

DOSAGE AND DIFFERENTIAL EFFECTIVENESS OF PREP, A HOME HEALTH
NURSING INTERVENTION FOR FRAIL ELDERLY AND FAMILY CAREGIVERS.

By

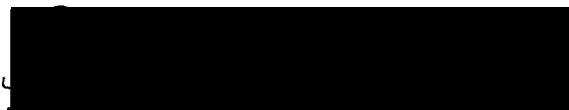
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ABSTRACT

Title: Dosage and Differential Effectiveness of PREP, a Home Health Nursing
Intervention for Frail Elders and Family Caregivers

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This dissertation study built upon the research findings of the Family Care Study (*PREP: Family-based Care for Frail Older Persons*, R01 AG17909, 1999-2005) and focused on understanding the predictors of intervention dosage and whether variation in intervention dosage predicted the effectiveness of PREP, an in-home and telephone intervention for frail elders and their family caregivers. Specifically, it assessed whether the associations between three intervention dosage components (PREP nurse visits, PREP aide visits, and home health visits) and effectiveness are predicted by care receiver (CR), caregiver (CG), or relationship variables.

The study was guided by four aims:

Aim 1: To describe variation in dosage components of PREP during the first 5 months.

Aim 2: To determine the extent to which baseline CR and CG characteristics predict variation in dosage components of PREP.

Aim 3: To determine the extent to which dosage components of PREP predict effectiveness of PREP.

Aim 4: To explore the extent to which baseline CR and CG characteristics explain variation in effectiveness of PREP, over and above the effects of dosage.

The data sample from the Family Care Study (Archbold, Stewart, & Hornbrook, R01 AG17909, 1999) consisted of baseline and 5-month data from 102 of the 116 participants of the PREP experimental condition of the parent study. The 102 care receiver-caregiver dyads were those in which the CG had completed the 5-month Home Care Effectiveness Scale (HCES). Of the 102 CRs in the sample 61% were female. The mean age of CRs was 80 years, with a SD of 7.3 years, their ages ranging between 65 and 102 years. The amount of care that CRs needed varied, with 20% of the sample needing help with only Instrumental Activities of Daily Living (IADL), while 52% of the CR's needed help with 3 or more ADLs. The mean age of CGs was 65 years, with a SD of 14.2 years, and their ages ranging between 32 and 92 year. 73% of CGs were female, 53% of CGs were spouses, and 93% identified themselves as white.

CR and CG baseline characteristics were measured on the 1-week Family Care Inventory (FCI-CR) and the 1-week FCI-CG version. CGs responded to the HCES (Archbold & Stewart, 1995) in the 5-month FCI, which asked questions to evaluate to what extent working with the PREP nurse or other home health providers had been effective. The utilization (number of contacts) of dosage components described as PREP nurse visits, PREP aide visits, home health visits, hospice/palliative care visits, and total visits were extracted from Kaiser Permanente Northwest electronic medical records.

Descriptive statistics were used to describe the number of home health care contacts received by the 102 PREP families during the first 5 months of the PREP intervention. Pearson correlations were inspected for significant relationship among the

dosage components, as well as CR-CG baseline characteristics. Stepwise and hierarchical multiple regression was used to identify parsimonious models for each component of dosage and to predict the variation in the effectiveness of PREP from each HCES subscale as dependent variables. Pearson correlations were also computed to estimate the strength of association between CR-CG baseline characteristics and to what extent they explained variation in effectiveness of PREP, over and above the effects of dosage.

Overall, CRs utilized more skilled home health visits than the other dosage components of PREP nurse visits and PREP aide visits. The highest intensity of skilled visits was provided in the first month after the initial skilled home health referral. The greatest number of PREP nurse visits were provided the first month, and then followed by more visits in the second month than in the next three months of the intervention. Higher CR's ADL Needs, CG Amount of Care Activities, and CG Role Strain were all predictive of greater numbers of PREP nurse visits, PREP aide visits, and home health visits. Lower CG socioeconomic status (SES) and increased CG Role Strain were both associated with more PREP nurse visits and explained 15% of the variance. PREP nurse visit was the only dosage component that had a significant correlation with overall intervention effectiveness, as well as with the HCES subscales of improved preparedness, improved collaboration with the healthcare system, and improved because of the PREP approach. The CR-CG characteristics that predicted variation in effectiveness over and above PREP nurse visits were the CG being a spouse, CG Amount of Care Activities, CG Health, and increased CG Cognitive Impairment.

Understanding the factors that predict dosage component utilization and intervention effectiveness can assist family caregiving researchers and healthsystem leaders in designing and directing interventions that are supportive to family caregivers and to home health providers.

TABLE OF CONTENTS

ACKNOWLEDGEMENT OF FINANCIAL SUPPORT.....	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT.....	vii
TABLE OF CONTENTS.....	xi
LIST OF TABLES.....	xv
LIST OF FIGURES.....	xvii
CHAPTER 1: INTRODUCTION.....	1
Significance to Nursing.....	2
Specific Aims.....	3
CHAPTER 2: REVIEW OF THE LITERATURE.....	5
Aging and Family Care.....	7
Tailoring Interventions in Family Care.....	8
Tailoring and the Measurement of Dosage.....	10
CR and CG Baseline Characteristics as Potential Predictors of Dosage.....	11
Demographics.....	11
Health.....	12
Family Care.....	13
Dosage and Effectiveness.....	14
CR and CG Characteristics Association with Effectiveness above Dosage.....	17
CHAPTER 3: METHODS.....	19
Parent Study.....	19
Purpose.....	19

Design.....	20
Setting and Sample.....	20
Times of Data Collection and Measures.....	21
PREP Intervention.....	22
Results.....	24
Current Study.....	25
Sample.....	25
Measures.....	30
Strengths of the Data Set.....	42
Limitations of the Data Set.....	42
Data Analysis.....	42
Aim 1.....	42
Aim 2.....	43
Aim 3.....	43
Aim 4.....	44
Data Management.....	45
Protection of Human Subjects.....	45
Human Subjects Involvement and Characteristics.....	45
Sources of Materials.....	45
Potential Risks.....	46
Protection Against Risks.....	46
Potential Benefits of the Proposed Research to the Subjects and Others..	46
Gender and Minority Inclusion for Research Involving Human Subjects.	46

CHAPTER 4: RESULTS.....	48
Aim 1.....	48
Aim 2.....	57
Parsimonious Regression.....	66
PREP Nurse Visits.....	66
PREP Aide Visits.....	67
Home Health Visits.....	68
Total Visits.....	69
Aim 3.....	70
Parsimonious Regressions: HCES Overall Effectiveness and Subscales.....	73
HCES Overall.....	73
HCES Improved Preparedness.....	73
HCES Improved Collaboration with Healthcare System.....	74
HCES Improved Because PREP Approach.....	74
Aim 4.....	76
Regression.....	81
CHAPTER 5: DISCUSSION.....	90
Meaning of Results.....	90
Dosage.....	90
Dosage and CR-CG Baseline Characteristics.....	93
Dosage and Effectiveness of PREP.....	96
CR-CG Baseline Characteristics and Effectiveness.....	97

CR-CG Baseline Characteristics and Effectiveness and Dosage.....	99
Validity of the Findings.....	101
Assumptions of Statistical Tests.....	101
Multiple Testing and Error Rate.....	101
Limitations of the Study.....	101
Implications for Theory, Research, and Practice.....	102
Theory.....	102
Research.....	102
Practice.....	105
REFERENCES.....	108
LIST OF APPENDICES.....	121

LIST OF TABLES

1 Measures and Times of Data Collection.....22

2 Comparison of Baseline Characteristics of CGs with and without HCES.....27

3 Comparison of Dosage Components of CGs with and without HCES.....28

4 CR Characteristics.....29

5 CG Characteristics.....29

6 Measures of CR and CG Baseline Characteristics.....31

7 Care Effectiveness Scale and Subscales.....37

8 Measure of Dosage Components.....40

9 Descriptive Statistics – Aim 1- Total Dosage (N = 102).....49

10 Month 1 to 5 Descriptive statistics for PREP Nurse, PREP Aide, Home Health,
and Total Visits.....56

11 Pearson’s Correlations – Aim 1 – Total Dosage (N = 102).....57

12 Descriptive Statistics CR-CG Baseline Characteristics (N = 102).....59

13 Pearson’s Correlations – Aim 2 – CR-CG Baseline Characteristics and Dosage
Components (N = 102).....62

14 Stepwise Multiple Regression of CR-CG Baseline Characteristics and PREP
Nurse Visits.....67

15 Stepwise Multiple Regression of CR-CG Baseline Characteristics and PREP Aide
Visits.....68

16 Stepwise Multiple Regression of CR-CG Baseline Characteristics and Home
Health Visits.....69

17	Stepwise Multiple Regression of CR-CG Baseline Characteristics and Total Visits.....	70
18	Pearson’s Correlations – Aim 3– Dosage Components and HCES.....	72
19	Stepwise Multiple Regressions of HCES Overall, HCES Improved Preparedness, HCES Improved Collaboration with Healthcare System, and Improved Because PREP Approach and Dosage Components.....	75
20	Pearson’s Correlations – Aim 4 - CR-CG Characteristics and HCES.....	77
21	Hierarchical Regression and Stepwise of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Overall Effectiveness.....	83
22	Hierarchical Regression of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Preparedness.....	85
23	Hierarchical Regression and Stepwise of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Collaboration with Healthcare System.....	87
24	Hierarchical Regression and Stepwise of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Because PREP Approach.....	89

LIST OF FIGURES

1	Conceptual Framework: Dosage and the Differential Effectiveness of PREP.....	6
2	Distribution of PREP CGs Ratings of Effectiveness.....	17
3	Dosage Component - Total Visits.....	50
4	Dosage Component - PREP Nurse Visits.....	51
5	Dosage Component - PREP Aide Visits.....	52
6	Dosage Component - Home Health Visits.....	53
7	Dosage Component - Hospice/Palliative Care Visits.....	54
8	Scatterplot of CG SES and PREP Nurse Visits ($r = -.31$).....	63
9	Scatterplot of CG SES and Home Health Visits ($r = -.05$).....	63
10	Scatterplot of CR ADL Needs and PREP Nurse Visits ($r = .20$).....	64
11	Scatterplot of CR ADL Needs and Home Health Visits. ($r = .39$).....	64
12	Scatterplot of CG Role Strain and PREP Nurse Visits ($r = .29$).....	65
13	Scatterplot of CG Role Strain and Home Health Visits ($r = .29$).....	65
14	Scatterplot of CG is Spouse and HCES Overall Effectiveness.....	78
15	Scatterplot of CG is Spouse and HCES Improved Preparedness.....	78
16	Scatterplot of CG is Spouse and HCES Improved Feelings about Caregiving and HCES Improved CG Health.....	79
17	Scatterplot of CG is Spouse and HCES Improved Feelings about Caregiving and HCES Improved CG Health.....	79
18	Scatterplot of CR ADL Needs and HCES Overall Effectiveness.....	80
19	Scatterplot of CR ADL Needs and HCES Improved Because PREP Approach...80	

CHAPTER 1: INTRODUCTION

This dissertation study builds upon the research findings of The Family Care Study (*PREP: Family-based Care for Frail Older Persons*, R01 AG17909, 1999-2005) in examining the effectiveness of PREP, an in-home and telephone intervention designed to increase Preparedness, Enrichment, and Predictability in family care for frail elders. PREP was a multi-component tailored intervention, including home visits by PREP nurses and PREP aides, phone calls with PREP nurses, and home visits by other skilled home health professionals. Caregivers (CGs) who received PREP rated its effectiveness in strengthening family care significantly higher ($p < .001$) than CGs in the control group rated the effectiveness of skilled home health care (Archbold & Stewart, 2005), though within group effectiveness ratings varied considerably.

The dramatic aging of our country's citizens and heightened attention to health care reform have prompted policy makers to examine the needs, values, and long-term care preferences of frail elders and their families (Feinburg & Newman, 2004; Feinburg & Newman, 2004). The Institute of Medicine's report *Crossing the Quality Chasm: A New Health System for the 21st Century* called for immediate improvement in customizing care according to patient needs and values (IOM, 2001). Studies of interventions for family care show that a one-size-fits-all approach to assisting CGs is not as useful as multi-component tailored interventions because CGs have different characteristics and needs (Given & Given, 1991; Knight, Lutzky, & Macofsky-Urban, 1993). Tailoring interventions is one way that nurse researchers have responded to the call to provide care that recognizes the uniqueness and multi-dimensionality of patients and their families (Lauver, Ward, Heidrich, Keller, Bowers, Brennan, Kirchhoff & Wells,

2002). Interventions that are comprehensive, intensive, and individually tailored to needs of care receivers (CRs) and CGs are likely to be more effective than those lacking these characteristics (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompson, Bourgeois, Steven, Ory, & Schulz, 2001; Kazdin, 2003; Kennet, Burgio, & Schulz, 2000; Pusey & Richard, 2001; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). To understand the efficacy of tailored interventions, however, it is necessary to understand how recipient characteristics are associated with intervention dosage (Mittleman, Roth, Haley, & Zarit, 2004), how dosage influences effectiveness, and what factors may predict the relationship between dosage and effectiveness.

Significance to Nursing

Home health nursing is one strategy for supporting elders and their families. In 1998, 7.6 million individuals received formal home health care services. Of these 70.5% were age 65 and over and more than 75% received skilled nursing care (CDC, 2004). The role of the home health nurse is to perform “skilled care” related to a medical problem and diagnosis of the CR. This includes assessments, nursing treatments, monitoring patient clinical status, and patient education. Medicare does not reimburse support for CGs, with the exception of limited CG training related to the skilled care needs of the CR, yet Medicare and the healthcare system rely on CGs to be trained and become competent in providing high levels of skilled care. Based on the investigator’s 10 years of experience in home health care delivery and administration, little time, training or focus is provided to home health nurses in teaching or tailoring nursing interventions to address family CG needs or concerns. Acknowledging the need of such expertise in

nursing and the outcomes of skilled care through the support of family CGs is critical to public policy associated with aging and long-term care.

Specific Aims

The purpose of this research was to examine not only predictors of intervention dosage but also whether variation in intervention dosage predicts the effectiveness of PREP, including whether the associations between three intervention dosage components (PREP nurse visits, PREP aide visits, and home health visits) and effectiveness are predicted by CR, CG or relationship variables. The specific aims of the study were:

Aim 1: To describe variation in dosage components of PREP during the first 5 months.

Aim 2: To determine the extent to which baseline CR and CG characteristics predict variation in dosage components of PREP.

Aim 3: To determine the extent to which dosage components of PREP predict effectiveness of PREP.

Aim 4: To explore the extent to which baseline CR and CG characteristics explain variation in effectiveness of PREP, over and above the effects of dosage.

The proposal for this study included PREP phone calls as a dosage component in predicting the effectiveness of PREP. In examining the dosage data for phone calls, however, we found the data were not reliable. This will be discussed in detail in Chapter 3. Thus, the dosage component of PREP phone calls were excluded in analysis of the current study. We found data on the three dosage components of PREP nurse visits, PREP aide visits, and Home health visits to be reliable. Although the dosage component

of hospice/palliative care visit was reliably recorded, it will be used in limited analyses because only few families (11%) had hospice/palliative care.

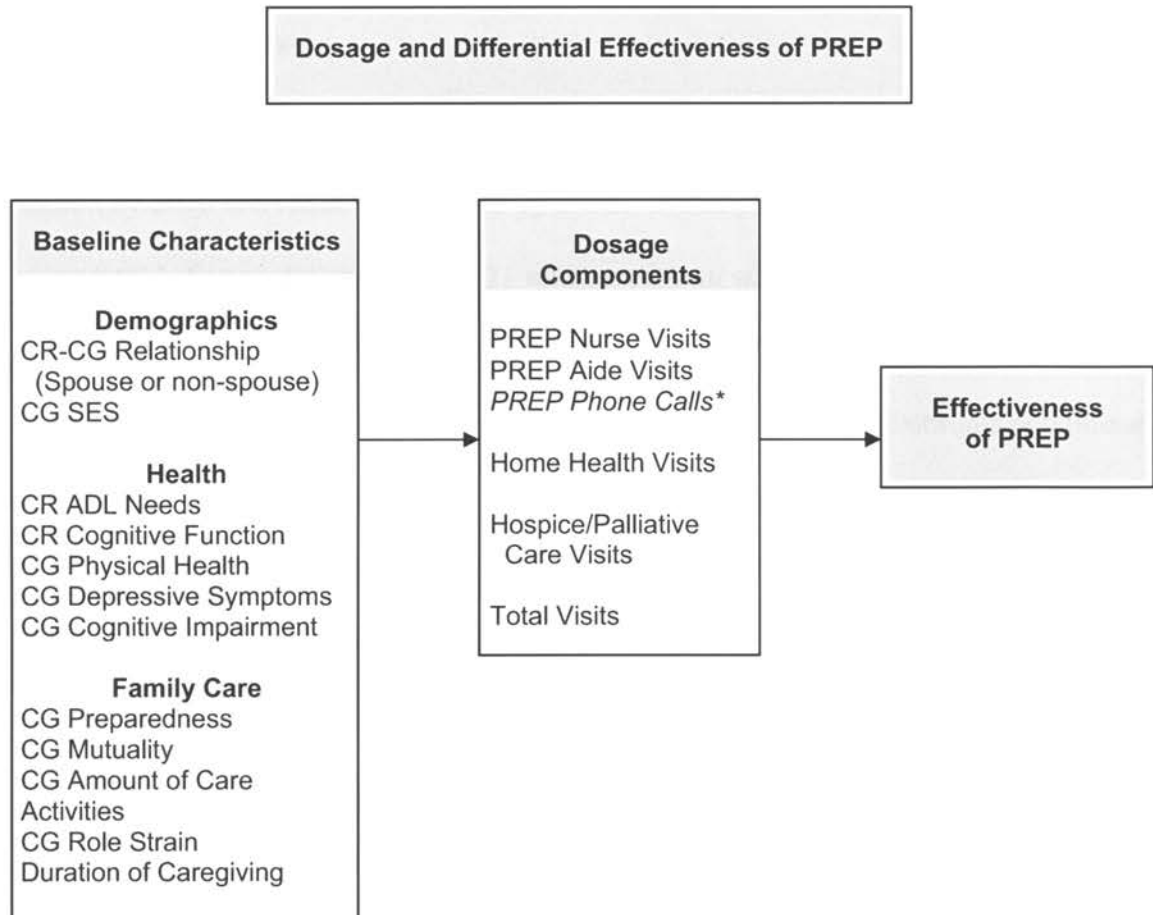
CHAPTER 2: REVIEW OF THE LITERATURE

As family and informal caregiving emerges as a prominent public-policy issue associated with aging and long-term care, intervention research must address methods to support CGS of frail elders (Feinburg & Newman, 2004; Metropolitan Life Insurance Company, 1999; Schulz, Newsom, Mittleman, Burton, Hirsch, & Jackson, 1997). At the 2005 Annual Scientific Meeting of the Gerontological Society of America, Stahl identified multi-component interventions as a priority for family care research—specifying the need to further understand dose-response and “how much dose is enough.” He also discussed the need to focus more on sub-group analysis to determine for which subgroups an intervention is effective (Stahl, 2005). This study seeks to understand effectiveness of PREP in family care for frail elders through examining how baseline characteristics of CRs and CGs may predict variation in dosage, as well as if associations between dosage and effectiveness are predicted by CR, CG or relationship variables.

The conceptual framework of the study is found in Figure 1. Dosage component variables include the numbers of PREP nurse visits, PREP aide visits, PREP phone calls, and home health visits. Baseline characteristics include the demographic variables of the CR-CG relationship (spouse or non-spouse) and CG socio-economic status (SES); health variables of the CR need for help in activities of daily living (CR ADL needs), CR cognitive function, CG physical health, CG depressive symptoms, and CG cognitive impairment; family care variables of CG preparedness, CG mutuality, CG amount of care activities, CG role strain, and duration of caregiving. Moderator variables include CR-CG relationship (spouse or non-spouse), CR cognitive function, CG depressive symptoms, and CG role strain. The CGs reported effectiveness of home health services,

including PREP services, was an outcome variable in the Family Care Study, however differential effectiveness of PREP in families receiving PREP will be the outcome evaluated in this study.

Figure 1. Conceptual Framework: Dosage and the Differential Effectiveness of PREP



*Not included in current study.

This chapter presents relevant background literature related to aging and family care, tailoring interventions in family care, tailoring and the measurement of dosage, CR and CG baseline characteristics as potential predictors of dosage and effectiveness, dosage as a potential predictor of effectiveness, and moderators of the association between dosage and effectiveness.

Aging and Family Care

The population of people age 65 and over is expected to double from 35 to 70 million by 2030 and reach 86.7 million by 2050. In that year, elders will comprise 21% of the total U.S. population and over 21 million of them will be age 85 and over—the age group most likely to need help in everyday activities (CDC, 2004; CDC, 2004; FIFARS, 2004). In 1999, 82% of aged Medicare beneficiaries had one or more chronic conditions, and 65% had multiple chronic conditions (FIFARS, 2004). Of all Medicare enrollees age 65 and over, two-thirds received informal care for a disability, and an additional 26% received a combination of informal and formal care (FIFARS, 2004). Age and greater disability were significant predictors of skilled home health use (Galantowicz, Wang, & Doty, 2004). As prevalence of chronic disease and disability rises, so do the healthcare resources that are directed to elders (Fried & Wallace, 1992). Because most elders with disabilities live in the community, reliance upon family and informal unpaid care is increasing (Feinburg & Newman, 2004; Feinburg & Newman, 2004).

Family care is increasingly a universal experience, affecting people of all races, ethnicities, lifestyles, and income levels (Dilworth-Anderson, William, & Gibson, 2002; Janevic & Connell, 2001; Riggs, 2003). The prevalence of family care for frail elders in this country is high (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999, Schulz & Martire,

2004). An estimated 22 million English-speaking households with telephones in the US contain an adult who provides, or who in the previous year provided, care for a family member or friend 50 years or older (NAC & AARP, 2004). Most long-term care received by elders is provided by spouses, adult children, and other family members (NAC & AARP, 2004; Riggs, 2003). Because families are the essential core of the long-term care system (Arno, Levine, & Memmott, 1999; Feinburg & Newman, 2004; Feinburg & Newman, 2004), it is important that the healthcare system supports them in managing the problems associated with frailty, chronic illness, transitions, and access to health services (Toseland, McCallion, Gerber, & Banks, 2002; Toseland, McCallion, Smith, & Banks, 2004). This is also relevant in that the annual economic value of family and informal care has been estimated at \$196 billion and is about 18% of the total national health care spending (\$1,092 billion) (Arno, 2002; Arno, Levin & Memmott, 1999).

Tailoring Interventions in Family Care

Tailoring is the process of customizing interventions to match or address select characteristics, needs or preferences of the individual or family (Knight, Lutzky, & Macofsky-Urban, 1993). Typically *tailored* interventions involve more dimensions on which to customize than do *targeted* or *standardized* interventions, which address a specific behavioral or psychosocial outcome.

Sorensen and colleagues' meta-analysis of CG intervention studies reported that multi-component interventions which include combinations of educational interventions, support, psychotherapy, and respite were more effective than single approach interventions (Sorensen, Pinquart, & Duberstein, 2002). For example, the *Resources for*

Enhancing Alzheimer's Caregiver Health (REACH) examined the combined effects of diverse interventions with CGs of elders with dementia. Multi-component interventions included: (a) individual information and support strategies, (b) group support and family systems therapy, (c) psychoeducational and skill-based training approaches, (d) home-based environmental interventions, and (e) enhanced technology support systems.

REACH was done at multiple community sites and health and social agency settings (Czaja & Rubert, 2002; Schulz, Belle, Czaja, Gitlin, Wisiniewski, & Ory, 2003). Results from this multi-component intervention trial led to the current follow-up study, REACH II, in which interventions are customized (*tailored*) based on CG risk (Stahl, 2005).

Montgomery and Borgatta's study of the effects of *tailored* support strategies demonstrated that CGs who could choose from a variety of respite or educational services reported lower levels of subjective burden than those who were in the control group (Montgomery & Borgatta, 1989). Their findings suggested that tailored services are more effective in responding to different needs and preferences of caregiving families.

PREP was a multi-component tailored intervention. The central thrust of the PREP assessment was to understand family care from the perspective of CRs and CGs. Families and PREP nurses worked together to tailor both the focus and the "dosage" of PREP. Working with the PREP nurse, the family identified health and family care issues that were of concern to them. The PREP nurse collaborated with the family to generate tailored strategies to resolve or manage the issues (Archbold, Stewart, & Hornbrook, 1999; Archbold, Stewart, Miller, Harvath, Greenlick, VanBuren, Kirschling, Valanis, Brody, Schook, & Hagan, 1995).

Tailoring and the Measurement of Dosage (Rationale for Aim 1)

PREP was a multi-component tailored intervention, including home visits by PREP nurses and PREP aides, phone calls with the PREP nurse, and home visits by other skilled home health professionals, three of these four dosage components will be examined as predictors of effectiveness in the proposed study. As indicated in Chapter One, phone calls will not be analyzed because they were not reliably recorded. Dosage can be described as the number of contacts and the type of contacts between the interventionist and the client (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompson, Bourgeois, Steven, Ory & Schulz, 2001). The importance of measuring dosage lies in the ability to determine the amount of intervention needed to attain desired outcomes (Kazdin, 2003). However, in almost all caregiver intervention research either dosage is constant with a prescribed number of sessions or intervention access, or variation in dosage is not measured or analyzed (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompson, Bourgeois, Steven, Ory, & Schulz, 2001; Sorenson, Pinguart, & Duberstein, 2002). Variability in PREP dosage was largely directed by the CG and CR who chose the family care issues they wanted to work on. Home visits from a PREP nurse or PREP aide and phone calls from a PREP nurse were often part of a family care strategy to resolve or manage an issue of concern. PREP families did not, however, determine home visit contacts for skilled home health care.

Understanding dosage in a home health care intervention study is important because in skilled care, dosage is determined only by the nurse's skilled assessment and the physician's orders. Variation in dosage is directed by prescribed treatment outcomes and the CR's defined skilled need under the Medicare guidelines. It is rare for other CR

or CG characteristics other than CR medical care needs to influence dosage in the provision of skilled home health care.

CR and CG Baseline Characteristics as Potential Predictors of Dosage

(Rationale for Aim 2)

Although there is some literature linking dosage to outcomes, limited research exists describing the association between baseline attributes of clients and the dosage of services received. One study that addressed the association was a clinical trial that evaluated a strengths-based case management model for substance abuse treatment. The researchers found few differences between clients who engaged in case management and those who did not. Domain specific severity scores were assessed in relation to contextual variables of the client such as medical status, general demographics, psychiatric status, family and social background. Clients who received more minutes of case management had higher (more severe) baseline family composite scores ($p = .009$) (Huber, Sarrazin, Vaughn & Hall, 2003).

Because of the limited research on the association between baseline characteristics and dosage, the selection of predictor variables for the proposed study was based on CR and CG characteristics that are important in the delivery of care and which have been identified in studies of family care as central variables. The rationale for selecting specific CR and CG characteristics is presented below.

Demographics: Two demographic variables were selected as possible predictors of dosage: CR-CG relationship of spouse versus non-spouse and CG socioeconomic status (SES). In a national sample of CGs who live with the CR, spouses accounted for about 62% of primary CGs (FCA, 2004). Considering the numbers of individuals

moving into old age, gaining understanding into the patterns and levels of caregiving is important in planning health and social support services for both spousal and non-spousal CGs (Burton, Zdaniuk, Schulz, Jackson, & Girsch, 2003; Carter, Stewart, Archbold, Inoue, et al., 1998; Clipp & George, 1993). SES and educational influences on caregiving are relevant when examining what kinds of interventions are most helpful to family CGs. Folkman and colleagues found that low social status was related to poor adaptational outcomes to caregiving, while higher education was related to coping and adaptation through the ability to search for information, and the capacity of problem solving (Folkman, Lazarus, Pimley & Novacek, 1987).

Health: Five health variables have been selected as possible predictors of dosage: CR ADL needs, CR cognitive function, CG physical health, CG depressive symptoms, and CG cognitive impairment. Although it is likely that poor CR physical health and cognitive function will be associated with higher dosage levels, CG health is also important to consider as a predictor of dosage. Because multiple studies link caregiving with serious health consequences including increased risk of coronary heart disease, hypertension, depressive symptoms, poorer immune function, slower wound healing, and mortality (Czaja, Schulz, Lee, & Belle, 2003; Kiecolt-Glaser & Glaser, 1999; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995), PREP guidelines encouraged nurses to work with CGs on their own health issues, unlike Medicare reimbursed skilled home health which does not allow home health nurses to focus on the health of the skilled patient's CG.

Although cognitive impairment of CGs may affect their ability of the CG to provide quality care and access health care services, research on CG cognitive

impairment is rare. Recently, Beach and colleagues reported a strong association ($p < .007$) between higher levels of CG cognitive impairment and potentially harmful CG behavior as reported by CRs (Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2005). Although it is unclear how CG cognitive impairment will predict dosage, such impairment is a growing concern because of aging CGs.

Family Care: Five family care variables have been selected as possible predictors of dosage: CG preparedness for family care, CG mutuality, amount of care activities done by the CG, CG role strain, and the duration of caregiving. Two of the variables – preparedness and mutuality – were identified by Archbold, Stewart and colleagues as CG attributes that were associated with lower levels of most aspects of CG role strain. (Archbold, Stewart, Greenlick, & Harvath, 1990; Archbold, Stewart, Greenlick, & Harvath, 1992; Archbold, Stewart, Miller, Harvath, Greenlick, VanBuren, Kirschling, Valanis, Brody, Schook, & Hagan, 1995). Archbold and Stewart designed the PREP intervention to strengthen preparedness and mutuality and to reduce CG role strain. Because greater role strain is associated with caring for an elder who requires more help with activities of daily living (ADLs) (Nourhashemi, Andrieu, Gillette-Guyonnet, Vellas, Albarede, & Grandjean, 2001; Toseland, McCallion, Gerber, & Banks, 2002) and has cognitive impairment (Coen, Swanwick, O’Boyle, & Coakley, 1997; Crespo, Lopez, & Zarit, 2005; George, & Gwyther, 1986; Gitlin, Corcoran, Winter, Boyce, & Hauk, 2001; Mittleman, Roth, Haley & Zarit, 2004; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996; Schulz, O’Brien, Czaja, Ory, Norris, Martire, Belle, Burgio, Gitlin, Coon, Burns, Gallaher-Thompson, & Stevens, 2002), strain and amount of care may predict higher dosage.

Currently, the average duration of caregiving to elders is 4.3 years (NAC & AARP, 2004). In recent years, however, shorter hospital stays and cuts to home health reimbursement have shifted greater responsibility for the care of frail elders to family and friend CGs (Feinburg, & Newman, 2004), and it is possible that the duration of caregiving may increase in the future. Duration of caregiving is of interest as a predictor of dosage because it allows examination of dosage for new and long time caregivers.

Dosage and Effectiveness (Rationale for Aim 3)

Although there is a growing consensus about the benefits of tailored interventions (Brooten, Youngblut, Dearick, Naylor, & York, 2003; Champion, Foster, Menon, 1997; Kreuter, & Wray, 20003; Lauver, Ward, Heidrich, Keller, Bowers, Brennan, Kirchoff, & Wells, 2002; Sorenson, Pinguart, & Dubertein, 2002), there is also recognition of the importance of examining the extent to which dosage may explain the outcome (Toseland, Rossier, Peak, & Smith, 1990; Whitlatch, Zarit, & von Eye, 1991; Zarit, Anthon, & Boutselis, 1987). Chang tailored an intervention for CGs of persons with dementia by providing videotapes demonstrating assisted modeling behavior and a nurse phone support program to assist the CG in exploring coping strategies. The nurse interventionist's thorough knowledge and understanding of the CG was considered in tailoring the study interventions to individual needs; the nurse could also tailor dosage through the length of phone calls. Significant effects in the decrease of emotion focused (avoidance) coping over time ($p < .01$) and a decrease in depressive symptoms was found in the intervention group (Chang, 1999). Although Chang measured duration of phone calls and found that phone calls were longer in the treatment group than in the

comparison group, she did not examine the association between dosage and effectiveness within either group.

