THE SATISFACTION OF FRAIL ELDERS WITH CARE RECEIVED FROM FAMILY MEMBERS

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A Dissertation

Presented to
Oregon Health & Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

2003

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ACKNOWLEDGEMENT OF FINANCIAL SUPPORT

Funding for this research was provided by The National Institute for Nursing Research via an Institutional Nursing Research Service Award, Nursing Care of Older People, Grant No. T32 NR07048 (1998-2000) and by a John A. Hartford Foundation Pre-Doctoral Scholarship (2001-2003).

ACKNOWLEDGMENTS

Although this dissertation bears my name, its completion was only possible because of the many wonderful people who encouraged, challenged, supported and finally cheered me on the way.

I would like to thank the members of my dissertation committee for their support and assistance. Pat Archbold provided inspiration and guidance throughout my doctoral program. Her vision of the importance of family care has provided a constant reminder of why research in this area is vital. Pat, thank you for believing in me, and inspiring me to expand my horizons. Barbara Stewart spent many hours helping me to analyze and understand the data. Thank you Barbara for showing me that well crafted research and careful statistical analysis can provide insights unavailable any other way. The consummate researcher, you have modeled how to do careful and thorough analysis, and have demonstrated great patience with my often fumbling attempts. Deb Messecar spent many hours helping me write the first draft of my proposal. Deb, thank you for the many hours of editing, and help in organizing my thoughts. Thank you also for your words of encouragement along the way.

Terri Harvath spent many hours helping me to clarify my ideas about family care research. Her insights and insistence that I challenge my pre-conceived ideas helped me grow and change not only as a nurse researcher, but as a person. Thanks Terri!

Special thanks to Gary Miranda, my editor, who challenged me not only to write well, but to think more clearly about family care.

Four of us started the doctoral program together in 1998—Maggie Emery, Seiko Izumi, Napaporn Wanitkun, and myself. Thank you Maggie, Seiko, and Napaporn for

providing the incredible support that only a cohort can share. We made the journey together, and that makes reaching our goal that much sweeter.

To my two dear friends—Sharron Francisco and RuthAnn Wyman. You have put up with my lack of time and my distractedness! Thanks for your understanding, your listening ears, and your warm hearts. May we share many future hours!

Thank you to my colleagues at Walla Walla College School of Nursing for your wonderful support, and willingness to work around my school schedule during the past five years.

Finally, I would like to thank my family for their love and support. Mom and Dad, thanks for the many times you came to help with projects around the house and yard, for bringing home cooked food, and for providing a wonderful place to escape the busyness of school. Above all, thanks for raising me to believe that I could reach my goals! Thank you, Scott and Ashley for allowing your mom to complete this journey. It meant hours away from you, and even some hours with you, had to be shared with books and articles! Thanks for putting up with an often tired and distracted mother—who loves you very much. Celebrating our triple graduations this year is a special treat. Gerry, thank you for supporting me—for always believing that I could make it—even when at times I wondered. I'm especially grateful for your support and patience during the final hectic months as I prepared for my dissertation defense and finished writing my dissertation—I could not have done it without you!

Five years ago I began this journey believing that God had opened the door to this wonderful opportunity. He has been with me all the way, and I thank Him for always being my quiet strength.

ABSTRACT

Title: The Satisfaction of Frail Elders with Care Received From Family Members

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This dissertation study focused on understanding the satisfaction of frail elder care receivers with care they received from a family member. Specifically, it assessed the relative contribution of care receiver, caregiver, and relationship variables in explaining care receiver satisfaction with family care.

The study was guided by three aims:

Aim 1: To describe the underlying factor structure of the Care Receiver Satisfaction with Care Scale, and determine whether the scale measures one global factor versus two or three separate but correlated factors.

Aim 2: To explore the association between care receiver evaluation of caregiver role enactment and selected care receiver, relationship, and caregiver variables. These variables include: (a) care receiver mutuality, cognitive function, functional health, subjective well-being, and demographic characteristics; (b) duration and type of the care receiver and caregiver relationship; and (c) caregiver mutuality, preparedness, physical health, depressive symptoms, caregiver role strain, and demographic characteristics.

Aim 3: To determine which care receiver, relationship, and caregiver variables predict variance in care receiver evaluation of caregiver role enactment.

The study used baseline data collected from the Family Care Study (Archbold, Stewart, & Hornbrook, R01 AG17909, 1999). The sample consisted of 123 care receiver-caregiver dyads. The 123 care receivers were mostly women (80), and Caucasian (117). Their ages ranged from 65-95, with a mean age of 78.8 years. Caregivers were divided between spouses (66), and other types of family members (57), and had a mean age of 63.7 (SD 16.3). Of the 123 caregivers, only 34 were employed outside the family care situation. The caregivers and care receivers had known each other for an average of 46.4 years, and 100 of the caregivers and care receivers lived in the same household.

The dependent variable, care receiver satisfaction with family care, was measured by the Care Receiver Satisfaction with Family Care Scale (Archbold, Stewart, & Lucas, 1986). The scale contained 12 items, asking the care receiver to rate the care they received from their family member on a 0-4 point scale, with response options of "never," "sometimes," "most of the time," "nearly always," or "always."

Hierarchical multiple regression was used to determine which care receiver, relationship, and caregiver variables predicted variance in care receiver satisfaction with family care. A parsimonious model was identified that included seven predictor variables: care receiver difficulty with activities of daily living (ADLs), care receiver positive affect, care receiver mutuality, caregiver physical health and depressive symptoms,

caregiver preparedness for family care, and caregiver role strain from feelings of manipulation.

Overall, the greatest amount of variance explained occurred for care receiver satisfaction with the affective components of family care (44%), followed by satisfaction with the caregiver's attentiveness to things important to the care receiver (26%), and satisfaction with the instrumental aspects of family care (17%).

Understanding the factors that influence care receiver satisfaction can assist health care providers in designing effective interventions that support all the participants in the family care situation.

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CHAPTER 1: INTRODUCTION

Specific Aims

Most frail elders prefer to remain at home. Family members understand this preference, and many are willing and eager to undertake the caregiving role. Recent changes in the healthcare system have increased caregiving demands on families who already provide 80% to 90% of the care needed by chronically ill older people (Family Caregiver Alliance, 1996). This increase is attributable to several factors, including reduced hospital length of stay, and a decline in nursing home use (Bishop, 1999; Boland, & Sims, 1996).

As in the past, family members who provide home care assume a role for which they have neither the professional training nor the professional detachment—a role that entails many demands, sacrifices, and risks (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Given, Given, Stommel, & Azzouz, 1999). In addition, however, the increased acuity of elderly patients living at home or discharged to the community has multiplied the amount of highly technical care provided in the home (Brickner, 1997). Thus there are reasons to think that the quality of family care may be threatened.

Quality of family care can be explored from several different perspectives: self-evaluation by the caregiver, evaluation by an outside authority, or evaluation of care by the elder care receiver. Each perspective is important, and provides unique information about the caregiving situation, but the views may or may not be consistent with one another (Morrow-Howell, Proctor, & Rozario, 2001). The caregiver's evaluation provides information about how he or she perceives the quality of care; the well-being of the elder may or may not be explicitly evaluated. Evaluation by a professional explores connections between the actions of the caregiver and the well-being of the elder receiving the care. Such an evaluation assumes an external standard of care or normative standard of excellence against which the individual caregiving situation can be measured and understood (Schumacher et al., 1998). The elder care receiver's evaluation of care includes how satisfied the care receiver is with the care received. This perspective provides us with information about the caregiver's success in meeting the care receiver's perceived needs and expectations—matters on which the care receiver is the ultimate authority (Williams, 1994; Morrow-Howell et al., 2001). Any discussion of the quality of family care must ultimately include all three of these perspectives, though individual research efforts may explore them separately.

Given the complexity of the role that caregivers assume, it is hardly surprising that most of the research on the quality of family caregiving has focused on the first of these three perspectives—that is, on better understanding the role of the caregiver from the caregiver's perspective (Martini et al., 2001; Wranesh Cook, 2000). This trend is reinforced by the inherent difficulty of acquiring reliable data from the care receivers themselves, many of whom are cognitively impaired. Despite these obstacles, however, the care receiver's experience is an important—one might even say the central—outcome of family care. Understanding what factors contribute to making that experience a positive one will benefit care receivers, caregivers, and health care providers in general. Yet few studies of the quality of family care have focused on the care receiver's satisfaction with care or the factors that affect it (Given & Given, 1991; Phillips, Morrison, & Chae, 1990; Schumacher, Stewart, & Archbold, 1998; Morrow-Howell et al., 2001).

The proposed study will approach the measurement of quality from the perspective of the elder care receiver. That is, I will explore only one indicator of overall quality of care--namely, how satisfied the care receiver is with the way in which a family member enacts the role of caregiver. This approach addresses a gap in the literature and affords an opportunity to begin exploring quality of family care from the perspective of the care receiver. The proposed study will use baseline data collected from the Family Care Study (Archbold, Stewart, & Hornbrook, R01 AG17909, 1999). Referred to throughout this proposal as the "parent study," the Family Care Study is a randomized controlled efficacy trial of PREP, a home health intervention designed to increase Preparedness, Enrichment, and Predictability in family care for frail elders. The parent study is funded by the National Institute on Aging (NIA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institute of Nursing Research (NINR).

The goal of this study is to better understand the concept of care receiver evaluation of caregiver role enactment. The study has three aims.

Aim 1: To describe the underlying factor structure of the Care Receiver Satisfaction with Care Scale, and determine whether the scale measures one global factor versus two or three separate but correlated factors.

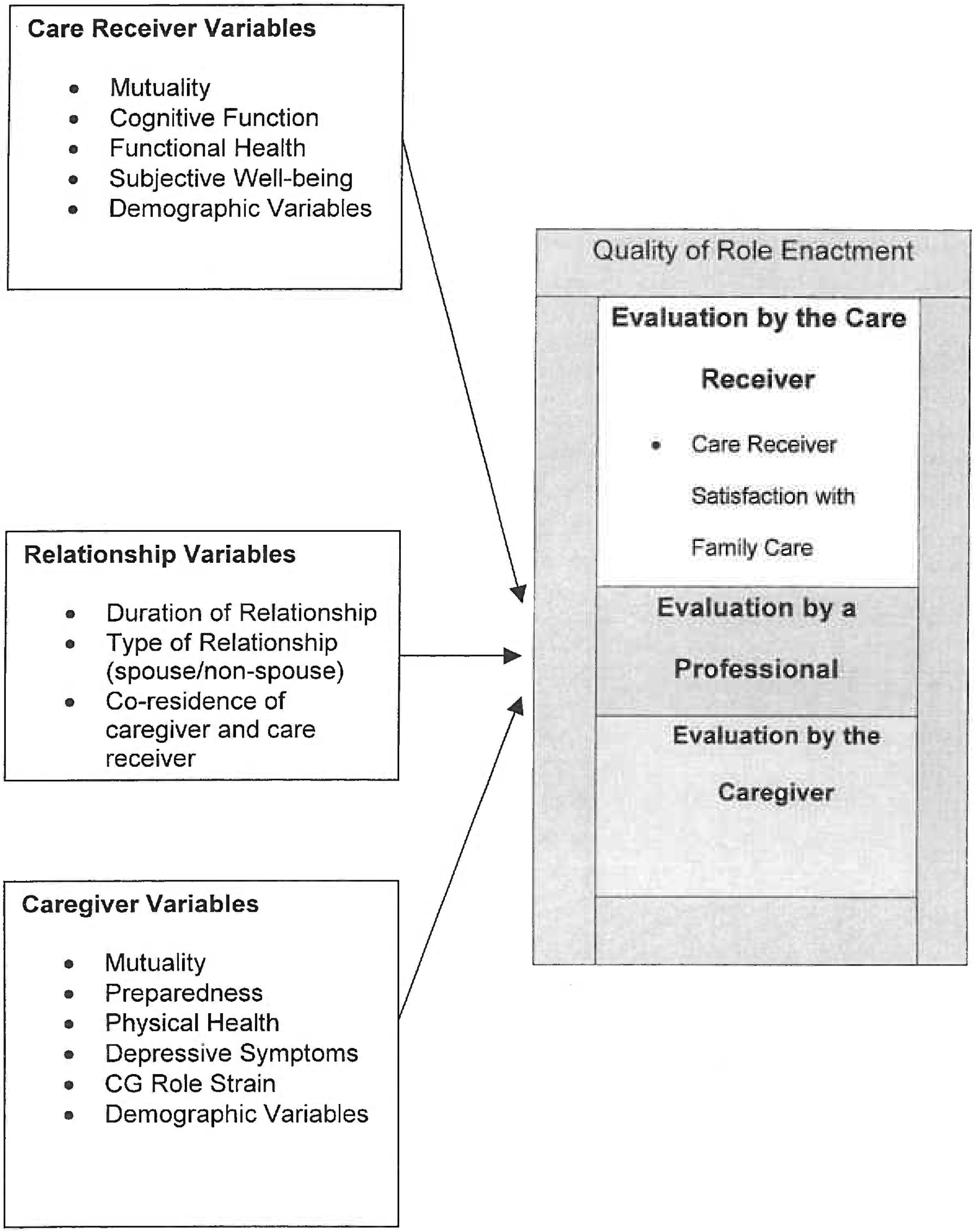
Aim 2: To explore the association between care receiver evaluation of caregiver role enactment and selected care receiver, relationship, and caregiver variables. These variables include: (a) care receiver mutuality, cognitive function, functional health, subjective well-being, and demographic characteristics; (b) duration and type of the care receiver and caregiver relationship; and (c) caregiver mutuality, preparedness, physical health, depressive symptoms, caregiver role strain, and demographic characteristics.

Aim 3: To determine which care receiver, relationship, and caregiver variables predict variance in care receiver evaluation of caregiver role enactment.

Figure 1 represents the conceptual model underlying the dissertation study. Three categories of variables are thought to affect the quality of caregiver role enactment: care receiver variables, relationship variables, and caregiver variables. The pertinent care receiver variables are mutuality, cognitive function, functional health, subjective well-being, and demographic variables. The relationship variables—those that apply to both the care receiver and caregiver—are the duration of the relationship, the type of relationship (spouse/non-spouse), and whether the care receiver and caregiver live together. The caregiver variables are mutuality, preparedness, physical health, depressive symptoms, caregiver role strain, and demographic variables. As seen in the box on the right, quality of role enactment can be evaluated from the perspective of the care receiver, the health care professional, or the caregiver.

This dissertation approaches the evaluation of caregiver role enactment from the perspective of the care receiver. Although the care receiver's evaluation of the caregiver's role enactment might encompass many components, for purposes of this dissertation I will henceforth be using the term “care receiver satisfaction” to represent the concept of care receiver evaluation of caregiver role enactment.

Figure 1: The Conceptual Model



CHAPTER 2: REVIEW OF THE LITERATURE

Background and Significance

Although sparse, the literature exploring the care receiver experience of family care looks at care receiver responses in a variety of ways. These include determining whether the care receiver regards the relationship as a positive, adaptive, and growth-oriented experience (Hollis-Sawyer, 2001); exploring the level of anger expressed by the care receiver (Walker et al., 1992); assessing care receiver satisfaction with life as a whole, rather than with caregiving (Dwyer, Lee, & Jankowski, 1994); exploring negotiations between the caregiver and care receiver (Russell et al., 1999); assessing care receiver satisfaction with the helping relationship (Martini et al., 2001); and evaluating care receiver satisfaction with care they received from their family member (Lucas, 1986).

In addition to being few in number, previous studies of the care receiver experience have considerable limitations, including the size and composition of the samples. Some studies included only mothers and their caregiving daughters (Hollis-Sawyer, 2001; Martini et al., 2001; Walker & Allen, 1991; Walker et al., 1992), studied dyads where supportive care rather than intensive caregiving was being provided (Martini et al., 2001), or were made up of small samples (Lucas, 1986; Russell et al., 1999). Given these limitations, the opportunity to explore care receiver satisfaction with family care using a large sample of caregivers and care receivers that has both spousal and parent-child dyads may provide a more complete understanding of this area.

Satisfaction

Patient satisfaction has been variously defined as an affective response to care (Applebaum, Straker, & Geron, 2000); an evaluation of the quality of health care received from the viewpoint of the recipient (Ryden et al., 2000); an individual's affective response varying in the amount of gratification with something (Burr et al., 1979); the fulfillment of positive expectations (Sitzia and Wood, 1997); and a positive evaluation of the instrumental aspects of care received and an expressed contentment with the affective aspects of caregiving (Lucas, 1986). The differing definitions of satisfaction arise from the variety of theoretical perspectives that have framed research in this area. Three theoretical perspectives covered for this study will be discussed: Social Exchange Theory, Expectation Theories, and Symbolic Interactionism.

Social Exchange Theory

Social Exchange Theory—also referred to as Equity Theory—posits that satisfaction is related to perceived equity, or balance, of inputs and outputs (Williams, 1994). It makes use of an economic market metaphor to describe human relationships, and assumes that people are continually seeking profit and reward in the form of socioemotional and instrumental rewards (Burr et al., 1979). It focuses on how relationships develop, on how they are experienced, on the patterns and dynamics that emerge within relationships, and on the role that expectations play in the evaluation of intimate relationships (Sabatelli & Shehan, 1993).

Core assumptions of this perspective include the following:

1. Individuals strive to maximize rewards and minimize costs in their social interactions or exchanges, and will continue to engage in exchanges for only as long as the benefits are greater than the costs, or until there is a better alternative (Bengtson, Burgess, & Parrott, 1997; Wright & Aquilino, 1998).
2. Each participant in an interaction brings resources to the interaction or exchange, and resources need not be material (Bengtson et al., 1997).
3. Exchanges are governed by norms of reciprocity with an understanding that when we give something, we trust that something of equal value will be received in exchange (Bengtson et al., 1997).
4. It is psychologically uncomfortable to be the party who consistently receives more in an exchange relationship than is given in return (Dwyer, Lee, & Jankowski, 1994).
5. The more inequitable the exchanges that exist between the two parties in an exchange relationship, the more distress each person will feel (Carruth, Tate, Moffett, & Hill, 1997).

Exchange resources play an important role in the interactions between individuals, and can be likened to the currency of power between individuals. Resources can be divided into two categories: 1) socioemotional and symbolic and 2) instrumental. Socioemotional and symbolic resources include love, status, and information; instrumental resources include money, goods, and services (Sabatelli & Shehan, 1993).

Research regarding family caregiving framed within this theoretical perspective focuses on the issues of exchange of emotional and instrumental support between the care receiver and others such as the caregiver, friends, and family (Carruth et al., 1997; Dwyer, Lee, & Jankowski, 1994; Lee, Netzer & Coward, 1995; Wright & Aquilino, 1998). Such research often explores issues of equity or reciprocity between the caregiver and the care receiver (Carruth et al., 1997; Clark & Huttlinger, 1998; Dwyer et al., 1994; Wright & Aquilino, 1998). Dwyer et al., (1994) hypothesized that reciprocity directly affects the stress and burden experienced by the primary caregiver, and indirectly affects satisfaction through stress and burden. Within this perspective, care receiver satisfaction would be affected by whether the care receiver viewed their contributions and those of the caregiver as being balanced within the caregiving situation.

To understand clearly the "lens" that Social Exchange Theory provides for exploration of family caregiving, it is important to understand that it arises from a positivist rather than interpretive tradition. Thus, the focus is on observation, description, and the classification of data, in order to explain and predict, in contrast to the focus on understanding and meaning that would be seen in a theoretical perspective arising from the interpretive tradition (Bengston et al., 1997). This positivist perspective allows researchers to quantify some of the components of the caregiving relationship that have been difficult to conceptualize and measure—for example, resources that the participants bring to a caregiving situation. As resources diminish in old age, elders may find themselves in unbalanced exchange relationships (Lee, Netzer, & Coward, 1995). Although they may be rich in socioemotional and symbolic resources such as love and information, they may have fewer instrumental resources such as money, goods, and services. Caregivers may view them as being in a dependent position where they consistently receive more than they give, and may fail to recognize the resources that they bring to the exchange relationship. Social Exchange Theory provides a lens that allows researchers to explicitly explore the resources that care receivers bring to the relationship, and to quantify the contribution they make in the exchange between the caregiver and care receiver. Because of the differential value that society places on various resources, the resources of love and the wisdom of old age and experience may be valued less than the ability to pay money or to provide physical services. In other words, how one conceptualizes what is of value determines whether an older person is seen as having greater or fewer resources. Further, the elder with dementia may be seen as having lost the socioemotional resources of information or wisdom as well as the instrumental resources of money, goods, and services. Researchers within the Social Exchange perspective attempt to measure socioemotional and symbolic resources as well as instrumental resources, thus providing a way to quantify the contribution of elder care receivers in the exchange relationship.

