

IMPACT OF CARE-RECIPIENT RESISTANCE DURING CARE PROVISION
ON CAREGIVER EMOTIONAL/PHYSICAL WELL-BEING:
A SEQUENTIAL MIXED METHOD DESIGN WITH
BETWEEN- AND WITHIN-PERSON ANALYSES AND
SEMI-STRUCTURED INTERVIEWS

by

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Within-Person Analyses and Semi-Structured Interviews.

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ABSTRACT

To address some remaining questions in the extant family caregiving literature, the present study examined a specific care-recipient (CR) problematic behavior that could be the most critical to family caregiver (CG) emotional and physical well-being—CR-resistance or uncooperative behaviors vis-à-vis the CG. In order to provide detailed descriptions of CR-resistance and to determine the impact of CR-resistance on CG emotional and physical well-being, the present study applied a sequential quantitative-qualitative mixed method design approach with 8-day diary survey data on 63 family CGs and follow-up semi-structured interview data from 19 of those CGs.

The quantitative data documented and revealed significant within- and between-person variance in CR-resistance. Hierarchical Linear Modeling (HLM) analyses results further revealed that neither the mean level nor the daily fluctuation of CR-resistance across 8 survey days by themselves appeared to have a significant impact on CG emotional or physical health. However, the combination of having relatively high mean level and daily fluctuation of CR-resistance brought had a significant impact on CG physical health; when CGs with relatively high mean level CR-resistance faced more than their usual amount of CR-resistance on a given day, they reported increases in physical health symptoms.

The qualitative inductive thematic analyses revealed that based on the context in which CR-resistance occurred and the occurrence patterns, CR-resistance experiences could be divided into four types, and these four types of CR-resistance seem to pose different types and/or magnitude of impact on CG emotional well-being.

Furthermore, informed by Social Cognitive Theory and Stress Theory, the present study also examined CG personal, interpersonal, and social resources as possible moderators of the link between CR-resistance and CG emotional/physical well-being. HLM analyses results revealed that CG sense of efficacy, community/professional service utilization, and family disagreement regarding care played significant moderating roles. The qualitative thematic analyses clearly suggested that specific CG cognitive resources—particularly those that were transferred and/or generalized from the CG's past professional or personal experiences—have a strong influence on CG resilience in the face of CR-resistance. The moderating results were interpreted light of theoretical frameworks and extant literature. Implications and future directions are discussed.

CHAPTER 1: INTRODUCTION

The Status of Family Elders and Caregivers in the United States

With a growing aging population, the need for family caregiving is increasing. Between 1900 and 2008, the percentage of people over age 65 in the United States has grown from 4% to 12.8% of the total U.S. population. Because the baby boomers will start turning 65 in 2011, this trend will accelerate even more between the years 2010 and 2030; the older population in 2030 is projected to be 20%. Although the majority of older adults (93% of those 65 years and older) remain in the community and not in care facilities, due to chronic and/or acute illness or gradual age-related functional/sensory declines, 42% of those older adults need a wide range of assistance in their daily life activities: instrumental activities of daily living (IADL), such as, shopping in stores, managing finances, and making appointments, and/or activities of daily living (ADL), such as dressing, bathing, and eating. Approximately 66% of assistance to those community-dwelling older adults is provided solely by unpaid informal caregivers (CGs)—mostly family members, whereas only 9% of assistance is provided solely by formal CGs (Federal Interagency Forum on Aging-Related Statistics, 2008). In contrast to formal CGs, family CGs typically provide care without private or public monetary compensation. As such, they represent an invaluable resource to the well-being of the elder population and to our society as a whole. However, family CGs may place their own emotional and physical well-being at risk (e.g., Pinquart & Sörensen, 2003; Turner, Killian, & Cain, 2004).

Family CG Well-Being

Indeed, researchers have found negative consequences of family caregiving captured in negative CG well-being indicators, such as increased anxiety and depressive symptoms (e.g., Li, Seltzer, & *Greenberg*, 1999; Schulz & Williamson, 1991), diminished perceived health (e.g., Beach, Schulz, Yee, & Jackson, 2000; Turner et al. 2004), increasing health risk behavior (Beach et al., 2000), lowered immune function (e.g., Cacioppo, Poehlmann, & Kiecolt-Glaser, 1998), and increased mortality (Schulz & Beach, 1999). Notably, researchers have also examined positive outcomes or rewards as part of their conceptualization of CG well-being. They have acknowledged the possible positive consequences of caregiving experiences, such as feeling more useful, feeling needed, adding more meaning to one's sense of self, enjoying being a CG, and gaining satisfaction from the caregiving role (e.g., Gold, Cohen, & Shulman, 1995; Harwood, Barker, Ownby, Bravo, Agüero, & Duara, 2000; Kramer, 1997). However, because taking on a caregiving role can greatly and often negatively affect CGs' personal lives due to provision of care as well as changes in family relationships and life circumstances (McKinlay, Crawford, & Tennstedt, 1995), negative outcomes remain the typical focus of CG well-being research (e.g., Beach et al., 2000; Li & Seltzer, 2003; Yates, Tennstedt, & Chang, 1999).

Care-Recipient (CR) Behavioral Problems as a Key Predictor of CG Well-Being:

Stress Model Based Studies

Caregiving researchers often examine the negative influences of the caregiving role on CGs' psychological and/or physical well-being through stress models (e.g., Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). Stress models provide a conceptual framework for researchers to investigate the CG coping process and how CG primary stressors associated and/or influencing other CG resources and background factors influence CG emotional and physical well-being. Primary stressors are conditions, experiences, and activities that are direct demands in the caregiving role (Pearlin, Light, Niederehe, & Lebowitz, 1994). Common CG primary stressors include the cognitive and functional impairment of the CR, level of required care, and CR problematic behaviors. Among these primary stressors, researchers have consistently found that CR problematic behaviors, such as verbal/physical aggression (e.g., hitting, accusing), agitation (e.g., pacing, repetitive questions), and resistance/uncooperative behaviors (e.g., refusing assistance), have a significant, negative emotional/physical impact on CGs. In fact, this wide range of different CR problematic behaviors has often been found to be more stressful to CGs than other stressors such as CRs level of required care or cognitive status (e.g., Pinquart & Sörensen, 2005).

Statement of the Problem

However, in most CR problem behavior studies, the wide range of those CR behaviors is assessed via a global measure (Cohen-Mansfield & Billings, 1986; Zarit,

Reever, & Bach-Peterson, 1980). These measures ask CGs to report on the occurrence of a *variety* of problem behaviors over a *long period*, for instance, in the past two weeks, during the past month; this results in one “aggregated” problem behavior score that reflects *different types of CR-behavioral problems* occurring across different *caregiving contexts* and *different time periods*. With the use of these conventional global measures, several major questions remain unaddressed. For example, (a) *which* of these specific behaviors occur in what contexts (e.g., during assistance with personal care, in unfamiliar places)? (b) *how often* do these specific behaviors occur (e.g., every day or a few days in the past month)? and (c) *how stressful are specific CR problem behaviors* for CGs (e.g., emotionally frustrated or draining, or physically demanding)?

Purpose of the Current Study

By applying a sequential quantitative-qualitative (Quan/Qual) mixed method approach (Hanson, Creswell, Clark, Petska, & Creswell, 2005) for addressing some of the remaining questions, the current study examined a specific behavior that could be the most critical CR problem behavior to CG emotional/physical well-being— CR resistance or uncooperative behaviors vis-à-vis the caregiver (Mahoney et al., 1999). Among different types of CR problem behaviors, CR-resistance could be the most critical and stressful for both the CG and CR because it most often happens in *necessary* routine daily care activities (Mahoney et al., 1999). This stressful caregiving event, CR-resistance, often happens where the CG is the main and active participant who initiates and manages the caregiving related activities. In the present study, in order to provide detailed descriptions of CR-resistance and determine impact of CR-resistance on CG emotional

and physical well-being, CR-resistance was examined through two study phases with two different types of methodologies: (a) a primary quantitative study with 8-day self-reported survey data and (b) a follow-up study with semi-structured individual interviews (see details in methods section in Chapter 3). The specific aims of the current study are threefold.

First, informed by previous studies that reported significant day-to-day fluctuations in CR problem behaviors (Koerner & Kenyon, 2007; Malonebeach, Zarit, & Farberman, 1995) and that addressed the importance of examination of specific CR behavioral problems in specific contexts (Volicer & Hurley, 2003), the current quantitative study documented the occurrence and the day-to-day fluctuation of CR-resistance across 8 consecutive caregiving days (see Figure 1) whereas the qualitative study captured in-depth descriptions of actual CR-resistance experiences in the CGs' own words.

Second, the current study also determined *how stressful* CR-resistance was, by examining the association between CR-resistance and CG emotional and physical well-being, assessed via both positive and negative indicators. Specifically, the impact of CR-resistance on CG well-being was examined in two distinct components of CR-resistance (see Figure 2): (a) individual CG's mean-level experience with CR-resistance and (b) the effects of daily fluctuations of CR-resistance within each CG. Specifically, the impact of mean level CR-resistance was determined with a focus on differences in CG well-being; that is, whether CGs who have higher mean level CR-resistance scores also have, on average, higher mean scores on negative well-being indicators and lower scores on

Figure 1. Examples of Daily CR-Resistance Occurrence Patterns on Four Different CG Participants

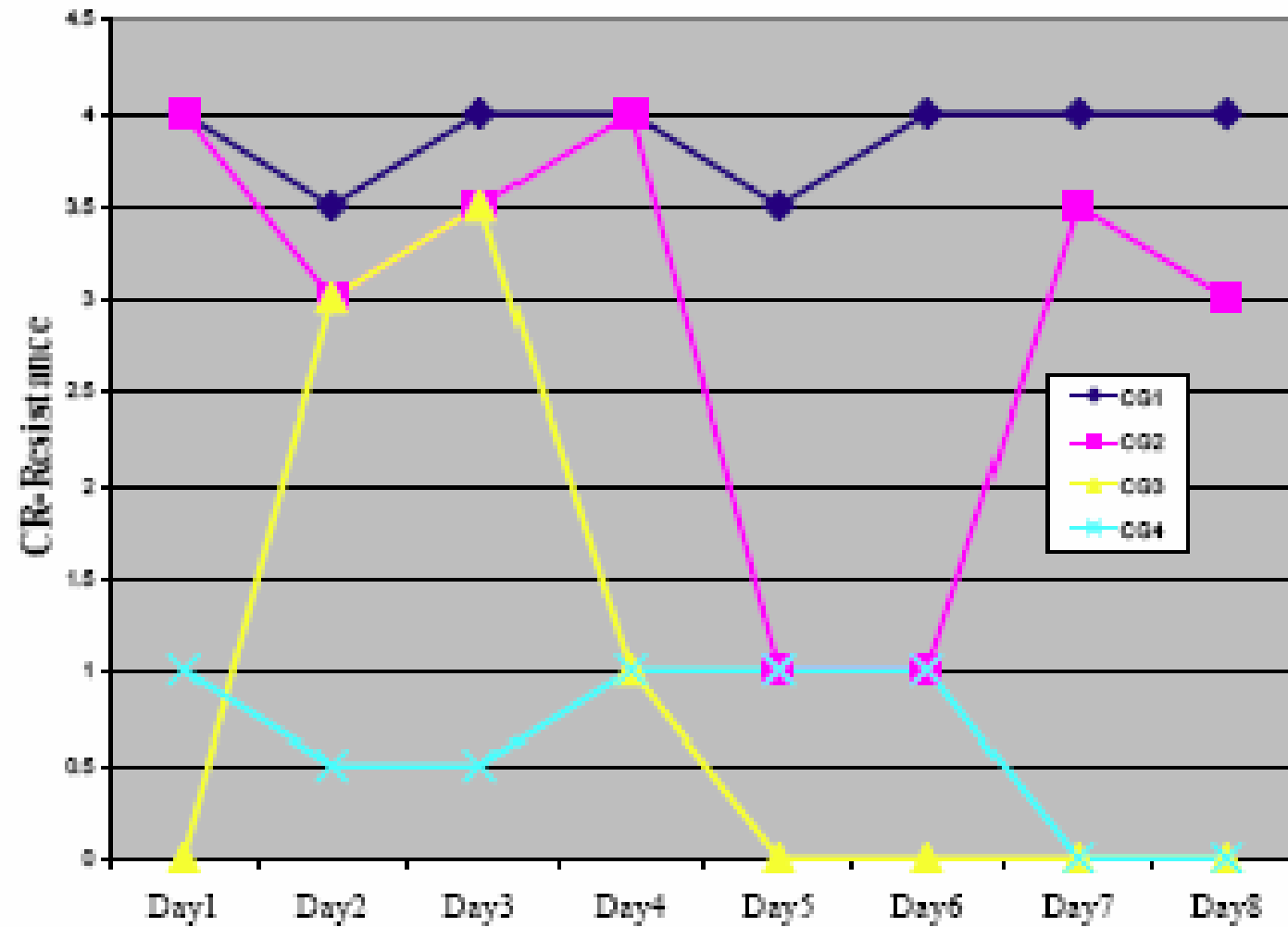
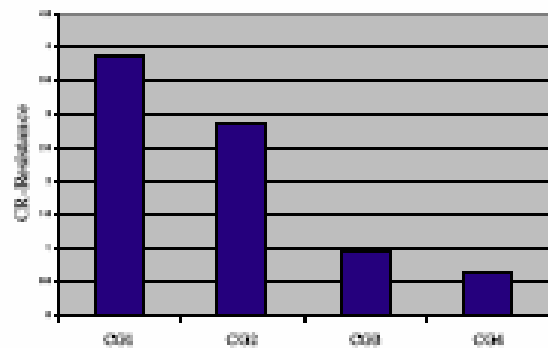
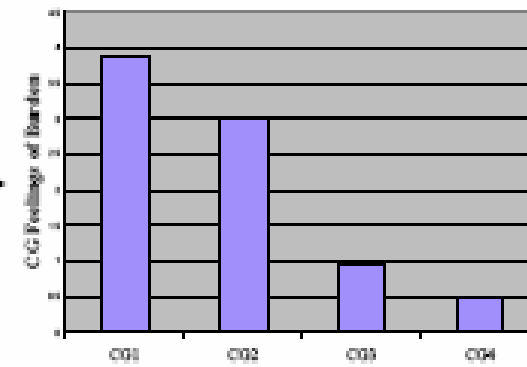


Figure 2. Example of (a) Mean-Level CR Resistance and (b) Daily Fluctuation of CR-Resistance Predicting One of CG Well-Being Indicator

(a) Mean level CR-resistance predicting mean level CG feelings of burden.
8-Day Average CR-Resistance Score

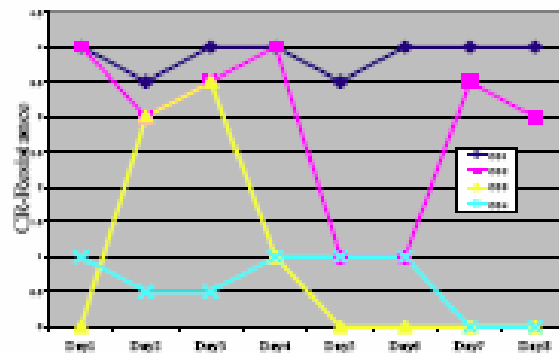


8-Day Average CG Feelings of Burden Score

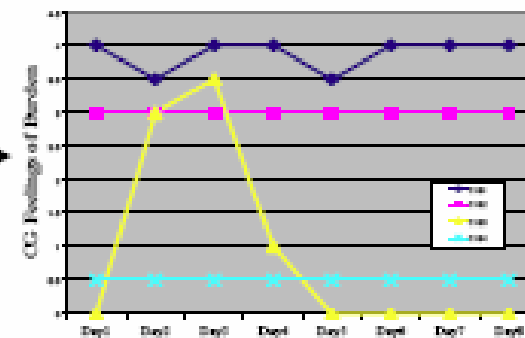


(b) Daily fluctuations of CR-resistance predicting daily fluctuations of CG feelings of burden.

Daily fluctuation of CR-Resistance



Daily fluctuation of CG feelings of Burden

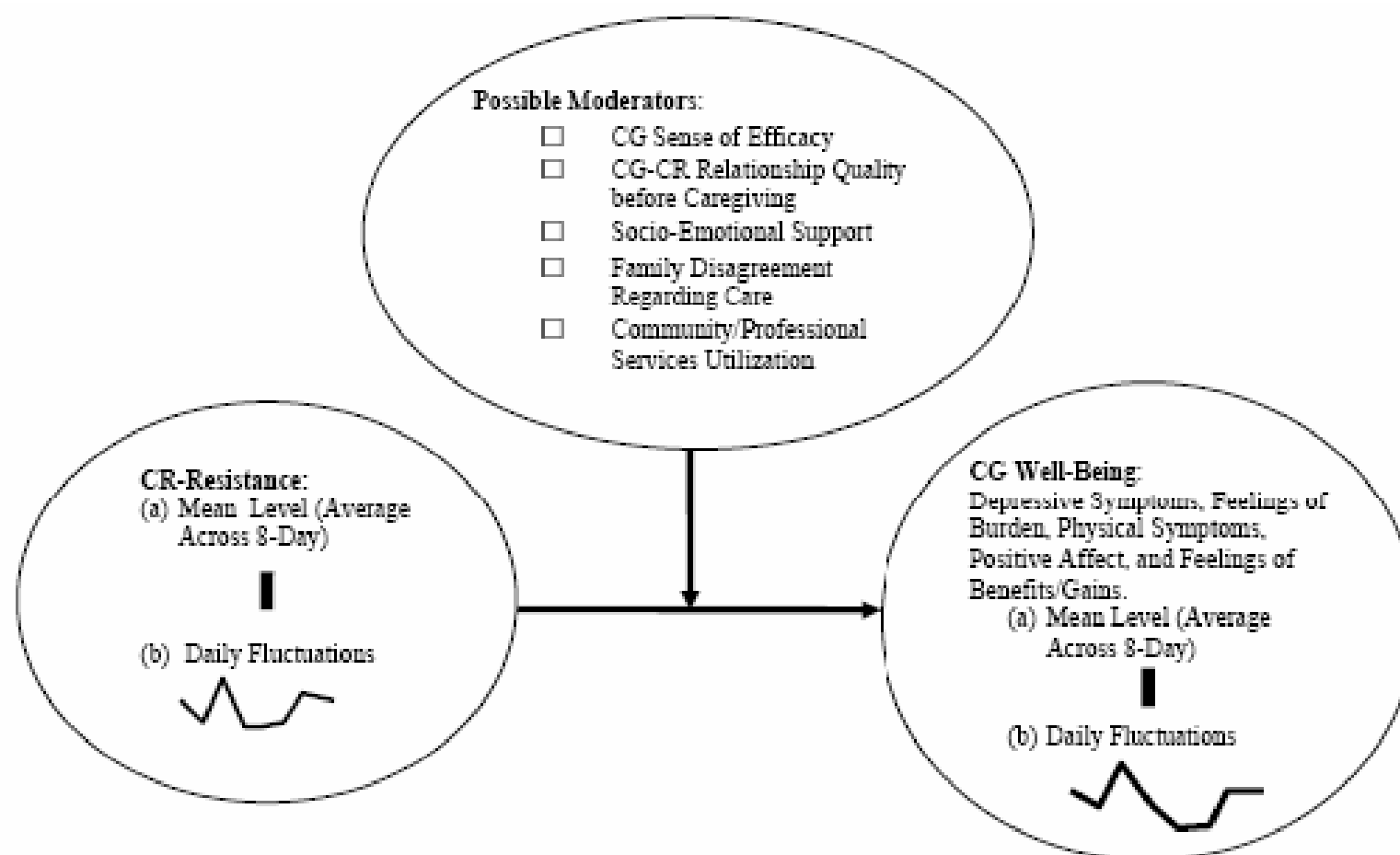


positive well-being indicators. The impact of CR resistance fluctuation was determined through daily changes within each CG; of interest was whether on days when CGs experience more than their usual (average) CR-resistance, they report heightened levels of emotional and physical stress symptoms compared to their usual (average).

Third, guided by Stress Theory and Social Cognitive Theory, the current study examined possible moderating factors such as CG personal, interpersonal, and social resources, including sense of efficacy, socio-emotional support, family disagreement regarding care, CG-CR pre-caregiving relationship quality, and community/professional service utilization, that may affect the degree to which CR-resistance influences CG emotional and physical well-being (see Figure 3). Specific tenets from Stress Theory and Social Cognitive Theory that drive the current study's hypotheses and research questions are discussed in detail in chapter two.

Finally, using follow-up semi-structured individual interviews, this study further attempted to describe and interpret diverse meanings and complexities of CG experiences of CR-resistance that go beyond the quantitative results gathered via the forced-choice surveys. All CG participants in the original primary survey study, regardless of how they had reported CR-resistance experiences in their survey, were recruited for semi-structured individual interviews. The interviews were guided by a set of interview question topics that were similar to those in the original survey questions (see details in the next section). CGs were asked to expand on their noteworthy experiences with specific examples and perceptions. Specific CR-resistance experiences presented in the CG's own words helped the current researcher not only properly interpret the quantitative

Figure 3. Possible Moderators Between (a) Mean Level CR-Resistance and CG Well-Being and (b) Daily Fluctuation of CR-Resistance and CG Well-Being



results but also discover different factors and themes that have not been adequately conveyed via existing standardized measures.

Significance to the Field

With a growing aging population in the United States and limited public resources to support their needs, family CGs are critical, and continued research on family CG well-being is vital in helping to maintain quality of life for dependent elders and family CGs. By examining the caregiving phenomenon through a multi-layered method—sequential Quan-Qual mixed-methods, the current study advances the field in two ways. First, supported by the complementary strengths of quantitative and qualitative research methods, this mixed methods design study provides a better conceptual understanding of the impact of CR-resistance on CG well-being. The quantitative daily data allow this researcher not only to document systematically the daily occurrence of caregiving events and CG experiences but also to determine the impact of *mean level differences* and the impact of *fluctuations in CR-resistance*. The qualitative in depth interview not only allows for better interpretation of the quantitative results, but also adds rich descriptive information including “caregiver perceptions, feelings, and internal responses” (Farran, Loukissa, Perraud, & Paun, 2004, p. 41) that may not be captured in the quantitative questionnaire. Second, with the systematic quantitative results and additional meaningful factors that were identified in qualitative results, professionals could provide additional components to strengthen or improve existing interventions, and assist in the development of tools to identify the most vulnerable CGs for specific intervention

programs as targeting a selective group is especially useful considering limited public resources.

CHAPTER 2: LITERATURE REVIEW

In this chapter, existing literature relevant to the current study is reviewed. After the rationale for the current study's focus, a specific CR behavioral problem—CR-resistance, is presented, studies in two distinct areas that have investigated CR behavioral problems are discussed. First, typical studies that have investigated the impact of CR-problem behaviors on CG emotional and physical well-being are discussed; findings from most of these studies were based on a one-time assessment of CR-problem behavior as cross-sectional studies. Second, longitudinal studies that captured changes of CR problem behaviors over time and/or the impact of the changes in CR problem behaviors on CG emotional and physical well-being are discussed; these study findings were based on multiple-time assessments of CR problem behaviors and CG emotional and physical well-being. At the end of the review of existing CR problem behavior studies, remaining, to date unaddressed questions regarding CR problem behaviors are presented as the foundation for our current hypotheses and research questions. Furthermore, two theoretical frameworks, Stress Theory and Social Cognitive Theory, are discussed. These theories serve as the basis from which the current hypotheses and research questions, and the choice of specific moderators in the primary quantitative study were derived. Finally, the role of the follow-up qualitative phase of the study is presented.

CR Behavior Problems: CR-Resistance

CR behavior problems are behaviors or reactions made by the CR that would typically be considered as inappropriate, disruptive, or abnormal relative to societal norms especially in the context in which they occur. These CR behavior problems could

be caused by many possible factors, such as CR cognitive declines/dysfunction and CR emotional frustrations due to disease, personality, medication, or age-related changes; these factors detract from the CR's abilities to act in rational and normative ways in the situation. Moreover, both CR internal stimuli (e.g., hallucination, anxiety, discomfort, pain) and external stimuli (e.g., interactions by third parties, temperature, noise, and scent) could trigger or exacerbate such CR behavior problems. Among possible CR problem behaviors, the current study examined a specific behavior problem that most often occurs in the context of personal care—*CR-resistance* (Mahoney et al., 1999). CR-resistance is verbal or nonverbal rejection by dependent elders of their CG during assistance in their necessary daily activities such as dressing, bathing, and monitoring of medications, which are essential in order to maintain the CR's health and quality of life.

Mahoney et al. (1999) have noted that in considering the impact of CR-resistance on both the CG and CR emotional well-being, the care provision context is an important factor to be closely monitored because the incidence of this specific CR problem behaviors often increase when personal care activities are initiated by others, namely CGs. In other words, not only CR characteristics, such as disease symptoms and personality, but also CG characteristics, such as personal, inter-personal, and social resources, that a CG brings into this care provision context play roles in the occurrence as well as management of CR-resistance.

In the current study, CR-resistance was examined with a particular focus on the context of daily routine care assistance and/or provision; and CG personal and interpersonal resource factors were examined as to their possible buffering or

exacerbating effects in the link between CR-resistance and CG emotional and physical well-being. Although the current study's focus was on CR-resistance, this behavior itself has received little research attention, except by a small group of researchers (e.g., Mahoney et al., 1999; Volicer & Hurley, 2003), and has been most often considered as a part of CR problem behaviors viewed in totality. Therefore, the following literature review highlights existing findings from the CR problem behavior literature and points out the limitations of extant studies.

Global CR Problem Behavior Measures

As previously noted, in the caregiving literature, CR-resistance has typically been examined as a part of CR problematic behaviors. CR problematic behaviors are aggregately called “behavioral problems,” “problem behaviors,” “agitations,” “challenging behaviors,” “aggressive behaviors,” and/or “disruptive behaviors” that include verbal/physical aggression, resistance/uncooperative behaviors, and agitation. These different types of behaviors are typically measured by *global* instruments that combine items across several different types. For example, the widely utilized Memory and Behavioral Checklist (Zarit, Reever, & Bach-Peterson 1980) includes a range of behaviors, such as wandering, repeating questions, arguing, dangerous to others to self or others. Similarly, the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield & Billing 1986) includes items that tap physically non-aggressive behavior (e.g., pacing), verbally agitated behavior (e.g., repetitive questions, arguing), and aggressive behavior (e.g., hitting, kicking).

Those global measures had been originally constructed to document and study behavior caused mainly by the cognitive declines of individuals with dementia. Therefore, CRs with dementia have been the main focus of the literature on CR behavioral problems. However, since the external validity of common global behavior measures has been established across different stages of dementia including early stage dementia (Weiner et al., 2000), those measures seem to appropriately capture common problem behaviors of CRs with and without diagnosed demented conditions (Gaugler, Davey, Pearlin, & Zarit, 2000). Therefore, the global measures have not been limited to the study of behavioral problems in CRs with cognitive impairment. Although the prevalence of problem behaviors is usually highest among dementia elders (e.g., 67% of study participants in Gilliam & Steffen, 2006) as compared to general dependent elders (e.g., 18% of study participants in Tennstedt & Assmann, 1998), similar findings have been found in the link between CR-behaviors and CG well-being regardless of whether the CR has dementia or not.

General Research Findings Using Global Problem Behavior Measures

Regardless of the sample under study, the impact of CR problem behaviors on CG well-being has been typically examined via *a global behavior score* that encompasses different types of CR-behaviors (e.g., verbally/physically aggressive behaviors, wandering, repetitive behavior; e.g., Alspaugh et al., 1999; Beach et al., 2000; Black & Almeida, 2005; Hooker, 2002; Schultz et al., 1993; Schultz et al., 1995). Most studies have found that the presence of CR problem behaviors as *a whole* has a significant association with various negative indicators of CG emotional/physical well-being, such

as increased levels of CG perceived stress, depressive symptoms, and perceived health problems. In other words, in general, CGs who report higher mean scores of CR problem behavior frequencies and/or severity, over a certain caregiving-period (e.g., in the past month), report elevated levels of emotional health symptoms, such as depressive symptoms and perceived overload, compared to those CGs who report lower mean scores of CR problem behavior frequencies and/or severity. Furthermore, a recent study by Mausbach and his colleagues (2007) provides some evidence that emotional distress caused by CR problem behaviors can also influence physiological well-being. With their 18-month longitudinal study of 1222 CGs of CRs with Alzheimer's disease or related disorders, they found that higher CG depressive symptoms and higher problem behaviors scores (measured via a global problem measure with frequencies and severity) together predict the timing of CG cardiovascular disease onset after controlling for socio-demographic and health factors (i.e., heart disease, heart attack, congestive heart failure, angina, or myocardial infarction).

Whereas the use of a global behavior problems score from global behavior problem measures has been the main tool for examining CR problem behavior in the family caregiving research literature, a few researchers have separately examined *sub-types* of CR problem behaviors (e.g., Covinsky et al., 2003; Davis & Tremont, 2007; Heok & Li, 1997). For example, Covinsky and his colleagues (2003) found that angry or aggressive behavior was a strong predictor of CG psychological well-being (i.e., depressive symptoms), whereas being a danger to self or others or waking a CG up at night were not. Similarly, Davis and Tremont (2007) found that among behaviors related

to dementia, executive dysfunction and disinhibition were significant predictors of CG burden whereas apathy was not. Heok and Li (1997), in their study of CGs for elders with dementia, also found that CR delusion, hallucination, depression, agitation, sleep disturbance, and incontinence were significantly related to CG emotional well-being based on simple bivariate correlation analyses whereas wandering and hostility were not. Surprisingly however, when these different types of CR behaviors were simultaneously entered in a multiple regression, they found that none of the individual symptoms (e.g., delusion, hallucination) or behaviors (e.g., agitation) significantly and uniquely predicted CG emotional health; only the aggregated behavioral problems score (including all CR symptoms and behaviors) did. Although Heok and Li's (1997) study did not find a significantly unique contribution of each sub-type of CR problem behavior to CG emotional well-being, their correlational results suggest some behaviors were highly associated with CG-well-being while others were not, and their non-significant findings in sub-types of CR problem behaviors could be due to the fact that their sample size was small ($N = 50$).

In short, contrary to the well-established aggregated impact of CR problem behavior shown in the conventional global CR behavior studies, there is limited knowledge about the impact of specific types of CR problem behavior. The small pieces of evidence from studies on sub-types of CR problem behavior suggests that there is variability in impact on CG emotional well-being from different types of CR problem behaviors. Thus, different types of and specific problem behaviors may require more

attention from researchers in order to fully understand the impact of CR problem behaviors on CG well-being.

Impact of Changes and the Unpredictable Nature of CR Problem Behavior

Although cross-sectional designs with one-time data collection is still the dominant method in the extant caregiving research for convenience reasons (e.g., cost-effectiveness, availability of data), a few studies have documented the unpredictable nature of CR problem behaviors via multiple-point longitudinal studies (e.g., Hooker et al., 2000) and a few have investigated on examining the impact of daily fluctuation of CR behaviors on CGs (e.g., Koerner & Kenyon, 2007). Based on the findings of these studies, it is possible that changes in CR problem behaviors, such as the unpredictable occurrence or increased level of CR problem behaviors on a particular occasion, perhaps causing CG stress or burden can be as troublesome as the behaviors themselves. In fact, stress theory (e.g., Lazarus & Folkman, 1984) also addresses the strong negative impact of the unpredictable nature of CR problem behavior (see the following Theoretical Framework section). In the following section, longitudinal studies that investigated changes in CR problem behaviors and CG well-being overtime are reviewed.

Change of CR Problem Behavior Over Time

The medium- to long-term longitudinal studies follow CRs and/or CGs over a timeframe of three months to three years. When viewing their samples as a whole, these studies report stability in the frequency of CR problem behaviors over time (e.g., Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Levy et al., 1996; Wagner, Teri & Orr-Rainey,

1995; Zarit, Anthony, & Boutseli, 1987). However, close examination of the sub-groups of the samples in the studies has revealed a substantial number of CRs who engage in increased or decreased problem behaviors over time. These changes, however, were averaged and thus masked in the “overall participants’ mean results” reported in many studies.

With an examination of sub-types of CR problem behaviors, Fauth and her colleagues (2006) also found that there was significant within-person variance in multiple domains of CR problem behaviors (e.g., memory loss-related behavior, restlessness) over a three-month period (with measurement taken at three points of data collection), although as a group, CRs appeared to remain stable in the frequency of CR problem behaviors. Importantly, similar to the pattern of CR problem behavior, some longitudinal studies have shown long-term within-person variance in CG emotional physical well-being (Alspaugh et al., 1999; Beach et al., 2000; Schulz et al., 1993). These studies that provide evidence of long-term changes in both CR problem behaviors and CG well-being suggest the need for examining not only *the impact of mean differences (between-person differences)* in CR problem behaviors but also *the impact of long-term changes*. Perhaps there is also a need for examining the impact of *shorter-term changes—day-to-day within-person variance*—in CR problem behavior.

Impact of CR Problem Behavior on CG Well-Being Over Time

Confirming the importance of examining the changes in CR problem behaviors, some previous research has demonstrated evidence of the significant impact of *changes in CR problem behaviors on changes in CG physical health* (Hooker et al., 2002) and

psychological health (Alspaugh, Zarit, Stephens, Townsend, & Greene, 1999; Aneshensel et al., 1995; Bédard et al., 1997; Gaugler et al., 2000; Hooker et al., 2002; Schulz et al., 1993). Whereas changes in CR problem behaviors have been consistently found to be significant predictors of changes in CG emotional and physical health overtime, changes in other caregiving stressors, such as ADL demands, have not. For example, Aneshensel and colleagues (1995) found that an elevated level of CR problem behaviors was significantly associated with an elevated level of CG perceived stress (i.e., role overload and role captivity) at each measurement point (i.e., T2: one year after the initial wave; and T3: three years after the initial wave), whereas an increased level of ADL dependencies was significantly associated with an increased level of perceived CG stress only for from T1 to T2 but not for from T2 to T3, indicating possible CG adaptation in the face of ADL dependencies. Similarly, Schulz and his colleagues (1993) found that an elevated level of CR problem behavior was a significant predictor of depression for each data point (i.e., T2: 6 months after the initial wave; T3: 12 months after the T2; and T4: 6 months after the T3) and the negative impact of CR problem behavior increased over time, whereas an increased level of ADL dependencies did not. Surprisingly, however, when caregiving demands as a whole, including CR problem behavior, ADL dependencies, and cognitive impairment were examined as a predictor, the researchers did not find direct impact on depressive symptoms.

These pieces of evidence suggest two things. First, results from aggregated analyses with sub-types of CG stressors, as well as CR problem behaviors, should be cautiously examined given the possible masking of both individual differences and

fluctuation in CR problem behavior over time. Second, there may be a significant impact of the over time changes (unpredictability and increases) in the CR problem behaviors on CG emotional and physical health that are beyond CG adaptability to the caregiving situation. However, due to statistical analyses applied in the above studies, there are still challenges with respect to how the results can be interpreted. This type of longitudinal analyses does not take into consideration each caregiver's T1 score (i.e., intercept of both predictors and dependent variables). Thus, the significant decrease in well-being for certain caregivers could be *partially* due to the increased level of CR problem behaviors and also *partially* due to the caregivers' initial well-being (T1). That is, as compared to caregivers with moderate level of well-being at T1, but non-significant decreases in well-being, caregivers with significant decreases in well-being may be those who start out with higher well-being scores at T1. In other words, the long-term impact of CR problem behaviors is confounded by both rate of change over time (how much they change: *within-person differences*) and mean level differences (where they start at: *between-person differences*).