Determining effectiveness of tailored interventions is complex because interventions vary on multiple dimensions that may be different for each participant. Acton's review of 73 published and unpublished research reports of interventions for family members caring for an elder with dementia found that approximately 32% of the study outcomes were changed in the desired direction after intervention (Acton & Winter, 2002). The authors note, however, that the interventions varied considerably in length and duration. In a meta-analysis to determine the effectiveness of interventions for family caregivers of elders, Sorensen pointed out that for intervention characteristics, the number of sessions ranged from 1 to 180 with a median of 8 sessions. She suggested that, although the length of intervention was an important component in some outcome variables, delivery characteristics such as dosage and intervention type were confounded. (Sorenson, Pinguart, & Duberstein, 2002). Burgio and Sorensen both recommended that a minimal requirement for any intervention is an accurate record of the frequency, duration, and types of contact between interventionist and client (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompon, Bourgeois, Steven, Ory, & Schulz, 2001; Sorenson, Pinguart, & Duberstein, 2002).

In secondary analysis of the efficacy of 20 different tailored intervention studies, Ryan and Lauver recommended that more research needs to examine whether repeated doses of an intervention are more effective at some times than at others (Ryan & Lauver, 2002). In showing how intervention dosage can make a difference in improving patient outcomes and reducing health costs, the dosage and contact time of advanced practice

nurses (APN) to 333 subjects in five randomized controlled trials (very low birthweight infant study, unplanned cesarean birth study, high-risk pregnancy study, hysterectomy study, elders with cardiac medical and surgical diagnoses) were compared (Brooten, Youngblut, Dearick, Naylor, & York, 2003). Findings in all five groups demonstrated variation in the frequency and type of intervention targets based on tailored individual and group problems. Results from the comparison showed that patient groups with more APN time and contacts per patient had greater improvements in patient outcomes and savings in health care charges. For the elder group, which received the least APN time and contact compared to the other groups, no significant difference was found in patient outcomes compared to the control group.

In the Family Care Study, which provides data for this dissertation study, a key measure of effectiveness was measured with the 43-item Home Care Effectiveness Scale (HCES). CGs rated the extent to which home health providers made a difference in their ability to do family care well. At 5 months after randomization, PREP CGs (N = 102 of 116 randomized) reported significantly higher effectiveness of home health services (M=1.99, SD = 1.04) than CGs (N = 102 of 118 randomized) who received only skilled home health services (M = 1.32, SD = 1.08) ($p < .001$) (Archbold, Stewart, Hornbrook, Leo, Lyons, Tetz, Miller, Hiatt, Hagen, O'Keefe-Rosetti, & Messecar, 2005) Within the PREP group, however, CG ratings of effectiveness varied considerably, ranging from 0.00 (not at all) to 4.00 (a great deal), with the distribution of scores shown in Figure 2.

Figure 2. Distribution of PREP CGs ratings of effectiveness.

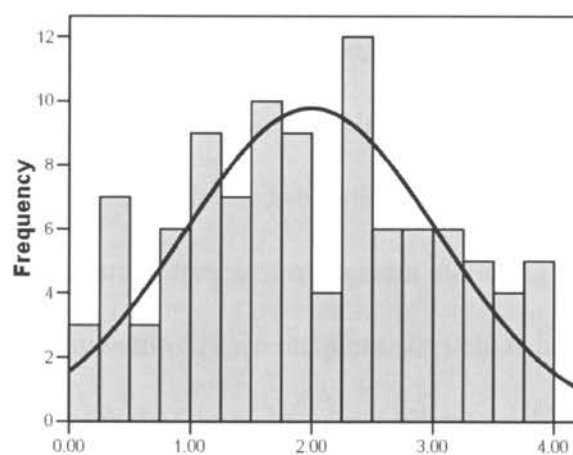


Fig 2. PREP CGs: 5-mo Home Care Effect Scale

CR and CG Characteristics Association with Effectiveness above Dosage

(Rationale for Aim 4)

Examining the characteristics of the caregiving situation and analyzing how they may predict intervention effectiveness is one way that researchers have explained how an intervention worked. (Chang, Brecht, & Carter, 2001; Sorenson, Pinquart, & Duberstein, 2002;). CGs react with marked individual differences to seemingly similar circumstances and much of the literature on caregiving can be characterized as an attempt to link antecedent variables to outcomes (Schulz & Matire, 2004; Stahl, 2005). In reexamining the methodology for describing and decomposing complex psychosocial and behavioral interventions in the *REACH* research project the investigators noted the need to identify entity and functional domains targeted by the interventions and delivery system characteristics that also captures the interactions among the caregiver, care recipient, and the environment (Czaja, Lee, Schulz, & Belle, 2003). Such an approach enables

researchers to identify specific elements of an intervention that causally related to desired outcomes.

In both generic and specific caregiving models there is recognition that contextual or situational and individual difference variables contribute to caregiving outcomes. This category of variables is broadly defined to include the social networks and support systems of caregivers; characteristics of caregivers including socioeconomic status, health, gender, and relationship to care recipient, as well as the availability and utilization of professional services. Some researchers treat these variables as interactive condition factors that predict the relationships between stressors and their impact on caregivers (Cohen, 1988), while others examine these variables in terms of their direct relationship to caregiving impact and predictors of outcome (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000).

PREP and the Family Care Process Models derived from by Archbold & Stewart's research on caregiving consists of antecedent factors, family care, and responses to family care (Archbold et al. 1995). It was expected that PREP would increase positive responses to family care for the CR and CG and decrease negative response to family care. These responses were dependent variables that would not occur in the absence of family care. The effects of home health on family care were dependent variables, reflecting the CG's view of how much home health care had affected their family care. The antecedent variables of CR-CG baseline characteristics may then predict differential effectiveness of PREP a multi-component tailored intervention, above the effects of dosage components.

CHAPTER 3: METHODS

The study “Dosage and the Differential Effectiveness of PREP” is a quantitative secondary analysis of data from the parent study PREP: Family-based Care for Frail Older Persons, R01 AG17909) to (1) describe variation in dosage of PREP during the first 5 months, (2) determine the extent to which baseline CR and CG characteristics predict variation in dosage of PREP, (3) determine the extent to which components of dosage predict effectiveness of PREP, and (4) explore the extent to which baseline CR and CG characteristics explain variation in effectiveness of prep, over and above the effects of dosage. Description of the parent study will be presented, followed by a comprehensive description of the research design and methods used in this study.

Parent Study

The parent study, PREP: Family-based Care for Frail Older Persons RO1 AG17909, also referred to as The Family Care Study was a randomized, controlled, efficacy trial of PREP, a home health intervention. The principal investigators of the study were Patricia G. Archbold, and Barbara J. Stewart, School of Nursing, Oregon Health & Science University, Portland, OR and Mark C. Hornbrook, Center for Health Research, Kaiser Permanente Northwest, Portland, OR. The parent study was funded between 1999 to 2005, with the delivery of the PREP intervention occurred between August 2000 and September 2002.

Purpose

The purpose of the PREP intervention was to increase PReparedness, Enrichment, and Predictability in family care for frail elders. A new model of in-home and telephone care, PREP was designed to help families manage the problems associated with frailty

and chronic illness, assist families at times of problematic transitions, and improve access to health and medical care. Focus was on CR and CG dyads.

Design

The Family Care Study used a randomized two group design to evaluate the effects of PREP on frail elders and their family CGs, and compared these effects with those of Standard Home Health (SHH).

Setting and Sample

The setting was the Kaiser Permanent Northwest (KPNW) Home Health/Hospice (HH/H). KPNW is a federally qualified, prepaid, nonprofit, group practice HMO with over 430,000 members in the Portland, Oregon metropolitan area.

The study used a sample of 234 families consisting of a frail elder and his or her primary CG, defined as a family member or friend who helped the CR with at least one *Activity of Daily Living* (ADL) (such as bathing, dressing), or two *Instrumental Activities of Daily Living* (IADL) (such as paying bills, providing transportation). For a family to be eligible for the study, the CR had to (1) be referred to the KPNW HH/H for evaluation; (2) be 65 years of age or older; (3) be referred for skilled home health care as defined by Medicare at the time of referral; (4) receive regular daily assistance with at least with 1 ADL or 2 IADLs from the primary CG; and (5) sign the consent to serve as a study participant, or have a proxy sign the consent. The CGs had to sign consent to serve as a study participant, including consent for project staff to access health record data. Families entered the study between August 2000 and March 2002.

The Family Care Study followed the 234 participant families (118 families in the control group and 116 families in the experimental group) for a 24-month period from the

point of randomization. Time of entry of families into the PREP group (N = 116) families was the point of randomization date and entry into the Family Care Study. The PREP group had 3 family cohorts receiving PREP for varied periods of 6 months (N = 18), 9 months (N = 24), and 12 months (N = 74) months. Because of budget and time limitations, not all families received 12 months of PREP.

Times of Data Collection and Measures

The Family Care Study collected questionnaire data from CRs and CGs at 1-week (baseline) and 5, 10, 15, and 20 months after study entry using the Family Care Inventory (FCI) (Appendices A & B). The FCI contains family care scales developed by Archbold, Stewart, and colleagues (1990, 1992), as well as published measures of health developed by other researchers. The FCI had both a CR version (FCI-CR) and a CG version (FCI-CG). A project recruiter gave the FCI-CG questionnaire booklet to CGs after they consented to participate. Approximately 1 week later, two research assistants (RAs) conducted in home interviews with the CR and CG, including the review of the CG's questionnaire booklet for completeness. Monthly health care utilization data for 12 months prior to study entry and 24 months following study entry was also collected from KPNW.

Dosage data were extracted both from DOCPlus and the PREP e-Chart for the PREP intervention and other home health dosage. DOCPlus, a computer-based electronic documentation system, was used by the PREP and home health teams at KPNW to input all skilled home health documentation. DOCPlus was also used by the PREP team to document all PREP home visits until the development of the PREP e-Chart documentation system was completed. The PREP e-Chart included only PREP

intervention documentation and was developed to document the intervention with a program template organized around the PREP principles. The measures and times of data collection is shown in Table 1.

Table 1
Measures and Times of Data Collection

Measure	Source	Time Collected
Family Care Inventory (FCI)	CG, CR	Baseline (1 week) Months 5, 10, 15, 20
Formal Healthcare Utilization	HMO Records	1 year before and 2 years after study entry.
Dosage Components (PREP Nurse, PREP Aide, Home Health, hospice/palliative care visit)	DOCPlus PREP e-Chart	Each time dosage component utilized

The HCES was used to measure the effectiveness of PREP. The HCES was included in the 5-month FCI (Appendix D), which CGs responded to 5 months after study entry. The 5-month FCI questionnaire booklet was mailed to the CG about 1 week prior to the 5-month home interview, where the booklet was reviewed by a RA for completeness. The HCES, the number of items that were used for measurement, and Cronbach's alpha of internal consistency reliability are shown in Table 7.

PREP Intervention

PREP was delivered by experienced home health nurses and home health aides who were experienced in working with elders and specifically trained to do the PREP. The PREP team was made up of a PREP supervisor, 3 PREP nurses, and 2-3 PREP aides during the intervention period. The PREP team received extensive training in the PREP intervention including 2 weeks of didactic training in PREP, readings in caregiving and

geriatric syndromes. Each PREP nurse delivered PREP to 3-4 training families, under the supervision of the investigators prior to the study period. PREP nurses and PREP aides participated in weekly clinical team meetings with the investigators and the PREP supervisor. Quality review was done through co-visits with an investigator to check for fidelity.

PREP was distinguished from usual home care by its family focus. The three parts of the PREP intervention that were introduced included:

- Part 1: Working Together on Family Care Issues, which included all skilled care the CR may have needed, and working with the family on family care issues using the five principles of PREP. The PREP Home Health Aide (HHA) was also a part of providing care and support to the families as a part of the PREP intervention.
- Part 2: PREP Advice Line (PAL), which was a 24-hour a day, 7 days-per-week advice line available to PREP families and staffed by PREP nurses.
- Part 3: Keep-In-Touch System (KIT), which was a system of PREP nurse-initiated telephone assessment that was used to monitor families. (1) in-home visits in which families and nurses work together to resolve family care issues, (2) a 24-hour PREP Advice Line, and (3) follow-up contact by the nurse, using the Keep-in-Touch system.

The three goals of PREP intervention were also introduced to the family.

They were:

Goal 1: To increase families' skill in, and preparedness for, family care.

Goal 2: To strengthen mutuality and increase rewards of caregiving by increasing enrichment.

Goal 3: To increase the predictability of unpredictable family care situations.

The PREP intervention was designed to influence the family process through the five underlying principles of (1) family care assessment and (2) family focus, (3) working together to blend family and nursing knowledge to develop (4) multiple intervention strategies tailored to the family and (5) detecting problematic transitions in family care.

The delivery of the PREP intervention and the amount of contact (dosage) a family had with a PREP nurse were tailored to the family and occurred according to family request and nursing judgment over the intervention period (6, 9, or 12 months).

Results

PREP was expected to increase positive responses to family care for the CR (e.g., satisfaction with family care) and for the CG (e.g., rewards of caregiving) and decrease negative responses to family care (e.g., CG role strain). Other expected outcomes of PREP were that several antecedent factors – CR and CG health, CG preparedness for family care, and CR and CG mutuality, including shared pleasurable activities – would improve because of PREP.

The findings of the parent study in response to the specific aims are not yet published, however as described in Chapter 2, one measure of effectiveness of PREP was the 43-item Home Care Effectiveness Scale (HCES) (Appendix D). At 5 months after study entry, CGs responded to the HCES which was included in the 5-month FCI. CGs rated the extent to which home health providers made a difference in their ability to do family care well. Sample questions included: “To what extent did working with your nurse, or other home health providers...help you feel more prepared to take care of your family member’s physical needs?” At 5 months after randomization, PREP CGs (N =

102 of 116 randomized) reported significantly higher effectiveness of home health services ($M = 1.99$, $SD = 1.04$) than CGs ($N = 102$ of 118 randomized) who received only skilled home health nursing ($M = 1.32$, $SD = 1.08$); ($p < .001$) (Archbold, Stewart, Hornbrook, Leo, Lyons, Tetz, Miller, Hiatt, Hagen, O'Keefe-Rosetti, & Messecar, 2005).

Current Study

The current study *Dosage and the Differential Effectiveness of PREP* examines whether variation in PREP dosage predicts its effectiveness, and whether baseline characteristics predict variation in effectiveness of PREP, over and above the effects of dosage. The current study uses quantitative data from the parent study. Specifically, baseline and 5-month data from families in the PREP group will be used to answer the research questions posed in the current study.

Sample

The data sample from the Family Care Study consists of baseline and 5-month data from participants of the PREP experimental condition of the parent study. The use of baseline and 5-month data provides an equivalent period of intervention contact no matter which of the 3 PREP family cohorts they were a part of (receiving PREP for varied periods of 6, 9, or 12 months in 18, 24, and 74 families respectively).

Of the 116 CRs and CGs initially randomized to the PREP experimental condition, data from only 102 CRs and CGs were used in the current study because 5-month HCES data were missing for 14 CGs. Of those 14 families with missing HCES data, 6 withdrew from the parent study at 5 months, 1 skipped the 5-month evaluation due to an emergency, 3 CGs had partial FCI data and were missing the HCES because of serious health transitions in their CR, 1 CR continued in the study although her CG had

moved to another state, 1 CR continued in the study but her CG was in jail, and 1 CR had a new CG. Data from the 118 families in the control condition were not used.

Preliminary analyses were done to determine if the 102 CGs who had completed the HCES differed from the CGs who had not. In Table 2 the mean differences on the CR-CG baseline characteristics were compared, and no significant differences were found. The variable of CG Role Strain was winsorized to a score range of 0.0 to 2.8, which brought in one participant who had a role strain score of 3.8 (greater than 3 SD's from the mean). Duration of Care was winsorized to bring 7 study participants who had been caregiving for 16 to 44 years (greater than 3 SDs from the mean) into the score range of 0.1 to 13 years which is within the range of 2 SDs. In Table 3 the mean differences on dosage components were compared, and no significant differences were found.

Table 2
Comparison of Baseline Characteristics of CGs with and without HCES

Baseline Characteristics	With HCES (N = 102) Mean (SD)	Missing HCES (N = 14) Mean (SD)	t	p (2 tailed)
Demographics				
CR-CG Relationship (spouse or non-spouse)	0.53 (0.50)	0.36 (0.50)	1.21	0.23
CG SES	40.55 (15.57)	47.21 (17.40)	-1.48	0.41
Health				
CR ADL Needs	2.82 (2.12)	3.00 (1.61)	-0.30	0.76
CR Cognitive Function	21.68 (8.63)	19.78 (7.62)	0.78	0.43
CG Physical Health	67.71 (23.14)	73.13 (21.51)	-0.83	0.41
CG Depressive Symptoms	13.37 (9.88)	12.30 (11.50)	0.38	0.71
CG Cognitive Impairment	4.00 (3.62)	4.0 (4.50)	-0.02	0.98
Family Care				
CG Preparedness	2.44 (0.83)	2.07 (1.05)	1.53	0.13
CG Mutuality	2.82 (0.90)	2.91 (1.00)	-0.36	0.72
CG Amount of Care	43.0 (14.25)	42.46 (15.37)	0.13	0.89
CG Role Strain (WI)*	1.21 (0.72)	1.30 (1.04)	-0.39	0.69
Duration of Care (WI)*	3.85 (4.06)	2.37 (2.34)	1.33	0.19

*Winsorized data used

Table 3
Comparison of CGs with and without HCES on Dosage Components

Dosage Component	With HCES (N = 102) Mean (SD)	Missing HCES (N = 14) Mean (SD)	t	p (2 tailed)
PREP Nurse Visits	5.3 (4.2)	3.1 (2.6)	-1.96	0.52
PREP Aide Visits	3.6 (6.5)	3.8 (9.4)	0.11	0.92
Home Health Visits (not PREP or Hospice)	8.0 (9.3)	4.1 (4.3)	-0.48	0.13
Hospice/Palliative Care Visit	2.6 (11.6)	1.1 (2.9)	-1.51	0.63
Total Visits	19.5 (17.0)	12.1 (10.8)	-1.58	0.12

Of the 102 CRs in the sample, 61% were female. The mean age of CRs was 80 years, with a SD of 7.3 years; their ages ranging between 65 and 102 years. The ADL needs of the CRs varied, with 20% of the sample only needing help with IADL's and 52% of CR's needing help with more than 3 ADLs.

The mean age of CGs was 65 years, with a SD of 14.2 years, and their ages ranging between 32 and 92 years old. 73% of CGs were female, and 93% of them were white. See Tables 4 and 5 of CR and CG characteristics.

Table 4
CR Characteristics

CR Characteristics	
Gender (% female)	61%
Age	M = 80 (SD = 7.3) Range = 65 to 102
ADLs (%)	
IADL only	20%
1-2 ADLs	28%
3-4 ADLs	21%
5-6ADLs	31%

Table 5
CG Characteristics

CG Characteristics	
Gender (% female)	73%
Relationship (Spouse-non Spouse)	53% Spouses
Age	M = 65 (SD = 14.2) Range = 32 to 92
Race	
White	93%
Other	7%

Measures

CR and CG baseline characteristics were measured on the 1-week FCI-CR and the 1-week FCI-CG version (Appendix B). Evidence supporting the content validity and construct validity of the FCI scales measuring family care variables developed by Archbold and Stewart has accumulated over the past decade (Archbold, Stewart & Hornbrook, 1999). Characteristics of these scales are summarized in Table 6. Scales developed by other researchers are also summarized in Table 6 which provides a description of the variable, the number of items that were used for measurement, and Cronbach's alpha internal consistency reliability.

The Home Care Effectiveness Scale ((HCES) was developed by Archbold and Stewart, and was first used in the PREP pilot study in 1990-1993 (Archbold et al, 1995). At 5 months after study entry, CGs responded to the HCES in the 5-month FCI, which asked questions to evaluate to what extent working with the PREP nurse or other home health providers had been effective. Table 7 provides the concept and scale definition, along with the number of items in each subscale, an example of a subscale question and the scoring options. The reliability of the subscale is provided, as is the mean response score, SD and range of scoring response.

Measures of dosage components in the conceptual framework are described as PREP nurse visits, PREP aide visits, home health visits, hospice/palliative care visit, and total visits are described in Table 8.

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
Demographic Variables		
Sample Statistic		
CR–CG relationship refers to whether the CG is the spouse or non-spouse of the CR.	<p><i>Item.</i> How are you related to the family member you are helping? Are you his or her ____?</p> <p><i>Response options.</i> Wife, Husband, Daughter, Son, Daughter-in-law, Son-in-law, Other relative, Neighbor or friend, Other.</p> <p><i>Scoring.</i> Wife, Husband = 1. Other non-spouse relationships = 0.</p>	<p>NA</p> <p>M = 0.5 (SD = 0.5)</p>
<p>CG socioeconomic status (SES) refers to a simple measure of social status based on employed status and educational attainment.</p> <p>Hollingshead 2-factor Index (Hollingshead, 1957).</p>	<p><i>Items.</i> 2</p> <p>e.g., “What is the highest grade in school that you completed?” “What kind of work have you done most of your working life?”</p> <p><i>Response options.</i></p> <p>Education: 1 (Completed 6th grade or less), 2 (Junior high school (7th-9th grade)), 3 (Partial high school (10th-11th grade)), 4 (High school graduate or GED), 5 (Partial college training), 6 (Completed college), 7 (Graduate professional training).</p> <p>Occupation (coded by raters): 1</p> <p><i>Scoring.</i> [7-point education scale X (-4)] + [7-point occupation scale X (7)].</p>	<p>NA</p> <p>M = 36.4 (SD = 15.6)</p>

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
Health Variables		
<p>CR ADL needs refers to the everyday activities of daily living (e.g., bathing dressing, eating) in which help is needed by the CR.</p>	<p><i>Items.</i> 6 (answered by CG)</p> <p>e.g., “Because of health or memory problems, does your family member NEED help with any of the following activities? Bathing or showering?”</p>	<p>Reliability = .80</p> <p>M = 2.8 (SD = 2.1) Range = 0 – 6</p>
<p>ADL Needs Scale (Items adapted from the Supplement on Aging Questionnaire, National Center for Health Statistics, 1984)</p>	<p><i>Response options.</i> Circled activity = 1 point.</p> <p><i>Scoring.</i> Sum of items circled.</p>	
<p>CR cognitive function refers to the cognitive aspects of mental functioning and detection of cognitive decline.</p>	<p><i>Items.</i> 30 (answered by CR)</p> <p>e.g., “Spell world backwards.”</p>	<p>Reliability = .94</p> <p>M = 21.7 (SD = 6.6) Range = 0 - 30</p>
<p>Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975).</p>	<p><i>Response options.</i> CRs were expected to say D, L, R, O, W.</p> <p><i>Scoring.</i> Correct responses were scored 1 and summed according to MMSE guidelines. Scores of 24-30 indicate good cognitive function; 18-23 indicate mild dementia; 11-17 indicate moderate</p>	

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability Sample Statistic
<p>CG physical health is the ability to perform physical activities and work without limitations, the absence of bodily pain, and excellent personal health.</p>	<p>dementia; 0-10 indicate severe dementia.</p> <p><i>Items.</i> 21 (answered by CG)</p> <p>e.g., “Does your health limit you in lifting or carrying groceries?”</p> <p><i>Response options.</i> 1 (Yes, I am limited a lot), 2 (Yes, I am limited a little), 3 (No, not limited at all).</p>	<p>Reliability = .92</p> <p>M = 67.7 (SD = 23.1)</p> <p>Range = 12.0 – 100</p>
<p>Physical Health Scale from the RAND 36-Item Health Survey (Ware & Sherbourne, 1992).</p>	<p><i>Scoring.</i> After recoding each item on a 0 to 100 scale, where 100 is the best health, item responses were averaged.</p>	
<p>Caregiver depressive symptoms refers to the affective components of depressed mood, psychomotor delay, loss of appetite, sleep disorders, and feelings of guilt, worthlessness, helplessness, and hopelessness.</p>	<p><i>Items.</i> 20 (answered by CG)</p> <p>e.g., How often during the past week did you feel or behave this way? “I had trouble keeping my mind on what I was doing.”</p> <p><i>Response options.</i> 1 (Rarely or none of the time), 2 (Some or a little of the time), 3 (Occasionally or a moderate amount of time), 4 (Most or all of the time).</p>	<p>Reliability = .87</p> <p>M = 13.4 (SD = 9.9)</p> <p>Range = 0 – 40</p>
<p>Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977).</p>	<p><i>Scoring.</i> After recoding all items to a 0 to 3 scale and reverse-coding 4 positively-worded items, the responses were summed.</p>	

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
<p>CG cognitive impairment refers to the level of cognitive failure or dementia.</p> <p>Blessed-Orientation-Memory-Concentration Test (BOMC) is a screen for dementia (Blessed, 1968).</p>	<p><i>Items.</i> 6 (answered by CG) e.g., “Count backwards 20 to 1.”</p> <p><i>Response options.</i> Caregivers were expected to count 20, 19, etc., to 1.</p> <p><i>Scoring.</i> Incorrect responses were scored 1 and weighted according to BOMC guidelines. Scores of 11 or more on a 0-28 scale indicate dementia</p>	<p>Test-retest $r = .63-.77$</p> <p>M = 4.0 (SD = 3.6) Range = 0 - 14</p>
Family Care Variables		
<p>CG preparedness for family care is how ready a caregiver thinks he or she is for the role of caregiver.</p> <p>Preparedness for Family Care Scale (Archbold et al., 1990)</p>	<p><i>Items.</i> 8 (answered by CG) e.g., “How well prepared do you think you are to take care of your family member’s physical needs?”</p> <p><i>Response options.</i> 0 (not at all prepared), 1 (not too well prepared), 2 (somewhat well prepared), 3 (pretty well prepared), 4 (very well prepared),</p> <p><i>Scoring.</i> Item responses were averaged.</p>	<p>Reliability = .92</p> <p>M = 2.4 (SD = 0.8) Range = 0.3 – 4.00</p>
<p>CG mutuality is the positive quality of</p>	<p><i>Items.</i> 15 (answered by CG)</p>	<p>Reliability = .94</p>

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
the care receiver-caregiver relationship, as viewed by the caregiver.	e.g., “How much do you like to sit and talk with him or her?”	M = 2.8 (SD = 0.9)
Mutuality Scale (Archbold et al., 1990).	<i>Response options.</i> 0 (not at all), 1 (a little), 2 (some), 3 (quite a bit), 4 (a great deal).	Range = 0.8 – 4.00
<i>Scoring.</i> Item responses were averaged.		
CG amount of care is the number of care activities the caregiver does for the care receiver.	<i>Items.</i> 86 (answered by CG) e.g., “Do you do shopping and errands for your family member?”	Reliability = .93 M = 43.0 (SD = 14.3)
Amount of Care Scale (Archbold et al., 1990).	<i>Response options.</i> 1 (yes), 0 (no). <i>Scoring.</i> Item responses were summed.	Range = 0 – 70
CG role strain from care activities is the felt difficulty in fulfilling the caregiving role because of caregiving tasks that are hard to do.	<i>Items.</i> 86 (potential) (answered by CG) For each activity that caregivers did on the Amount of Care Scale (above), they were asked: “How hard is it for you to do that?” <i>Response options.</i> 0 (easy), 1 (not too hard), 2 (somewhat hard), 3 (pretty hard), 4 (very hard).	Reliability = .91 M = 1.23 (SD = 0.7) Range = 0.0 – 3.8
Strain from Care Activities Scale (Archbold et al., 1990).	<i>Scoring.</i> Item responses were averaged.	Range = 0.0 – 2.8*
		*(WI) - Winsorized

Table 6
Measures of CR and CG Baseline Characteristics

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
Duration of caregiving is the number of years that the CG has been providing care for the CR.	<p><i>Item. 1</i></p> <p>“How long have you personally been involved in providing the needed extra help to your family member because of his or her health or memory problems?”</p> <p><i>Response options.</i> ____ years ____ months ____ days</p> <p><i>Scoring.</i> Responses for months and days were converted to proportion of years and then years, months and days were summed.</p>	<p>NA</p> <p>M = 3.85 (SD =4.1)*</p> <p>Range = 0.1 – 44 Range = 0.1 – 13*</p> <p>*WI – (Winsorized)</p>

Note. Reliability is Cronbach’s alpha for the parent study sample.

Table 7
Care Effectiveness Scale and Subscales (Archbold et al., 2005).

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
<i>Care Effectiveness</i>		
<i>General features of Overall HCES and HCES Subscales</i>	<p><i>Response options.</i> 0 (<i>not at all</i>), 1 (<i>a little</i>), 2 (<i>some</i>), 3 (<i>quite a bit</i>), 4 (<i>a great deal</i>).</p> <p><i>Scoring.</i> Item responses were averaged for the overall scale and all subscales</p>	
<p>Home care effectiveness overall is the extent to which working with home health care providers has helped improve the overall caregiving situation.</p> <p><i>HCES Overall Scale</i></p>	<p><i>Items.</i> 43 (answered by CG)</p> <p>e.g., “To what extent did working with your nurse, or other home health providers help....?”</p>	<p>Reliability = .99</p> <p>M = 2.00 (SD = 1.04) Range = 0.00 – 4.00</p>
<p>Improved preparedness is the extent to which working with home health care providers has improved the CG’s readiness and ability for the role of caregiving.</p> <p><i>HCES Improved Preparedness Scale</i></p>	<p><i>Items.</i> 9 (answered by CG)</p> <p>e.g., “To what extent did working with your nurse, or other home health providers help you feel more prepared to take care of your family member’s emotional needs?”</p>	<p>Reliability = .95</p> <p>M = 2.44 (SD = 1.06) Range = 0.00 – 4.00</p>
<p>Improved feelings about caregiving is the extent to which working with home</p>	<p><i>Items.</i> 10 (answered by CG)</p>	<p>Reliability = .97</p>

Table 7
Care Effectiveness Scale and Subscales (Archbold et al., 2005).

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
<p>health care providers has improved the CG's feelings about caregiving.</p> <p><i>HCES Improved Feelings About Caregiving Subscale</i></p>	<p>e.g., "To what extent did working with your nurse, or other home health providers help you feel more self-assured?"</p>	<p>M = 1.82 (SD = 1.13) Range = 0.00 – 4.00</p>
<p>Improved relationship with CR is the extent to which working with home health care providers has improved the CG's relationship with the CR.</p> <p><i>Improve Relationship with CR Subscale</i></p>	<p><i>Items.</i> 3 (answered by CG)</p> <p>e.g., "To what extent did working with your nurse, or other home health providers help you think about your relationship with your family member?"</p>	<p>Reliability = .92</p> <p>M = 1.91 (SD = 1.32) Range = 0.00 – 4.00</p>
<p>Improved CG health is the extent to which working with home health care providers has improved how a CG thinks about their own health.</p> <p><i>Improved CG Health Subscale</i></p>	<p><i>Items.</i> 2 (answered by CG)</p> <p>e.g., "To what extent did working with your nurse, or other home health providers help you find ways to keep yourself health?"</p>	<p>Reliability = .89</p> <p>M = 1.34 (SD = 1.27) Range = 0.00 – 4.00</p>
<p>Improved collaboration with healthcare is the extent to which working with home</p>	<p><i>Items.</i> 7 (answered by CG)</p>	<p>Reliability = .94</p>

Table 7
Care Effectiveness Scale and Subscales (Archbold et al., 2005).