Some researchers, using Social Exchange Theory, have explored the possibility of life-course equity or reciprocity. This is in contrast to many researchers within family caregiving who focus primarily on the experiences of care receivers and caregivers within the present caregiving situation. Accounting for a life-course perspective may allow an older person to accept unreciprocated support or help from a spouse or child, and not feel that the relationship is unbalanced (Carruth, Holland, & Larsen, 2000). In assessing their exchange resources, they include a longer time perspective in which they may have provided support to the caregiver (e.g., caring for the children when they were young) (Clark & Huttlinger, 1998).

Because it is positioned within a positivist tradition, Social Exchange Theory measures and quantifies the experiences of caregivers and care receivers from an external stance, rather than assessing the meaning and importance of the interaction to the participants (Bengtson et al., 1997). Researchers within this perspective often measure the number and types of activities that a participant brings to the caregiving relationship, rather than the meaning of the experience. While one caregiver may find an activity very "costly" emotionally and physically, another caregiver may find what would be externally measured as a "much greater" amount of care less "costly." This theoretical perspective may ignore individual attributions of importance or value. Thus, use of an external measurement standard to capture the costs, exchange, and reciprocation components of caregiving may not fully capture how the caregiver or care receiver would interpret or conceptualize the "exchange event" (Bengtson, et al., 1997).

Expectation Theories

Several theoretical perspectives within satisfaction research are based in the relationship between the patient's expectations and the actual care that is received. These theories have primarily been used in exploring *patient* satisfaction with *formal* care.

They hold three assumptions in common:

1. Values and expectations exist (Williams, 1994).

2. Expressions of satisfaction are a function of some prior process such as the meeting of the patient's values and expectations (Williams, 1994).
3. An expression of satisfaction implies approval of certain attributes of the care by the patient (Williams, 1994).

Within this perspective patients are viewed as making a cognitive evaluation of the perceived performance or quality of the care based on their previously held expectations, and having an affective response to that evaluation (Applebaum et al., 2000). Researchers hypothesize that satisfaction (or dissatisfaction) is the result of the perceived discrepancy or disconfirmation between what an individual desires or expects and what is experienced (Williams, 1994; Applebaum et al., 2000). Desires have been defined as including expectations of "what is important" or "what should be," and are viewed as arising from averaging past experiences and predictions of what should occur. Categories of expectations may differ: background (result from accumulated learning), interaction (expectations regarding the interaction between the persons in the situation), and action (expectations about what actions will be taken in providing care) (Sitzia & Wood, 1997). Patients have been found to be able to hold different expectations for different aspects of care; when patient expectations match services, the patients express higher levels of satisfaction (Sitzia & Wood, 1997).

The expectancy disconfirmation model has most often been used to evaluate patient reactions to discrete care experiences provided by professional caregivers. It is unclear how appropriate this model would be for measuring satisfaction with care that occurs continuously over an extended period of time (Applebaum et al., 2000). This perspective focuses primarily on the response of the care receiver, rather than including all participants in the situation. Because of its use in formal care settings where many different caregivers may provide care for one patient, this is understandable. In family care, however, an important focus is the relationship between the care receiver and caregiver, and how this affects care receiver satisfaction. Thus, the value of the expectancy disconfirmation model for use in this setting is unclear.

Researchers have noted that a drawback of this theory is that patients may become accustomed to poor care and lower their expectations, making otherwise unsatisfactory care appear to be satisfactory. One way of dealing with this is to frame satisfaction instruments within a standard of ideal expectations, and to ask respondents to compare care they have received to this standard (Applebaum et al., 2000).

Symbolic Interactionism

Symbolic Interactionism "focuses on the connection between symbols (i.e., shared meanings) and interactions (i.e., verbal and nonverbal actions and communications)" (LaRossa & Reitzes, 1993). Symbolic Interactionism places emphasis on the ideas that families are social groups and that through social interaction individuals develop a concept of self and their identities (LaRossa & Reitzes, 1993).

Symbolic Interactionism rests on three central assumptions:

1) "Human beings act toward things on the basis of the meanings that the things have for them" (LaRossa & Reitzes, 1993, p. 143). Meanings arise through the process of interaction between people (Burr, Leigh, Day, & Constantine, 1979; O'Neill & Sorensen, 1991; LaRossa & Reitzes, 1993); they are handled in and modified through an

interpretive process; they are tentative and emergent, and may change over time (O'Neill & Sorensen, 1991; LaRossa & Reitzes, 1993). Beliefs about the importance of meanings influence human behavior (Burr et al., 1979).

2) An individual has a thoroughly social and active self and focuses on the development and importance of self-concept (LaRossa & Reitzes, 1993). Individuals develop self concepts through social interaction, negotiation, and discourse, and this process of developing the self concept is ongoing, ever changing, and dynamic (Burr et al., 1979; LaRossa & Reitzes, 1993; Bengston et al., 1997).

3) There are important interactions between individuals and society as a whole. The relationship between society and the individual is dynamic, allowing learning through interaction (Burr et al., 1979). Individuals are influenced by larger cultural and societal processes and social structures, and, in turn, individuals become the society, and work out the details of social structure (Burr et al., 1979; LaRossa & Reitzes, 1993; Bengston et al., 1997).

Four sets of concepts emerge from the current research regarding Symbolic Interactionism: Identities, roles, interactions, and contexts. I will discuss each of these concepts separately. However, it is important to remember that in reality they are interrelated.

Identities. This refers to the "self-meanings in a role"—the ways in which people define themselves in their various roles. Symbolic Interactionism looks at identities as being hierarchically organized by "salience." Salience refers to the probability of an identity being assumed in any given situation, which in turn depends on a person's commitment or motivation to perform role-related behaviors (LaRossa & Reitzes, 1993).

Roles. These are defined as "more or less integrated sets of social norms that are distinguishable from other sets of norms that constitute other roles" (Burr et al., 1979, p.54). Roles are porous and flexible boundaries within which individuals may construct different identities. Roles are situational, and may be formal as in father, brother, teacher, or student, or informal as in best friend, encourager, or spectator (Burr et al., 1979). They are best understood in relation to positions within society or interpersonal relationships, may arise through negotiation and discourse, and may shift over time (LaRossa & Reitzes, 1993; Bengston et al., 1997).

Interactions. LaRossa & Reitzes state "it is through social interaction that individuals apply broad shared symbols and actively create the specific meanings of self, others, and situations" (LaRossa & Reitzes, 1993, p. 149). Interaction is a formative process that includes the actions, responses and subjective meanings of other people and situations (O'Neill & Sorensen, 1991; LaRossa & Reitzes, 1993). Individuals negotiate and formulate their identities through these interactions (Bengston et al., 1997).

Contexts. This refers to the relationship between individuals and society. These relationships involve negotiation and have structure (LaRossa & Reitzes, 1993). The context in which negotiation and interactions take place affects the meanings and roles that emerge (Bengston et al., 1997).

Because it is positioned within an interpretive tradition, Symbolic Interactionism focuses on assessing the meaning and importance of interactions to the participants, rather than on the perception of an external objective reality (Bengtson et al., 1997). Its dyadic focus allows this perspective to be more inclusive of all "players" in the situation. Rather than care receivers being objectified as passive recipients of care, they are viewed as active participants in the caregiving process, thus providing a more comprehensive understanding of the context in which caregiving occurs, and of the perceptions and responses of all the participants (O'Neill & Sorensen, 1991). This allows for recognition of how individual behavior influences the formulation of roles and identities (Bengston et al., 1997), and on the way in which the interactions between the care receiver and other persons within his or her social network, such as the caregiver, are changed by the caregiving situation (Vernooij-dassen, Persoon, & Felling, 1996). Where research regarding family caregiving positioned in other theoretical perspectives has often focused on the responses of the caregiver to the caregiving situation, Symbolic Interactionism includes all participants, their roles, interactions, the contexts in which the interactions occur, and the meanings that are created. This more comprehensive view of the caregiving situation provides an appropriate lens to explore care receiver satisfaction with family care.

The central position and recognition of the importance of roles within Symbolic Interactionism allow the researcher to explore the concept of role enactment. Role enactment refers to the behavior of people in positions or situations. Within the broad concept of role enactment, one can explore more specific aspects such as the number of roles, how involved an individual is in enacting the role, or the quality of role enactment (Burr et al., 1979). For this dissertation the quality of role enactment is the variable of interest, and is defined as "how well a person performs a role relative to the expectations for the role" (Burr et al., 1979, p. 58). This broad definition allows the exploration of the quality of role enactment within family caregiving from more than one angle. All parties could provide input into what expectations of the role would be. Self-assessment by the caregiver, assessment of care by the elder care receiver, or assessment by an outside authority could all be included in the measurement of the quality of role enactment from this theoretical perspective (Burr et al., 1979).

Thus, Symbolic Interactionism provides an appropriate lens for the exploration of care receiver satisfaction with family care. Within Symbolic Interactionism, satisfaction is viewed as "a subjectively experienced phenomenon of pleasure versus displeasure, contentment versus discontentment, or happiness versus unhappiness" (Burr et al., 1979, p. 67). Factors that influence satisfaction include the congruence of expectations and rewards, a habitual predisposition towards satisfaction or dissatisfaction, how one's experience compares to that of others with whom one has reference, and the interpersonal relationships of the participants within a given situation (Burr et al., 1979).

To expand on these factors further—within a given relationship, the participants interact with each other and assume a variety of roles. Each participant brings expectations of how they will enact their roles within the relationship, and, in addition, expectations of how the other participants in the situation should enact their roles. These role expectations are normative beliefs about how people ought to behave in certain situations (Burr et al., 1979). When people undertake a role they have expectations of what that role entails, how it should be enacted, and how important enactment of the role is. Role expectations are shaped by many factors, such as the context of the interaction, social norms, learned meanings, and past interactions between the participants. Both caregivers and care receivers bring role expectations to the family care situation, and these expectations affect how each party evaluates the interactions within the situation. They may hold socially shared expectations, but may also bring significant personal and situational differences to the experience (Burr et al., 1979). The level of congruence that exists between caregiver and care receiver role expectations is one of the factors that affects how satisfied care receivers are with the care they receive (Burr et al., 1979).

Summary and Comparison of Theoretical Perspectives

All three of these theories have been used to explore patient satisfaction. Each provides a different way of looking at the family care situation, and allows for exploration of different facets of the care experience. Research from the Symbolic Interactionism and Social Exchange perspectives is explicit in its focus on both the giver and receiver in the family care situation, while research from the expectation disconfirmation perspective focuses primarily on responses of the care receiver. Social Exchange Theory, with its focus on exchange and reciprocity, and the measurement of objective characteristics of the situation, provides a lens through which the contributions, costs, and benefits of care receivers and caregivers can be explored. In contrast, Symbolic Interactionism—with its focus on the interactions between, and the appraisal of meaning by, participants—provides a way of understanding how the family care situation is experienced by the care receiver and caregiver. It recognizes that, given a similar set of circumstances, individuals may perceive or appraise situations differently, and that these differences may affect how they respond. Expectation disconfirmation theory has provided a way of eliciting patient response to discrete episodes of care. However, it may not be as effective in exploring patient response to care that occurs over an extended time period and involves a long-term relationship with one caregiver.

Thus, while each lens provides a different way of exploring and understanding the family care situation, there are advantages and disadvantages inherent in each perspective. Questions asked within each will differ, and a researcher may choose a particular perspective because it can more effectively frame the questions he or she wishes to explore.

Measurement of Satisfaction

Qualitative vs. Quantitative Methods

Satisfaction with care can be evaluated in a variety of ways. Past research has used quantitative questionnaires, structured or unstructured interviews, or a combination of methods in order to obtain input from care receivers in both formal and informal health care settings. Each method has its particular strengths and weaknesses. In addition, discrepancies may arise between quantitative and qualitative evaluations of patient satisfaction with care (Williams, Coyle, & Healy, 1998).

One of the drawbacks of assessing patient satisfaction by administering a closed-ended questionnaire is that such questionnaires are often designed without input from patients, and thus they reflect what the health care provider or health care system administrators view as important rather than what the patient views as important (Applebaum et al., 2000; Coyle & Williams, 2000). In addition, questionnaires have less ability to capture the ambiguity, variation, and rich detail possible with a qualitative interview (Coyle & Williams, 2000).

However, the use of open-ended, qualitative interviews also has drawbacks. Using qualitative data may make it more difficult to compare and contrast findings between participants and across settings and to clearly identify patterns. In addition, conducting lengthy interviews may increase participant burden when compared to asking an elder to complete a questionnaire.

One way of addressing this problem is to design quantitative instruments based on areas of importance identified during explorative in-depth qualitative interviews with patients or care receivers (Personal communication, P. Archbold & B. Stewart, July 2000). This process allows the researcher to gain a more accurate and complete picture of the experience of the care receiver (Coyle & Williams, 2000) while using an instrument that collects data in a way that reduces participant burden, and provides data that can be used in powerful statistical analyses.

Issues that Affect Measurement

Reluctance to Criticize. Several factors may make care receivers unwilling to criticize their caregivers—especially family members (Morrow-Howell et al., 2001).

Care receivers may feel gratitude to the caregivers who provide needed care (Coyle, 1999) and enable them to stay in their own home. They may be unwilling to rate the care they receive as insufficient—and may actually lower their standard of acceptability in order to remain at home (Morrow-Howell et al., 2001). In a few cases care receivers may be unwilling to rate care as unsatisfactory because of fear of repercussions if the caregiver found out (Coyle and Williams, 2000). Although several researchers briefly discussed these issues, I found no family care studies where they were included as variables or studied in a systematic manner.

Cognitive impairment. Presumed logistical and methodological difficulties in accessing input from care receivers with cognitive impairment have led to a lack of representation of the needs of this population (Brod, Stewart, Sands, & Walton, 1999; Morrow-Howell et al., 2001; Feinberg & Whitlatch, 2001). Proxy responses completed by family members are often used in lieu of direct input from elders with cognitive impairment, but previous research has demonstrated low correlations between patient and proxy ratings of satisfaction with health care ($r=.43$, $p <.05$) (Epstein, Hall, Tognetti, Son, & Conant, 1989).

Recent research has demonstrated that individuals with cognitive impairment retain a sense of self into the late stages of the illness, and are able to report on their present situation (Feinberg & Whitlatch, 2001). While elders with cognitive impairment may not be able to provide accurate historical details, they can express how they are experiencing the "here and now" (Cotrell & Schulz, 1993). In a study of elders with cognitive impairment, Feinberg & Whitlatch (2001) found that participants with mild to moderate cognitive impairment (Mini-Mental State Exam scores 13-26) were able to respond consistently to questions about preferences and choices and to participate in decisions about daily living.

Satisfaction and Family Care

Most patient satisfaction research focuses on care received from a health care professional within a formal health care setting (Ryden et al., 2000; Applebaum et al., 2000). Comparatively, exploring care receiver satisfaction with care received from a family member or friend has received little attention, which may be due to difficulty in gaining access to this population (Morrow-Howell et al., 2001) and a lack of consensus about the roles of care receiver and caregiver within the less formal family care situation. Because of differences in context and issues of importance between settings, information gained about patient satisfaction in acute and long-term care is inadequate for evaluating care receiver satisfaction with family care (Applebaum et al., 2000; Chou, Boldy, & Lee, 2001).

Formal acute and outpatient care is episodic, and may not promote development of a consistent formal caregiver-patient relationship. Even in long-term care the care receiver may receive care from many different caregivers during the course of a day or week. In addition, the relationship between care receivers and formal caregivers differs from that of a care receiver with a family caregiver. While most care receivers within formal care situations know their professional caregivers only in that role, the family care situation involves participants who have multi-faceted and long-standing relationships. The complexities of these relationships become a part of the family care situation and may affect how satisfied the care receiver is with the care received from their family member. In addition, family caregivers often undertake the role with limited training and experience. Because of these differences, and in order to better understand how care is perceived by elder care receivers, it is important to listen carefully as they tell us about what is important to them.

Another difference between research focusing on patient satisfaction with formal care and care receiver satisfaction with family care is the components that have been identified within these two areas. Most authors agree that measurement of satisfaction includes at least two components: a cognitive evaluation of the perceived quality of various attributes of the situation, and an affective response to that evaluation (Applebaum et al., 2000). However, within these two broad components researchers in satisfaction measurement have identified a multitude of possible areas within which satisfaction could be assessed.

Patient Satisfaction with Formal Care. Several researchers identified components that reflect the technical or instrumental aspects of care such as competence (Staniszewska & Ahmed, 1999), and physical comfort and satisfaction with the environment (Ryden et al., 2000). However, most of the components identified in the literature are affective or social psychological aspects of care such as interpersonal comparisons, entitlement (Sitzia & Wood, 1997), humanness and informativeness (Staniszewska & Ahmed, 1999), respect for patients' values, preferences and expressed needs, emotional support and alleviation of fear and anxiety, involvement of family or friends, transition, and continuity (Ryden et al., 2000). In addition, researchers have also asked patients to rate satisfaction with specific care providers and other more general areas such as coordination and integration (Ryden et al., 2000), and overall quality (Staniszewska & Ahmed, 1999).

Care Receiver Satisfaction with Family Care. Conceptualizing satisfaction in the family care setting, Lucas (1986) identified two components: instrumental aspects of care delivery and affective aspects of care received. The instrumental aspects of care include factors such as whether the care is given in a skillful, competent, and thorough manner, and whether the care given is appropriate for what the care receiver needs. The affective aspects of care include factors such as how patiently care is given, whether care is given with devotion and affection, and whether concern is shown for the care receiver's comfort.

Factors Associated with Care Receiver Satisfaction

The relationship between the caregiver and the care receiver can affect how the care receiver experiences family care. Factors within this relationship found to be associated with increased care receiver satisfaction include how much control care receivers and caregivers perceive that they have in the relationship, how accurately the caregiver perceives the care receiver's feeling about the helping relationship, and what feelings the care receiver attributes to the caregiver during negative helping situations (Martini et al., 2001). In addition, both caregiver and care receiver mutuality have been significantly related to care receiver satisfaction with the instrumental and affective aspects of caregiving ($r = .33$ and $.45$ respectively, $p < .05$) (Lucas, 1986).

Another factor found to be important to care receiver satisfaction is the length of acquaintance between the caregiver and care receiver. Care receivers who have known their caregivers longer have expressed greater satisfaction with instrumental aspects of caregiving such as skill, accuracy, and thoroughness ($r=.32$, $p <.05$) (Lucas, 1986). This is consistent with Russell, Phillips, Cromwell, and Gregory (1999), who conducted a qualitative study of the care experience. They likened caregiving to a dance, and found that familiarity of the caregiver and care receiver with each other may foster a smooth performance in the caregiving situation. Given the above findings, one might expect that spousal relationships, especially those of long duration, would be the most conductive to care receiver satisfaction. However, Lucas (1986) did not find a significant relationship between the type of dyadic relationship (spousal or child/parent) and care receiver satisfaction with care. Her study, however, had a small sample, and further exploration of the effect of relationship in a study containing a larger sample is warranted.

Other factors that have been found to contribute to care receiver satisfaction include how well-prepared the caregiver felt to provide care to the care receiver, and how much strain the caregiver experienced in the caregiving role. Both caregiver preparedness ($r=.34$, $p <.05$) and caregiver role strain ($r=-.34$, $p<.05$) have been significantly correlated with care receiver satisfaction with such affective aspects of care as concern, consideration, and patience (Lucas, 1986).

In a study exploring how elder care receivers and health care professionals rated the sufficiency of family care, Morrow-Howell et al., (2001) found that care receivers rated the family care they received as more sufficient if the family caregiver lived with them. Care was also rated as more sufficient when provided by healthier caregivers. This study compared sufficiency ratings between care receivers and health care professionals, and found that overall, health care professionals rated the sufficiency of family care lower than did the elder care receivers.

Variables

Care Receiver Variables

Mutuality

In a previous study composed of a small sample of care receivers, care receiver mutuality was significantly related to care receiver satisfaction with the affective aspects of caregiving ($r = .45$, $p < .05$) (Lucas, 1986). In order to further clarify this relationship, the dissertation reported here used a larger sample of care receivers and explored the relationship between care receiver mutuality and care receiver satisfaction with the care they receive. I hypothesized that care receiver mutuality is positively associated with care receiver satisfaction.

Cognitive Function

A large body of caregiving research explores how caring for cognitively impaired elders affects caregivers (Aneshensel et al., 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995). In addition, an increasing number of studies have highlighted the challenges inherent in accessing input from elders with cognitive impairment (Brod, Stewart, Sands, & Walton, 1999; Morrow-Howell et al., 2001; Feinberg & Whitlatch, 2001). However, in the few studies available that have explored how satisfied elder care receivers are with the care they receive from a family member, cognitive function was either not included as a variable (Lucas, 1986; Martini et al., 2001), or was not a significant predictor of how the elder rated the care they received (Morrow-Howell et al., 2001). Given the complexities of this issue, the present study was limited to examining how care receivers with good cognitive function perceive and evaluate the care they receive.