Impact of Mean Level (Between-Person Differences) vs. Rate of Change Over Time (Within-Person Differences)

In order to clarify the previous findings on differences in the long-term effects of different caregiving demands (i.e., CR problem behavior, ADL dependencies, and cognitive impairment), Gaugler and his colleagues (2000) examined the same Aneshensel (1995) dataset but maximized the benefits of having four-wave longitudinal data with an advanced statistical technique. By applying multilevel analyses with a structural equation

modeling, they examined the impact of two separate components in caregiving demands: *mean level differences (between-person differences)* and *rate of change over time (within-person differences)* across different types of caregiving demands: CR problem behavior, ADL dependencies, and cognitive impairment. They found that the rate of change, as opposed to the initial level, in both ADL demands and CR problem behaviors (but not cognitive impairment) was found to be a strong predictor of increases in CG perceived stress (i.e., role overload). Notably, however, when covariates between ADL demands and CR problem behaviors were taken into consideration, only the rate of change in CR problem behavior was a strong predictor of CG perceived stress.

These medium- to long-term longitudinal research studies (Hooker et al., 2000) suggest that a possible partial cause of the high level of stress among CGs affected by CR problem behaviors are the nonlinear (unpredictable) changes in behavioral problems, as opposed to linear (predictable) changes observed in cognitive and functional declines. However, these longitudinal studies, that focused on how CR problem behaviors change over a relatively long period, such as over three months and over three years, still leaves unaddressed the issue of daily fluctuation. In order to examine the actual daily unpredictable occurrence of CR problem behavior and its impact on CG emotional and physical well-being, daily data on CR problem behaviors are needed.

Daily Data

Only a few studies have examined CR problem behaviors and CR well-being using a daily method. These studies found significant daily variability in CR problem behavior (Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Koerner & Kenyon, 2007;

MaloneBeach, Zarit, & Farberman, 1995). For example, based on 14 daily diaries from 43 family CGs of Alzheimer's patients, MaloneBeach et al., (1995) compared three caregiving groups: (a) cluster one, those who experienced no variability in CG emotional well-being (i.e., mood), (b) cluster two, those who experienced medium variability in CG emotional well-being, and (c) cluster three, those who experienced large variability in CG emotional well-being across 14 days. Although these researchers found no significant differences in the daily variability of CR problem behavior across the three clusters, when cluster one (no variability) and three (large variability) were contrasted with post hoc analyses, they found significant differences in CR problem behavior daily variability. However, unlike multilevel analyses, which specifically could test the association between the *increases* in the CR behaviors and *increases* in the CG well-being by controlling for the individual mean level, a cluster comparison could compare only the CR well-being across different groups with different levels of CR variability. Therefore, these researchers could only assume that the variability in CG emotional well-being could be caused by the variability in CR problem behavior. However, it is possible that the group differences in CG well-being could be caused by other third variables that are different across groups.

A recent daily diary study by Koerner and Kenyon (2007) took a further step by examining the impact of the daily (within-person) variance of CR problem behavior on daily variability in CG emotional and physical well-being with multilevel analyses. With 8 consecutive days of data, within-person analyses revealed that, on days when CG experienced more CR problem behaviors than their average, CGs reported an increased

level of negative indicators of CG well-being compared to their average (i.e., increased CG depressive symptoms, feelings of burden, and physical symptoms). However, this study examined the impact of daily fluctuations in CR problem behaviors based upon a global problem behavior score. Therefore, the impact of daily fluctuations in each specific problem behavior is still unknown.

These daily diary studies confirm the importance of examining the impact of daily variability of CR problem behavior on the daily fluctuation of CG well-being. However, none of these studies has examined the impact of daily fluctuations of a specific CR problem behavior such as CR-resistance. It is particularly important to examine specific behaviors because, as noted in Fauth et al. (2006), there are different levels of mid-term (three-month) variability across sub-types of CR problem behavior. It is certainly possible that these differences in variability could be observed at the daily level across sub-types of CR problem behavior.

What Are the Remaining Questions from the Conventional Global CR Problem Behavior Studies?

In the studies that utilize global measures, because specific types of CR problem behaviors are often aggregated *over an extended period* and *across different caregiving contexts*, three sets of interrelated questions remain unaddressed. These questions fall into the domain of context, occurrence, and impact:

(a) context: *which* of these specific problem behaviors do occur in *what contexts* (e.g., during assistance with personal care, in unfamiliar places)?

(b) occurrence: on average (over the past month), *how often/if ever* do these specific behaviors occur; do these specific behaviors *vary from day-to-day*? and

(c) impact: *how stressful are specific CR problem behaviors* for CGs on average, and how do CGs react to the day-to-day fluctuations of CR problem behaviors?

First Remaining Question: Which of these Specific Behaviors Do Occur?

Although scholars have addressed the importance of examining CR-problem behaviors in a specific context (Volicer & Hurley, 2003), only a limited amount of research, mainly on intervention programs, has examined specific CR problem behaviors in specific contexts. These intervention programs are typically built within a psycho-educational skill building program often based on the Antecedent-Behavior-Consequences (ABC) model and the Progressively Lowered Stress Threshold (PLST) model (e.g., Teri et al., 2003; Teri et al., 2005). These programs focus on CGs' better understanding and handling of caregiving challenges. In the process of an intervention program, in order for a CG to identify a specific problematic behavior (targeted behavior) and to learn skills to manage or to reduce the behavior, this type of study typically focuses on a specific context in which the targeted behavior occurs.

For example, in one of the typical intervention programs using the ABC model, CGs were asked to identify the most stressful targeted CR problem behavior and observe the antecedents and consequences of the targeted behavior. Then, in order to reduce the occurrences of that targeted behavior, CGs worked on monitoring and managing the antecedents and the consequences of the targeted behavior. Studies of this kind are useful

and practical to educate CGs with a specific targeted behavior based on their own experience that they can continue to work on at their home.

As evidenced in the intervention literature, in order for professionals to develop effective and efficient intervention programs, it is important to conceptually understand a specific CR problem behavior in association with the specific context in which this behavior occurs. Thus, the current study implemented a 8-consecutive-day daily measure to systematically capture CR-resistance and CG physical and emotional well-being focusing on the context of daily routine care assistance or provision. The follow-up qualitative part of this study further explored possible different types of CR-resistance and CG personal factors that influenced CG development of self survival strategies under caregiving challenges, including CR-resistance, by paying close attention to different levels of the caregiving context (care provision specific vs. caregiving in general).

Second Remaining Question: On Average, How Often/If Ever Do these Specific Behaviors Occur; Does the Occurrence of these Specific Behaviors Vary Day-to-Day?

In the conventional global CR problem behavior studies as well as in those studies that focus on sub-types of CR problem behaviors, CR problem behaviors are often retrospectively reported by the CG at one-time regarding their experience over a certain time-period (e.g., in the past week: Gilliam & Steffen, 2006; in the past two weeks: Lawrence, Tennstedt, & Assmann, 1998). Therefore, in the one-time point data collection method, CGs report on CR problem behaviors in terms of their perception of aggregated CR problem behavior experience—a global CR problem score [e.g., asking CGs to think back over the past month and to report the frequency of each problem behavior (e.g., 0 =

has not occurred to 4 = 16 or more days) or report the severity of each problem behavior (e.g., how bothered or upset: 0=not at all to 4=extremely) and, then, a total problem behavior score is aggregated for each CG]. The global problem behavior score not only includes the CG's experience of a wide range of CR problem behaviors, it masks any uneven occurrences of CR problem behaviors across days—day-to-day fluctuations. In this type of data, researchers cannot take into consideration the different fluctuations among the sub-types of CR problem behaviors.

For instance, with the type of global problem behavior scale which asks each CG to report the occurrence as well as the level of difficulty across a wide range of CR problem behaviors, a CG who experiences one traumatic CR behavioral incident with a level 4 difficulty score (e.g., physical aggressiveness toward the CG) within the past two weeks would have the same global behavior score as a CG who experiences minor problem behaviors with a level one difficulty (e.g., wandering around the house) on four days. When researchers evaluate the impact of CR problem behaviors only by the global score without examining the different levels of difficulty across different behaviors, the impact of these variations in levels of difficulty and types of behaviors can be ignored. Although, as discussed in an earlier section, the sub-types of CR problem behaviors has been and can be examined by separately analyzing sub-scales within the global measure, examining sub-types of CR problem behaviors via one-time data still masks any day-to-day fluctuation in the behavior and, therefore, in CG daily experience.

Third Remaining Question: How Stressful are Specific CR Problem Behaviors for CGs On Average, and How Do CGs React to the Day-To-Day Fluctuations of CR Problem Behaviors?

Because this particular CR problem behavior, CR-resistance, itself has received little research attention, we do not know whether this particular stressor brings emotional and physical impact on CGs; and whether typical moderators of the link between CG stressors and CG emotional and physical well-being that have been identified in the extant literature and theoretical frameworks, is applicable for this particular stressor at between-person mean level.

Moreover, limited numbers of studies that have investigated day-to-day fluctuation of CR problem behaviors and its impact on CG emotional and physical well-being, have provided evidence that different types of CR-problem behaviors vary day-to-day and that this daily fluctuation could have a negative impact on CG emotional and physical well-being. However, research has not yet precisely documented the day-to-day occurrence of this critical CR behavior—CR-resistance, nor has it investigated the impact of daily fluctuation in CR-resistance on CG emotional and physical well-being.

Furthermore, even if those typical moderators play roles for CR-resistance at CG between-person mean level, we do not know whether those moderators influence in the same ways to the daily fluctuation level: the link between CR-resistance within-person daily fluctuation and CG daily emotional and physical reactivity. Examinations of this CR-resistance daily fluctuation impact and possible moderators were important topics in the field since negative consequence of CG short-term reactivities on individual long-

term emotional and physical health has been documented in other fields (e.g., general cardiovascular health literature: Uchino, Cacioppo, & Kiecolt-Glaser, 1996).

Theoretical Framework

The current study, grounded in selected tenets from Stress Theory (Pearlin, 1990) and the Social Cognitive Theory of Bandura (1989; 2001), examined CG experience of CR-resistance and its impact on CG emotional and physical well-being. Specifically, several tenets of Stress Theory support the main conceptual themes of the current study regarding (a) an *examination of a specific stressor*—CR-resistance, (b) the *notion of ongoing change and ambiguity* in the caregiving situation—day-to-day fluctuation, and (c) the *role of background/contextual factors*—as sources of CG resources. For the specific hypotheses and research questions, several tenets from Social Cognitive Theory were applied in selecting possible moderating factors in the link between CR-resistance and CG emotional and physical well-being. In the following sections, before the detailed applied tenets are discussed, a brief summary of Stress Theory and Social Cognitive Theory is provided.

Stress Theory

In the family caregiving literature, Stress Theory has been a dominant framework (e.g., Lazarus & Folkman, 1984). Based on the Lazarus and Folkman's (1984) general model of stress and coping, caregiving researchers have developed several stress models (e.g., Pearlin et al., 1990) to examine psychological and physical effects of caregiving. These stress models usually include common core components, such as

background/contextual factors, stressors, resources, appraisals, and outcomes. Briefly describing the main tenets of the general stress-coping model, stress is defined within the context of the environment and individuals. Stress is experienced when demands from the environment exceed the available resources. For determining the levels of stress, the mediating processes of appraisal--CG cognitive processes-- are crucial factors. As noted earlier, caregiving stressors are the problematic conditions and difficult circumstances experienced by a CG, such as CR functional levels, CR cognitive impairments, behavioral status of the CR. Appraisal evolves over time as the individual re-appraises the stressor (e.g., caregiving situations). Some models separate stressors into objective (e.g., numbers of tasks provided by the CG) and subjective stressors (e.g., level of overload reported by the CG), and/or into primary (e.g., CR functional impairment) and secondary stressors (e.g., family disagreement regarding caregiving; see Pearlin et al., 1990).

A primary appraisal is made when a person evaluates a care-related stressor (e.g., the amount of CR-resistance) whereas a secondary appraisal is made when the evaluation entails what can be done to deal with the situation (e.g., whether the CR-resistance is manageable or overwhelming). Stress Theory suggests that individuals' cognitive appraisals and resources influence how individuals deal with their challenging situations, and that is reflected in their emotional and physical well-being. By applying this stress model, caregiving researchers have examined which CGs manage better or worse in their caregiving situations and what factors in the stress model play roles in their successes and challenges.

Stress Theory: Examining a Specific Stressor

Stress Theory (Pearlin et al., 1990) suggests that the mechanism by which specific caregiving stressors influence CG well-being would vary depending on the type of stressor. In other words, different types of specific CR problem behaviors (e.g., CR-resistance, wandering, repetitive actions) could differently influence a CG's cognitive appraisal of whether the specific behavior is stressful to manage with their available personal and interpersonal resources (e.g., sense of mastery, social support), and thus, could differently influence CG emotional and physical well-being. It is surprising that, despite the wide use of stress models in the caregiving literature, the majority of CR problem behavior studies do not acknowledge the possibility that, with different types of CR problem behaviors, different stress mechanisms may exist in association, and, thus, researchers continue to utilize global CR problem behavior measures. The current study focused on a specific CR problem behavior—CR-resistance.

Stress Theory: Notion of Ongoing Change and Unpredictability

CGs experience continuous changes and transitions in their caregiving situation. Pearlin and his colleagues (1994) refer to this caregiving journey as a caregiving career. Although Pearlin is referring to change from a rather in a long-term perspective, over months or years (rather than short-term), some empirical studies (e.g., Koerner & Kenyon, 2007) suggest that CGs can face changes and transitions in the much shorter-term, such as over weeks or days. As noted earlier, recent daily diary study findings (Koerner & Kenyon, 2007) revealed some of the day-to-day fluctuations in caregiving stressors and CG well-being, and the fluctuations in CG well-being were accounted for

by fluctuations in CG stressors such as increased levels of care that CGs needed to provide.

Moreover, Stress Theory suggests that unpredictable stressors in the caregiving context, such as suddenly exhibited CR aggressive behaviors, would entail greater stress on CGs than other stressors which CGs can predict, such as cognitive declines and level of required care. This tenet supports the extant findings in the caregiving literature that CR problem behaviors pose more CG emotional/physical stress than CR cognitive decline and required instrumental care for the CR. In fact, stress researchers (Boss, 2002; Lazarus & Folkman, 1984) also discuss ambiguous situations as one of the most taxing conditions where individuals can lose a sense of control. According to Lazarus and Folkman (1984) ambiguous situations are ones wherein the CG cannot know exactly “what is going to happen *and* the likelihood of its occurrence (event uncertainty) *and* when it will happen (temporal uncertainty) *and* how long it will last (duration)” (p. 103).

Although the ambiguity described in stress theory refers to a wider context--a situation--instead of a specific incident such as a CR problem behavior experience, perhaps an intense or ongoing occurrence of a particular CR behavior problem could increase the ambiguity of the caregiving situation because of its unpredictable nature; the CG may not know when and/or how long the behaviors will occur or if they will continue. Therefore, the CG cannot easily anticipate caregiving demands and can easily lose control over the situation. Importantly, Stress Theory also suggests that, in an ambiguous situation, some personal factors, such as sense of efficacy and socio-emotional support, might play greater roles, perhaps moderating roles; “whenever there is

ambiguity, person factors shape the understanding of the situation, thereby making the interpretation of the situation more a function of the person than of objective stimulus constraints” (Lazarus & Folkman, 1984, p. 104). In this regard, it is important to include personal and interpersonal factors in the current study, examining the impact of an unpredictable stressor—CR-resistance—that could increase ambiguity in the caregiving situation.

Stress Theory: Role of Background/Context

Stress theory recognizes that the stress process unfolds within the context of social, economic, cultural, personal, historical, and political factors. These background and contextual factors, as moderators, influence the extent to which subgroups of individuals are likely to experience and display factors in the stress model (Anesensel et al., 1995), such as in cognitive process, coping style, and other resources. Background and context factors in Stress Models can be identified at different levels—from small to large contextual units, such as individual (e.g., health, age, and type of illness), dyad (e.g., types of CG/CR relationship, history of relationship), family (e.g., household structure), ethnic/cultural groups (e.g., cultural view of aging and caregiving), and historical time (e.g., available social resources, technologies). These background and contextual factors are unique characteristics that provide strengths or challenges in the individual’s coping process. Applying this concept in a specific caregiving situation, depending on CG background/context factors, the mechanisms by which CR problem behaviors influence CG emotional and physical well-being varies.

Among those possible backgrounds and contexts, the current study focused on several factors that provide CG personal, inter-personal, and social resources that are relevant to the caregiving context: (a) an individual level—CG sense of efficacy, (b) a dyadic level—CG and CR relationship quality before caregiving, (c) a family/friends level—socio-emotional support and family disagreement, and (d) a community level—community/professional service utilization. These background/context factors were examined as moderating factors which may influence the link between CR-resistance and CG emotional/physical well-being. They are discussed in detail later with the extant literature in the potential moderators section.

In the Stress Theory framework, personal, inter-personal, and social resources are addressed as both mediating and moderating factors that influence or modify causal relationships between stressors and CG emotional and physical well-being. Specifically, whereas mediating factors are key causal mechanisms in the link between CG stressors (e.g., CR problem behaviors) and CG well-being, such as feelings of burden, the moderators are key interacting factors which influence the degree to which CG stressors influence CR emotional and physical well-being. This study focused on the latter, the potential moderators. Moderator analysis allows researchers to reveal which CGs are likely to do better or worse than others in caregiving situations. In other words, the current study examined whether potential moderators—sense of efficacy, socio-emotional support, family disagreement, community/professional resource utilization, or CG-CR relationship quality before caregiving, buffer or exacerbate the impact of CR-resistance on CG emotional and psychological well-being. Particular attention was paid

in these moderating effects to two different links between CR-resistance and CG emotional/physical well-being: (a) the link between average occurrence of CR-resistance and CG average emotional and physical well-being and (b) the link between day-to-day within-person fluctuation of CR-resistance and day-to-day CG fluctuation of emotional and physical well-being.

In order to further explain the selection of moderators from Stress Theory for the current study, the overall premise and several tenets of Social Cognitive Theory (Bandura, 1989; 2001) are discussed in the following section.

Social Cognitive Theory

Social Cognitive Theory, derived from traditional learning theory, is a multidimensional framework that focuses on human agency (Bandura, 1989; 2001). Social Cognitive Theory favors a model of causation involving a “triadic reciprocal determinism” (Bandura, 1989, p. 2) between *cognition*, *environment*, and *behavior*. In this model of reciprocal causation, all these elements interact bi-directionally with each other. The unique characteristic of this theory, and its usefulness in caregiving research, is the recognition that a person, as an active agent, has the capacity to produce different outcomes in a given situation. Of these three key elements of social cognitive theory—cognition, environment, and behavior, the current study paid close attention to specific factors: CG sense of efficacy as CG cognition; social network including socio-emotional support and community/professional service utilization, and CG-CR relationship as the CG environment that evolves within caregiving activities; and CG behavior. When the premise of active agent is applied to these caregiving factors, Social Cognitive Theory

proposes that, even with the same caregiving demands—CR-resistance—individual CGs may *perceive* and *approach* the situation differently depending on their *level of sense of efficacy* in relation to their *social network*, including the amount of available socio-emotional support or strain, community resources, and the quality of relationship with their CR. In turn, based on their sense of efficacy, the same caregiving demand, CR-resistance, differently influence CG emotional and physical well-being. In the following section, specific tenets from Social Cognitive Theory and previous research on each moderating factor are discussed.

CG Cognitive Resource: Sense of Efficacy

The terms “self-efficacy” and “mastery” have often been used synonymously in caregiving research. According to Bandura (1997), “sense of efficacy” refers to both context-specific and generalized beliefs that one has the ability to be effective in producing expected outcomes (Skinner, 1995). Although Bandura (1997) acknowledged that particular types of efficacy beliefs can be transferred or cultivated across settings, he emphasizes that different efficacy beliefs are “linked to distinct realms of functioning” (p. 36). In the current study, this researcher refers to caregiving context-specific efficacy as CG sense of efficacy unless otherwise specified. Social Cognitive Theory proposes that among the core features of human agency, a person’s cognitions—in particular, a sense of efficacy (beliefs in one’s ability)—play an important role in influencing his or her perception of the nature of a given situation. An individual with a higher sense of efficacy would hold an optimistic view in a given situation and would react with much less distress, and, thus, have a higher likelihood of fully applying potential skills. Therefore,

one is more likely to succeed and gain satisfaction from the experience (Bandura, 2001). Moreover, because of optimistic views regarding one's ability in influencing situations, an individual with a higher sense of efficacy has strengthened resiliency and reduced vulnerability to negative consequences (e.g., suffering from depressive symptoms, feelings of burden) in challenging situations; and, thus, would have a more positive perception of a quality of life and psychological well-being in general.

Applying this tenet of Social Cognitive Theory, sense of efficacy, in a specific caregiving setting, Social Cognitive Theory explains that CGs who have a higher sense of efficacy would have an optimistic view in their caregiving situation. As such, compared to CGs who have lower sense of efficacy, these CGs who have a higher sense of efficacy would have an optimistic view in the face of CR-resistance because of their belief in their abilities to deal with CR-resistance and other caregiving challenges. Therefore, these CGs would perform better with strengthened resiliency and reduced vulnerability to negative consequences, such as suffering from depressive symptoms and feelings of burden.

In the caregiving literature, *CG sense of efficacy* has been conceptualized as both a moderating and a mediating factor between CG stressors and emotional/physical well-being. When researchers conceptualize CG sense of efficacy as a stable personal trait throughout their caregiving career, CG efficacy is treated as a moderator which can buffer the impact of care-related stressors on CG emotional/physical well-being. When researchers conceptualize CG efficacy as a changeable state which can be influenced by the level of caregiving stressors or interventions, then caregiving efficacy is considered as a mediator. However in real life settings, as seen in the previous literature (reviewed

below), it is not clear whether the CG sense of efficacy should be considered solely as a moderator (stable resource) or mediator (changeable state) of the link between CG stressors and emotional/physical well-being. As a CR's condition worsens, researchers have also addressed the possible change in the level of CG sense of efficacy required to provide for the CR (Steffen, McKibbin, Zeiss, Callagher-Thompson, & Bandura, 2002). In this regard, when researchers include CG sense of efficacy in their research design, it is important to consider the specific given study period (e.g., over a week, over a month, over a year) and whether both *level of CG sense of efficacy* and *required level of CG sense of efficacy (due to changing caregiving demands)* are likely to change. In the current study, CG sense of efficacy is viewed as a stable trait or resource, particularly during the 8 consecutive survey days, and was measured one-time in the initial questionnaire. Therefore, it was considered as a moderator.

Although theoretical frameworks (e.g., Stress Theory and Social Cognitive Theory) discuss possible moderating or mediating roles of "sense of efficacy" within a caregiver stress mechanism, most empirical caregiving studies have examined CG's sense of efficacy in its direct association to CG's emotional/physical well-being. For example, many caregiving studies reveal significant negative associations between CG sense of efficacy and caregiving negative outcomes, such as anger (Steffen et al., 2002), depression (Yates, Tennstedt, & Chang, 1991), upset (Gitlin et al., 2001), and role strain (Miller, Campbell, Farran, & Kaufman, 1995); and significant positive associations between CG sense of efficacy and caregiving positive outcomes, CG self-esteem (Talkington-Boyer & Snyder, 1994) and feelings of gain (Sanders, 2005).

Among studies that have investigated the mediating and moderating effects, caregiving mastery (efficacy) has consistently been found to be a key moderator, specifically a buffer, of the link between caregiving stressors (e.g., CR behavioral problems) and CG emotional and physical well-being (e.g., depressive symptoms, fatigue; Adams, Smyth, & McClendon, 2005; Goode, Haley, Roth, & Ford, 1998; Li, Seltzer, & Greenberg, 1999; Mausbach et al., 2007). For example, in their study of 115 adult daughter CGs, Li, Seltzer, and Greenberg (1999) studied changes in CG depressive symptoms over 18 months. They found that adult daughter CGs with higher levels of mastery reported reduced depressive symptoms over 18 months as compared to those with lower levels of mastery because CGs with different levels of mastery applied different coping strategies. Notably, none of the studies has examined the moderating effect of CG sense of efficacy on a *daily* basis. In the current study, CG sense of efficacy was examined as a moderator in a short-term study (8 consecutive survey days)--a moderator within the link between daily levels of CR-resistance and daily levels of CG emotional and physical well-being. As noted earlier, the current study particularly examined the moderating role of the two components within this link: (a) average occurrence of CR-resistance on CG average emotional/physical well-being and (b) day-to-day within-person fluctuation of CR-resistance on day-to-day CG fluctuation of emotional and physical well-being.

CG Background: CG-CR Quality Relationship Before Caregiving

The quality of the CG-CR relationship before caregiving may play an important background role in how CGs perceive and approach the given caregiving situation,

perform their caregiving role, and evaluate their contributions to family members through caregiving. Social Cognitive Theory portrays how individuals develop their personal values and standard in their immediate environment (e.g., family), and the immediate environment could also influence their evaluation of whether a given situation is rewarding or hindering. In the caregiving case, CGs develop caregiving values and standards in interactions with their family members. In most cases, their current CRs have been a part of their immediate environment which influenced their personal values and standards. If CGs had a positive relationship with their CRs before caregiving started, the caregiving situation would be perceived more positively than if it had been a negative relationship. Most importantly, the CRs could be also a part of the social network which provides positive and negative acknowledgements on caregiving performances which influence CGs' reflection on whether their caregiving situation is rewarding or hindering.

In the extant caregiving literature, some researchers have been interested in the role of CG-CR relationship quality prior to caregiving (Lawrence, Tennstedt, & Assmann, 1998; Williamson & Shaffer, 2001; Quinn, Clare, & Woods, 2009). These researchers have been interested in how the CG's perception of the quality of the relationship prior to caregiving influences the CG's perception of the caregiving situation, CG well-being, and caregiving behavior (how CGs provide care to their CRs). Although the number of studies is limited, in general, these researchers have found that a higher level of CG-CR relationship quality before caregiving was significantly related to a lower level of feelings of burden (Horowitz & Shindelman, 1983; Steadman, Tremont, & Davis, 2007; Teusink & Mahlen, 1984; Williamson & Schulz, 1990). However, there

have been mixed findings in relation to depressive symptoms; whereas some studies have found that a higher level of CG-CR relationship quality before caregiving was associated with a lower level of depressive symptoms (Lawrence et al., 1998; Williamson & Shaffer 2001), another did not (Williamson & Schulz, 1990).

Concerning the possible moderating effect of CG-CR relationship quality before caregiving, researchers (Lawrence et al. 1998) have described this factor as a possible buffer, “providing a particular lens through which stressors are interpreted or appraised. Thus,...relationship quality modifies the linkage between the stressors and negative consequences” (Lawrence et al., 1998, p. 150). However, the findings are mixed and suggest that the influence of CG-CR relationship quality on CG emotional/physical well-being is rather complicated. In the Lawrence et al. (1998) study, a moderating effect of relationship quality was found but with opposite results than the researcher’s hypotheses. A higher level of relationship quality did not offset the association between CR disability and CG perceived overload. Rather, that association was offset at the lower level of relationship quality. Other complicated findings are in Williamson and Schulz’s (1990) study. They found that male CGs who did not have a close relationship with their CRs were more depressed than were their counterparts; however, among those CGs who were low in communal orientation, female CGs who had a close relationship with their CRs were more depressed than their counterparts. More studies on moderating effects of CG-CR relationship quality are needed.

Relevant to the current study on the impact of CR-resistance, some studies show that the CG-CR relationship quality before caregiving can also influence CG approach

such as effective CG communication and harmful behavior toward the CR. That these CG approaches to dealing with CRs seem to be related to their past relationship with the CRs could be a key issue in managing CR problem behaviors such as CR-resistance. When two groups of CGs, who have a higher and lower quality of CG-CR relationship before caregiving, were compared in a study by Stedman et al. (2007), they found that the high quality relationship group not only reported less burden, but also these CGs were less distressed by CR problem behaviors and had more effective communication with the CR.

It is possible that the high CG-CR relationship quality influenced CG effective communication, which in turn influenced levels of CR problem behaviors and CG reactions to the behaviors, although the investigators did not report the differences in the level of CR problem behaviors and did not test these associations in a mediation model. Furthermore, Williamson and Shaffer (2001) found that CG-CR relationship quality prior to caregiving was negatively associated with potential CG's harmful behavior toward a CR, and that association was mediated through CG depressive symptoms. This finding suggests that CG-CR relationship quality possibly influences CG behaviors and how CGs approach or interact with their CRs.

In the current study, the quality of the CG and CR relationship before caregiving was considered as a moderator in quantitative analyses without a specific directional hypothesis of whether it buffers or exacerbates the relationship between CR-resistance and CG emotional and physical well-being.

CG Environment: Social Network

Another important tenet of Social Cognitive Theory focuses on the role of a broad

network of socio-structural influences (Bandura, 2001). According to Social Cognitive Theory, social networks as environments and sources of an individual's resources play important roles (a) in increasing an individual's sense of confidence and (b) in evaluating an individual's role performances, such as provision of care to dependent family members. The collective resources of a social network that includes the skills, knowledge, and action of the network members can increase the individual's sense of confidence. This increased confidence, and peace of mind in the individual that the members of a social network together can provide, exceeds what the individual can accomplish on their own. The individual members of a social network with their shared values and standards regarding the role can provide advice and/or feedback, such as acknowledgement of the individual's role performance.

When these tenets are applied to the caregiving situation--the CG's socio-structural context including their social network, culture, and community together with additional resources, such as skills, knowledge, and treatments--all these in concert can provide the CG confidence in his/her ability in meeting current and future caregiving demands beyond what they can manage by themselves. Individuals weight personal values and standards in relation to their designated roles, and in the role of caregiver, embedded as it is in values and standards of the immediate social network, that network contributes a great deal in CG evaluation of their caregiving situation. Specifically, positive recognition from the members of the social network could greatly influence the individual's *evaluation of not only role performance but also a given situation*—the perception of whether the situation is self-enhancing (e.g., valued) or self-hindering (e.g.,

the cause of missed social opportunities). This positive/negative perception of their caregiving situation may buffer or intensify the impact of the demanding situation on an individual's emotional/physical well-being.

Within elder caregiving studies, as well as in research in other fields (e.g., parenting), social networks have been identified as important resources for individuals facing challenging situations (e.g., Li, Seltzer, & Greenberg, 1997; Williams, 2005). Social networks, made up of family members, friends and/or community programs, are potential sources of instrumental, informational, and emotional support. Most stress models recognize social support as a moderator between CG stressors and outcomes. However, as noted in Pinquart and Sörensen's meta-analysis (2005), many studies have examined only the direct effects, or associations, of these resource factors on CG well-being, without testing their moderating effects (Williams, 2005). Moreover, when researchers examined social support as a buffer in the link between CG stressors and psychological and physical well-being, the results have not been consistent. On the one hand, a limited number of studies have found that different types of social support (e.g., instrumental, informational, emotional) do serve as buffers of the impact of different types of stressors (e.g., levels of CR's functional difficulty, behavioral problems) and on CG mental health, such as depression and anxiety (e.g., Li, Seltzer, & Greenberg, 1997).

On the other hand, the moderating hypothesis of social support for CG emotional and physical well-being has often not been supported (Adams, Smyth, & McClendon, 2005; Aneshensel et al., 1995; Miller et al., 2001; Pot, Deeg, & Dyck, 2000). Miller et al. (2001) suggested that these non-supportive results might be due to possible complex

constructs in social support and possible multiple pathways through which social support influences CG well being. Further investigation is needed in this area. In the current study, this researcher examined two different types of support: (a) emotional support from informal social network members—*socio-emotional support from partner, family, and friends*, and (b) instrumental, informational, and emotional support from formal community services—*community/professional service utilization*. Additionally, possible negative influences of social networks including *family disagreement regarding care* and *absence of a social network* were considered.

Socio-emotional support from partner, family, and friends. Of the various forms of social support, *socio-emotional* support has been identified as the most crucial predictor of CG well-being (Roth, Mittelman, Clay, Madan, & Haley, 2005). The importance of the buffering function of emotional support may be, in part, that emotional support provides and secures anticipated support for the CG (Barrera, 1986). Anticipated support is the CG's belief that significant others will provide assistance when needed in the future. This anticipated support perhaps increases the CG's sense of confidence and peace of mind not only in his or her current but also future ability to manage caregiving demands.

According to Barrera (1986), anticipated support is rooted in past experience, observation, and prevailing social norms. This anticipated support, the assurance that significant others can be counted upon to act in the best interest of the CG in the future, enhances personal control. Researchers have found that those forms of support (emotional support rather than instrumental) are typically associated with indicators of

CG psychological well-being. For example, in a longitudinal caregiving study, Schulz et al. (1993) found that the perceived availability of social support was a direct predictor of CG's psychological well-being at all measurement points; higher levels of available perceived support were associated with fewer depressive symptoms. Similarly, Williams (2005) found that CGs with larger social networks reported higher levels of reward from caregiving and fewer depressive symptoms.

In the current study, socio-emotional support from partner, family, and friends was examined as a key moderator that might buffer the negative effect of CR-resistance on CG emotional and physical well-being. As compared to distant social network members, close family members and friends have likely been in the CG's past and current life and, thus, are more likely to be a part of the immediate environment in which CG may have experienced (a) an increased (or undermined) sense of confidence regarding collective resources and (b) a positive (or negative) evaluation of their caregiving situation with positive (or no) acknowledgement of their caregiving effort.

Community/professional service utilization. In addition to support from family members and friends, community/professional services can provide instrumental (e.g., bathing, transportation), informational (e.g., referral, education), and emotional (e.g., support group) support for family CGs. Community/professional services to family CGs and their CR can be largely divided into two different types: health services and human services (Toseland et al., 1999), both provided by paid professionals rather than unpaid informal service providers (e.g., family members, friends). Health services are provided through medical professionals, such as with out- and in-patient health care, visiting

nurses, emergency medical services, nursing homes, and other medical related services. These health services could offer necessary medical treatments that cannot be provided by family CGs. Human services are provided through paid-private or public services, such as in-home and out-of-home respite, homemaker, information/referral, transportation, support group, and other community, private, or public services. These human services offer emotional and/or physical respite for family CGs to ease some of the demands of caregiving. These formal, professionally provided services have been identified as important resources that allow family CGs to provide higher-quality care for a longer period of time (Zarit, Gaugler, & Jarrott, 1999).

In the extant caregiving literature, these community/professional services have been examined in studies of a particular service use (e.g., adult day-care, home care, support groups) or as a multi-component study, examining a range of different community-based services (Toseland et al., 1999). These previous studies have consistently documented the needs of family CGs unmet by community/professional services and particular factors which predict service utilization, such as knowledge about the services, access to services, and CG resistance to support groups or educational programs (Toseland et al., 1999). However, according to a review article by Zarit and his colleagues (1999) and other recent articles, examination of the consequences of the extent of community/professional service utilization, such as impact on CG psychological and physical well-being and delayed institutionalization has revealed modest or mixed results.