Concept, Definition, Scale	Items, Response Options, Scoring	Measure Reliability
		Sample Statistic
health care providers has improved how the CG is getting their needs met from the healthcare system.	e.g., “To what extent did working with your nurse, or other home health providers help you get services you needed from Kaiser?”	M = 1.95 (SD=1.12) Range = 0.00 – 4.00
<i>Improved Collaboration with Healthcare System Subscale</i>		
Improved because of PREP approach measures is the extent to which working with home health care providers has helped improve the caregiving experience because of the PREP intervention and principles in their caregiving situation.	<i>Items. 7</i> (answered by CG) e.g., “To what extent did working with your nurse, or other home health providers improve the predictability of your caregiving situation?”	Reliability = .94 M = 1.90 (SD = 1.12) Range 0.00 – 4.00
<i>Improved Because of PREP Approach Subscale</i>		

Table 8

Measure of Dosage Components

Dosage Component	Description
PREP Nurse Visits	Number of visits made by a PREP nurse to give skilled nursing care or conduct the PREP intervention. A PREP nurse visit was a home visit during which the PREP nurse systematically assessed family care and worked with the family to develop, implement, and evaluate strategies to increase preparedness, enrichment, and predictability in the family care situation.
PREP Aide Visits	Number of visits made by a PREP aide to give skilled care as supervised by the PREP nurse or to conduct the PREP intervention.
Home Health Visits	Number of skilled home health visits to the CR by other skilled providers. Home health visits include: <ul data-bbox="621 795 1800 1136" style="list-style-type: none">• Physical therapy visits,• Occupational therapy visits,• Speech therapy visits,• Social work visits,• Home health aide visits,• Community-based long term service visits for members of KPNW the Social Health Maintenance Organization (SHMO) health plan benefit.• Outside home health visits provided by a home health agency other than KPNW. (These visits met Medicare criteria for skilled home health care).

Table 8
Measure of Dosage Components

Dosage Component	Description
Hospice/Palliative Care Visit	<p>Number of hospice/palliative care visits to the CR (if hospice or palliative care was provided) by hospice nurses.</p> <p><i>** Hospice/palliative care visits are included in the dosage component of Total Visits, but are otherwise described as a separate variable due to the nature of care and frequency of service which differs from other disciplines of home health.. Also, only 11% of the study sample had hospice/palliative care visits.</i></p>
Total Visits	<p>Total sum of PREP nurse visits, PREP aide visits, home health visits, and hospice/palliative care visit that a CR – CG received.</p>

Strengths of the Data Set

Baseline CR and CG characteristics were measured with scales with established reliability and validity. There were little missing data. Detailed dosage data were also available from the electronic medical records at KPNW

Limitations of the Data Set

Limitations of the data set include the incomplete data from the PREP dosage component of PREP phone calls from the DOCPlus computer system. This limitation is significant in that two parts of the PREP intervention included phone contact – the PREP Advice Line (PAL) and the Keep-In-Touch System (KIT).

Other limitations of the parent study affected this dissertation study including the missing 5-month HCES data from 14 CGs. Order of entry (month of randomization) into the PREP intervention was not controlled due to the sample size limitation, however analyses from the parent study did not indicate that order of entry was a significant predictor of outcome.

There was no description in the DOCPlus system of the outside home health visits or of the community-based long-term service visits for those PREP CRs who had the SHMO health plan benefit from KPNW.

Data Analysis

Aim 1: To describe variation in dosage components of PREP during the first 5 months.

Descriptive statistics were used to describe the number of home health care contacts received by the 102 PREP families during the first 5 months of the PREP intervention. These contacts include PREP nurse visits, PREP aide visits, home health visits (home visits by Physical Therapy [PT], Occupational Therapy [OT], Speech

Therapy [ST], Social Work [SW], Home Health Aide [HHA], Community-based Long-term Service Visits [SHMO] or Outside Home health visits), hospice/palliative care visit to the CR. For each, the mean and median was used to indicate the typical or average dosage level and the range, standard deviation, and inter-quartile range will be used to describe variability in dosage. Frequency polygons were used to depict distributions graphically. Pearson correlations were inspected for significant relationship among the three dosage variables, as well as to detect multi-collinearity.

Aim 2: To determine the extent to which baseline CR and CG characteristics predict variation in dosage components of PREP.

Descriptive statistics were used to describe the CR-CG baseline characteristics of the 102 PREP families in the study sample.

Pearson correlation coefficients were computed to estimate the strength of the association between four of the dosage components (PREP nurse visits, PREP aide visits, home health visits, and total visits) and CR-CG baseline characteristics. Scatterplots will be inspected to determine whether the variables form a linear or nonlinear pattern of relationship, and if any outliers are present. To determine the best linear combination of baseline characteristics as predictors of dosage, a multiple regression analysis was used to derive a parsimonious model for each component of dosage as a dependent variable.

Aim 3: To determine the extent to which dosage components of PREP predict effectiveness of PREP.

Pearson correlation coefficients were computed to estimate the strength of the association between the effectiveness of PREP (HCES Overall Effectiveness and HCES Subscales) and each of the dosage components CR-CG baseline characteristics and the

effectiveness of PREP (HCES Overall Effectiveness and HCES Subscales). Multiple regression was used to determine how much variance in effectiveness of PREP was explained by the three components of dosage. Hierarchical multiple regression analysis will be used. At Step 1, the dosage of other home Health (PT, OT, ST, SW, HHA, and Hospice) that was received by some PREP families, but not provided as a part of the PREP intervention, will be entered as a control variable. At Steps 2, 3, and 4, the dosage variables of PREP nurse visits, and PREP aide visits, respectively, will be entered.

Aim 4: To explore the extent to which baseline CR and CG characteristics explain variation in effectiveness of PREP, over and above the effects of dosage.

Pearson correlation coefficients were computed to estimate the strength of the association between each of the CR-CG baseline characteristics and the effectiveness of PREP (HCES Overall Effectiveness and HCES Subscales). Scatterplots were inspected to determine whether the variables formed a linear or nonlinear pattern of relationship, and if any outliers were present. Hierarchical multiple regression analysis was used to determine the best linear combination of CR-CG baseline characteristics as predictors of effectiveness of PREP to derive a parsimonious model for each HCES Subscale as a dependent variable. For analyses the entry format of: the dosage components were entered in Step 1 and CR-CG baseline characteristics were entered in Step 2. SPSS sequenced the CR-CG baseline characteristics and the dosage components with the goal of deriving a parsimonious model for predicting the variation in the effectiveness of PREP from each HCES Subscale as a dependent variable.

Data Management

Data for this proposed study, including the measures of the variables of effectiveness of Home Care (PREP) and baseline characteristics were in the form of SPSS data files. Data representing dosage had been extracted from the KPNW DOCPlus system and the PREP e-Chart and had been inputted into SPSS data files. Family Care Study investigators provided a file containing the variables required for the analyses on a secure jump drive and were stored on a password-protected computer

Protection of Human Subjects

Human Subjects Involvement and Characteristics

The project was a data-only study. No names or identifying information as defined by HIPAA were included in the cleaned data. The project used a subset of quantitative data from, the 116 PREP intervention families in the Family Care Study. The setting for the Family Care Study was the Home Health/Hospice (HH/H) Department of KPNW. The average age of CRs in the PREP sample was 79.9 years and over half reported that their health was fair to poor. Seventeen percent of CRs were cognitively impaired or too frail to respond to the research instruments, proxy data was obtained from their CGs. Data from this group of elders are important to include because the group represents a large and growing portion of the population, and because their problems are especially complex and difficult for families.

Sources of Materials

All data were in the form of SPSS files that contained no personal identifiers. The data files were secured on password protected files and on password protected computer accessible only to the investigator.

Potential Risks

The primary risk to individuals whose data was used from participating in this research was the potential breach of confidentiality, however all personal identifiers had been removed from the data (name, date of birth, health record number, etc) for this dissertation study, the risk was minimal. The avoidance of such breaches was a high priority.

Protection Against Risks

The identity of the subjects was not known to the principal investigator of this dissertation study as all personal identifiers had been removed. All data was safeguarded in password protected files and on a password protected computer.

Potential Benefits of the Proposed Research to the Subjects and Others

No direct benefits accrue to subjects from participating directly in this dissertation project. However, family care can be very difficult for CGs. Family care can adversely affect the mental and physical health of CGs, regardless of age or ethnic background. The potential benefits for finding ways to make family care easier far exceeded any risk of participation. Minimizing the risk of loss of confidentiality was a high priority, and safeguards were in place to ensure that confidentiality was not breached.

Gender and Minority Inclusion for Research Involving Human Subjects

The study was a secondary data analysis; the sample from the parent study had a large proportion of women, 60% CR and 71% CG's. Additional recruitment of minorities did not occur as this study was a secondary data design. The parent study sample was made up of 5.5% African-American CGs and 6.4% African American CRs. The percentage of people living in the Portland PMSA that reported being African-

American in 2000 was 1.6%, while the range of people reporting being African-American in surrounding cities and counties was 0.6% - 6.6%. The parent study purposely oversampled African-American families, however because of small number of African American, it was not possible to examine race separately as a unique CR-CG characteristics or as a moderator of association.

CHAPTER 4: RESULTS

In this chapter, the results of data analysis are presented and summarized by aims of the study.

Aim 1: To describe variation in dosage of PREP during the first 5 months.

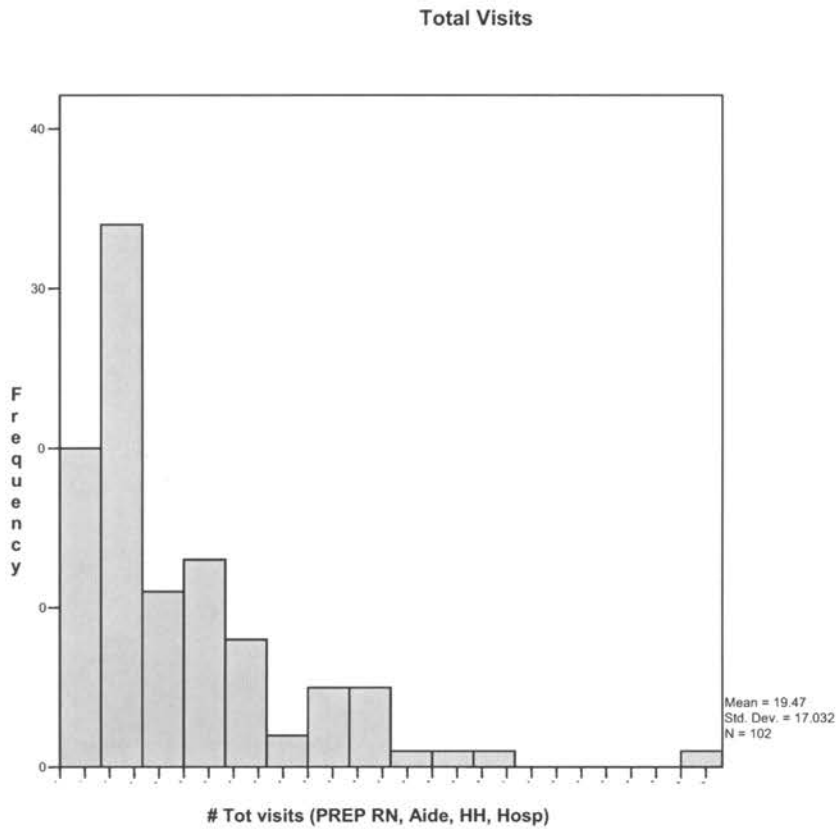
Table 9 presents descriptive statistics on the number of contacts of each dosage component received by the 102 PREP families during the first 5 months of the PREP intervention. The mean and median are presented to indicate the typical or average dosage level, and the range, standard deviation, and inter-quartile range describe the variability in dosage of PREP nurse visits, PREP aide visits, home health visits, hospice/palliative care visits and the total visits. The dosage component of home health visits is presented as a whole, followed by its parts of the specific skilled home health discipline that CRs received in the context of home health visits. The disciplines of home health visits that were provided include physical therapy, occupational therapy, speech therapy, social work, home health aides, community-based long term care services, and outside home health.

As shown in Table 1, 99% of PREP families received at least one PREP nurse visit and 96% of PREP CRs received at least one home health visit. Physical therapy was used at least once by 81% of the CRs, with other specific home health disciplines used by 6% to 31% of CRs. As is common for health services utilization data, the distribution for all variables are positively skewed and kurtic. Frequency histograms are presented in Figures 3 to 7, and graphically depict the distribution of each dosage component.

Table 9
Descriptive Statistics – Aim 1- Total Dosage (N = 102)

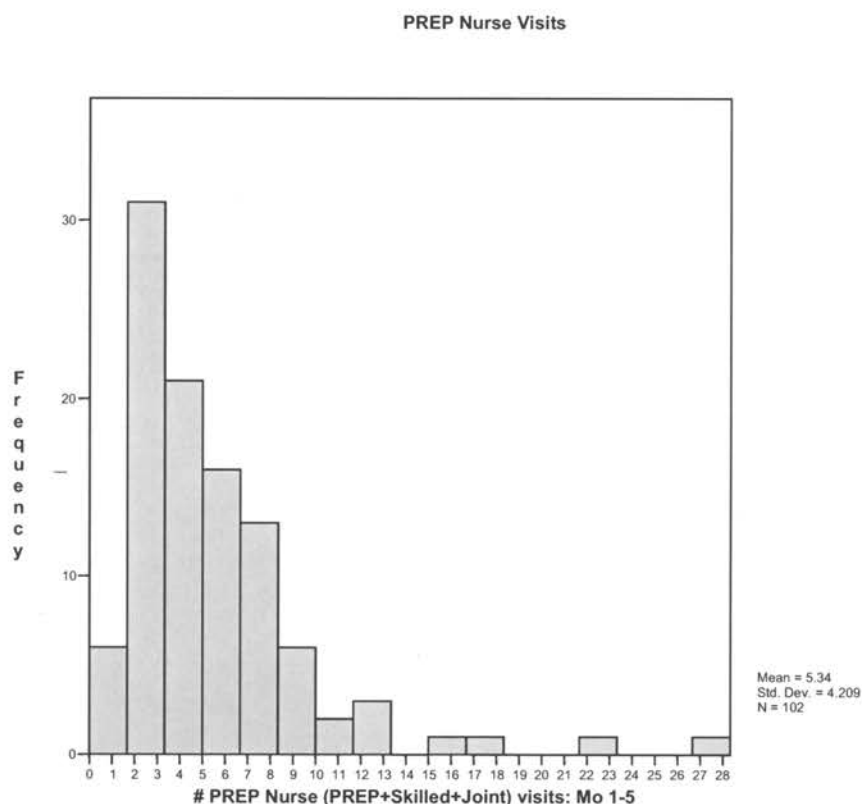
Dosage Components	Range	% with		Mean	Median	SD	Interquartile		% Missing	
		visits \geq 1					Range	Skewness (SE)		Kurtosis (SE)
PREP Nurse Visits	0-27	99		5.3	4.0	4.2	3.0 – 7.0	2.5 (0.2)	9.1 (0.5)	0
Skilled Nurse Visits	0-20	35		1.5	0.0	3.5	0.0 – 20.0	3.6	14.9	
PREP Aide Visits	0-33	42		3.6	0.0	6.5	0.0 – 4.0	2.4 (0.2)	6.3 (0.5)	0
Home Health Visits (Non-PREP, Non-Hospice)	0-64	96		8.0	4.5	9.3	2.0 – 10.3	2.9 (0.2)	12.8 (0.5)	0
Physical Therapy	0-16	81		2.7	0.3	2.0	1.0 – 7.0	2.0 (0.2)	5.3 (0.5)	0
Occupational Therapy	0-11	27		0.8	0.0	1.7	0.0 – 4.0	3.2 (0.2)	12.7 (0.5)	0
Speech Therapy	0-15	13		0.5	0.0	1.8	0.0 – 0.0	6.0 (0.2)	44.0 (0.5)	0
Social Work	0-7	16		0.3	0.0	1.0	0.0 – 4.0	4.5 (0.2)	24.6 (0.5)	0
Home Health Aide	0-16	17		1.1	0.0	3.0	0.0 – 1.0	3.2 (0.2)	11.0 (0.5)	0
Community-based long term care services	0-21	31		2.3	0.0	4.2	0.0 – 3.0	2.2 (0.2)	4.6 (0.5)	0
Outside Home Health	0-16	6		0.4	0.0	2.0	0.0 – 0.0	6.5 (0.2)	47.1 (0.5)	0
Hospice/Palliative Care Visit	0-100	11		2.6	0.0	11.6	0.0 – 0.0	6.6 (0.2)	51.2 (0.5)	0
Total Visits	2-100	100		19.5	13.0	17.0	8.0 – 26.0	1.9 (0.2)	5.0 (0.5)	0

Figure 3. Dosage Component - Total Visits



During the first 5 months in the study, the average PREP family received 19.5 total visits (median = 13 visits, range = 2 to 100). The middle 50% of families received from 8 to 26 visits, with one outlier family receiving 100 visits. PREP families received at least two total visits during the first 5 months.

Figure 4. Dosage Component - PREP Nurse Visits

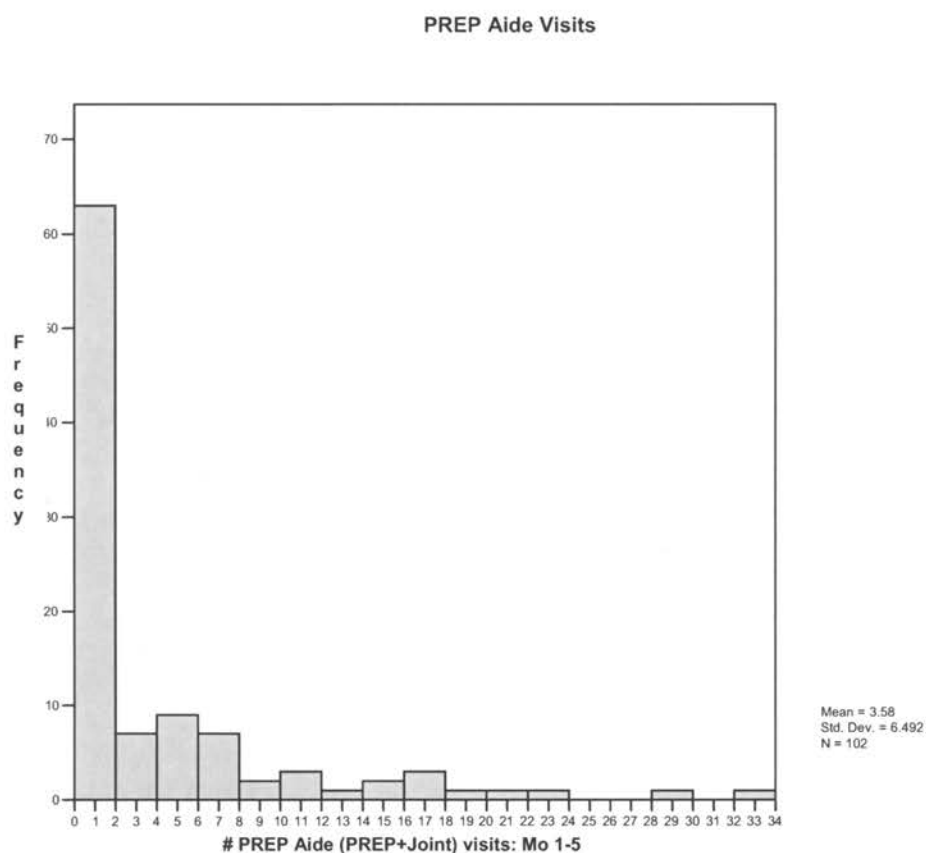


During the first 5 months, the average PREP family received 5.3 PREP nurse visits (median = 4 visits), with the middle 50% of families receiving 3 to 7 visits. Two families fell more than 3 SD above the mean, receiving 23 and 27 PREP nurse visits, respectively. Only 1 CR – CG did not receive a PREP nurse visit.

Included in the PREP nurse dosage component were skilled home health nursing visits, in which the skilled nursing care was provided by the PREP nurse. 34% (N = 35) of CRs received skilled nursing care from a PREP nurse, with a mean of 1.5 visits and a SD of 3.5. The range of visits was between 0 to 20, with 11% of CRs receiving only 1

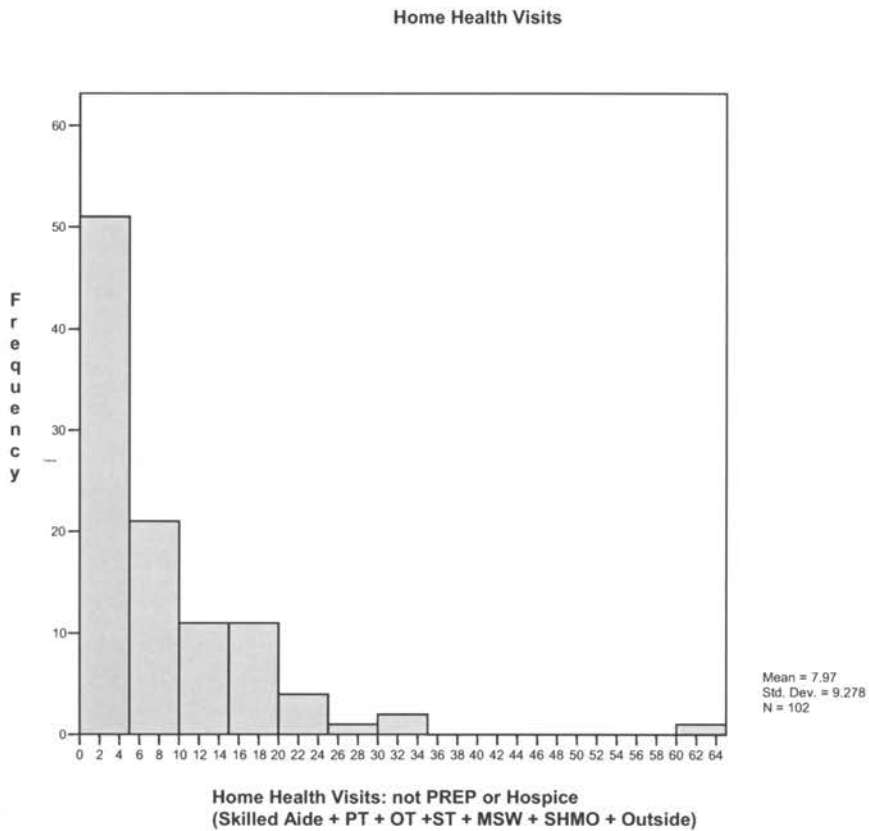
skilled nursing visit, 13% receiving 2 to 4 nursing visits, 16% receiving 5 to 7 nursing visits, and then 6% receiving greater than 8 skilled nursing visits.

Figure 5. Dosage Component - PREP Aide Visits



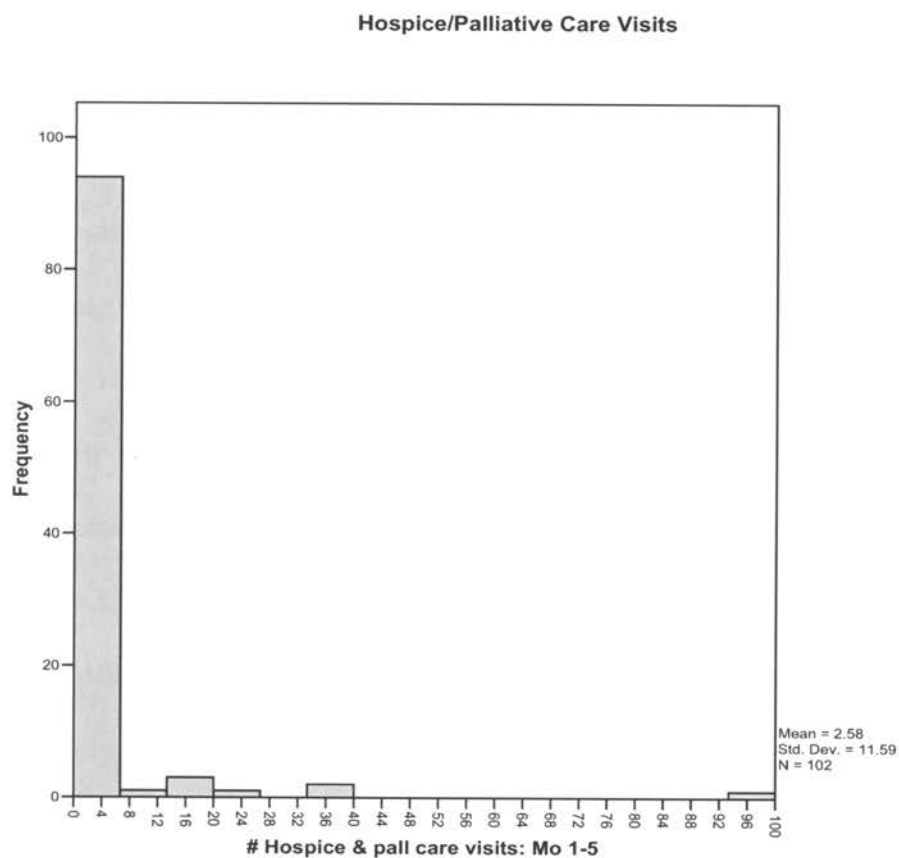
During the first 5 months the mean number of PREP aide visits was 3.6, with a SD of 6.5 and a range of 0 to 33 visits during the first 5 months. Of the 102 PREP families, 43 received visits from a PREP aide, 44% of those received 1 to 5 visits, 26% received 6 to 10 visits, and 30% received 11 or more visits. Two families were outliers at 29 and 33 visits.

Figure 6. Dosage Component - Home Health Visits



During the first 5 months, the average PREP family CR received 8.0 home health visits (median = 4.5 visits), with the middle 50% of families receiving 2 to 10 visits. 8 CRs received > 20 visits, with one CR receiving 64 home health visits which is greater than 3 SD from mean. Only four CRs did not receive a home health visit.

Figure 7. Dosage Component - Hospice/Palliative Care Visits



During the first 5 months, only 11 PREP families received hospice/palliative care services. The mean number of hospice/palliative care visits was 2.6, with a SD of 11.6 and a range of 0 to 100 visits during the first 5 months. Four families had fewer than 10 visits, with 5 families receiving between 15 and 40 visits, and 1 family receiving 100 visits. Hospice/palliative visits are represented as a separate dosage component in that the nature of care and frequency of service differs from other disciplines of home health. Such visits were analyzed only in the context of total visits.

In Table 10 monthly descriptive statistics for PREP nurse visits, PREP aide visits, home health visits, and total visits for the first 5 months are presented. For each of the four dosage components, change in mean number of visits was evaluated using a one-way repeated measure ANOVA with Tukey post hoc pairwise comparisons ($p < .05$). Significant changes in mean number of visits across months occurred for PREP nurse visits, home health visits, and total visit, but not for PREP aide visits.

The mean number of PREP nurse visits somewhat steadily declined from 1.8 visits in Month 1 to 0.6 visits in Month 5. Pairwise comparison indicated that mean number of PREP nurse visits in Month 1 was significantly greater than in Months 2, 3, 4, or 5, and the mean number of PREP nurse visits in Month 2 was significantly greater than visits in Month 5.

PREP aide visits, which did not differ across months, ranged on average from 1.1 to 1.7 visits.

Home health visits dropped from a mean of 3.1 visits in Month 1 to roughly 1 visit per month in Months 2 through 5. Total visits dropped from a mean of 5.7 to roughly half that in Months 2 through 5. Significant pairwise comparisons were found between Month 1 and Months 2, 3, 4, and 5 for both home health visits and total visits with Month 1 having **Error! No bookmark name given.** significantly greater number of visits than in Months 2, 3, 4, and 5.

Table 10

Month 1 to 5 Descriptive statistics for PREP Nurse, PREP Aide, Home Health, and Total Visits

	Month 1	Month 2	Month 3	Month 4	Month 5	F test for time df=4, 404	Tukey Pairwise comparisons, p < .05
PREP Nurse Visits						12.66 p < .001	1 > 2, 3, 4, 5 2 > 5
Range	0-9	0-6	0-15	0-10	0-9		
Mean	1.76	1.26	0.92	0.76	0.60		
SD	1.53	1.10	1.67	1.46	1.35		
PREP Aide Visits						1.39 p = .24	None
Range	0-14	0-8	0-8	0-10	0-9		
Mean	1.53	1.10	1.68	1.46	1.35		
SD	2.28	1.56	1.62	2.16	2.25		
Home Health Visits						12.82 p < .001	1 > 2, 3, 4, 5
Range	0-23	0-22	0-33	0-31	0-24		
Mean	3.07	0.89	0.82	0.99	1.11		
SD	3.20	3.02	3.68	3.72	3.66		
Total Visits						7.22 p < .001	1 > 2, 3, 4, 5
Range	1-33	0-27	0-33	0-31	0-24		
Mean	5.67	2.92	2.60	2.84	2.86		
SD	5.22	3.97	4.56	4.94	4.92		

Pearson correlations were inspected for significant relationships between the dosage components of PREP nurse visits, PREP aide visits, home health visits, hospice/palliative care visits and total visits. There was a positive correlation between PREP nurse visits and PREP aide visits ($r = .38, p < .01$). There were no significant correlations between any other pairs of dosage components, with the exception that each dosage component was correlated with total visits. Table 11 shows the correlation matrix of all dosage components.

Table 11
Pearson's Correlations – Aim 1 – Total Dosage (N = 102)

	PREP Nurse Visits	PREP Aide Visits	Home Health Visits	Hospice/ Palliative Care Visits	Total Visits
PREP Nurse Visits	1.00				
PREP Aide Visits	.38**	1.00			
Home Health Visits (Non-PREP, Non-Hospice)	.15	.15	1.00		
Hospice/Palliative Care Visits	-.14	-.09	-.07	1.00	
Total Visits	.38**	.50**	.60**	.58**	1.00

* $p < .05$, ** $p < .01$, 2-tailed tests

Aim 2: To determine the extent to which baseline CR and CG characteristics predict variation in dosage of PREP.

In Table 12 descriptive statistics are presented reporting the range, mean, median, standard deviation, interquartile range, skewness and standard error, and kurtosis and standard error of the baseline characteristics (CR-CG Relationship, CG SES, CR ADL Needs, CR Cognitive Function, CG Physical Health, CG Depressive Symptoms, CG

Cognitive Impairment, CG Preparedness, CG Mutuality, CG Amount of Care Activities, CG Role Strain, and Duration of Caregiving) of the PREP families.

More than half of CGs were spouses, and the mean CG SES was 36.4 with a median of 37 on the Hollingshead 2-factor socioeconomic status scale with a range of 0 – 66 with lesser scores reflecting lower employment status or educational attainment. More than 45% of CRs had some cognitive impairment, with 22% having mild impairment and 23% having moderate to severe impairment. CGs with clinically elevated depressive symptoms (CESD of 16 or greater) comprised 39% of the sample. Duration of caregiving ranged from less than a month to 40 years; however the duration data was winsorized to reflect a range of 0 – 13 years (M = 3.8 years) to offset the 6 extreme outliers who reported they had been caregiving for greater than 13 years.