Functional Health

Family caregiving researchers have explored how the health of the care receiver affects caregiver role strain and depression (Carter et al., 1998; Given et al., 1999). Few, however, have explored the relationship between care receiver health and satisfaction with care. Lucas (1986) explored three health-related variables in relation to care receiver satisfaction: mobility, subjective health compared to others the same age, and subjective health as compared to one year ago. Care receivers who reported their health to be better than in the previous year expressed more satisfaction with the affective aspects of care than did care receivers who reported their health to be worse than in the previous year ($r=.34$, $p<.05$). In order to gain a better understanding of this relationship, the present study includes care receiver functional health as an independent variable. I hypothesized that care receiver functional health is positively associated with care receiver satisfaction.

Subjective Well-being

"Subjective well-being can be represented by a balance or regulation of emotional reactions" (Grann, 2000, p. 148). It consists of two independent dimensions of positive and negative affect. These dimensions are seen as independent of one another, and in order to gain a complete picture of affect, both must be measured.

I found no studies that looked specifically at the relationship between affect balance and care receiver satisfaction with family care. However, several studies explored how affect balance changes throughout the life-span. These studies report that as people age there is generally a decrease in negative affect (Charles, Reynolds, & Gatz, 2001; Mroczek & Kolarz, 1998); in contrast, positive affect was found to be quite stable over time (Charles et al., 2001), or to increase slightly with age (Mroczek & Kolarz, 1998). The present study provides a beginning look at how subjective well-being affects care receiver satisfaction with family care.

Demographic Variables

The literature addressing care receiver demographic variables and their relation to care receiver satisfaction is sparse. In one such study care receiver ratings of the sufficiency of care did not vary significantly by age, gender, race, or socioeconomic status (Morrow-Howell et al, 2001). In another study, older care receivers reported significantly higher satisfaction with the instrumental aspects of care when compared to younger care receivers, ($r=.28$, $p<.05$) (Lucas, 1986). In order to further clarify the relationship of these variables to care receiver satisfaction, this study will include the care receiver demographic variables of age, gender, ethnicity, and socioeconomic status.

Relationship Variables

Duration of Relationship

Few studies have explored how the length of time the care receiver and caregiver have known each other affects care receiver satisfaction. One study found that familiarity of the caregiver and care receiver with each other fostered a smooth performance in the caregiving situation (Russell, Phillips, Cromwell, and Gregory, 1999). Lucas (1986) found that care receivers who had known their caregivers longer expressed greater satisfaction with instrumental aspects of caregiving such as skill, accuracy, and thoroughness ($r=.32$, $p<.05$). This study will more fully explore the relationship between the length of the care receiver-caregiver relationship and care receiver satisfaction. Given the above findings, I hypothesized that there is a positive relationship between the duration of the care receiver-caregiver relationship and care receiver satisfaction.

Type of Relationship

Past studies of care receiver satisfaction have often studied only one type of relationship, such as mothers and their caregiving daughters (Martini et al., 2001), or did not find a significant relationship between the type of dyadic relationship (spousal or child-parent) and care receiver satisfaction with care (Lucas, 1986). This study affords the opportunity to explore care receiver satisfaction with family care using a large sample of caregivers and care receivers that includes both spousal and child-parent dyads, and may provide a more complete understanding of this area. In the present study no direction was hypothesized for the relationship between type of relationship and care receiver satisfaction.

Co-residence of the Care Receiver and Caregiver

Numerous studies in the family caregiving literature explore how co-residence of the caregiver and care receiver affects the caregiver (Dwyer, Lee & Jankowski, 1994; Navaie-Walister, Feldman, Gould, Levine, Kuerbis & Donelan, 2001). However, I found only two articles that addressed this variable in relation to care receivers. In one study care receivers who resided with their caregivers rated their care as more sufficient (Morrow-Howell et al., 2001). Conversely, Dwyer et al., (1994) found that while co-residence reduced the stress and burden experienced by the caregiver, it also moderately decreased the psychological well-being of the elderly care receiving parent. Because of the conflicting findings in the literature, no direction was hypothesized for the relationship between co-residence and care receiver satisfaction.

Caregiver Variables

Mutuality

Caregiving is known to affect the relationship between the caregiver and elder. Caregivers have been found to have lower mean marital companionship (Wright, 1991) and decrements in the marital relationship (Russo & Vitaliano, (1995). Over time, caregiving leads to declines in marital happiness, an increased perception that the marriage was in trouble (Kramer & Lambert, 1999), a decrease in the bond or intimate exchange between the caregiver and the care receiver (Aneshensel et al., 1995), and a decrease in marital openness (Arefjord, Hallaraker, Havik, & Maeland, 1998). In a study of daughters caring for parents with cognitive impairments, daughters who perceived a lack of recognition from their parents were more likely to express parent loss and emotional distancing responses (McCarty, 1996), and caregiving daughters who perceived more frequent conflict between caregiving and their responsibilities as wives reported less intimacy in their relationships with their care-receiving mothers (Walker & Allen, 1991). Although none of these studies directly measured mutuality, the variables measured are similar to the components of mutuality such as love and affection, reciprocity, and shared pleasurable activities. It is important to note that in all of these studies, caregiving had a negative effect on the caregiver's perception of the quality of their relationship with the elder care receiver.

In a previous study of care receiver satisfaction, caregiver mutuality was positively and significantly related to care receiver satisfaction with the affective aspects of caregiving ($r = .33$, $p < .05$) (Lucas, 1986). In order to further clarify this relationship, the proposed study will explore how caregiver mutuality affects care receiver satisfaction. I hypothesized that caregiver mutuality is positively associated with care receiver satisfaction.

Preparedness

Because of the increasingly complex nature of family care, family caregivers may face situations for which they feel unprepared. This may be because they are unclear about what the caregiving role entails, or because they do not feel they have the necessary skills to provide care. Caregivers bring a variety of experience and skill levels to the caregiving role (Aneshensel et al., 1995)—a role that involves multiple domains, including the provision of emotional support, provision of physical care, and setting up services at home (Schumacher et al., 1998). Caregivers use multiple strategies, including trial and error, written information, and talking with friends and health care providers to increase their understanding, skill, and feeling of comfort with their new role (Stewart, Archbold, Harvath, & Nkongho, 1993). Transition points, such as worsening health of the elder or changes in home care services, may create feelings of unpreparedness and lead caregivers to experiment in order to establish new routines and increase their preparedness to provide care (Bull & Jervis, 1997; Harvath et al., 1994).

Feeling unprepared may increase the caregivers' discomfort in the family care situation, and may affect their ability to enact the caregiver role.

In a previous study, caregiver preparedness was positively and significantly correlated ($r=.34$, $p <.05$) with care receiver satisfaction with such affective aspects of care as concern, consideration, and patience (Lucas, 1986). However, this study used a small sample, and further exploration of the caregivers' perception of their preparedness and how satisfied care receivers are with the care they receive is warranted. I hypothesized that caregiver preparedness has a positive association with care receiver satisfaction.

Caregiver Physical Health

While caregiving researchers have explored caregiver physical health as an outcome (Berry & Murphy, 1995; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Jutras & Lavoie, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995), this study looked at how caregiver physical health affects care receiver satisfaction. In a review of the literature, only two studies were found that explored the relationship between caregiver health and care receivers' evaluation of the care they received. In one study caregiver health and care receiver satisfaction were not significantly correlated (Lucas, 1986). However, another study found that family caregivers with higher levels of health were associated with elder care receivers rating their care as more sufficient (Morrow-Howell et al., 2001). Many family caregivers are spouses, and are themselves elderly (National Alliance for Caregiving and American Association of Retired Persons, 1997). Because the incidence of chronic illness increases with age (Kane, Ouslander, & Abrass, 1999) many older caregivers may have chronic illnesses, some of which (e.g. those that affect the sensory, muskuloskeletal, and cardiopulmonary systems) may or may not impair the caregiver's physical ability to provide care. The stressors inherent in the caregiving situation, such as lifting, disrupted sleep, and fatigue, may further exacerbate the physical illnesses of the caregiver, and affect their ability to enact the role of caregiver. This study explored the relationship between the physical health of the caregiver and how satisfied the care receiver is with the care they receive. I hypothesized that caregiver physical health is positively associated with care receiver satisfaction.

Caregiver Depressive Symptoms

Many caregiving researchers have explored caregiver depressive symptoms as an outcome (Carter et al., 1998; Given et al., 1999; Grafstrom et al.,1992; Schulz et al., 1995; Schwarz & Roberts, 2000). Caregivers of persons with dementia reported elevated levels of depressive symptomatology, clinical depression, anxiety and use of psychotropic drugs when compared with non-caregivers (Schulz et al., 1995). However, the literature regarding caregivers of elders without cognitive impairment has not consistently demonstrated this connection (Carter et al., 1998; Grafstrom et al., 1992; Schulz et al., 1995). Rather than looking at depressive symptoms as an outcome, this dissertation looks at the relationship between caregiver and care receiver satisfaction with the care they receive. Although I did not find any studies that looked at this specific relationship, in one study researchers found that when caregivers' emotional health deteriorates, they are more likely to institutionalize the family member for whom they are caring (Brodaty, McGilchrist, Harris, & Peters, 1993). It is possible that when caregivers experience depressive symptoms, they may be less able to enact the role of caregiver. Thus, it is important to explore the relationship between the emotional health of the caregiver and how satisfied the care receiver is with the care they receive. I hypothesized that caregiver depressive symptoms has a negative association with care receiver satisfaction.

Caregiver Role Strain

A large body of research focuses on role strain as an outcome of caregiving (Aneshensel et al., 1995; Archbold, Stewart, Greenlick, & Harvath, 1990; Carter et al., 1998; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Factors found to increase the level of role strain reported by caregivers include caring for an elder who requires more help with activities of daily living ($r = .36; p<.001$) (Vitaliano et al., 1991), has cognitive impairment or related behavioral symptoms (Aneshensel et al., 1995), and is in a higher stage of disease (Carter et al., 1998). In addition, having insufficient funds to pay monthly expenses, and conflict with family members other than the elder care receiver, also increase role strain (Aneshensel et al., 1995). Factors associated with lower levels of caregiver role strain include higher levels of preparedness for caregiving and higher levels of mutuality (Archbold et al., 1990).

This dissertation differed from these studies in that it explored the relationship between caregiver role strain and how satisfied care receivers are with the care they receive. Although a lot is known about the factors within the caregiving situation that lead to increased caregiver role strain, it is unclear how this increased strain affects the satisfaction of the care receiver. It has been suggested that as role strain increases, the ability to enact the caregiver role is reduced, causing a lower level of quality care (Burr et al., 1979; Cartwright et al., 1991). However, the implications for care receiver satisfaction with care remain unclear. Lucas (1986) found that when caregivers rated the positive aspects of caregiving as outweighing the negative, their care receivers expressed greater satisfaction with care from the caregiver. Dwyer, Lee, & Jankowski (1994) however, found that the level of caregiver stress was positively associated with elder life satisfaction. It is important to note that life satisfaction differs from the more specific variable of satisfaction with care. The proposed study will extend our knowledge by exploring the relationship between caregiver role strain and care receiver satisfaction with care. I hypothesize that caregiver role strain will be negatively associated with care receiver satisfaction.

Demographic Variables

A large body of research explores the effect of demographic variables on caregivers (Navaie-Waliser et al., 2001). However, in the few studies available that explored how satisfied elder care receivers are with the care they receive from a family member, caregiver demographic variables such as age, gender, and ethnicity either were not included as variables (Martini et al., 2001; Morrow-Howell et al., 2001), or were not significant predictors of how the elder rated the care they received (Lucas, 1986).

The caregiver demographic variables included in this study were whether the caregiver was employed or unemployed, and whether the caregiver had minor children. In a study of mother-daughter caregiving relationships the highest proportion of employed daughters occurred in the conflicted group, suggesting that caregiver employment may affect the relationship between the caregiver and care receiver, and thus may affect care receiver satisfaction. In the same study, caregiving daughters with a greater number of minor children were more likely to be in a conflicted relationship with their care receiving mother (Walker & Allen, 1991).

Selection of Variables

The variables proposed for study were selected based on the literature, discussion with investigators from the parent study, and on the investigator's observed experiences of elder care receivers and their caregivers over 10 years as a home health nurse. Justification for the choice of variables is provided in the literature review. All of the variables have been shown to be important in understanding the caregiving situation. Role strain, depressive symptoms, and physical health have often been studied as outcome variables, and mutuality and preparedness have been studied as predictors of role strain. The proposed research however, configures the relationships between the variables differently than has occurred in the past. It provides a beginning exploratory step towards understanding the relationship between these variables and care receiver satisfaction.

Caregiver Characteristics

Demographic data on caregivers will be obtained from the parent study. Gender, relationship, age, ethnicity, and socioeconomic status will be used to describe the sample. Nationally, a demographic profile reveals that among those providing informal caregiving to elders, 91 percent are family members. One-fourth of the caregivers are spouses and a little over half are children providing help to elder parents (U.S. Department of Health & Human Services, 1999). Seventy percent of persons who provide family care are women, usually spouses, daughters or daughters-in-law (Doty, Jackson, & Crown, 1998; Neal, Ingersoll-Dayton, & Starrels, 1997). Approximately one-third of family caregivers are men, and of these, the majority are husbands (Neufeld & Harrison, 1998). However, wives are more likely than husbands to provide care for their spouse (U.S. Department of Health & Human Services, 1999).

The average age of caregivers of persons over 50 years of age is 46, but caregivers who are caring for elders with high levels of impairment are much more likely to be 65 years of age or older (National Alliance for Caregiving and American Association of Retired Persons, 1997). The median annual household income of caregivers is $35,000, and over half of all caregivers have some college education (National Alliance for Caregiving and American Association of Retired Persons, 1997). The proposed study uses a moderate sample size that is limited to elders referred for home health services.

CHAPTER 3: METHODS

The dissertation used data on care receiver satisfaction with care, and other care receiver and caregiver variables, from the parent study. The study tested new hypotheses not addressed in the parent study and makes cost-effective use of an existing data set in order to contribute to the body of scientific knowledge and to generate new information and understanding (Gleit & Graham, 1989; Jacobson, Hamilton, & Galloway, 1993). The use of data collected from another study decreases expenditure in terms of time, money, and demands placed on research subjects, and promotes more thorough scientific utilization of existing research data (Gleit & Graham, 1989; Jacobson et al., 1993; Kasl, 1995; Talerico, 1999).

In using a previously gathered data set, it is important to ensure that variables are defined in a manner consistent with the way in which they were defined in the parent study, and with the way in which the data were gathered (Jacobson et al., 1993). In the dissertation, the variable of care receiver satisfaction with care was defined the same way as in the parent study. I also had the benefit of close association and consultation with the primary researchers in the parent study. Prior to describing the dissertation, the salient features of the parent study are described.

Parent Study

The parent study focuses on the family, and was developed to assist families in managing the chronic illness care of elders. The duration of the parent study is five years.

Setting

The setting for the parent study is the Home Health/Hospice (HH/H) department of Kaiser Permanente, Northwest Region (KPNW). KPNW is a federally qualified, prepaid, nonprofit, group practice HMO with over 430,000 members in the Portland, Oregon and Vancouver, Washington metropolitan area. The membership includes over 25% of the 155,000 elders in the metropolitan area. The setting is appropriate for this study because KPNW's older membership is representative of the community and includes persons at all levels of frailty, and because the KPNW HH/H Department is committed to The Family Care Study.

Sample

The study uses a sample of 234 families consisting of a frail elder who has been referred for skilled home health care and his or her primary caregiver. Family member is defined by the elder, and may include a spouse, child, or other family member, or a friend who functions in the role of a family member. Eligibility criteria for the Family Care Study are elders who are referred to the KPNW HH/H for evaluation, are 65 years of age or older, meet Medicare criteria for skilled home health nursing care at the time of referral, receive regular daily assistance with at least 1 ADL or 2 IADLs from the primary caregiver, plan to stay in the Portland/Vancouver metropolitan area for 12 months, and sign the consent to serve as a study participant, or have a proxy sign the consent. The care occurred in the elder's home. Exclusion criteria were elders living in an assisted living or adult foster home facility at the time of referral (Archbold et al., 1999).

The study was conducted in a metropolitan area that is typical of many other U.S. metropolitan areas, except that the percentage of minority elders is lower. Each family was involved in the parent study for a period of 20 months. Recruitment of families continued until the 18th month of the study (Archbold et al., 1999).

Data Collection Methods within the Parent Study

Data in the parent study were collected using mail surveys and structured interviews with study participants using the Family Care Inventory (FCI). Variables were measured 1 week and 5, 10, 15, and 20 months after entry into the parent study. A team of research assistants (RAs) administered the FCI to the caregiver and elder. One RA reviewed the caregiver's responses to the mail questionnaire and obtained any missing data on that instrument before conducting the caregiver interview; a second RA collected interview data from the elder (see Appendix B) (Archbold et al., 1999).

Data used in the Proposed Study

The data from the parent study that were used for the proposed study include caregiver and care receiver demographic variables, caregiver physical health, depressive symptoms, mutuality, preparedness and role strain, and care receiver mutuality and affect balance. These were collected one week after entry into the study.

Demographic variables. Age, gender, relationship of the care receiver to the caregiver, ethnicity, and socio-economic status relative to the care receiver were measured using six items on the Family Care Inventory (FCI). Ethnicity was identified by the answer to one item on the FCI that asked the respondent to define their race as African American, Asian/Pacific Islander, Hispanic, Native American, White, or Other, and to specify what "other" means. Investigators in the parent study defined socio-economic status as level of education, level of income, and income adequacy. Education was measured using an item that has the following seven options: completed 6th grade or less, junior high school, partial high school, high school graduate, partial college training, completed college or graduate professional training. Income was measured by asking the respondent to indicate what range their annual income was in. This was divided into under $2,499, or over $100,000, and 14 divisions in between $2,499 and $100,000. Income adequacy was indicated by the respondent's answer to a question which has four options: I can't make ends meet; I have just enough, no more; I have enough, with a little extra sometimes; or I always have money left over.

The Care Receiver Satisfaction with Care Scale. The definition and dimensions of the care receiver satisfaction with care scale were drawn from the patient satisfaction literature. Satisfaction was defined as: A positive evaluation of the instrumental aspects of care received, and an expressed contentment with the affective aspects of caregiving (Lucas, 1986). As stated in the definition, satisfaction contains two dimensions: Instrumental aspects of care and affective aspects of care.

An inductive process was used to identify the domains of the construct. This included interviews with family caregivers (17), care receivers (13), and health care professionals (2).

Open-ended questions were asked reflecting the two dimensions of care. See Tables 1 and 2 for the questions and responses.

Table 1. Questions and Responses Reflecting the Instrumental Aspects of Care

Questions	Responses
"The things (CG) does the best in helping me are….;"	• Does cooking. He loves to cook. • Whatever he does, he does it good. I have no complaints. • Taking complete care of me. Knows what, how to do, thorough job, comfortable, dependable: you bet. • Helps reorient. Very prompt with medicine. Makes own meals and does dishes. Taking care of self.
"The things I'd like to see (CG) change in what (she/he) does to help me are…."	• Oh nothing. I'm happy. • None. • There is nothing to change. • Nothing.

Table 2. Questions and Responses Reflecting the Affective Aspects of Care

Questions	Responses
"What I enjoy most about the way (CG) helps me include…."	That we do everything together. Expresses interest in my care – absolutely Allows enough time for care – sure. Shows concern for my care – oh, yes. Expresses devotion/affection – yes. Is patient – very. Is responsive to needs – sure. Is considerate – oh, yes. Comes when I call – oh, sure. I don't know how to answer that. Turns on TV at the right time. Gets me candy bar. Patient for the most part.
"What I enjoy least about the way (CG) helps me include…."	I can't think of anything. There isn't anything that is "least". She (my wife) should have a halo (joking). Nothing.

Content analysis of the responses to these questions, as well as previous patient satisfaction literature, provided the basis for wording of items in the Satisfaction with Care scale (Lucas, 1986).

During instrument development the goals were to design an instrument that contained simple language in order to ensure comprehension and to avoid socially desirable responses.

The scale was originally constructed with a "yes/no" response from the care receiver. If the care receiver answered yes, then they were further asked whether this was true "sometimes," "most of the time," or "always" (Lucas, 1986). For administration during the present study, the response wording was changed. It did not include a "yes/no" response, but asked the care receiver if the care was administered in the specified way "never," "sometimes," "most of the time," "nearly always," or "always." A copy of the Care Receiver Satisfaction with Family Care Scale is contained in Appendix A.