For example, in-home services have been found, in general, to have only a small effect on care-related stressors (decreased time spend in care activities: Berry, Zarit, &

Rabatin, 1991), CG emotional well-being (improved mood: Curran, 1995; reduced distress: Harper, Manasse, James, & Newton, 1993; reduced feelings of upset: Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001), and delaying institutionalization (e.g., in-home health care: Zimmer & Groth-Juncker, 1982; visiting nurse: Mohide, Pringle, Streiner, & Gilbert, 1990). However, some CGs from studies that reported small positive effects of in-home services, also reported problems with in-home services regarding the reliability and quality of services, whereas no significant differences between study and control groups were found in psychological well-being in the Levin et al. (1989) study.

Studies of out-of-home services such as adult day services or overnight respite reveal mixed results. In a study by Zarit (1998), CGs, whose CRs participated in a day program more than two days a week over at least three months had significantly lower levels of care-related stressors (feelings of overload and strain) and those benefits were apparent after one year with lower feelings of overload and depression than the control group. However, other studies have found either no effect (Moriarty, & Levin, 1993) or a reversed effect (early institutionalization: Montgomery & Borgatta, 1989, Winslow, 1997; elevated CG feelings of burden: Toseland, McCallion, Gerber, & Banks, 2002). Important to the current study, Bass, Noelker, and Rechlin (1996) found that receiving personal care services moderated the relationship between CR behavioral problems and CG depression as well as CG perceived health and social isolation. That is, the negative effect of CR behavior problems was reduced when CGs utilized more personal care services.

However, mixed findings should be regarded with caution because some studies

(e.g., Gitlin et al, 2001; Zarit et al., 1998) carefully took consideration of third variables that may associate with community/professional services use, whereas other studies did not. In other words, on the one hand, some studies examined the effect of service utilization by including a control group with similar background but which did not get services or a treatment. By comparing the two groups of CGs, these intervention/experimental research endeavors can identify what specific effects (e.g., increase in CG emotional health) resulted from community/professional service use. On the other hand, other studies examined the association between care-related factors and service use in one statistical model so the effect of community/professional service use effect is confounded with many other factors (e.g., level of CR functional/cognitive impairment, CR problem behaviors). Although these studies could control other variables to examine the unique contribution of community/professional service use on CG outcomes (e.g., emotional well-being), typically this type of study focuses on what factors *predict* service use in natural caregiving settings, not necessarily the effects of service use.

Moreover, there are clear differences between an intervention/experimental research study and a naturalistic study in how research teams influence the process of CG community/professional services utilization (e.g., how CGs are informed about community/professional services and how CGs make decisions in utilizing the services). For example, in Zarit's (1998) study, CGs were informed and financially supported to participate in an adult day care program for an extended period of time whereas in Toseland's (1999) study, CGs were asked to retrospectively report their

community/professional services use along with their needs and possible barriers to use of these services. Therefore, the results from different types of studies should be interpreted cautiously, bearing in mind the circumstances under which the studies were conducted and the degree to which a study did or did not intervene in the subject behavior under examination.

Possible negative influence of social network. In the current study, as in the extant caregiving literature, researchers focus mainly on the positive influences of both informal and formal community-based support. However, the possible negative impact of social networks in the case of an absence of positive support or of negative interaction within the social network, such as family disagreements, should also be considered (Barrera, 1986). In fact, according to Krause (2001), far greater attention is given by individuals to negative rather than positive interactions, and causal attributions of negative exchanges are easier to establish than those of positive exchanges. Researchers have furthermore reported that often unpleasant social interaction is nonetheless a stable attribute of some social networks (Krause, 2001).

In this regard, it is ideal to have data to specifically measure negative exchanges between CGs and their social network. However, the existing quantitative data with which the current study was conducted did not include instruments that capture negative exchanges, except family disagreement regarding care. Possible negative family influences, such as negative family function, conflict, and disagreements have received little research attention in the caregiving literature. Among the limited number of studies that have examined the impact of family dynamics on CG emotional and physical well-

being, most have examined family disagreement as a background factor with which these study determined family dynamics in general, except a few studies. Therefore, only a few studies have determined the impact or the role of care related conflicts and disagreements for family CGs, and identified its negative impact on CG emotional health (e.g., Deimling, Smerglia, & Schaefer, 2001; Koerner & Kenyon, 2007; Scharlach, Li, & Dalvi, 2006). This negative social network factor, family disagreement regarding care, was examined as a possible moderator in the current analyses.

Further, in order to recognize other negative exchanges within or absent from other social networks, the current study carefully interpreted the moderating effects of social networks by running post-hoc analyses. With these post-hoc analyses, the associations between CR-resistance and each caregiver well-being indicator for two different groups of CGs—those with higher and lower levels of each social network support—could be plotted in terms of socio-emotional support and community/professional service utilization. It is possible that, even when significant interaction effects of a social network are found, post-hoc analyses could reveal that a social network could provide sufficient support to CGs only when CR-resistance is not so high for either groups of CGs, with high or low levels of social network support.

What a Qualitative Study Can Provide

Although CG emotional and physical well-being has been studied intensively with quantitative methods based on stress models, when the quantitative results are presented, researchers should ask themselves (a) whether the quantitative results are interpreted accurately and reflect actual CG experiences and (b) whether the quantitative results can,

by their nature, entirely capture important aspects of CG experiences that are uncommon or marginalized, or (c) whether the quantitative surveys miss important questions that should be included. Qualitative interviews can be a useful method to fulfill these possible faults or shortcomings of a quantitative study. In fact, in order to improve caregiver intervention programs, evidence-based practice evaluated by qualitative study has been promoted in the nursing literature (Sandelowski, 1996) as well as other mental health fields (e.g., school psychology; Flemming, Adamson, & Atkin, 2008).

In the primary, quantitative part of the current study, the incidence of CR-resistance, and the roles of CG personal, interpersonal, and social network resources for maintaining CG emotional and physical well-being in the face of a single CR-resistance were systematically captured. In the sequential component of the current study, qualitative data first assisted the researcher in accurately interpreting and validating the quantitative results; second, highlighted uncommon or marginalized but important CG experiences; and finally provide detailed descriptions of CR-resistance through CG perceptions that were not captured in the quantitative surveys.

Highlighting the third contribution of the sequential qualitative interviews, the qualitative data provided detailed descriptions and captured “caregiver perceptions, feelings, and internal responses” (Farran, Loukissa, Perraud, & Paun, 2004, p. 41) that could be substantially and practically important for CGs but might not be captured by standardized instruments in quantitative studies (e.g., Farran et al. 2004). To further develop conceptual understanding of the CG coping process under caregiving demands, including CR-resistance, it may be useful to learn from CGs themselves in their own

words. Although in the primary quantitative study, CG cognitive resource, sense of efficacy, and social network resources including socio-emotional support, family disagreement regarding care, and community/professional services were independently examined, some questions remained unanswered. For instance, we still do not know how CGs incorporate these internal, inter-personal, and social resources into their coping process in the face of CR-resistance and how they develop their own survival strategies for maintaining emotional well-being over a sometimes long caregiving career.

In fact, several qualitative CG well-being studies have reported the important role of one of our study's focus topics--CG cognitive resources--in successfully meeting caregiving demands. Although our primary quantitative part of study was limited to capturing CG cognitive resources in regard to one factor, sense of efficacy, qualitative data can provide more detailed information about CG cognitive processes including other related factors. For instance, some qualitative studies identified a possible linkage between CG key cognitive resources that are usually not measured in standardized quantitative instruments, such as personal attitudes and values, and sufficiency of CG identification and utilization of his/her support system and resources (e.g., Brown & Chen, 2008; Farran et al., 2004).

Moreover, one qualitative study further identified that the process of this link differed between skillful and unskillful CGs (Farran et al., 2004). Skilled CGs were able to acknowledge and accept caregiving related challenges so that they were able to better utilize available external resources in meeting caregiving demands as well as maintaining CG emotional well-being. However, these study results were limited in that they were

derived from intervention *facilitator descriptive reports* and lacked in-depth *CG self descriptions*.

In other words, little is still known about the sources and development of CG key attitudes and values. Therefore, further exploration of CG cognitive processes (noted as important in Social Cognitive Theory) under caregiving stress is needed. As noted by Sandelowski (1996), using a small sample but with in-depth qualitative interview data is particularly useful for intensive examination of “the particularities of complex phenomenon” (p. 359), here CG cognitive process within a complex CG coping process. This sequential qualitative part of the study not only assisted interpretation of the primary quantitative results but also provided valuable information to further illuminate the detailed descriptions of CG CR-resistance experiences and develop conceptual understanding of the CG cognitive process under caregiving demands.

Hypotheses and Research Questions

Quantitative Study

Hypotheses

Two hypotheses (H) focused on the impact of CR-resistance between-person *mean level differences* (see Figure s 1-3).

H1: CGs with higher mean scores on CR-resistance will have higher mean scores on negative well-being indicators and lower mean scores on positive well-being indicators.

H2: Social network influence (i.e., socio-emotional support, family disagreement, and community support/services), a CG background factor (CG-CR relationship quality before caregiving), and personal resources (i.e., sense of efficacy) will moderate the link between mean level CR-resistance and CG well-being such that the well-being of CGs with higher levels of the positive and lower levels of the negative moderators will be less negatively affected by CR-resistance.

Research Questions

Three research questions (RQ) addressed the impact of within-person *day-to-day fluctuation* in CR-resistance (see Figure s 1- 3).

RQ1: How much across-day (within-person) variation exists in CR-resistance?

RQ2: On days when CGs face more than their usual amount of CR-resistance, do they experience decreases in well-being (i.e., greater feelings of burden, depressive symptoms, physical symptoms, feelings of benefits/gains and less positive affect)?

RQ3: Are the within-person patterns of reactivity stronger for certain CGs, for those who have lower levels of efficacy, socio-emotional support, and community/professional support, and higher level of family disagreement regarding care; and those who had a poor quality pre-caregiving relationship with their CR.

Qualitative Study

In order to gather rich insights on the CG experience of CR-resistance, open-ended semi-structured interviews asked CGs about their experience with CR-resistance. The quantitative hypotheses and research question topics guided the development of the semi-structured interview questions. Example questions include:

When/how often does the CG experience CR-resistance?

How much/often can the CG predict the occurrence of CR-resistance?

How stressful is CR-resistance to the CG?

Which kind(s) of CR-resistance have been the most stressful for the CG?

How does the CG emotionally react to CR-resistance?

What personal, interpersonal, and social factors helped or did not help to overcome/avoid the impact of a CR-resistance experience on CG's emotional health?

CHAPTER 3: METHODOLOGY

This chapter describes the research methodology for the current study, including design, sampling procedure, and instruments. This methodology was designed based on the purpose of this study--investigating the impact of a specific CG problematic behavior, CR-resistance, on CG emotional/physical well-being and possible moderating factors of the link between CR-resistance and CG emotional/physical well-being. The specific research hypotheses and questions were generated based on previous family caregiving literature and two theoretical frameworks, Stress Theory (e.g., Pearlin, 1990) and Social Cognitive Theory (Bandura, 1986, 2001). As described in the previous section, negative consequences of CR general problematic behaviors, as a whole, have been widely studied in the caregiving literature. However, only a few specific behaviors have been independently examined in detail; thus, we know little about CGs' experience of CR-resistance. By applying a sequential quantitative and qualitative mixed methods design, the current study provides detailed and holistic information concerning CGs' experience of CR-resistance; the quantitative data analyses, based on quantitative 8-day daily diary data, provided numerical trends around CG experiences of CR-resistance (e.g., impact on CG emotional/physical well-being and buffering/exacerbating factors) whereas the supplemental qualitative data analyses, based on semi-structured individual interviews, provided detailed in-depth description of CG experience of CR-resistance that provided support to interpret quantitative results as well as further to expand conceptual understanding of the phenomenon.

Design

The current sequential mixed methods design consisted of two phases: the primary quantitative phase and the secondary qualitative phase. Specifically, the two kinds of data (quantitative and qualitative) were collected in sequential timing in which the quantitative data were collected and analyzed first, and then, the qualitative data were collected and analyzed (Creswell & Clark, 2007). Using Creswell and Clark's (2007) terminology, the qualitative data were, however, "embedded" within the quantitative design; the quantitative data played the primary role and qualitative data played supplemental role.

In the primary phase, by utilizing 8-day daily data, the quantitative analyses addressed the quantitative research hypotheses and questions, concerning (a) numeric description of CR-resistance occurrence; (b) the impact of CR-resistance on CG well-being viewed from a between-person 8-day mean level perspective, and from a within-person daily fluctuation perspective (see details in Chapter 4, Analytic Strategies); and (c) possible moderating factors of the link between CR-resistance and CG well-being. In the second phase, qualitative individual semi-structured interviews were used to address qualitative research questions, concerning CG perceptions of CR-resistance experiences: kinds/types of CR-resistance, circumstances around CR-resistance, CG behavioral/emotional reactions to CR-resistance, and strategies used in managing the emotional impact of CR-resistance on the CG.

Procedure

Existing quantitative data from the Daily Understanding of Caregiving Study (DUCS; Koerner & Kenyon, 2007) were used for the primary phase of the proposed research, whereas qualitative data were newly collected as supplemental data from a subset of the original DUCS participants.

DUCS Forced-Choice Self-Report Surveys

The study participants were recruited for the larger project, DUCS, from a variety of sites in southern Arizona (e.g., family practice clinics, medical supply stores) between August 2003 and July 2004. When potential participants called the number on the recruitment flyer, they received information about the project and were asked a set of eligibility questions. To be eligible, the caller had to (a) be the primary CG for a dependent family member (e.g., spouse, parent, in-law) who was at least 60 years of age, and (b) provide at least 10 hours/week of assistance with either instrumental activities of daily living (IADL: e.g. shopping, paying bills, monitoring medication) and/or activities of daily living (ADL: e.g., dressing, bathing, eating). In addition, the CR had to be community-dwelling (i.e., living in his/her own home or in the home of the CG and not receiving extensive in-home professional care).

Eligible callers were asked a few questions regarding their CR's impairments and, if interested in participating (all were), were sent an introductory letter. Within one week, each CG was mailed a questionnaire packet. Questionnaire packets were sent to 78 CGs, and 63 (81%) returned completed questionnaires.

The packet contained (a) a consent form, (b) a form to report the CG's Social Security number (for taxation purposes), (c) an initial questionnaire, (d) eight daily questionnaires (DQs), (e) one envelope labeled "initial survey", (f) eight envelopes labeled "Day 1" - "Day 8", (g) a small postage-paid, preaddressed envelope for return of the completed consent form and Social Security form, and (h) a large postage-paid, pre-addressed envelope for the return of all the completed questionnaires. First, CGs were asked to report stable personal and other characteristics and demographics (e.g., income) in the initial questionnaire, and then, CGs were asked to report their daily experiences at the end of each day on eight consecutive survey days (e.g., CR-resistance, depressive symptoms) in the DQs. An ID number was given to each participant; the ID number, but no participant name appeared on the questionnaires. For their participation, CGs received \$40 and were entered in a drawing to win a \$100 giftcard to a national retail chain.

DUCS original 63 participants. Of the 63 CGs who comprised the sample, 46 were female and most were non-Hispanic White ($n = 51$) or Hispanic ($n = 9$). At the time of the original surveys, participants ranged in age from 20 to 85 years ($M = 56.7$, $SD = 13.2$ years), with 62% older than 55. Nineteen were CGs for their spouse/partner, 39 for their parent, four for their parent-in-law, and one for their grandmother. The length of time as CG ranged from 2 months to 20 years ($M = 4$ years 4 months; $SD = 4$ years 1 month); however, for 70% of the participants, length of time as a CG ranged between one and eight years. CGs' annual household income was less than \$60,000 for 78% of the sample; mean income was between \$30,000 and \$39,000. Education ranged as follows: 33% of the CGs had a four-year college degree or more, 56% had some college or

vocational/technical school education, 5% completed high school only, and 6% had some high school education or less.

The CRs included 41 females and 22 males; most were non-Hispanic White ($n = 50$) or Hispanic ($n = 10$). At the time of the original surveys, they ranged in age from 59 to 99 ($M = 81$ years, $SD = 10$ years; the DUCS PI decided that 59 was close enough to the age 60 criterion). The health conditions that put them in need of caregiving included cognitive impairment, mobility problems, heart conditions, chronic obstructive pulmonary disease (COPD), renal problems, and diabetes. Most ($n = 53$) suffered from multiple conditions.

Supplemental Semi-Structured Interview

All 63 original DUCS survey participants, regardless of their current caregiving status (e.g., continuing CG, former CG), were targeted during recruitment for the supplemental semi-structured interviews conducted between July and December 2009. Using the contact information provided during the original DUCS survey, these 63 potential follow-up participants were contacted with a letter reminding them about the previous DUCS study and explaining that they would be getting a phone call regarding a possible follow-up interview (see Appendix A). Of these 63 letters, 25 were returned to the sender with postal notification of no forwarding address. Following the introductory letter, the current project principal investigator (PI) tried to make contact with the 38 potential interviewees via phone (Appendix B). Of these 38, the PI spoke with 23 either by (a) the CG initiating a call in response to the letter, (b) the PI calling the CG one week after the letter was sent, or (c) the CG calling back the PI after the PI left a phone

message. The reasons for unreached other 15 CGs were unknown; they might have changed their phone numbers or addresses (but the IP did not get undelivered notifications from the post office) from original DUCS survey or had other life circumstance changes (e.g., death, did not pay the bill). During the phone conversation with the 23 potential interview participants, the PI described the interview procedures and asked the CG whether they were interested in participating. Of these 23 CGs, 20 agreed to participate in the follow-up interview; three CGs declined to participate because of their current life circumstances (e.g., busy. At the end of the phone conversation). For these 20 CGs who agreed to participate, interviews were scheduled. The interviewees had the choice of having the interview take place in their own home, in a private study room at one of public libraries, or in one of the closed/private offices in the McClelland Park Building on the University of Arizona campus. One CG who agreed to participate ended up not participating in an interview because the CG missed multiple interview appointments. Thus, a total of 19 CGs were interviewed.

The PI could have continued to recruit more participants by contacting potential interviewees via email addresses provided by about half of the original DUCS CGs. However, the PI decided that the 19 interviews contained sufficiently rich data to address the current research questions. Data collection reached a saturation (Creswell, 1998) point by the last few interviews where the same themes repeatedly appeared without adding new themes.

Each interview was conducted by the PI. Just prior to the start of each interview, the participant CG read through the informed consent form (see Appendix C) to confirm

the purpose, selection criteria, procedure, and potential risks/benefits of the study. After answering CG questions regarding the study, the consent of the CGs was requested with their signature on the last page of the consent form. Each interview was lasted approximately one to two hours and guided by a set of research question topics (Appendix N); CGs were asked to expand on their noteworthy experiences with specific examples and their perceptions. The interviewees received \$25 for their participation. The interviews were audio-recorded and transcribed for data analyses. During and immediately after the interviews, the PI took observation-based field notes to capture participants' behaviors and expressions.

Instruments

DUCS Forced-Choice Self-Report Measures: Predictor and Outcome Variables

In the original DUCS quantitative study, each CG completed one initial questionnaire and 8 daily questionnaires. The initial questionnaire tapped stable personal and other characteristics via several measures. Of interest to the proposed study are demographic variables (e.g., age, gender, level of education), three possible moderators (i.e., sense of efficacy, pre-caregiving relationship quality, and socio-emotional support). The DQs tapped CG experiences “in the past 24 hours”. Among the measures included in the DQ, CR-resistance, five CG emotional/physical well-being indicators (i.e., depressive symptoms, feelings of burden, positive affect, feelings of benefits/gains, and physical symptoms), and two possible moderators (i.e., family disagreement regarding care and community service/support utilization) were used in the current study. For each of these

eight daily measures, in addition to a “daily score” described below, an “individual CG mean score” was created for the current study. To arrive at an “individual CG mean score” the eight “daily scores” for each measure were averaged; each CG has one “individual CG mean score” for each daily measure.

CR-resistance. Occurrence of CR-resistance during care assistance on each day was determined via 22 items adapted in part from Lawton and Brody (1969). Those 22 items included questions about assistance with ADLs (e.g., bathing/showering, mobility), IADLs (e.g., meal preparation, transportation), management tasks (e.g., arranging for services, ordering medications), and two “other” items. Participants indicated whether they had provided assistance for each of the 22 items in the past 24 hours, and if so, whether they had experienced resistance from their CR Responses regarding CR-resistance were summed across the 22 items to arrive at a “CR-resistance daily score” for each day and could range from zero through 22, with higher scores representing more occurrences of CR-resistance (see Appendix D).

Depressive symptoms. Participants’ feelings of depression were assessed daily via six items based on Gaugler, Davey, Pearlin, and Zarit’s (2000) revised version of the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). Example items included, I lacked enthusiasm for doing anything and I cried easily or felt like crying. CGs indicated the extent to which they felt these emotions in the past 24 hours on a 4-point scale with choices ranging from 1 (not at all) through 4 (very much). Responses were averaged across the six items to arrive at a “depressive symptoms daily

score” for each day, with higher scores representing greater depressive symptoms. The scale had good internal consistency ($\alpha = .89$; see Appendix E).

Feelings of burden. Participants’ feelings of caregiving burden were assessed daily via the 12-item short version of the Zarit Burden Interview (Bédard et al., 2001). Example items included, [In the past 24 hours, how much did you feel...] that because of the time you spent with [care recipient], you didn’t have enough time for yourself, and you should be doing more for [care recipient]. CGs indicated the extent to which they felt the negative impact of caregiving on a 4-point scale with choices ranging from 1 (not at all) through 4 (very much). Responses were averaged across the 12 items to arrive at a “feelings of caregiving burden daily score” for each day, with higher scores representing higher levels of felt burden. The scale had good internal consistency ($\alpha = .89$; see Appendix F).

Physical health symptoms. Participants’ physical symptoms were assessed daily via a 16-item physical symptoms checklist (Larsen & Kasimatis, 1991). Participants were asked to think back to the past 24 hours and check all the physical symptoms they experienced from a list of 15 (e.g., headache, dizziness, tightness in chest) plus one “other” category. Responses were summed across the 16 items to arrive at a “physical health symptoms daily score” for each day and could range from 0 through 16, with higher scores representing higher numbers of physical symptoms (see Appendix G).

CG feeling of benefits/gains. Participants’ perceptions of benefits/gains derived from caregiving were measured on a daily basis via 10 items from the revised Positive Aspects of Caregiving Scale (Schulz et al., 1997). Example items included: [Providing

help to my relative...] made me feel more useful, and enabled me to learn more skills. CGs indicated the extent to which they felt these emotions in the past 24 hours on a 4-point scale: 1 (not at all) through 4 (very much). Responses were averaged across the 10 items to arrive at a “caregiving benefits/gains daily score” for each day, with higher scores representing higher levels of CG feelings of benefits/gains. The scale had good internal consistency ($\alpha = .96$; see Appendix H).

Positive affect. Participants’ positive affect was assessed daily via six items—four based on the Positive Affect Scale (Diener & Emmons, 1984) and two based on the Positive and Negative Affect Schedule (PANAS) scale (Watson, Clark, & Tellegen, 1988). Example items include, I felt happy and I felt strong. Each day CGs indicated the extent to which they felt these positive emotions in the past 24 hours on a 4-point scale with choices ranging from 1 (not at all) through 4 (very much). Responses were averaged across the six items to arrive at a “positive affect daily score” for each day, with higher scores representing higher levels of positive affect. The scale had good internal consistency ($\alpha = .96$; see Appendix E).

DUCS Forced-Choice Self-Report Measures: Moderators

The participants were asked to report on five scales to assess constructs viewed, in the proposed study, as possible moderating factors of the link between CR-resistance and CG emotional/physical well-being. Participants reported their personal and interpersonal resources (i.e., sense of efficacy, family disagreement regarding care, socio-emotional support, and community service utilization) and a pre-existing background factor (i.e., pre-caregiving CG-CR relationship) either in the initial questionnaire or the daily

questionnaires. As was noted above, in order to obtain each participant's "individual CG mean score" for the measures reported in the daily questionnaires (i.e., family disagreement regarding care and community service utilization), "daily scores" were averaged across all eight days.

CG sense of efficacy. CG sense of efficacy was measured by a seven-item revised version of the Caregiving Mastery Scale (Christensen, Stephens, & Townsend, 1998) in the one-time, initial questionnaire. Those seven items were derived from previous studies on mastery (Lawton, Kleban & Moss, 1989; Pearlin & Schooler, 1978), self-efficacy (Bandura & Adams, 1977), and control (Rotter, 1966) and modified to make them applicable to caregiving. Example items included: In general, I am able to handle most problems in the care of [CR], and I believe I am mastering most of the challenges in caregiving. CGs indicated the extent to which they agreed with each item on a 4-point scale with choices ranging from 1 (strongly disagree) through 4 (strongly agree). Three items with negative statements (e.g., I am not doing as well as I would like as a CG) were reverse coded. Responses were averaged across the seven items to arrive at a "caregiving mastery" score for each CG, with higher scores representing higher levels of caregiving mastery. The scale had adequate internal consistency ($\alpha = .70$; see Appendix I).

CG-CR relationship quality before caregiving. Participants' relationship with their relative (the CR) *before* they began caregiving was assessed via a 20-item measure with some items adapted from an existing intimacy scale (Walker & Thompson, 1983). In the one-time, initial questionnaire, participants rated how well a series of statements described their relationship on a scale ranging from 1 (*not at all*) through 4 (*very much*).

The measure asks participants how they felt about their relative with 10 statements, such as *I enjoyed spending time with him/her* and *I didn't get along with him/her very well* (reverse coded). Those same 10 statements are then paralleled, and participants are asked how their relative felt about them with statements such as *He/she enjoyed spending time with me* and *He/she didn't get along with me very well* (reverse coded). Responses were averaged across the 20 items to arrive at a “pre-caregiving relationship” score for each CG, with higher scores representing higher quality of pre-caregiving relationship. The scale had good internal consistency ($\alpha = .93$ see Appendix J).

Socio-emotional support. In the one-time, initial questionnaire, participants reported their perceptions of socio-emotional support from three sources—family, friends, and spouse/partner. The measure consisted of four support items for each of the three sources (i.e., family, friends, and spouse/partner; Walen & Lachman, 2000). An example item was: *How much do/does your (family members, friends, spouse/partner) understand the way you feel about things?* CGs reported on a 4-point scale: 1 (*not at all*) through 4 (*a lot*). Responses across all items were averaged to arrive at “socio-emotional support” score for each CG, with higher scores representing higher levels of socio-emotional support. Each scale had good internal consistency ($\alpha = .83$ for family, .89 for friend, and .82 for spouse/partner; see Appendix K).

Family disagreements regarding care. The occurrence of family disagreements regarding caregiving was assessed daily via three forced-choice items designed for DUCS but based in part on an existing longer scale (Pearlin et al., 1990). Participants indicated if there was any disagreement between them and anyone in their family in the

past 24 hours about the following: *What should (or should not) be done for your relative; The way you care for your relative; and How much (or how little) they are involved in your relative's care.* Scores reflected the sum of the disagreements experienced in the past 24 hours and could range from zero through three on each day (see Appendix L).

Community service/support utilization. Participants' use of community/professional service was assessed daily via an 18-item service use checklist, which was based on previous research (Williams & Dilworth-Anderson, 2002). Each day the participants were asked to place a check mark next to those services that they used in the past 24 hours to assist in caregiving for their relative. Example items include *legal services, respite care, home health aide, and support groups*. In addition to checking the listed services, the participants could also write in up to two services that were not listed, or check *none*. Responses were summed across 20 items to arrive at a "community/professional service use daily score" for each day and could range from 0 through 20, with higher scores representing greater community/professional service utilization (see Appendix M).

Because the community service/support utilization scale involves a wide range of service and support items, in order to interpret quantitative results, all items were separated into four different categories, and these sub-scales were used for post-hoc analyses.

1. Instrumental activities of daily living service/support (IADL Serv; i.e., transportation, financial advice/planning, legal advice, informational/referral service, shopping, and homemaker services).

2. Professional health service received (Pro Serv; i.e., home health aide, treatment/therapy, and visiting nurse services)
3. Daily CR services (Daily Serv; i.e., meal delivery, congregate meals, and companion services)
4. CG services/assurances that relieves CG from direct care and care management (CG Serv; i.e., respite, day care, counseling, support group, and case management).

Supplemental Semi-Structured Interview

Open-ended interview question topics. In order to understand specific CG experiences of CR-resistance, an open-ended semi-structured interview was conducted. The current quantitative research hypotheses and questions based on the previous caregiving literature and theoretical frameworks (Stress Theory and Social Cognitive Theory) were bases for the open-ended question topics (see example questions listed in Appendix N):

- 1) When/how often does the CG experience CR-resistance?
 - a. How much/often can the CG predict the occurrence of CR-resistance?
- 2) How stressful is CR-resistance to the CG?
 - a. Which kind(s) of CR-resistance have been the most stressful for the CG?
- 3) How does the CG behaviorally/emotionally react to CR-resistance?
- 4) What personal and interpersonal factors help/do not help to overcome/avoid the impact of CR-resistance experience on CG's emotional health?

- a. What does the CG think about why CR-resistance happens?
- b. What kind of interpersonal resources does the CG use and view as helpful?

CHAPTER 4: ANALYTIC STRATEGIES

This chapter describes analytic strategies applied to address the current hypotheses and research questions. As discussed in the previous chapters, because previous caregiving literature and theoretical models have provided some conceptual understanding of CGs' experience of CR behavioral problems, including CR-resistance, the current study used a largely deductive approach; that is, the current study was designed based on pre-existing research and theoretical frameworks (i.e., Stress Theory and Social Cognitive Theory). However, the qualitative analyses of the interviews involved a mixed stand between deductive and inductive approaches. As is described in more detail below, the researcher approached the interview data analyses by letting the data form conceptual patterns of the CR-resistance phenomenon, but she did have loose ideas about the phenomenon based on preliminary quantitative analyses results, as well as previous literature and theoretical frameworks. Although many researchers use an exclusively inductive approach to qualitative study design and analyses, according to Gilgun (2005), by conducting deductive qualitative studies that were designed based on previous research and theory, researchers can explore more nuanced understanding or refine conceptual models by comparing an extant conceptual model and the patterns derived from the new data. The ultimate purpose of this study was, based on multi-dimensional information (quantitative and subjective qualitative), to further refine pre-existing conceptual models in order to develop a conceptual model that better describes and explains CG experience of CR-resistance.

Software programs. For the quantitative survey data, the SPSS program version 16 (SPSS inc., 2008) was used for data management, data manipulation, and preliminary analyses; and the Hierarchical Linear Modeling program (HLM: Raudenbush & Bryk, 2002) was used for multi-level modeling, simultaneously examining the research hypotheses and questions. For the qualitative interview data, DSS Player Pro Transcription Module version 2.0.5 and Microsoft Word (2002) were used for transcription and data management; and NVivo qualitative analyses program version 2.0 (QSR International Pty. Ltd., 2002) was used to assist in qualitative data analyses.

Quantitative Data Analyses

Preliminary Analyses

Prior to the start of the current project, all quantitative survey data were collected, coded, and entered into an SPSS database by trained research personnel in the Daily Understanding of Caregiving Study research team (DUCS; PI: Susan Silverberg Koerner). Before proceeding to the current quantitative analyses, descriptive analyses were run to screen normality and outliers of the variables of interest including the predictor (CR-resistance); the five moderators (CG sense of efficacy, pre CG-CR relationship quality, socio-emotional support, family disagreement regarding the caregiving, and community/professional services utilization); and the five CG well-being outcome variables (depressive symptoms, feelings of burden, physical health symptoms, caregiving benefits/gains, and positive affect). Histograms and statistics indicated normal distribution for all dependent and independent variables except CR-resistance. CR-

resistance was positively skewed; in order to meet the normal distribution requirement for the current analyses, square-root data transformation was applied. Because a substantial amount of missing data was identified across the three socio-emotional support subscales for 2 participants, only 61 of the original 63 DUCS participants were included in the current quantitative data analyses.

Control Variables

Although the effects of CG age, gender, and ethnicity were not the focus of this study, previous caregiving literature has noted possible age, gender, and ethnicity differences in CG experiences and in how CG experiences influence CG well-being (e.g., Pinquart & Sörensen, 2005). In order to determine whether those CG characteristics should be included as control variables in the current study, the relationships between CG age, gender, ethnicity, and the variables of interest were evaluated via either Pearson's correlation analyses or analyses of covariance (ANOVA). For variables that were assessed on a daily basis (CR-resistance and the five CG well-being variables), 8-day average scores were used for the analyses. The correlation results indicated that CG age was significantly associated with CG experiences of depressive symptoms ($r = -.274$, $p < .05$) and family disagreement regarding care ($r = -.269$, $p < .05$), such that, older CGs tended to report fewer depressive symptoms and fewer family disagreement regarding care than younger CGs. The ANOVA results indicated that CG experiences of CR-resistance differed as a function of CG gender, $F(2, 60) = 4.67$, $p = .04$, indicating that female CGs reported more CR-resistance than did male CGs. The ANOVA results also indicated that CG age, and experiences of positive affect and depressive symptoms

differed as a function of CG ethnicity (non-Hispanic White: $n=51$, Hispanic: $n=9$, and other: $n=3$). Specifically, Hispanic and “other” ethnic group CGs were significantly younger than non-Hispanic White CGs, $F(2, 60) = 6.84, p = .002$; Hispanic and non-Hispanic White CGs reported lower levels of positive affect than “other” ethnic group CGs, $F(2, 60) = 4.27, p = .02$; and Hispanic CGs reported higher levels of depressive symptoms than the other two groups, $F(2, 60) = 2.71, p = .08$. However, there were substantial differences in the number of CGs in each ethnic group so these results should be cautiously interpreted. When ethnic groups were separated into two groups and compared (non-Hispanic White, $n=51$ vs. other, $n=12$), no group differences were found except in CG age, $F(1, 61) = 13.64, p < .001$. Because CG age and ethnicity were significantly associated to each other in both ethnic group analyses, only CG age and gender were included as control variables in the current analyses.

Primary Analyses

To address the research hypotheses and questions, a series of multi-level random coefficient analyses was applied. Multi-level random coefficient analysis or hierarchical linear modeling (HLM; Raudenbush & Bryk, 2002), is a statistical approach that considers the nested relationship or non-independence of repeated within-person measures (Nezlek, Feist, Wilson, & Plesko, 2001). For the current research, this means that HLM considers the non-independence of 8 days of data nested within CGs and allows for simultaneous estimation of: (a) within-person across day variability (daily fluctuation) and between-person variability (individual CG differences); (b) a separate within-person model of regression slope and intercept, through level 1 HLM analyses

(CG daily emotional/physical reactivity to daily CR-resistance fluctuation); and (c) a between-person model in which the within-person slopes and intercepts are treated as dependent variables regressed on, for example, “person-level predictor variables” (i.e., mean level CR-resistance), or “moderators” (e.g., sense of efficacy), through level 2 HLM analyses (Dempster, Laird, & Rubin, 1977).