Table 12

Descriptive Statistics – Aim 2 - CR-CG Baseline Characteristics (N = 102)

Baseline Characteristics	Range	Mean	Median	SD	Interquartile Range	Skewness (SE)	Kurtosis (SE)	% Missing
Demographics								
CR-CG Relationship (spouse or non-spouse)	0 - 1	0.5	-	-	-	-	-	0
CG SES	4 - 66	36.4	37.0	15.6	26.0 - 48.0	-0.2 (0.2)	-0.7 (0.5)	0
Health								
CR ADL Needs	0 – 6	2.8	3.0	2.1	1.0 – 5.0	0.1 (0.2)	-1.5 (0.5)	0
CR Cognitive Function	0 – 30	21.7	25.0	6.6	19.8 – 28.0	-1.4 (0.2)	1.0 (0.5)	0
CG Physical Health	12 – 100	67.7	72.0	23.1	51.3 - 86.0	-0.7 (0.2)	-0.5 (0.5)	0
CG Depressive Symptoms	0 – 42	13.4	12.0	9.9	5.0 – 19.0	0.8 (0.2)	0.3 (0.5)	0
CG Cognitive Impairment	0 – 14	4.0	4.0	3.6	2.0 – 6.0	0.8 (0.2)	-0.2 (0.5)	0
Family Care								
CG Preparedness	0.3 – 4.0	2.4	2.4	0.83	1.9 – 3.0	-0.2 (0.2)	-0.3 (0.5)	0
CG Mutuality	0.8 – 4.0	2.8	3.1	0.9	2.2 – 3.6	-0.6 (0.2)	-0.7 (0.5)	0
CG Amount of Care Activities	0.0 – 70.0	43.0	44.8	14.3	33.0 – 53.2	-0.5 (0.2)	0.1 (0.5)	0
CG Role Strain (WI)	0.0 - 3.8	1.2	1.2	0.7	0.7 - 1.7	0.6 (0.2)	0.5(0.5)	0
Duration of Caregiving (WI)	0.1 – 13.0	3.8	2.4	4.1	0.8 – 5.8	1.2 (0.2)	0.1 (0.5)	2

Pearson correlations were inspected for significant relationships between CR-CG baseline characteristics and dosage components (see Table 13). The CR-CG demographic baseline characteristic of CG SES was significantly negatively correlated with both PREP nurse visits ($r = -.31, p < .01$) and PREP aide visits ($r = -.27, p < .01$), but not with home health visits. Being a spouse versus non-spouse CGs was not significantly correlated with any dosage component.

Of the CR-CG health baseline characteristics CR ADL Needs was significantly positively correlated with PREP nurse visits ($r = .20, p < .05$), PREP aide visits ($r = .24, p < .05$) and more strongly with home health visits ($r = .39, p < .01$) and total visits ($r = -.47, p < .01$). CR Cognitive Function was negatively correlated with home health visits ($r = -.37, p < .01$) and total visits ($r = .47, p < .01$), but not with PREP nurse or PREP aide visits. CG Physical Health was not correlated with any dosage components, though CG Depressive Symptoms was positively correlated with PREP nurse visits ($r = .20, p < .05$). CG Cognitive Impairment was not correlated with any dosage component.

Family care baseline characteristics of family care showed no significant correlations of CG Preparedness and CG Mutuality with any dosage component. CG Amount of Care Activities was positively correlated with all dosage components with the exception of hospice/palliative care visits. CG Role Strain correlated most strongly with PREP nurse visits ($r = .29, p < .01$), but correlated also with home health visits ($r = .21, p < .05$) and total visits ($r = .22, p < .05$). Duration of Caregiving was not significantly correlated with any dosage component.

In summary two baseline characteristics consistently predicted use (or receipt) of more PREP nurse, PREP aide and home health visits. They were higher CR ADL needs

and greater amounts of care activities done by the CG. CG Role strain was also predictive of PREP nurse and home health visits.

The main distinction between correlates of PREP nurse visits and home health visits was that more CR ADL needs and poor CR cognitive functions were more strongly associated with use of home health visits, whereas lower CG SES and higher CG role strain were more strongly associated with use of PREP nurse visits.

Significance between the Pearson correlations of CG SES between PREP nurse visits and home health visits were found at $t = -2.94$ ($p < .01$), as were CR ADL Needs between PREP nurse visits and home health visits, $t = 2.14$ ($p < .05$). No significance differences were found between the Pearson correlations of CR Cognitive Function between PREP nurse visits and home health visits, nor was there significance of correlation for CG Role Strain.

Table 13 shows the correlation matrix of CR-CG Baseline Characteristics and Dosage Components.

Table 13

Pearson's Correlations - Aim 2 – CR-CG Baseline Characteristics and Dosage Components (N = 102)

	PREP Nurse Visits	PREP Aide Visits	Home Health Visits	Hospice Visits	Total Visits
Demographic					
CR-CG Relationship (spouse or non-spouse)	-.04	.03	.01	.07	.07
CG SES	-.31**	-.27**	-.05	.13	-.12
Health					
CR ADL Needs	.20*	.24*	.39**	.17	.47**
CR Cognitive Function	-.10	-.14	-.33**	-.09	-.32**
CG Physical Health	-.03	.09	-.05	-.03	-.02
CG Depressive Symptoms	.20*	.12	.17	-.01	.18
CG Cognitive Impairment	.09	.09	.07	-.05	.06
Family Care					
CG Preparedness	-.15	-.09	-.11	.05	-.10
CG Mutuality	-.12	-.16	-.16	.14	-.08
CG Amount of Care Activities	.20*	.21*	.26**	.15	.37**
CG Role Strain (WI)	.29**	.15	.21*	-.04	.22*
Duration of Caregiving (WI)	.08	-.06	.13	-.10	.00

*p < .05, **p < .01, 2-tailed test

Scatterplots presented in Figure 8 and 9 graphically compare the significant negative correlation of CG SES and PREP nurse visits ($r = -.31, p < .01$) and the lack of significant correlation of CG SES and home health visits ($r = -.05$). T-tests between the correlations of PREP nurse visits and home health visits showed significance difference between the two ($t = -2.94, p < .01$).

Figure 8. Scatterplot of CG SES and PREP Nurse Visits ($r = -.31$)

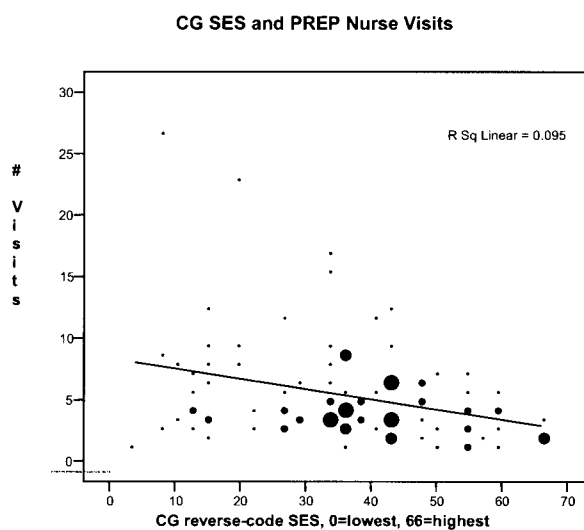
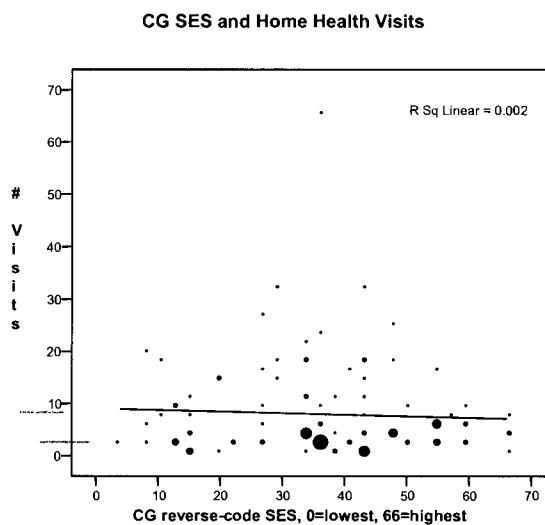


Figure 9. Scatterplot of CG SES and Home Health Visits ($r = -.05$)



Scatterplots presented in Figure 10 and 11 graphically compare the significant correlation of CR ADL Needs with PREP nurse visits ($r = .20$, $p < .05$) and its stronger correlation with home health visits ($r = .39$, $p < .01$). T-tests between the correlations of PREP nurse visits and home health visits showed significance difference between the two $t = -2.14$ ($p < .05$).

Figure 10. Scatterplot of CR ADL Needs and PREP Nurse Visits ($r = .20$)

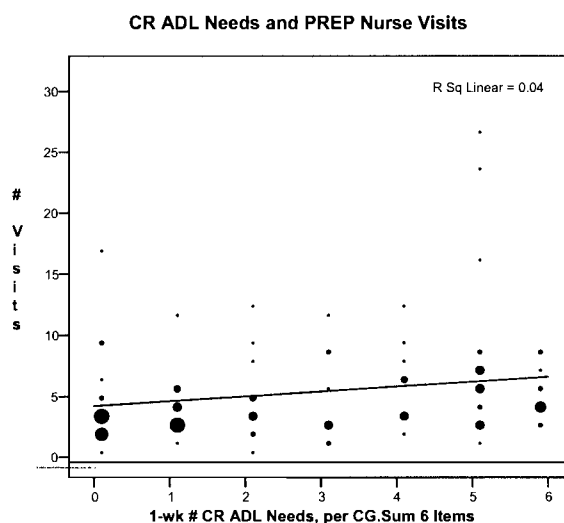
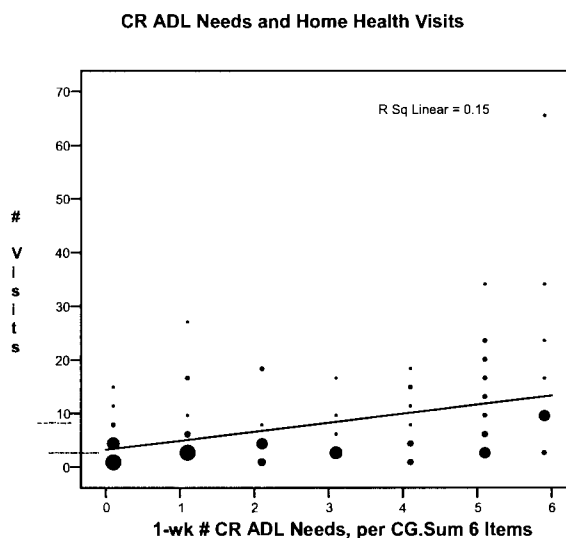


Figure 11. Scatterplot of CR ADL Needs and Home Health Visits. ($r = .39$)



Scatterplots presented in Figure 12 and 13 graphically compare the significant correlation of CG Role Strain and PREP nurse visits ($r = .29$, $p < .01$) and the somewhat lesser correlation with home health visits ($r = .21$, $p < .05$). T-tests between the correlations between the two showed no significance difference.

Figure 12. Scatterplot of CG Role Strain and PREP Nurse Visits ($r = .29$)

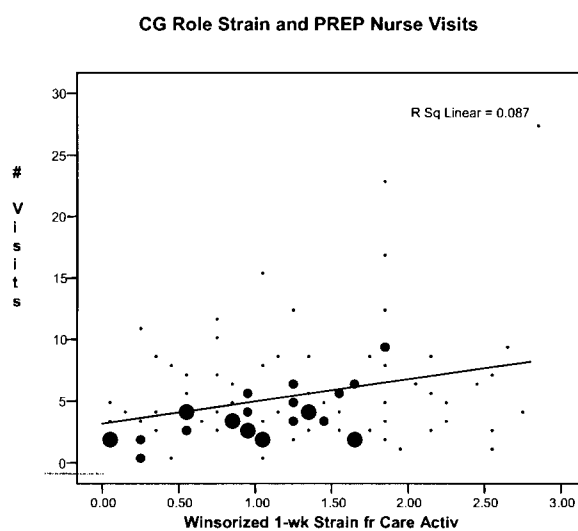
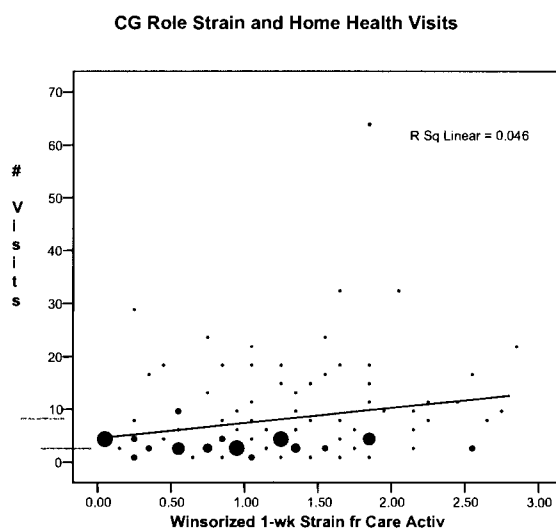


Figure 13. Scatterplot of CG Role Strain and Home Health Visits ($r = .21$)



Parsimonious Regression

Four standard regression analyses were performed, one for each dosage component (PREP nurse visits, PREP aide visits, home health visits, and total visits).

An exploratory stepwise multiple regression analysis was done, letting SPSS sequence the CR-CG baseline characteristics by selecting the CR-CG baseline characteristic variables that had the largest sr^2 and made the largest contribution to the R^2 in each dosage component. The goal of the analysis was to derive a parsimonious model for predicting the variation in each dosage component. Table 14 to 17 display the stepwise multiple regression of CR-CG baseline characteristics and dosage components showing the correlations between the variables, the unstandardized regression coefficients (B) and intercept, the standardized regression coefficients (β), the semipartial correlations (sr^2), and (R) and (R^2), and adjusted (R^2) after entry of significant CR-CG baseline characteristics. (R^2) was significantly different from zero at the end of each of the two steps.

Parsimonious Regression: PREP Nurse Visits. At Step 1, CG SES entered the equation and explained 10% ($R^2 = .095$, Adj. $R^2 = .086$) of the variance of PREP nurse visits ($F = 10.47$, $df = 1, 100$, $p = .002$). At Step 2, CG SES and CG Role Strain were in the regression equation and together explained 15% ($R^2 = .17$, Adj. $R^2 = .15$) of the variance of the dosage component of PREP nurse visits ($F = 10.20$, $df = 2, 99$, $p < .001$). The remaining 10 independent variables were not included in the model and were not found to be statistically significant at the $p = .05$ level. Table 14 displays the stepwise multiple regression of CR-CG baseline characteristics and home PREP nurse visits.

Table 14
*Stepwise Multiple Regression of CR-CG Baseline Characteristics
 and PREP Nurse Visits*

<u>Variable</u>	<u>Step 1</u>			<u>Step 2</u>		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
PREP Nurse Visits						
Constant	8.37	1.02		6.18	1.22	
CG SES	-0.08	0.01	-.31	-0.08	0.02	-.29
CG Role Strain				1.68	0.56	.28
F Change		10.47			9.08	
R ²		.09			.17	
Adj. R ²		.09			.15	

* $p < .05$, 1-tailed test

Parsimonious Regression: PREP Aide Visits. After Step 1, CG SES was in the regression equation which explained 6% ($R^2 = .07$, Adj. $R^2 = .06$) of the variance of the dosage component of PREP aide visits and contributed significantly ($F = 7.99$, $df = 1, 100$, $p = .01$). After Step 2, CG SES and CR ADL Needs were in the regression equation and explained 9% ($R^2 = .111$, Adj. $R^2 = .09$) of the variance of the dosage component of PREP aide visits and contributed significantly ($F = 6.21$, $df = 2, 99$, $p = .003$). The remaining independent variables were excluded from the model and were not found to statistically significant at the $p = .05$ level. Table 15 displays the stepwise multiple regression of CR-CG baseline characteristics and PREP aide visits.

Table 15
*Stepwise Multiple Regression of CR-CG Baseline Characteristics
 and PREP Aide Visits*

<u>Variable</u>	<u>Step 1</u>			<u>Step 2</u>		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
PREP Aide Visit						
Constant	7.71	1.59		5.48	1.91	
CG SES	-0.11	0.04	-.27	-0.10	0.04	-.24
CR ADL Needs				0.60	0.29	.20
F Change		7.99			4.18	
R ²		.07			.11	
Adj. R ²		.06			.09	

* $p < .05$, 1-tailed test

Parsimonious Regression: Home Health Visits. At Step 1, CR ADL entered the equation and explained 14% ($R^2 = .15$, Adj. $R^2 = .14$) of the variance of the dosage component of home health visits and contributed significantly ($F = 17.60$, $df = 1, 100$, $p < .001$). After Step 2, CR Cognitive Function entered the regression equation and together with CR ADL Needs explained 16% ($R^2 = .17$ Adj. $R^2 = .16$) of the variance of the dosage component of home health visits and contributed significantly ($F = 10.44$, $df = 2, 99$, $p < .001$). CG Preparedness entered the regression in Step 3, and along with CR ADL Needs and CR Cognitive Function 17% ($R^2 = .20$, Adj. $R^2 = .17$) of the variance of the dosage component of home health visits and contributed significantly ($F = 8.07$, $df = 3, 98$, $p < .001$) was explained. The remaining independent variables were excluded from the model and were not found to statistically significant at the $p < .05$ level.

Table 16
Stepwise Multiple Regression of CR-CG Baseline Characteristics and Home Health Visits

<u>Variable</u>	<u>Step 1</u>			<u>Step 2</u>			<u>Step 3</u>		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
Home Health Visits									
Constant	3.18	1.42		8.47	3.39		13.12	4.32	
CR ADL Needs	1.70	0.40	.39	1.31	0.46	.30	1.32	0.45	.30
CR Cognitive Function				-0.19	0.11	-.18	-0.21	0.11	-.20
CG Preparedness							-1.75	1.02	-.16
F Change		17.59			2.94			2.94	
R ²		.15			.17			.20	
Adj. R ²		.14			.16			.17	

* $p < .05$ 1-tailed test

Parsimonious Regression: Total Visits. After Step 1, CR ADL Needs was in the regression equation which explained 21% ($R^2 = .22$, $\text{Adj. } R^2 = .21$) of the variance of the dosage component of Total Visits and contributed significantly ($F = 27.70$, $df = 1,100$, $p < .001$). Table 17 displays the stepwise multiple regression of CR-CG baseline characteristics and Total Visits.

Table 17
*Stepwise Multiple Regression of CR-CG
 Baseline Characteristics and Total Visits*

<u>Variable</u>	<u>Step 1</u>		
	<i>B</i>	SE	β^*
Total Visits			
Constant	8.89	2.51	
CR ADL Needs	3.75	0.71	.47
F Change		27.70	
R ²		.22	
Adj. R ²		.21	

* $p < .05$ 1-tailed test

Aim 3: To determine the extent to which dosage components predict effectiveness of PREP.

Pearson correlations were inspected for significant relationships between dosage components and the effectiveness of PREP as described through the concepts of the Home Care Effectiveness Scale (HCES) and its subscales (HCES Overall Effectiveness, HCES Improved Preparedness, HCES Improved Feelings about Caregiving, HCES Improved Relationship with CR, HCES Improved CG Health, HCES Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach). As shown in Table 18 the only significant relationships between dosage components and effectiveness of PREP was found between the dosage component of PREP nurse visits and HCES and selected subscales. PREP nurse visits were positively correlated with HCES Overall Effectiveness ($R = .21, p < .05$), HCES Improved Preparedness ($R = .21, p$

< .05), HCES Improved Collaboration with Healthcare System ($R = .24, p < .05$), and HCES Improved because PREP Approach ($R = .21, p < .05$). PREP aide visits, home health visits, hospice/palliative care visit, and total visits had no significant relationship.

Table 18

Pearson's Correlations – Aim 3– Dosage Components and HCES

Dosage Components	HCES Overall	HCES Improved Preparedness	HCES Improved Feelings about Caregiving	HCES Improved Relationship with CR	HCES Improved CG Health	HCES Improved Collaboration with HCS	HCES Improved because PREP Approach
PREP Nurse Visits	.21*	.21*	.16	.10	.15	.24*	.21*
PREP Aide Visits	.03	.00	-.01	-.02	.06	.10	.09
Home Health visits	-.03	-.03	-.03	-.05	-.04	-.04	.02
Hospice/Palliative Care Visits	.05	.05	.03	.05	.04	.07	.07
Total Visits	.08	.07	.04	.02	.06	.12	.14

*p < .05, **p < .01, 1-tailed tests

Parsimonious Regressions: HCES Overall Effectiveness and HCES Subscales

An exploratory stepwise multiple regression analysis was done letting SPSS sequence the dosage components with the goal of deriving a parsimonious model for predicting the variation in the HCES effectiveness through the selection of dosage components that had the largest sr^2 and made the largest contribution to the R^2 .

Table 19 displays the stepwise multiple regressions of dosage components and HCES Overall Effectiveness and the HCES Subscales that showed significant correlations between the variables, the unstandardized regression coefficients (B) and intercept, the standardized regression coefficients (β), the semipartial correlations (sr^2), and (R) and (R^2), and adjusted (R^2) after entry of all dosage components (PREP nurse visits, PREP aide visits, and home health visits). (R) was significantly different from zero at the first step only with HCES Overall Effectiveness, HCES Improved Preparedness, HCES Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach. (R) was not significantly different for the variables of HCES Improved Feelings about Caregiving, HCES Improved Relationship with CR, or HCES Improved CG Health.

HCES Overall: After Step 1, PREP nurse visits was in the regression equation which explained 3% ($R^2 = .04$, Adj. $R^2 = .03$) of the variance of the dosage component of HCES Overall Effectiveness and contributed significantly ($F = 4.57$, $df = 1,100$, $p = .03$). PREP aide visits and home health visits were excluded from the model.

HCES Improved Preparedness: After Step 1, PREP nurse visits was in the regression equation which explained 4% ($R^2 = .05$, Adj. $R^2 = .04$) of the variance of the dosage component of HCES Improved Preparedness and contributed significantly ($F =$

4.78, $df = 1,100$, $p = .03$). PREP aide visits and home health visits were excluded from the model.

HCES Improved Collaboration with Healthcare System: After Step 1, PREP nurse visits was in the regression equation which explained 5% ($R^2 = .06$, Adj. $R^2 = .05$) of the variance of the dosage component of HCES Improved Collaboration with Healthcare System and contributed significantly ($F = 6.37$, $df = 1, 100$, $p = .01$). PREP aide visits and home health visits were excluded from the model.

HCES Improved Because PREP Approach: After Step 1, PREP nurse visits was in the regression equation which explained 4% ($R^2 = .04$, Adj. $R^2 = .04$) of the variance of the dosage component of HCES Improved because PREP Approach and contributed significantly ($F = 4.74$, $df = 1,100$, $p = .03$). PREP aide visits and home health visits were excluded from the model.

Table 19
Stepwise Multiple Regressions of HCES Overall, HCES Improved Preparedness, HCES Improved Collaboration with Healthcare System, and Improved because of PREP Approach and Dosage Components

HCES Overall (DV)				
Dosage Component	(DV)	<i>B</i>	β	sr^2
PREP Nurse Visits	.21	0.05	0.21	.04
		Intercept = 1.72		
			$R^2 = .04$	
		Adjusted	$R^2 = .03$	
			$R = .21^*$	
HCES Improved Preparedness (DV)				
Dosage Component	(DV)	<i>B</i>	β	sr^2
PREP Nurse Visits	.21	0.05	0.21	.04
		Intercept = 2.15		
			$R^2 = .05$	
		Adjusted	$R^2 = .04$	
			$R = .21^*$	
HCES Improved Collaboration with Healthcare System (DV)				
Dosage Component	(DV)	<i>B</i>	β	sr^2
PREP Nurse Visits	.24	0.06	0.24	.06
		Intercept = 1.60		
			$R^2 = .06$	
		Adjusted	$R^2 = .05$	
			$R = .24^*$	
HCES Improved Because PREP Approach (DV)				
Dosage Component	(DV)	<i>B</i>	β	sr^2
PREP Nurse Visits	.24	0.06	0.21	.04
		Intercept = 1.60		
			$R^2 = .04$	
		Adjusted	$R^2 = .04$	
			$R = .21^*$	

* $p < .05$, 1-tailed test

A separate regression was done to analyze whether the dosage component total visits by itself was significant for predicting effectiveness of the HCES Overall

Effectiveness or any of the HCES Subscales. Total visits was not found to be significant in the variance of HCES Overall Effectiveness, or in any of the HCES Subscales.

Aim 4: To explore the extent to which baseline CR and CG characteristics explain variation in effectiveness of PREP, over and above the effects of dosage.

Pearson correlation coefficients were computed to estimate the strength of the association between each of the CR- CG baseline characteristics and the effectiveness of PREP as described through the concepts of the Home Care Effectiveness Scale and the HCES subscales (HCES Overall Effectiveness, HCES Improved Preparedness, HCES Improved Feelings about Caregiving, HCES Improved Relationship with CR, HCES Improved CG Health, HCES Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach). As shown in Table 20 significant associations were found between the CR-CG Relationship of being a spouse and all concepts of the HCES Overall Scale and HCES Subscales. Poorer CG SES was significantly correlated with HCES Improved CG Health ($r = -.26, p < .01$). CR ADL Needs was significantly correlated with all concepts of the Home Care Effectiveness Scale, with the exception of HCES Improved Feelings about Caregiving and HCES Improved Relationship with CR. CG Cognitive Impairment was also significantly correlated with all concepts of the HCES Overall Scale and HCES Subscales, with the exception of HCES Improved Preparedness and HCES Improvement because PREP Approach. The CG Amount of Care Activities was significantly correlated with each concept of the Home Care Effectiveness Scale, with the strongest association being HCES Improved Preparedness ($r = .32, p < .01$).

Table 20

Pearson's Correlations – Aim 4 - CR-CG Characteristics and HCES

CR-CG Characteristics	HCES Overall	HCES Improved Preparedness	HCES Improved Feelings about Caregiving	HCES Improved Relationship with CR	HCES Improved CG Health	HCES Improved collaboration with HCS	HCES Improved because PREP Approach
Demographic							
CR-CG Relationship (spouse or non-spouse)	.30**	.21*	.34**	.33**	.37**	.28**	.23*
CG SES	-.15	-.06	-.16	-.14	-.26**	-.17	-.11
Health							
CR ADL Needs	.26**	.29**	.20	.17	.20*	.27**	.26**
CR Cognitive Function	-.18	-.22*	-.15	-.16	-.17	-.16	-.17
CG Physical Health	.16	.16	.12	.17	.06	.18	.19
CG Depressive Symptoms	.09	.10	.06	-.01	-.01	.10	.13
CG Cognitive Impairment	.20*	.13	.20*	.21*	.33**	.22*	.14
Family Care							
CG Preparedness	-.05	-.03	-.01	-.08	-.08	-.03	.08
CG Mutuality	-.01	-.04	.05	.02	-.06	-.04	-.00
CG Amount of Care Activities	.31**	.32**	.25*	.23*	.21*	.31*	.31**
CG Role Strain (WI)	.11	.12	.08	.01	.12	.11	.11
Duration of Caregiving (WI)	.03	.03	.02	.03	.07	.02	-.03

*p < .05, **p < .01, 2-tailed test

Scatterplots were inspected to determine whether the variables formed a linear or nonlinear pattern of relation, and if any outliers were present. Scatterplots presented in Figures 14 and 15 graphically compare the significant correlation of the CR-CG Relationship of being a spouse and with the concept of HCES Overall Effectiveness ($r = .30, p < .01$) and HCES Improved Preparedness ($r = .21, p < .05$).

Figure 14. Scatterplot of CG is Spouse and HCES Overall Effectiveness

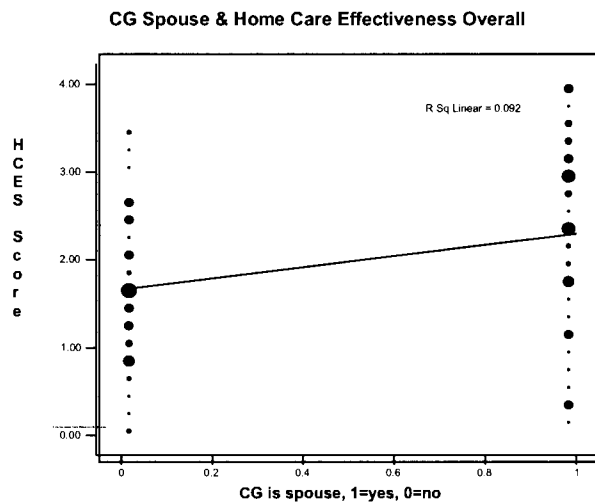
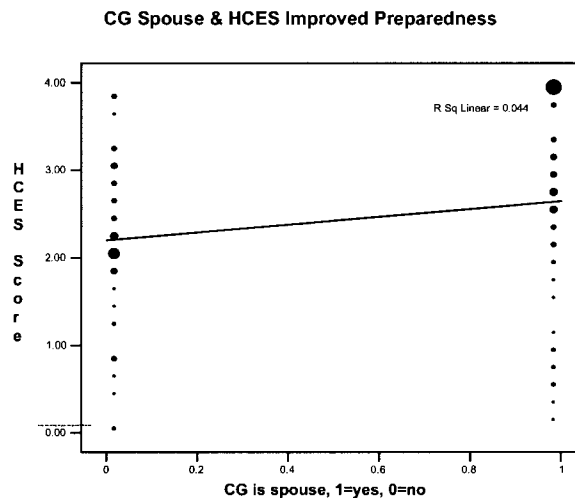


Figure 15. Scatterplot of CG is Spouse and HCES Improved Preparedness



Figures 16 and 17 graphically compare the significant correlation of the CR-CG Relationship of being a spouse, and with the concept of HCES Improved Feelings about Caregiving ($r = .34$, $p < .01$) and HCES Improved CG Health ($r = .37$, $p < .01$).

Figure 16. Scatterplot of CG is Spouse and HCES Improved Feelings about Caregiving and HCES Improved CG Health

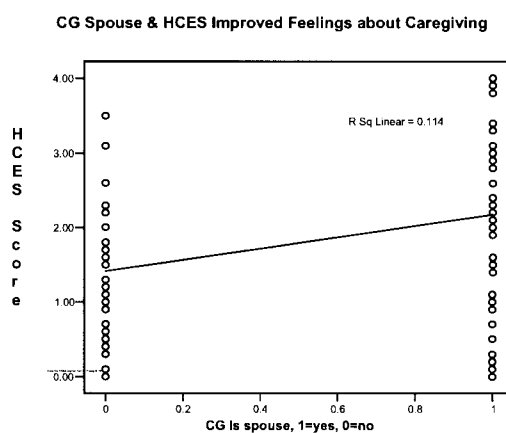
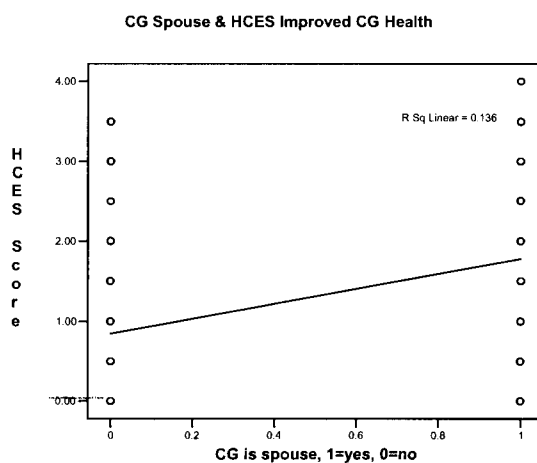


Figure 17. Scatterplot of CG is Spouse and HCES Improved Feelings about Caregiving and HCES Improved CG Health



Figures 18 and 19 graphically compare the significant correlation of the CR ADL Needs and HCES Overall ($r = .26, p < .01$) and HCES Improved because PREP Approach ($r = .26, p < .01$).

