to care for them.

* "(R)" indicates item was reversed during scoring.

Note: Scoring was completed so **higher scores reflect more compromised well-being.**

APPENDIX C

APPENDIX C

The "Grand Analysis" -- Hypothesized Item Overlapping

On the basis of the subjects/topics covered by the items contained within the different factors, it was hypothesized that the following actions would occur during the combined ("grand") analysis:

1. The **Financial** factors identified during the independent analyses would merge.

2. Likewise, the items contained within the independently derived **Caregiver Health Status** factors would combine to form one factor.

3. The items constituting the **Feeling "Needed"** factor were expected to be absorbed by several conceptually related factors, i.e., **Family Responsiveness, Caregiver Sense of Responsibility,** and **Role-Related Reinforcers.**

4. As the various arrows indicate, a number of other factors were expected to "exchange" items. These "signs" were intentionally, bidirectional because there was not enough data--of a theoretical or empirical nature--to prompt statements regarding which factors would actually draw items from the others.

These predictions are presented graphically in **Figure 7.**

Significantly, the following events were not anticipated:

1. The marked degree of overlap detected between the **Role-Related Reinforcers** and **Positive Affect** factors.

2. The absorption of the **Social Affirmation** factor by **Social Support.**

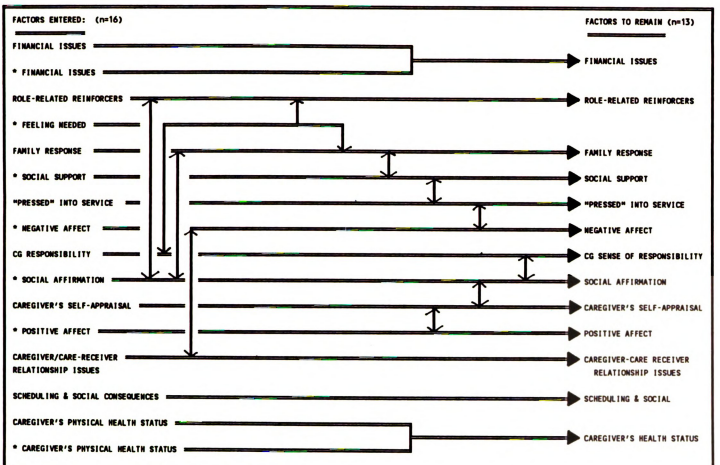

Figure 7 HYPOTHESIZED ITEM OVERLAPPING IN LIGHT OF THE 9-FACTOR BURDEN AND 7-FACTOR WELL-BEING SOLUTIONS PROPOSED

NOTE: * SIGNIFIES FACTORS DERIVED FROM THE CAREGIVER WELL-BEING INSTRUMENT