Using these advantages of HLM analyses, the research hypothesis and questions were simultaneously analyzed via three different HLM models (see the list below). Because these analyses involved two levels of predictors (mean level and daily level CR-resistance) that were created from a single daily variable--daily CR-resistance, simple notations for these two variables are listed below for clarification:

“Person-Mean CR-resistance”: an averaged occurrence score of daily CR-resistance across 8 survey days for each CG.

“Daily CR-resistance Fluctuation”: daily fluctuation score created by subtracting the “Person-Mean CR-resistance” from daily CR-resistance scores for each day.

These notations for these variables are used throughout the rest of this report.

Three HLM models:

1) Unconditional Model, addressing RQ1, documented within-person and between-person variability in CR-resistance and the five CG well-being variables;

2) Model 1, addressing H1 and RQ2, examined the impact of CR-resistance on CG emotional/physical well-being at two different levels of the predictors: differences in “Person-Mean CR-resistance” and “Daily CR-resistance Fluctuation”; and

3) Model 2, addressing H2 and RQ3, examined moderators of the link between CR-resistance on CG-emotional/physical well-being at two different levels in the Model 1.

RQ1: How Much Between-Caregiver (between-person) and Across-Day (within-person) Variation Exists in CR-Resistance and CG Emotional/Physical Well-Being?

A series of HLM unconditional models was run to document both between-person and within-person across day variability in CR-resistance and the five CG well-being variables (i.e., daily depressive symptoms, feelings of burden, physical health symptoms, caregiving benefits/gains, and positive affect). These models provide information about within-person variability (σ^2) and between-person variability (τ) in each variable. Within-person units reflect how much people vary from themselves across study days and between-person units reflect how much people vary from each other. Based on these parameters for each variable, the proportion of within-person and the proportion of between-person variance to total variance were determined; a proportion of between-person variance (intraclass correlation) was calculated, $\rho = \tau / (\tau + \sigma^2)$; and a proportion of within-person variation, $1 - \rho$, was then determined.

H1: CGs with Higher Mean Level CR-Resistance will Have Higher Scores on Negative Well-Being Indicators and Lower Scores on Positive Well-Being Indicators

RQ2: On Days When CGs Face More than Their Usual Amount of CR-Resistance, Do They Experience Decreases in Well-Being (e.g., greater feelings of burden, depressive symptoms, physical symptoms, and less positive affect)?

A series of HLM analyses, Model 1, was conducted with “control variables” (i.e., CG age and gender) and “Person-Mean CR-resistance” as the level 2 predictors for both intercept and slope; “Daily CR-resistance Fluctuation” as the level 1 predictor; and each of the five CG well-being variables as the outcome variable.

The following model was used, illustrated here with depressive symptoms (DepS) as the well-being variable.

Model 1 Level 1: $\text{DepS}_{it} = \beta_{0i} + \beta_{1i} (\text{Daily CR-resistance}_{it} - \text{Person-Mean CR-resistance}_t) + r_{it}$

Level 2: $\beta_{0i} = \gamma_{00} + \gamma_{01} (\text{CG age}) + \gamma_{02} (\text{CG gender}) + \gamma_{03} (\text{Person-Mean CR-resistance}_t) + u_{0i}$

$\beta_{1i} = \gamma_{10} + \gamma_{11} (\text{CG age}) + \gamma_{12} (\text{CG gender}) + \gamma_{13} (\text{Person-Mean CR-resistance}_t) + u_{1i}$

At level 1, “DepS” refers to CG depressive symptoms for Person_t on Day_i; a function of the intercept, β_{0i} which is defined as mean depressive symptoms for Person_t (on days when CG has his/her usual amount of CR-resistance), and β_{1i} which is the expected change in depressive symptoms associated with “Daily CR-resistance Fluctuation”. At

level 2, γ_{00} represent the sample average depressive symptoms and γ_{10} represents the sample average changes in depressive symptoms associated with “Daily CR-resistance Fluctuation”; γ_{01} indicates age differences in the average CG depressive symptoms and γ_{11} indicates age differences of the changes in depressive symptoms associated with “Daily CR-resistance Fluctuation”; γ_{02} indicates gender differences in the average CG depressive symptoms and γ_{12} indicates gender differences of the changes in depressive symptoms associated with “Daily CR-resistance Fluctuation”; and γ_{03} indicates “Person-Mean CR-resistance” influences on the average CG depressive symptoms and γ_{13} indicates “Person-Mean CR-resistance” influences on the changes in depressive symptoms by “Daily CR-resistance Fluctuation”. Finally, u_{0i} and u_{1i} are variances allowing for individual differences in the average level of depressive symptoms and the changes in depressive symptoms associated with “Daily CR-resistance Fluctuation”, while r_{it} is a residual variance. A chi-square statistic of random effects as used to decide whether to constrain u_{0i} and u_{1i} (Raudenbusch & Bryk, 2002).

H2: Social Network and Personal Resources (e.g., socio-emotional support and sense of efficacy) will Moderate the Link between Mean Level CR-Resistance and CG Well-Being such that the Well-Being of CGs with Higher Levels of Socio-Emotional Support or Sense of Efficacy will be Less Negatively Affected by Mean Level CR-Resistance.

RQ3: Are the Within-Person Patterns of Reactivity to Daily CR-Resistance Stronger for Certain CGs (e.g., those who have lower levels of efficacy and socio-emotional support)?

Prior to the HLM analyses, as recommended by Aiken and West (1991), predictor and moderator variables were centered and product variables of “Person-mean CR-resistance” and each moderator were created via SPSS. A series of HLM analyses, Model 2, was conducted with “Daily CR-resistance Fluctuation” as the level 1 predictor; control variables, “Person-mean CR-resistance”, each moderator (i.e., sense of efficacy, pre-caregiving relationship quality, socio-emotional support, family disagreement, and community/professional services utilization) as the level 2 predictors for both intercept and slope; and a product variable as the level 2 predictor for intercept; and each of the five CG well-being variables as the outcome variable. The following model was used, illustrated here with CG sense of efficacy (CGEFFI) as the between-person moderator, and physical health symptoms (PHS) as the well-being (outcome) variable.

Model 2 Level 1: $PHS_{it} = \beta_{0i} + \beta_{1i} (CR-resistance_{it} - Person-Mean\ CR-resistance_t) + r_{it}$

Level 2: $\beta_{0i} = \gamma_{00} + \gamma_{01}(CG\ age) + \gamma_{02}(CG\ gender) + \gamma_{03}(Person-Mean\ CR-resistance_t) + \gamma_{04}(CGEFFI_t) + \gamma_{05}(Mean\ CR-resistance_t * CGEFFI_t) + u_{0i}$

$$\beta_{1i} = \gamma_{10} + \gamma_{11}(\text{CG age}) + \gamma_{12}(\text{CG gender}) + \gamma_{13}(\text{Person-Mean CR-resistance}_i) + \gamma_{14}(\text{CGEFFI}_i) + u_{1i}$$

In addition to the parameters in Model 1, Model 2 adds three level 2 predictors; γ_{04} indicates CG sense of efficacy influences on the average CG depressive symptoms, and γ_{14} indicates CG sense of efficacy influences on the average changes in depressive symptoms associated with “Daily CR-resistance Fluctuation”; and γ_{05} indicates the moderating effect of CG sense of efficacy on the link between “Person-Mean CR-resistance” and CG depressive symptoms. A chi-square statistic of random effects was used to decide whether to constrain u_{1i} (Raudenbusch & Bryk, 2002).

To determine final parsimonious HLM Model 2s, sub-models were analyzed. The sub-models were nested within the original full HLM Model 2 but omitted insignificant moderators from the full model one by one. Then, the original full HLM Model 2 and the sub-models were compared by model fit statistics, chi-square of deviance statistics (Singer & Willett, 2003). The differences in chi-square of deviance scores between these two models (chi-square change) were evaluated based on the number of the degrees of freedom. When the chi-square change was not significant, the more parsimonious model was kept for interpretation.

Post Hoc Simple Slope Analysis

For the models with significant interaction effects, post-hoc simple slope analyses were performed for interpretation of the results (Aiken & West, 1991; Bauer & Curran, 2005; Preacher, Curran, & Bauer, 2004). For each model, conditional effects of

the moderator were assessed; simple intercepts and slopes of the CR-resistance effects on a CG well-being variable were calculated at two different levels of a moderator (i.e., -1SD and +1SD). T-tests were also conducted to determine whether simple slopes differ from zero. Based on the simple slopes analysis results, relationships between the predictor and the outcome variable at two different levels of the moderator were graphically plotted by entering lower and upper values of the predictor (i.e., -1SD and +1SD of mean or daily level CR-resistance) for each model.

Qualitative Data Analyses

As described in the previous sections, a semi-structured qualitative interview was the follow-up part of the current project. Based on the findings from preliminary analyses of the quantitative data and two theoretical frameworks—Stress Theory and Social Cognitive Theory, specific qualitative interview question topics were derived. However, the purpose of the qualitative analysis was not only to validate or confirm and add detailed descriptive data to the quantitative results, but also to gather meaningful and/or additional key features of CGs' experiences around CR-resistance which were not captured in the quantitative findings or explicitly described in the theoretical frameworks.

In other words, the specific aims of the qualitative analyses were two-fold: 1) to provide rich descriptions of CG experiences around CR-resistance and related factors which validate or confirm and add detailed information to the quantitative findings, and 2) to capture broader structures or concepts that further articulate caregiver CR-resistance experience; as part of this aim, the PI will develop a refined conceptual model based in part upon existing theoretical frameworks and extended using the current study results.

In order to achieve these aims, a thematic analysis approach was utilized in the current qualitative analyses.

Thematic Analysis

As compared to other qualitative analysis methods, a thematic analysis provides a broader perspective within which the investigator can approach the particular research questions either with or without a conceptual framework as long as the researcher makes his/her assumptions explicit up front (Braun & Clarke, 2006). Thematic analysis allowed the current investigator to approach the qualitative data with concepts based on the quantitative preliminary results and theoretical frameworks. At the same time, thematic analysis provides flexibility in developing a conceptual model with themes that emerge from the qualitative data. With the specific study aims described above, this flexibility of thematic analyses was well suited for our current multi-layered research project—a sequential quantitative and qualitative research method approach.

Although thematic analysis has been applied in a variety of fields (e.g., psychology, health sciences, education, political sciences, business.), it has been often identified as a tool to be used under one of several specific qualitative analysis methods such as grounded theory and cultural ethnography (Boyatzis, 1998). However, Braun and Clarke (2006) have claimed that thematic analysis is an independent qualitative research methodology and provide specific steps for its application in order to set a quality standard for researchers. Depending on the investigator's research questions and specific aims, thematic analysis can provide two kinds of information that are parallel to the current qualitative analyses aims: 1) rich detailed descriptions of the entire data set that

capture predominant and/or important themes, and 2) more detailed and interpreted themes underlying the phenomenon (Boyatzis, 1998; Braun & Clarke, 2006).

Following Braun and Clarke's (2006) six phases (or steps) of thematic analysis, data obtained from the 19 individual semi-structured interviews were analyzed by the six research team members, including the PI (who was the primary coder), a trained independent coder, and four trained research assistants. Although the analysis process involved a consistent movement back and forth between different phases of data analysis and different levels of data (the entire data set, coded extracts of data, and analysis write-up), each phase of analysis is chronologically presented below.

Phase 1: Transcription

All 19 audio-taped interviews and field notes were transcribed by six research team members. Specifically, each transcriber was assigned two to four interviews to transcribe; each interview ranged in length from 57 to 134 minutes. Transcribers were trained to prioritize accuracy over speed of transcription and were directed to transcribe one to two hours at a time. Transcribing pace varied between transcribers; each transcriber transcribed 4-20 minutes of interview-time/one hour (transcription-time). To familiarize themselves with the voices and contents of the interview prior to actual transcription, each transcriber listened to the audiotaped interview for the amount that they would transcribe for the day. Transcription accuracy was reviewed by the PI on a randomly selected six transcriptions (31%). Only minor errors were found, and revisions were made, including correcting spelling mistakes, anonymizing individuals mentioned in interviews, and correcting format. During this transcribing phase, in preparation for the

next phase of generating initial codes, the PI and the independent coder separately re-read transcriptions (the PI read the entire dataset whereas the independent coder was assigned 6 interviews) and noted initial coding ideas which were interesting and meaningful points that emerged from the interviews.

Phase 2: Generating Initial Codes

Initial codes were first created by the PI. All initial codes that captured meaningful/unique features of the data were identified in a systematic fashion across the entire data set. First, the PI repeatedly read entire transcriptions to identify initial codes that captured meaningful and/or unique features of the data. Although presumptions about the data set based on components from theoretical frameworks and the preliminary results from the prior quantitative analyses were in the coder's mind, all statements in the dataset were equally treated. In other words, when the PI reviewed the statements, she paid equal attention to each statement and determined whether the statement deserved an initial code. Furthermore, all identified possible codes were given the same importance without any hierarchical order or priorities even if there were such hierarchical order or associations identified in the quantitative analyses or in the theoretical frameworks.

Second, two research assistants independently applied the initial codes on four transcriptions (two transcriptions for each coder) to see whether the initial codes reflected important features of their assigned interviews. Each research assistant took notes on ideas for additions and revisions to the initial codes, and discussed those ideas with the PI. Based on these discussions, a few new items were added and several initial coding items were revised.

Phase 3: Searching Initial Themes

In order to create “thematic categories,” first all initial codes were collated into potential categories by the PI; some thematic categories emerged within a certain individual CG whereas others emerged across many or all CGs. At this point, the revised initial codes and thematic categories were again shared with the two research assistants. These two research assistants separately applied the revised initial codes/thematic categories on a few different transcriptions and took notes on ideas for additions and revisions. Based on feedback from the research assistants and the independent coder (see the reliability section below), the initial coding items (initial codes) and thematic categories were revised multiple times. During this initial theme searching process, and particularly during the feedback sessions with the research assistants and the independent coder, organization of the themes was considered for the next phase of analysis—reviewing themes. Specifically, potential main themes and related sub-themes were written down on a large piece of paper, so connections between codes, themes, and sub-themes could be considered, creating an initial thematic map.

Phase 4: Reviewing Themes

First, all coded statements, highlighted interview text by thematic categories (collated data extracts) were reviewed for coherence patterns to determine whether additional, sub-, or larger categories should be created, and/or whether two or more categories should be merged. Second, an initial thematic map was created in which all relevant thematic categories were examined regarding their connection to the current research questions. Although some categories mirrored components from the theoretical

frameworks (i.e., Stress Theory and Social Cognitive Theory) and others did not, this thematic map was not derived from the theoretical frameworks; instead it was organized regarding the current qualitative questions.

Phase 5: Defining and Themes

All thematic categories and sub-categories in the revised thematic map were defined and further refined by clarifying their essence in regards to the data set. Specifically, in order to generate a parsimonious thematic map by again going back to the collated data extracts for each theme, some sub-categories were integrated into broader categories (e.g., *CR resistance during bathing* and *CR resistance for eating* were merged into a larger category--*CR resistance during daily personal assistive activities*), and relationships between categories were refined (e.g., "family oriented caregiving value" and "respect feelings for CR" share a mutual role for CG strategies dealing with CR-resistance). Finally, the parsimonious thematic map was intentionally compared to the theoretical frameworks for similarities and differences. Pre-existing theoretical frameworks, particularly components of Social Cognitive Theory, shared similar thematic categories with ones in the thematic map, and thus, aided in clarifying and simplifying the organization of the final thematic map. Based on this final thematic map each theme was described regarding its importance and unique features, and its relationships to other themes and to the entire dataset. During this phase, the PI consulted several times with her research committee members to get a fresh view and feedback on the thematic map.

Reliability

During thematic analysis phases three to five, two levels of reliability were examined: *coding scheme development reliability* and *application reliability* (Patton, 2002). First, *coding scheme development reliability* determines whether two independent coders would develop the same coding categories from the same interviews. A trained independent coder, who did not have prior knowledge about the initial codes and categories created by the PI, independently developed a coding scheme (i.e., codes and thematic categories) based upon a randomly selected six transcriptions (about one third). Through in-person meetings with the PI, these two independently developed coding schemes (codes and thematic categories) were compared. Except for some differences in naming, the two independently developed initial code item lists shared a large number of the same code items. There were a few differences found between the lists developed by the PI and the independent coder; there were coding items and thematic categories in one of the initial list that did not appear in the other (e.g., sacrifices that CG has made for CR, CG financial condition), and there were differences in how sub-categories were assigned under a broader category. For example, the PI and the independent coder assigned same text with two different sub-categories: “CG personal beliefs/morals” and “CG personal/professional experiences” which were under one boarder category: “source of CG strategy”. These differences between the PI and the independent coder were carefully examined to determine whether missing items should be kept in the final coding list, and which broader categories should be assigned as sub-categories. Specifically, the PI and the independent coder together reviewed the original text examples that identified the

specific coding items and thematic categories, and the PI made the final decision based on whether the items and the categories were important or relevant topics to answer the current research questions. These comparisons and revisions of coding items and thematic categories (and sub-categories) were repeated multiple times until clear definitions and names of each code/theme were confirmed by the PI and the independent coder and a thematic map was created.

Second, coding scheme *application reliability* (i.e., whether the coding scheme is applied the same way across trained coders) was determined. During the final coding process, independently derived coding scheme application results were compared for cross-check (inter-coder agreement). Using the thematic map, the PI independently applied the code to the entire dataset, while the independent coder and the other research assistants were assigned 6-7 interviews each to apply the coding scheme. These several sets of independently applied codes (for 6 interviews) were compared for one third of transcriptions. Although there was agreement about the higher units of thematic category assignment among the coders, a few differences were found: a) missing assignment at sub-category level in general, and b) having different length of texts assigned by different coders.

For example, in some cases, the higher category was applied in the same way by the PI and the second coder (e.g., emotional support; or CG attitude), but one assigned a specific sub-category (e.g., from person who cares about CG or who understand a similar caregiving situation; or acceptance in current condition) whereas the other didn't assign the same sub-category. In order to keep precise and consistent coding application, the

entire dataset was reviewed for sub-category assignment by the PI. The second difference was the length of coded texts. While the PI tended to highlight larger amounts of text that included the context in which the coded features emerged, the other coders tended to highlight smaller amounts of text in which specific statements reflecting the code(s) were captured, but often missed the context. Because understanding broader structures or concepts that articulate caregiver CR-resistance experience was one of the aims of this analysis, all coders went back to their assigned transcripts to reassign the code items by including the contexts of key codes or features.

CHAPTER 5: RESULTS

The quantitative results section is presented in five parts. First, group comparison results of study participant demographic characteristics are presented (i.e., CGs who reported experience of CR-resistance vs. who did not; and 63 DUCS original vs. 19 follow-up interview participants, are presented). Second, descriptive statistics and correlations among the CG well-being variables and CR-resistance are presented. Third, the results for Research Question 1, examining between- and within-person variability in CR-resistance and CG well-being variables, are presented. Fourth, the results for Hypothesis 1 and Research Question 2 determining whether “Person-Mean CR-resistance” and “Daily CR-resistance Fluctuation” predict CG emotional/physical well-being are presented. Finally, the results for Hypothesis 2 and Research Question 3, determining moderating effects, whether CG personal and interpersonal factors buffer/exacerbate the link between “Person-Mean CR-resistance” and CG well-being, and the link between “Daily CR-resistance Fluctuation” and CG well-being, are presented.

Quantitative Analyses Results

Demographic Characteristics

Before conducting analyses designed to address the research hypotheses and questions, basic descriptive analyses (means, standard deviations, range) were conducted on demographic variables. Table 1 separately presents the demographic information for DUCS original ($N = 63$) and for follow-up interview ($N = 19$) participants.

Table 1. *Demographic Characteristics of the Sample*

Variable	Original DUCS Participants <i>N</i> (%)	Follow-up Interview Participants <i>N</i> (%)
Sex		
CG Female	46 (73.0)	13 (68.4)
Male	17 (27.0)	6 (31.6)
CR Female	41 (63.1)	13 (68.4)
Male	22 (43.9)	6 (31.6)
CG Ethnicity		
Non-Hispanic White	51 (81.0)	18 (94.7)
Hispanic	9 (14.3)	1 (5.3)
Other	3 (4.8)	0 (0)
CG Relationship to CR		
Spouse or partner	19 (30.2)	7 (36.8)
Child	39 (61.9)	10 (52.6)
Child-in-law	4 (6.3)	2 (10.5)
Grandchild	1 (1.6)	0 (0)
CG Education		
4-year college degree or more	21 (33.0)	7 (36.9)
Some college or vocation/technical school	35 (56.0)	10 (52.7)
Completed high school only	3 (5.0)	1 (5.3)
Some high school or less	4 (6.0)	1 (5.3)
CG Annual household income		
Less than \$60,000	49 (78.0)	14 (73.7)
Age at the time of Original DUCS		
Caregivers <i>M</i> (<i>SD</i>)	56.7 (13.2)	62.5 (8.22)
Care-Recipient <i>M</i> (<i>SD</i>)	80.98 (9.99)	83.4 (11.48)

Who Reported Experiences of CR-Resistance?

Of the 63 original DUCS survey participants, 31 participants reported that they experienced CR-resistance: 27 are female (87 % vs. 73% female in the DUCS sample) and most are non-Hispanic White ($n = 24$: 77% vs. 81% non-Hispanic White in the DUCS sample) or Hispanic ($n = 5$: 16% vs. 14% Hispanic in the DUCS sample). At the time of the initial quantitative data collection (between August 2003 and July 2004), six were CGs for their spouse/partner, 21 for their parent, three for their parent-in-law, and one for their grandmother; they ranged in age from 20 to 77 ($M = 55.45$, $SD = 13.25$ years), with 71% over the age of 50.

Who Participated in The Follow-Up Semi-Structured Interview

Of 63 original DUCS survey participants, 19 participated in the follow-up semi-structured interview. Of those 19 participants, 13 are female and nearly all are non-Hispanic White ($n = 18$). At the time of original DUCS, seven were CGs for their spouse/partner, ten for their parent, and two for their parent-in-law. At the time of the follow-up interview (between July 2009 and December 2009), five CGs were continuing to provide care to the same relative from the time of the original DUCS; one CG transferred the CR to a facility; and thirteen CRs died between the time of the original DUCS and the follow-up interview. At the time of the follow-up interview, CGs ranged in age from 48 to 80 years ($M = 68.47$, $SD = 8.22$ years); the length of time as CG ranged from two years to 25 years ($M = 9.53$; $SD = 5.49$ years).

Between Group Comparisons

In order to determine if there were demographic differences between CGs who reported experiences of CR-resistance in the original DUCS survey and those who did not, and between the DUCS original survey participants and the follow-up interview participants, chi-square non-parametric statistics were used with categorical variables, whereas independent samples t-tests were used with continuous variables.

CGs who reported experiencing CR-resistance vs. who did not. When the CGs who reported experiencing CR-resistance in the DUCS original survey ($n = 31$) were compared to those CGs who did not ($n = 32$), t-tests and chi-square statistics indicated that there were no significant differences in their demographic information and background (i.e., CG ethnicity, CG educational level, CG annual income, CR gender, and CG-CR relationship type) except CG gender, $\chi^2(1, N = 63) = 6.12, p = .01$; and CR age, $t(61) = -2.06, p < .05$. The group of CGs who reported experience of CR-resistance had a significantly higher proportion of female CGs (87% vs. 44%) and were caring for slightly older CRs ($M = 83.6$ vs. 78.5 years old) than the other group.

Follow-up and non-follow-up participants. When the 19 follow-up interview participants were compared to the 44 CGs who were not interviewed, t-tests and chi-square statistics indicated that there were no significant differences in their demographic information and background (i.e., CG gender, CG ethnicity, CG educational level, CG annual income, CR age, CR gender, and CG-CR relationship type) except CG age, $t(61) = -2.38, p < .05$. The follow-up interview participants consisted of slightly older CGs than non-follow-up interview participants ($M = 62.47$ vs. 54.18 years old).

Preliminary Analyses Results

Table 2 presents basic descriptive (means, standard deviations, range) and correlation results for the five CG well-being variables (i.e., depressive symptoms, feeling of burden, physical health symptoms, caregiving benefits/gains, and positive affect), CR-resistance, and CG personal and interpersonal variables (i.e., sense of efficacy, pre-caregiving relationship quality, socio-emotional support, family disagreement, and community service/support utilization). To derive values for the variables that were assessed on a daily basis (i.e., five CG well-being variables and CR-resistance), an 8-day average score for each variable was calculated for each CG.

The current study predictor, CR-resistance, was significantly correlated with one of the CG well-being variables, feeling of burden, $r(59) = .29, p < .05$. CR-resistance was also significantly correlated with two of the CG interpersonal variables: pre-caregiving relationship quality, $r(59) = -.33, p < .01$ and level of family disagreement, $r(59) = .44, p < .01$. Specifically, CGs with a higher number of CR-resistance occurrences tended to report higher feelings of burden, more family disagreement, and lower quality of pre-caregiving relationship as compared to CGs with a lower number/no experience of CR-resistance.

CG personal and interpersonal resources were also correlated with some of the CG well-being variables. CG sense of efficacy and socio-emotional support were negatively correlated with depressive symptoms, $r(59) = -.40, p < .01$; $r(59) = -.33, p < .01$, and positively correlated with CG positive affect, $r(59) = .37, p < .01$; $r(59) = .35, p < .01$. CG sense of efficacy and quality of pre-caregiving CG-CR relationship were

Table 2. Means, Standard Deviations, and Correlations

Variable	<i>M</i>	<i>SD</i>	Observed Range	α	1	2	3	4	5	6	7	8	9	10
1. Depressive symptoms	1.58	.55	1 – 3.1	.89	—									
2. Feelings of burden	1.80	.55	1 – 3.4	.89	.713**	—								
3. Physical health symptoms	1.71	1.58	0 – 7.1	n/a	.642**	.479**	—							
4. Positive affect	2.56	.77	1 – 4.0	.96	-.548**	-.516**	-.316**	—						
5. Caregiving benefits/gains	2.25	.85	1.1 – 4.0	.96	-.271*	-.430**	-.010	.621**	—					
6. Care-recipient resistance	.38	.52	0 – 2.2	n/a	.198	.294*	.246	-.130	-.163	—				
7. Sense of efficacy	2.85	.43	1.9 – 4.0	.71	-.395**	-.387**	-.137	.365**	.408**	-.159	—			
8. CG-CR relationship before	3.54	.53	2.0 – 4.0	.93	-.236	-.363**	-.082	.244	.262*	-.329**	.255*	—		
9. Socio-emotional support	3.07	.54	1.8 – 4.0	.79	-.330**	-.227	-.251	.350**	.134	.038	.206	.012	—	
10. Family disagreement	.27	.52	0 – 2.5	.75	.220	.119	.205	.044	.187	.438**	-.027	-.037	.153	—
11. Community support/services	.51	.67	0 – 3.25	n/a	.027	.006	.239*	.083	.164	.079	-.014	-.156	-.042	.302*

Note. *N* = 63. CR refers to care recipient. To derive values for the variables that were assessed on a daily basis, an 8-day average was calculated for each caregiver.

*Values in this row are based on *n* = 61. ^aSixty-two percent of the caregivers were over age 55. ^b*p* < .05. ***p* < .01.

negatively correlated with feelings of burden, $r(59) = -.39, p < .01$; $r(59) = -.36, p < .01$ and positively correlated with feelings of benefits/gains, $r(59) = .41, p < .01$; $r(59) = .26, p < .05$. Specifically, CGs who reported higher sense of efficacy and/or socio-emotional support, and/or greater quality of pre CG-CR relationship tended to report better emotional health as compared to their counterparts. In contrast, community service/support utilization was significantly correlated with CG physical health symptoms, $r(59) = 2.59, p < .01$, indicating that CGs who utilized more community service/support tended to report more physical health symptoms as compared to their counterparts.

Primary Analyses Results

HLM Unconditional Model: RQ 1

How Much Between-Caregiver (between-person) and Across-Day (within-person) Variation Exists in CR-Resistance and CG Emotional/Physical Well-Being?

Tables 3-7 present results of the unconditional HLM models revealing within-person (σ^2) and between-person (τ) variability in the daily CR-resistance and CG well-being variables. Only the proportion of within-person variance is presented below while the proportions of between-person variance can be easily obtained ($1 - \text{proportion of within-person variance}$). On the one hand, with respect to CR-resistance, CGs were more likely to vary from themselves than from each other; 61% of the variance in CR-resistance existed within-person. On the other hand, with respect to CG well-being, CGs were more likely to vary from each other than themselves; as compared to between

Table 3. Multilevel Regression Results for CR-resistance Predicting Daily Depressive Symptoms as Moderated by CG Sense of Efficacy, CG-CR Relationship Quality, Family Disagreement, Socio-Emotional Support, and Community/Professional Support Utilization

		Unconditional	Model 1	Model 2a Sense of Efficacy	Model 2b CG-CR Relationship	Model 2c Family Disagreement	Model 2d Socio- emotional Support	Model 2e Community/Professional Support use
<i>Fixed Effects (SE)</i>								
	Mean level CR-resistance		.11 (.07)	.08 (.07)	.07 (.08)	.11 (.07)	.11 (.07)	.11 (.07)
	Daily level CR-resistance		.22 (.33)	.22 (.33)	.22 (.33)	.63 (.34) ^a	.24 (.33)	.21 (.33)
	Mean*Daily CR-resistance		.09 (.08)	.08 (.08)	.08 (.08)	.24 (.09) ^a	.09 (.08)	.09 (.08)
	Moderator (Mod.)			-.21 (.07)**	-.11 (.07)	.	-.20 (.08)**	-.01 (.07)
	Mean CR-resistance*Mod.							
	Daily CR-resistance*Mod.					-.23 (.08)**		
<i>Random Effects (SD)</i>								
	Variance of Intercept	.26 (.31)***	.26 (.31)***	.23 (.48)***	.25 (.30)***	.26 (.31)***	.21 (.48)***	.27 (.32)***
	Variance of Slope	N/A	.08 (.28)***	.08 (.28)***	.08 (.28)***	.04 (.20) ^a	.08 (.28)***	.08 (.28)***
	Residual	.20 (.45)	.19 (.43)	.19 (.43)	.19 (.43)	.19 (.43)	.19 (.43)	.19 (.43)
	Deviance	733.38	733.68	746.87	752.87	748.89	746.91	733.32

Note: All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centred (i.e., centered relative to the person's own mean).

^a Socio-emot supp refers to perceived available socio-emotional support.

^b *p* values are not available.

^c A chi-square statistic was used to decide whether to constrain random variance. ^a*p* < .10. ^{*}*p* < .05. ^{**}*p* < .01. ^{***}*p* < .001.

Table 4. Multilevel Regression Results for CR-resistance Predicting Daily Feelings of Burden as Moderated by CG Sense of Efficacy, CG-CR Relationship Quality, Family Disagreement, Socio-Emotional Support, and Community/Professional Support Utilization

		<i>Unconditional</i>	<i>Model 1</i>	<i>Model 2a Sense of Efficacy</i>	<i>Model 2b CG-CR Relationship</i>	<i>Model 2c Family Disagreement</i>	<i>Model 2d Socio- emotional Support</i>	<i>Model 2e Community/Professional Support use</i>
<i>Fixed Effects (SE)</i>								
	<i>Mean level CR-resistance</i>		.14 (.07) [#]	.11 (.07)	.09 (.07)	.16 (.08) [#]	.14 (.07) ⁺	.14 (.07) [#]
	<i>Daily level CR-resistance</i>		.03 (.30)	.04 (.30)	.05 (.30)	.03 (.30)	.06 (.30)	.03 (.30)
	<i>Mean * Daily CR-resistance</i>		.10 (.07)	.10 (.07)	.10 (.07)	.10 (.07)	.11 (.07)	.10 (.07)
	<i>Moderator (Mod.)</i>			-.18 (.07)**	-.16 (.07)*	-.05 (.08)	-.14 (.07)*	-.02 (.07)
	<i>Mean CR-resistance * Mod.</i>							
	<i>Daily CR-resistance * Mod.</i>							
<i>Random Effects (SD)</i>								
	<i>Variance of Intercept</i>	.27 (.52)***	.27 (.51)***	.24 (.49)***	.25 (.50)***	.27 (.52)***	.25 (.50)***	.27 (.52)***
	<i>Variance of Slope</i>	N/A	.09 (.29)***	.08 (.29)***	.08 (.29)***	.08 (.29)***	.08 (.29)***	.08 (.29)***
	<i>Residual</i>	.11 (.33)	.09 (.30)	.09 (.30)	.09 (.30)	.09 (.30)	.09 (.30)	.09 (.30)
	<i>Deviance</i>	495.97	456.23	451.78	452.80	457.24	454.07	457.88

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

[#] Socio-emot supp refers to perceived available socio-emotional support.

⁺ *p* values are not available.

^{*} A chi-square statistic was used to decide whether to constrain random variance. [#]*p* < .10. ^{*}*p* < .05. ^{**}*p* < .01. ^{***}*p* < .001.

Table 5. Multilevel Regression Results for CR-resistance Predicting Daily Physical Health Symptoms as Moderated by CG Sense of Efficacy, CG-CR Relationship Quality, Family Disagreement, Socio-Emotional Support, and Community/Professional Support Utilization

		Unconditional	Model 1	Model 1a Sense of Efficacy	Model 1b CG-CR Relationship	Model 1c Family Disagreement	Model 1d Socio- emotional Support	Model 1e Community/Professional Support use
<i>Fixed Effects (SE)</i>								
	Mean level CR-resistance		.40 (.21) [#]	.35 (.21) [*]	.44 (.22) [#]	.31 (.23)	.41 (.20) [*]	.28 (.20)
	Daily level CR-resistance		1.08 (.73)	1.12 (.71)	1.09 (.72)	1.12 (.72)	1.16 (.71)	1.37 (.68)
	Mean * Daily CR-resistance		.34 (.17) [*]	.31 (.15) [*]	.34 (.16) [*]	.33 (.16) [*]	.29 (.15) [#]	.33 (.13) [*]
	Moderator (Mod.)			-.30 (.20)	.12 (.20)	.10 (.22)	-.46 (.18) [*]	.43 (.17) [*]
	Mean CR-resistance * Mod.							.67 (.17) ^{***}
	Daily CR-resistance * Mod.							
<i>Random Effects (SD)</i>								
	Variance of Intercept	2.34 (1.33) ^{***}	2.27 (1.31) ^{***}	2.23 (1.30) ^{***}	2.33 (1.33) ^{***}	2.31 (1.32) ^{***}	2.11 (1.43) ^{***}	1.89 (1.38) ^{***}
	Variance of Slope	N/A	.35 (.37) ^{***}	.31 (.35) ^{***}	.33 (.37) ^{***}	.32 (.37) ^{***}	.31 (.36) ^{***}	.27 (.32) ^{***}
	Residual	1.17 (1.08)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)
	Deviance	1619.09	1569.48	1566.85	1568.72	1568.06	1563.26	1555.31

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

[#] Socio-emot supp refers to perceived available socio-emotional support.

^{*} *p* values are not available.

^{*} A chi-square statistic was used to decide whether to constrain random variance. [#]*p* < .10. ^{*}*p* < .05. ^{**}*p* < .01. ^{***}*p* < .001.