Figure 18. Scatterplot of CR ADL Needs and HCES Overall Effectiveness

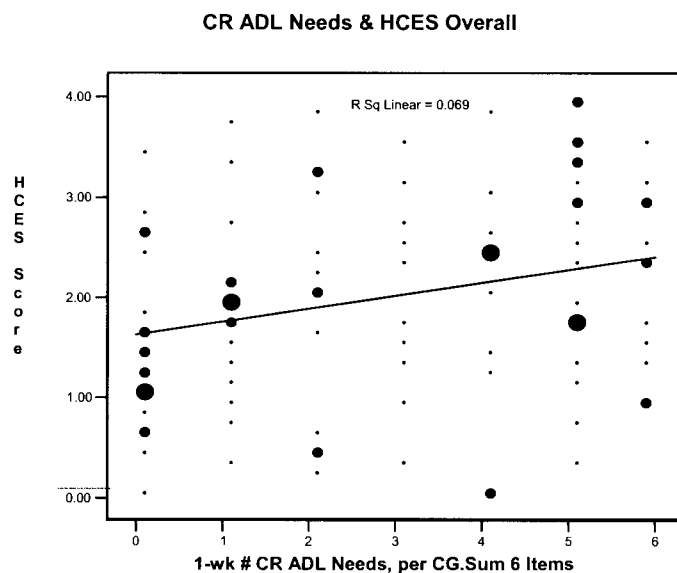
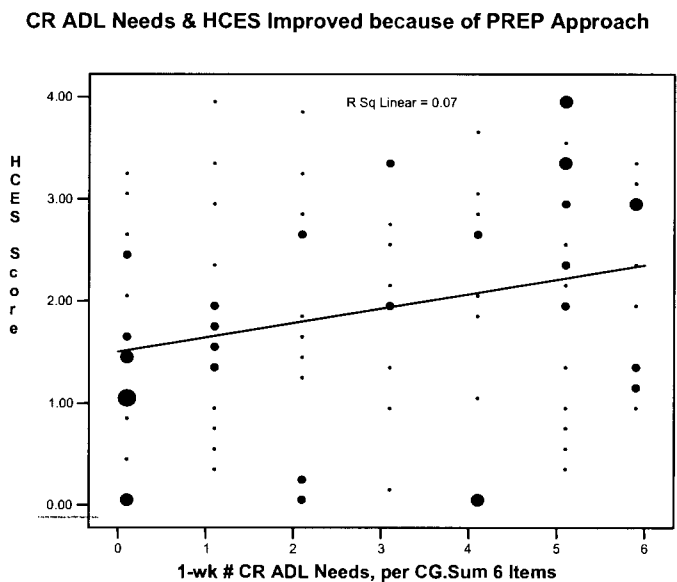


Figure 19. Scatterplot of CR ADL Needs and HCES Improved Because PREP Approach



Regression

To examine if CR-CG baseline characteristics had a unique contribution in explaining variation in HCES (effectiveness of PREP), over and above the effects of the dosage components hierarchical multiple regression analysis was performed. For analyses the entry format of: the dosage components (PREP nurse visits, PREP aide visits, and home health visits) (Step 1); and CR-CG baseline characteristics (CR-CG Relationship (spouse or non-spouse), CG SES, CR ADL Needs, CR Cognitive Function, CG Physical Health, CG Depressive Symptoms, CG Cognitive Impairment, CG Preparedness, CG Mutuality, CG Amount of Care Activities, CG Role Strain, and Duration of Caregiving) (Step 2) letting SPSS sequence the CR-CG baseline characteristics and the dosage components with the goal of deriving a parsimonious model for predicting the variation in the effectiveness of PREP from each HCES Subscale as a dependent variable.

PREP nurse visits was the only dosage component found to have a unique contribution in explaining any variation in effectiveness of PREP. Four CR-CG baseline characteristics were found to explain variation in the effectiveness of PREP, over and above the effects of the dosage component. The four CR-CG baseline characteristics were: CR-CG Relationship of being a spouse, CG Amount of Care Activities, CG Health, and CG Cognitive Impairment. Those same four baseline CR-CG baseline characteristics were also found to explain variance in some of the three HCES Subscales (HCES Improved Feeling about CG, HCES Improved Relationship with CR, and Improved CG Health) of which the dosage component, PREP nurse visits was not significantly correlated. For the HCES Overall Effectiveness and the HCES Subscales (HCES

Improved Preparedness, HCES Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach) of which the dosage component of PREP nurse visits significantly contributed, the same four CR-CG baseline characteristics were also shown to contribute to the variation in the effectiveness of PREP in varied order and quantity. Tables 21 - 24 will be presented to show the contribution of these four CR-CG baseline characteristics in the HCES Overall Effectiveness and HCES Subscales.

Table 21 displays the CR-CG baseline characteristics of CG Relationship of being a spouse, CG Amount of Care Activities, and CG Health that did significantly contribute to the variance of HCES Overall Effectiveness after PREP nurse visits. In Model 1, PREP nurse visits in the regression equation explained 3% ($R^2 = .04$, Adj. $R^2 = .03$) of the variance of the HCES Overall Effectiveness and contributed significantly ($F = 4.57$, $df = 1,100$, $p = .03$). In Model 2, however the CR-CG baseline characteristic of the CG Relationship of being a spouse was added to effect of PREP nurse visits and 11% ($R^2 = .13$, Adj. $R^2 = .11$) of the variance of the HCES Overall Effectiveness and contributed significantly ($F = 7.45$, $df = 2, 99$, $p = .001$). In Model 3 and Model 4, the CR-CG baseline characteristics of CG Amount of Care Activities and CG Health were added to the effect of PREP nurse visits and the CG Relationship of being a spouse for a total of 19% ($R^2 = .22$, Adj. $R^2 = .19$) of the variance of the HCES Overall Effectiveness and contributed significantly ($F = 6.89$, $df = 4, 97$, $p < .001$). The remaining independent variables of CR-CG baseline characteristics of CG SES, CR ADL Needs, CR Cognitive Function, CG Depressive Symptoms, CG Cognitive Impairment, CG Preparedness, CG Mutuality, CG Role Strain, Duration of Caregiving, and other dosage components were

excluded from the model and were not found to statistically significant at the $p = .05$ level.

Table 21
Hierarchical Regression and Stepwise of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Overall Effectiveness

Variable	HCES Overall Effectiveness											
	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
Constant	1.72	0.16		1.41	0.18		0.71	0.31		0.13	0.43	
PREP Nurse Visits	0.05	0.02	.21	0.05	0.02	.20	0.04	0.02	.15	0.04	0.02	.15
CG Spouse				0.61	0.19	.30	0.56	0.19	.27	0.53	0.19	.26
CG Amt. Care Acts.							0.02	0.01	.25	0.02	0.01	.27
CG Health										0.01	0.004	.17
F Change	4.57			9.93			7.31			3.75		
R ²	.04			.13			.19			.22		
Adj. R ²	.03			.11			.17			.19		

* $p < .05$, 1-tailed test

Table 22 displays the CR-CG baseline characteristics that have a unique contribution variation in explaining variation in HCES Improved Preparedness over and above the effect of PREP nurse visits. The CR-CG baseline characteristics were CG Amount of Care Activities, CG Health, and CG Relationship of being a spouse. In Model 1, PREP Nurse Visits in the regression equation explained 4% ($R^2 = .05$, Adj. $R^2 = .04$) of the variance of the HCES Improved Preparedness and contributed significantly ($F = 4.78$, $df = 1,100$, $p = .03$). In Model 2, the CR-CG baseline characteristic of CG Amount

of Care Activities was added to effect of PREP Nurse Visits and 11% ($R^2 = .12$, Adj. $R^2 = .11$) of the variance of the HCES Improved Preparedness and contributed significantly ($F = 7.19$, $df = 2$, 99 , $p = .001$). In Model 3 the CR-CG baseline characteristic of CG Health was added to effect of PREP Nurse Visits and CG Amount of Care Activities and 14% ($R^2 = .16$, Adj. $R^2 = .14$) of the variance of the HCES Improved Preparedness and contributed significantly ($F = 6.37$, $df = 3$, 98 , $p = .001$) and in Model 4, the CR-CG baseline characteristics of CR-CG Relationship of being a spouse was also added for a total of 15% ($R^2 = .18$, Adj. $R^2 = .15$) of the variance of the HCES Improved Preparedness and contributed significantly ($F = 5.62$, $df = 4$, 97 , $p < .001$). The remaining independent variables of CR-CG baseline characteristics of CG SES, CR ADL Needs, CR Cognitive Function, CG Depressive Symptoms, CG Cognitive Impairment, CG Preparedness, CG Mutuality, CG Role Strain, Duration of Caregiving, and other dosage components were excluded from the model and were not found to statistically significant at the $p = .05$ level.

Table 22
Hierarchical Regression of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Preparedness

Variable	HCES Improved Preparedness											
	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
Constant	2.15	0.17		1.30	0.32		0.64	0.45		0.57	0.45	
PREP Nurse Visit	0.05	0.25	.21	0.04	0.02	.15	0.04	0.02	.16	0.04	0.02	.15
CG Amt Care Act.				0.02	0.01	.29	0.02	0.01	.31	0.02	0.01	.29
CG Health							0.01	0.004	.19	0.01	0.004	.18
CG Spouse										0.34	0.19	.16
F Change	4.78			9.20			4.25			2.98		
R ²	.05			.13			.16			.19		
Adj. R ²	.04			.11			.14			.15		

* $p < .05$, 1-tailed test

Table 23 displays that CR-CG baseline characteristics did have a unique contribution in explaining variation in HCES Improved Collaboration with Healthcare System after the effect of the dosage component of PREP nurse visits. The CR-CG baseline characteristics were CG Relationship of being a spouse, CG Amount of Care Activities, CG Health, and CG Cognitive Impairment. In Model 1, PREP nurse visits in the regression equation explained 5% ($R^2 = .06$, $\text{Adj. } R^2 = .05$) of the variance of the HCES Improved Collaboration with Healthcare System and contributed significantly ($F = 6.37$, $df = 1,100$, $p = .01$). In Model 2, however the CR-CG baseline characteristic of CG Relationship of being a spouse was added to effect of PREP nurse visits, and 12% ($R^2 =$

.13, Adj. $R^2 = .12$) of the variance of the HCES Improved Collaboration with Healthcare System and contributed significantly ($F = 7.60$, $df = 3$, 98 , $p = .001$). In Model 3, Model 4, and Model 5 the CR-CG baseline characteristics of CG Amount of Care Activities, CG Health, and CG Cognitive Impairment were added for a total of 22% ($R^2 = .25$, Adj. $R^2 = .22$) of the variance of the HCES Improved Collaboration with Healthcare System and contributed significantly ($F = 6.49$, $df = 5$, 96 , $p < .001$). The remaining independent variables of CR-CG baseline characteristics and other dosage components were excluded from the model and were not found to statistically significant at the $p = .05$ level.

Table 23

Hierarchical Regression and Stepwise of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Collaboration with Healthcare System

Variable	HCES Improved Collaboration with Healthcare System														
	<u>Model 1</u>			<u>Model 2</u>			<u>Model 3</u>			<u>Model 4</u>			<u>Model 5</u>		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
Constant	1.60	0.18		1.29	0.20		0.56	0.34		-0.13	0.46		-0.37	0.47	
PREP Nurse Visits	0.06	0.03	.24	0.06	0.02	.19	0.05	0.02	.19	0.05	0.02	.19	0.05	0.02	.18
CG Spouse				0.61	0.21	.27	0.55	0.20	.25	0.51	0.20	.23	0.42	0.20	.19
CG Amt. Care Act.							0.02	0.01	.24	0.02	0.01	.27	0.02	0.01	.26
CG Health										0.01	0.004	.19	0.01	0.004	.23
CG Cog. Impairment													0.05	0.03	.17
F Change	6.37			8.36			6.91			4.64			3.56		
R ²	.06			.13			.19			.23			.25		
Adj. R ²	.05			.12			.17			.19			.22		

*p<.05, 1-tailed test

Table 24 displays that the CR-CG baseline characteristics of CG Amount of Care Activities, CG Health and CG being a spouse did have a unique contribution in explaining variation in HCES Improved because PREP Approach in addition to the effect of PREP nurse visits. In Model 1, PREP nurse visits in the regression equation explained 4% ($R^2 = .04$, Adj. $R^2 = .04$) of the variance of the HCES Improved because PREP Approach and contributed significantly ($F = 4.74$, $df = 1,100$, $p = .03$). In Model 2, the CG Amount of Care Activities was added to effect of PREP nurse visits and 10% ($R^2 = .12$, Adj. $R^2 = .10$) of the variance of the HCES Improved because PREP Approach and contributed significantly ($F = 6.67$, $df = 2, 99$, $p = .02$). In Model 3 CG Health was added for a total of 14% ($R^2 = .17$, Adj. $R^2 = .14$) of the variance of the HCES Improved because PREP Approach and contributed significantly ($F = 6.56$, $df = 3, 98$, $p < .001$). In Model 4 the CG being a Spouse was added for a total of 17% ($R^2 = .20$, Adj. $R^2 = .17$) of the variance of the HCES Improved because PREP Approach and contributed significantly ($F = 6.04$, $df = 4, 97$, $p < .001$). The independent variables of CR-CG baseline characteristics of CG SES, CR ADL Needs, CR Cognitive Function, CG Depressive Symptoms, CG Cognitive Impairment, CG Preparedness, CG Mutuality, CG Role Strain, Duration of Caregiving, and other dosage components were excluded from the model and were not found to be statistically significant at the $p = .05$ level.

Table 24

Hierarchical Regression of Dosage Components and CR-CG Baseline Characteristics in Variance of HCES Improved Because PREP Approach

Variable	HCES Improved because PREP Approach											
	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*	<i>B</i>	SE	β^*
Constant	1.60	0.17		0.74	0.34		-0.06	0.48		-0.15	0.48	
PREP Nurse Visit	0.06	0.03	.21	0.04	0.03	.16	0.04	0.02	.16	0.04	0.02	.16
CG Amt Care Act.				0.02	0.01	.28	0.02	0.01	.30	0.02	0.01	.28
CG Health							0.01	.004	.22	0.01	.004	.20
CG Spouse										0.41	0.20	.18
F Change	4.74			8.26			5.70			3.90		
R ²	.04			.12			.17			.20		
Adj. R ²	.04			.10			.14			.17		

* $p < .05$, 1-tailed test

CHAPTER 5: DISCUSSION

For over one hundred years home health nursing has played an important role in the American health care system (Buhler-Wilkerson, 2002). In traditional home health care there is often little time to explore or address family care issues of CGs beyond those that affect the skilled needs of the CR. The Family Care Study (PREP: Family-based Care for Frail Older Persons, R01 AG17909, 1999-2005) offered CGs an in-home and telephone intervention designed to increase Preparedness, Enrichment, and Predictability in family care beyond the scope of the skilled care that the CR would receive through home health services. CGs who received PREP (N = 102) rated its effectiveness in strengthening family care significantly higher ($p < .001$) than CGs in the control group rated the effectiveness of skilled home health.

This dissertation has further examined the variation in dosage of PREP during the 5 months of the PREP intervention, and explored whether CR-CG baseline characteristics and the contacts of dosage components of PREP predict the extent to which working with the PREP Nurse and home health care providers helped improve the overall and varied aspects of the caregiving situation. This section discusses the meaning of the study results, followed by limitations of the study, and implications for theory, research, and practice.

Meaning of Results

Dosage

CRs received more home health visits during the first 5 months than any other of the dosage components. 79% of the CRs in the study sample had skilled physical therapy needs, and 29% had skilled nursing care. The PREP nurses provided all of the skilled

nursing care to CRs who had a skilled nursing referral. Only 9 CRs had a skilled home health referral that did not include the disciplines of physical therapy or nursing in the first month.

More skilled visits were provided in the first month than in the following four months of the PREP intervention. These findings are consistent with the national home care data which reports that the median length of skilled home health services is 25 days for CRs who have a primary CG in the home, and 27 days for adults over the age of 65 (NCHS, 2004). The only noticeable irregularity in what would be expected in the numbers of skilled home health visits is that typically there are more skilled nursing referrals than other skilled disciplines. This was explainable in that CRs who had “same day” skilled referrals were not able to participate in the parent study due to the 24-hour period needed for study consent, thus potentially reducing more acute or urgent skilled nursing referrals. The wide range of the number of home health visits beyond the first month however represents that some CRs have chronic care needs that require long-term skilled care, and that CGs are involved in managing skilled medical care needs for long periods of time.

All but one of the intervention families received PREP nurse visits. The greatest numbers of PREP nurse visits were provided during the first month after the randomization to PREP, followed by more visits in the second month than in the next three months of the intervention. This finding is consistent with both PREP nurses providing skilled nursing care to CRs as directed by the physician, but also with the process that PREP nurses used to introduce the PREP intervention to CR-CGs, and engaging the family care assessment. Typically families received at least two PREP

nurse visits during the first and second month of the intervention in addition to any skilled nursing visits. The first PREP nurse visit would be used to introduce the CR-CG to the principles of PREP, which was often followed by a second visit where the summary of the Family Care Assessment from the FCI was reviewed with the family. It was often during these first PREP nurse visits that CGs would identify family care issues they would want to work on with the PREP nurse. Further PREP nurse visits, PREP phone calls, and/or PREP aide visits were then often utilized to implement and evaluate strategies that had been tailored to the family situation. PREP nurse visits were one component of the PREP intervention where families were able to tailor the intervention through initiating or requesting more “dose” (contact). Therefore, increased PREP nurse visits would often be indicative of ongoing work related to family care issues that were not yet resolved.

PREP nurse visits were positively correlated with the number of home health visits. This finding is consistent in that sometimes CRs were receiving both skilled nursing care from the PREP nurse, along with additional care from another skilled home health discipline. Also, at times the PREP nurse’s active involvement through systematic assessment of family care and the CR’s health condition may have generated additional skilled home health referrals.

The dosage component of PREP aide visits did not differ significantly over the first 5 months of the intervention, and were positively correlated with the PREP nurse visits. The PREP aide involvement with CR-CGs was always an intervention strategy of an identified family care issue and used to assist or support the CR or CG in working on

or seeking to resolve such issues. It was only under the direction of a PREP nurse that a PREP aide would be involved in family care.

The variation in the dosage of skilled care to CRs is defined by a skilled need, and directed by prescribed treatment and outcomes under Medicare guidelines. In 1999 HCFA introduced the Outcome and Assessment Information Set (OASIS) to Medicare certified home health agencies as a mandatory mechanism of collecting a comprehensive assessment for the adult home care patient (CDC, 2004). The OASIS acts as a measurement of patient outcomes for outcome-based quality improvement and a prospective payment system for home health services.

The pattern of increased PREP nurse visits in the first 2 months of the intervention, and with a leveling of contact in future months of the intervention offers healthcare providers and healthcare systems insight into how CR-CGs may not be adequately getting care issues addressed within the context of home health services. Further exploration of how families can identify and seek resolution of concerns with a skilled provider will be important in examining the use and effectiveness of home and community-based services.

Dosage and CR-CG Baseline Characteristics

Understanding that family caregivers comprise the backbone of long-term-care provision in the United States (Wolff & Kasper, 2006) provides impetus for identifying and understanding how CR-CG characteristics influence how home health services are utilized and optimized in a system that focuses on patient-centered outcomes. In the PREP intervention over half of the CGs were spouses, indicative that many of them were older adults themselves, and had chronic health conditions that were impacting their own

activities of daily living. 39% of the CGs had clinically elevated depressive symptoms, and 5% were found to have dementia. Over 45% of the CRs had some level of cognitive impairment and over half of all the CRs needed assistance with more than 3 ADLs,

In examining correlations of dosage components and CR-CG baseline characteristics, CR ADL Needs, CG Amount of Care Activities and CG Role Strain were associated with higher numbers of visits from both PREP nurses and home health providers. CRs with poorer cognitive function also had more home health visits. Each of these baseline characteristics can easily be identified as impacting either the skilled care needs of a CR, or the ability of a CG to manage an acute or chronic need of a worsening disability.

CG SES had a negative correlation with the number of both PREP nurse visits and PREP aide visits, while having no significant impact on the number of home health visits. In consideration as to why poorer CG SES would be predictive of more PREP nurse and PREP aide visits, findings from the parent study showed that one of the family care issues most often identified by CGs in the PREP intervention was CG strain from lack of resources (Messeccar, 2004). PREP nurses had the opportunity to work together with families to try and resolve care needs. PREP principles allowed CGs to identify issues that impacted any aspect of their family care situation allowing service utilization to be provided for issues other than those related to the skilled care needs of the CR. Providing more PREP nurse and PREP aide dosage to families with lower SES could also be reflective of the blending of family and nurse knowledge in facilitation of issue identification and family care support (Harvath et al. 1994) in allowing CG's who had

less socioeconomic resources to utilize the expertise and services from the PREP nurse or PREP aide.

CG Depressive Symptoms was also positively correlated with PREP nurses visits, indicating that CGs with greater depressive symptoms had more contact with the PREP nurse. Systematic assessment of the family care situation included the CES-D questionnaire of the CG in the FCI to detect any depressive symptoms. As caregiving research has revealed, caregiving is a significant risk factor for the development of depressive symptoms and can intensify a variety of health threats (Kiecolt-Glaser & Glaser, 1999) in CGs. The CES-D score and clinical implications of that score were shared with CGs at the first or second PREP nurse visit when the summary of how the CG had responded to questions in the Family Care Assessment from the FCI was reviewed with the CG.

CGs with higher role strain also utilized more PREP nurse visits. Assessment results from the FCI and the family assessment allowed PREP nurses to report and respond to the psychosocial affects of depression and strain that CGs may be experiencing. In predicting the variation in dosage, lower CG SES and higher CG role strain accounted for 15% of the variance in PREP nurse visits.

It is also important to examine those CR-CG baseline characteristics which did not have either a positive or negative correlation with dosage components. CR-CG Relationship being a spouse, CG Physical Health, CG Cognitive Impairment, CG Preparedness, CG Mutuality, or Duration of Caregiving were not found to be predictive of variation in any of the dosage components. It is interesting to note that some of the CR-CG baseline characteristics that did not have a significant correlation to a particular

dosage component were conceptual characteristics that were related to some of the family care issues that CGs reported. For example issues related to CG Health and CG Preparedness were among the most common issues that CGs had wanted to work on with the PREP nurse (Messecar, 2004). It will be important to evaluate what impact these CR-CG baseline characteristics may have in the utilization of dosage components later in the intervention period (10, 15, 20-month evaluations) to see if the outcome is consistent with the first 5-month evaluation, or if it changed.

Dosage and Effectiveness of PREP

In the Family Care Study all CGs were given opportunity to rate the extent to which working with their nurse, or other home health provider helped them improve their overall caregiving situation and various other aspects of caregiving (HCES Improved Preparedness, HCES Improved Feelings about Caregiving, HCES Improved Relationship with CR, HCES Improved CG Health, HCES Improved Collaboration with Healthcare System, and HCES Improvement because of PREP Approach). Of the three dosage components (PREP nurse visits, PREP aide visits, and home health visits) only PREP nurse visits were found to influence how CGs reported improvement and the effectiveness of the home health services that they received during the first 5 months of the PREP intervention.

Consideration of how effective or relevant an intervention may be is often found in the timing and setting of the intervention, as well as when the relevance of the intervention for the particular problem is clear (Conn, Rantz, Wipke-Tevis, & Maas, 2001). The areas of their caregiving situation that were found to be positively correlated with PREP nurse visits were CG's reporting improvement in 1) their overall caregiving

situation, 2) feeling more prepared to address caregiving needs, 3) their ability to collaborate with the healthcare system, and 4) their caregiving situation because of the PREP approach. Previously reported findings from the parent study indicated that there was significantly higher overall effectiveness reported by CGs who had received the PREP intervention (N = 102 of 116) than the control group (N = 118) (who received only home health services) (Archbold et al. 2005). For PREP families, the opportunity to increase and tailor treatment dose the likelihood of enhancing significant changes in the outcome and effectiveness may have been relevant. Although these findings are modest, they are significant especially when the dosage component of home health visits were found to have a negative correlation or no correlation (though not statistically significant) with HCES overall effectiveness and all of the HCES subscales.

Further investigation needs to be done in understanding how much dosage improves effectiveness and how the treatment process is explained (Bourgeois et al, 1996), as well as how the delivery of dose over time impacts effectiveness (Sechrest, West, Phillips, Redner & Yeaton, 1979). These findings are similar to the findings where patient groups discharged to home with more APN time and contact had greater improvements in patient outcomes (Brooten et al, 2003). Determining effectiveness however is complex considering the multiple dimensions that differ within a tailored caregiving intervention such as PREP.

CR-CG Baseline Characteristics and Effectiveness

Exploring if antecedent variables may influence or predict intervention effectiveness is important in multi-component tailored interventions such as PREP in that highly individualized interventions may be difficult to standardize and disseminate

otherwise. In PREP the effectiveness of home health was a dependent variable reflecting the CG's evaluation of just how much working with their nurse, or other home health provider had affected their family care situation. The antecedent or baseline characteristics that were shown to most impact how CGs perceived effectiveness of PREP were the CG being a spouse, the more impaired a CR was (CR ADL Needs), if the CG themselves had cognitive impairment, and how much the CG was having to do for the CR (CG Amount of Care Activities). The CG being a spouse (CR-CG Relationship) and the increased amount of care the CG provided (CG Amount of Care Activities) were positively correlated with HCES Overall Effectiveness and all the HCES Subscales. When CR's had greater physical impairment (CR ADL Needs) there was a positive correlation with HCES Overall Effectiveness, HCES Improved Preparedness, HCES Improved CG Health, HCES Improved collaboration with Healthcare System, and HCES Improvement because of PREP Approach. For those CGs who themselves had greater cognitive impairment, they reported more improvement in their caregiving situation through HCES Overall Effectiveness, HCES Improved Feelings about Caregiving, HCES Improved CG Health, and HCES Improved Collaboration with the Healthcare System.

For CGs with fewer resources (CG SES) there was a negative relationship with all aspects of HCES. Less education and fewer financial resources is predictive of poorer effectiveness in how home health can actually support or improve families' overall caregiving situations. Also, predictive of finding less support in improving preparedness (HCES Improved Preparedness) through the involvement of nurses or home health providers were CGs who were caring for a CRs with greater cognitive impairment (CR Cognitive Function).

CR-CG Baseline Characteristics and Effectiveness and Dosage

Four CR-CG baseline characteristics were found to explain variation in the effectiveness of PREP, over and above the effect of PREP nurse visits, which was the only dosage component that was predictive of the effectiveness of PREP. Those characteristics were: 1) the CG being a Spouse, 2) the CG Amount of Care Activities, 3) CG Health, and 4) CG Cognitive Impairment. These four baseline characteristics explained variation in effectiveness HCES Overall Effectiveness and the HCES subscales of HCES Improved Preparedness, HCES Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach in various amounts and order. These same four baseline characteristics were also found to contribute to variation in effectiveness in the remaining HCES Subscales (Improved Feelings about Caregiving, Improved Relationship with CR, and Improved CG Health) of which PREP nurse visits was not correlated with PREP effectiveness.

It is interesting to consider why the PREP intervention was found to more effective for those CGs who are spouses, especially in that studies on caregiving have reported that spousal CGs were significantly less likely to use services than non-spousal CGs (Robinson, Buckwalter, & Reed, 2005). Though being a spouse was not predictive of variation in the amount of contact that a PREP nurse had with a family, spouses found working with the nurses or home health providers more useful overall than other CGs. Institutional barriers, waiting too long to use services, and an accepted role that caregiving must be performed alone and without help have been found to be reasons that spousal CGs have not utilized services (Zarit, Stephens, Townsend, Greene, & Leitsch, 1999). One possible interpretation of why CG being a spouse might have been predictive

of greater effectiveness of the PREP intervention was because of the principles of PREP that included (1) family care assessment and (2) family focus, (3) working together to blend family and nursing knowledge to develop (4) multiple intervention strategies tailored to the family and (5) detecting problematic transitions in family care. Such an approach allowed spousal CGs to identify their own family care issues and utilize support without betraying the spousal relationship.

It is also important to review which CR-CG baseline characteristics did not impact explain, or predict any variation in either dosage or effectiveness in PREP. For example, though higher CG depressive symptoms and role strain were predictive of greater PREP nurse visits, these baseline characteristics were not found to be associated with any aspect of HCES intervention effectiveness at the 5-month intervention evaluation. Though one might expect that more contact with care providers might increase effectiveness it may be possible as Mittelman and Gallagher-Thompson, experienced researcher in CG interventions have reported, some interventions may need to be delivered and assessed for 1 to 2 years before demonstrated effects on strain and depressions are seen (Mittleman & Gallagher-Thompson, 1996). The baseline family care characteristics of CG Preparedness and CG Mutuality were also not shown to have a significant correlation with either dosage or effectiveness. Archbold & Stewart have pointed out in previous research that both CG preparedness and mutuality are strongly associated with CG role strain (Archbold & Stewart, 1999) which again may explain the lack of association in measuring intervention effectiveness at only 5 months.

Validity of the Findings

Assumptions of Statistical Tests

Statistical assumptions underlying multiple regression analysis include normality, linearity, and homoscedasticity (Tabachnick & Fidell, 2001). These assumptions were assessed using descriptive statistics, histograms, and scatterplots.

Multiple Testing and 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 examine whether the independent variables of CR-CG baseline characteristics and dosage components were associated with effectiveness of PREP (HCES Overall Effectiveness and the six HCES Subscales).

Limitations of the Study

The sample size ($N = 102$) was adequate but modest in terms of a desired sample size for the regressions that were conducted as part of this study.

The dosage component of PREP Phone Calls was not able to be used in this study, due to the fact that it was found to be incomplete and reported inconsistently. PREP phone calls were an integral part of the PREP intervention in that families were offered access to the PREP nurse 24 hours through PAL (PREP Advice Line) to discuss family care issues. The PREP nurses also used the phone for CIM (Check-In-Monitoring) for current family care needs and KIT (Keep-In-Touch) for ongoing monitoring of family care issues that were stable or resolved. For some PREP families, PREP Phone calls were more convenient than PREP nurse visits.

The sample for this study was 93% Caucasian which does not reflect the society at large, though it is consistent with the metropolitan area in the NW United States in which the parent study was conducted.

The description of the length of individual visits of the three dosage components was not available for evaluation, limiting the ability to compare how the intervention was provided during a single dosage contact.

Implications for Theory, Research, and Practice

Theory

The conceptual model underlying this study proposed that CR-CG baseline characteristics would predict variation in the different types of the intervention dosage components (PREP nurse visits, PREP aide visits, and home health visits) and that dosage components would predict variation in effectiveness of PREP. While six different CR-CG baseline characteristics were significantly correlated with various dosage components, six were not. Only CG SES, CG Role Strain, CR ADL Needs, and CR Cognitive Function offered significant explanation within the regression models. The PREP nurse visits was the only dosage component that correlated with effectiveness of PREP (HCES Overall Effectiveness and three of the HCES subscales (HCES Improved Preparedness, Improved Collaboration with Healthcare System, and HCES Improved because PREP Approach), and were found to be significant in the regression model.

The conceptual model of this study cannot stand alone, but must be examined and evaluated in the context of PREP and the Family Care Process, the conceptual model of the parent study which was derived from the Archbold and Stewart's research on caregiving and from role theory (Archbold, Stewart, & Hornbrook, 1999). PREP was

expected not only to improve how family care was done, but to increase positive responses to family for the CR and CG, and decrease negative responses to family care. This study most closely relates to the dependent variables that Archbold, Stewart, and Hornbrook examined in measuring the effects of home health of family care and the CGs view of how much home health care had affected their family care, and if antecedent variables predicted differential effectiveness of the intervention (Archbold, Stewart, & Hornbrook, 1999).

Research

While moderate amounts of variance were found to be significant in predicting variation between: 1) certain CR-CG baseline characteristic and the dosage components of PREP nurse visits, PREP aide visits, and home health visits, and 2) only PREP nurse visits and any of the variance in the effectiveness of home health services, a large amount of the variance remains unexplained. Directions for further research include both the context of the secondary analysis of the parent study; as well the design of future caregiving intervention studies that more definitely describe and examine intervention dose, and its impact upon intervention effectiveness.

Next steps in secondary analysis of the parent study should include the evaluation of the PREP intervention documentation in the form of the DocPLUS and PREP eChart visit entries of all contacts to the CR-CGs provided through the different dosage components (PREP nurse visits, PREP aide visits, and home health visits). A qualitative analysis of contact documentation compared to actual contact amounts could provide greater insight into what may have been themes and/or confounding factors to both family care through PREP and through other skilled care. Categorizing and computing

family identified family care issues while examining if there are significant associations between CR-CG baseline characteristics and/or dosage components would also be helpful in recognizing what CGs have identified as needing help with. Comparing this to how effective CGs found PREP during the first 5 months of the PREP intervention would provide a more complete view of the family caregiving situation.