During the drafting and revising phase several versions of the scale were administered to five older persons. The goal of this phase was to test the clarity of the wording of the items and the relevance of the items to the construct as perceived by the respondents. In addition, a panel of 15 experts, knowledgeable regarding instrument construction and gerontology or family caregiving, evaluated the items. They were asked to evaluate the fit of the items to each specific construct; whether the items adequately sampled the domain of the construct; whether any items were measuring a construct outside the domain of interest; and the clarity of the items. This review assisted in establishing content and face validity of the instrument (Lucas, 1986).

Sample items from the instrumental dimension of the scale include: "How often is the care you receive from your family member skillful and competent?" and "How often are your needs taken care of promptly?" Sample items from the affective dimension of the scale include: "How often is care given to you with devotion and affection?" and "How often is care given to you patiently?"

In order to obtain psychometric evaluation of the Satisfaction with Caregiving scale, the final draft was pre-tested in a sample of 38 caregiving dyads. The care receivers in this sample were older frail persons receiving supportive care at home from a family member or friend. The scale was administered during a face-to-face interview with the care receiver. The participants included care receivers from a variety of situations, including a Parkinson's clinic, a home health clinic, and referrals from nurses in other clinical settings. The sample consisted of 18 males and 20 females who ranged in age from 44 to 89, with a mean of 76 years of age (Lucas, 1986).

Cronbach's alpha was calculated to determine the internal consistency reliability of the scale. Cronbach's alpha for the overall scale was .88, with a mean inter-item correlation of .47. The alpha coefficient for the instrumental subscale was .72, and for the affective subscale was .84, with mean inter-item correlations of .39 and .56 respectively.

CES-D Depression Scale. The CES-D was created to measure the affective components of depression in the general population. It has been found to work well with older adults (Ossip-Klein, Rothenberg, & Andresen, 1997) (see Table 3).

Rand SF-36. Physical health was measured using the RAND SF-36. Reliability, content validity, and construct validity have been evaluated in numerous studies, and the SF-36 has been found to be highly reliable and valid for diverse patient groups and individuals. The SF-36 was developed to capture multiple domains of health across the entire continuum of health status (Archbold et al., 1999).

Mutuality, Preparedness, and Caregiver Role Strain Scales. Measures of caregiver and care receiver mutuality, caregiver preparedness, and caregiver role strain were developed by Archbold and Stewart (1986), as part of the FCI. The development involved several steps: (1) defining concepts based on qualitative data from families; (2) generating items to measure the concepts using the words of elders and caregivers; (3) obtaining evidence for content validity from expert reviews of the new measures; (4) pretesting the new measures with 50 elders and caregivers; (5) conducting additional validity tests using larger samples, including caregivers who provided care to special populations of elders; and (6) evaluating the measures with Black families (Archbold et al., 1999). These instruments have been used in multiple studies on caregiving (Archbold et al., 1995; Carter et al., 1998), and have demonstrated reliability over time (see Table 3).

Bradburn Affect Balance Scale. The Bradburn Affect Balance Scale distinguishes between positive affect and negative affect, and has been used extensively in geriatric settings. The scale consists of five positive affect questions and five negative affect questions to which the respondents agree or disagree. Positive responses count toward the positive or negative affect score, respectively. An affect balance score can be computed by subtracting positive affect score from the negative affect score and adding five (Grann, 2000). Scores can also be computed for the individual negative and positive scales.

Data Collection Procedure

No additional data were collected for this study; all data were collected as part of the parent study.

Protection of Human Subjects

Approval for this data only study was obtained from the Institutional Review Boards of Oregon Health and Science University and Kaiser Permanente, Northwest Region (Appendix C). Because no new data were collected during this study, no additional consent was required.

Table 3. Concepts, Definitions, Measures and their Characteristics.

Concept & Definition	**Measure** • **Name, Number of items** **Example of items**	**Reliability**	**Response Format, Meaning of Scores & Administration**
CR Satisfaction with Family Care (Archbold, Stewart, & Lucas, 1986). How satisfied the CR is with the care received from a family member.	CR satisfaction with family care 12 items • How often is care given to you patiently? • How often is care given to you with devotion and affection?	Reliability = .91	Higher scores reflect greater satisfaction with care received from a family member. Administered to CR at 1 week after entry into the Family Care Study.
CR Bradburn Affect Balance Scale	10 items (5 positive affect and 5 negative affect) • During the past few weeks, did you ever feel particularly excited or interested in something? • During the past few weeks, did you ever feel very lonely or remote from other people.		Positive responses count toward the positive or negative affect score respectively. An affect balance score can be computed by subtracting positive affect score from the negative affect score and adding five (Grann, 2000). Scores can also be computed for the individual negative and positive scales.
CG Depressive Symptoms	CES-D Depression Scale 20 items		
0-3 response format, score is summed and higher scores indicate greater levels of depressive symptoms. Self-administered during an interview at 1 week.	RAND SF-36 36 items: Measures eight domains of health including: Physical functioning, emotional functioning, role functioning, mental health, social functioning, pain, vitality & general health perceptions.	Reliability .84-.91 in studies reported by Archbold & Stewart.	

Concept & Definition	**Measure** - **Name, Number of items** **Example of items**	**Reliability**	**Response Format, Meaning of Scores & Administration**
Mutuality: The positive quality of the relationship between a family CG and CR (Archbold, Stewart & Hornbrook, 1999).	Mutuality Scale 15 items Example items: - How close do you feel to him or her? How much love do you feel for him or her?	Reliability = .91-.95 in studies reported by Archbold & Stewart.	Scores on each item range from 0 to 4. Higher scores reflect greater perceived mutuality. The scores on all items are added, and a mean score is computed. Administered to the CG & CR during an interview at 1 week.

Preparedness of CG: How ready a CG believes they are for their role (Archbold, Stewart, & Hornbrook, 1999).	Preparedness for Caregiving Scale 8 items Example items: • How well prepared do you think you are to take care of your spouse's physical needs? How well prepared do you think you are for the stress of caregiving?	Reliability = .86-.92 in studies reported by Archbold & Stewart.	Scores on each item range from 0 to 4. Higher scores reflect greater perceived preparedness for caregiving. The scores on all items are added and a mean score is computed. Self-administered during an interview at 1 week.
CG Role Strain: The felt difficulty in performing the family CG role (Burns, Archbold, Stewart & Shelton, 1993).	Role strain from feelings of manipulation scale 4 items Example items: • Has assisting your family member increased attempts by him/her to manipulate you? • Has assisting your family member added to your feelings that you are being taken advantage of?	Reliability = .79 in studies reported by Archbold & Stewart.	Scores on each item range from 0 to 4. On three items higher scores reflect greater perceived strain. One item is reverse scored. The scores on all items are added and a mean score is computed. Self-administered during an interview at 1 week.

Analysis of Data

In the parent study data were entered on SPSS, verified, and corrections made, item level frequencies were inspected and scales constructed. Investigators on the parent study provided an SPSS data file containing the items of the Care Receiver Satisfaction with Care Scale and the other variables to be examined. I evaluated descriptive and psychometric statistics for all measures used, and inspected for outliers and normality of variables.

<u>Aim 1: To describe the underlying factor structure of the Care Receiver Satisfaction with Care Scale and determine whether the scale measures one global factor versus two or three separate but correlated factors.</u>

To address Aim 1, I used principal components factor analysis, followed by a varimax rotation (for orthogonal or uncorrelated factors) and an oblique rotation (for correlated factors) to determine whether responses to the scale are best described by a one-, two- or three-factor solution.

<u>Aim 2: To explore the association between care receiver evaluation of caregiver role enactment and selected care receiver, relationship, and caregiver variables.</u>

To address Aim 2, I computed Pearson correlations between care receiver satisfaction with family care and three sets of variables: (a) care receiver variables of mutuality, cognitive function, functional health, subjective well-being, and demographic characteristics; (b) relationship variables of duration and type of relationship; and (c) caregiver variables of mutuality, preparedness, depressive symptoms, physical health, role strain, and demographic characteristics. Based on previous work of the parent study's principal investigators, positive correlations within the .30-.45 range were expected. Power for the study was estimated at .86-.99 using alpha = .01. Where the amount of missing responses on a scale did not exceed 30%, missing item responses were handled by substituting the group mean for the item.

Aim 3: To determine which care receiver, relationship, and caregiver variables predict variance in the care receiver evaluation of caregiver role enactment.

To address Aim 3, hierarchical multiple regression was employed to answer the question: Can we predict care receiver satisfaction with family care from a linear combination of the care receiver, relationship, and caregiver variables examined in Aim 2? In Step 1, I entered demographic and relationship variables; in Step 2, care receiver variables; and in Step 3 caregiver variables.

The computer program SPSS was used in statistical analysis. It is anticipated that there will be no missing data for the outcome variable. Appropriate regression diagnostics, such as residual analysis and lack of fit, were utilized to assess the final equation.

Description of the Sample

Initially, 194 care receiver-caregiver dyads were included in the sample. However, significant differences in correlations between care receiver satisfaction and several independent variables were found between care receivers scoring lower than 24 on the Mini-Mental Status Exam (MMSE), and those scoring between 24-30. In light of this, the sample was revised to include only the 123 care receivers scoring 24-30 on the MMSE.

The 123 care receivers who scored 24-30 on the Mini-mental status exam were mostly women (80), and Caucasian (117). Their ages ranged from 65-95, with a mean age of 78.82 years. Caregivers for this sample were divided between spouses (66), and other types of family members (57), and had a mean age of 63.73 (SD 16.30). Of the 123 caregivers, only 34 were employed outside of the family care situation. The caregivers and care receivers had known each other for an average of 46.37 years, and 100 of the caregivers and care receivers lived in the same household.

CHAPTER 4: RESULTS

Results are organized in the following manner. First, descriptive statistics are presented relating to the outcome variable of care receiver satisfaction with care and results of the factor analysis. Second, descriptive results are presented in relation to the variables included in the proposed model. These include the care receiver variables of mutuality, cognitive function, functional health, subjective well-being, and demographic variables; the relationship variables of the duration of the relationship, the type of relationship (spouse/non-spouse), and whether the care receiver and caregiver live together; and the caregiver variables of mutuality, preparedness, physical health, depressive symptoms, role strain, and demographic variables. Third, I will present zero-order correlations representing the relationship between the independent variables and the dependent variable, and lastly, the results of the hierarchical multiple regression analyses.

Factor Analysis

The dependent variable, care receiver satisfaction with family care, had a scale score range of 0 to 4. Table 4 displays the frequency of responses falling along the response options and the mean of responses for each item.

Table 4: Descriptive Statistics for the CR Satisfaction With Family Care Scale (n=123)

Items: CR Satisfaction with Family Care Scale "How often…"	Mean (SD)	% of CRs Responding				
		Never 0	**Some times** 1	**Most of the time** 2	**Nearly alway s** 3	**Alway s** 4
…is the care you receive from your family member skillful and competent?	3.36 (0.78)	0	0	18.7	26.8	54.5
…are your needs taken care of thoroughly? [a]	3.31 (0.82)	0	0	22.8	22.8	53.7
…is care given to you patiently?	3.41 (0.82)	0.8	0.8	13.8	25.2	59.3
…does your family member do special things for you that you count on and look forward to? [b]	3.19 (1.00)	2.4	2.4	20.3	22.0	51.2
…does your family member express interest in the care you need? [c]	3.48 (0.87)	0.8	4.1	8.1	20.3	65.9
…are your needs taken care of promptly?	3.33 (0.77)	0.8	0	16.3	32.5	50.4
…is care given to you with devotion and affection?	3.53 (0.79)	0	2.4	11.4	17.1	69.1
…is the care you receive from your family member appropriate for what you need?	3.46 (0.72)	0	0	13.0	27.6	59.3
…are your needs taken care of dependably? [d]	3.50 (0.77)	0	2.4	9.8	22.8	64.2
…is enough time allowed for your care? [e]	3.34 (0.77)	0	0.8	16.3	30.9	51.2
…are consideration and concern shown for your comfort? [f]	3.53 (0.83)	0.8	2.4	9.8	16.3	69.9
…does your family member make sure you have a chance to do social activities that are important to you? [g]	3.09 (1.03)	3.3	6.5	10.6	21.1	40.7

a. For item 2, 1 CR (0.8%) answered "don't know" (coded –8).
b. For item 4, 1 CR (0.8%) answered "don't know" (coded –8).
1 CR (0.8%) answered "does not apply" (coded –7).
c. For item 5, 1 CR (0.8%) answered "don't know" (coded –8).
d. For item 9, 1 CR (0.8%) answered "don't know" (coded –8).
e. For item 10, 1 CR (0.8%) left question blank (coded –9).
f. For item 11, 1 CR (0.8%) left question blank (coded –9).
g. For item 12, 2 CRs (1.6%) left question blank (coded –9).
1 CR (0.8%) answered "don't know" (coded –8).
19 CRs (15.4%) answered "does not apply" (coded –7).

The 12 care receiver satisfaction with care items were factor analyzed. Using a combination of eigenvalues >1.00 (Tabachnick & Fidell, 1996) and inspection of the scree plot, three factors were identified (eigenvalues = 5.18, 1.06, 0.94). These factors accounted for a total of 63.09 % of the variance. The factors were orthogonally rotated using the varimax procedure, and the results are presented in Table 5. The items are ordered and blocked by size of loading to facilitate interpretation of the factor matrix.

Table 5. Factor Analysis of 12-item Satisfaction with Care Scale (n=123)

Item	Component		
Items: Satisfaction with Care Scale "How often…"	**1 CR Satisfaction with Affective Aspects of Family Care**	**2 Satisfaction with the CG's Attentiveness to Things Important to the CR**	**3 CR Satisfaction with Instrumental Aspects of Family Care**
…is care given to you with devotion and affection?	**.84**	.25	-.05
…does your family member express interest in the care you need?	**.71**	.41	.31
…are consideration and concern shown for your comfort?	**.70**	.23	.25
…is care given to you patiently?	**.63**	.01	.46
…is the care you receive from your family member appropriate for what you need?	**.47**	.40	.27
…does your family member make sure you have a chance to do social activities that are important to you?	.07	**.81**	.09
…does your family member do special things for you that you count on and look forward to?	.30	**.69**	.11
…is enough time allowed for your care?	.25	**.66**	.38
…are your needs taken care of promptly?	.32	**.59**	.30
…is the care you receive from your family member skillful and competent?	.15	.17	**.86**
…are your needs taken care of thoroughly?	.20	.19	**.73**
…are your needs taken care of dependably?	.33	.31	**.59**

Overall, the factor structure that emerged was clear and interpretable. The first factor, which accounted for 46.36% of the variance, had 4 items with loadings above .60, and 1 item that loaded at .47. This factor appears to capture the affective components of family care.

The second factor had 4 items with loadings above .50, and accounted for 8.87% of the variance. This factor involves satisfaction with time from the caregiver for things important to the care receiver.

Three items had loadings of greater than .50 on the third factor, which accounted for 7.86% of the variance. This factor appears to capture satisfaction with the instrumental aspects of family care.

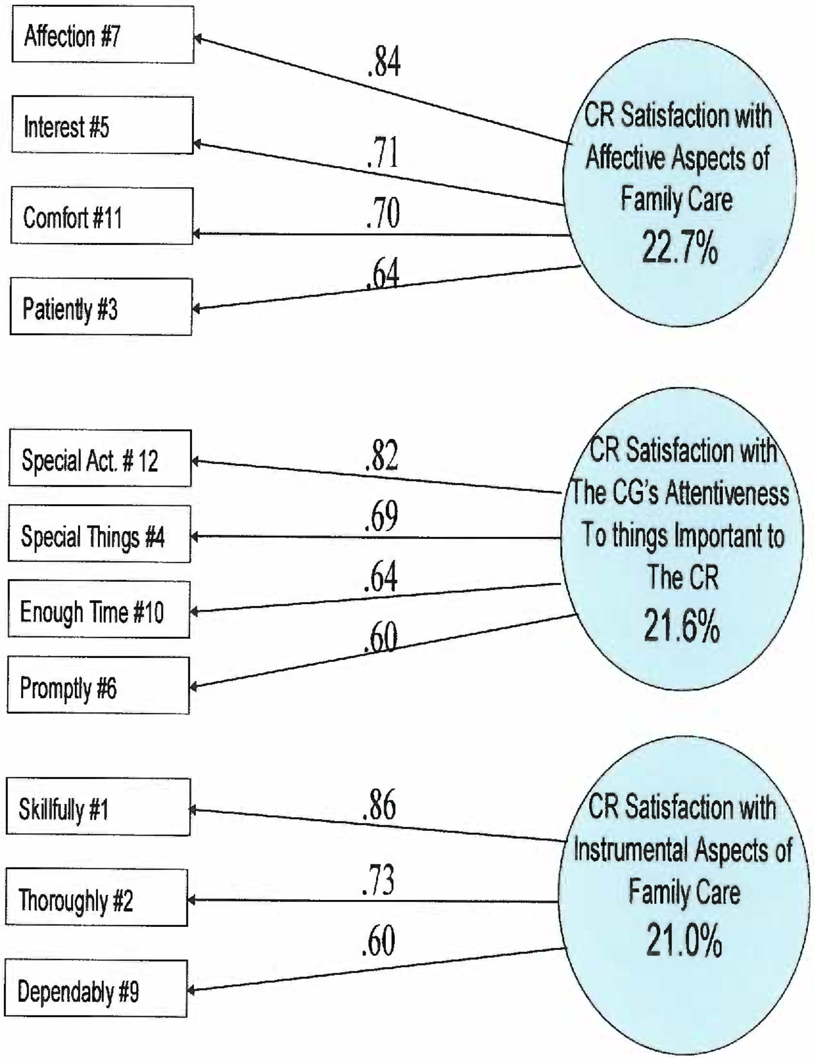
Overall, the only item that loaded at less than .50 was the item asking the care receiver to rate how often the care given by the caregiver was appropriate for their needs. In addition to having the lowest loading, this item was thematically inconsistent with the other items with which it loaded. Thus this item was deleted, and a second factor analysis was performed with the 11 remaining satisfaction with care items.

The second factor analysis resulted in extraction of the same three factors, accounting for a total of 65.28 % of the variance. All items loaded on their factors at .60 or greater (see table 6). Figure 2 provides a graphic representation of the factors, items, and their loadings on their respective factors. Within this new analysis, the factors of care receiver satisfaction with affective aspects of care, satisfaction with the caregiver's attentiveness to things important to the care receiver, and care receiver satisfaction with instrumental aspects of care, accounted for 47.06%, 9.65%, and 8.56% of the variance respectively. Oblique rotation yielded virtually identical results, with factor correlations of .37 (Instrumental/Attentiveness), .46 (Attentiveness and Affective), and .48 (Instrumental and Affective).

Table 6. Factor Analysis of 11-item CR Satisfaction with Family Care Scale (n=123) Item "How often is care appropriate…" removed. Principle Components Extraction with Varimax Rotation.

Item	**Component**		
Items: Satisfaction with Care Scale "How often…"	**1 CR Satisfaction with Affective Aspects of Family Care**	**2 Satisfaction with the CG's Attentiveness to Things Important to the CR**	**3 CR Satisfaction with Instrumental Aspects of Family Care**
…is care given to you with devotion and affection?	**.84**	.27	.06
…does your family member express interest in the care you need?	**.71**	.25	.26
…are consideration and concern shown for your comfort?	**.70**	.41	.32
…is care given to you patiently?	**.64**	.02	.46
…does your family member make sure you have a chance to do social activities that are important to you?	.09	**.82**	.09
…does your family member do special things for you that you count on and look forward to?	.30	**.69**	.12
…is enough time allowed for your care?	.20	**.64**	.41
…are your needs taken care of promptly?	.31	**.60**	.31
…is the care you receive from your family member skillful and competent?	.15	.16	**.86**
…are your needs taken care of thoroughly?	.20	.19	**.73**
…are your needs taken care of dependably?	.32	.31	**.60**
Eigenvalues (final) after varimax rotation	2.50	2.37	2.31
% of Variance	22.7%	21.6%	21.0%

Figure 2: Care Receiver Satisfaction with Family Care



Reliability

Internal consistency reliabilities were obtained for the entire Care Receiver Satisfaction with Family Care scale and each of the subscales and are displayed in Table 7.

Table 7. Internal Consistency Reliabilities for the Total Scale and Subscales (n=123)

Scale	Number of Items (5 response options per item)	Alpha Reliability (n)
CR Satisfaction with Family Care: Total Scale	11	.89 (99)
CR Satisfaction with Affective Aspects of Family Care	4	.83 (121)
Satisfaction with the CG's Attentiveness to Things Important to the CR	4	.74 (121)
CR Satisfaction with Instrumental Aspects of Family Care	3	.77 (101)

Table 8 presents the correlations of the subscales to the total scale and to each other, and Table 9 presents the correlations of the items with each of the scales.