Table 6. Multilevel Regression Results for CR-resistance Predicting Daily Feelings of Benefits/Gains as Moderated by CG Sense of Efficacy, CG-CR Relationship Quality, Family Disagreement, Socio-Emotional Support, and Community/Professional Support Utilization

		Unconditional	Model 1	Model 2a Sense of Efficacy	Model 2b CG-CR Relationship	Model 2c Family Disagreement	Model 2d Socio- emotional Support	Model 2e Community/Professional Support use
<i>Fixed Effects (SE)</i>								
	Mean level CR-resistance		-.05 (.11)	-.08 (.11)	-.04 (.12)	-.23 (.12) [#]	-.10 (.11)	-.12 (.11)
	Daily level CR-resistance		.18 (.23)	.18 (.23)	.18 (.23)	-.03 (.26)	.18 (.23)	.27 (.23)
	Mean * Daily CR-resistance		-.01 (.06)	-.04 (.06)	-.03 (.06)	-.15 (.07)*	-.04 (.06)	-.04 (.03)
	Moderator (Mod.)			.23 (.11)*	.18 (.11)	.33 (.12)**	.11 (.11)	
	Mean CR-resistance * Mod.			-.28 (.11)*				.22 (.11)*
	Daily CR-resistance * Mod.					.16 (.06)**		-.16 (.06)**
<i>Random Effects (SD)</i>								
	Variance of Intercept	.68 (.83)***	.69 (.83)***	.57 (.73)***	.67 (.82)***	.61 (.78)***	.68 (.83)***	.62 (.79)***
	Variance of Slope	N/A	.04 (.19)***	.04 (.19)**	.04 (.19)**	.02 (.14)*	.04 (.19)**	.02 (.15)**
	Residual	.12 (.34)	.11 (.33)	.11 (.33)	.11 (.33)	.11 (.33)	.11 (.33)	.11 (.34)
	Deviance	568.82	581.75	578.16	583.91	578.14	585.44	582.39

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

* Socio-emot supp refers to perceived available socio-emotional support.

[#] *p* values are not available.

* A chi-square statistic was used to decide whether to constrain random variance.

[#] *p* < .10. **p* < .05. ***p* < .01. ****p* < .001.

Table 7. Multilevel Regression Results for CR-resistance Predicting Daily Positive Affect as Moderated by CG Sense of Efficacy, CG-CR Relationship Quality, Family Disagreement, Socio-Emotional Support, and Community/Professional Support Utilization

		Unconditional	Model 1	Model 2a Sense of Efficacy	Model 2b CG-CR Relationship	Model 2c Family Disagreement	Model 2d Socio- emotional Support	Model 2e Community/Professional Support use
<i>Fixed Effects (SE)</i>								
	Mean level CR-resistance		-.09 (.11)	-.08 (.10)	-.09 (.11)	-.09 (.11)	-.10 (.10)	-.10 (.11)
	Daily level CR-resistance		-.14 (.47)	-.14 (.47)	-.19 (.43)	-.63 (.49)	-.13 (.47)	-.15 (.47)
	Mean*Daily CR-resistance		-.10 (.11)	-.11 (.11)	-.11 (.10)	-.28 (.12)*	-.10 (.11)	-.10 (.11)
	Moderator (Mod.)			.25 (.10)*	For slope	For slope	.28 (.10)**	.08 (.10)
	Mean CR-resistance*Mod.			-.25 (.11)*				
	Daily CR-resistance*Mod.				-.17 (.09) [#]	.28 (.12)*		
<i>Random Effects (SD)</i>								
	Variance of Intercept	.58 (.76)***	.59 (.77)***	.49 (.70)***	.59 (.77)***	.59 (.77)***	.52 (.72)***	.60 (.77)***
	Variance of Slope	N/A	.17 (.41)***	.17 (.41)***	.14 (.38)***	.12 (.33)**	.17 (.41)***	.17 (.41)***
	Residual	.30 (.55)	.28 (.53)	.28 (.53)	.28 (.53)	.28 (.53)	.28 (.53)	.28 (.53)
	Deviance	950.26	954.81	947.92	952.66	950.30	947.86	953.11

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

* Socio-emot supp refers to perceived available socio-emotional support.

[#] *p* values are not available.

* A chi-square statistic was used to decide whether to constrain random variance. [#]*p* < .10. **p* < .05. ***p* < .01. ****p* < .001.

person variance, a smaller portion (through still notable proportion) of within-person variance existed in CG well-being variables: 43% in depressive symptoms, 28% in feelings of burden, 34% in the physical health symptoms, 15% in feelings of benefits/gains, and 34% in positive affect.

HLM Model 1: H1 and RQ2

The Model 1 entries in Tables 3-7 present the results of HLM analyses that simultaneously examined the unique influence of “Person-Mean CR-resistance” (H1) and “Daily CR-resistance Fluctuation” (RQ2) on CG emotional/physical well-being.

H1: CGs with higher mean level CR-resistance will have higher scores on negative, and lower scores on positive, well-being indicators.

H1 examined how individual CG differences in “Person-Mean CR-resistance” were associated with individual CG differences in emotional/physical well-being. The HLM Model 1 results indicated that “Person-Mean CR-resistance” was moderately associated with two of the CG well-being variables: feelings of burden ($b = .26$, $SE = .14$, $p = .07$) and physical health symptoms ($b = .75$, $SE = .40$, $p = .07$) when “Daily CR-Resistance Fluctuation” was controlled (on days when CGs had their usual amount of CR-resistance: “Daily CR-Fluctuation” = 0). In other words, CGs with greater “Person-Mean CR-resistance” scores reported higher feelings of burden and physical health symptoms than those CGs with lower “Person-Mean CR-resistance” scores. Specifically, having one higher unit of “Person-Mean CR-resistance” was associated with an increase in CG feelings of burden by .26 units and in physical health symptoms by .75 units. There were no significant associations between “Person-Mean CR-resistance” and the

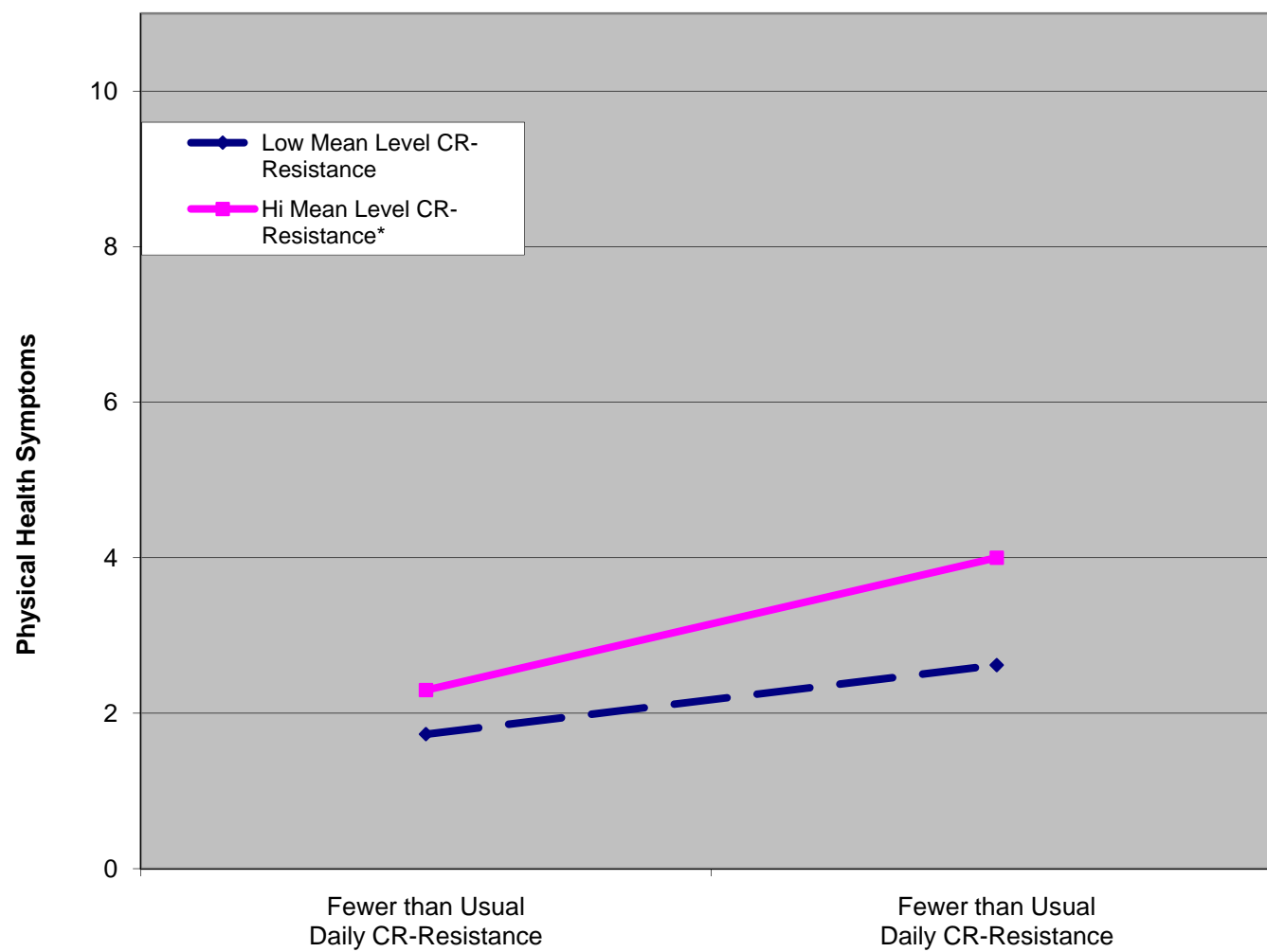
other CG well-being variables: depressive symptoms, feelings of benefits/gains, and positive affect.

RQ2: On days when CGs face more than their usual amount of CR-resistance, do they experience decreases in well-being (e.g., greater feelings of burden, depressive symptoms, physical symptoms, and less positive affect)?

RQ2 asked whether daily fluctuation in CR-resistance influences CG daily emotional/physical well-being; that is, it addressed the issue of CG reactivity to CR-resistance. The HLM Model 1 results indicated that there were no significant direct associations between “Daily CR-resistance Fluctuation” and CG well-being variables when the level of “Person Mean CR-resistance” was controlled (when CG had the sample average “Person-Mean CR-resistance”). Specifically, having additional CR-resistance on a given day was not associated with increases in CG emotional and physical well-being for CGs with the sample average “Person-Mean CR-resistance” score.

However, the HLM Model 1 results revealed a significant interaction effect between “Person-Mean CR-resistance” and “Daily CR-resistance Fluctuation” on physical health symptoms ($b = .34$, $SE = .17$, $p < .01$). That is, on days when a CG faced more CR-resistance than his/her usual amount, significant increases in physical health symptoms existed for CGs with relatively high “Person-Mean CR-resistance” scores, but not for CGs with relatively low scores. Simple slopes analyses further revealed that for CGs with higher “Person-Mean CR-resistance” scores, having a one unit increase in CR-resistance, on a given day, was associated with a 1.42 unit increase in physical health symptoms ($p < .05$; see Figure 4).

Figure 4. Daily CR-Resistance Predicting CG Physical Health Symptoms Moderated by Mean CR-Resistance Score



However, for CGs with lower “Person-Mean CR-resistance” scores, “Daily CR-resistance Fluctuation” was not significantly associated with changes in physical health symptoms.

HLM Model 2: H2 and RQ3

Model 2 entries in Tables 3-7 present results of HLM analyses that simultaneously examined the moderators (i.e., sense of efficacy, CG-CR relationship quality, socio-emotional support, family disagreement, community service/support utilization) of the link between CR-resistance and CG emotional/physical well-being at two different levels: between-person mean (H2) and within-person daily fluctuation (RQ3).

H2: Social network and personal resources (e.g., socio-emotional support and sense of efficacy) will moderate the link between mean level CR-resistance and CG well-being such that the well-being of CGs with higher levels of sense of efficacy or socio-emotional support will be less negatively affected by mean level CR-resistance.

The HLM Model 2 results revealed that CG sense of efficacy and community service/support utilization played significant moderating roles in the link between “Person-Mean CR-resistance” and two of the CG well-being variables: (a) sense of efficacy: feelings of benefits/gains ($b = -.28, SE = .11, p < .05$) and positive affect ($b = -.25, SE = .11, p < .05$); and (b) community service/support use: feelings of benefits/gains ($b = .22, SE = .11, p < .05$) and physical health symptoms ($b = .67, SE = .17, p < .001$).

However, the simple slope analyses revealed that, although HLM results showed significant moderating effects, these effects were not always "buffer" for all participants.

Specifically, the positive buffering influence of CG feeling of efficacy existed only for CGs with relatively low “Person-Mean CR-resistance” scores; this group of CGs with a higher sense of efficacy reported significantly higher feelings of benefits/gains and positive affect as compared to CGs with lower sense of efficacy. However, for CGs with relatively high “Person-Mean CR-resistance” scores, sense of efficacy did not act as a buffer; there were no significant differences in feeling of benefits/gains and positive affect between CGs with higher and with lower sense of efficacy (Figures 5 – 6). Sense of efficacy exacerbated the impact of “Person-Mean CR-resistance” on CG well-being. For CGs with a relatively high sense of efficacy, having a one unit higher “Person-Mean CR-resistance” score was associated with a .35 unit decrease in feelings of benefits/gains ($p < .05$) and a .31 unit increase in positive affect ($p < .05$). However, for CGs with lower sense of efficacy, there were no significant associations between “Person-Mean CR-resistance” and CG well-being variables.

The simple slope analyses also revealed significant results for the moderating impact of community service/support utilization. Community service/support utilization played a significant buffering role of the link between “Person-Mean CR-resistance” and CG feelings of benefits/gains. For those CGs with relatively low community service/support utilization, CGs with higher “Person-Mean CR-resistance” scores reported significantly lower feelings of benefits/gains as compared to those CGs with lower “Person-Mean CR-resistance” scores; having a one unit higher “Person-Mean CR-resistance” score was associated with a .39 unit decrease in feelings of benefits/gains ($p < .05$; Figure 7).

Figure 5. Mean CR-Resistance Predicting CG Feeling of Benefits/Gains Moderated by Sense of Efficacy

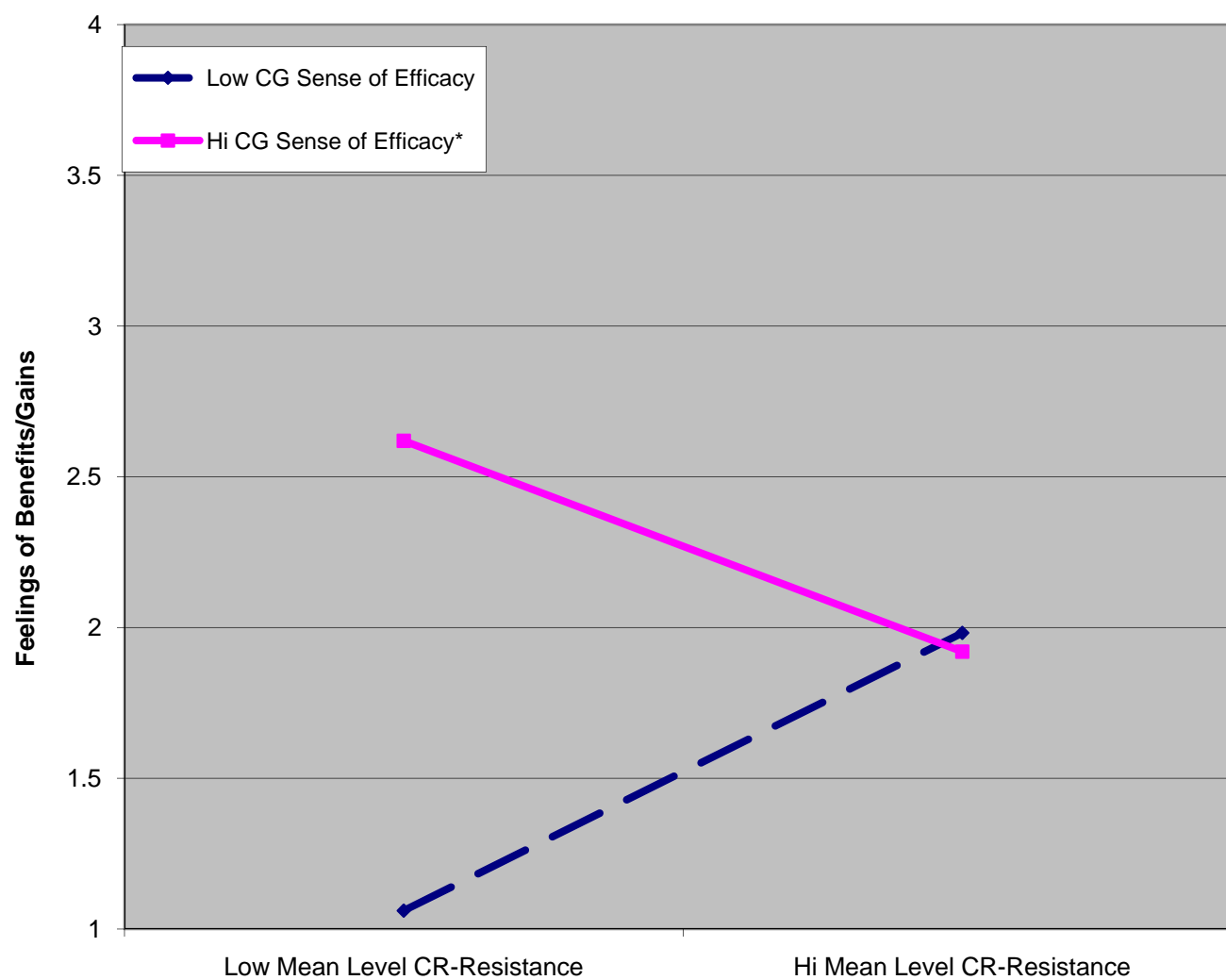


Figure 6. Mean CR-Resistance Predicting CG Positive Affect Moderated by Sense of Efficacy

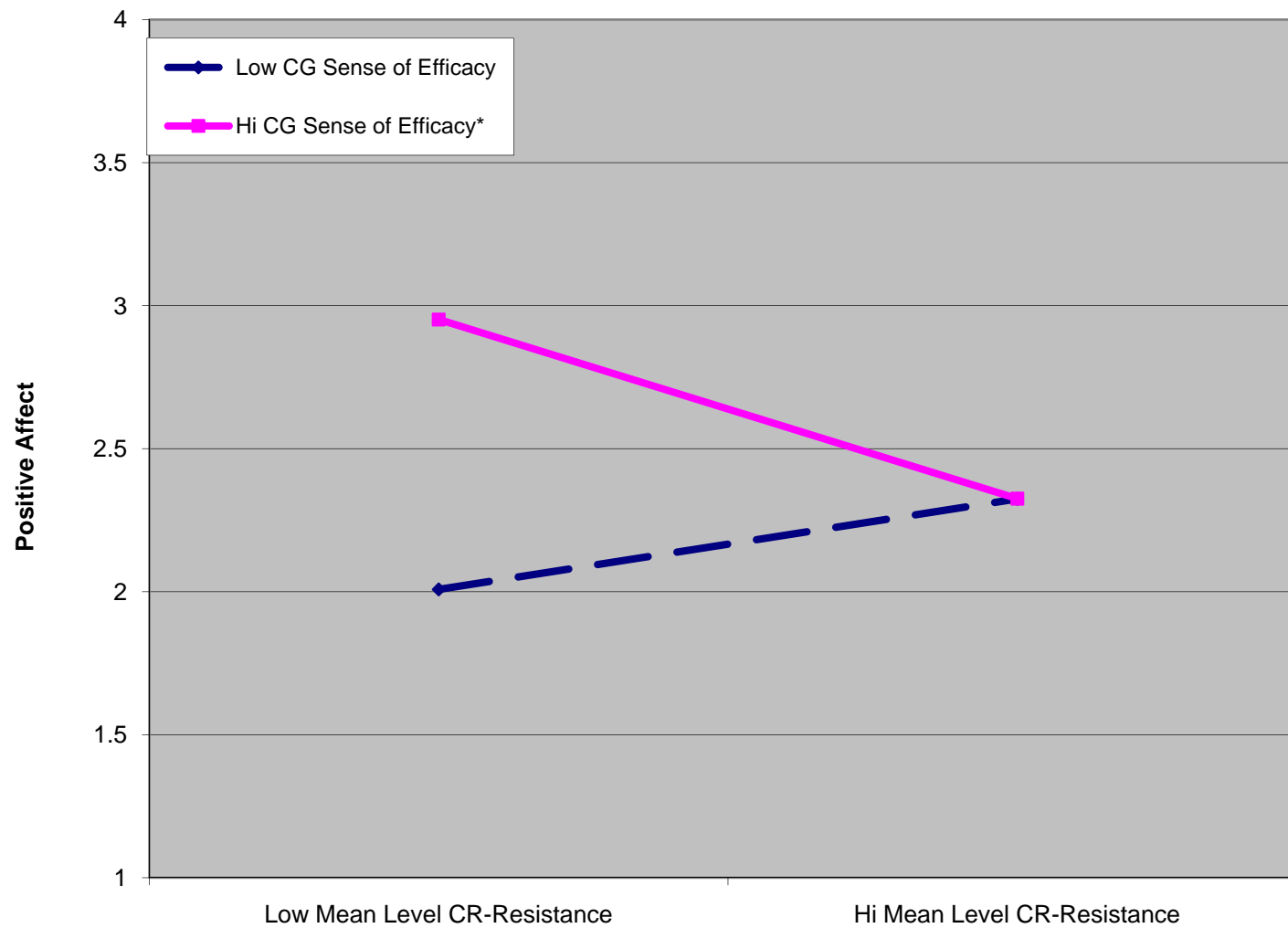
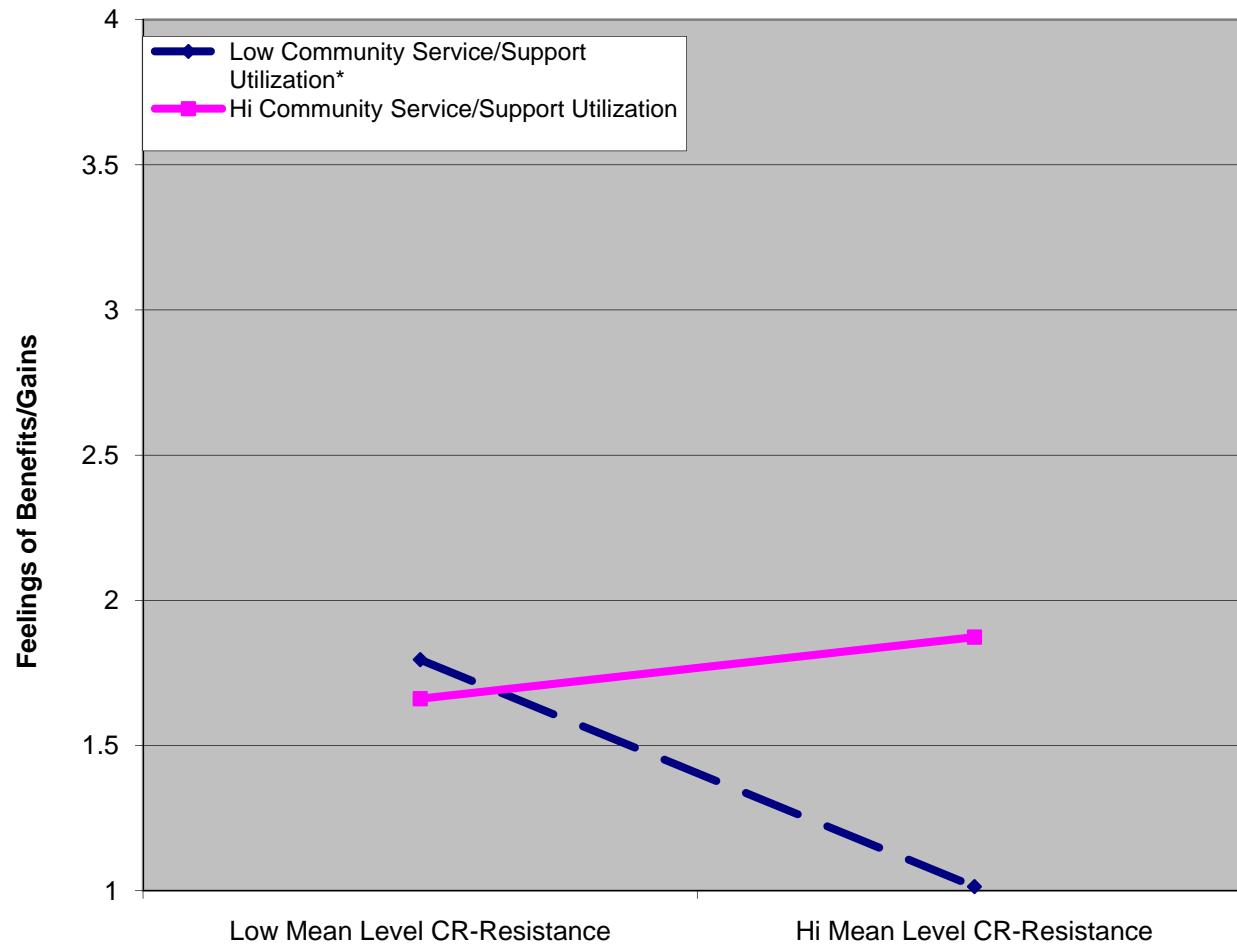


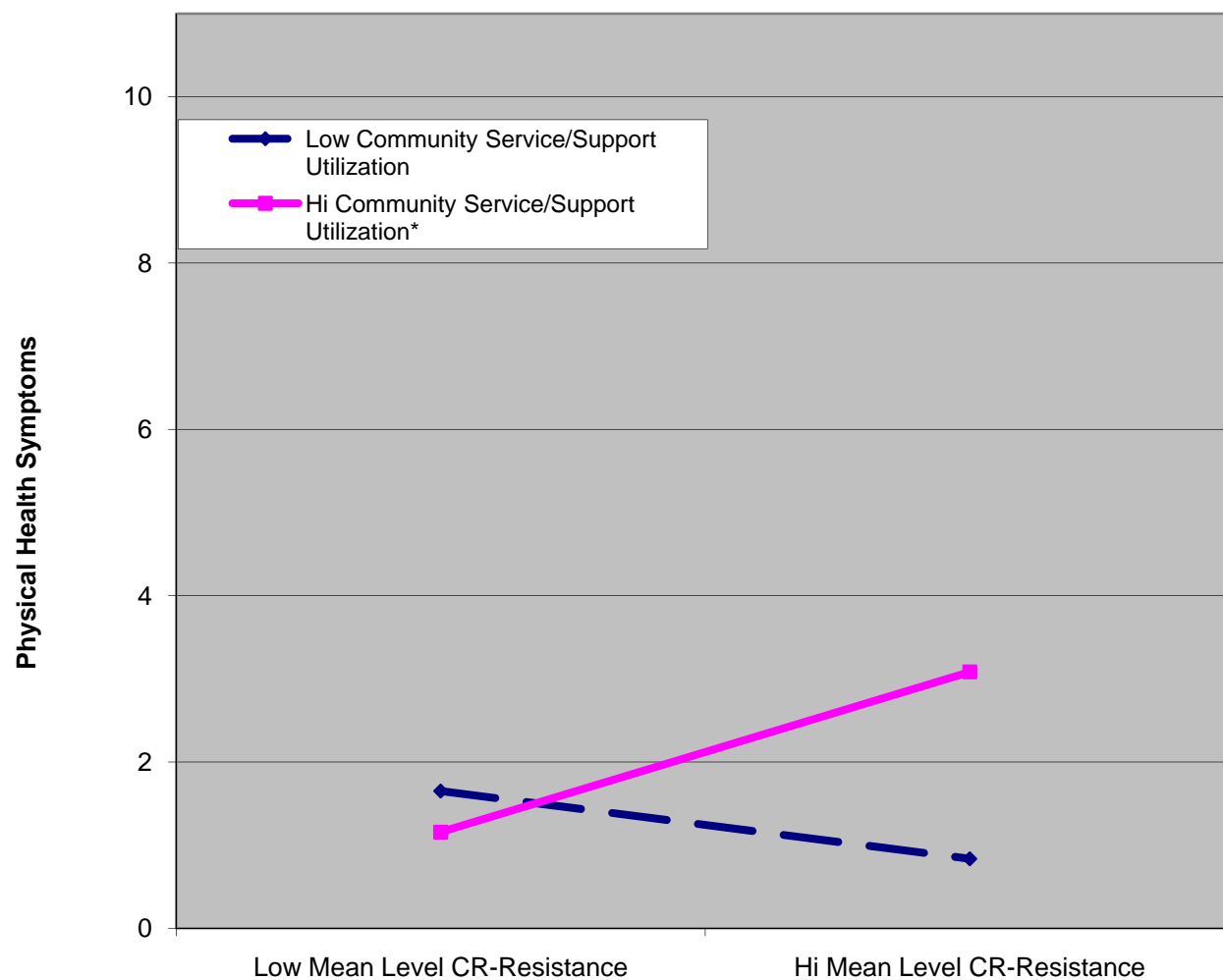
Figure 7. Mean CR-Resistance Predicting CG Feeling of Benefits/Gains Moderated by Community Service/Support Utilization



However, CGs with relatively high community service/support utilization as compared to CGs with relatively low community service/support utilization, reported higher feelings of benefits/gains, regardless of their level of “Person-Mean CR-resistance” scores.

In contrast, community service/support utilization did not buffer but instead appeared to exacerbate the association between “Person-Mean CR-resistance” and physical health symptoms. Specifically, among CGs with relatively high community service/support utilization, CGs with higher “Person-Mean CR-resistance” scores reported significantly greater numbers of physical health symptoms as compared to CGs with lower “Person-Mean CR-resistance” scores; having a one unit higher “Person-Mean CR-resistance” score was associated with a .95 unit increase in physical health symptoms ($p < .001$). However, among those CGs with relatively low community service/support utilization, there was no significant association between “Person-Mean CR-resistance” and CG physical health symptoms (Figure 8).

Figure 8. Mean CR-Resistance Predicting CG Physical Health Symptoms Moderated by Community Service/Support Utilization



RQ3: Are the within-person patterns of reactivity to “Daily CR-resistance Fluctuation” stronger for certain CGs (e.g., those who have lower levels of efficacy or socio-emotional support)?

RQ3 addressed possible moderators of daily CG reactivity to the daily fluctuation in CR-resistance. The HLM Model 2 results revealed that family disagreement, community service/support utilization, and CG-CR relationship quality played significant to marginal moderating roles of the link between “Daily CR-resistance Fluctuation” and three CG well-being variables: a) family disagreement: depressive symptoms ($b = -.23$, $SE = .08$, $p < .01$), feelings of benefits/gains ($b = .16$, $SE = .06$, $p < .01$), and positive affect ($b = .28$, $SE = .12$, $p < .05$); b) community service/support use: feelings of benefits/gains ($b = -.16$, $SE = .06$, $p < .05$); and c) CG-CR relationship quality: positive affect ($b = -.17$, $SE = .09$, $p = .06$).