The findings of this study may also contribute to further thinking about how dose and effectiveness are being measured. Meta-analysis's of treatment effectiveness (Wilson & Lipsey, 2001) and effectiveness of interventions for family caregivers of older adults (Sorensen et al. 2002) have both identified that design features and targeted outcomes of interventions must be further described and justified in science. The relationship of dose and effectiveness is such that targeted outcomes or improvements may require different sets of intervention techniques, and that the length of the intervention must be matched to previous science in response to effectiveness. Burgio has reported that a minimal requirement for any intervention is an accurate record of the frequency, duration, and types of contact between interventionist and client. This information provides the essentials for assessing both treatment delivery and receipt among CGs (Burgio et al, 2001). Clearer description of dosage in definition of the type of contact and amount will help provide researchers ways to explain the features of interest, whether it be dose or treatment effectiveness. This is especially necessary in multi-component tailored interventions such as PREP.

Nurse dose as a concept related to the delivery of high quality health care (Brooten & Youngblut, 2006) is another area of research that could be furthered explored based on some of the findings of this study. Brooten and Youngblut conceptualize and

describe nurse dose as having the three equally necessary components: dose (number of nurses or amount of care by nurses), nurse (education, expertise, and experience), and host response (organizational or patient receptiveness). The PREP intervention used expert and extensively trained home health nurses to provide the PREP intervention through both in-home visits and phone calls. Tailored nursing interventions such as PREP offer opportunity to explore PREP nurse dose in the amount of nurse time in minutes or hours and the number of contacts, and see if those additional pieces of information may inform the outcome of the effectiveness of home health and PREP services. Brooten and Youngblut also discuss how the effectiveness of nurse dose depends on the host response. In the PREP intervention, host response would be the CR and CG. Further evaluation and comparison of CR-CG's baseline characteristics and CGs rating of effectiveness in relation to the amount of nurse dose actually received would be very informative. Additional secondary analysis could potentially provide further insight into evaluating the findings from this study of just how much dose was used, and for whom the PREP intervention was most effective in supporting identified family care issues and care needs.

Practice

Home health nurses and other skilled home health care providers are important in providing skilled care to older adults in their homes. With the U.S. population aged 65 and over expected to double by 2030, and older adults age 85 and over being the fastest growing population group and having the greatest need of care, the importance of supporting family caregivers of frail elders cannot be minimized. Understanding that

current home health services are not always viewed as being useful by CGs is important information for home health providers, health system leaders, and policy makers.

For home health providers, broadening assessment skills and care planning goals to include a more complete view of the family caregiving situation would be helpful. Knowing that over half of family caregivers in the Family Care Study were spouses, and that the mean age of all caregivers in the study was 65 year old, alerts home health providers that many CGs potentially have health and care concerns themselves.

For health system leaders and policy makers, who are ever seeking mechanisms to provide quality care within cost-effective programs, an increased awareness of the current economic value of supporting family caregivers in the home, who have been estimated to provide between \$45 to \$200 billion annually cannot be minimized (Arno, Levine, & Memmott, 1999). PREP nurse visits increased for CGs with fewer financial and educational resources, and for those CGs who reported more strain PREP nurse visits, PREP aide visits, and home health visits were greater. Medicare guidelines and the OASIS assessment need to be informed and evaluating the influence of CR-CG characteristics on service utilization. The scope of assessment and service matrix may need to be more broadly defined in determining a CRs eligibility for admission and ongoing skilled services.

CGs reported that PREP nurse visits were effective in improving their ability to collaborate with the formal health care system, whereas other types of home health visits had no impact. Home health agencies and health maintenance organizations responsible for the care of older adults should consider ongoing evaluation of their systems of communication and access to services in relation to ease and as technology and systems

are continuing to change. Tailoring communication systems to meet the communication and functional limitations of older adults may be necessary.

References

- Acton, G. J. & Winter, M. A. (2002). Interventions for family members caring for an elder with dementia. In P. Archbold & B. Stewart (Eds). *Annual Review of Nursing Research*. (Vol. 20, pp. 149-179). New York: Springer.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R. & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13. 375-384.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R. & Harvath, T. (1992). Clinical assessment of mutuality and preparedness in family caregivers role strain to frail older people. In S. G. Funk, E. M. Tornquist, M. T. Champagne, & R. A. Wiese (Eds.), *Key aspects of elder care*. 328-339. New York: Springer
- Archbold, P. G., Stewart, B. J., & Hornbrook, M. C. (1999). PREP: Family-based care for frail older persons. Final Proposal R01 AG17909.
- Archbold, P. G., Stewart, B. J., Hornbrook, M. C., Leo, M., Lyons, K. S., Tetz, K., Miller, L. L., Hiatt, S. O., Hagen, C., O'Keefe-Rosetti, M., Messecar, D. (2005). Does PREP Reduce Caregiver Role Strain and Improve Health Outcomes? Paper presented at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.
- Archbold, P. G., Stewart, B. J., Miller, L. L., Harvath, T. A., Greenlick, M. R., VanBuren, L., Kirschling, J. M., Valanis, B. G., Brody, K. K., Schook, J. E., & Hagan, J. M. (1995). The PREP system of nursing interventions: A pilot test with families caring for older members. *Research in Nursing and Health*, 18, 3-16.

Arno, P. S.(2002). Economic Value of Informal Caregiving," presented at the American Association of Geriatric Psychiatry, February 24, 2002.

Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs, 18*,(2), 182-188.

Baron, R. M. & Kenny, D. A. (1986). The moderator-mediatory variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*,(6), 1173-1182.

Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F., & Lance, C. E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society, 53*,(2),255-261.

Blessed, G., Tomlinson, B., Roth, M. I., & Wade, D. T. (1992). Measurement in neurological rehabilitation. New York: Oxford University Press.

Blumer, H. (1969). Symbolic Interactionism: Perspective and method. New Jersey: Prentice-Hall.

Bougeois, M. S., Beach, S., Schulz, R., & Burgio, L. (1996). When primary and secondary caregivers disagree: Predictors and psychosocial consequences. *Psychology and Aging, 11*, (3), 527-537.

Brooten, D., Youngblut, J. M., Dearick, J., Naylor, M., & York, R. (2003). Patient problems, advanced practice nurse (APN) intervention, time and contacts among five patient groups. *Journal of Nursing Scholarship, 35*,(1), 73-79.

Buhler-Wilkerson, K. (2002). No place like home a history of nursing and home care in the U.S. *Home Healthcare Nurse, 20*, (10), 641-647.

Burgio, L., Corcoran, M., Lichstein, K. L., Nichols, L., Czaja, S., Gallagher-Thompson, D., Bourgeois, M., Steven, A., Ory, M., & Schulz, R. (2001). Judging outcomes in psychosocial interventions for dementia caregivers: The problem of treatment implementation. *The Gerontologist*, *41*,(4), 481-489.

Burr, W. R. (1979). Edited by: Burr, W. R., Hill, R., Nye, F. I., & Reiss, I. R. In *Contemporary theories about the family*. New York: The Free Press.

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S. & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, *43*,(2), 230-241.

Carter, J., Stewart, B. J., & Archbold, P.G., Inoue., et al. (1998). Living with a person who has Parkinson's disease: The spouse's perspective by stage of disease. *Movement Disorders*, *13*, (1), 20-28.

CDC (2004). 2003 National health interview survey, Hyattsville, MD. Retrieved from: [http://www.cdc.gov/nchs/about major/nhis/released200406.htm](http://www.cdc.gov/nchs/about%20major/nhis/released200406.htm) fig.12.

CDC (2004). National health care survey: Current home health care patients. Retrieved from: <http://www.cdc.gov/nchs/data/nhhcsd/curhomecare00.pdf>

CDC (2004). National health care survey: Family care component. Retrieved from: <http://www.cdc.gov/nchs/nhcs.html>.

CDC (2002). The burden of chronic diseases and their risk factors: National and state perspectives. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2002.

Champion, V., Foster, J. L., & Menon, U. (1997). Tailoring interventions for health behavior change in breast cancer screening. *Cancer Practice*, *5*, 283-288.

- Chang, B. L. (1999). Cognitive-behavioral intervention for homebound caregivers of persons with dementia. *Nursing Research, 48*, 173-182.
- Chang, B. L., Brecht, M., & Carter, P. A. (2001). Predictors of social support and caregiver outcomes. *Women & Health, 33*, (1), 39-61.
- Clipp E. C. & George L. K. (1993). Dementia and cancer: a comparison of spouse caregivers. *Gerontologist, 33*, (4). 534-541.
- Coen, R. D., Swanwick, G. R., O'Boyle C. A., & Coakley, D. (1997). Behavioural disturbance and other predictors of carer burden in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 12*, 351-356.
- Conn, V. S., Rantz, M. J., Wipke-Tevis, D. D., & Maas, M. L. (2001). Designing effective nursing interventions. *Research in Nursing & Health, 24*, 433-442.
- Connell, C. M. & Gibson, G. D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist, 37*, 355-364.
- Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J. G., & Newman, S. P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging & Mental Health, (2)*, 120-135.
- Crespo, M., Lopez, J., & Zarit, S. H. (2005). Depression and anxiety in primary caregivers: a comparative study of caregivers of demented and nondemented older persons. *International Journal of Geriatric Psychiatry, 20*, (6), 591-592.
- Czaja, S. J. & Rubert, M. P. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine, 64*, 469-476.

Czaja, S. J., Schulz, R., Lee, C. C., & Belle, S. H. (2003). A methodology for describing and decomposing complex psychosocial and behavioral interventions.

Psychology and Aging, 18, 385-395.

Dilworth-Anderson, P., William, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist, 42*, 237-272.

Family Caregiver Alliance, National Center on Caregiving (2004). Selected caregiver statistics. Retrieved on March 7, 2005 from: <http://www.caregiver.org/caregiver>.

Federal Interagency Forum on Aging Related Statistics (2004). Older Americans 2004: Key indicators of well-being. Retrieved on March 7, 2005 from: <http://www.agingstats.gov/chartbook2004/population.html>.

Feinburg, L. F., & Newman, S. L. (2004). A study of 10 states since passage of the national family caregiver support program: Policies, perceptions, and program development. *The Gerontologist, 44*, (6), 760-769.

Feinburg, L. F. & Newman, S. (2004). Family caregiving and long-term care: A crucial issue for America's families. Family Caregiver Alliance: National Center on Caregiving.

Folkman, S., Lazarus R., Pimley, S. & Novacek, J. (1987). Age differences in stress and coping processes. *Psychology and Aging, 2*, 171-184.

Fried L. P. & Wallace R. B. (1992). The complexity of chronic illness in the elderly: From clinic to community. In: *The epidemiologic study of the elderly*. New York, NY: Oxford University Press.

Galantowicz, S., Wang, S., & Doty, P. (2004). Changes in Medicare home health us. Results from the 1999 National Long-Term Care Survey for Chronically Disabled Seniors. Paper presented at the 57th Annual Scientific Meeting of The Gerontological Society of America, Washington D.C.

George, L. K. & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253-259.

Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41, (1), 4-14.

Given, B. A. & Given, W. C. (1991). Family caregiving for the elderly. In J.J. Fitzpatrick & J. S. Stevenson (Eds). *Annual review of nursing research*, Vol. 9, 77-92. New York: Springer Publishing Co.

Harvath, T. A., Archbold, P. G., Stewart, B. J., Gadow, S., Kirschling, J. M., Miller, L., Hagan, J., Brody, K., & Schook, J. (1994). Establishing partnerships with family caregivers: Local and cosmopolitan knowledge. *Journal of Gerontological Nursing*, 20, (2), 29-35.

Hooker, K., Monahan, D. J., Bowman, S. R., Frazier, L. D., & Shifren, K. (1998). Personality counts for a lot: Predictors of mental and physical health of spouse caregivers in two disease groups. *Journal of Gerontology: Psychological Sciences*, 53B, 73-85.

Huber, D. L., Sarrazin, M. V., Vaughn, T., & Hall, J. A. (2003). Evaluating the impact of case management dosage. *Nursing Research, 52*,(5), 276-288.

Institute of Medicine / Committee on Quality Health Care in America (2001). *Crossing the quality chasm: a new health system for the 21st Century*. National Academic Press.

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist, 41*, 334-347.

Kazdin, A. E. (2003). Clinical significance: Measuring whether interventions make a difference. In *Methodological Issues & Strategies in Clinical Research*, (3rd ed.). American Psychological Association: Washington D.C.

Kennet, J., Burgio, L., & Schulz, R. (2000). Interventions for in-home caregivers: A review of research 1990 to present. In R. Schulz (Ed.), *Handbook of dementia caregiving: Evidence-based intervention for family caregivers*. 61-125. New York, NY: Springer Publishing Co.

Kiecolt-Glaser, J. & Glaser, R. (1999). Chronic stress and mortality among older adults. *Journal of American Medical Association, 28*, (23), 2259-2260.

Kiecolt-Glaser, J. & Glaser, R. (2001). Stress and immunity: Age enhances the risks. *Current Directions in Psychological Science, 10*, 18-21.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *33*, (2), 240-248.

Kreuter, M. W. & Wray, R. J. (2003). Tailored and target health communication: Strategies for enhancing information relevance. *American Journal of Health Behaviors*, 27. (Suppl. 3), S227-S232.

Lauver, D. R., Ward, S. E., Heidrich, S. M., Keller, M. L., Bowers, B. J., Brennan, P. F., Kirchhoff, K. T., & Wells, T. J. (2002). Patient-centered interventions. *Research in Nursing & Health*, 25, 246-255.

Maindonald, J. & Richardson, A. M. (2004). This passionate study: A dialogue with Florence Nightingale. *Journal of Statistics Education*, 12, (1).

Metropolitan Life Insurance Company (1999). The MetLife juggling act study: Balancing caregiving with work and the costs involved. Westpoint, CT: Author.

Mittleman, M. S. & Gallagher-Thompson, D. (1996). Valuing intervention research. *Journal of Gerontology: Social Sciences*, 51B,(5), S268.

Mittleman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences*, 59B,(1), 27-34.

Mittleman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease: A randomized controlled trail. *Journal of the American Medical Association*, 276. 1725-1731.

Montgomery, R. J. V. & Borgatta, E. F. The effects of alternative support strategies on family caregiving. *The Gerontologist*, 29, (4), 457-464.

National Alliance for Caregiving & AARP (2004). Caregiving in the U. S.
Retrieved from: <http://www.caregiving.org/data/04finalreport.pdf>.

Nourhashemi, F., Andrieu, S., Gillette-Guyonnet, S., Vellas, B., Albarede, J. L., & Grandjean, H. (2001). Instrumental activities of daily living as a potential marker of frailty. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 56, 448-453.

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, (2), 177-185.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process. An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.

Pusey, H. & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*, 5, (2), 107-119.

Riggs, J. A. (2003). A family caregiver policy agenda for the twenty-first century. *Generations*. 68-73.

Robinson, K. M., Buckwalter, K. C., & Reed, D. (2005). Predictors of use of services among dementia caregivers. *Western Journal of Nursing Research*, 27, (2), 126-140.

Ryan, P. & Lauver, D. R. (2002). The efficacy of tailored interventions. *Journal of Nursing Scholarship*, 34, (4), 331-337.

Sechrest, L., West, S., Phillips, M., Redner, R., & Yeaton, W. (1979). Some neglected problems in evaluation research: Strength and integrity of treatments. In L. Sechrest, S. West, M. Phillips, R. Redner, & W. Yeaton (Eds). *Evaluation studies review annual* (Volume 4, pp. 15-35). Newberry Park, CA: Sage

Schulz, R. (2000). Introduction and overview. In *Handbook on Dementia Caregiving: Evidence-Based Intervention for Family Caregivers*. (xi). New York, NY: Springer Publishing.

Schulz, R. & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *The Journal of American Medical Association*. 282, (23), 2215-2219.

Schulz, R., Belle, S.H., Czaja, S. J., Gitlin, L. N., Wisniewski, S. R., & Ory, M. G. (2003). Introduction to the special section on Resources for Enhancing Alzheimer's Caregiver Health (REACH). *Psychology & Aging*, 18, 357-360.

Schulz, R., Gallagher-Thompson, D., Haley, W., & Czaja, S. (2000). Understanding the interventions process: A theoretical/conceptual framework for intervention approaches to caregiving. In *Handbook on Dementia Caregiving: Evidence-Based Intervention for Family Caregivers*. (Chapter 2 – pp.33). New York, NY: Springer Publishing:

Schulz, R. & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*. 12, (3), 240-249.

Schulz, R., Newsom, U. T., Mittleman, M., Burton, L.C., Hirsch, C.H., & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects study. *Annals of Behavioral Medicine, 19*, 110-116.

Schulz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*, (6), 771-791.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., Belle, S. H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D., & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist, 42*, (5), 589-602.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*, (3), 356-372.

Spector, W. D. & Fleishman, J. A. (2000). The characteristics of long-term care users (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD.

Stahl, S. (2005, November). REACH II Randomized Clinical Trial for Alzheimer's Caregivers. Symposium at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.

Toseland, R. W., McCallion, P., Gerber, T., & Banks, S. (2002). Predictors of health and human services use by person with dementia and their family caregivers. *Social Science & Medicine, 55*, 1255-1266.

Toseland, R. W., McCallion, P., Smith, T. & Banks, S. (2004). Supporting caregivers of frail older adults in an HMO setting. *American Journal of Orthopsychiatry*, 74, (3), 349-364.

Toseland, R. W., Rossier, C. M., Peak, T., & Smith, G. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. *Social Work*, 35, 209-217.

Vernooij-Dassen, M., Felling, A. & Persoon, J. (1997). Predictors of change and continuity in home care for dementia patients. *International Journal of Geriatric Psychiatry*, 12, 671-677.

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129,(6), 946-972.

Whitlatch, C. J., Zarit, S. H., & von Eye, A. (1991). Efficacy of intervention with caregivers: A reanalysis. *The Gerontologist*, 31, 9-14.

Wilson, D. B. & Lipsey, M. W. (2003). The role of method in treatment effectiveness research: Evidence from meta-analysis. *Psychological Methods*, 6, (4), 413-429.

Wolff, J. L, Starfield, B., & Anderson, G. (2002). Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Archives of Internal Medicine*, 162, (11), 2269-2276.

Wolff, J. L, & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist*, 46, (3), 344-356.

Yee, J. L. & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40, 147-164.

Zarit, S., Anthon, C. R., & Boutselis, M. (1987). Interventions with caregivers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2*, 225-232.

Zarit, S. H., Stephens, M. A. P., Townsend, A., Greene, R., & Leitsch, S. A. (1999). Patterns of adult day service use by family caregivers. A comparison of brief versus sustained use. *Family Relations, 48*, 355-361.

LIST OF APPENDICES

- A Family Care Inventory – CR Version – 1-Week Interview
- B Family Care Inventory – The Caregiver’s View – 1-Week Interview
- C The Blessed Orientation - Memory Concentration Test
- D Home Care Effectiveness Scale – The Caregiver’s View – 5-Month Interview
- E Institutional Review Board Letter of Approval

Appendix A

Family Care Inventory – CR Version – 1-Week Interview

1-week Interview

FAMILY CARE INVENTORY – CR VERSION

**OHSU/KPNW Family Care Study
(503) 494-4560**

FCI CR 1-WEEK INTERVIEW

School of Nursing
Oregon Health Sciences University

Center for Health Research
Kaiser Permanente Northwest Region

Principal Investigators:
Patricia G. Archbold, RN, DNSc, FAAN
Barbara J. Stewart, PhD
Mark C. Hornbrook, PhD

OHSU Project Director:
Shirin O. Hiatt, RN, BS
(503) 494-3978

Interviewer's Name: _____

PRINTER __ __

Coder's Name: _____

PRCODER __ __

Date of Visit 1: _____

PRVISIT1 __/__/__

Time Begun 1: _____

PRTIMB1 --:--

Time End 1: _____

PRTIME1 --:--

Length of Visit 1: _____

PRTIM1 __:--

Date of Visit 2: _____

PRVISIT2 __/__/__

Time Begun 2: _____

PRTIMB2 --:--

Time End 2: _____

PRTIME2 --:--

Length of Visit 2: _____

PRTIM2 __:--

I. Living Situation

1. During this interview I will be asking you some questions about your (Insert relationship), Mr., Mrs., Ms. (Family name of Caregiver). When I do so, how would you like me to refer to him/her? Would you like me to use his/her first name, family name, or just refer to him/her as your (Insert relationship)? _____

1A. During this interview, I will also need to refer to you. How would you prefer that I address you? Would you like me to use your first name or your family name?

2. What is your current marital status? Are you: (Read choices unless already known) PR2 _____

- Married 1
- Widowed 2
- Divorced 3
- Separated 4
- Never married 5
- Partnered 6

3. What is your current living situation? (If CR lives with Caregiver, skip to Q.3B)

- | | <u>No</u> | <u>Yes</u> | |
|---|-----------|------------|--------------------------------------|
| A. Do you live alone? | 0 | 1 | PR3A _____
(If Yes, skip to Q 3F) |
| <i>(If No, then ask)</i> | | | |
| B. Do you live with your spouse or partner? | 0 | 1 | PR3B _____ |
| C. Do you live with your child(ren)? | 0 | 1 | PR3C _____ |
| D. Do you live with other relatives? | 0 | 1 | PR3D _____ |
| E. Do you live with non-relatives? | 0 | 1 | PR3E _____ |
| F. Altogether, counting yourself, how many people live in your household most of the time?
_____ persons | | | PR3F _____ |

II. Health

4. **Could you tell me a little about yourself, both before you needed help from (CG), and now.**
(Omit this question if the CR is frail.)

5. **Compared to other persons your age, would you say your health is:**

- Excellent** 5
- Very Good** 4
- Good** 3
- Fair** 2
- Poor** 1
- (Don't know)* -8

PR5 _____

6. **How does your health now compare to your health one year ago? Is your health now:**

- Much better** 5
- A little better** 4
- About the same** 3
- A little worse** 2
- Much worse** 1

PR6 _____

II. Health

7. Mini-Mental State Examination

Now I would like to ask you some questions to see if you are having any problems with your memory. Some of these questions may be difficult for you to answer, others may seem easy. I want you to just do the best you can.

A. What is today's date (five points)?

	<u>Incorrect</u>	<u>Correct</u>
Year	0	1
Season	0	1
Date	0	1
Day	0	1
Month	0	1

If respondent gives an incomplete answer, prompt him/her for the missing data (e.g., "What season is it?"). If respondent has watch with date, ask "Without looking at your watch, tell me what day it is."

PR7AYR ____
 PR7ASEA ____
 PR7ADAT ____
 PR7ADAY ____
 PR7AMO ____

B. Where are you (five points, one for each correct answer and one bonus if all correct)?

	<u>Incorrect</u>	<u>Correct</u>
State	0	1
County	0	1
City	0	1
Street	0	1
(Bonus)	0	1

If respondent gives an incomplete answer, prompt him/her for the missing data (e.g., "What city are we in?").

PR7BSTA ____
 PR7BCNT ____
 PR7BPLA ____
 PR7BBRM ____
 PR7BBON ____

C. I am going to name three objects. I want you to repeat them after me and remember them. (Give one point for each correct answer, on the first trial only. Repeat objects until he/she learns all three. Count trials and record number.)

	<u>Incorrect</u>	<u>Correct</u>
Robin	0	1
Peach	0	1
House	0	1
(# of trials)	<input style="width: 50px; height: 20px;" type="text"/>	

Name the objects, allow 1 second to say each. Then ask the respondent to repeat all 3 after you have said them. Repeat them until CR learns all three.

PR7CROB ____
 PR7CPEA ____
 PR7CHOU ____
 PR7CNUM ____

D. Spell "world" backwards (one point for each correct letter)

	<u>Incorrect</u>	<u>Correct</u>
___ D	0	1
___ L	0	1
___ R	0	1
___ O	0	1
___ W	0	1

Record respondent's answer in the space provided. If he/she omits one letter, count as one wrong. If rest of letters are in correct order, count as correct.

PR7DD ____
 PR7DL ____
 PR7DR ____
 PR7DO ____
 PR7DW ____

II. Health

E. What were those three objects I asked you to remember? (Give one point for each correct answer.)

	<u>Incorrect</u>	<u>Correct</u>	
Robin	0	1	PR7FROB ____
Peach	0	1	PR7EPEA ____
House	0	1	PR7EHOU ____

F. What is this? (Show a pencil and a watch, two points)

	<u>Incorrect</u>	<u>Correct</u>	
Pencil	0	1	PR7FPEN ____
Watch	0	1	PR7FWAT ____

G. Repeat the following: "No ifs, ands, or buts." (one trial only, one point)

	<u>Incorrect</u>	<u>Correct</u>	
Statement	0	1	PR7G ____

H. "Take this paper in your right hand; fold it in half, and put it on the floor." (A three-stage command, three points. CR must follow command exactly.)

	<u>Incorrect</u>	<u>Correct</u>	
Takes paper in right hand	0	1	PR7H1 ____
Folds in half	0	1	PR7H2 ____
Puts on floor	0	1	PR7H3 ____

If needed, alter the initial instructions to have them put the paper on their lap.

I. Read and obey the following: (Show subject the written item on next page, "DO NOT READ THE SENTENCE", one point only if CR actually closes his/her eyes.)

	<u>Incorrect</u>	<u>Correct</u>	
Command	0	1	PR7I ____

J. Write a sentence, any sentence you want. (Give subject paper and pen. Score one point for a complete sentence that makes sense.)

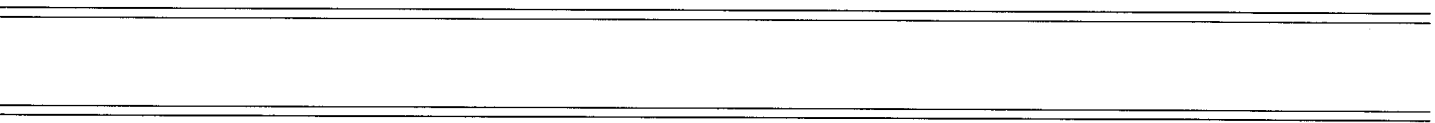
	<u>Incorrect</u>	<u>Correct</u>	
Sentence	0	1	PR7J ____

K. I want you to draw a picture that looks just like this, anywhere on the page. (Hand subject copy of intersecting pentagons and pencil, score one point if both objects are pentagons and intersect.)

	<u>Incorrect</u>	<u>Correct</u>	
Polygon	0	1	PR7K ____

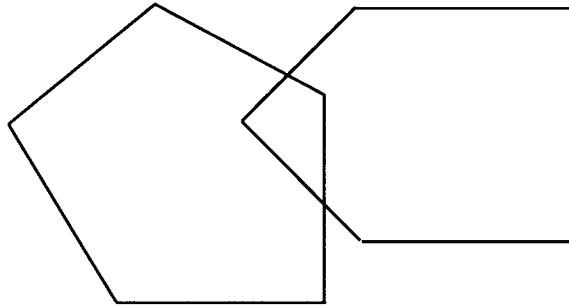
Total points scored:

PR7TOT ____



Close your eyes

1-week Interview



II. Health

8. Now, I would like to ask you some questions about your daily activities and the degree of difficulty you may have doing the following activities

Because of a health or physical problem,					
how much difficulty do you have: (<i>Read Option</i>) Would you say: (<i>Read responses</i>)					
	<u>None</u>	<u>Some</u>	<u>A lot</u>	<u>Unable</u>	
A. Bathing or showering?	0	1	2	3	PR8A _____
B. Dressing?	0	1	2	3	PR8B _____
C. Eating?	0	1	2	3	PR8C _____
D. Getting in and out of bed or chairs?	0	1	2	3	PR8D _____
E. Walking?	0	1	2	3	PR8E _____
F. Getting around outside?	0	1	2	3	PR8F _____
G. Using the toilet, including getting to the toilet?	0	1	2	3	PR8G _____
H. Preparing meals?	0	1	2	3	PR8H _____
I. Shopping for personal items (such as toilet items or medicines)?	0	1	2	3	PR8I _____
J. Managing money (such as keeping track of expenses or paying bills)?	0	1	2	3	PR8J _____
J1. Who manages the money in your (CR) household? _____					
K. Using the telephone?	0	1	2	3	PR8K _____
L. Doing light housework (like doing dishes, straightening up, or light cleaning)?	0	1	2	3	PR8L _____
M. Doing heavy housework (like scrubbing floors or washing windows)?	0	1	2	3	PR8M _____
N. Taking medications	0	1	2	3	PR8N _____
O. Driving or taking a bus or taxi to where you need to go?	0	1	2	3	PR8O _____

- If CR states that they do not do a particular activity, ask them how much difficulty they would have if they DID do the activity.
- If CR states that the CG or someone else does the activity for them, ask them how much difficulty they would have if they HAD to do the activity themselves.
- Another way to give “unable” option is to say “can’t do it any more” or “unable to do at current time”.

II. Health

9. Please tell me if you have any difficulty when you do the following activities, by yourself and not using aids.

	How much difficulty do you have: <i>(Read options)</i>	Would you say: <i>(Read responses)</i>				
		<u>None</u>	<u>Some</u>	<u>A lot</u>	<u>Unable</u>	
A.	Walking for a quarter of a mile (that is about 2–3 blocks)?	0	1	2	3	PR9A ____
B.	Walking up 10 steps without resting?	0	1	2	3	PR9B ____
C.	Standing or being on your feet for about 2 hours?	0	1	2	3	PR9C ____
D.	Sitting for about 2 hours?	0	1	2	3	PR9D ____
E.	Stooping, crouching, or kneeling?	0	1	2	3	PR9E ____
F.	Reaching up over your head?	0	1	2	3	PR9F ____
G.	Reaching out (as if to shake someone's hand)?	0	1	2	3	PR9G ____
H.	Using your fingers to grasp or handle?	0	1	2	3	PR9H ____
I.	Lifting or carrying something as heavy as 25 pounds (such as two full bags of groceries)?	0	1	2	3	PR9I ____
J.	Lifting or carrying something as heavy as 10 pounds?	0	1	2	3	PR9J ____

- If CR states that they do not do a particular activity, ask them how much difficulty they would have if they DID do the activity.
- If CR states that the CG or someone else does the activity for them, ask them how much difficulty they would have if they HAD to do the activity themselves.
- Another way to give “unable” option is to say “can’t do it any more” or “unable to do at current time”.

 II. Health

Notes by Interviewer: Section II.

For this section, did the respondent exhibit: (Circle)

	<u>No</u>	<u>Yes</u>	
A. Anxiety, distress or discomfort	0	1	PRN2A ____
B. Frustration with the questions	0	1	PRN2B ____
C. Fatigue	0	1	PRN2C ____

III. Satisfaction with Care

Question 10

Now I would like to know how satisfied you are with the assistance you have been receiving from (CG). We know that people, for a variety of reasons, may be satisfied with some aspects of the care they receive from family members or friends, and less satisfied with other aspects of this care. I would like you to read the following questions and circle the answer that best describes how you feel about the care you receive from (CG)? If you'd rather, I can read the questions to you. If CR wants you to read him/her the questions, then say: If you'd like, you can look at the questions which I am going to read to you with me.

(If respondent does not want/or is not able to read and answer questionnaire on own, then proceed by reading questions to him/her.)

(Following the interview, indicate whether the questionnaire was read or self-administered.)

10.	Were these items self-administered?
	No 0
	Yes 1

PR10 ____

PRSAT1 ____

PRSAT2 ____

PRSAT3 ____

PRSAT4 ____

PRSAT5 ____

PRSAT6 ____

PRSAT7 ____

PRSAT8 ____

PRSAT9 ____

PRSAT10 ____

PRSAT11 ____

PRSAT12 ____

PRSAT13 ____

Satisfaction With Care

	<u>Never</u>	<u>Some-</u> <u>times</u>	<u>Most of</u> <u>the Time</u>	<u>Nearly</u> <u>Always</u>	<u>Always</u>
1. How often is the care you receive from your family member skillful and competent? ... 0	0	1	2	3	4
2. How often are your needs taken care of thoroughly? 0	0	1	2	3	4
3. How often is care given to you patiently? .. 0	0	1	2	3	4
4. How often does your family member do special things for you that you count on and look forward to? 0	0	1	2	3	4
5. How often does your family member express interest in the care you need? 0	0	1	2	3	4
6. How often are your needs taken care of promptly? 0	0	1	2	3	4
7. How often is care given to you with devotion and affection? 0	0	1	2	3	4
8. How often is the care you receive from your family member appropriate for what you need? 0	0	1	2	3	4
9. How often are your needs taken care of dependably? 0	0	1	2	3	4
10. How often is enough time allowed for your care? 0	0	1	2	3	4
11. How often are consideration and concern shown for your comfort? 0	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	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					

IV. Mental Health

Now I would like to ask you some questions about some of your feelings over the past few weeks.