Table 8. Scale to Scale Correlations including Overall Satisfaction Rating (n=123)

Scale	**CR Satisfaction with Affective Aspects of Family Care**	**Satisfaction with the CG's Attentiveness to Things Important to the CR**	**CR Satisfaction with Instrumental Aspects of Family Care**
CR Satisfaction with Affective Aspects of Family Care	1.0		
Satisfaction with the CG's Attentiveness to Things Important to the CR	.60**	1.0	
CR Satisfaction with Instrumental Aspects of Family Care	.61**	.56**	1.0
Overall Satisfaction Rating (1-10)	.62**	.56**	.50**

** p < .01

Table 9. Item to Scale Correlations (n=123)

Items: Satisfaction with Care Scale "How often…"	CR Satisfaction: Total Scale	CR Satisfaction with Affective Aspects of Family Care	Satisfaction with the CG's Attentiveness to Things Important to the CR	CR Satisfaction with Instrumental Aspects of Family Care
…is care given to you with devotion and affection?	.69**	**.83****	.47**	.40**
…does your family member express interest in the care you need?	.70**	**.79****	.48**	.51**
…are consideration and concern shown for your comfort?	.83**	**.88****	.64**	.58**
…is care given to you patiently?	.65**	**.76****	.38**	.51**
…does your family member make sure you have a chance to do social activities that are important to you?	.64**	.41**	**.82****	.38**
…does your family member do special things for you that you count on and look forward to?	.68**	.49**	**.79****	.40**
…is enough time allowed for your care?	.71**	.51**	**.76****	.53**
…are your needs taken care of promptly?	.69**	.52**	**.74****	.50**
…is the care you receive from your family member skillful and competent?	.66**	.48**	.44**	**.87****
…are your needs taken care of thoroughly?	.64**	.48**	.42**	**.80****
…are your needs taken care of dependably?	.69**	.55**	.50**	**.78****

** $p < .01$

Figures 3-5 represent the distribution of mean scores on each of the subscales, while figure 6 includes all three subscales, and allows for comparison of the distribution of mean scores.

Figure 3: Distribution of Mean Scores for CR Satisfaction with Affective Aspects of Family Care

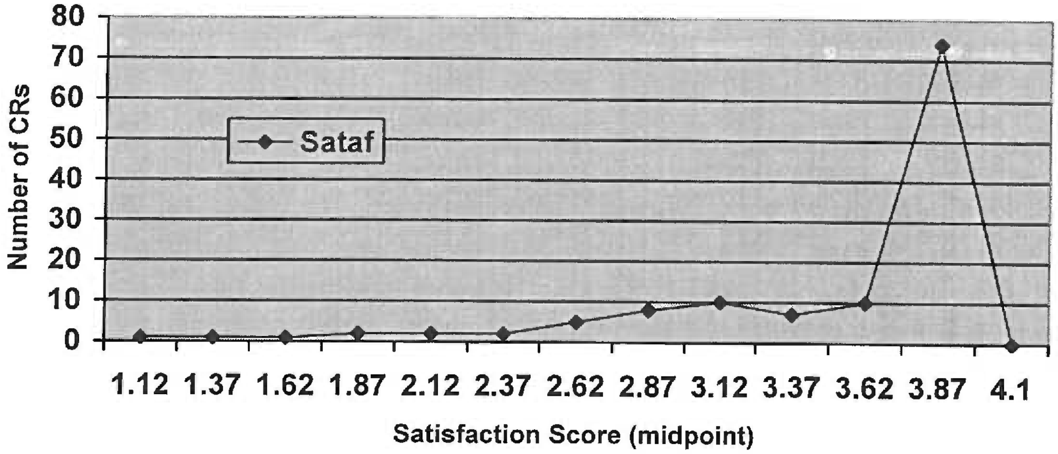


Figure 4: Distribution of Mean Scores for CR Satisfaction with Instrumental Aspects of Family Care

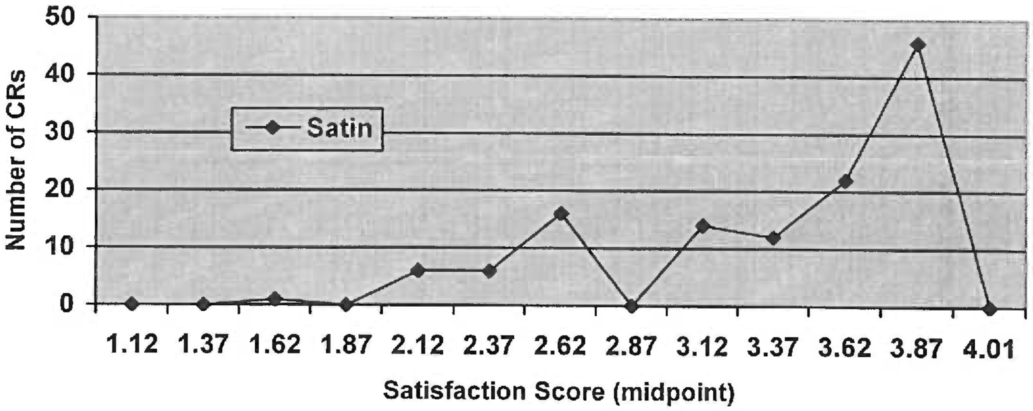


Figure 5: Distribution of Mean Scores for CR Satisfaction with CG's Attentivenss to Things Important to the CR

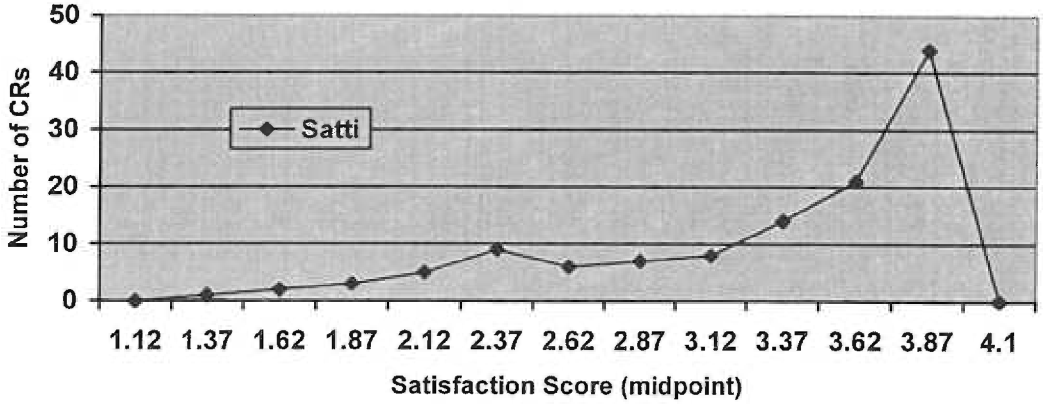
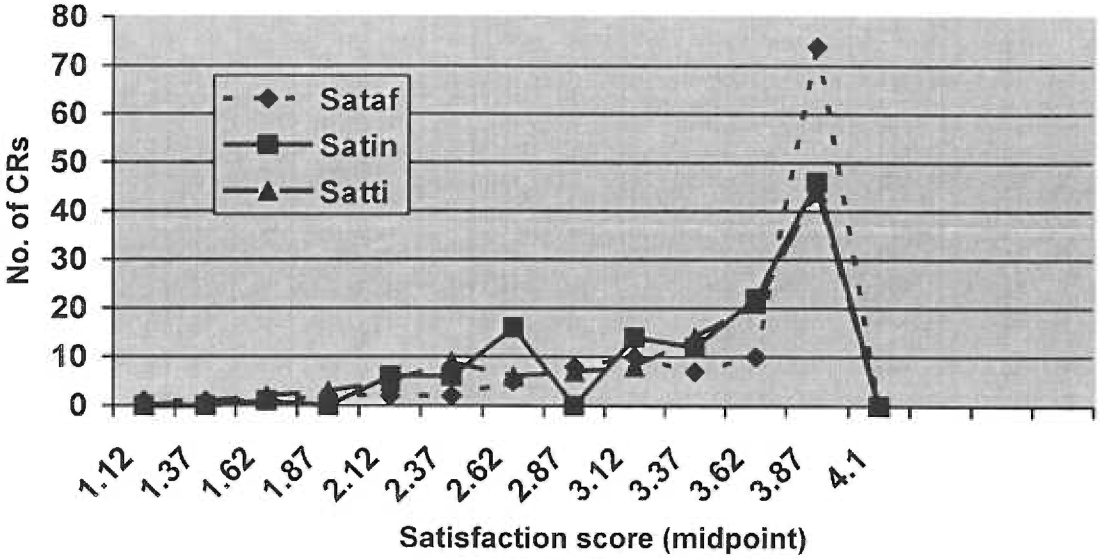


Figure 6: Comparison of Mean Scores for CR Satisfaction Subscales



Descriptive Statistics

Descriptive statistics for the care receiver, demographic, relationship, and caregiver variables are displayed in Tables 10-12.

Table 10. Descriptive Statistics for Care Receiver Independent Variables (n=123)

Variable	n	M (SD)	Possible Range	Actual Range
CR ADL (6 items)	123	2.3 (1.8)	0-6	0-6
CR IADL (9 items)	123	5.8 (2.0)	0-9	1-8
CR Mini-mental Status exam (30 items)	123	27.0 (1.8)	0-30	24-30
CR Positive Affect Balance (5 items)	120	2.6 (1.5)	0-5	0-5
CR Negative Affect Balance (5 items)	122	1.7 (1.4)	0-5	0-5
CR Mutuality: Total scale (15 items)	119	3.40 (0.51)	0.00-4.00	1.67-4.00
• CR Mutuality: Love subscale (3 items)	119	3.76 (0.41)	0-4	1.67-4.00
• CR Mutuality: Shared Values subscale (2 items)	117	3.26 (0.70)	0-4	0.50-400
• CR Mutuality: Shared Pleasurable Activities subscale (4 items)	119	3.33 (0.67)	0-4	1.50-4.00
• CR Mutuality: Reciprocity subscale (6 items)	120	3.33 (0.67)	0-4	0.67-4.00

Table 11: Descriptive Statistics for Demographic and Relationship Variables (n=123)

Variable	n	M (SD)	Possible Range	Actual Range
CR Age	122	78.8 (6.5)	65 to highest	65-95
CR/CG – length of relationship	123	46.34 (16.4)	----------	0.7-80

Table 12. Descriptive Statistics for Caregiver Independent Variables (n=123)

Variable	n	M (SD)	Possible Range	Actual Range
CG Rand Phys Health (21 items)	123	67.6 (23.6)	0-100	6.0-100
CG CESD (20 items)	123	11.6 (9.1)	0-60	0-40
CG Mutuality: Total scale (15 items)	123	3.00 (0.83)	0.00-4.00	0.2-4.00
• CG Mutuality: Love subscale (3 items)	123	3.52 (0.76)	0.00-4.00	0.67-4.00
• CG Mutuality: Shared Values subscale (2 items)	123	3.01 (0.83)	0.00-4.00	0.00-4.00
• CG Mutuality: Shared Pleasurable Activities subscale (4 items)	123	2.99 (0.90)	0.00-4.00	0.00-4.00
• CG Mutuality: Reciprocity subscale (6 items)	123	2.74 (1.01)	0.00-4.00	0.00-4.00
CG Preparedness (8 items)	123	2.46 (0.80)	0.00-4.00	0.63-4.00
CG Strain – Strain from Care Activities (86 items)	122	1.03 (0.73)	0.00-4.00	0.00-3.77
CG Strain – Communication Problems (3 items)	123	0.54 (0.69)	0.00-4.00	0.00-3.67
CG Strain – Frustration with Communication Problems (3 items)	123	0.97 (0.96)	0.00-4.00	0.00-4.00
CG Strain – Role Conflict (14 items)	123	0.86 (0.82)	0.00-4.00	0.00-3.64
CG Strain – Manipulation (4 items)	122	0.52 (0.83)	0.00-4.00	0.00-3.5
CG Strain – Tension (4 items)	122	1.07 (0.98)	0.00-4.00	0.00-3.25
CG Strain – Global Strain (4 items)	123	1.31 (0.81)	0.00-4.00	0.00-3.5

Correlations

Correlations with Care Receiver Variables

Correlations were examined between the dependent variable of care receiver satisfaction with family care and the care receiver variables of mutuality, cognitive function, functional health and affect balance.

Care Receiver Mutuality. The care receiver mutuality total scale and subscales correlated positively correlated with care receiver satisfaction—both the total satisfaction scale and the subscales (see table 13). Overall, care receivers who experienced higher levels of mutuality expressed more satisfaction with the care they received.

Care Receiver Functional Health. Care receiver functional health was assessed by asking the caregiver how much difficulty the care receiver had in performing activities of daily living (ADLs). This had a negative correlation with care receiver satisfaction, but was only significant for its relationship with care receiver satisfaction with the affective aspects of family care.

Care Receiver Affect Balance. Care receivers with a more positive affect balance were more likely to express higher levels of satisfaction with the care they received. This relationship held true for both the total satisfaction scale and all three subscales. Care receivers with a more negative affect balance appear to be more likely to express lower levels of satisfaction overall. However, upon closer examination, there was no significant relationship between negative affect balance and care receiver satisfaction with the affective aspects of family care (see Table 13).

Table 13: Correlations: Care Receiver Variables with Satisfaction with Care (n=123)

Care Receiver (CR) Variables	CR Satisfaction: Total Scale	CR Satisfaction with Affective Aspects of Family Care	Satisfaction with the CG's Attentiveness to Things Important to the CR	CR Satisfaction with Instrumental Aspects of Family Care
Care receiver (CR) Mutuality (total scale)	.55**	.58**	.46**	.34**
• CR Mutuality (Love & Affec.)	.35**	.35**	.29**	.24**
• CR Mutuality (Shared Values)	.37**	.38**	.36**	.26**
• CR Mutuality (Shared Pleas. Activities)	.45**	.45**	.42**	.26**
• CR Mutuality (Reciprocity)	.56**	.60**	.44**	.38**
CR Functional Health: ADL difficulty	-.14	-.15*	-.10	-.09
CR Positive Affect	.31**	.19*	.30**	.29**
CR Negative Affect	-.18*	-.11	-.15*	-.19*

* p < .05; ** p < .01

Correlations with Relationship and Demographic Variables

Two of the relationship variables demonstrated significant correlations with care receiver satisfaction (see Table 16). The length of time the care receiver and caregiver had known each other was negatively correlated with care receiver satisfaction with the instrumental aspects of family care, indicating that care receivers who had known their caregivers longer expressed less satisfaction with this aspect of the care they received. In addition, when care receivers and caregivers lived together, care receivers expressed lower levels of satisfaction with the affective aspects of family care.

When the type of relationship was defined as spouse/non-spouse, there was no significant correlation between the type of relationship and care receiver satisfaction. However, further exploration, examining specific types of relationships, revealed significant differences. Having a husband as a caregiver was associated with lower levels of satisfaction, than with other types of relationships such as having a caregiver who was a wife, daughter, or other type (son, daughter-in-law, niece, granddaughter, etc.) (see Tables 14 & 15). This was true for the total satisfaction scale, and for satisfaction with the affective aspects of family care. For satisfaction with the caregiver's attentiveness to things important to the care receiver, having a husband as a caregiver was associated with lower levels of satisfaction than with having a caregiver who was a wife or other type of caregiver, and for satisfaction with the instrumental aspects of family care, having a husband as a caregiver was associated with lower levels of satisfaction than with having a caregiver who was an other type of caregiver (son, daughter-in-law, niece, granddaughter, etc.).

Table 14. Analysis of Variance Comparing Caregiver-Care Receiver Type of Relationship on CR Satisfaction with Care

Satisfaction subscales	df	*F*	p
CR Satisfaction with Family Care Total Scale	3, 119	8.66	<.001
CR Satisfaction with Affective Aspects	3, 119	9.02	<.001
CR Satisfaction with CG Attentiveness	3, 116	7.76	<.001
CR Satisfaction with Instrumental Aspects	3, 119	2.86	<.05

Table 15. Means (and Standard Deviations) on CR Satisfaction with Care for Dyads Where the CG is a Wife, Husband, Daughter or Other Type of CG-CR Relationship

Satisfaction Subscales	Wife CG N=35	Husband CG N=31	Daughter CG N=30	Other CG N=27	Significant pairwise differences[a]
CR Satisfaction with Family Care Total Scale	3.56 (0.42)	2.97 (0.68)	3.38 (0.59)	3.58 (0.40)	Husband < wife, daughter & other.
CR Satisfaction with Affective Aspects	3.71 (0.41)	3.00 (0.85)	3.52 (0.63)	3.71 (0.50)	Husband < wife, daughter & other.
CR Satisfaction with CG Attentiveness	3.35 (0.62)	2.94 (0.78)	3.28 (0.76)	3.46 (0.60)	Husband < other.
CR Satisfaction with Instrumental Aspects	3.66 (0.47)	2.99 (0.77)	3.34 (0.61)	3.56 (0.49)	Husband < wife & other.

[a] Pairwise differences significance at $p<.05$ using the Tukey correction for multiple tests.

Only one demographic variable—gender of the care receiver—demonstrated a significant correlation with family care (see Table 17). Overall, female care receivers expressed lower levels of satisfaction with the instrumental aspects of family care than male care receivers (.19; $p<.05$).

Table 16. Correlations: Relationship Variables with CR Satisfaction with Care (n=123)

Relationship Variables	CR Satisfaction: Total Scale	CR Satisfaction with Affective Aspects of Family Care	Satisfaction with the CG's Attentiveness to Things Important to the CR	CR Satisfaction with Instrumental Aspects of Family Care
Duration of Relationship[a]	-.15	-.11	-.06	-.25**
Type of Relationship[b]	-.16	-.17	-.14	-.08
Co-residence of CG & CR[b]	-.12	-.20*	-.06	-.04

* p < .05; ** p < .01
a=1-tailed test, b=2-tailed test

Table 17. Correlations: CR & CG Demographic Variables with CR Satisfaction with Care (n=123)

Demographic Variables	CR Satisfaction: Total Scale	CR Satisfaction with Affective Aspects of Family Care	Satisfaction with the CG's Attentiveness to Things Important to the CR	CR Satisfaction with Instrumental Aspects of Family Care
CR age[a]	.08	.02	.05	.13
CR gender[b]	.10	.12	-.03	.19*
CR SES[b]	-.03	-.01	-.06	.02
CR Ethnicity[a]	-.02	.06	-.00	-.12
CG employment[b]	.03	.07	-.06	.08
CG minor children[a]	.06	.08	.08	.01

* p < .05
a=1-tailed test, b=2-tailed test

Correlations with Caregiver Variables

Three caregiver variables—caregiver mutuality, caregiver preparedness and caregiver depressive symptoms—did not have significant correlations with care receiver satisfaction (see Table 18).

Caregiver Physical Health. Caregiver physical health had a significant positive correlation with care receiver satisfaction. This held true for the relationship with the total scale, and two of the subscales: satisfaction with the caregiver's attentiveness to things important to the care receiver ($r=.25$, $p<.01$), and satisfaction with instrumental aspects of family care ($r=.23$, $p<.01$). Thus, caregivers who reported better physical health were more likely to have care receivers who expressed higher levels of satisfaction in these two areas.

Table 18: Correlations: Caregiver Variables with Satisfaction with Care (n=123)

Caregiver Variables	CR Satisfaction: Total Scale	CR Satisfaction with Affective Aspects of Family Care	Satisfaction with the CG's Attentiveness to Things Important to the CR	CR Satisfaction with Instrumental Aspects of Family Care
CG Mutuality (total scale)	.07	.06	.09	.01
• CG Mutuality (Love & Affection	-.00	-.01	.02	-.02
• CG Mutuality (Shared Values)	.00	.03	.01	-.07
• CG Mutuality (Shared Pleas. Act.)	.10	.09	.09	.04
• CG Mutuality (Reciprocity)	.08	.05	.11	.02
CG Preparedness	.11	.14	.08	.02
CG Physical Health	.22**	.09	.25**	.23**
CG Depressive Symptoms	.03	.10	-.05	.02

** $p < .01$

All tests are 1-tailed

Caregiver Role Strain. I explored the relationship between care receiver satisfaction and several measures of caregiver role strain. Two caregiver role strain measures – role strain from care activities and role strain from feelings of being manipulated, were negatively correlated with the total care receiver satisfaction scale. Caregiver role strain from feelings of being manipulated was also negatively correlated with care receiver satisfaction with the affective aspects of family care. None of the caregiver role strain measures was significantly correlated with the care receiver's satisfaction with the instrumental aspects of family care. Five role strain measures—strain from care activities, strain from providing little extras and emotional support, strain from role conflict, strain from feelings of being manipulated, and strain from increased tension—demonstrated small but significant negative correlations with satisfaction with the caregiver's attentiveness to things important to the care receiver. In summary, all of the correlations were negative, indicating that caregivers who experience higher levels of role strain are more likely to have care receivers who express lower levels of satisfaction with some aspects of the care they receive (see Table 19).