Surprisingly, the simple slope analyses results revealed opposite directional moderating effects that were in the opposite direction than expected. Interestingly, more frequent experience as opposed to less/no experience of family disagreement about caregiving played a significant buffering role for CG daily emotional reactivity to CR-resistance (Figures 9-11). CGs with relatively high family disagreement did not report significant increases in depressive symptoms, or significant decreases in feeling of benefits/gains and positive affect, on days when CGs experienced more than their usual level of CR-resistance. However, CGs with relatively low family disagreement reported significant increases in depressive symptoms and decreases in positive affect, on days

Figure 9. Family Disagreement Moderates the Within-Person Association between Daily CR-Resistance and CG Depressive Symptoms

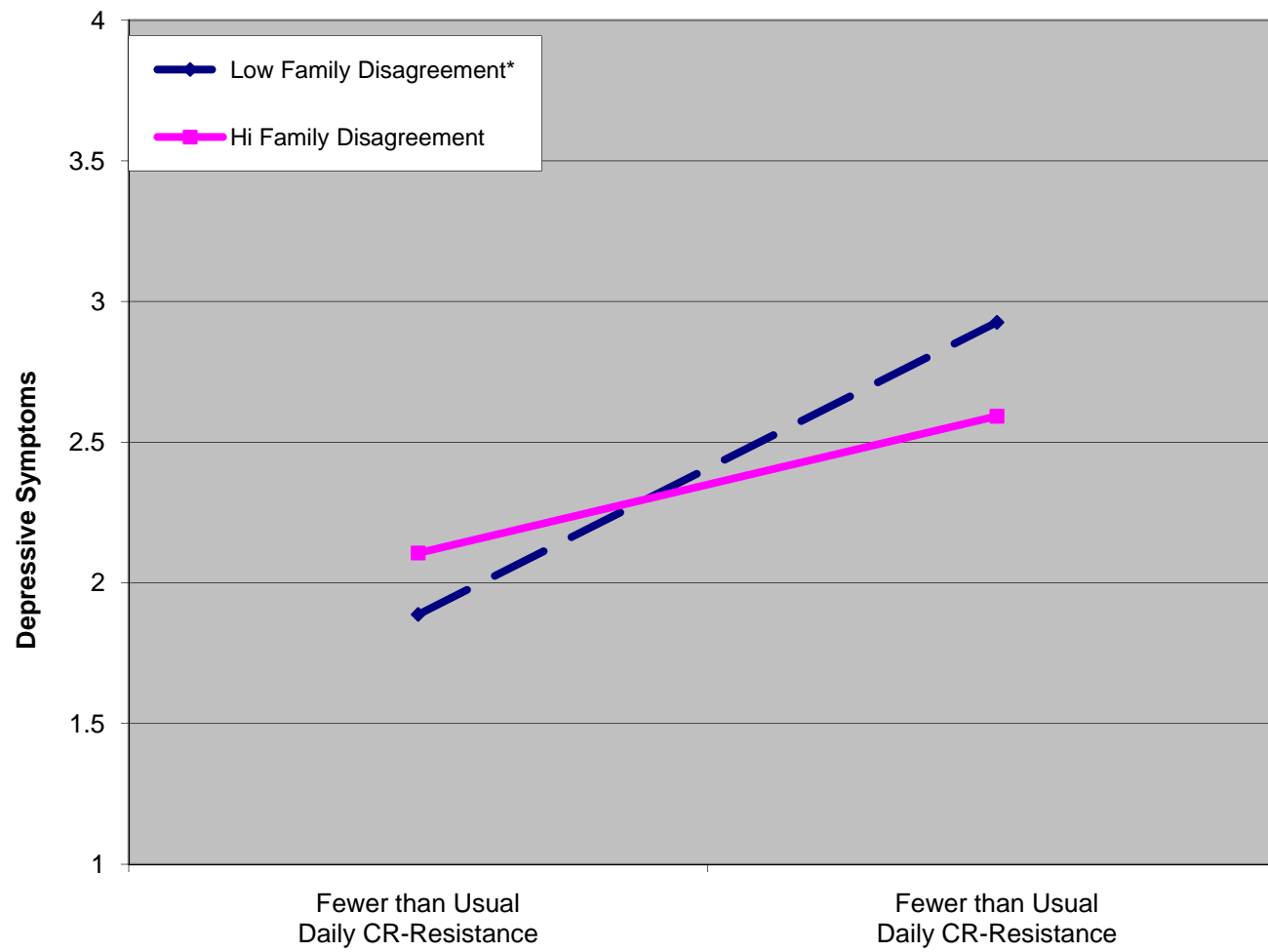


Figure 10. Family Disagreement Moderates the Within-Person Association between Daily CR-Resistance and CG Feeling of Benefits/Gains

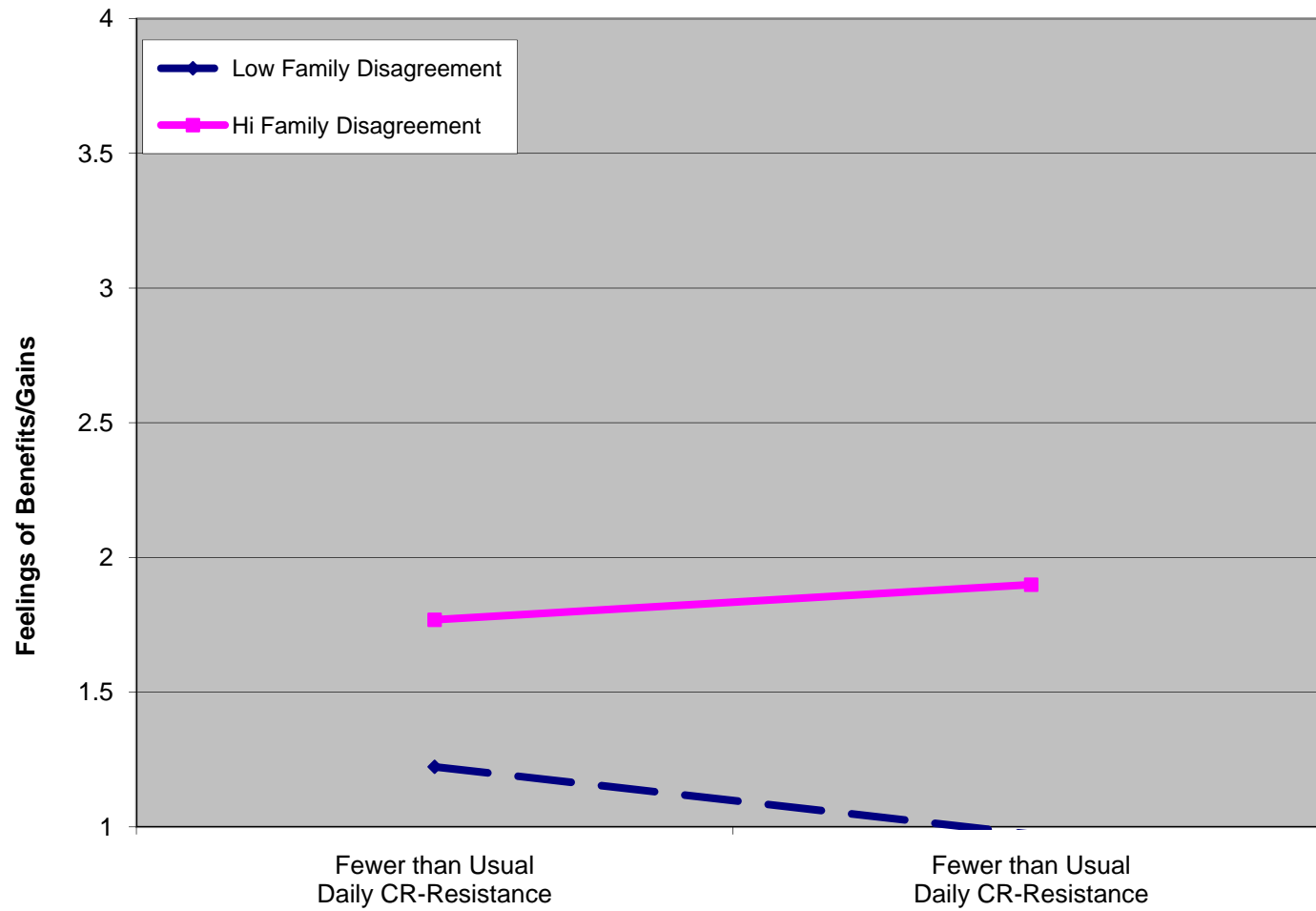
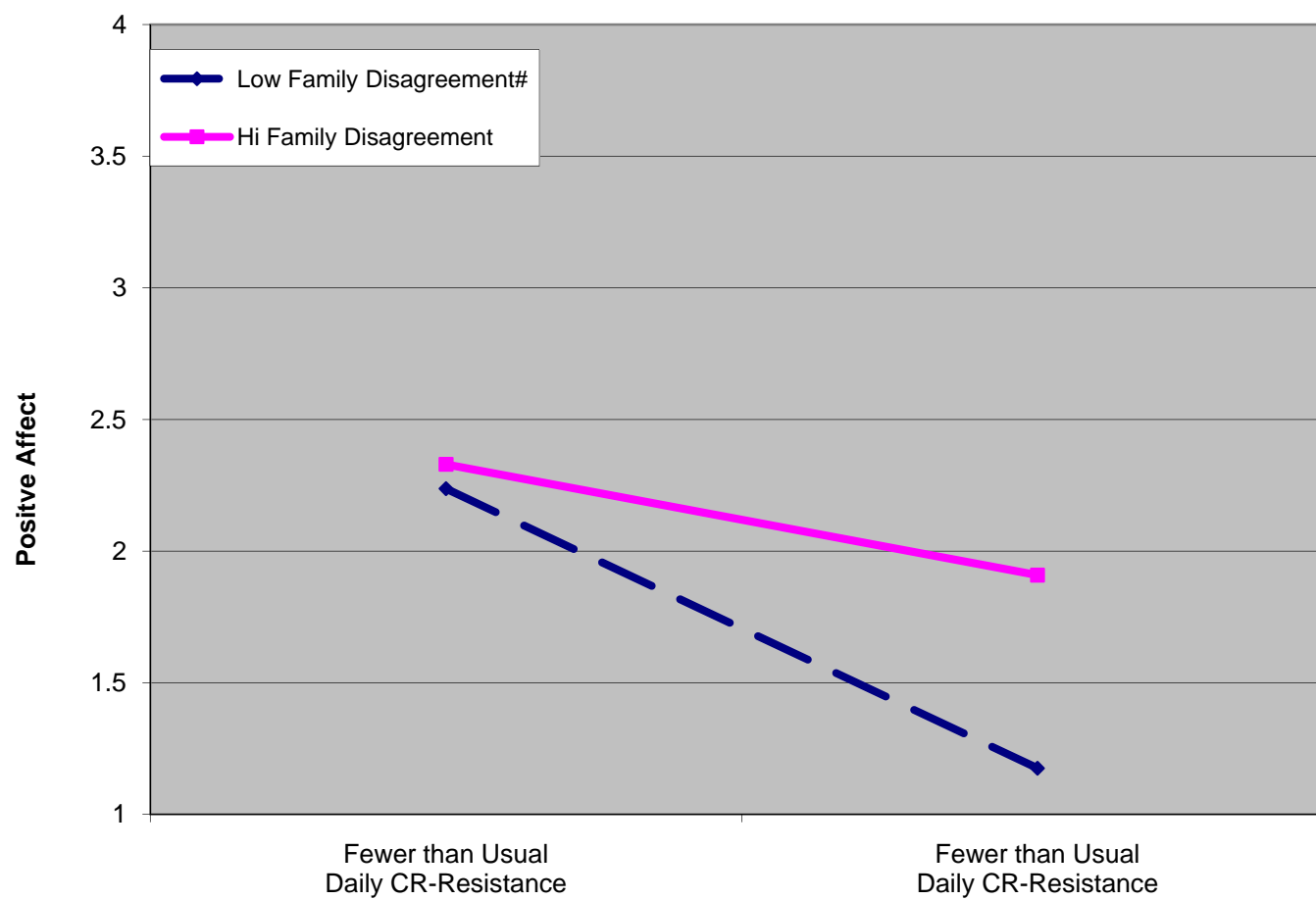


Figure 11. Family Disagreement Moderates the Within-Person Association between Daily CR-Resistance and CG Positive Affect



when they experienced more than their usual level of CR-resistance; having a one unit increase in CR-resistance, on a given day, was associated with a .87 unit increase in depressive symptoms ($p < .05$) and a .89 unit decrease in positive affect ($p < .10$).

The simple slope analyses results also revealed that pre-caregiving relationship quality and community service/support utilization, surprisingly, exacerbated the *CG daily reactivity* to “Daily CR-resistance Fluctuation” in two CG well-being variables: positive affect and feeling of benefits/gains. On days when CGs faced more than their usual level of CR-resistance, those CGs with relatively high pre-caregiving relationship quality reported significant decreases in positive affect; having a one unit increase in CR-resistance, on a given day, was associated with a .31 unit decrease in positive affect ($p < .05$). However, for those CGs with relatively low pre-caregiving relationship quality, having an additional CR-resistance, on a given day, was not associated with changes in positive affect (Figure 12). Similarly, on days when CGs faced more than their usual level of CR-resistance, those CGs with relatively low community service/support utilization reported a increase in feelings of benefits/gains; having a one unit increase in CR-resistance, on a given day, was associated with a .41 unit decrease in feelings of benefits/gains ($p = .11$). However, for those CGs with relatively high community service/support utilization, having an additional CR-resistance, on a given day, was not associated with changes in feelings of benefits/gains, (Figure 13).

Figure 12. Pre CG-CR Relationship Quality Moderates the Within-Person Association between Daily CR-Resistance and CG Positive Affect

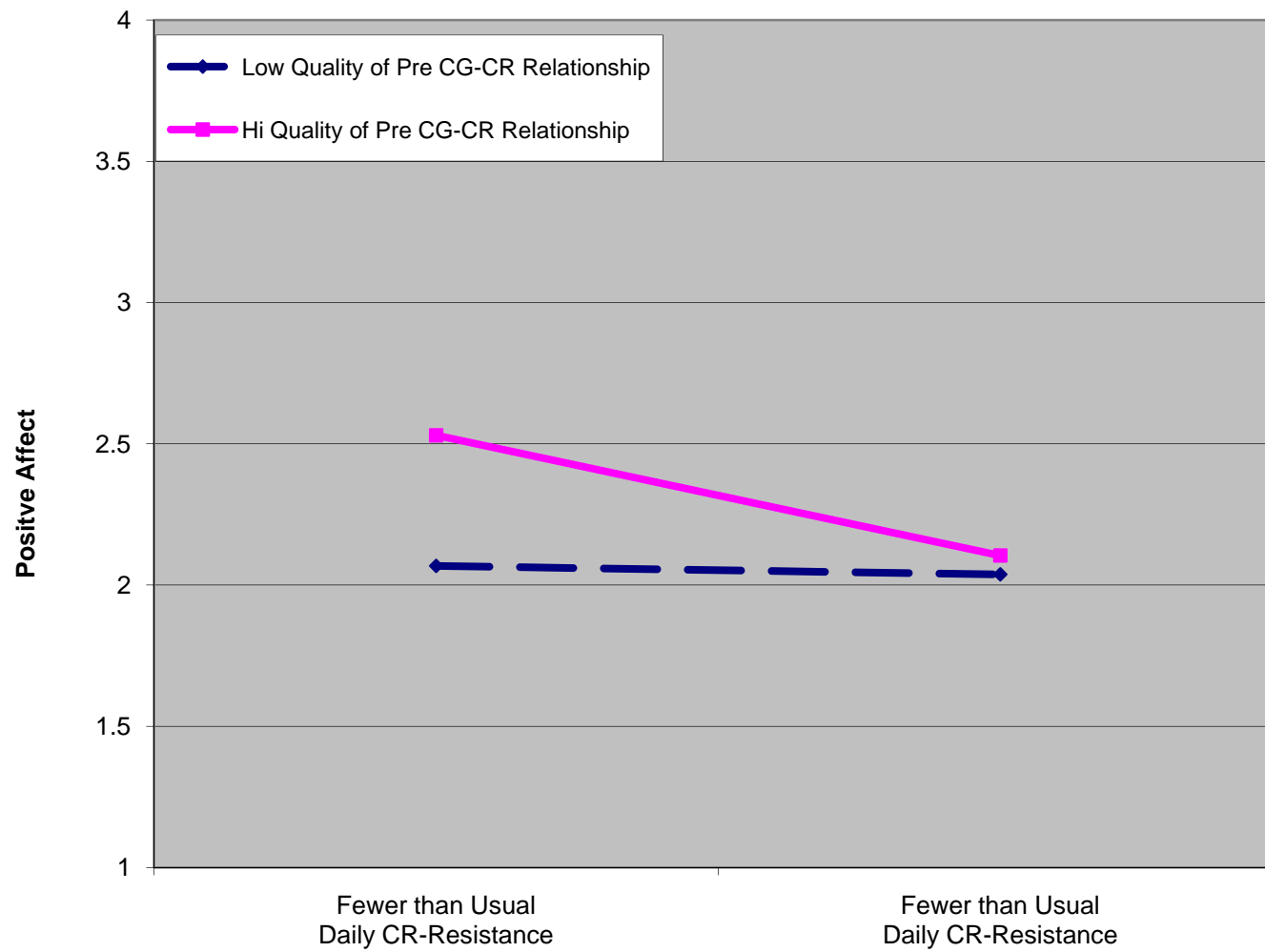
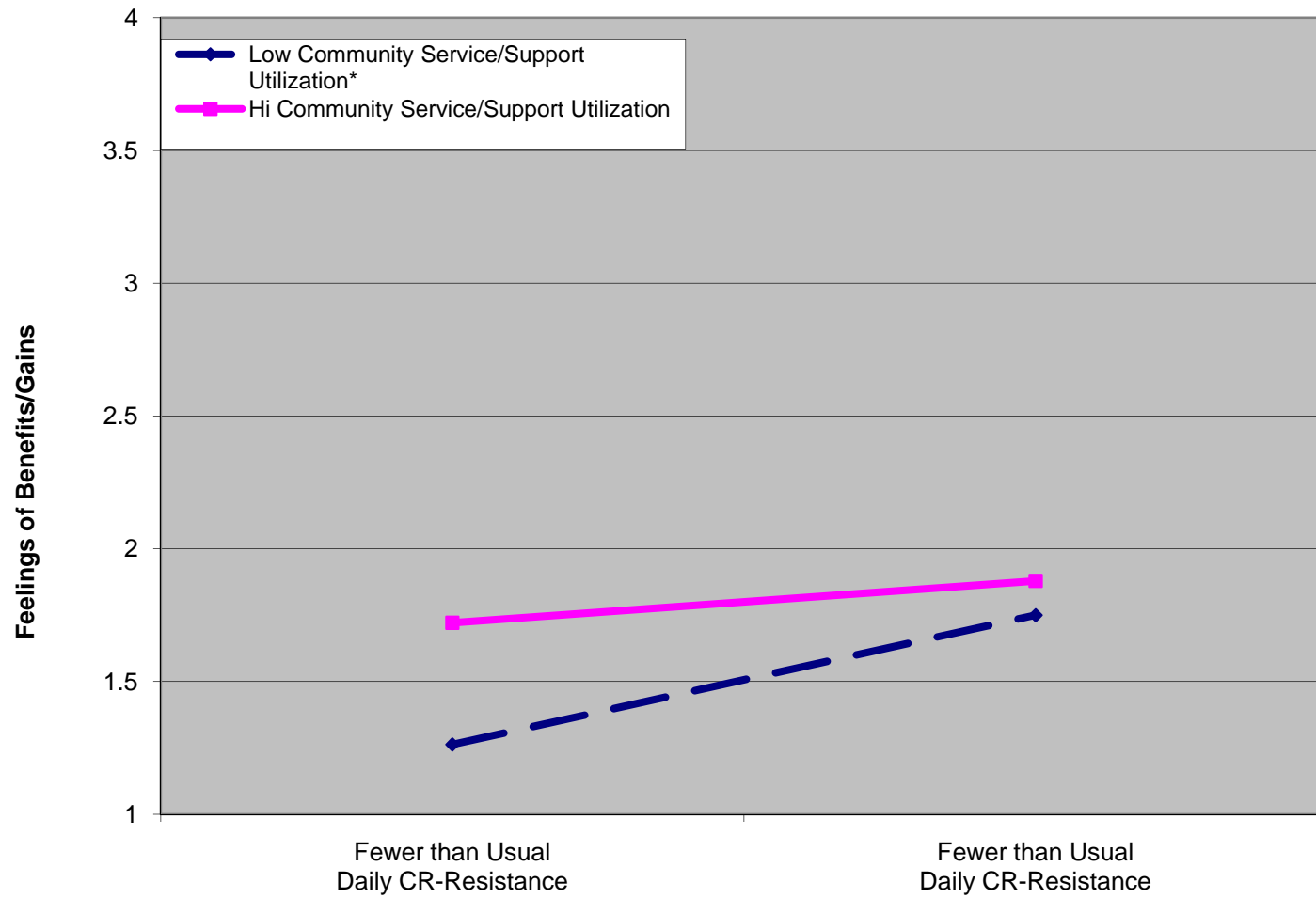


Figure 13. Community Service/Support Utilization Moderates the Within-Person Association between Daily CR-Resistance and CG Feeling of Benefits/Gains



Additional Analyses Results on Community Service/Support Utilization

Because the community service/support utilization scale involves a wide range of service and support items, in order to interpret quantitative results, all items were separated into four different categories, and these sub-scales were used for post-hoc analyses. Community service/support utilization as a whole (averaging different types of support/services that CG utilized across 8 survey days) played a moderating role between “Person-Mean CR-resistance” and physical health symptoms; “Person-Mean CR-resistance” and feeling of benefits/gains; and “Daily CR-resistance Fluctuation” and feeling of benefits/gains. In order to better interpret these results, the same HLM analyses were run with sub-scales of community service/support utilization. All 18 items from community service/support utilization were divided into similar four service/support categories (see detailed list of the items in the measurement section of the Chapter 3) Detailed items in the measurement section):

- a) IADL assistance (IADL Serv),
- b) Professional health service received at home (Por Serv),
- c) Daily necessary activity assistance (Daily Serv), and
- d) CG services/assurances that relieves CG from direct care and care management (CG Serv).

Tables 8 and 9 present the community survive/support utilization subscale analyses results. Except for the analyses with “CG Assist” sub-scale, similar results emerged as did in the original community service support analyses. Following the community

service utilization sub-scale analyses results were discussed for physical health symptoms and feelings of benefits and gains.

Physical health symptoms. Similar to the pattern in the originally community service/support utilization analyses, three of four subscales: “IADL Serv”, “Pro Serv”, and “Daily Serv” sub-scales found to moderate the link between “Person-Mean CR-resistance” and physical health symptoms. For CGs with relatively high utilization of these three services, having higher “Person-Mean CR-resistance” scores was associated with greater physical health symptoms. However, for those CGs with relatively low utilization of these three services, level of “Person-Mean CR-resistance” was not associated with the level of CG physical health symptoms. This pattern did not hold for the “CG Serv” subscale; CG Assist utilization did not moderate the link between “Person-Mean CR-resistance” and physical health symptoms.

Feelings of benefits/gains. At mean level analyses, “Pro Serv” and “Daily Serv”, played significant buffering roles of the link between “Person-Mean CR-resistance” and feelings of benefits/gains. For CGs with relatively high utilization of these services,

Table 8. Multilevel Regression Results for CR-resistance Predicting Daily Physical Health Symptoms as Moderated by CG Community/Professional Support Utilization Sub-Scales

		Unconditional	Model 1	Model 2a1 LADL support	Model 2a2 Health services	Model 2a3 not
<i>Fixed Effects (SE)</i>						
	Mean level CR-resistance		.40 (.21) [#]	.36 (.19) [#]	.42 (.21) [*]	.76 (.24) ^{**}
	Daily level CR-resistance		1.08 (.73)	1.03 (.83)	1.13 (.73)	1.17 (.73)
	Mean*Daily CR-resistance		.34 (.17) [*]	.31 (.16) [#]	.34 (.16) [*]	.30 (.16) [#]
	Moderator (Mod.)			.36 (.19) [#]	.03 (.19)	1.13 (.42) ^{**}
	Mean CR-resistance*Mod.			.46 (.17) ^{***}	.44 (.19) [*]	1.55 (.57) ^{**}
	Daily CR-resistance*Mod.					
<i>Random Effects (SD)</i>						
	Variance of Intercept	2.34 (1.53) ^{***}	2.27 (1.51) ^{***}	1.85 (1.36) ^{***}	2.11 (1.45) ^{***}	2.02 (1.42) ^{***}
	Variance of Slope	N/A	.33 (.57) ^{***}	.37 (.61) ^{***}	.34 (.58) ^{***}	.35 (.59) ^{***}
	Residual	1.17 (1.08)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)	1.00 (1.00)
	Deviance	1619.09	1589.48	1599.55	1586.93	1582.80

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

^a Socio-emot supp refers to perceived available socio-emotional support.

^b *p* values are not available.

^c A chi-square statistic was used to decide whether to constrain random variance. [#]*p* < .10. ^{*}*p* < .05. ^{**}*p* < .01. ^{***}*p* < .001.

Table 9. Multilevel Regression Results for CR-resistance Predicting Daily Feelings of Benefits/Gains as Moderated by CG Community/Professional Support Utilization Sub-Scales

		Unconditional	Model 1	Model 2a1 LADI support	Model 2a2 Health services	Model 2a3 not
<i>Fixed Effects (SE)</i>						
	Mean level CR-resistance		-.09 (.11)	-.09 (.11)	-.08 (.11)	.11 (.13)
	Daily level CR-resistance		.18 (.25)	.28 (.19)	.14 (.25)	.23 (.23)
	Mean*Daily CR-resistance		-.05 (.06)	-.02 (.03)	-.06 (.06)	-.09 (.05)*
	Moderator (Mod.)					.67 (.25)**
	Mean CR-resistance*Mod.				.26 (.11)*	.83 (.34)*
	Daily CR-resistance*Mod.			-.24 (.07)***		-.35 (.17)*
<i>Random Effects (SD)</i>						
	Variance of Intercept	.68 (.83)***	.69 (.83)***	.69 (.83)***	.65 (.81)***	.63 (.80)***
	Variance of Slope	N/A	.04 (.19)***	ns	.04 (.19)**	.02 (.15)**
	Residual	.12 (.34)	.11 (.33)	.11 (.34)	.11 (.33)	.11 (.33)
	Deviance	568.82	585.75	578.75	567.25	575.63

Note. All models adjust for the effects of caregiver age and sex; see footnote 3 for details. All predictors were person-centered (i.e., centered relative to the person's own mean).

^a Socio-emot supp refers to perceived available socio-emotional support.

^b *p* values are not available.

^c A chi-square statistic was used to decide whether to constrain random variance.

^d *p* < .10. **p* < .05. ***p* < .01. ****p* < .001.

having higher “Person-Mean CR-resistance” scores was associated with higher feelings of benefits/gains. However, for CGs with relatively low utilization of these services, level of “Person-Mean CR-resistance” was not associated with level of CG feelings of benefits/gains. This pattern did not hold for the other two subscales: “IADL Serv” and “CG Serv”; utilization of these services did not moderate the link between “Person-Mean CR-resistance” and feelings of benefits/gains.

For daily CG reactivity to CR-resistance, “IADL Serv” and “Daily Serv” played significant moderating (exacerbating) roles in feelings of benefits/gains. On days when CGs faced more than their usual level of CR-resistance, CGs with relatively high utilization in these services reported significant decreases in feelings of benefits/gains. However, for those CGs with relatively low utilizations in these services, having an additional CR-resistance was not associated with changes in feelings of benefits/gains. This pattern did not hold for the other two subscales: “Pro Serv” and “CG Assist”; utilization of these services did not moderate the link between “Daily CR-resistance Fluctuation” and feelings of benefits/gains.

Qualitative Analyses Findings and Interpretations





In this chapter, the primary findings that were relevant to the current research questions are presented. Two major themes emerged from the qualitative thematic analysis: *four different types of CR-resistance* and *CG cognitive resources and other CG background factors* that influenced CG strategies for managing CR-resistance and maintaining CG emotional well-being under caregiving challenges, including CR-resistance. First, four different types of CR-resistance experiences are discussed (see Table 10), focusing on the occurrence, the contextual factors, the predictability, and the possible emotional impact on the CGs. Second, CG cognitive resources and other background factors (e.g., CG attitude, knowledge, values) that influenced CG strategies in managing CR-resistance as well as CG emotional well-being are discussed and interpreted in light of tenets from Social Cognitive Theory.

Four Types of CR-Resistance

The types of CR-resistance are discussed in light of the first two qualitative research question topics:

- 1) When/how often does the CG experience CR-resistance?
 - a. How much/often can the CG predict the occurrence of CR-resistance?
- 2) How stressful is CR-resistance to the CG?
 - a. Which kind(s) of CR-resistance have been the most stressful for the CG?
 - b. How does the CG emotionally react to CR-resistance?

Table 10. Four Type of CR-Resistance

CR-Resistance	Causes	Characteristics	Common Reaction by CG	Common Outcome
1. Frequently Occurred Across Many Different Daily Activities (e.g., personal care shopping)	a. CR strong personality (e.g., independent, hardheaded) and/or b. CR demented/hallucinated symptoms	<ul style="list-style-type: none"> Constant demands Chronic 	CG often got: a. exhausted from trying to meet CR demand across many settings b. Irritated from not being able to satisfy, calm down, or please the CRs	Accumulated exhaustion and irritation often lead CG occasional emotional outburst.
2. Occurred often in One or a Few Specific Daily Activity(ies; e.g., bathing, eating)	a. CR specific preference and personality (e.g., private, hardheaded, independent) and/or b. CR demented/hallucinated symptoms	<ul style="list-style-type: none"> Predictable based on CG knowledge of CR personality, preferences, and illness 	If CG had patience and knowledge about CR, CG could identify : a. CR 's un-met needs and preferences b. CR mood	CGs came up with strategies dealing with their CR-resistance over time
3. Occurred during Transitional Events(e.g., giving up driving, wheelchair use, residential change)	a. CR protests for giving up independence and/or familiar routine/place	<ul style="list-style-type: none"> Associated with CR functional/mobility Independence 	CG tried to: a. help CR understand the transition needs for CR and/or family well-being b. set the process best fit the CR characteristics (e.g., personality and illness)	CGs understood the transitional needs, CR got used to the change/gave up, CG needed to force the change for CR safety or well-being
4. Infrequently Occurred due to Unfamiliar or Unexpected Situations(e.g., nursing home, respite, emergency room)	a. Disrespectful formal CG approach without understanding CR ability/preference b. CR personality/ preference: disliking receiving help other than family members c. CR demented/hallucinated symptoms	<ul style="list-style-type: none"> Unfamiliar place/context Could be a dramatic/traumatic event for CR and CG Could happen to a CR who is usually easy going at home 	CGs usually did not have much control over the situation although certain things helped: a. having familiar person/voice around b. knowing or asking CR ability/preferences c. CG advocating CR preference/needs	CR persisted behaviors until: a. the CR got back to his/her normal environment by CG efforts, or b. the situation could not be changed and became a transitional event (see above)

CG experiences of CR-resistance were organized by their occurrence and contextual factors. The qualitative thematic analysis identified largely four different kinds of CR-resistance:

CR-resistance that occurred (a) frequently across many different daily activities, (b) often in one or a few specific daily activity (ies) (e.g., bathing, eating, going out to a doctor's appointment), (c) during transitional events (e.g., giving up the CR's driver's license, moving residence), and (d) due to unfamiliar or unexpected situations (e.g., being in an emergency room, having an unfamiliar caregiver).

Which specific type of CR-resistance was displayed by the CR was based on a combination of contextual factors and CR related characteristics. The contextual factors involved CG specific routine activity(ies), such as bathing and eating, or situational factors, such as an unfamiliar place or an emergency room. CR related characteristics involved CR personality, illness type, and changes in CR health and/or functional conditions. These contextual factors and CR characteristics were also closely associated with how often the CR-resistance occurred and how much the CG could predict the occurrences, and thus, could explain some variability in the *magnitude of emotional impact* experienced by the CG. In the following section, each type of CR-resistance is discussed in regard to contextual factors, CR related characteristics, predictability, and the possible emotional impact on CGs.

CR-Resistance that Frequently Occurred Across Many Different Daily Activities

The first type of CR-resistance was characterized by CRs frequently displaying resistive behavior to their CGs across many different daily routine activities including going out, choosing clothes, eating—*frequent chronic type CR-resistance*:

She would just... upset her, you know? ...little things to if we put down her clothes, she would ... resist because she would be mad because she didn't want to wear that...even as little as making..., I would always try to please her, 'what would you like for dinner today?' you know? And always, it seemed like it had too much salt, I had too much this, it was always, always a complaining thing....

Although, as seen here, each resistance could be not a significant incident, the cluster of reoccurring small incident across many activities could wear CGs down over time.

This type of CR-resistance seemed to be caused by two main factors: the CR's strong personality (e.g., independent, hardheaded) and/or dementia/hallucinating symptoms from illnesses. For instance, this type of CR-resistance was often reported by CGs for CRs with dementia who also had a strong personality. This resistance was often caused by the CR's inability to comprehend or misunderstanding the care situation or necessity of the activities. The occurrence of the resistance could be swayed by the CR's mood at that moment and thus CGs could often identify the CR's mood by observation:

Sometimes she would just get angry all of the sudden and then she would start telling me, you know ugly things... You could generally tell what was going to happen there. You have to kind of be there close by and you can kind of read what is going on...if she didn't wanna take them and I had put them beside her, she would knock them off the table...

Other examples of this frequent/chronic type of CR-resistance were reported by CGs for CRs who had a strong personality but without dementia. Those CGs expressed how their CR's particular personality type, such as independent and hardheaded, limited the CR

from receiving assistance from them in their daily care and assistance activities: “Like I said, very independent woman...so it was very hard for her to have to depend somebody to do it for her, you know?” or “Just his personality. Yeah just independent, hard headed, determined, blood... you now just being a man, they don’t want to admit that they need help.” Although most CGs knew their CRs’ personality well before caregiving started, and thus could anticipate certain levels of CR-resistance, it was still difficult for CGs to face frequent arguments in order for them to perform each daily care or assistance activity.

Overall, regardless of the cause of the CR-resistance, whether it was mainly caused by a disease related condition of the CR (e.g., dementia) or by CR personality, a common challenge of this type of CR-resistance for the CGs was emotional and physical *exhaustion* from trying to meet CR demands across many settings and *often without a break*, and faced with continuing *irritation* from not being able to satisfy, calm down, or please the CR with the CG’s efforts: “I never felt completely free of responsibility.” For some CGs, this chronic exhaustion and irritation sometimes lead to severe arguments with their CRs, and that intense incident often emotionally drained CGs: “Sometimes I get frustrated probably even certain amount of stress...sometimes it’s combined up.” These CGs who experienced these occasional intense incidents also often did not know how to change their chronic stressful patterns:

I’d felt horrible for getting into the argument with her to begin with... I’d felt horrible for not doing what she wanted to do, but this is when she would just get these... crazy ideas that she wanted to go to the store, she wanted to go buy this, she wanted to go buy that...

Very, very hard... after we'd be arguing with her, or not be arguing with her, I'd go to my room and I was, I was emotionally drained. I would cry and cry because I felt like...I would argue with her because sometimes...it's very frustrating when, it would get really frustrating, you know? And so then I'd talk to myself, 'Oh my god, am I a bad daughter?' You know, you start thinking all these things, cause I'm making her more upset? And you don't know...how to deal with some of these situations. It's really hard, you know. It's just really really hard.

Moreover, this frequent/chronic type of CR-resistance could be one of the most difficult kinds for CGs, considering the impact on CG emotional and physical health. Our qualitative evidence suggests that, for a few CGs, this continuing additive stress greatly impacted their emotional and/or physical health: "I'd had a nervous breakdown. I mean I was crying all the time, I was walking around in circles not getting anything done and I know enough I read enough to know this was all the signs."

Social Cognitive Theory would explain the possibly adverse impact of this type of CR-resistance; although CGs could foresee or predict the occurrence of CR-resistance incidents, the frequent/chronic nature of the occurrence pattern could exhaust CGs without giving them a chance to recover from one incident before another occurred. Thus, those CGs with this type of CR-resistance could not maintain their optimal emotional and physical states and bringing about a decreased level of CG sense of efficacy, as evidenced in the interviews: "It's when I'm feeling bad and having trouble coping generally uh she uh get's to me more...." Their decreased level of sense of efficacy in managing the demands from frequent/chronic CR-resistance could not only induce occasionally intense incidents but also negatively impact the CG's general emotional and physical health.

CR-Resistance that Occurred Often in One or A Few Specific Daily Activity (ies)

The second type of CR-resistance often occurred in one or a few specific routine personal care or assistance activity (ies) in which CGs had problem with their CRs corporation—a *few specific activities type of CR-resistance*. “The only places that I was getting some real resistance uhhh were...when I would try to get her into the shower...”

These CGs who experienced this type of CR-resistance could easily identify their problematic activity (ies) during their interviews. Examples of specific contexts included CR-resistance in regard to activities of daily living, such as refusing to eat, to bathe and to take medication, and to instrumental activities of daily living, including refusing to go to doctors’ appointments and to a beauty shop, and refusing to allow CGs to manage their finances. Because this resistance occurred repeatedly in one or more specific context(s) in which CGs managed and arranged their CR routine care, CGs could often learn and foreseen how and when the resistance occurred. Thus, although some incidents could be challenging and required a certain level of CG patience, most CGs came up with a strategy for dealing with this type of CR-resistance over time.

Based on CG examples, this type of resistance was displayed based on two main CR characteristics: CR personal factors, having specific preferences and personality, and CR illness type, particularly having dementia.

On the one hand, for CRs without dementia, this behavior often was displayed due to CR not being able to conduct daily activities in the CR’s preferred/customary ways. Some CRs, particularly with certain personalities (e.g., stubborn, independent),

instead of communicating their needs/preferences, expressed their unmet needs in resistive behavior:

He was a real stubborn person and so am I... so towards the end when it was getting hard for him to eat...he would ask me to, 'Well the next time you fix this would you chop up the food a little bit smaller.'

Because these CRs had functional limitations, their ways of conducting daily activities and personal care often and largely depended on their CGs. Therefore, CRs expressed their unmet needs and preferences in their resistive behavior toward to their CGs (e.g., how to bathe CR, how to prepare food). In order to resolve the resistance problems, CGs needed to adjust their approach and/or strategies to their daily assistance activities for their CRs. First, the CG needed to be willing to understand why the CR resisted (CR unmet needs/preference and personality). Second, they needed to come up with an adjustment plan for meeting the CR needs. Third, they needed to be willing to pursue the plan, sometimes with patience. If a problem got solved for the CR, it often did for the CG:

When I would try to get her into the shower and I had to devise some special ways of doing that and she became much more tractable after, after that. The main thing that I did was uhhh...I covered, I covered the shower cuz, cuz she couldn't get into the bath tub, ... so I covered the shower head, uhhh...put it with a long, with a long umm hose on it.

However, sometimes even with a CG's good understanding of their CR's needs/preferences, other activities, such as using wheelchair and different ways of bathing, could not be easily adjusted for the needs or the safety of the CR. For instance, using a wheelchair could be problematic:

Oh my god, it would just freak her out. We would try to transport her from the wheelchair to the toilet or into the shower and it would freak her out because she

was so afraid. And we used to tell her, 'Mom. You're going to make yourself fall because you're so afraid of falling. You know, we've got you. You're okay.' You know, and...we had real trouble with that for awhile.