11. BRADBURN AFFECT/BALANCE SCALE

During the past few weeks, did you ever feel:	<u>No</u>	<u>Yes</u>	
A. Particularly excited or interested in something?	0	1	PR11A ____
B. So restless you couldn't sit long in a chair?	0	1	PR11B ____
C. Proud because someone complimented you on something you had done?	0	1	PR11C ____
D. Very lonely or remote from other people?	0	1	PR11D ____
E. Pleased about having accomplished something?	0	1	PR11E ____
F. Bored?	0	1	PR11F ____
G. On top of the world?	0	1	PR11G ____
H. Depressed or very unhappy?	0	1	PR11H ____
I. That things were going your way?	0	1	PR11I ____
J. Upset because someone criticized you?	0	1	PR11J ____

IV. Mental Health

Notes by Interviewer: Section IV. Mental Health
For this section, did the respondent exhibit: (Circle)

	<u>No</u>	<u>Yes</u>	
A. Anxiety, distress or discomfort	0	1	PRN4A _____
B. Frustration with the questions	0	1	PRN4B _____
C. Fatigue	0	1	PRN4C _____

V. Personal Characteristics

2. What is your birth date:

___/___/_____
MO DA YEAR

PRBIRTH ___/___/___

3. Care receiver's gender (*Record without asking, if obvious, or check records*)

- Male 1
- Female 2

PR13__

4. Are you Spanish, Hispanic, or Latino?

- No 0
- Yes 1

PR14__

5. What is your race? (*Check ALL that apply*)

- African American, Black, or Negro 1
- American Indian or Alaska Native 2
- Asian or Pacific Islander 3
- White 4
- Other 5
- If other, write in _____
- (*Don't know*) -8
- (*Prefer not to answer*) -9

PR15__

5. What is the highest grade in school that you completed?

- Completed 6th grade or less 1
- Junior high school (7th-9th grade) 2
- Partial high school (10th-11th grade) 3
- High school graduate or GED 4
- Partial college training 5
- Completed college 6
- Graduate professional training 7
- Other _____ 8

PR16__

What kind of work have you done most of your working life?

Which of the following four statements describes your ability to get along on your income?

- I can't make ends meet 1
- I have just enough, no more 2
- I have enough, with a little extra sometimes 3
- I always have money left over 4
- (*Don't know*) 5

PR18__

V. Personal Characteristics

Here is a list of income categories. (Hand card to respondent with yearly income categories on one side and monthly on the other side.) Which income category comes closest to the total amount of your household income before taxes? The total income should include the income of each person in the household including social security, pensions, rent from property, dividends, interest, earned income, financial help from relatives and any other income. (Clarify that this includes any income of the caregiver or others with whom the Care Receiver lives.)

Annual Household Income

\$1–\$2,499	1
\$2,500–\$4,999	2
\$5,000–\$9,999	3
\$10,000–\$14,999	4
\$15,000–\$19,999	5
\$20,000–\$24,999	6
\$25,000–\$29,999	7
\$30,000–\$34,999	8
\$35,000–\$39,999	9
\$40,000–\$44,999	10
\$45,000–\$49,999	11
\$50,000–\$74,999	12
\$75,000–\$99,999	13
\$100,000 and more	14
(Don't know)	-8
(Blank/Refused)	-9

PR19____

(If Care Receiver does not know annual household income and the Caregiver is a spouse, circle (Don't know). If not a spousal relationship, then ask the Care Receiver if s/he thinks the Caregiver would know the income category and if it would be OK to ask the Caregiver. If so, record accordingly in PR19.)

Was the income information provided by the CR, CG, or other person?

Care Receiver	1
Caregiver	2
Other person	3

(If care receiver states that his/her yearly income is variable, ask: "What was it last year?")

 VI. Mutuality

Now we would like you to let us know how you and (CG) feel about each other. Here is another set of questions that I'd like you to read and answer on your own. (*Hand mutuality questionnaire to respondent*). Please read through the questions and circle the number **THAT** best describes you and (CG). If you'd rather, I can read the questions to you.

20. Were these items self-administered?

No 0

Yes 1

PR20_____

PRMUT1_____

PRMUT9_____

PRMUT2_____

PRMUT10_____

PRMUT3_____

PRMUT11_____

PRMUT4_____

PRMUT12_____

PRMUT5_____

PRMUT13_____

PRMUT6_____

PRMUT14_____

PRMUT7_____

PRMUT15_____

PRMUT8_____

YOU AND YOUR FAMILY MEMBER

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. To what extent do the two of you see eye to eye (agree on things)?	0	1	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him or her?	0	1	2	3	4
8. How much love do you feel for him or her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

VI. Mutuality

NOTES BY INTERVIEWER: Section VI. Mutuality

For this section, did the respondent exhibit: (Circle)

	<u>No</u>	<u>Yes</u>	
A. Anxiety, distress or discomfort	0	1	PRN6A _____
B. Frustration with the questions	0	1	PRN6B _____
C. Fatigue	0	1	PRN6C _____

VII. YOUR VIEWS

(The following questions are optional. If the elderly respondent seems able to continue without too much fatigue or distress, please ask the remainder of the questions. If the elderly respondent is tired, skip to Q. 23.)

1. **What is the best part of receiving care [in your home, in the care facility, etc.]?**

2. **What is most enjoyable in your life right now?**

3. **This concludes the interview. Thank you very much! We really appreciate your willingness to share your thoughts and opinions with us!**

Did you have any other questions you'd like to ask or any comments you'd like to make?

Again, thank you very much for answering my questions.

Time interview ended _____ *(Also record on front sheet.)*

Appendix B

Family Care Inventory – The Caregiver’s View – 1-Week Interview



Family Care Inventory

The Caregiver's View

1-WEEK INTERVIEW

ID#

--	--	--	--	--	--

Date of Interview: _____

Time interview started: _____

Time interview ended: _____

Name of Interviewer: _____

DATE AND TIME YOU BEGIN QUESTIONNAIRE _____ DATE _____ TIME _____

YOU AND YOUR FAMILY MEMBER

Family member refers to **your relative or friend who has health or memory problems**. Please tell us about you and your family member. For all questions, fill in the blank or **CIRCLE** the answer that best describes you and your family member.

1. How are you related to the family member you are helping?
Are you his or her _____ ?
Wife 1
Husband 2
Daughter 3
Son 4
Daughter-in-law 5
Son-in-law 6
Other relative 7
Neighbor or friend 8
Other: _____
2. About how many years have you and your family member known each other?
_____ years _____ months
3. How many years, if any, have you lived with him or her while you were an adult (age 18 or over)?
_____ years _____ months
4. At this time, do you and your family member live in the same household?
Yes 1
No 0
↓
4a. If **NO**, how far away do you live from your family member?
_____ miles

Because of health or memory problems, does your family member **NEED** help with any of the following activities? (**CIRCLE** the number next to **ALL** that apply.)

5. Bathing or showering?
6. Dressing?
7. Eating?
8. Getting in and out of bed or chairs?
9. Walking?
10. Getting around outside?
11. Using the toilet, including getting to the toilet?
12. Preparing meals?
13. Shopping for personal items (such as toilet items or medicines)?
14. Managing money (such as keeping track of expenses or paying bills)?
15. Using the telephone?
16. Doing light housework (like doing dishes, straightening up, or light cleaning)?
17. Doing heavy housework (like scrubbing floors or washing windows)?
18. Taking medication?
19. Driving or taking a bus or taxi to where he or she needs to go?
20. Others: _____
21. None of the above

YOUR FAMILY MEMBER

Please tell us about your family member. (Fill in the blank or **CIRCLE** the answer that describes your family member.)

1. How old is your family member?

Age: _____ years

Date of birth ___/___/19___
mm dd yy

2. Is your family member female or male?

Female 1

Male 2

3. What is the highest grade in school that your family member completed?

Completed 6th grade or less 1

Junior high school(7th-9th grade) 2

Partial high school (10th-11th grade) 3

High school graduate or GED 4

Partial college training 5

Completed college 6

Graduate professional training 7

Other _____ 8

4. What kind of work has he or she done most of his or her working life?

5. What is your family member's current marital status ?

Married 1

Widowed 2

Divorced 3

Separated 4

Never married 5

Partnered 6

6. With whom does your family member usually live?
(Circle **ALL** that apply.)

No one, lives alone 0

With spouse or partner 1

With child(ren) 2

With other relative(s) 3

With friend(s) that are "just like a family" 4

With other friend(s), housemate(s) 5

In a nursing home or care facility 6

Paid live-in helper 7

7. Altogether, counting your family member, how many people live in your family member's household?

_____ people

8. Who manages the money in your family member's household? (For example, managing health care expenses)

9. What type of residence does your family member live in?

Apartment 1

House 2

Trailer 3

Assisted Living 4

Other _____ . 5

YOUR FAMILY MEMBER

(Fill in the blank or **CIRCLE** the answer that describes your family member.)

Please answer **BOTH** questions 10 and 11.

10. Is your family member Spanish, Hispanic, or Latino?

No 0

Yes 1

11. What is your family member's race?

(Circle **ALL** that apply to him/her)

African American, Black, or Negro .. 1

American Indian or Alaska Native ... 2

Asian or Pacific Islander 3

White 4

Other 5

If other, write in _____

12. What does your family member consider his or her racial or ethnic or cultural background or heritage? This may be the countries or regions his or her ancestors were from.

13. How much does this background affect his or her everyday life?

Not at all 0

A little 1

Some 2

Quite a bit 3

A great deal 4

YOUR FAMILY MEMBER'S CURRENT SITUATION

We'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing some things. (**CIRCLE** your answer.)

How difficult is it for your family member to:	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
1. Remember recent events?	0	1	2	3	4
2. Know what day of the week it is?	0	1	2	3	4
3. Remember his or her home address?	0	1	2	3	4
4. Remember words?	0	1	2	3	4
5. Understand simple instructions?	0	1	2	3	4
6. Find his or her way around the house?	0	1	2	3	4
7. Speak sentences?	0	1	2	3	4
8. Recognize people that he or she knows?	0	1	2	3	4

CAREGIVING ACTIVITIES

This set of questions is very long. However, your answers are very important to us because we want to have a really good idea about what you are now doing to take care of your family member. Sometimes helping someone is no problem, but for a number of people, giving this help is very difficult to do, both physically and emotionally.

Below is a list of types of help that may be given to a person who has health or memory problems. We would like for you to tell us whether you do each type of help and, if so, how it goes for you.

For each question, Circle **NO** if you do NOT do that type of help or if your family member doesn't have that problem. Circle **YES** if you do that type of help.

If you circled **YES**, indicate how hard it is for **you** to do that type of help.

Please circle **Very Hard** (4), **Pretty Hard** (3), **Somewhat Hard** (2), **Not Too Hard** (1), or **Easy** (0).

Do you do this type of help for your family member?	NO	YES	If YES, how hard is it for you to do this.				
			Very Hard	Pretty Hard	Some-what Hard	Not Too Hard	Easy
1. Do you do shopping and errands for your family member?	NO	YES	4	3	2	1	0
2. Do you have to assist him or her with walking around the house? For example, do you have to give your family member your arm or get him or her a walker?	NO	YES	4	3	2	1	0
3. Do you have to assist him or her with getting around outside the house?	NO	YES	4	3	2	1	0
4. Do you have to keep one eye on your family member to make sure he or she is safe?	NO	YES	4	3	2	1	0
5. Do you assist your family member with his or her medications or shots?	NO	YES	4	3	2	1	0
6. Do you have to help him or her with eating?	NO	YES	4	3	2	1	0
7. Do you protect him or her from falls?	NO	YES	4	3	2	1	0
8. Do you help make major decisions about his or her health care -- such as surgery or a change in treatment?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

Do you do this type of help for your family member?	NO	YES	If YES, how hard is it for you to do this.				
			Very Hard	Pretty Hard	Some-what Hard	Not Too Hard	Easy
9. Do you try to keep your family member active and involved in activities that he or she enjoys?	NO	YES	4	3	2	1	0
10. Do you keep the doctor informed about changes in his or her health?	NO	YES	4	3	2	1	0
11. Do you keep nurses and other health care workers informed about changes in his or her health?	NO	YES	4	3	2	1	0
12. Do you lift or transfer him or her from one place to another? For example, do you lift your family member out of a chair, or transfer him or her from a bed to a chair? ...	NO	YES	4	3	2	1	0
13. Do you have to go with your family member as he or she does shopping or errands?	NO	YES	4	3	2	1	0
14. Do you have to make sure he or she gets the right amount of liquids? (Circle NO if he or she can do that on his or her own.) ...	NO	YES	4	3	2	1	0
15. Do you assist him or her with bathing, washing, or taking a shower?	NO	YES	4	3	2	1	0
16. Do you do any of the driving for your family member?	NO	YES	4	3	2	1	0
17. Do you have to handle his or her paranoia or suspiciousness? (Circle NO if he or she does not have that problem.)	NO	YES	4	3	2	1	0
18. Do you take part in leisure activities with him or her, such as watching TV, playing games, or listening to music?	NO	YES	4	3	2	1	0
19. Do you have to handle his or her crying spells? (Circle NO if he or she does not have that problem.)	NO	YES	4	3	2	1	0
20. Do you have to make sure he or she eats the right amount or types of food? (Circle NO if he or she can do that on his or her own.) ...	NO	YES	4	3	2	1	0
21. Do you have to clean up if he or she has a bladder accident?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for your family member?

NO

YES

Very Hard

Pretty Hard

Some-what Hard

Not Too Hard

Easy

22. Do you do writing for your family member? (Circle NO if your family member can do that on his or her own.)	NO	YES	4	3	2	1	0
23. Do you have to handle his or her yelling? (Circle NO if he or she does not have this problem.)	NO	YES	4	3	2	1	0
24. Do you have discussions with your family member about the future, the meaning and purpose of life, or how he or she has lived his or her life?	NO	YES	4	3	2	1	0
25. Do you cook or help prepare meals for him or her?	NO	YES	4	3	2	1	0
26. Do you apply lotions to his or her skin?	NO	YES	4	3	2	1	0
27. Do you have to listen to, and answer, questions that he or she asks over and over again?	NO	YES	4	3	2	1	0
28. Do you have to help him or her on stairs? ..	NO	YES	4	3	2	1	0
29. Do you take care of your family member's dentures or brush his or her teeth?	NO	YES	4	3	2	1	0
30. Do you handle or manage medical equipment or machines, such as oxygen, a feeding tube, IV equipment, or catheters?	NO	YES	4	3	2	1	0
31. Do you help him or her get legal matters taken care of?	NO	YES	4	3	2	1	0
32. Do you have to deal with his or her problems with fatigue?	NO	YES	4	3	2	1	0
33. Do you have to watch your family member in case he or she wanders off?	NO	YES	4	3	2	1	0
34. Do you assist him or her with dressing or undressing?	NO	YES	4	3	2	1	0
35. Do you keep other family members informed about his or her health?	NO	YES	4	3	2	1	0
36. Do you sit and spend time with him or her?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for your family member?

NO

YES

Very Hard

Pretty Hard

Some-what Hard

Not Too Hard

Easy

37. Do you have to get up at night to help your family member?	NO	YES	4	3	2	1	0
38. Do you have to help him or her with emotional ups and downs?	NO	YES	4	3	2	1	0
39. Do you assist him or her with banking or paying bills?	NO	YES	4	3	2	1	0
40. Do you have to deal with his or her unsafe driving? (Circle NO if he or she does not have that problem.)	NO	YES	4	3	2	1	0
41. Do you have to handle situations when your family member doesn't remember who or where he or she is?	NO	YES	4	3	2	1	0
42. Do you have to check on or treat skin problems that he or she has?	NO	YES	4	3	2	1	0
43. Do you check in on your family member to make sure he or she is OK?	NO	YES	4	3	2	1	0
44. Do you have to handle his or her hallucinations? (Circle NO if he or she does not have this problem.)	NO	YES	4	3	2	1	0
45. Do you take him or her to see the doctor? ..	NO	YES	4	3	2	1	0
46. Do you have to protect your family member from poisoning him or herself (e.g., taking too much medication, household poisons)?	NO	YES	4	3	2	1	0
47. Do you take him or her to other places such as to friends' homes, to church, or out to eat?	NO	YES	4	3	2	1	0
48. Do you have to clean up when he or she has a bowel accident?	NO	YES	4	3	2	1	0
49. Do you have to help him or her with bowel problems like constipation or diarrhea?	NO	YES	4	3	2	1	0
50. Do you have to manage his or her nausea?	NO	YES	4	3	2	1	0
51. Do you fix things and do odd jobs to maintain his or her house?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

Do you do this type of help
for your family member?

NO

YES

Very
Hard

Pretty
Hard

Some-
what
Hard

Not
Too
Hard

Easy

If YES, how hard is it for you
to do this.



Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some- what Hard	Not Too Hard	Easy
52. Do you have to help your family member in getting to the bathroom?	NO	YES	4	3	2	1	0
53. Do you change his or her bed linens?	NO	YES	4	3	2	1	0
54. Do you have to watch out for and treat his or her infections?	NO	YES	4	3	2	1	0
55. Do you help him or her use the toilet or bedpan?	NO	YES	4	3	2	1	0
56. Do you have to deal with him or her because of problems related to keys and locks for doors?	NO	YES	4	3	2	1	0
57. Do you assist him or her in filling out forms such as taxes, Medicare, Social Security, or insurance?	NO	YES	4	3	2	1	0
58. Do you have to make sure he or she gets enough rest?	NO	YES	4	3	2	1	0
59. Do you do things for your family member like hold hands or rub his or her back?	NO	YES	4	3	2	1	0
60. Do you have to help him or her with breathing problems?	NO	YES	4	3	2	1	0
61. Do you help him or her make major financial decisions?	NO	YES	4	3	2	1	0
62. Do you have to help him or her with tasks that require fine motor control such as to cut, to button, or to open jars?	NO	YES	4	3	2	1	0
63. Do you have to handle his or her physical pain?	NO	YES	4	3	2	1	0
64. Do you have to handle his or her hitting or pushing people? (Circle NO if he or she does not have that problem.)	NO	YES	4	3	2	1	0
65. Do you do light housekeeping for him or her?	NO	YES	4	3	2	1	0
66. Do you have to watch out for problems that he or she has with swelling?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for your family member?

NO

YES

Very Hard

Pretty Hard

Some-what Hard

Not Too Hard

Easy

67. Do you assist him or her with hair care or shampooing?	NO	YES	4	3	2	1	0
68. Do you help your family member to get going in an activity?	NO	YES	4	3	2	1	0
69. Do you help him or her use the phone?	NO	YES	4	3	2	1	0
70. Do you have to handle your family member's hiding things and forgetting where he or she put them?	NO	YES	4	3	2	1	0
71. Do you have to deal with his or her agitation or restlessness? (Circle NO if he or she does not have that problem.) ...	NO	YES	4	3	2	1	0
72. Do you have to handle his or her showing sexual behavior or interests at the wrong time or place?	NO	YES	4	3	2	1	0
73. Do you read to him or her?	NO	YES	4	3	2	1	0
74. Do you have to monitor the number of people who come to see him or her?	NO	YES	4	3	2	1	0
75. Do you have to handle emergencies related to his or her illness?	NO	YES	4	3	2	1	0
76. Do you help trim and take care of your family member's fingernails or toenails?	NO	YES	4	3	2	1	0
77. Do you help to meet his or her spiritual needs? (For example, do you arrange for a religious person to come, or arrange to watch religious programs on TV, or read religious books to him or her?)	NO	YES	4	3	2	1	0
78. Do you have to handle his or her swearing or foul language? (Circle NO if he or she does not have that problem.)	NO	YES	4	3	2	1	0
79. Do you have to help your family member because of problems with his or her eyesight?	NO	YES	4	3	2	1	0
80. Do you have to help your family member because of his or her slowness in moving?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do that.

Do you do this type of help for your family member?

NO

YES

Very Hard

Pretty Hard

Some-what Hard

Not Too Hard

Easy

Sometimes people who take care of a family member get extra help from a health or social service agency.

81. Have you had to help your family member by getting information from a doctor or other professional?	NO	YES	4	3	2	1	0
82. Have you contacted a health or social service agency to find out if they had a service that might assist in caring for him or her?	NO	YES	4	3	2	1	0
83. Have you ever arranged for someone from a health or social service agency to assist him or her?	NO	YES	4	3	2	1	0
84. Have you had to make sure that people from a health or social service agency continued to provide the needed service? ..	NO	YES	4	3	2	1	0
85. Have you had to check and make sure people from a health or social service agency gave help in a skillful way?	NO	YES	4	3	2	1	0
86. Have you tried to get help for him or her but were not able to find someone?	NO	YES	4	3	2	1	0
87. Have you made doctor appointments for your family member?	NO	YES	4	3	2	1	0
88. Are there any other things you do for him or her because he or she has health or memory problems? (Please describe below)							
a)_____	NO	YES	4	3	2	1	0
b)_____	NO	YES	4	3	2	1	0
c)_____	NO	YES	4	3	2	1	0

EXTENT OF HELP

1. Altogether, how long has your family member needed extra help from you **or** someone else because of health or memory problems?
 _____ **years** _____ **months** _____ **days**

2. How long have you **personally** been involved in providing the needed extra help to your family member because of his or her health or memory problems?
 _____ **years** _____ **months** _____ **days**

3. How many days in the past week did you spend time helping him or her? _____ **days**

4. On the days you help your family member, about how many hours per day (including time you get up at night) do you spend in helping him or her? _____ **hours**

MEDICAL DIAGNOSES

What main medical diagnoses has your family member received? (Please **CIRCLE** all that apply.)

Diagnosis	NO	YES	If YES, in about what year did this diagnosis occur?
1. Heart Disease (e.g., congestive heart failure)	0	1	In _____
2. Cancer	0	1	In _____
3. Stroke	0	1	In _____
4. Alzheimer's Disease or other dementia	0	1	In _____
5. Parkinson's Disease or other movement disorder	0	1	In _____
6. Arthritis	0	1	In _____
7. Diabetes	0	1	In _____
8. Other: _____	0	1	In _____

HELP FROM OTHERS IN CARING FOR YOUR FAMILY MEMBER

On pages 4 through 10, we asked you questions about the kinds of things you do to help your family member. Now we would like to know if other people have helped out in these activities.

HELP FROM RELATIVES

1. How much help have relatives given to your family member?
None at all 0 (**Go to Q. 4**)
A little 1
Some 2
Quite a bit 3
A great deal 4
2. About how many relatives have helped out?
_____ (*Number of relatives*)
3. How happy are you with the help given by relatives?
Very happy 4
Pretty happy 3
Somewhat happy 2
Not too happy 1
Very unhappy 0

HELP FROM PEOPLE WHOSE JOB IT IS

7. How much help have paid people (such as health professionals or household help) given to him or her?
None at all 0 (**Go to Q. 10**)
A little 1
Some 2
Quite a bit 3
A great deal 4
8. About how many paid people have helped out?
_____ (*Number of people*)
9. How happy are you with the help given by paid people?
Very happy 4
Pretty happy 3
Somewhat happy 2
Not too happy 1
Very unhappy 0

HELP FROM FRIENDS AND NEIGHBORS

4. How much help have friends and neighbors given to him or her?
None at all 0 (**Go to Q. 7**)
A little 1
Some 2
Quite a bit 3
A great deal 4
5. About how many friends and neighbors have helped out? _____ (*Number of friends and neighbors*)
6. How happy are you with the help given by friends and neighbors?
Very happy 4
Pretty happy 3
Somewhat happy 2
Not too happy 1
Very unhappy 0

HELP NOT RECEIVED

10. Is there a person you thought would help you more in caring for your family member, but who has **not** done so?
No 0
Yes 1
↓
- 10a. If **YES**, how upsetting has it been for you that this person has **not** helped as you expected?
Not at all upsetting 0
A little upsetting 1
Somewhat upsetting 2
Quite upsetting 3
Extremely upsetting 4

AREAS OF CONCERN

We would like to know how much you worry about each of the items listed below.

How much do you worry about . . .	Not at all	A little	Some	Quite a bit	A great deal
1. your family member's health condition?	0	1	2	3	4
2. obtaining enough help for the things you can't do for him or her?	0	1	2	3	4
3. his or her mood or state of mind?	0	1	2	3	4
4. financial problems related to his or her care? ..	0	1	2	3	4
5. your ability to continue taking care of him or her because of your own health?	0	1	2	3	4
6. safety when he or she uses the stove?	0	1	2	3	4
7. how you can go on if he or she gets worse?	0	1	2	3	4
8. having to leave him or her alone when you go out? (If you never leave him or her alone, if you had to go out and leave him or her alone, how much would you worry?)	0	1	2	3	4
9. his or her safety because of traffic problems?	0	1	2	3	4
10. your own future?	0	1	2	3	4
11. who will take care of him or her if something happens to you?	0	1	2	3	4
12. safety because guns or other weapons are present in the home?	0	1	2	3	4
13. having to make the decision about whether to put him or her into a nursing home?	0	1	2	3	4
14. whether the care and advice you receive from doctors and nurses are adequate?	0	1	2	3	4
15. safety when he or she uses lawn, shop, or other equipment?	0	1	2	3	4
16. the negative effects of taking care of him or her on the rest of your family?	0	1	2	3	4
17. the progression of his or her disease?	0	1	2	3	4
18. Are there any other things you worry about?					
_____	0	1	2	3	4
_____	0	1	2	3	4

HEARING, SPEECH, AND MEMORY PROBLEMS

The next questions focus on communication between you and your family member. People sometimes have hearing, speech, or memory problems that can interfere with how well they can understand or talk with others.

1. To what extent does your family member have difficulty hearing?

- Not at all 0 → (Go on to Q. 2)
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4
- } **Answer Q. 1a**

1a. To what extent does his or her hearing problem make it hard for you to provide care to him or her?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

2. To what extent does he or she have difficulty with speech?

- Not at all 0 → (Go on to Q. 3)
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4
- } **Answer Q. 2a**

2a. To what extent does his or her speech problem make it hard for you to provide care to him or her?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

3. To what extent does he or she have difficulty with remembering or understanding what is said?

- Not at all 0 → (Go on to Q. 4)
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4
- } **Answer Q. 3a**

3a. To what extent does his or her problem with remembering or understanding what is said make it hard for you to provide care to him or her?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

4. To what extent do **you** have difficulty hearing?

- Not at all 0 → (Go on to next page)
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4
- } **Answer Q. 4a**

4a. To what extent does **your** hearing problem make it hard for you to provide care to your family member?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

HEARING, SPEECH, AND MEMORY PROBLEMS (continued)

To what extent do any of these hearing, speech or memory problems...	Not at all	A little	Some	Quite a bit	A great deal
5. create feelings of frustration in you?	0	1	2	3	4
6. make it hard for you to talk with your family member?	0	1	2	3	4
7. create feelings of impatience in you?	0	1	2	3	4

CAREGIVING PROBLEMS

Sometimes people find that the following problems make it harder to give care to their family member.

Have any of the following been a problem for you?	Not a problem	A small problem	A moderate problem	A big problem	A very big problem
8. Not having enough money?	0	1	2	3	4
9. Your being too tired emotionally?	0	1	2	3	4
10. Your being too tired physically?	0	1	2	3	4
11. Not having enough time?	0	1	2	3	4
12. Not having enough help from other people? ..	0	1	2	3	4
13. Not having enough space in the home?	0	1	2	3	4
14. Not having a separate room for him or her? ...	0	1	2	3	4
15. Decreased time you have for sleep?	0	1	2	3	4

16. Who would you turn to if you needed extra help in caregiving? (Give initials and relationship to you.)

Initials

Relationship to you (spouse, sister, friend, etc.)

YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member? ...	0	1	2	3	4
9. Is there anything specific you would like to be better prepared for? _____					

YOUR EVERYDAY LIFE

Now we are interested in your everyday life and how predictable it is.

1. How predictable are your family member's needs?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

2. How predictable is your caregiving routine, or the activities that you do for your family member?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

3. How often is your routine unexpectedly interrupted because of your family member's problems?

- Never 0
- Rarely 1
- Sometimes 2
- Usually 3
- Always 4

4. How often does your day go pretty much as you planned it or as you expected it to go?

- Never 0
- Rarely 1
- Sometimes 2
- Usually 3
- Always 4

5. How much do you currently feel in control of your life?

- Not at all in control 0
- In control a little 1
- Somewhat in control 2
- Pretty much in control 3
- Very much in control 4

6. How predictable is your current life situation?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

7. When you think about your overall family care situation, would you say...

- You would like your family situation to be more predictable 1
- The predictability is about right 2
- Things are too predictable and routine, and you would like some more change in your everyday life 3

8. Is there anything specific you would like to be more predictable? _____

REWARDS OF CAREGIVING

We know that some people find aspects of their caregiving situation rewarding and others do not. These questions are about things that you may or may not find rewarding because of caring for your family member. There are no right or wrong answers to these questions.

To what extent...	Not at all	A little	Some	Quite a bit	A great deal
1. does caring for him or her help you understand your own aging?0		1	2	3	4
2. does caring for him or her help you feel like you are doing something important?0		1	2	3	4
3. does caring for him or her help you understand the situation of older people in general?0		1	2	3	4
4. is caring for your family member rewarding for you because it keeps him or her out of a nursing home?0		1	2	3	4
5. does caring for him or her help you feel good about yourself?0		1	2	3	4
6. is it rewarding because you feel you make life a little easier for him or her?0		1	2	3	4
7. does caring for him or her add meaning to your life?0		1	2	3	4
8. have you learned a lot about health and illness because of caregiving?0		1	2	3	4
9. does caring for him or her give you a sense of accomplishment?0		1	2	3	4
10. is just "being there" for him or her rewarding to you?0		1	2	3	4
11. have you personally grown as a result of being a caregiver?0		1	2	3	4
12. do you feel glad that you are the one who is providing care to him or her?0		1	2	3	4
13. do you understand more about the aging process because of caregiving?0		1	2	3	4
14. is caring for your family member rewarding because it makes him or her happy?0		1	2	3	4
15. is it rewarding to know that you are helpful to him or her?0		1	2	3	4

YOUR ROLES

These questions focus on the different roles you may have and the extent to which your caregiving interferes with these other roles. If the role listed does **not** apply to you, check the box at the right.

To what extent does caring for your family member interfere with your ability to be . . .	Not at all	A little	Some	Quite a bit	A great deal	<input checked="" type="checkbox"/> Check if not applic.
1. the kind of spouse or partner you think you should be?	0	1	2	3	4	<input type="checkbox"/>
2. the kind of parent you think you should be?	0	1	2	3	4	<input type="checkbox"/>
3. the kind of daughter/son you think you should be?	0	1	2	3	4	<input type="checkbox"/>
4. the kind of sister/brother you think you should be?	0	1	2	3	4	<input type="checkbox"/>
5. the kind of grandparent you think you should be?	0	1	2	3	4	<input type="checkbox"/>
6. the kind of relative you think you should be to people other than those listed in Q1–Q5? ...	0	1	2	3	4	<input type="checkbox"/>
7. the kind of friend you think you should be to other people?	0	1	2	3	4	<input type="checkbox"/>
8. the kind of worker you think you should be outside the house?	0	1	2	3	4	<input type="checkbox"/>
9. the kind of worker you think you should be around or in the house?	0	1	2	3	4	<input type="checkbox"/>
10. the kind of student you think you should be? ..	0	1	2	3	4	<input type="checkbox"/>
11. active in your religious group in the way you think you should be?	0	1	2	3	4	<input type="checkbox"/>
12. active in the community in the way you think you should be?	0	1	2	3	4	<input type="checkbox"/>
13. good to yourself?	0	1	2	3	4	
14. To what extent do your other responsibilities interfere with your ability to care for your family member in the way you would like to? ..	0	1	2	3	4	

YOU AND YOUR FAMILY MEMBER

Now we would like you to let us know how you and your family member feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
1. To what extent do the two of you see eye to eye (agree on things)?	0	1	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him or her?	0	1	2	3	4
8. How much love do you feel for him or her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

YOUR REACTIONS TO HELPING YOUR FAMILY MEMBER

1. Is there some kind of help you think you **should** give to your family member that you are not able to give him or her?