Table 19: Correlations: CR Satisfaction with CG Role Strain (n=123)

Caregiver Role strain scales	**CR Satisfaction: Total Scale**	**CR Satisfaction with Affective Aspects of Family Care**	**Satisfaction with the CG's Attentiveness to Things Important to the CR**	**CR Satisfaction with Instrumental Aspects of Family Care**
Care Activities (86 items)	-.15*	-.14	-.17*	-.06
Little Extras (12 items)	-.10	-.09	-.16*	.01
Communication Problems (3 items)	-.08	-.15	-.09	.06
Frustration from communication (3 items)	-.04	-.10	.-.03	.09
Role Conflict (14 items)	-.08	-.06	-.15*	.05
Feelings of Being Manipulated (4 items)	-.17*	-.19*	-.16*	-.07
Increased Tension (4 items)	-.13	-.13	-.17*	-.02
Global Strain (4 items)	-.11	-.08	-.15	-.02

*$p < .05$

Regression

Stepwise hierarchical multiple regressions with the care receiver and caregiver demographic and relationship variables were performed, with the care receiver satisfaction with family care subscales as the outcome variables. The independent variables were entered in the following order: care receiver age, gender, socioeconomic status, and ethnicity; the type of relationship between the caregiver and care receiver (spouse/non-spouse), duration of the caregiver care receiver relationship, and whether or not they lived together. Finally, caregiver employment and whether minor children lived with the caregiver were entered. The independent variables explained only 1% of the variance in care receiver satisfaction with the affective aspects of family care, and less than 1% of the variance in satisfaction with the caregiver's attentiveness to things important to the care receiver. However, they explained 13% of the variance in care receiver satisfaction with the instrumental aspects of family care ($R^2 = .20$, Adj. $R^2 = .13$). The independent variables that contributed significantly either at entry or in the final step were the age (β at entry = .15, $p > .05$; β at final step = .22 $p < .05$) and gender of the care receiver (β at entry = .22, $p < .05$; β at final step = .18, $p > .05$), and the number of years the caregiver and care receiver had known each other (β at entry = -.33, $p < .01$; β at final step = -.34, $p = .01$).

I performed exploratory stepwise hierarchical multiple regressions with the goal of identifying key predictors. Seventeen predictor variables were included in order to avoid missing key variables. The three demographic and relationship variables mentioned above were entered in the first step, and care receiver and caregiver variables were entered in subsequent steps. Care receiver and caregiver variables were chosen for inclusion based on the following criteria: 1) there was strong theoretical support for inclusion, and/or 2) the variable had demonstrated a significant correlation with the Care Receiver Satisfaction with Family Care total scale or one of the three subscales. Once again, the outcome variables were the care receiver satisfaction with care subscales. Variables were entered in the following order:

Step 1: Care receiver age, care receiver gender, and duration of the care receiver--caregiver relationship.

Step 2: Care receiver difficulty with activities of daily living (ADL)

Step 3: Care receiver Positive Affect Balance

Step 4: Care receiver Negative Affect Balance

Step 5: Care receiver Mutuality

Step 6: Caregiver physical health

Step 7: Caregiver depressive symptoms (CESD)

Step 8: Caregiver Blessed test of Orientation Memory and Concentration

Step 9: Caregiver Mutuality

Step 10: Caregiver Preparedness

Step 11: The number of caregiver care activities

Step 12: Caregiver predictability

Step 13: Caregiver role strain care activities,

Step 14: Caregiver role strain from feelings of being manipulated

Step 15: Caregiver global strain.

Hierarchical regression with the above set of predictor variables explained 37% ($R^2 = .46$) of the variance in care receiver satisfaction with the affective aspects of family care, 23% ($R^2 = .34$) of the variance in satisfaction with the caregiver's attentiveness to things important to the care receiver, and 21% ($R^2 = .32$) of the variance in care receiver satisfaction with the instrumental aspects of family care.

Residual Analysis. Residual analysis of the three regressions revealed only one case beyond ± 3 standard errors of the estimate. This case occurred in the regression looking at care receiver satisfaction with affective aspects of family care. In looking at that specific case I found that the caregiver had a high CESD score (32). Comments made by the caregiver within the Family Care Inventory (FCI), indicated that this was due to the caregiver's sadness over the recent deaths of three close family members, rather than being related to caregiving. The CESD score was much lower in subsequent FCIs completed by this caregiver (10 mo. CESD = 0; 15 mo. CESD = 8). This case was deleted for all further analyses relating to this outcome variable.

Continued refinement of the model based on the contributions of individual predictors within the above regressions resulted in a regression model that included seven predictor variables: care receiver difficulty with ADLs, care receiver positive affect balance, care receiver mutuality, caregiver physical health and depressive symptoms, caregiver preparedness for family care, and caregiver strain from feelings of manipulation.

Care Receiver Satisfaction with the Affective Aspects of Family Care.

All of the predictor variables contributed to the variance explained in care receiver satisfaction with the affective aspects of family care, except for care receiver positive affect. This variable entered at a significant level in Step 2. However, once care receiver mutuality had been entered in Step 3, care receiver positive affect ceased to contribute significant unique explanation, indicating that the variance in care receiver positive affect and care receiver mutuality overlap in this analysis. Conversely, caregiver physical health was not significant on entry, but once caregiver depressive symptoms were entered, caregiver physical health began to make a significant contribution to the amount of variance explained. Care receiver mutuality had a beta weight of .55 upon entry, and .50 at the final step—decreasing by only .05 after all the other variables had been entered, and having the highest beta weight throughout the regression analysis. The three variables that contributed most significantly to the explained variance in this aspect of care receiver satisfaction were: care receiver mutuality, caregiver depression, and care receiver difficulty with ADLs (see Table 21). Table 20 demonstrates shifts in beta weights at each step of the regression analysis.

Table 20. Care Receiver Satisfaction with the Affective Aspects: 7 Predictors $R^2 = .47$, Adj. $R^2 = .44$ (n=123)

Step	Predictors	Step 0	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
1	CR ADL	-.17	**-.17***	**-.15**	**-.13**	**-.12**	**-.17***	**-.19****	**-.20****
2	CR Pos. Affect Bal.	.21	.19*	**.19***	**.03***	**.03**	**.01**	**.01**	**.05**
3	CR Mutuality	.57	.56**	.55**	**.55****	**.55****	**.57****	**.56****	**.50****
4	CG Physical health	.11	.08	.06	.04	**.04**	**.16***	**.16***	**.17***
5	CG CESD	.13	.18*	.19*	.23**	.31**	**.31****	**.35****	**.43****
6	CG Preparedness	.16	.17	.15	.11	.11	.18*	**.18***	**.16***
7	CG Strain from manipulation	-.19	-.19*	-.24*	-.06	-.06	-.21*	-.19*	**-.19***

* p≤ .05
* p≤ .01

Table 21. Care Receiver Satisfaction with the Affective Aspects of Family Care (n=123)

Step	Variable	Regression weights and variance explained at step entered		Regression weights and variance explained at final step	
		β to enter	% of variance explained at entry	β at final step	% of unique variance
1	CR ADL	-.17	3.0	-.20*	3.8
2	CR Positive Affect Balance	.19*	3.7	.05	0.2
3	CR Mutuality	.55**	28.0	.50**	20.2
4	CG Physical Health	.04	0.1	.17*	2.2
5	CG CESD	.31**	7.1	.43**	11.0
6	CG Preparedness	.18*	2.8	.16*	2.2
7	CG Strain from Manipulation	-.19*	2.4	-.19*	2.4

* $p \leq .05$
* $p \leq .01$

Caregiver depressive symptoms (CESD) had a positive relationship with care receiver satisfaction with the affective aspects of family care, indicating that caregivers who had higher levels of depressive symptoms were associated with care receivers who had higher levels of satisfaction with this aspect of family care. This relationship between CESD and care receiver satisfaction was in the opposite direction to that hypothesized prior to analysis. Examination of the data set for cases where this relationship was most apparent, revealed six cases where the CESD score was ≥ 30, and care receiver satisfaction with the affective aspects of family care was ≥ 3.5. Table 22 lists these specific cases.

Further analysis is needed to fully understand this relationship. Possible avenues of exploration include: 1) looking at care receiver satisfaction scores in subsequent waves of data to see if they remain high, 2) looking at caregiver depression scores in subsequent waves of data to see if the high levels of depression persist, 3) looking at both care receiver and caregiver mutuality scores in data at 5, 10, 15, 20 months, 4) evaluating qualitative comments from both care receivers and caregivers to better understand other factors in the family care situation that may have led to this interesting, if unexpected, finding.

Table 22. Cases with high CESD & high Satisfaction with Affective Aspects

Case	CESD Score	C R Satisfaction with the Affective Aspects of Family Care	CR Mutuality	CG Mutuality
1	30	4.00	3.67	3.40
2	33	3.50	Missing	1.13
3	34	4.00	3.73	2.60
4	36	3.75	2.93	0.20
5	36	4.00	3.93	3.73
6	40	3.75	2.40	1.53

Residual Analysis. Residual analysis revealed only five cases beyond ± 2 standard errors of the estimate and one case at 3.0 standard errors beyond the estimate. The scatter diagram of standardized predicted versus standardized residual scores produced a scatterplot that met the assumptions of normality, and linearity of residuals, with a modest departure from homoscedasticity.

Care Receiver Satisfaction with the Caregiver's Attentiveness to Thing Important to the Care Receiver.

Two of the predictor variables—care receiver mutuality and caregiver physical health—contributed significantly to the variance explained in care receiver satisfaction with the caregiver's attentiveness to things important to the care receiver (see Table 22). Care receiver positive affect entered at a significant level in Step 2. However, once again, when care receiver mutuality was entered in Step 3, care receiver positive affect ceased to contribute significant unique explanation. Care receiver mutuality entered with a beta weight of .40, and had a beta weight of .37 at the final step—decreasing by only .03 after all the other variables had been entered, once again making it the variable with the highest beta weight throughout the regression analysis. Caregiver physical health entered at .19, and increased to .25 with the entry of caregiver depressive symptoms. Table 23 demonstrates shifts in beta weights at each step of the regression analysis.

Residual Analysis. Residual analysis revealed only five cases beyond ± 2 standard errors of the estimate and none beyond ± 3 standard errors of the estimate. The scatter diagram of standardized predicted versus standardized residual scores produced a scatterplot that met the assumptions of normality, linearity, and homoscedasticity of residuals.

Table 23. Care Receiver Satisfaction with the CG's Attentiveness to things important to the CR: 7 Predictors $R^2 = .30$, Adj. $R^2 = .26$

Step	Predictors	Step 0	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
1	CR ADL	-.12	-.12	-.08	-.07	-.03	-.05	-.05	-.05
2	CR Pos. Affect Bal.	.30	.29**	.29**	.18*	.15	.13	.13	.17
3	CR Mutuality	.46	.45**	.40**	.40**	.40**	.41**	.41**	.37**
4	CG Physical health	.26	.24**	.20*	.19*	.19*	.25**	.25**	.25**
5	CG CESD	-.02	.00	-.00	.03	.14	.14	.13	.18
6	CG Preparedness	.06	.07	.03	.00	-.04	-.02	-.02	-.03
7	CG Strain from manipulation	-.14	-.14	-.20*	-.08	-.05	-.12	-.12	-.12

* $p \leq .05$

* $p \leq .01$

Table 24. Care Receiver Satisfaction with the Caregiver's Attentiveness to Things Important to the Care Receiver

Step	Variable	Regression weights and variance explained at step entered		Regression weights and variance explained at final step	
		β to enter	% of variance explained at entry	β at final step	% of unique variance
1	CR ADL	-.12	1.4	-.05	0.3
2	CR Positive Affect Balance	.29**	8.4	.17	2.2
3	CR Mutuality	.40**	14.7	.37**	11.0
4	CG Physical Health	.19*	3.3	.25**	4.8
5	CG CESD	.14	1.4	.18	2.1
6	CG Preparedness	-.02	0.0	-.03	0.1
7	CG Strain from Manipulation	-.12	1.1	-.12	1.1

* $p \leq .05$

* $p \leq .01$

Care Receiver Satisfaction with the Instrumental Aspects of Family Care.

Four of the predictor variables—care receiver positive affect, care receiver mutuality, caregiver physical health, and caregiver depressive symptoms—contributed to the variance explained in care receiver satisfaction with the instrumental aspects of family care (see Table 26). Care receiver positive affect entered at .28 in Step 2. When care receiver mutuality was entered in Step 3, care receiver positive affect lost some of its contribution. However, it continued to provide significant unique explanation and had a beta weight of .19 at the final step. Care receiver mutuality had a beta weight of .28 upon entry, and .26 at the final step—decreasing by only .02 after all the other variables had been entered (see Table 25). Caregiver physical health entered at .17, increased to .25 with the entry of caregiver depressive symptoms, and had a beta weight of .26 at the final step. Thus, care receiver mutuality and caregiver physical health contributed equally to the explanation of variance in this aspect of care receiver satisfaction. Caregiver depressive symptoms entered at .18 in step five, and gradually increased to a beta weight of .21 by the final step. Table 25 demonstrates shifts in beta weights at each step of the regression analysis.

Residual Analysis. Residual analysis revealed only two cases beyond ± 2 standard errors of the estimate and none beyond ± 3 standard errors of the estimate. The scatter diagram of standardized predicted versus standardized residual scores produced a scatterplot that met the assumptions of normality, and linearity of residuals, with a modest departure from homoscedasticity.

Table 25. Care Receiver Satisfaction with the Instrumental Aspects of Family Care: 7 Predictors $R^2 = .22$, Adj. $R^2 = .17$

Step	Predictors	Step 0	Step1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
1	CR ADL	-.10	**-.10**	**-.06**	**-.05**	**-.02**	**-.04**	**-.04**	**-.04**
2	CR Pos. Affect Bal.	.29	.28**	**.28****	**.20***	**.18***	**.16**	**.16**	**.19***
3	CR Mutuality	.34	.34**	.28**	**.28****	**.28****	**.29****	**.29****	**.26****
4	CG Physical health	.23	.22*	.18*	.17*	**.17***	**.25****	**.26****	**.26****
5	CG CESD	.04	.06	.05	.08	.18	**.18**	**.17**	**.21***
6	CG Preparedness	.01	.01	-.03	-.05	-.08	-.06	**-.06**	**-.07**
7	CG Strain from manipulation	-.06	-.06	-.12	-.02	.00	-.09	-.09	**-.09**

* $p \leq .05$
* $p \leq .01$

Table 26. Care Receiver Satisfaction with the Instrumental Aspects of Family Care

Step	Variable	Regression weights and variance explained at step entered		Regression weights and variance explained at final step	
		β to enter	% of variance explained at entry	β at final step	% of unique variance
1	CR ADL	-.10	0.9	-.04	0.2
2	CR Positive Affect Balance	.28**	7.7	.19*	2.8
3	CR Mutuality	.28**	7.3	.26**	5.7
4	CG Physical Health	.17*	2.8	.26**	5.2
5	CG CESD	.18	2.6	.21*	2.8
6	CG Preparedness	-.06	0.3	-.07	0.4
7	CG Strain from Manipulation	.09	0.5	-.09	0.5

* $p \leq .05$
** $p \leq .01$

Summary of Three Regressions

The predictor variables contributed varying amounts to the explanation of variance in the three subscale regressions. Overall, care receiver mutuality consistently contributed the largest amount of explanation to the variance in each regression. However, the percent of variance explained by mutuality varied among subscales. It explained the largest amount of variance in care receiver satisfaction with the affective aspects of care, followed by care receiver satisfaction with the caregiver's attentiveness to things important to the care receiver, and satisfaction with the instrumental aspects of care (see Figure 8). Relatively little shrinkage occurred in the percent of variance explained by care receiver mutuality between entry and the final step in each of the three regressions.

The only other predictor variable that consistently explained a significant amount of the variance in all three regressions was caregiver physical health. This variable explained the greatest amount of variance in care receiver satisfaction with the instrumental aspects of care, followed closely by satisfaction with the caregiver's attentiveness to things important to the care receiver, and finally care receiver satisfaction with the affective aspects of family care (see Figures 7 & 8). In all three regressions, the relative explanatory value of caregiver physical health increased with the entrance of caregiver depressive symptoms (see Tables 20, 23, & 25).

Care receiver positive affect entered at a significant level in all three regressions (see Figure 7 and Tables 20, 23, & 25). However, with the entry of other variables—most importantly, care receiver mutuality—it ceased to offer significant unique explanation for the variance in satisfaction with the affective aspects of care and attentiveness of the caregiver (see Tables 20 & 23), while continuing to be significant in explaining variance in satisfaction with the instrumental aspects of care (see Table 25). Conversely, caregiver depressive symptoms was significant on entry for only satisfaction with affective aspects of care, but by the last step it offered significant explanation of variance in satisfaction with both the affective and instrumental aspects of care (see Tables 20 & 25). The three remaining variables—care receiver difficulty with ADLs, caregiver preparedness, and caregiver strain from feelings of manipulation—explained significant variance in satisfaction with the affective aspects of family care (see Table 21). They neither entered at a level of significance, nor attained it by the final step for satisfaction with instrumental aspects or satisfaction with caregiver attentiveness.

Overall, the greatest amount of variance was explained for care receiver satisfaction with the affective components of family care (44%), followed by satisfaction with the caregiver's attentiveness to things important to the care receiver (26%), and satisfaction with the instrumental aspects of family care (17%) (see Figure 8).