Another problem area was bathing the CR:

I think he was shy and I think it was private area...your daughter is younger than you taking care of you like a baby you know that's kind of an assault on your sense of...I don't know your adulthood your sense of who you are, what your are, what your capable of doing...I think...he couldn't except or didn't want to except that he couldn't care for himself plus he was st-stubborn anyhow...on and off but he knew that I loved him very much and that he had to do it and a yea I remember we had... some real problems with that aspect.

In these cases, the CR-resistance continued until the CR got used to the care arrangements or understood her or his own limitation and/or care or assistance need and accepted the situation. These cases often shared common patterns with transition type CR-resistance that is discussed in the following section.

On the other hand, CRs with dementia displayed this type of resistance often based on CR's cognitive inability to comprehend/track the needs of certain activities and/or CR mood at that moment. Eating, taking medication, and bathing/showering were the major contexts in which CRs displayed this type of CR-resistance. Compared to those CRs who displayed CR-resistance across many different daily activities, these CGs who displayed CR-resistance in one of a few specific daily activity(ies) tended to have more agreeable personalities in general. Although these CRs might initially display resistive behavior when their CGs mentioned the activities (e.g., "Let's take a shower"), once they got started with the activity or the CGs took a break and re-introduced the activity, they could often move forward with the activity without giving much difficulty to their CGs: "But, uh she didn't like to take a shower, no way... I tell people, ...Don't, don't, don't

say these things that they don't want to do. Just say, come on, we're going in here and, you know." Therefore, as much as those CGs understood the pattern of their CR resistance, "we enter a routine and our problems are always the same thing", they could predict the occurrence of the behavior and manage the CR-resistance.

In summary, although it required of the CG a certain level of patience, this *a few specific activities type* of CR-resistance was one of manageable types of CR-resistance. If CGs understood their CR's personality and preferences, had good knowledge about the CR's illness, and also had some patience, they often found effective solutions for managing their specific CR-resistance. Stress Theory would explain the manageability in this type of CR-resistance in the predictability of the occurrence. Because CGs could anticipate the CR-resistance event, CGs could prepare and manage the CR-resistance incident as compared to dealing with other unpredictable ones. Social Cognitive Theory would also add that because of repeated CG observations of their CR-resistance in a few specific activities, CGs could learn to work around the specific CR-resistance and develop a management strategy over time. Thus, CGs with increased levels of sense of efficacy often well managed this type of CR-resistance.

CR-Resistance that Occurred During Transitional Events

Several CGs reported that their CRs displayed resistance to their CGs when they face a transitional event although these transitional events did not frequently occur for each CG and accompanying *transition type CR-resistance*. In the interviews, a majority of CGs discussed a period of time when their CRs went through different transitional events caused by their increased care needs and health/functional decline. Most of

transitional events occurred with anticipating pre-event(s) and/or gradual awareness in the CR of cognitive/functional decline. “He said I really don’t feel safe driving...one time...I was in the house, and he came in and, he said...I couldn’t, I couldn’t remember how to turn the car on, or how to drive...he wanted to put the car away. It was in the driveway.” Examples of transitional events included getting assistance in personal care and daily activities, giving up a driver’s license, using a cane, and moving to a residential facility. Although these transitional events only occurred for a few times for each of the CGs, CRs often displayed resistance in these situations as a protest to giving up their independence and/or giving up a familiar routine/place. The length of a transitional event and magnitude of CR-resistance seemed to vary based on two CR factors: CR level of understanding of transition needs (e.g., getting assistance, giving up driver’s license) and CR characteristics, such as CR personality and illness. Based on these two key factors, transition can be a lengthened and difficult period for both the CG and CR.

Although giving up or taking away CR independence and/or familiar routine/place seemed to be very difficult transitions particularly for CRs with certain personalities, (e.g., private, hardheaded, independent), *CR understanding of the transitional need* was a key factor for the CR to be able accept the changes due to a transition. Although the length of time needed, the amount of CG effort spent, and the strategies varied depending on the CRs and the CGs, knowing CR personality and tendencies through their past relationship helped CGs to be able to anticipate this type of CR-resistance and to prepare strategies for managing the CR-resistance. However, even

with good CG knowledge about the CR, the magnitude of emotional stress on the CG could vary *depending on CR personal factors*, such as personality and illness type.

A transitional event seemed to go more smoothly for a mild mannered CR than for a CR with a strong personality. On the one hand, for a CR with a mild mannered personality, CGs could anticipate CR-resistance based on the CR's past history and the CR's particular personality, and the CG could well prepare and manage any CR-resistance. For instance, when a CG who was a private person started needing personal care assistance, the CG, with other family members' help, managed the CR-resistance well by giving explanations. Although the process took an extended period with ongoing efforts from all family members, the CR came to understand the need for assistance and accepted the situation over time:

I knew she was a very private woman, and so I figured it would be uncomfortable for her and ...may be a little embarrassing...at the beginning for her...Afterword as she got older I think she just kind of realized...I can't resist any more. This is for my own good....it is what it is and I have to deal with it, so she was okay with it. But it was hard for her...I think it was hard for everybody (who were involved in the process).

On the other hand, for a CR with a strong personality—independent, hardheaded, and stubborn—and even with appropriate support from others, such as medical professionals, the process of the CR accepting the transition could be emotionally hard on both the CG and the CR. The CG might need to face intense CR-resistance before the CR understood the transitional needs or gave up CR preferred ways and/or independence. Even though the CR might understand the transitional needs, he/she might need to express his/her frustration or emotional upset to the CG in CR-resistance before finally the CR could let the independence go:

You can have a doctor say you can't drive anymore and in fact that's what we did with my husband, because um when they start putting him on really heavy medication for the pain...we had quite argue, heated argument on day when we're, he was going down for chemo and he wanted to drive... I said, I'm not getting in the car with you. I'll meet you down there, but I am not going to get in the car with you, if you, if we have an accident even if it's not your fault your under so much medication it's going to be your fault...so he ugh said a few words back but he let me drive and after that there was no argument...Just that one time he he really...cause that's the last piece of a independence that they have.

Additionally, although it was not reported by many CGs, the strategy—letting the CR understand transition needs—was not applicable for CRs with cognitive limitations.

Because their CRs were no longer able to cognitively understand the transitional needs, a few CGs described that they applied creative ideas for their transitions. CGs who particularly had good knowledge of dementia related symptoms and tendencies often tried to not explain details of the transitional events but pursued the transitional plan and provided single step directions as it needed. For example, telling the CR that “we will go for a ride” instead of telling the CR “we will take you to a new home because you are moving.” The level of difficulty faced by the CGs could vary depending on the CR personality that was expressed in dementia symptoms. The examples of these transitions in our qualitative data could be highly detailed and depended on the CR's very particular condition and circumstances, and thus are not quoted here.

In general, for CRs with dementia, not telling detailed sequences of the transition to the CRs seemed help CGs avoid extra or unnecessary CR emotional upset and resistance, and thus CGs maintained control over the transitional events. However, within the limited numbers of our examples, even though those CGs tried to not tell the CRs about the transitions, most of the CRs somehow seemed to sense their transitions

although it was not certain if it was caused by CR understanding of the transitional needs and the frequency/severity of their CR-resistance. This area needs further exploration.

Overall, the transition type of CR-resistance was somewhat manageable. Perhaps, the level of difficulty in this type of CR-resistance could be caused by two factors: timing of the occurrence and CR personal factors. When CR demands/circumstances associated with a transition did not require an urgent change, the CGs could plan and prepare according to other caregiving demands and CG other life circumstances. Thus, dealing with CR-resistance could be more manageable as compared to an urgent transition, such as unfamiliar/unexpected situations that are discussed in the next section. Stress Theory would explain this situation as similar to the *a few specific activities type* CR-resistance in that because CGs could observe gradual changes in CR demands, they could anticipate future needs and prepare well for these foreseen needs. Moreover, during this preparation or planning for an upcoming transition, if CGs have good knowledge about their CR's personality and health condition, these CGs could prepare well for how and when the transitional would take place.

CR-Resistance Occurred Infrequently Due to Unfamiliar or Unexpected Situations

Several CGs expressed that their CR displayed resistive behavior in an unfamiliar situation, such as being at urgent care, during a hospital stay, or with an unfamiliar formal caregiver—thus the unfamiliar/unexpected type CR-resistance. As compared to other types of CR-resistance, this type of CR-resistance happened the most unpredictably because of sudden/unexpected changes in the CR's care environment or in perceptions of the CR about the environment. Although, for most cases in our qualitative data, this

intense CR-resistance incident happened for a short-period of time, for a few cases this incident could happen over an extended-period and might shift into the transition type of CR-resistance. Moreover, many of those CGs who experienced this unfamiliar/unexpected type of CR-resistance expressed that their CRs hardly displayed resistive behavior throughout their long-term caregiving career, and they often shared their rare but significant CR-resistance incidents toward the end of their interviews.

There seemed to be three main causes for this type of CR-resistance. First, an unfamiliar situation or an environment caused CR disorientation or confusion. Our examples provided evidence that this CR disorientation could be caused by CR disease, such as dementia, and side effects from medications heightened by an unfamiliar environment. Once a CR got disoriented, a familiar person or things seemed to be helpful in calming the CR. Here is an example of a CR with dementia:

I was very surprised...but it was very rare. She was generally of a good nature...so I didn't really get resistance. She would refuse to turn, to go in the direction of the caregiver was trying to take her in, and then she would start screaming and getting all disoriented and that happened once or twice. And, and uhhh...once she would panic—which was not very often. Once she would panic like that... it was impossible to calm her down until maybe I would show up. When I would show up, I was there—I could usually get her...to calm down. She recognized my voice... There was something in the way that I could talk to her.

The next example is that of a CR who got disoriented from medications during a hospital stay:

I remembered two of his hospitalizations I'd insisted I'd take him home. He became delusional and extremely violent and had to be um, restrained and it was such a shock to me. The first time the hospital called me at about 10:30 at night and asked me to come down. And then there were two security men in the room with him and he was, H (CR) had been a Southern gentleman...He never swore, never used bad words in front of ladies and... he was using God's name, he was just horrible. And, I-uh he kept thinking the nurse was a Korean, um, not Tokyo

rose, but he called her something like that...That she was his enemy and she was trying to kill him...And, he tried to strangle people. He hurt me, not, not severely. But...He'd grab and twist. I learned to just stay the heck away from him. I never had him in the hospital long after that. I always stayed there with him. Sometimes I slept there. Um, because once he could hear my voice...The rest of the time he felt that he was under attack.

The second cause for a CR to display this type of CR-resistance was because an unfamiliar CG provided personal or care assistance in a disrespectful manner without understanding the CR's ability/preference. Here is an example:

I think the times...that he reacted...while that last... trip to the emergency room... my daughter was with me and and I said (to a nurse), "you know do you have a sponge or something, his mouth really needs to be cleaned out" and we both watched her and she just was like this [demonstrating] and he bit and my daughter is very assertive and she said she said, "I'll do that"...I think... it really helps to say...how you do it..., well my daughter was fine cause once she got a sponge then she could gently clean out his mouth for him...It was this nurse who was in the emergency room...yes and then she was 'Oh well he's really violent!' And my daughter said 'He's not violent'...this was at the emergency room ...that was not a real great time but once we got into a room...the care was fine and everybody was careful with uh any tubes or shots they needed to do. But uh..It's very startling if they don't say...you know, I need to do this....

The third cause for a CR to display this type of CR-resistance was because they did not want to receive help from other than family members:

He sometimes didn't even want the paramedics to come because he'd fall down a lot, he fell, I don't know how many times. And I did have to call them onetime I just literally couldn't get him up. And then the other time he broke his him...he would just, absolutely refuse to allow me to call the paramedics I mean he'd get very argumentative and, he'd tell me all these things that he wanted me to do that were ludicrous....

This unfamiliar/unexpected type of CR-resistance could bring an intense impact on the CGs. Stress Theory would explain that because this type of CR-resistance happened the most unexpectedly as compared to other types of CR-resistance, CGs who faced this type of CR-resistance could not anticipate the occurrence and prepare for this intense event.

Social Cognitive Theory also would add that these unfamiliar/unexpected events rarely happened and involved unfamiliar people or environment, and therefore, CGs could have lower sense of efficacy in dealing with this type of CR-resistance as compared to a situation that frequently happened.

CG Cognitive Resources and Other Background Factors that Influenced CG strategies

Managing CR-Resistance as well as CG Emotional Well-Being

CG cognitive resources and other back ground factors that influenced CG strategies managing CR-resistance as well as CG emotional well-being are discussed in light of third qualitative research question topic:

What personal, interpersonal, and social factors helped or did not help to overcome/avoid the impact of a CR-resistance experience on CG's emotional health?

When CG strategies, particularly those dealing with the emotional impact of CR-resistance, were determined, the thematic analyses revealed that those CGs strategies seemed to be less influenced by the specific types of CR-resistance (discussed above section), and highly influenced by two main CG characteristics: *CG specific knowledge* and *attitudes*. Moreover, thematic analysis also identified patterns that *CG specific transferred and/or generalized knowledge, attitudes, and CG coping experiences* from CG past challenges seemed to influence CG overall emotional resiliency under caregiving demands.

CG Specific Knowledge

Through the thematic analysis, two types of CG knowledge were identified that played critical roles for CG management of CR-resistance: (a) one of essential knowledge for maintaining CR health and well-being--CR disease-specific information and (b) CR personal information including CR personality and preferences in daily activities. The thematic analysis further revealed that (c) the combination of particular CG knowledge and CG enactable skills--knowing exactly how to implement CG knowledge in a specific situation--were important factors for CGs to maximally utilize their personal resources. These three key findings are presented and discussed with quotes in the following.

CR disease specific information. CR disease-specific knowledge was important information that aided the CG to manage the daily occurrence of CR-resistance; typical disease-specific information included causes, symptoms, prognosis, and required medications and treatments. Several CGs stated that knowing what is normal for the CR disease--"This is a usual thing,"--particularly for Alzheimer's patients, helped CGs deal with CR-resistance as well as enabled the CGs to avoid unnecessary personal blame and emotional upset toward to the CR: "So then I began to understand and comprehend, you know, the disease and it's not her; it's the disease so that made it a lot easier, so rough up until that time."

CR personality and preferences in daily activities. Knowing their CR's personal information seemed to help these CGs in two ways: to avoid occurrence of CR-resistance and to effectively deal with CR-resistance.

Specifically, several CGs expressed that they rarely faced CR-resistance, and those CGs seemed to share three characteristics; (a) their CR had a specific personality, such as agreeable and gentle, and, based on the CG's previous close and positive relationship with the CR, (b) the CG understood what exactly the CR wanted in daily care: "I just know her so well, it's like almost my own body because I just have been doing this for so long that she doesn't even really need to talk to me," and (c) the CG supported the CR, despite functional or cognitive decline, to maintain his/her normal personal and social life routine: "She was part of our everyday lives...we included her in everything we did...So we would go to the movies...the restaurants... everywhere with her...we didn't let the fact that she had limited ability to move stop us." CGs who had prior pleasant relationships with their CRs often took extra efforts to have CRs "be involved," "be understood," and "feel useful," despite their cognitive and functional declines. Although it could be over influenced by CR characteristics, such as CR personality and disease type, having a meaningful daily life routine seems to help CGs avoid unnecessary CR-resistance.

Moreover, when or if a CR exhibited resistance to the CG, knowing CR personality and preferences often helped the CG identify specific strategies for handling the CR-resistance. For instance, one CG shared his strategy for CR-resistance: because of the CR's personality, the CG and his family decided to deal with resistance with an assertive attitude. "You just have to talk to her like a teenager. No, you gotta be strong, you gotta tell her, if you back down, she'll walk, they'll walk all over you...Ya, she knew who she could manipulate---like the kids." However, another skilled CG took a different

approach based on her knowledge about her CR, "She likes to be joked with...She likes to, she likes to, have cheerfulness around her. She likes to be spoken to politely...She does not like to be spoken to in a harsh way." For developing an effective strategy in the face of CR-resistance for a specific CR, the CR's personality and preferences were important pieces of information that CGs should consider and could utilize.

Combination of CG knowledge and additional CG enactable skills. Although each piece of CG knowledge brought advantages to the CGs in the face of caregiving challenges, such as CR-resistance, when combined that knowledge was sometimes distracting and other times constructing. On the one hand, having multiple pieces of knowledge could work against a CG's good intentions, if the CG did not have an enactable skill. For instance, one CG knew what she should be doing to maintain the CR well-being: encouraging the CR to do physical therapy at home. The CG also knew the CR's personality and preferences well, namely that the CR was an independent person and did not like to be told what/when to do anything. However, the CG did not know exactly how to encourage the CR without upsetting him, and her efforts often induced an incident of CR-resistance:

I mean he can go to physical therapy twice a week but if he doesn't practice...at home, he's wasting his... and my time...But he resents it if I try to tell him, and I suppose there's a better way I could do it but... I don't have any training as a care caregiver so... I have to force him to do more.

On the other hand, having different pieces of knowledge come together sometimes worked to successfully carry out the CG's good intentions, particularly if the CG had an enactable skill. For instance, another CG knew what she should be doing to maintain the CR well-being: monitoring the CR's blood pressure when the CR worked alone in the

heated garage at his hobby--polishing rocks. The CG also knew about the CR's personality and preferences that, very similar to the CR in the previous example, the CR was an independent and resistive person and did not like to be told what to do. But the CG knew exactly how to talk to the CR--instead of forcing him to rest, telling him the consequences of not taking a rest multiple times. With her enactable skill, despite the CR-resistance, the CG was able to balance the CR's health and quality of life, thus allowing the CR to continue his hobby:

He would like to work in the garage... he had hobbies...OK it's the polishing of rocks... And he continued to insist that he work in the garage...But, if he was out there in the heat, the heat... And standing was not good for him...we were married 49 years...So, I knew his nature...very private and to being resistant... I would say, '...'. Then, 30 minutes later, I would come back and I'd say, '...how do you feel?' 'I feel fine.'. Then uh 30 minutes later I'd go back out and I'd say 'I'd like you to come in now. And I have to take your blood pressure. You're not looking so hot.' And he'd mumble and grumble but he'd do it. The only thing he... did not want paramedics coming to lift him. That just...bothered him... Terribly.

In summary, CR disease-specific information and CR personal information were critical pieces of knowledge for CGs to successfully manage CR-resistance. Having CR disease-specific information, several CGs were able to alter their attribution of CR-resistance at least partially to their CR diseases so that they were able to reduce their emotional reaction to the CR-resistance. This confirmed empirical evidence (e.g., Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003) and a tenet of Stress Theory (Lazarus & Folkman, 1984) that individual attribution to a stressful event, such as CR-resistance, influenced personal significance or meaning to the event. Another important and even key type of CG knowledge to enable the CG to manage CR-resistance was related to CR personal information. In order to provide quality care, CGs often employed

their personal knowledge of, for example, CR personality and preferences; this resulted in minimizing the occurrence of CR-resistance. These CGs also utilized their personal knowledge when they faced CR-resistance by identifying specific strategies for their CRs. One tenet of Social Cognitive Theory, the power of observation in learning, would explain that, through observations and direct involvements in daily routine, family and cultural activities, CGs developed an understanding of their CR's personality and preferences as well as the CR's confrontation styles. In this sense, family CGs, particularly those who shared a great proportion of their life together with their CRs, had advantages in providing quality care as well as identifying specific strategies in dealing with their CRs. By lighting this family CG strength--knowing CR's personal information, the findings inform not only for family CG but also for professional CG interventions.

Overall, having particular types of knowledge seemed to provide great advantages to CGs in the face of CR-resistance. However, as noted in the intervention literature (e.g., Farran et al., 2004), our study confirmed the importance of CG enactable skills in order for CGs to maximally apply their knowledge in a specific challenging situation. Our study further provided two opposite CG experiences regarding enactable skills that although having the discrepancy in CG knowledge and enactable skills could induce considerable emotional distress for both the CG and the CR, having right combinations enabled CGs to provide quality care by managing CR-resistance as well as monitoring CR quality of life and health.

CG Personal Attitude

The thematic analysis identified four key CG personal attitudes for maintaining their emotional well-being under caregiving challenges: (a) acceptance of the current caregiving condition, (b) being in charge, (c) the value of family-oriented caregiving, and (d) respect for the CR. Although all of these CG attitudes were somehow interrelated to each other, the first two and latter two attitudes shared similar trends, and thus are discussed together in the following section.

Acceptance of the current caregiving condition and being in charge. Two particular CG attitudes--acceptance of their current caregiving condition and being in charge--helped CGs emotionally ground themselves and efficiently search for solutions.

Acceptance of the current caregiving condition. Many CGs described their caregiving situations with acceptance, such as a caregiving arrangement (e.g., being a sole or primary CG, placing CR in a nursing home), CR condition (e.g., daily care demands, cognitive ability), support system (e.g., family involvement, professional support), and the CG's own limits in meeting caregiving demands. On the one hand, the acceptance came naturally for CGs with particular personal attitudes, including being in charge: "You go with...what do you need to do"; family-oriented caregiving value: "gotta be with family"; or personal and/or spiritual belief: "God gives you what you can bear." These CGs were able to make peace with their caregiving situation without making any effort. On the other hand, acceptance was a process for other CGs, and those CGs often needed assistance from professionals, such as therapists and a community agency (e.g., Alzheimer's Association), or to take their own personal time. For instance, one CG

mentioned that while she was frustrated with her family members who did not provide much help in caregiving, going to therapy sessions was very helpful for her to accept her unchangeable caregiving circumstances: "Because I just...went to therapy and I got to the point where I figured what, they're not going to change, so I'm gonna have to either accept it or...." Another CG told how she needed to take her own time to realize and to accept her own limitations by trying things, first, by herself: "I decided what I'm going to take her (CR) home...the group at Alzheimer's...said, 'Don't do it...but I said I have to try, because if I don't try, then I'll never be able to say 'Well, I tried' you know."

CGs with this attitude or CGs who were able to attain this attitude, *acceptance*, seemed to be at peace with their caregiving situation without being burdened by regret, frustration, and/or anger, and believed that what they should do was to do their best with their abilities, "You just don't sweat it you know, you just kind of have faith and say ok, this is what it is and we're just going to do the best we can." Therefore, without distraction from excessive emotional reactions, for instance, complaining about others and getting frustrated with their CR, these CGs often put the majority of their efforts into making adjustments for dealing with care-related challenges, including CR-resistance. Additionally, it was reported by one CG that this acceptance attitude could also help a CG put a non-pleasant past relationship with the CR behind them and move forward with the current new relationship: "She was not a nice mother-in-law for many parts of my life...you get past that... it's like you establish a whole different relationship. You decide you're the parent, they're the one to be cared for."

Being in charge. Several CGs presented themselves with a *being in charge* attitude when they discussed how they had approached their caregiving role and/or resolved their caregiving related challenges, such as CR-resistance. This caregiver attitude, being in charge, seemed to have originated from the CG's personality (e.g., responsible and independent), sometimes a combination of their family or personal life experiences. For instance, one CG mentioned that her *being in charge* attitude was influenced by her upbringing with her parents: "No matter what, you do what needs to be done." Another CG shared how one of her leisure pursuits, hiking, manifested in her general attitude toward her life including caregiving challenges: "I joined this hiking club...helped me in life...I just believe in being strong ...nobody is going to do anything for you."

CGs with *being in charge* attitudes often seemed to be quite aware of their responsibilities that they faced: "It was just one of those things you have to do." Because of their awareness, these CGs actively took the leading role in caregiving by proactively assessing current and foreseen needs and searching for solutions. For instance, one CG mentioned that with her attitude; "You're gonna have to be in charge" and "Like, you can make adjustments, well that's my thinking... And it's all attitude... Ya, you can do what you want... It's your responsibility...that is what you should do, so this is what you should do. You don't really have a problem with whether I can or can't. There are no excuses." By obtaining nurse assistant training at a nursing home, she prepared herself for the caregiving role long years before the CR started needing assistance. CGs with this attitude often reported that they applied their *being in charge* attitude in daily caregiving

activities, for instance, when they faced CR-resistance: "Something my mother (CR) wants me to do or whatever... somewhere you have to make the firm decision that... it's not necessary...we still have the same kind of respect...but they are now the child and you're the parent."

Moreover, some of those CGs with this *being in charge* attitude, but not all CGs, were also aware of their own personal and social needs; "...don't feel um, trapped you know, try to build your own life...Do what you can do. Don't be, um, you know, try to, to get as much as of, of your own personal needs met." Thus, they often actively attended to their needs with regular personal or social activities, for instances, "My prayer life has grown... I'm much aware of when I'm annoyed or resentful, angry....I would do that things that used to bring me peace. Like I used to have a lot of flowers and work outside ad lack. And that would expand my energy.", "I would have couples over for dinner and I'd cook, so we'd have a social evening together and the girls would, you know, the wives would talk and what not...well you gotta take care of your own self too so that you are there for them, I just, you know, use faith, lean on, on, on faith, get your friends who might have been in similar", "I would leave 3 days a week and play golf," or "I found one [thing] that worked for me, and I started doing yoga regularly, and I'm doing Tai Chi... and I think that's been my stress-buster."

These CGs who carried their *being in charge* attitude over to their own lives, by acknowledging their own abilities, needs, and limitations, seemed to be also able to accept outside resources, such as respite care and doctor's advice For instance, some CGs faced pressures from others, such as family complaints, to only focus on the caregiving

tasks and no need to attend CG own personal and social needs. It was helpful for CG to have professional or friends assuring that taking care of their own health is good thing, "They (family member) really um, don't feel that the caregiver should go out or go do anything you know, you should be there all the time...so that made it hard and I just said to them, I said, the doctor, the case manager, they've all talked to me they say it's important that I do go out and do something for a little while...". For other CGs, tangible help from family or professional was necessary (e.g., respite) in order to regularly have outside activities, "I went to the gym... I talked to my girlfriends um I tried to have as much fun as I could the respite was the best darn thing going for me um [pause] and I've always tried to take care of myself".

Moreover, CGs who know their own limits also tended to say "yes" to receive help from friends, family, and/or professionals, "But you have to be willing to say yes, I'll take that all...you know it's not like, something that you, just have to realize. It's a, it's a job like anything that you become equipped for...". Yet, in real situation, when CG caught in demanding and responsible caregiving role, it seemed to be hard to first realize own health risks, until it shows in their health even for these CGs who knew that they needed to take care of themselves, "I'm going against everything and everything I know about caring for myself number one, my health was going down the tube fast, cause I couldn't get a good night sleep...."

In summary, beyond confirming the extant qualitative literature that *acceptance* and *being in charge* were two of key CG characteristics of skilled CGs (e.g., Farran et al., 2004), our findings further provide descriptions about possible sources and development

of these key CG attitudes. These CGs particular attitudes seemed be originated from different CG life experiences (e.g., family, culture, personal pleasure) and/or particular personal characteristics (e.g., personality, spiritual belief). These CGs with acceptance and being in charge attitudes, because of their awareness of their leading role, current and foreseen needs, and abilities/limitations, often proactively searched and reached out for additional external support. Thus, CGs with these attitudes, as compared to other CGs without these, were more likely to be resourceful, and emotionally and instrumentally prepared for care-related challenges, including CR-resistance.

By interoperating the findings through a lens from Social Cognitive Theory, we could further develop conceptual understanding in this phenomenon. Because of their increased level of internal and external resources, CGs with these attitudes had a higher sense of efficacy which gave them greater confidence in managing caregiving demands, as compared to other CGs without these attitudes. Moreover, with their optimistic view of their ability, these CGs were also able to actually deliver their skills at their potential at the occurrence of an adverse event such as CR-resistance, resulting in their positive reflections regarding their caregiving role and experiences. Importantly, our data confirmed the study findings of Farran et al. (2004) that having these attitudes, *acceptance* and *being in charge*, was a key factor not only in the caregiving context but also in the CGs' own personal life for the CGs' survival for what sometimes was a long career. Not surprisingly, Bandura (1997) stated the notion that individual efficacy beliefs are influenced by the individual emotional state associated with other cognitive resources, such as attitudes, values, skills, and knowledge. Thus, CGs who took care of their own

emotional health with regular personal and social routines were also able to maintain not only their sense of efficacy but also, with their positive outlook on their ability and caregiving role, their delivery of quality care to their CRs. Moreover, those CGs were likely to avoid or reduce the risk for typical adverse CG health consequences, such as depression and reduced physical health that have been often reported in the caregiving literature (Pinquart & Sörensen, 2005). This regular emotional and physical maintenance could be particularly important for family CGs because the caregiving role could bring chronic demands, emotionally and physically consuming the CGs' personal life, and could also be unexpectedly lengthened. These CG attitudes, *acceptance* and *being in charge*, over both caregiving and CG personal life contexts were two of the key constructs that could be screened to prioritize CGs' specific needs for specific and appropriate CG interventions.

A family-oriented caregiving value and feelings of respect for the CR. Although a family-oriented caregiving value and respectful feelings for CRs were not directly associated with CR-resistance, they set up a positive background for the CGs' perception of their caregiving role, and thus often indirectly influence a CG's approach to CR-resistance.

The family-oriented caregiving value. For many CGs, the belief that family members ought to be the ones who provide care for a dependent family member was a given standard: "It's gotta be with family, with family helping out." For them, letting someone outside of the family provide care for the CR was often not an option; "Dad got sick so I had the room, I had the energy, I had the love... and he needed help...and I

wasn't going to let him be with strangers, no way." This *family-oriented caregiving value* was often related to a close family relationship history, and was sometimes embedded within a cultural background passed down over generations (e.g., "Italian family back there, every Sunday you went to grandma's house."). When or if this unspoken family value was commonly shared by family members, it provided an unquestionable precondition for the CG by setting a positive tone over the family caregiving arrangement without any hesitation: "We'd always planned on doing that, you know before we had to, we thought...that would make it less stressful...it wasn't...anything we thought of as an option."

Another outstanding trend of the *family-oriented caregiving value* was associated with a CG respectful role model, such as mother or father. Several CGs stated that the strongest influence on their caregiving decision, becoming a primary family caregiver, was their respectful role models: "My mother was a good role model for me, she took good care of my dad so it just continued" and "she (mother) and her sisters took very good care of their mother...and they would fight over the privilege of getting to take care of their mother. And it was... that was the way that I wanted to treat my mother." Those CGs felt that taking on the caregiving role was a part of honoring their respected family members, forbearers, who had passed. It was reported by only one CG, but the feelings of needing to honor to a loved one (her mother) helped that CG overcome a formerly disengaged relationship with the CR (her father): "As a child...he didn't have much interest in me...I was kinda distant from him but because she loved my father so much...I felt that I should love and take care of my father because I adored my mother."

This family-oriented caregiving value inherited from family and/or a role model seemed to provide a sense of pride for the CGs. Thus, for those CGs, taking on a caregiving role was an anticipated opportunity, so that *acceptance* was not often much of an issue. These CGs have such strong obligations to meet caregiving demands that, similar to CGs with the *being in charge* attitude, they often proactively assessed the CR's needs, searching and reaching out for solutions. However, cautions should be made; in our data, two different patterns were found with CGs who had family-oriented caregiving value. On the one hand, several CGs with this attitude took an active leading role in both the caregiving context and in continuing to give attention to their own needs; by recognizing their own and/or family limits in meeting caregiving demands, they provided quality tangible care as well as reached out for additional resources. On the other hand, a few CGs with this value only focused on their caregiving obligation but not much on their own needs; they experienced difficulty in accepting outside resources at all or until they encountered their own health problems, such as experiencing depressive symptoms and decreases in general physical health (as with an example in the *acceptance* section).

Respect for the CR. Many CGs addressed their feelings of respect for their CRs, often expressed in relation to their past history with their CRs. Some CGs mentioned that their CR had provided great partnership and/or support for the CG and the family, so they would like to "honor" the person's "dignity" by providing quality care. CGs who had a long-time positive relationship with their CRs seemed to see the CR within the context of their relationship history, for example, as a loving husband who cared for a dependent mother, not just as a "person who's always sat in a wheelchair." Therefore, these CGs

often carry out their respectful feelings in their caregiving role. For instance, CGs with this attitude often try to provide care from their CRs' viewpoint rather than the CGs'; "You say well...who am I doing it for ? Am I doing it for my mother or...for myself?" They also try providing quality care by not only respecting their CR's functional and cognitive abilities but also maintaining regular daily routines preferable to the CR, as examples quoted in CG specific knowledge section (CR personality and preferences). With this respectful caregiving style, these CGs also often dealt with CR-resistance by taking extra time to explain what was going on to their CR; "What I tried to do was try to talk to her..., in a, in a nice tone of voice and...try to explain to her why it had to be done." This method was often used rather than forcing or rushing to accomplish caregiving tasks.

In summary, although family-oriented caregiving value and respectful feelings for CRs were not directly associated with CR-resistance, they set up a positive background in the CGs' perception of their caregiving role. When CGs discussed their caregiving experiences, their feelings of respect for their culture, family, CRs, or role models were often expressed in positive terms: "She still enjoys having lots of people around her", "She (mother) loved him (CR father) so much", and "Whatever she did was so optimistic." Thus, these CGs seemed to perceive the caregiving role as a given opportunity, rather than a burdensome one: "My father wanted her with me so...I know this is my purpose, I know this is what I'm supposed to be doing, it's a, it's a... even with 6 years, I'll say this is a very small window of time." For CGs with these attitudes, the family caregiving was a valued opportunity to honor their culture, family, and loved ones.

Social Cognitive Theory addresses how an individual's values and standards in a given role influence the individual's motivations and thus regulate the individual's role performance. Applying this tenet in the caregiving context, CGs who placed high value on their caregiving role were motivated to provide the best quality care for their CRs at their potential. Thus, these CGs, as compared to other CGs without this value, also tried to maximally utilize available resources including CG knowledge, skills, and an optimal attitude, and, for some CGs, this also included actively seeking external support. Their quality care and active search for solutions often resulted in better management of CR-resistance by minimizing its occurrence and having skilled or workable strategies to deal with it when it did arise.

Moreover, our findings confirmed existing literature (Quinn, Clare, & Woods, 2009) that the quality of the relationship between CGs and CRs prior to caregiving was an important factor in how an individual CG placed meaning into that caregiving role and related stressful events, such as CR-resistance. Our findings further provide in-depth descriptions; CGs with prior quality relationship with their CRs viewed their CRs from the perspective of that relationship history--not just as a dependent person and a CG, and thus they had extra patience in the face of CR-resistance. Therefore, those CGs who had feelings of respect for their CRs not only provided quality and thoughtful care for their CRs but also were able to handle CR-resistance well and in a respectful manner.

Transferred and Generalized CG Cognitive Resources

Many of the key CG cognitive resources already discussed (e.g., the family-oriented caregiving value, respect for the CR, the being in charge attitude) have been

transferred and/or generalized from the CG's personal history, mostly from CG family and cultural contexts. In this section, two additional important CG cognitive resources that emerged from the thematic analysis are presented: (a) knowledge and attitudes from the CG's past medical and/or health care related experiences and (b) coping strategies from the CG's past challenging life events over a wide variety of contexts (e.g., work, family, social activity).