No 0 (Go to Q. 2)
Yes 1
↓ Unsure -8 (Go to Q. 2)

1a. If **YES**, what is it? _____

- 1b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

2. Are there things you do for your family member that, after you've done them, you think "It's not really my place to do that"?

No 0 (Go to Q. 3)
Yes 1
↓ Unsure -8 (Go to Q. 3)

2a. If **YES**, what are they? _____

- 2b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

3. Are there things that your family member tries to do for him or herself that you think he or she should let you help with?

No 0 (Go to Q. 4)
Yes 1
↓ Unsure -8 (Go to Q. 4)

3a. If **YES**, what are they? _____

- 3b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

4. Are there things that you do for your family member that you think he or she should try to do for himself or herself?

No 0 (Go to Q. 5)
Yes 1
↓ Unsure -8 (Go to Q. 5)

4a. If **YES**, what are they? _____

- 4b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

YOUR REACTIONS TO HELPING YOUR FAMILY MEMBER

5. How often do you feel your family member expects too much from you?

- Never 0
- Rarely 1
- Sometimes 2
- Much of the time 3
- Always 4

6. Is there some help that your family member needs that is difficult for you to provide because it is embarrassing for either you or him or her?

- No 0 (**Go to Q. 7**)
- Yes 1



6a. If **YES**, how much stress does this embarrassment cause you?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

7. How much family conflict has occurred because of your family member's health situation and need for help?

- No conflict 0
- A little conflict 1
- Some conflict 2
- Quite a bit of conflict 3
- A great deal of conflict ... 4

8. At this time, do you provide care for one or more ill persons other than your family member?

No 0 (**Go on to next page**)

Yes 1



8a. If **YES**, could you please describe this situation and the kind of help you give?

YOUR REACTIONS TO HELPING YOUR FAMILY MEMBER

Now we would like to know whether assisting and having other contact with your family member has negatively affected your life.

Has assisting your family member. . .	Not at all	A little	Moderately	A lot	A great deal
1. decreased the time you have to yourself?	0	1	2	3	4
2. increased the stress in your relationship with him/her?	0	1	2	3	4
3. restricted personal privacy?	0	1	2	3	4
4. increased attempts by him/her to manipulate you?	0	1	2	3	4
5. decreased the time you have to spend in recreational activities?	0	1	2	3	4
6. increased the number of unreasonable requests made of you?	0	1	2	3	4
7. added tension to your life?	0	1	2	3	4
8. restricted the vacation activities and trips you take?	0	1	2	3	4
9. increased the nervousness and depression you have concerning your relationship with him/her	0	1	2	3	4
10. added to your feelings that you are being taken advantage of?	0	1	2	3	4
11. reduced the time you have to do your own work and daily chores?	0	1	2	3	4
12. increased demands made by him/her that are over and above what he/she needs?	0	1	2	3	4
13. increased your anxiety about things?	0	1	2	3	4
14. decreased the time you have for friends and other relatives?	0	1	2	3	4
15. decreased the money available to meet the rest of your expenses?	0	1	2	3	4

YOUR OVERALL EXPERIENCE

1. From our discussions with many caregivers, we know that for some people, caregiving is very confining, while for others, it is not. How confined do you feel because of all the caregiving things you do for your family member?

Not at all confined 0
 Confined a little 1
 Somewhat confined 2
 Confined a lot 3
 Extremely confined 4

2. How often would you say that taking care of your family member is very difficult?

Never 0
 Rarely 1
 Sometimes 2
 Much of the time 3
 Always 4

3. How much stress do you feel because of **all** your obligations, including taking care of your family member?

No stress 0
 Very little stress 1
 Some stress 2
 A lot of stress 3
 Overwhelming stress 4

4. How much of the time do you feel you are patient in caring for your family member?

Never 0
 Rarely 1
 Sometimes 2
 Most of the time 3
 Always 4

5. Overall, would you say that the positive aspects of caring for your family member outweigh the negative, that the negative aspects outweigh the positive, or that the positive and negative aspects are about equal?

Positive outweighs the negative
a lot 4
 Positive outweighs the negative
somewhat 3
 Positive and negative are about
equal 2
 Negative outweighs the positive
somewhat 1
 Negative outweighs the positive
a lot 0

6. The needs of people who are receiving care change with time as do yours. Would you say that, as time goes on, giving care to your family member has:

Become much easier for you 4
 Become somewhat easier for you 3
 Stayed about the same for you 2
 Become somewhat more difficult for you . 1
 Become much more difficult for you 0

7. What if your family member's care needs increase? How confident are you that you would be able to provide more care than you are doing now?

Not at all confident 0
 Not too confident 1
 Somewhat confident 2
 Pretty confident 3
 Very confident 4

YOUR HEALTH

We have been asking you questions about caring for your family member. Now we would like to ask some questions about **your** own health.

1. How many times during the past week did you make sure you got some exercise, for example, taking a walk?
 - None 0
 - One time 1
 - Two times 2
 - Three times 3
 - Four or more times 4
2. How often do you eat a balanced diet?
 - Every day 4
 - Most days 3
 - Some days 2
 - Rarely 1
 - Never 0
3. How often do you take pills to help you sleep?
 - Never 0
 - Once a week or less 1
 - Several days each week 2
 - Every day 3
 - More than once a day 4
4. How often do you take pills for your nerves (*not including for sleep*)?
 - Never 0
 - Once a week or less 1
 - Several days each week 2
 - Every day 3
 - More than once a day 4
5. During **the past 12 months**, how many separate times were **you** admitted as a patient in a hospital?
 - None 0
 - Once 1
 - 2-3 times 2
 - 4-6 times 3
 - Over 6 times 4

6. During **the past 6 months**, how many times did **you** use an emergency room or urgency care center at a hospital?
 - None 0
 - Once 1
 - 2-3 times 2
 - 4-6 times 3
 - Over 6 times 4
7. During **the past 6 months**, how many separate times did **you** visit a medical doctor or clinic (not counting hospital, emergency room, or urgency care)?
 - None 0
 - Once 1
 - 2-3 times 2
 - 4-6 times 3
 - Over 6 times 4
8. During **the past 6 months**, how many times have **you** felt like going for medical care or follow-up, but did not because of your caregiving and other responsibilities?
 - None 0
 - Once 1
 - 2-3 times 2
 - 4-6 times 3
 - Over 6 times 4
9. Do you usually use any special equipment to help **you** in getting around inside or outside the house?
 - No 0 **(Go to next page)**
 - Yes 1



9a. If YES, what equipment do you use?

- Cane 1
- Walker 2
- Wheelchair 3
- Other 4
- Please describe _____

YOUR HEALTH (cont.)

Some caregivers have the following health problems. If you DO NOT have the problem, CIRCLE **NO**. If you DO have the problem, CIRCLE **YES** and then indicate how much the problem bothers you by circling **1 = Not At All**, **2 = A Little**, **3 = Some**, or **4 = A Lot**.

During the past 4 weeks have you had a problem with your:

→ **If YES, CIRCLE how much the problem bothers you.**

			Not at all	A little	Some	A lot	
1.	Back?	NO	YES	1	2	3	4
2.	Eyes?	NO	YES	1	2	3	4
3.	Feet or legs?	NO	YES	1	2	3	4
4.	Hands or arms?	NO	YES	1	2	3	4
5.	Hearing or ears?	NO	YES	1	2	3	4
6.	Heart?	NO	YES	1	2	3	4
7.	Lungs or breathing?	NO	YES	1	2	3	4
8.	Memory?	NO	YES	1	2	3	4
9.	Teeth or dentures?	NO	YES	1	2	3	4
Do you have:							
10.	Allergies or hay fever? ...	NO	YES	1	2	3	4
11.	Arthritis?	NO	YES	1	2	3	4
12.	Asthma?	NO	YES	1	2	3	4
13.	Cancer?	NO	YES	1	2	3	4
14.	Circulatory problems?	NO	YES	1	2	3	4
15.	Diabetes?	NO	YES	1	2	3	4
16.	High blood pressure?	NO	YES	1	2	3	4
17.	A psychiatric disorder? ...	NO	YES	1	2	3	4

YOUR HEALTH (cont.)

During the past 4 weeks have you had:

→ If YES, CIRCLE how much the problem bothers you.

			Not at all	A little	Some	A lot	
18.	Dizziness?	NO	YES	1	2	3	4
19.	Fainting spells?	NO	YES	1	2	3	4
20.	A cold or flu?	NO	YES	1	2	3	4
21.	Headaches?	NO	YES	1	2	3	4
22.	Minor infections?	NO	YES	1	2	3	4
23.	Pain?	NO	YES	1	2	3	4
24.	Sinusitis?	NO	YES	1	2	3	4
25.	Skin disorders (ulcers, sores, severe itching)? ...	NO	YES	1	2	3	4
26.	Stomach or bowel problems?	NO	YES	1	2	3	4
27.	Urinary problems?	NO	YES	1	2	3	4
28.	A fall?	NO	YES	1	2	3	4
Have you had:							
29.	An amputation?	NO	YES	1	2	3	4
30.	A recent fracture or injury?	NO	YES	1	2	3	4
31.	A stroke?	NO	YES	1	2	3	4
32.	Any other health problems? (Please specify)						
	_____	NO	YES	1	2	3	4

YOUR HEALTH (cont.)

1. In general, would you say your health is
(Circle One Number):

- Excellent 1
- Very Good 2
- Good 3
- Fair 4
- Poor 5

2. Compared to one year ago, how would you rate your health in general now?
(Circle One Number)

- Much better now than one year ago 1
- Somewhat better now than one year ago 2
- About the same 3
- Somewhat worse now than one year ago 4
- Much worse now than one year ago 5

The following items are about activities you might do during a typical day. Does **your health now limit YOU** in these activities? If so, how much?

(Circle One Number on Each Line)

Activities	Yes, I am Limited A Lot	Yes, I am Limited A Little	No, Not Limited At All
3. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports 1	1	2	3
4. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf 1	1	2	3
5. Lifting or carrying groceries 1	1	2	3
6. Climbing several flights of stairs 1	1	2	3
7. Climbing one flight of stairs 1	1	2	3
8. Bending, kneeling or stooping 1	1	2	3
9. Walking more than a mile 1	1	2	3
10. Walking several blocks 1	1	2	3
11. Walking one block 1	1	2	3
12. Bathing or dressing yourself 1	1	2	3

YOUR HEALTH (cont.)

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Circle One Number on Each Line)

	<u>Yes</u>	<u>No</u>
13. Cut down the amount of time you spent on work or other activities	1	2
14. Accomplished less than you would like	1	2
15. Were limited in the kind of work or other activities	1	2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	<u>Yes</u>	<u>No</u>
17. Cut down the amount of time you spent on work or other activities	1	2
18. Accomplished less than you would like	1	2
19. Didn't do work or other activities as carefully as usual	1	2

20. During the **past 4 weeks**, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle One Number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

21. How much **bodily** pain have you had during the **past 4 weeks**?

(Circle One Number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

YOUR HEALTH (cont.)

22. During the **past 4 weeks** how much did **pain** interfere with your normal work (including both work outside the home and housework)?

(Circle One Number)

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

(Circle One Number on Each Line)

How much of the time during the past 4 weeks ...	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks**, how much of the time have your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle One Number)

- All of the time 1
- Most of the time 2
- Some of the time 3
- A little of the time 4
- None of the time 5

YOUR HEALTH (cont.)

How **true** or **false** is **each** of the following statements for you?

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

37. During the past two months have you experienced a weight gain or loss of more than five pounds?

- No 0 → (Go to Question 38)
- Gained more than five pounds 1
- Lost more than five pounds 2
- Don't know -8

37a. Were you trying to lose weight?

No 0

Yes 1

37b. Were you trying to gain weight?

No 0

Yes 1

38. Do you smoke cigarettes, cigars, or a pipe?

- A. Cigarettes
- No 0
- Yes 1 If **YES**, how many per day? _____
- B. Cigars
- No 0
- Yes 1 If **YES**, how many per day? _____
- C. Pipes
- No 0
- Yes 1 If **YES**, how many per day? _____

YOUR HEALTH (cont.)

39. Have you **ever** had a drink of beer, wine or hard liquor (*not just a sip or a taste of someone else's drink*)?

No 0 → (Go to Question 1 at bottom of page)

Yes 1 → (Answer Question 40)

40. How long has it been since you **last** had a drink of beer, wine, or hard liquor?

More than 3 months ago 1 → (Go to Question 1 at bottom of page)

Less than 3 months ago 0 → (Answer Question 41)

41. On a typical day in which you drink, about how many drinks of alcohol (*12 ounces of beer, 4 ounces of wine, 1-1/2 ounces of hard liquor*) do you drink ?

8 or more drinks 1

6-7 drinks 2

4-5 drinks 3

3 drinks 4

2 drinks 5

1 drink 6

BEFORE YOUR FAMILY MEMBER HAD HEALTH OR MEMORY PROBLEMS

Think back to the time before your family member had health or memory problems. We would like you to describe how you and your family member felt about each other at that time, before he or she had health or memory problems.

Before he or she had health or memory problems	Not at all	A little	Some	Quite a bit	A great deal
1. To what extent did you enjoy the time the two of you spent together?	0	1	2	3	4
2. How close did you feel to him or her at that time? ...	0	1	2	3	4
3. How much emotional support did he or she give you?	0	1	2	3	4

YOUR FEELINGS DURING THE PAST WEEK

Listed below are some statements. We would like you to tell me how often you felt or behaved this way — **DURING THE PAST WEEK.**

1 = Rarely or none of the time (less than 1 day)

2 = Some or a little of the time (1–2 days)

3 = Occasionally or a moderate amount of time (3–4 days)

4 = Most or all of the time (5–7 days)

During the PAST WEEK, on how many days did you feel or behave this way?	Rarely or None less than 1 day	Some or A Little 1–2 days	Occasionally or Moderate 3–4 days	Most or All 5–7 days
1. I was bothered by things that usually don't bother me.	1	2	3	4
2. I did not feel like eating; my appetite was poor.	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
4. I felt that I was just as good as other people.	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.	1	2	3	4
7. I felt that everything I did was an effort.	1	2	3	4
8. I felt hopeful about the future.	1	2	3	4
9. I thought my life had been a failure.	1	2	3	4
10. I felt fearful.	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.	1	2	3	4
13. I talked less than usual.	1	2	3	4
14. I felt lonely.	1	2	3	4
15. People were unfriendly.	1	2	3	4
16. I enjoyed life.	1	2	3	4
17. I had crying spells.	1	2	3	4
18. I felt sad.	1	2	3	4
19. I felt that people disliked me.	1	2	3	4
20. I could not get "going."	1	2	3	4

EMPLOYMENT ISSUES

1. Are you currently employed, including self employment?

1. No, I am not employed
 2. No, I am retired
 3. No, I am looking for employment
 4. No, I quit work because of my family member's health condition

→ **Go on to Q.1 at the bottom of this page**
 5. Yes, part-time or on-call
 6. Yes, full-time
2. Approximately how many hours per week do you work? _____ hours/week
 3. How much flexibility do you have in your work schedule to handle family responsibilities?
 1. A lot of flexibility
 2. Some flexibility
 3. Hardly any flexibility
 4. No flexibility at all
 4. Circumstances differ and some people find it easier than others to combine working with family responsibilities. In general, how easy or difficult is it for you?

1. Very easy	4. Somewhat difficult
2. Easy	5. Difficult
3. Somewhat easy	6. Very difficult
 5. How often have you worked less effectively at your job because you were worried or upset about your family member?

1. Never	4. Frequently
2. Seldom	5. Most or all of the time
3. Sometimes	

YOUR HEALTH INSURANCE

1. Do you currently have health insurance?

No 0

Yes 1
- If **YES**, What is your current health insurance? (CIRCLE **ALL** that apply)
- | | YES | NO |
|-------------------------------|-----|----|
| 1. Kaiser | 1 | 0 |
| 2. Medicare | 1 | 0 |
| 3. Regence BCBS | 1 | 0 |
| 4. VA | 1 | 0 |
| 5. Other (write in name)..... | 1 | 0 |

TELL US ABOUT YOU

1. How old are you?
Age: _____ years

Date of birth ___/___/19___
 mm dd yy

2. Are you female or male?

Female 1
Male 2

Please answer BOTH questions 3 and 4.

3. Are you Spanish/Hispanic/Latino?

No 0
Yes 1

4. What is your race?

(Circle ALL that apply)

African American, Black, or Negro ... 1
American Indian/Alaska Native 2
Asian/Pacific Islander 3
White 4
Other 5
If other, write in _____

5. What do you consider your racial, ethnic or cultural background or heritage? This may be the countries or regions your ancestors were from.

6. How much does this background affect your everyday life?

Not at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

7. What is the highest grade in school that you completed?

Completed 6th grade or less 1
Junior high school (7th - 9th grade) 2
Partial high school (10th - 11th grade) ... 3
High school graduate or GED 4
Partial college training 5
Completed college 6
Graduate professional training 7
Other _____ 8

8. What kind of work have you done most of your working life?

9. What is your current marital status ?

Married 1
Widowed 2
Divorced 3
Separated 4
Never married 5
Partnered 6

10. Counting yourself, how many people live in your household?

_____ people

11. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?

No 0

Yes 1

If YES,

11a. How many? _____

11b. About how many hours per week do you spend in caring for or supervising these children?
_____ hrs/wk?

TELL US ABOUT YOU

12. What is your religious affiliation?

- | | |
|-----------------------------------|----|
| Baptist | 1 |
| Buddhist | 2 |
| Catholic | 3 |
| Episcopalian | 4 |
| Holiness | 5 |
| Jewish | 6 |
| Lutheran | 7 |
| Methodist | 8 |
| Mormon | 9 |
| Muslim | 10 |
| Non-Denominational | 11 |
| Pentecostal | 12 |
| Presbyterian | 13 |
| Protestant | 14 |
| Unitarian Universalist | 15 |
| Do not have any affiliation | 16 |
| Other | 17 |

If other, write in _____

13. On a scale from 1 to 5, to what extent do you consider yourself to be religious?

- | | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| Not
religious | | | | Very
religious |

14. On a scale from 1 to 5, to what extent do you consider yourself to be spiritual?

- | | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| Not
spiritual | | | | Very
spiritual |

15. Does your religion or spirituality make a difference or influence the care that you provide to your family member?

- | | |
|-----------|---|
| No | 0 |
| Yes | 1 |

15a. If YES, please describe how or in what way your religion or spirituality makes a difference in the care you provide.

FAMILY EXPENSES AND CAREGIVING

Next are some questions about your family expenses. We ask you these questions because it is important for us to describe the financial situation of families who are caring for a relative with health problems. We treat all answers you give as confidential.

16. Which of the following four statements describes your ability to get along on your income?

- | | |
|---|---|
| I can't make ends meet | 1 |
| I have just enough, no more | 2 |
| I have enough, with a little
extra sometimes | 3 |
| I always have money left over | 4 |

17. For your own home, we are interested in whether you have to pay rent or make mortgage payments?

- | | |
|--|---|
| I pay rent | 1 |
| I make mortgage payments | 2 |
| I own my home outright and
do <i>not</i> pay mortgage or rent | 3 |
| Other | 4 |
| If other, explain _____ | |
| _____ | |

TELL US ABOUT YOU

18. What is the total amount of your yearly **household** income before taxes? Please include money from jobs, net income from a business or farm, dividends, interest, net income from rent, social security, gifts, and any other money income. Include the income of your family member if he or she lives with you.

Yearly Household Income

\$1–\$2,499	1
\$2,500–\$4,999	2
\$5,000–\$9,999	3
\$10,000–\$14,999	4
\$15,000–\$19,999	5
\$20,000–\$24,999	6
\$25,000–\$29,999	7
\$30,000–\$34,999	8
\$35,000–\$39,999	9
\$40,000–\$44,999	10
\$45,000–\$49,999	11
\$50,000–\$74,999	12
\$75,000–\$99,999	13
\$100,000 and more	14

19. Do you pay other people out of your own pocket to take care of your family member?

No 0 → **(Go on to Q. 1 at the bottom of this page)**
 Yes 1

19a. If YES, how much of a financial burden is it? Would you say:

Not a burden	0
A little burden	1
Some burden	2
A lot of burden	3
Overwhelming burden	4

To what extent...	Not at all	A little	Some	Quite a bit	A great deal
1. does caring for him or her help you financially <i>(such as by providing you a place to live or by giving you his/her Social Security check to cover expenses related to caregiving)?</i>	0	1	2	3	4
2. will caring for him or her help you financially in the future?	0	1	2	3	4
3. does caring for your family member help you live more comfortably financially than if you put him or her in a nursing home?	0	1	2	3	4

YOUR DIFFICULT ISSUES

In this Family Care Inventory, we have asked you many questions about your family member's health, the caregiving activities you do to help your family member, and how you feel about your family care situation and your own health.

In conclusion, we would like you to identify the 3 specific health or family care issues that are hardest for you at this time. These issues may be ones we have asked you about or others that are not included in this inventory.

(Please circle how hard each issue is for you.)

Issue # 1. _____

0 1 2 3 4 5 6 7 8 9 10

Not at all
hard

Moderately
hard

Extremely
hard

Issue # 2. _____

0 1 2 3 4 5 6 7 8 9 10

Not at all
hard

Moderately
hard

Extremely
hard

Issue # 3. _____

0 1 2 3 4 5 6 7 8 9 10

Not at all
hard

Moderately
hard

Extremely
hard

YOUR VIEW

1. How different does your family member seem to you now as compared to the time before he or she had health or memory problems? Does he or she seem like a different person, or pretty much the same as before?

A different person 1

The same as before 2

1a. If **different**, in what ways is he or she different? _____

2. Do you have any regrets about the things that have happened during the time you have been caring for your family member?

No 0

Yes 1

2a. If **YES**, what are they? _____

3. Are there any special things that you do on a regular basis for your family member or with your family member that you both count on and look forward to?

No 0

Yes 1

3a. If **YES**, what are they and what makes them special? _____

4. Are there any enjoyable activities you have had to give up because of your family member's health or memory problems and your own caregiving responsibilities?

No 0

Yes 1

4a. If **YES**, what are the enjoyable activities you have had to give up? _____

YOUR VIEW (cont.)

5. Has your family member's health or memory problems changed the physical intimacy between you and your family member?

No 0

Yes 1

5a. If **YES**, please explain. _____

6. Are there things going on in your life, **other than caregiving**, that have been especially upsetting or difficult for you?

No 0

Yes 1

6a. If **YES**, please explain. _____

7. Please tell us any other questions that we should have asked you in order to have a good picture of your situation. _____

Please take a few minutes to check back through the questionnaire and make sure that no pages were stuck together and that you did not miss any questions.

DATE AND TIME YOU COMPLETED QUESTIONNAIRE _____
DATE TIME

About how long did it take you to complete this questionnaire?

_____ **hours** _____ **minutes**

Purpose

These questions are designed for people who assist a relative or friend who has health or memory problems. In these questions, we use the term **family member** to refer to your relative or friend who has health or memory problems.

Your answers will help us to understand your situation.

Directions

It should take about 1 1/2 hours to answer these questions. You may want to take two or three blocks of time to complete them.

Answer the questions as honestly as you can; there are no right or wrong answers. Please do not consult with other people before you answer the questions. It is **your** view that we need.

Your role as a caregiver

We will be asking you many detailed questions because we would like to have a good picture of what you do now to help your family member.

In some questions, we use the term **caregiver** to refer to you. Although you may not think of yourself as a caregiver, we use the term caregiver very broadly as **someone who helps a family member because of the family member's health or memory problems.**

The help a caregiver provides may range from help with walking, to help in making health care decisions, to just being there to give support.

Some of the questions will **not** apply to you, but try to answer all that you can. As you know from the consent form you signed, if you object to any question, you can skip it and go on to the next one.

Questions?

If you have any questions, please contact:

Shirin Hiatt (503) 494-3978

We thank you for your thoughtful answers.

Other comments (use space below)

Thank you very much for sharing your experience and opinions with us. Your responses will be very helpful to us in getting a good idea of what it is really like for families in your situation.

When you are done with the questionnaire, please keep it until researchers come to your home to pick it up.

Thank you again for your participation!

**OHSU/KPNW Family Care Study
(503) 494-4560**

Family Care Inventory

School of Nursing
Oregon Health Sciences University

Center for Health Research
Kaiser Permanente Northwest Region

Principal Investigators:
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Appendix C

The Blessed Orientation – Memory Concentration Test

The Blessed Orientation-Memory Concentration Test

<u>Items</u>	<u>Max. Error</u>	<u>Score</u>	<u>Weight</u>
1. What year is it now?	1	_____ x 4 =	_____
2. What month is it now?	1	_____ x 3 =	_____

Memory Phrase:

Please repeat this phrase after me and try to remember it:

John Brown, 42 Market Street, Chicago

Number of trials _____

3. About what time is it? (within an hour)	1	_____ x 3 =	_____
---	---	-------------	-------

Response: _____

Actual Time: _____

4. Count backwards 20 to 1. <i>(Draw a line through correctly sequenced numbers. Score 1 point for 1 error; score 2 points for 2 or more errors.)</i>	2	_____ x 2 =	_____
20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3 2 1			

5. Say the months of the year in reverse order. Start with December D N O S Au Jl Jn My Ap Mr F Ja	2	_____ x 2 =	_____
--	---	-------------	-------

6. Repeat the name and address I asked you to remember: <i>(Draw a line through each segment of the phrase correctly repeated. Score 1 point for each error.)</i>	5	_____ x 2 =	_____
---	---	-------------	-------

John Brown, 42 Market Street Chicago

If no cue is necessary and the CG recalls both name and address, score "0." If the CG cannot spontaneously recall the name and address, cue with "John Brown" one time only. If this cue is necessary, the patient automatically has 2 errors. Score 1 point for each subsequent "unit" the CG cannot recall. The three units are: 42; Market Street; Chicago.

Score 1 for each incorrect response; maximum weighted score = 28

Total Weighted Score: _____

Appendix D

Home Care Effectiveness Scale – The Caregiver’s View – 5-Month Interview

EVALUATION OF HOME HEALTH CARE FOR YOU AND YOUR FAMILY MEMBER

About 5 months ago, your family member was referred to Kaiser home health. Since that time, one or more home health visits have been made to your family member's home. These visits may have been made by a home health nurse, PREP nurse, physical therapist, social worker, occupational therapist, or home health aide. Please give us your opinions about how your contact with these home health care providers has affected you and your family. You may or may not be receiving home visits at this time, but please try to recall any home visits or phone contacts and answer the following questions.

To what extent did working with your nurse, or other home health providers...	Not at all	A little	Some	Quite a bit	A great deal
1. help you feel more comfortable talking with your doctor about caregiving or health issues? ..0	1	2	3	4	4
2. give your confidence a boost?	1	2	3	4	4
3. make you feel more comfortable in the things you were doing to help your family member?	1	2	3	4	4
4. help you feel more prepared to take care of your family member's physical needs?	1	2	3	4	4
5. help you have more patience?	1	2	3	4	4
6. help you think about your relationship with your family member?	1	2	3	4	4
7. help you feel more prepared to take care of your family member's emotional needs?	1	2	3	4	4
8. help you work out a system to make your family care go more smoothly?	1	2	3	4	4
9. help you feel more prepared to find out about and set up services for your family member?	1	2	3	4	4
10. help you feel reassured that you were doing a good job?	1	2	3	4	4
11. help you to plan ahead for future changes in your family care situation?	1	2	3	4	4
12. give you helpful ideas about caregiving?	1	2	3	4	4
13. help you manage your family member's symptoms better?	1	2	3	4	4
14. make things easier for you?	1	2	3	4	4
15. help you make things safer for your family member?	1	2	3	4	4

**EVALUATION OF HOME HEALTH CARE
FOR YOU AND YOUR FAMILY MEMBER (cont.)**

To what extent did working with your nurse, or other home health providers...	Not at all	A little	Some	Quite a bit	A great deal
16. help you make caregiving more pleasurable?0	1	2	3	4	4
17. help you improve your communication with your family member?0	1	2	3	4	4
18. improve the quality of the care you were providing to your family member?0	1	2	3	4	4
19. help you find solutions for difficult situations that you had with your family member?0	1	2	3	4	4
20. help you feel more in control of your life?0	1	2	3	4	4
21. make caregiving more satisfying to you?0	1	2	3	4	4
22. reduce the stress you were feeling?0	1	2	3	4	4
23. increase the positive aspects of caregiving for you?0	1	2	3	4	4
24. help you feel more self-assured?0	1	2	3	4	4
25. help you feel more prepared to handle the stress of caregiving?0	1	2	3	4	4
26. increase your ability to manage specific caregiving issues?0	1	2	3	4	4
27. decrease your anxiety about managing difficult situations?0	1	2	3	4	4
28. help you understand more about what your family member needed?0	1	2	3	4	4
29. increase your confidence in talking with doctors or other health care providers at Kaiser?0	1	2	3	4	4
30. help you change your attitude about your situation to a more positive one?0	1	2	3	4	4
31. increase your peace of mind?0	1	2	3	4	4
32. help you feel more prepared to get the help and information you need from the health care system?0	1	2	3	4	4
33. improve the predictability of your caregiving situation?0	1	2	3	4	4

EVALUATION OF HOME HEALTH CARE FOR YOU AND YOUR FAMILY MEMBER (cont.)

To what extent did working with your nurse, or other home health providers...	Not at all	A little	Some	Quite a bit	A great deal
34. help you find ways to keep yourself healthy?0	1	2	3	4	4
35. increase your confidence in your ability to continue caring for your family member?0	1	2	3	4	4
36. improve your ability to make health care decisions?0	1	2	3	4	4
37. help you monitor your own health problems?0	1	2	3	4	4
38. help you know what to do in emergency health situations?0	1	2	3	4	4
39. help you get services you needed from Kaiser? .0	1	2	3	4	4
40. help you get ideas for strategies to address difficult issues in your family care?0	1	2	3	4	4
41. help you understand your family member's health condition?0	1	2	3	4	4
42. help you in making medical appointments?0	1	2	3	4	4
43. help you find ways to make your caregiving activities more enriching?0	1	2	3	4	4

44. Overall, how useful was the assistance you received from your nurse or other home health providers?

0 1 2 3 4 5 6 7 8 9 10

Not at all useful A little useful Somewhat useful Quite a bit useful Very useful Extremely useful

Other comments:

Appendix E

Institutional Review Board Letter of Approval

January 24, 2006

Carla M. Hagen, MPH, RN
Principal Investigator
12910 SW Wisbey Place
Gaston OR 97119

NW-06PArch-01: Dosage and Differential Effectiveness of PREP

The above named study was reviewed and approved by the full Kaiser Permanente Northwest Institutional Review Board (KPNW IRB) on January 18, 2006. *This approval expires January 18, 2007.*

The IRB waived the requirement to obtain informed consent.

The proposed research does not access private health information therefore privacy rule authorization or waiver is not required.

Although the IRB has approved the data transfer method outlined in the IRQ and/or protocol please note that no data transfer can take place until a data transfer form has been completed, signed and approved.

If your study or study-related documents require modification, you must seek IRB approval for these changes before they are implemented. In addition, you must promptly notify the IRB of any unanticipated serious adverse events affecting research participants or controls as well as any complications that occur during any experimental procedure associated with this study.

Federal regulations require that all studies be reviewed at least annually. It is your responsibility to ensure that you reapply for approval at least one month prior to the study approval expiration date.

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.



David Holt, JD
Director
Research Subjects Protection

01/18/06-C

cc: P. Archbold, DNSc, RN, FAAN