Figure 7. % of Variance Explained at Entry for Three Regressions

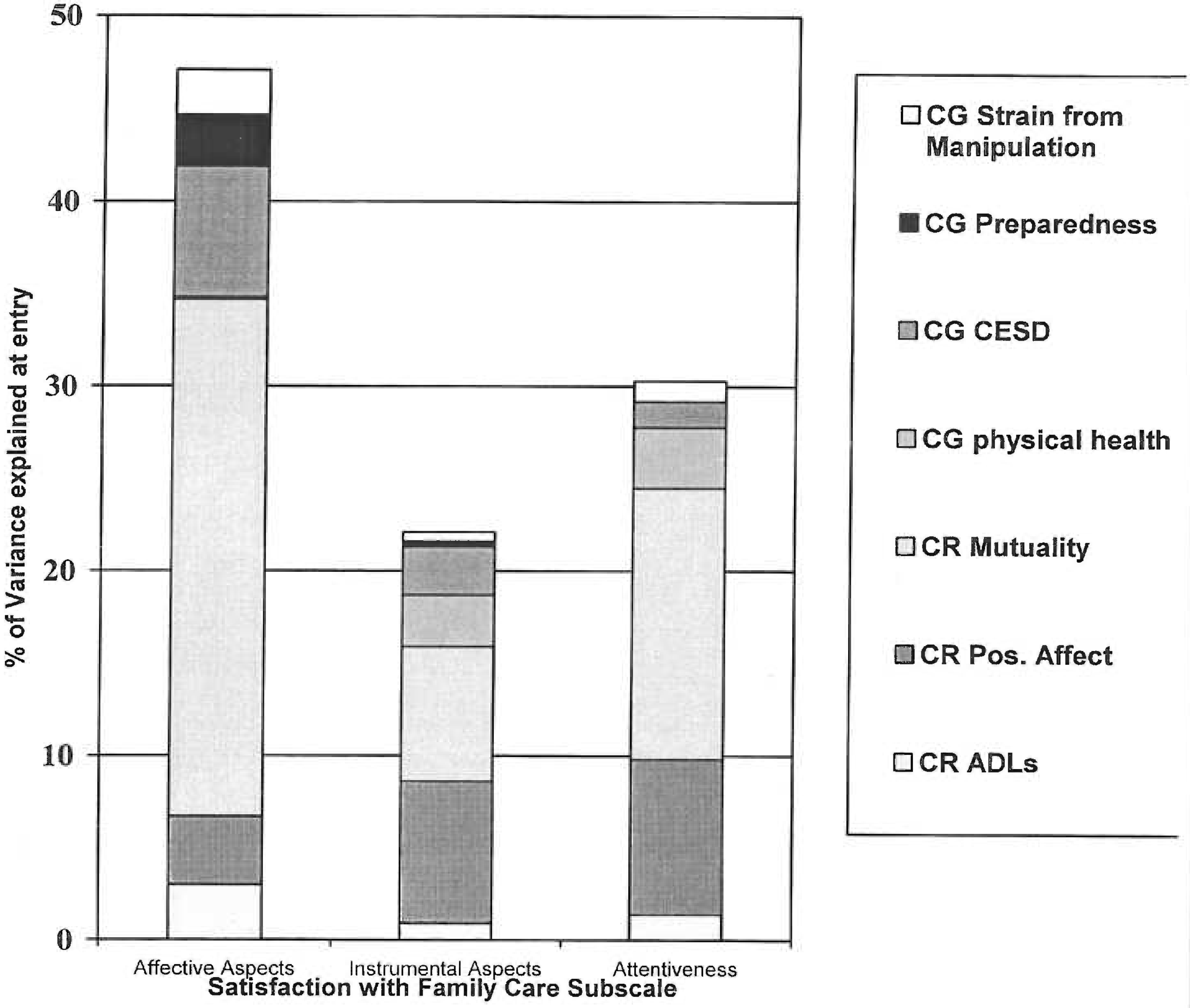
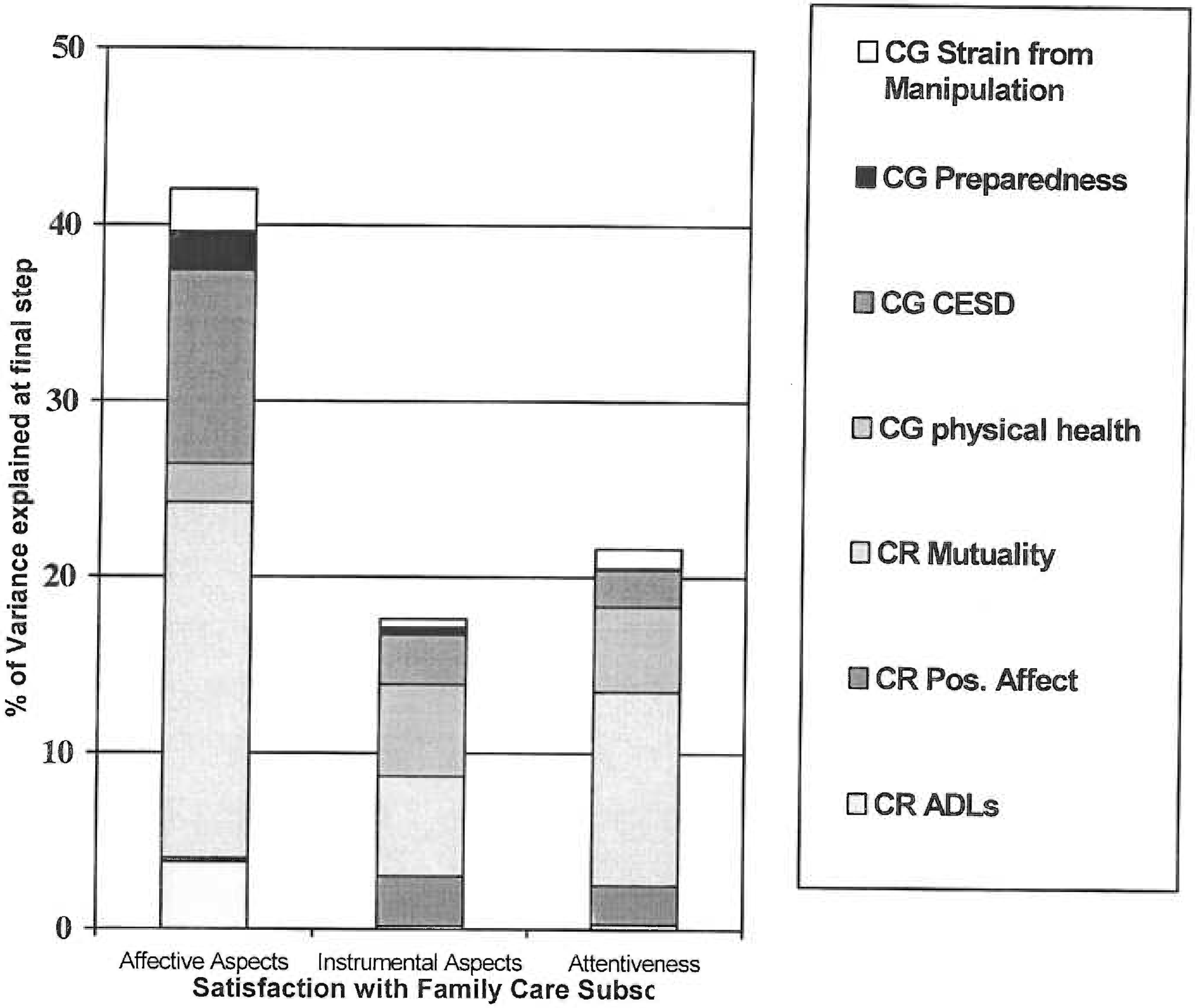


Figure 8. % of Variance Explained at the Final Step for Three Regressions



CHAPTER 5: DISCUSSION

This section begins with a description of the meaning of study results, followed by discussion of issues related to the reliability and validity of the findings, limitations of the study, and implications for theory, research, and practice.

Meaning of Results

The factor analysis of the Care Receiver Satisfaction with Family Care Scale revealed three distinct factors: care receiver satisfaction with the affective aspects of family care, care receiver satisfaction with the caregiver's attentiveness to things important to the care receiver, and care receiver satisfaction with the instrumental aspects of family care. These factors are consistent with, and extend the work of Lucas (1986) where the dimensions related to affective and instrumental care were identified. Having a three-factor structure rather than two allowed for greater sensitivity in identifying relationships among the variables during subsequent analyses.

Since Lucas's work with the Satisfaction with Care instrument, two additional items were added: How often does your family member make sure you have a chance to do social activities that are important to you? and How often does your family member do special things for you that you count on and look forward to? In the present factor analysis, these two items loaded together on a single factor, along with the items addressing whether enough time was allowed for care, and whether care was given promptly. The combination of these four items described an area that had not previously been identified—that of the attentiveness of the caregiver to things important to the care receiver.

This new factor is consistent with Symbolic Interactionism—the theoretical perspective underlying this study. Symbolic Interactionism focuses on assessing the meaning and importance of interactions to the participants (Bengtson et al., 1997; Blumer, 1969). As the care receiver and caregiver interact with each other, meaning is created. The factor relating to attentiveness of the caregiver allows us to better understand a facet of this meaning not previously captured by the factors of affective and instrumental aspects of care, and increases our ability to identify variables within the caregiving situation that are uniquely related to the concept of attentiveness.

One such set of variables relates to caregiver role strain. Where, previously, only one caregiver role strain measure correlated with satisfaction with the affective aspects of family care, and none of them correlated with satisfaction with the instrumental aspects of family care, several of the role strain measures demonstrated significant correlations with satisfaction with the caregiver's attentiveness to things important to the care receiver. This allows greater understanding of how the meaning of role strain—created by the caregiver—affects the meaning that the care receiver creates within the caregiving situation. When caregivers experience increased role strain it may be that their ability to be attentive to providing enough time for care, and arranging for special things and social activities for the care receiver, is diminished.

Care receivers who expressed higher levels of satisfaction with instrumental aspects of care were more likely to have known their caregivers a shorter period of time. This appears to contradict past research (Lucas, 1986) and intuition. However, it is important to look more closely at the sample of caregivers and care receivers in this study. The duration of the care receiver-caregiver relationship and the health of the caregiver had a small but significant negative correlation (-.16; p<.05), indicating that caregivers with the longest relationships with their care receivers tended to have lower levels of health. Many elder caregivers are themselves frail, and this may affect their ability to enact the caregiving role. The instrumental aspects of care may entail performing physical activities that are difficult for a caregiver in poor health. Thus, it is understandable that this may be reflected by care receivers expressing lower levels of satisfaction with this aspect of family care.

Care receivers who lived with their caregivers expressed less satisfaction with the affective aspects of their care. A previous study also found an association between co-residence and a moderate decrease in the psychological well-being of the elderly parent care receiver (Dwyer et al., 1994). In contrast, Morrow-Howell et al., (2001) found that when care receivers and caregivers lived together the care receiver was more likely to rate their care as sufficient, and Walker & Allen (1991) found that care receiving mothers and caregiving daughters who shared a residence were less likely to have conflicted relationships. The sample in the study by Morrow-Howell et al. (2001) included only 17% spouses, and Walker & Allen (1991) and Dwyer et al. (1994) included only caregiving daughters and care receiving mothers. The caregivers in the present study included 54% spouses and had a mean age of 63.7 years (SD=16.30). Thus, in the present study caregivers who resided with their care receivers were more likely to be spouses (.52; p<.01), and to be older (.38; p<.01). These older spouse caregivers were also shown to have poorer physical health than other types of caregivers (.16; p<.05). In summary, it may not be the length of time the caregiver and care receiver have known each other, or the fact that they live together, that caused lower levels of satisfaction, but other factors such as increased age and poorer physical health, which may decrease the caregiver's ability to enact the caregiver role.

Several care receiver variables were significant predictors of high levels of satisfaction. Of all the care receiver variables, mutuality demonstrated the strongest relationship with care receiver satisfaction. These findings are consistent with Lucas (1986), who found a significant relationship between mutuality ($r=.45$, $p\leq.05$) and satisfaction with the affective aspects of care.

I found no other studies that looked specifically at this variable in relation to care receiver satisfaction, but two studies explored related concepts, and their findings can shed light on this important area. Martini et al. (2001) found that care receiving mothers who made more negative dispositional attributions about their caregiving daughters during a negative exchange indicated less satisfaction with the care they received. In a study of care receiving mothers and their caregiving daughters, Walker & Allen (1991) found that in pairs with the most positive relationships there was a high degree of sharing between the participants—who described themselves as companions and friends and expressed enjoyment in time spent together.

The present study extends our understanding in this area, because the mutuality scale includes specific aspects of the relationship between the caregiver and care receiver such as love and affection, shared values, shared pleasurable activities, and reciprocity. The strong association between each of these aspects of mutuality and satisfaction provides greater understanding of how specific areas within the caregiver-care receiver relationship affect satisfaction.

Care receiver difficulty with ADLs was negatively correlated with care receiver satisfaction with the affective aspects of family care. This finding is consistent with Lucas (1986), who found a positive correlation between care receiver health ($r=.34$, $p<.05$) and satisfaction. Thus it appears that as the care receivers' functional health decreases and they require more assistance with ADLs, they may express less satisfaction with the affective aspects of the care they receive. Other studies of care receiver satisfaction included samples of care receivers with little physical impairment (Martini et al., 2001), did not find a significant relationship (Dwyer et al., 1994; Hollis-Sawyer, 2001), or did not include care receiver functional health as an independent variable (Morrow-Howell et al., 2001).

Care receivers who expressed higher levels of satisfaction also had higher levels of positive affect and lower levels of negative affect. In exploratory regression analysis, negative affect did not offer significant explanation. Positive affect, on the other hand, was significant on entry in each regression equation. However, once care receiver mutuality entered, positive affect lost some or all of its significant contribution to the explanation of variance, indicating that there is a great deal of overlap in the concepts of positive affect balance and mutuality. The only regression where it continued to be significant was satisfaction with the instrumental aspects of family care. Thus, this aspect of satisfaction involves areas where the care receivers' affect—or subjective well-being—has an effect on their satisfaction, which is separate from their relationship with the caregiver.

I found no studies that looked specifically at the relationship between affect balance and care receiver satisfaction with family care. However, Krause (1995) looked at the relationship between negative interaction and satisfaction with received social support. Krause asked elders to report the incidence of negative interactions with people within their support systems. One of the items asked the elders to rate how often their significant others were demanding or critical (Krause, 1995). The Bradburn Affect Balance Scale, used in the present study, includes an item that asks elders "During the past few weeks, did you ever feel upset because someone criticized you?" (Grann, 2000). Krause (1995) found that when elder care receivers experienced negative incidents, such as being criticized, they tended to express lower levels of satisfaction with the support received from family.

Overall, higher care receiver satisfaction was associated with better caregiver physical health. This finding differs from that of Lucas (1986), who found no significant relationship between caregiver health and care receiver satisfaction. However, Lucas's sample was small (34) when compared to that of the present study. The present finding is, however, consistent with Morrow-Howell et al., (2001), who found that family care was rated as more sufficient by care receivers when the caregiver was healthier.

The effect of caregiver physical health on satisfaction increased with the entry of caregiver depressive symptoms into the regression equation. These variables are significantly correlated ($r = -.43$; $p < .01$), and thus may have an effect on one another. Interestingly, as mentioned earlier, the relationship between care receiver satisfaction and caregiver depressive symptoms was in the opposite direction to that hypothesized. The reason for this is unclear. However, there are several possible explanations that require further exploration and evaluation. The present study used cross-sectional data gathered at baseline. It may be that caregiver depression that persists over time is associated with decreased care receiver satisfaction—an effect not seen at this early stage. There may be other factors in the caregiving situation, such as physical illness of the caregiver, that cause the care receiver to be hesitant to criticize. Other factors that were not included in this analysis may have an effect that complicates the relationship between care receiver satisfaction and caregiver depressive symptoms. Further investigation is warranted in order to better understand this interesting, if unexpected finding.

Finally, the finding that higher levels of caregiver strain from feelings of manipulation are associated with lower levels of care receiver satisfaction is consistent with Lucas (1986), who found an association between caregivers who rated the positive aspects of caregiving as outweighing the negative, and care receivers who expressed greater satisfaction with their care. While not directly assessing care receiver satisfaction, Walker, Pratt, & Wood (1993) found that caregiving daughters who perceived more frequent conflict between caregiving and their responsibilities as wives and mothers reported less intimacy in their relationships with their mothers. In contrast, Dwyer, Lee, & Jankowski (1994) found a positive association between the level of caregiver stress and elder life satisfaction. However, these findings are not directly comparable, since life satisfaction is much more general than the more specific variable of satisfaction with family care.

Validity of the Findings

Assumptions of Satistical Tests

Statistical assumptions underlying multiple regression analysis include normality, linearity, and homoscedasticity (Tabachnick & Fidell, 1996). These assumptions were assessed using descriptive statistics, histograms, and scatterplots. Although two of the residual plots demonstrated a moderate departure from the assumption of homoscedasticity, the assumptions of normality and linearity were met. The departure from homoscedasticity indicates that the errors of prediction increase at lower predicted values of the dependent variable, care receiver satisfaction with family care.

Multiple Testing and the Error Rate

This is an exploratory study in which multiple testing was done. One of the risks in such a study is the increased risk of Type I errors. Because of the exploratory nature of the study this risk was deemed acceptable in order to test hypotheses related to factors that were associated with care receiver satisfaction with care.

Reliability of Measures

Internal consistency reliability for the Care Receiver Satisfaction with Family Care total scale was .89, and for each of the subscales were: Satisfaction with Affective Aspects (4 items) = .83; Satisfaction with Caregiver Attentiveness (4 items) = .74; and Satisfaction with Instrumental Aspects (3 items) = .77. Thus, even though the subscales contained few items, their reliability fell within acceptable limits (Nunnally, 1994).

Construct Validity

Ideally, construct validity could have been established by testing hypotheses of association with other measures of care receiver satisfaction. I was unable to identify existing measures of this concept, and could not carry out this comparison. In addition to asking care receivers to complete the 12-item Satisfaction with Family Care Scale, they were asked to complete a one-item, 1-10 rating of how satisfied they were with the care they received from their family member. Correlations between the satisfaction scale and subscales and this one-item rating ranged from .50-.66, indicating that although they are measuring related concepts, there are significant differences (see Table 8).

Limitations of the Study

The data for this study were cross-sectional—providing a picture of care receiver satisfaction with care at one point in time. Exploring how satisfaction changes over time, and how other factors that affect satisfaction change over time, would provide a more comprehensive and complete picture.

Following initial evaluation of descriptive data, a decision was made to include only care receivers who had MMSE scores of 24-30. Recent research underscores the importance of including elders with varying levels of cognitive impairment in order to more fully understand how they experience the care they receive (Feinberg & Whitlatch, 2001; Morrow-Howell et al., 2001). Thus, while the findings of this study will be valuable as a comparison group for further analysis of data from care receivers with MMSE scores of ≤ 23, the present findings cannot be generalized to care receivers with cognitive impairment.

The sample for this study was predominantly Caucasian (111), and does not reflect society at large. Thus, the study findings may not hold true for minority care receivers and caregivers.

The sample size (123) was adequate but modest in terms of the desired sample size for a factor analysis and the regressions conducted as part of this study.

Implications for Theory, Research, and Practice

Theory

The conceptual model underlying this study proposed that care receiver satisfaction would be influenced by a triad of factors: care receiver variables, caregiver variables, and relationship variables. While variables from all three groups demonstrated significant correlations with care receiver satisfaction, only care receiver and caregiver variables offered significant explanation within the regression models, with care receiver variables having the greatest effect.

Care receiver satisfaction is viewed as one of three perspectives from which to assess quality of caregiver role enactment. Thus, findings from this study form a part of a puzzle, the entirety of which should always be kept in mind.

Research

While variables in this study explained a significant amount of variance in care receiver satisfaction, a large amount of the variance remains unexplained. One direction for further research is to look at other factors that could help to explain these differences. Several possible areas come to mind.

In qualitative interviews with caregivers, conducted as part of the parent study, one area that has come up repeatedly is the importance of knowing the care receivers, and taking their preferences into account in providing care. I think that asking the care receiver about their preferences, and whether they feel that these are taken into account in planning and providing care, may shed light on an area that could explain differences in satisfaction. At present, one item on the Care Receiver Satisfaction with Family Care scale asks the care receiver if their family member makes sure they have a chance to do social activities that are important to them. This begins to explore the importance of preferences—but in a limited way. From my work as a home health nurse, and as a research assistant interviewing caregivers and care receivers, I believe that attention to care receiver preferences in "every day" seemingly mundane activities is an important component that we have not addressed adequately.

Another area that I believe warrants further investigation is the personal optimism or pessimism of the care receiver. Subjective well-being was assessed in this study, and found to have some effect. However, optimism and pessimism are different from subjective well-being, and were not assessed at this data collection point for this sample of care receivers.

An interesting concept that may shed light on how care is evaluated by care receivers and satisfaction levels arrived at is that of "culpability." In research regarding patient satisfaction with formal health care services, Williams, Coyle, & Healy (1998) found that in qualitative interviews patients described care that was clearly sub-standard, and that they would admit had not met their needs, and yet when asked to rate how satisfied they were with the care, they gave relatively high satisfaction ratings. When asked about the discrepancy between their description of the care and their satisfaction rating, patients often stated that they did not feel that the health care provider was "culpable" or responsible for the poor care. Sometimes they blamed this on lack of resources within the system, or personal problems that the health care provider was experiencing.

Although the research by Williams et al., (1998) occurred in a formal health care system, the concept may apply to family care. Often caregivers themselves have poor health, or face limitations in personal or financial resources. Care receivers are often aware of these, and may be unwilling to criticize a caregiver who they feel is "doing the best they can" under difficult circumstances.

Practice

Evaluating the satisfaction of family care receivers provides greater insight into how they experience the caregiving situation—matters on which the care receiver is the ultimate authority (Williams, 1994; Morrow-Howell et al., 2001). Symbolic Interactionism provides a theoretical framework that is explicit in its focus on the importance of meaning created in a situation by the participants (Bengtson et al., 1997; Blumer, 1969). Understanding how family care is experienced by the care receiver and caregiver—the two primary participants in the family care situation—provides us with a window through which we can see that meaning more clearly. This perspective provides greater understanding of factors that affect care receiver satisfaction and can assist health care providers in focusing interventions more effectively.

Nurses are often the major health care providers who interact with family care receivers and caregivers. As such, they play a pivotal role in influencing the future direction of health care and the services that support both elder care receivers and their family caregivers. Understanding, for instance, that the relationship between the care receiver and the caregiver has a major influence on care receiver satisfaction highlights the importance of interventions to promote and maintain a strong relationship. Traditionally, home health nurses have focused on the identified skilled needs of the care receiver such as wound care or medication administration and teaching. While important, these tasks are only a piece of a much larger picture. Placing them in the context of a family care situation where a caregiver and care receiver interact, face transitions, create new roles and meanings, and need support to meet challenges effectively, changes the focus from the technical performance of tasks to fostering an environment that is supportive to all participants.

Recommendations and Future Directions

Exploratory factor analysis was performed as part of this study. A next step is confirmatory factor analysis of the 11-item Care Receiver Satisfaction with Care scale using a larger sample of care receivers. In addition, it is not clear that the same factors would emerge for other populations such as care receivers who have cognitive impairment, or care receivers who are from minority groups. Thus, testing of the scale is needed to establish its validity for other groups of care receivers.

Caregiving occurs over time, during which there may be significant changes for both the care receiver and caregiver. The present study brought up several interesting questions about the relationships between satisfaction and several of the predictor variables. As mentioned previously, longitudinal research would allow greater understanding of changes over time, and their effect on the care receiver and caregiver.

Care receiver satisfaction is viewed as one way of evaluating the quality of cargiver role enactment. Future research involving evaluation by a professional, or self-evaluation by the caregiver, would enhance our understanding of this complex area. Ideally, measurement from all three perspectives could then be compared to provide a more complete picture.

Summary

This dissertation study focused on understanding the satisfaction of frail elder care receivers with care they received from a family member. Specifically, it assessed the relative contribution of care receiver, caregiver and relationship variables in explaining care receiver satisfaction with family care.

The study was guided by three aims:

Aim 1: To describe the underlying factor structure of the Care Receiver Satisfaction with Care Scale, and determine whether the scale measures one global factor versus two or three separate but correlated factors.

Aim 2: To explore the association between care receiver evaluation of caregiver role enactment and selected care receiver, relationship, and caregiver variables. These variables include: (a) care receiver mutuality, cognitive function, functional health, subjective well-being, and demographic characteristics; (b) duration and type of the care receiver and caregiver relationship; and (c) caregiver mutuality, preparedness, physical health, depressive symptoms, caregiver role strain, and demographic characteristics.

Aim 3: To determine which care receiver, relationship, and caregiver variables predict variance in care receiver evaluation of caregiver role enactment.

The study used baseline data collected from the Family Care Study (Archbold, Stewart, & Hornbrook, R01 AG17909, 1999). The sample consisted of 123 care receiver-caregiver dyads. The 123 care receivers were mostly women (80), and Caucasian (117). Their ages ranged from 65-95, with a mean age of 78.82 years.

Caregivers for this sample were divided between spouses (66), and other types of family members (57), and had a mean age of 63.73 (SD 16.30). Of the 123 caregivers, only 34 were employed outside of the family care situation. The caregivers and care receivers had known each other for an average of 46.37 years, and 100 of the caregivers and care receivers lived in the same household.

The dependent variable, care receiver satisfaction with family care, was measured by the Care Receiver Satisfaction with Family Care Scale (Archbold, Stewart, & Lucas, 1986). The scale contained 12 items, asking the care receiver to rate the care they received from their family member on a 0-4 point scale, with response options of "never," "sometimes," "most of the time," "nearly always," or "always." Factor analysis during this study resulted in the identification of three factors: care receiver satisfaction with the affective aspects of family care, care receiver satisfaction with the caregiver's attentiveness to things important to the care receiver, and care receiver satisfaction with the instrumental aspects of family care. In addition, the item "How often is the care you receiver from your family member appropriate for what you need?" was dropped from the scale as a result of the factor analysis.

Sample items from the affective aspects subscale include: "How often is care given to you with devotion and affection?" and "How often is care given to you patiently?" Sample items from the satisfaction with caregiver attentiveness subscale include: "How often does your family member do special things for you that you count on and look forward to?" and "How often are your needs taken care of promptly?" Sample items from the instrumental aspects subscale include: "How often is the care you receive from your family member skillful and competent?" and "How often are your needs taken care of dependably?"

Hierarchical multiple regression was used to determine which care receiver, relationship, and caregiver variables predicted variance in care receiver satisfaction with family care. A parsimonious model was identified that included seven predictor variables: care receiver difficulty with ADLs, care receiver positive affect, care receiver mutuality, caregiver physical health and depressive symptoms, caregiver preparedness for family care, and caregiver role strain from feelings of manipulation.

Variables found to explain significant variance in the affective aspects of family care included: care receiver difficulty with ADLs, care receiver mutuality, caregiver physical health, caregiver depressive symptoms, caregiver preparedness, and caregiver role strain from feelings of manipulation. Variables found to explain significant variance in the care receiver's satisfaction with the caregiver attentiveness to things important to the care receiver included: care receiver mutuality and caregiver physical health. Variables found to explain significant variance in the instrumental aspects of family care included: care receiver positive affect, care receiver mutuality, caregiver physical health, and caregiver depressive symptoms.

The predictor variables contributed varying amounts to the explanation of variance in the three subscale regressions. Overall, care receiver mutuality consistently contributed the largest amount of explanation to the variance in each regression. However, the percent of variance explained by mutuality varied among subscales. It explained the largest amount of variance in care receiver satisfaction with the affective aspects of care, followed by care receiver satisfaction with the caregiver's attentiveness to things important to the care receiver, and satisfaction with the instrumental aspects of care (see Figure 8). Relatively little shrinkage occurred in the percent of variance explained by care receiver mutuality between entry and the final step in each of the three regressions.

Overall, the greatest amount of variance was explained for care receiver satisfaction with the affective components of family care (44%), followed by satisfaction with the caregiver's attentiveness to things important to the care receiver (26%), and satisfaction with the instrumental aspects of family care (17%) (see Figure 8).

Limitations of the Study

The data for this study were cross-sectional—providing a picture of care receiver satisfaction with care at one point in time. Exploring how satisfaction changes over time, and how other factors that affect satisfaction change over time, would provide a more comprehensive and complete picture.

The care receivers in the sample had MMSE scores of 24-30. While the findings of this study will be valuable as a comparison group for further analysis of data from care receivers with MMSE scores of ≤ 23, the present findings cannot be generalized to care receivers with cognitive impairment. In addition, the sample for this study was predominantly Caucasian (111). Thus, the study findings may not hold true for minority care receivers and caregivers. Finally, the sample size (123) was adequate but modest in terms of the desired sample size for a factor analysis and the regressions conducted as part of this study.

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Appendix A

Care Receiver Satisfaction with Family Care Scale

Satisfaction With Care

	Never	Sometimes	Most of the Time	Nearly Always	Always
1. How often is the care you receive from your family member skillful and competent?	0	1	2	3	4
2. How often are your needs taken care of thoroughly?	0	1	2	3	4
3. How often is care given to you patiently?	0	1	2	3	4
4. How often does your family member do special things for you that you count on and look foward to?	0	1	2	3	4
5. How often does your family member express interest in the care you need?	0	1	2	3	4
6. How often are your needs taken care of promptly?	0	1	2	3	4
7. How often is care given to you with devotion and affection?	0	1	2	3	4
8. How often is the care you receive from your family member appropriate for what you need?	0	1	2	3	4
9. How often are your needs taken care of dependably?	0	1	2	3	4
10. How often is enough time allowed for your care?	0	1	2	3	4
11. How often are consideration and concern shown for your comfort?	0	1	2	3	4
12. How often does your family member make sure you have a chance to do social activities that are important to you?	0	1	2	3	4

13. On a scale of 1 to 10, how satisfied are you with the care you receive from your family member with 1 being very dissatisfied, and 10 being very satisfied?

1........2........3........4........5........6........7........8........9........10

Very Dissatisfied — Very Satisfied

Archbold, Stewart & Lucas (1986, 2000)

Appendix B

Consent Form for the Parent Study

KAISER PERMANENTE NORTHWEST REGION (KPNW)
and
OREGON HEALTH & SCIENCE UNIVERSITY (OHSU)
CONSENT FORM

TITLE: PREP: Family-based Care for Frail Older Persons

PRINCIPAL INVESTIGATORS

Patricia G. Archbold, RN, DNSc	503-494-3840
Barbara J. Stewart, PhD	503-494-3835
Mark C. Hornbrook, PhD	503-335-6746

PURPOSE

You have been invited to join in the OHSU/KPNW Family Care Study because you meet both of the following criteria: one of you is 65 years of age or older, was referred for home health care in KPNW, and receives daily help from a family member or friend with at least one activity such as dressing or help with two activities such as shopping or banking; one of you is the main family member or friend who gives that help.

The purpose of the Family Care Study is to compare two ways of delivering home health care. Until studies such as this one are done, health care providers will not know for sure which of these ways of delivering home health care is more effective. Your participation in the Family Care Study will help answer this question. If you agree to join the study, you will be randomized (assigned by chance, as in the flip of a coin) to one of the two groups. At the end of the study you will be informed about which group you were in, and given a copy of the results of the study, if you are interested.

The OHSU/KPNW Family Care Study is being done jointly by Kaiser Permanente Northwest Region and the Oregon Health & Science University. The study is funded by the National Institute on Aging, the Agency for Healthcare Research and Quality, and the National Institute of Nursing Research.

INTERVENTION PROCEDURES

You will receive the home health care prescribed for you and, in addition, you may receive some additional consultation from a nurse.

DATA COLLECTION PROCEDURES

If you agree to participate in the study, you will be asked to provide the following data:

Step 1: Family Care Inventory – Caregiver Questionnaire: The caregiver will be asked to fill out the inventory provided prior to the first interview. The Family Care Inventory takes about one and one-half to two hours to complete. However, if the caregiver is not able to complete the inventory prior to the interview, a research assistant will assist in its completion.

Step 2: Home Interview - About 1 week after you join the study, the two of you will be interviewed separately for 45 minutes in your home. If the caregiver was not able to complete the Family Care Inventory, the interview will take about one and one-half hours to complete. The questions will focus on background and health information. If the person referred for home health care is too ill or is unable to answer the questions, the caregiver will be asked to answer the questions for him or her.

For some of you, the information you provide in the inventory and interviews may be shared with your home health care providers so that they will not need to ask you the same questions again.

The research assistant will explain how we collect health and family care expense information and will leave a copy of the Month 1 "Family / Health Care Expense Diary" (the "FED") with whoever takes care of the health and family care expenses in the family.

Step 3: At 1 month, the person who is most knowledgeable about health and family care expenses for both of you will be asked to answer questions about these expenses that are not covered by Kaiser. This information may be obtained in a home interview or a phone interview, whichever works better. This Month 1 interview usually takes between 15 and 30 minutes for most families, but sometimes takes as long as one hour, depending on your situation.

We request this information because families like yours do lots of things for their ill relatives and sometimes pay a lot of money to give this care. One aim of this research is to improve our understanding of the health care and caregiving-related services that families use and the costs of these services to them. This type of information is needed to improve long-term care policy.

Step 4: At 5, 10, 15, and 20 months after entering the study, the family or friend caregiver will be asked to complete the Family Care Inventory sent by mail and an in-home interview. However, if the caregiver is not able to complete the inventory prior to the interview, a research assistant will assist in its completion. The Family Care Inventory will take approximately one and one-half to two hours to complete and include questions about your health and the care you provide. The inventory will be mailed to your home about one week prior to the in-home interviews. The in-home interviews will each take about one hour to complete.

The person referred for home health care will be asked to complete an in-home interview. The interview will take about 45 minutes to complete. The questions will focus on your health and care needs and your satisfaction with your care from home health.

The person who is most knowledgeable about health and family care expenses for both of you will be asked to answer questions about health and family-care expenses that are not covered by Kaiser. The interview usually takes between 15 and 30 minutes for most families.

Step 5: Data will also be collected from your health records at Kaiser Permanente. These data include such things as the number of clinic and emergency room visits, the number of days of hospitalizations, and the number of home health visits you receive.

The attached timeline chart shows the sequence of events that will occur if you join the study.

RISKS AND DISCOMFORTS

The Family Care Inventory and interviews may touch on painful topics that may be disturbing to you, although in previous studies most people enjoyed completing the inventory and interviews. If you object to any question, you may refuse to answer it.

The Family Care Inventory and interview questions used in this study are not intended for individual medical diagnosis or care. If study personnel come across any medical or other problems, they will refer you to appropriate sources of care.

BENEFITS

You may receive consultation from a nurse directed toward solving family care problems that you think are important. Other families have said that this consultation was helpful to them.

Each of you will be given a gift of $10 at the Week-1 interview and at the 5, 10, 15, and 20-month interviews.

You may or may not personally benefit by participating in the Family Care Study. However, by joining this study you will be helping health care providers better understand what ways of delivering home health care are most helpful to people in your situation.

If you participate in the study, you may find the research interviews as enjoyable and helpful as most families in previous studies have reported.

ALTERNATIVE

If you decide not to participate in the Family Care Study, you will receive usual home health care as prescribed by your physician and currently available under your health plan coverage.

CONFIDENTIALITY

To ensure your privacy, all information furnished by you during the course of this study is strictly confidential and is maintained at Kaiser Permanente Northwest Region and the Oregon Health & Science University. A Certificate of Confidentiality has been obtained from the Federal Government for this study to help insure your privacy. This certificate means that the researchers cannot be forced to tell people who are not connected with the study, including the courts, about your participation, unless you request disclosure. Neither your names nor your identity will be used for publication or publicity purposes. In the unlikely event that, during the interviews or home health care visits, Family Care Study staff become aware of serious harm to yourself or others, they will take steps to protect you.

COSTS

There are no additional costs to you for participating in this study above your usual Kaiser co-pays and fees.

SIGNIFICANT FINDINGS DISCLOSURE STATEMENT

You will be informed of significant new developments during the course of this study if they might affect your willingness to continue participation.

LIABILITY STATEMENT

Because researchers in this study are from both Kaiser Permanente Northwest Region and the Oregon Health & Science University, both liability statements are included in this consent form.

KAISER REGIONAL POLICY STATEMENT

Should you incur physical injury determined by physicians of Kaiser Permanente to result from your participation in this study, all medical care and hospitalization will be provided free of charge in Kaiser Permanente facilities. Except as specified in this document, no other reimbursement or compensation is due you as a result of your participation in this study.

OREGON HEALTH & SCIENCE UNIVERSITY LIABILITY STATEMENT

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you, subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Support Office at 503-494-7887.

ASSURANCE THAT MEDICAL CARE AND HEALTH PLAN BENEFITS ARE NOT AFFECTED BY REFUSAL OR WITHDRAWAL

Participation in this study is voluntary. You may refuse to participate in this study, or may withdraw from it at any time without affecting your or your family's rights to medical care and any other health benefits under your Kaiser Permanente Northwest Region and Medicare coverage, or your relationship with or treatment at the Oregon Health & Science University.

HOW TO CONTACT THE INVESTIGATORS AND PROJECT STAFF

You can reach any of the three investigators for the Family Care Study at the numbers listed on the front page of this consent form. If you have questions about appointment times for interviews, you may call Shirin Hiatt, Project Director, at 503-494-3978.

CONSENT

We have carefully read the above explanation and are satisfied after having the opportunity to ask further questions. We voluntarily consent to participate in the OHSU/KPNW Family Care Study as described in the material we have been given. In addition, we consent to KPNW giving our names, addresses, phone numbers, age, gender, and directions to our home to the Family Care Study Research Team at OHSU so that they can contact us. We will be given a copy of this consent form.

____________________ Printed Name of Person Referred for Home Health Care	____________________ Health Record Number for Person Referred for Home Health Care
____________________ Signature of Person Referred for Home Health Care	Date: ________________
____________________ Signature of person with Power Of Attorney for the person referred for home health care (if applicable)	Date:________________
____________________ Printed Name of Caregiver	____________________ Kaiser Health Record Number (if a current member or member in past 1 year)
____________________ Signature of Caregiver	Date: ________________
____________________ Person Obtaining Participants' Signature	Date: ________________

If you have any questions about this research, your rights and responsibilities as a research subject, or about research-related injuries, you may contact Mary L. Durham, Ph.D., Vice President for Research, Kaiser Foundation Hospitals, 503-335-2400.

Appendix C

Institutional Review Board Letters of Approval

OREGON HEALTH & SCIENCE UNIVERSITY
Research Integrity Office, L106 (503) 494-7887

MEMO

Date: April 4, 2003

To: *Patricia Archbold RN, DNSc, FAAN SN-5S*

From: Gary T. Chiodo, DMD, Chair, Institutio[redacted]106
Susan Hansen, MD, MPH, Co-Chair, Institutional Review Board, L106 APR - 4 2003
Charlotte L. Shupert, PhD, Manager, Research Integrity Office, L106

Subject: ***5175 FB***
PREP: Family-based Care for Frail Older Persons

Project Revision Amendment (PRAF) Communication

Addition of Researcher

[X] Your PRAF dated 3/31/03 was reviewed and administratively approved by the IRB on APR - 4 2003

[ ] Your PRAF dated __________ was reviewed by the full Board on __________ and will be considered for approval upon receipt of the required changes (see attached IRB REVIEW SUMMARY). Please submit changes by__________.

[ ] **No new subjects may be enrolled until you receive an approved revised consent form.**

[ ] Your PRAF dated __________ was reviewed by the full Board on __________. Your response to that review was received on ______________. The PRAF was reviewed and administratively approved on ________________.

[ ] You may use only copies of the attached approved consent form for the informed consent process.

[ ] **All subjects must be re-consented with attached approved consent form.**

[ ] Your PRAF dated __________ requesting that the above study be closed to subject accrual was reviewed by the IRB and administratively approved by the IRB on___________. Note that if you wish to reopen this study in the future, you must obtain IRB approval prior to enrolling any new subjects.

[ ] Other directions:

Kelly Kidner/1

134

'03 APR 2 AM 10:30

OHSU Institutional Review Board

PROJECT REVISION/AMENDMENT FORM

Federal regulations require IRB approval before implementing proposed changes.

Please complete this form and attach changed research documents. Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as Investigator's Brochures, questionnaires, surveys, advertisements, results from related studies, etc.)

Principal Investigator: Patricia G. Archbold, RN, DNSc.
Date: 3/31/03

Contact: Patricia G. Archbold, RN, DNSc.
IRB# 5175, FB

Phone #: 503-494-3840
Mail Code: SN5N

Study/Protocol Title: The Family Care Study (R0117909)

THE CURRENT STATUS OF THE OHSU PROJECT IS (Check one; provide # of subject as requested):

- ☐ Currently in progress (subjects entered:) # ____
- ☐ Project not yet started (no subjects entered)
- ☒ Closed to subject entry (remains Active; # of subjects still on medication/intervention): ____

THIS SUBMISSION CHANGES THE STATUS OF THIS STUDY IN THE FOLLOWING WAY(S):

- ☐ Protocol Revision
- ☐ Protocol Amendment
- ☐ Close to Subject Entry
- ☐ Revised Consent Form (two copies, one with changes highlighted, the other without)
- ☐ Addendum (New) Consent Form
- ☒ Other (specify) Add a researcher

If you would like to terminate this study, please submit a Project Termination form available at: http://www.ohsu.edu/ra/forms.shtml#hsf

1. Briefly describe, and explain the reason for, the *revision* or *amendment*. ***Highlight, or otherwise indicate, any changes/revisions/additions to consent form / protocol / research questionnaire / other study document(s), or the PRAF will be returned to you.***

I request that Karen Tetz, RN, MS, be added as a co-investigator on the Family Care Study. Ms Tetz's dissertation is a secondary data analysis of data from the Family Care Study. No new data will be collected, and all data will be stripped of identifiers. The aims of the proposed secondary data analysis are consistent with the original aims of the Family Care Study.

2. Does this revision/amendment revise or add a genetic component? Yes ☐ No ☒
If yes for OHSU studies, please see the OHSU IRB sample genetic consent form (www.ohsu.edu/ra/forms.shtml#hsf).

3. Does the change affect subject participation (e.g. procedures, risks, costs, etc.)? Yes ☐ No ☒

4. Does the change affect the consent document? *Please discuss briefly.* Yes ☐ No ☒
If yes, please include the revised consent form with the changes highlighted.

(Cell will expand)

[redacted]
Signature of Principal Investigator

April 1, 2003
Date

FOR OHSU CANCER INSTITUTE PROJECTS ONLY

Cancer Institute Signature ____ Date ____

TO BE COMPLETED BY IRB

IRB Signature ____ Date APR - 4 2003

FOR IBC (HUMAN GENE TRANSFER) PROJECTS ONLY

IBC Signature ____ Date ____

Please submit to RC&A, Mail Code L106 (Suite 125, ADP Building). Questions: 503-494-7887

Rev. 10/02

KAISER PERMANENTE®

Kaiser Foundation Hospitals

April 22, 2003

Karen Tetz, RN, MS, PhD Candidate
School of Nursing
Oregon Health and Science University
3181 SW Sam Jackson Park Road
Portland, Oregon 97201

Your data only study ***"The Satisfaction of Frail Elders with Care Received from Family Members"*** was reviewed by the full KPNW Institutional Review Board (IRB) at its meeting on April 16, 2003.

The IRB approved your proposed study and waived the requirement for you to obtain informed consent and written privacy rule authorization. **This approval expires on April 16, 2004.**

Please use this notification of approval should the funding agency require documentation of IRB approval. Our Federal Wide Assurance number is FWA 00002344 - IRB 00000405.

[redacted]

Sandy Heintz
Acting Director
Research Subjects Protection

cc: M. Durham, PhD
R. Potts, MD
P. Archbold, PhD – KP Sponsor

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