Personal and/or professional experiences. Several CGs who had worked in medical and/or health system-related fields expressed that their professional experiences provided great additional resources in managing caregiving challenges. They stated that their past experiences tremendously helped them not only to manage day-to-day care for their CRs but also to be emotionally resilient in the face of CR-resistance. For instance, a CG who had worked as a professional care provider for community elders mentioned that her field experiences of knowing and actually helping and seeing her clients who had similar conditions as her CR helped the CG to be emotionally prepared when she faced CR-resistance and other daily caregiving challenges: "I do pretty well...because, I guess maybe because I've had things before...on days when she (the CR) doesn't talk... that's okay you know. I don't let it bother me...because I know some days can be different from the day before..." Those CGs with medical and/or health system-related experience had solid medical related knowledge about, for example, CR symptoms, efficient utilization of the medical system, and the possible side effects of medication, as well as other hands-on field experiences. Thus, they had some expectations and preparedness in their own caregiving role. In the face of challenges, these CGs often knew exactly what they should

do without experiencing excessive emotional reactions, such as getting nervousness at not knowing what to do, or shocked or upset from an incident, and they were thus able to efficiently provide appropriate and quality care for their CRs. These CGs often reflected upon their caregiving experiences with feelings of satisfaction and accomplishment: "I'm glad...It was worth it... and I'm proud...and I'm happy, I did it."

Transferring coping strategies from the past. When CGs were asked how they coped with their emotional upset from their CR-resistance experiences, many CGs discussed their strategies by referring back to past challenging experiences, such as work, personal relationship, and family challenges:

You get emotionally frustrated just like you do on a job...But...you can get over it. You just...don't take it too personally. Just say, 'Hey, I'm probably just tired'; Hey, of course, that hurts...I just...let the hurt, you know, I can feel it, and then I can tell somebody about it...or just share it or write it down and then forget about it, you know?

He can yell at me one minute and turn around and be nice as pie the next minute...and I do mean that literally...I [laughter] never have chance to get over it um I don't carry grudges he carry grudges my husband um I turn everything over to the Lord and let him handle it so I don't worry about anything.

Hey, of course that hurts. It always hurts when someone says something ugly to you... or if you get criticized, you know, by, by someone... I just, you know, I just...let the hurt, you know, I can feel it, and then I can tell somebody about it, you know, or just, you know, share it or write it down and then forget about it, you know?

I know she (mother: CG confidant)... she's praying for me, with me, because there would be times when I would get so aggravated and she used to say...'Honey, just say a prayer behind his back and send him off, in prayer.' Okay, mom, alright. Well, she said it always worked for me.

Because these CGs had experienced or observed (e.g., with their role models) overcoming significant challenging events in their past, they had confidence in their

ability to overcome the current caregiving challenges, including CR-resistance. Although particular strategies varied across CGs, as presented in quotes above, they knew what strategies would work specifically for them so that they could emotionally ground themselves in order to actually deal with the challenges they faced.

In summary, CG cognitive resources, regardless of the sources (e.g., family, work), that were transferred and/or generalized from the CG past experiences provided not only *additional* advantages in management of day-to-day caregiving tasks but also emotional resilience in the overall caregiving role. Because these CGs with transferred and/or generalized CG resources recognized the similarities between their past and currently faced challenges, they were able to identify their already existing strengths--generalizable personal resources that could be applicable in the caregiving context (e.g., skills, abilities, attitudes, coping skills). Based on their recognition of their own strengths, these CGs had a relatively high sense of efficacy with which they could face their caregiving challenges with confidence without excessive emotional reactions, and thus they could deal with their challenging situations to their best ability. This confirmed existing study findings on CG sense of efficacy that, as compared to context specific efficacy beliefs, CG global sense of efficacy has been found to be a consistent moderator of the link between CG stressors and CG emotional well-being (Pinquart, & Sörensen, 2005). Further, our findings help us interpret one of tenets of Social Cognitive Theory in caregiving specific context: although Bandura (1997) stated that different efficacy beliefs were "linked to distinct realms of functioning" (p. 36), he acknowledged that specific types of efficacy beliefs can be transferred or cultivated across settings, such as self-

regulatory skills: individual strategies managing stress and debilitating intrusive thoughts under taxing activities; and generalizable coping skills: individual ability to exert control over different life challenges. Perhaps, whereas context specific efficacy beliefs provide CG tools (e.g., knowledge and skills), the generalizable efficacy beliefs provide foundation in CG emotional resiliency for CGs to efficiently utilize their tools. Thus, in the adverse, often lengthened, caregiving context, the generalizable efficacy beliefs should be one of the prior concerns for CG emotional well-being under intense and chronic nature of caregiving demands.

As found in the intervention literature (e.g., Lavoie et al., 2005) reframing CG perceptions of the caregiving role and situation could be an effective intervention strategy for CG emotional well-being. Perhaps, identifying transferrable and/or generalizable CG strengths with professional assistance could be a key factor to enable CGs to change their perspective on their challenging situations; they might start viewing the caregiving role from a wider perspective as a part of continuing personal development. These CGs could highlight their own existing strengths that could be applicable as well as further developed in their caregiving context. They may also recognize that they would be able to use their further refined strengths in their future. Thus, this transferrable and/or generalizable sense of efficacy brings CGs' positive perception over the caregiving role to that of a personal growth opportunity, and influences CG emotional well-being in general. In fact in our data, these CGs, who discussed their caregiving role from this larger perspective often highlighted positive aspects of the caregiving role: "The joy...you're really missing out, if you don't", and "I think that is a gift that you can be

given the light to see something as it isn't", and to identify personal growth: "It was such a growing experience for me...it was a good thing" under challenging conditions. This reframing approach could be particularly helpful for CGs who do not have strong positive background, a family-oriented caregiving value, or feelings of respect for their CRs.

CHAPTER 6: DISCUSSION

The current project determined CG experiences of CR-resistance via a sequential quantitative-qualitative mixed methods approach. By applying multilayered methods, the study was able to provide detailed and in-depth information about CR-resistance. On the one hand, the quantitative data results from the 8-day daily surveys allowed for systematic and objective analyses of CR-resistance and its association with CG emotional/physical well-being and other CG resource factors. On the other hand, qualitative data from the semi-structured interviews captured detailed descriptions of CR-resistance experiences in the CGs' own words as well as CG self perceptions regarding experiences that are related to their survival strategies. In this chapter, the main quantitative results and qualitative findings that are presented in Chapter 4 and 5 are summarized and interpreted in reference to the current hypotheses and research questions and in light of the theoretical frameworks and the extant literature reviewed earlier. Finally, implications for future programs and research, and limitations of the study are presented.

CR-Resistance: Four Types with Different Occurrence Patterns

Informed by the existing conceptual (e.g., Mahoney et al., 1999) and the qualitative (e.g., Farran et al., 2004) literature, the quantitative phase of the current study focused on a *specific* context--daily routine care assistance or provision, objectively and systematically documenting CG experience of CR-resistance. In order to develop a deeper understanding of CG experiences of CR-resistance, in the qualitative phase of this study the current researcher explored these CG experiences across the broader, more

inclusive caregiving context using the CGs' own examples, and systematically identified the different types of CR-resistance.

Quantitative Documentation of CR-resistance

In the original DUCS survey, CGs reported their CR-resistance experiences in their routine personal care or assisting activities for their CR over 8 consecutive survey days. The quantitative analyses revealed that half of the original DUCS study participants ($n = 30$ of 61) experienced resistive behavior from their CRs during care provision. As evidenced in the current quantitative HLM unconditional model results, there was significant variability in how those 31 CRs displayed CR-resistance. Specifically, CRs displayed CR-resistance in different ways in regard to *the number of days* in the study period on which resistance occurred and *the number of CR-resistance occurrences on a given day*. Over the 8 survey days, whereas many CRs displayed resistance on only few days (1-2 days, $n = 17$), some CRs displayed resistance on several days (3-6 days, $n = 11$), and the other a few CRs displayed resistance nearly every day (7-8 days, $n = 2$). CRs also displayed CR-resistance in different numbers of daily personal care and assisting activities on a given day; whereas many CRs displayed this behavior only in a few activities (1-3 activities, $n = 23$), others displayed resistance behavior across multiple activities (4-10 activities, $n = 7$). Statistically speaking, on the one hand, some variability, 39%, in CR-resistance existed in between caregivers; some CRs displayed a greater total number of CR-resistance behaviors across the 8-survey days than other CRs. However, a greater proportion, 61%, of variability in CR-resistance existed in within-caregiver; instead of having the same numbers of CR-resistance episodes on every day of the 8-

survey days, some CGs experienced daily fluctuation, with fewer or greater numbers of CR-resistance occurrences on a given day as compared to their own average number.

This current quantitative documentation of CR-resistance yielded results that are consistent with the extant literature that indicates that CR problem behaviors vary day-to-day (Fauth et al., 2006; Koerner & Kenyon, 2007; MaloneBeach et al., 1995); and it provides additional specific information by confirming that this day-to-day variability of CR problem behaviors also exists in this specific behavior—CR-resistance. Because the long- and short-term changes in CR problem behaviors and the impact of these changes on CG emotional and physical health have been documented (e.g., Gaugler et al., 2000; Koerner & Kenyon, 2007), documenting the daily variability in this specific and critical behavior—CR-resistance—is an important first step for exploring the possible impact of the daily variability in CR-resistance on CG emotional and physical well-being.

Qualitative Documentation of CR-Resistance

In the qualitative interview, 19 participants were asked to discuss their CR-resistance experiences not just within the context of care provision but also for caregiving in general. The qualitative analyses reveal that based on the different occurrences and contexts in which CR-resistance occurred, CR-resistance experiences could be divided into four types: (a) *frequently occurred across many different daily activities*; (b) *occurred often in one or a few specific daily activities* (e.g., bathing, eating, going out to a doctor's appointment); (c) *occurred during significant transitional life events* (e.g., giving up driver's license, moving residence); and (d) *occurred due to unfamiliar or unexpected situations* (e.g., being in an emergency room, having an unfamiliar caregiver),

as presented in Table 11. The first two types of CR-resistance occurred in daily routine personal care or assistance activities, and thus, these were also likely to be captured in the 8-day quantitative survey. In contrast, resistance episodes in the latter two occurrence categories happened during specific transitional periods or unusual events. Thus, these were likely to be captured only by the qualitative CG descriptions in the individual interviews.

Although the first two types of CR-resistance that happened in routine personal care or assistance activities shared a context, these two types of CR-resistance have substantially different patterns of occurrence from one another, and these different patterns provide possible explanations of some within-person and between-person variability in CR-resistance documented in the current quantitative results. On the one hand, the first type of CR-resistance, the type that frequently occurred across many different activities, was reported as both chronic and frequent. The CGs who experienced this type of CR-resistance seemed to have a relatively high total amount of average CR-resistance as compared to those CGs who experienced other three types of CR-resistance. The CGs who experienced this first type of CR-resistance were likely to experience CR-resistance on a majority of caregiving days with the possibility of some day-to-day fluctuation—different numbers of CR-resistance occurrences across the 8 survey days.

On the other hand, the second type of CR-resistance that occurred often in one or a few specific daily activities was reported as somewhat predictable incidents, and thus it could hold that different patterns exist for specific personal care or assistance activities. If the specific activity happened on a daily basis, such as eating or taking medication, these

CGs had a moderate or high total number of CR-resistance episodes and minimum day-to-day fluctuation. If the specific activity was a non-daily activity, such as getting a haircut or bathing, those CGs had a relatively low total number of CR-resistance episodes but moderately large day-to-day fluctuation across the 8 survey days.

Although the primary focus of the current study is CR-resistance in the context of care provision, our qualitative results revealed that CR-resistance in these two contexts--transitional events and unfamiliar or unexpected situations--could be critical types and should be further examined in future research. According to our participants' experiences, the frequency of these two types of CR-resistance occurrences for each CG seemed to be relatively low. However, the prevalence of these types of CR-resistance across our interview participants was quite noticeable and these types of CR-resistance were reported even by CGs who reported in the quantitative survey that they hardly ever experience CR-resistance within usually routine daily care and assisting activities in general. Because, as documented in the extant literature (e.g., Aneshensel et al., 1995; Hooker et al., 2000), the health and functional condition of a CR changes over time, the circumstances around care provision, such as care arrangements and the level of required assistance to the CR in personal care and daily activities, also changes over time. Therefore, transitional or unfamiliar events and situations, such as moving to a professional medical care facility and getting assistance in unfamiliar places or from unfamiliar individuals, could be faced by most CGs at some point(s) over a long-term caregiving career, circumstances in which CRs possibly display resistance. Because of the prevalence of these transitional and unfamiliar or unexpected events, and especially

because of their unpredictable nature, our qualitative results highlighted the importance of considering them in order to fully understand the impact of CR-resistance on CG emotional and physical well-being. Our qualitative results suggest that if CR-resistance was measured over the inclusive general caregiving context, there might be even greater within- and between-caregiver variance than the variances currently documented in the quantitative results.

Additionally, although the qualitative results highlighted unique occurrence patterns for each of the four types of CR-resistance, caution should be taken in interpretation. The occurrences of these four types of CR-resistance were not totally exclusive from one another. In other words, different types of CR-resistance could be experienced by the same CG during a same study period (for instance, during 8 consecutive survey days), and thus, if these four types of CR-resistance were measured and statistically examined together in aggregate, variability in each type of CR-resistance would be masked. For instance, if a CG experiences the “chronic” type of CR-resistance and the “few specific activities” type of CR-resistance together, the daily variability of CR-resistance for this CG would be reported less than if the CG experiencing the same second type by itself. Therefore, a CR-resistance scale that involves more than one type of CR-resistance, such as the current CR-resistance scale, should be cautiously interpreted.

Impact of CR-Resistance on Caregiver Emotional and Physical Well-Being

The impact of CR resistance on CG emotional and physical well-being was determined through both quantitative multi-level HLM analyses and qualitative thematic

analyses. Whereas the quantitative analyses statistically captured that impact via standardized caregiver well-being measures, including CG depressive symptoms, feelings of burden, physical health symptoms, positive affect, and feelings of benefits and gains, the qualitative thematic analysis explored CG nuanced experiences with actual CG examples in order to develop deeper understanding of the phenomena.

Quantitative Interpretation

Based on the quantitative HLM analyses results, neither the mean level, “Person-Mean CR-resistance,” nor the daily fluctuation of CR-resistance, “Daily CR-resistance Fluctuation”, by themselves appeared to have a significant impact on CG emotional or physical health. However, the combination of having relatively high “Person-Mean CR-resistance” and “Daily CR-resistance Fluctuation” brought significant impacts on CG physical health; when CGs with relatively high “Person-Mean CR-resistance,” they faced a more than usual amount of CR-resistance (having an additional CR-resistance incident) on a given day, they reported increases in physical health symptoms. However, this association was not evident for CGs with relatively low “Person-Mean CR-resistance.” These interaction results are further discussed in the following section with our qualitative results.

The quantitative results highlight three important points in examining the impact of CG stressors. First, by examining one type of CG stressor at a time, the 8-day daily quantitative data provide detailed documentation about *the occurrence patterns* of CR-resistance without the masking effects of a global measure that aggregates different types of CR problem behaviors. Second, HLM analyses allowed the researcher to

simultaneously determine the unique impacts of two distinct components of CR-resistance on CG emotional and physical health: mean level and daily fluctuation. Third, the HLM analyses revealed the importance of examining *the interaction effect of the CG mean level stressor and the daily fluctuation* even though the mean level or daily fluctuation itself might not be a significant predictor for CG emotional and physical health.

Qualitative Interpretation

Qualitative results revealed that the four different types of CR-resistance have different general patterns in how each CR-resistance appeared to affect CGs' emotional and physical health; however, these patterns might not be applicable for some CGs with particular types of resources that are discussed in the next section. Specifically as described in Chapter 5, the intensity and duration of the impact of each type of CR-resistance differed. Generally speaking, on the one hand, two of the four types of CR-resistance could, in different ways, provoke significant CG emotional and physical health impacts: (1) the unfamiliar/unexpected type of CR-resistance brought the *most intense magnitude of emotional impact* for both CGs and CRs and (2) the chronic type of CR-resistance brought *the most chronic and lengthy emotional impact* on CGs. On the other hand, the other two types of CR-resistance, the few activities type and the transitional type, seemed to be *somewhat manageable* in that the CGs had some control over the situation in order to manage their emotional and physical health impact.

As described in the occurrence patterns in the qualitative findings section, the unfamiliar/unexpected type was one of the most difficult CR-resistance situations for CGs because it was hard to anticipate its occurrence. Indeed, the unpredictable nature of

this CR-resistance could be noted both in *the CR behavior* and in *the environment*. Based on the current study participant examples, all cases of this type of CR-resistance happened *only a few times* for each CG throughout their long caregiving career, and these, often intense, CR-resistance incidents were often unusual behaviors for the CRs in their usual environment such as being at home. The unfamiliar environment in which this behavior occurred was *outside of the CR and CG residence*, such as during a walk or in an emergency room, and often involved a third person aside from the CG and CR, such as a health care professional. Stress Theory (Lazarus & Folkman, 1984) suggests that without warning events or anticipation, an unpredictable stressful event can have a heightened impact for which the individual would not be prepared, and thus the individual could easily lose control over the situation. In cases when the two unfamiliar factors come together (i.e., an unexpected CR behavior in an unfamiliar environment) the impact could be that much more difficult. Indeed, an unfamiliar environment for the CR might partially cause the occurrence of the unfamiliar CR behavior; and having this unfamiliar CR behavior occur in an unfamiliar environment (even for the CG) may increase the chances that the CG might lose control, feel shocked, and emotionally distress.

Another one of the most difficult types of CR-resistance was that type which frequently occurred across many daily care and assistance activities and was characterized by its chronic nature and duration. Because this type of CR-resistance frequently and persistently occurred, those CGs who experienced this type of CR-resistance were often physically exhausted and emotional drained, and thus many of these

CGs with chronic demands often reported that these demands occasionally led to intense arguments or fights with their CRs.

This particular type of CR-resistance experience provides a possible explanation for one of our significant quantitative interaction effects: CGs with relatively high mean level of CR-resistance, “Person-Mean CR-resistance,” experienced significant increases in physical health symptoms on days when they faced more than their usual amount of CR-resistance. According to our participant examples, although these CGs who faced this type of CR-resistance could foresee the CR-resistance based on their CR’s personality, care history, and typical disease related symptoms, they often did not know how to alter their own chronic stress caused by this CR-resistance. Perhaps due to their emotional and physical exhaustion, these CGs were often not in a position to be able to handle any additional stress or events. Therefore, if these CGs faced an increased number of CR-resistance incidents as compared to their usual, they could be greatly impacted, resulting in an increased level of negative physical health symptoms.

This phenomenon confirms one of the tenets in Social Cognitive Theory: an individual’s emotional and physical states if under chronic stress can lower his/her sense of efficacy, influencing his/her general perception of a given situation and role performance. Viewing the CG situation through this lens, depending on a CG’s general emotional and physical states, the CG would approach a caregiving demand in different ways even with the same set of caregiving skills and knowledge, and thus, the outcome of the CG approach would be also different. In other words, even with the same CG, when the CG is emotionally and physically exhausted, he/she would differently manage the

same CR-resistance as compared to when she/he is in a stronger emotional and physical state. Thus, those CGs who were chronically exhausted due to chronic caregiving demands in association with repeated CR-resistance could not maintain an optimal emotional and physical state. Therefore, particularly when these CGs faced an additional CR-resistance event, they might approach their caregiving demands in different ways than their optimal abilities would suggest they are capable of, and they also could be greatly impacted in their emotional and physical health.

Considering the supportive evidence in our qualitative results and the theoretical tenet, it is surprising that, in our quantitative analyses, the interaction effect between the mean level and daily fluctuation of CR-resistance was only observed in CG *physical health symptoms* but not in *emotional health* indicators, such as CG depressive symptoms and feelings of burden. It is possible that those CGs who faced this type of chronic CR-resistance, in general, already had a chronically low level of emotional well-being reflected in increased level of depressive symptoms and feelings of burden, and a decreased level of positive affect and feelings of gains. Thus, their sustained low emotional status created a ceiling effect from which there was not much leeway to report a decreased level of emotional health on days when they faced an additional CR-resistance demand. In order to test this ceiling effect, this topic should be examined in future research.

In contrast to these most difficult types of CR-resistance discussed above, the types of CR-resistance that occurred often and in association with one of a few specific daily activity (ies) or during transitional events due to declined CR condition were often

somewhat manageable if CGs had appropriate knowledge and skills, such as knowing disease specific characteristics and CR personality and preferences. Therefore, these types of CR-resistance, as compared to the other two types, were less likely to bring an adverse emotional and physical health impact on CGs. As noted in Stress Theory, these differences in the magnitude of impact might be caused by the predictable nature of these two types of CR-resistance and that due to this predictability CGs were able to identify the specific activities or transitional needs in which the CRs might exhibit CR-resistance. Because CGs could anticipate when and how these CR-resistance episodes would occur, CGs had a chance to emotionally and physically prepare by considering not only their CR's needs but also their own needs, such as their health or emotional status, and other caregiving-related or life demands in order to have a better sense of control. By anticipating resistance events or signs as discussed in the current qualitative findings, CGs were also often able to choose when/how they might handle the CR-resistance. As regarding CG anticipation and preparedness, Social Cognitive Theory would also add that, particularly, those CGs who shared a large proportion of mutual family, cultural, and social environment with their CRs could easily identify changes in CR needs and adopt workable strategies based on their shared background and history. Perhaps, with their workable solutions, these CGs also could keep minimum the occurrence of CR-resistance in general, a relatively low level of "Person-Mean CR-Resistance," and maintain their optimal emotional and physical states, and thus they would not be much impacted by additional CR-resistance or stress, such as occasional increased CR demands.

Personal, Interpersonal, and Social Factors

that Influence the Impact of CR-Resistance on CG Well-Being

CG personal, interpersonal, and social resources were examined as possible moderators that influence the impact of CR-resistance on CG emotional and physical well-being via both quantitative and qualitative data. Specifically, CG cognitive resource, CG-CR relationship background, and CG social network resources were the current study focus. Through the quantitative HLM analyses, the current researcher investigated CG resource factors that have been identified as possible moderators in the theoretical frameworks and in the extant literature, such as sense of efficacy, socio-emotional support, and community/professional support. These moderators were examined as regarding two different components of the current stressor, CR-resistance: “Person-Mean CR-resistance” and “Daily CR-Fluctuation.” In addition, the qualitative thematic analyses closely focused on the factors that were related to CG perception and cognitive process dealing with CR-resistance and caregiving demands in general. The findings from the qualitative thematic analysis provide unique detailed descriptive information to address the current research questions as well as provide supportive evidence for interpretation of the quantitative analyses results.

CG Cognitive Resources: Sense of Efficacy and Other Related Factors

Regarding CG cognitive resources, informed by the theoretical frameworks and the extant literature (see details in chapter 2), the HLM analyses focused on CG sense of efficacy—CGs belief in their ability in manage the challenging caregiving situation—

which played a moderating role of the link between CR-resistance and CG emotional and physical well-being, whereas the qualitative analyses expanded its focus on CG cognitive factors that were associated with CG approach, perception, and development of CGs' own survival strategies to the CR-resistance.

The quantitative preliminary analyses revealed that CG sense of efficacy was positively associated with CG positive emotional well-being indicators and negatively associated with CG negative emotional well-being indicators. However, when CG sense of efficacy was included as a moderator of the link between CR-resistance and CG well-being at two levels, "Person-Mean CR-resistance" and "Daily CR-resistance Fluctuation," significant findings were found at *the mean level*. Specifically, sense of efficacy played a significant moderating role between "Person-Mean CR-resistance" and positive CG well-being variables including feelings of benefits/gains and positive affect. As presented in the quantitative results section, these positive influences of sense of efficacy only existed for CGs with relatively low "Person-Mean CR-resistance" scores.

Specifically, among CGs who had no or relatively low CR-resistance in general, "Person-Mean CR-resistance," those with a relatively high sense of efficacy, as compared to CGs with a relatively low sense of efficacy, seemed to be able to highlight the positive side of their caregiving role evidenced in their higher feelings of benefits/gains and positive affect. However, if even these CGs with relatively high sense of efficacy experienced relatively high CR-resistance, they reported relatively low level of feelings of benefits/gains and positive affect -- similar to those CGs with no or relatively low sense of efficacy. In other words, according to our HLM analyses, sense of efficacy,

which has been consistently found as a moderator—specifically, a buffer—of the link between CG stressors and CG emotional and physical well-being in the extant literature, did not bring its positive moderating impact for this specific stressor, CR-resistance.

In the current study, CG sense of efficacy was measured by a standardized instrument (Chritensen et al., 1998); the scale items included, among others, “I am usually certain about what to do in caregiving for their CRs,” “In general, I am able to handle most problems in the care of CRs,” “I believe that I am mastering most of the challenges in caregiving,” and “I feel that I have a great deal of influence over the things that happen in caregiving.” Although those CGs who participated in the original DUCS surveys were asked in the printed instructions to answer these questions in reference to their current caregiving context, their responses might reflect more the CG’s general/global sense of efficacy. Perhaps this particular sense of efficacy, as seen in the correlation results, was a valuable resource for CG emotional well-being in *the general caregiving context*. In fact, in the extant literature, the consistent significant moderating impact of sense of efficacy for CGs have mostly been derived from studies using CG global sense of efficacy as measured by the Personal Mastery Scale (Pearlin et al., 1990; Adam, Smyth, & McClendon, 2005; Mausbach et al., 2007; Miller et al, 1995). However, our non-significant buffering results indicated that this general sense of efficacy might not transfer to some of specific caregiving demands, such as CR-resistance.

Although Bandura (2001) recognizes generalizable and transferable sense of efficacy beliefs, such as self regulatory skills and learning capabilities, he also emphasizes domain specificity in sense of efficacy beliefs. An individual’s sense of

efficacy varies in its level, generality, and strength, depending on the domain because different domains require different skill sets under different circumstances. This means that CG sense of efficacy could vary depending on the sub-domains within the caregiving context, such as managing finances and appointments, providing actual hands-on care, and managing CG emotional stress. Perhaps CGs who reported high sense of efficacy in the current study effectively managed caregiving demands in general through their global sense of efficacy. However, this sense of efficacy was not transferable or applicable to this specific caregiving demand—CR-resistance—that can induce instant CG emotional reactions. The effect of global sense of efficacy might be sensitive to the *timing* of how the stressor impacts the CGs, and thus it is difficult to bring its positive influence to bear on a quick-impact stressor such as CR-resistance.

As reported in the qualitative examples, CR-resistance has specific characteristics that often bring strong emotional impact on the CGs. A majority of the interview participants expressed that they often or sometimes experienced emotional upset due to CR-resistance, and the magnitude and duration of emotional upset varied based on the CR-resistance incidents and CG strategies undertaken to address them. Perhaps CGs who reported relatively high sense of efficacy, with their general sense of efficacy, could recover well and/or faster from the initial emotional impact of CR-resistance, particularly with their ability to highlight positive aspects of caregiving. However, the *initial emotional impact* of CR-resistance was not easy to avoid even for CGs with relatively high sense of efficacy. Therefore, CG sense of efficacy did not play a buffering role between mean *CG level* CR-resistance and CG emotional well-being, and did not at all

play a moderating role between *daily fluctuation* of CR-resistance and CG emotional well-being with its implosive nature. If CGs experienced an unpredictable kind of CR-resistance, this initial emotional impact could be heightened.

Additionally, based on tenets of Social Cognitive Theory and our qualitative examples, the significant mean-level moderating effects of sense of efficacy might be better interpreted from the other direction: CGs who had relatively high sense of efficacy, with their positive attitude, such as having higher feelings of benefits/gains and positive affect, could keep the occurrences of CR-resistance relatively low. Interpreting the results through the lens of Social Cognitive Theory, CGs with a relatively high sense of efficacy approached their caregiving demands with a positive sense of their ability to manage their challenges and provide quality CR care that often proactively met CR needs and thus unnecessary CR-resistance was avoided.

According to our thematic analysis, one of the important sources of CG sense of efficacy, CG confidence in their ability to provide quality care, was partially supported by different types of CG knowledge. Some CGs repeatedly expressed that they knew exactly what to do in a certain caregiving situation because of their particular knowledge of their CRs and their needs, including CR personality, CR preferences in daily activities, CR health requirements and disease specific symptoms, and also knowledge of additional CG resources such as CG support groups, hospices, and family members (see the qualitative results section). Having this knowledge helped CGs with a relatively high sense of efficacy to provide quality care by meeting their CR's needs and, thus, prevented the unnecessary occurrence of CR-resistance even when there were some resistive

behaviors or conflicts associated with CR emotional states (depression) or dementia condition that might not be avoidable.

Moreover, the qualitative analysis results highlighted additional CG knowledge that helps CGs manage caregiving demands with high confidence in the face of CR-resistance and other care related challenging conditions. Specifically, knowledge and skills that were gained from CG health care related professional or personal experiences helped CGs because they had some expectations of CR potential changes and behaviors. These CGs were often able to efficiently deal with the CR-resistance without excessive emotional impact on themselves such as getting highly upset or frustrated. Moreover, once the CG was emotionally impacted by the CR-resistance, CGs who had a successful recovery from challenging experiences in their past seemed to manage well the emotional impact from their CR-resistance experience. Because these CGs were able to identify specific strategies that worked specifically for them in dealing with their emotional stress, they had confidence in their ability to recover from the emotional shock of CR-resistance. Because most of the questions in the original DUCS survey were stated in reference to the caregiving context, the transferred/generalized CG knowledge and skills gained from CG past experiences might not have been captured in the current quantitative analyses. These qualitative results provided additional key information that was associated with CG emotional resiliency. Highlighting transferable/generalizable CG skills and knowledge from CG life experiences and history might play a key role in improving the impact of existing intervention programs.

CG Background Factor: CG-CR Relationship Quality before Caregiving

Regarding the CG background factor, informed by the theoretical frameworks and the extant literature (see details in chapter 2), the quantitative HLM analyses indicated that CG-CR relationship quality before caregiving played a moderating role in the link between CR-resistance and CG emotional and physical well-being. The qualitative thematic analysis revealed detailed descriptions of the important role of CG-CR relationship before caregiving in association with CG emotional well-being, and the qualitative examples also assisted in interpretation of the current quantitative results.

According to the preliminary quantitative correlation analyses results, having a positive relationship with the CR prior to caregiving was associated with fewer instances of CR-resistance, higher sense of efficacy, lower feelings of burden, and higher feelings of benefits/gains as compared to those CGs with a poor prior relationship. However, when CG-CR relationship quality before caregiving was examined as a moderator between CR-resistance and CG emotional and physical well-being, relationship quality played a moderating role in only one link and only at a marginal level: between “Daily CR-Fluctuation” and positive affect. Specifically, CGs with a relatively high quality CG-CR relationship before caregiving reported a decreased level of positive affect on days when these CGs experienced more than their usual amount of CR-resistance; whereas CGs with a relatively low quality CG-CR relationship before caregiving maintained a similar level of positive affect regardless of CR-resistance level on a given day. Although these results did not reach the status of being statistically significant and should be interpreted with caution, receiving resistive behavior from a CR who was a close person

to the CG might emotionally upset the CG to a greater degree than from a CR who was not so close.

The current qualitative findings provide detailed information about the role of CG-CR relationship quality before caregiving that might further explain these quantitative results. According to our qualitative thematic analysis results, having a high quality relationship with the CR when the CR was not affected by disease or age-related declines seemed to predetermine the CG's approaches to and perception of the CR in the caregiving context. CGs who had a prior quality relationship with their CRs often viewed their CRs within their mutual relationship history; for instance, they viewed the CR as a loving husband who helped care for the family rather than as an old individual in a wheelchair. Thus, these CGs often practiced/continued a positive quality relationship with their CR in the current caregiving context in which both shared in pleasurable activities and interactions even with the CRs' functional and cognitive declines. This quality of life and the quality care derived from the CG-CR quality relationship often reduced or minimized the occurrence of CR-resistance. Moreover, once CR-resistance occurred, with their prior knowledge, those CGs who had a high quality relationship with their CRs knew about the CR's personality and preferences, and often managed the CR-resistance quite well.

However, regardless of the quality of their prior relationship with their CR, once such CGs faced CR-resistance, their initial emotional reaction to CR-resistance might not be avoidable. Because of the greater gaps in current and past behaviors or reactions and the close nature of the CG-CR relationship, CR resistance sometimes could bring a

greater impact on those CGs with positive prior relationship quality as compared to other CGs without such a prior relationship. In our qualitative examples, based on their past relationship and knowledge about their CRs' personality, a few CGs who had a somewhat distant relationship with their CRs expressed that their CR-resistance experiences were somehow predictable, and the incidents brought little emotional impact on the CGs whereas other CGs who had a higher quality relationship expressed that they were greatly surprised by the CRs' unfamiliar behaviors, especially from CRs who were usually gentle and agreeable individuals; and the incidents brought a great emotional impact on the CGs at least initially. CR-resistance that most unpredictably occurred seemed to bring the hardest impact on CG initial emotional reactions.

In summary, our current quantitative and qualitative findings also support and provide some explanations of the existing mixed findings in the caregiving CG-CR relationship literature (Quinn et al., 2009). In general, having a CG-CR quality relationship before caregiving could be one strong and positive background factor for how CGs provide quality care to their CRs by maximally utilizing their ability and, perhaps, highlighting the positive side of caregiving (see examples in the qualitative findings and interpretation section). However, these positive characteristics of a quality CG-CR relationship sometimes could bring exacerbated emotional impact on the CGs because of large discrepancy between the past and present. In fact, one existing qualitative study documented that one of the difficult family caregiver challenges was CG feelings of loss or loneliness due to declined or a changed relationship between the CG and CR subsequent to the start of caregiving (e.g., Siriopoulos, Brown, & Wright, 1999).

The current study focused on and clarified role of one type of CG-CR relationship variable on the link between CR-resistance and CG emotional and physical well-being, the role of CG-CR relationship quality before caregiving, and the results indicated that this possibly exacerbate the impact of CR-resistance on CG emotional health. However, as discussed in Quinn et al. (2009), different dimensions and the changeable nature of the CG-CR relationship, in areas such as affection, marital reciprocity, and shared pleasurable activities, should not be disregarded considering influence on CG emotional and physical well-being over time.

Social Network Resources

With regard to social network, informed by the theoretical frameworks and the extant literature (see details in Chapter 2), the potential moderating effects of CG socio-emotional support and community/professional service utilization were examined in the current quantitative HLM analyses. Additionally, in order to also determine negative or absent socio-emotional support, family disagreement regarding care, was included; this was only negative interpersonal resource variable that was available in the current data set. Although the current qualitative thematic analysis did not reveal a significant theme regarding socio-emotional support itself, the qualitative results provided unique and important patterns regarding how CGs utilized their social network resources, such as socio-emotional support and community/professional services, in developing their own strategies for dealing with CR-resistance and other care-related demands. Moreover, the qualitative examples provided supporting information that assisted in interpreting the current quantitative results.

Socio-Emotional Support and Family Disagreement Regarding Care.

The preliminary correlation analyses indicated that socio-emotional support was negatively associated with depressive symptoms and positively associated with positive affect; CGs with higher socio-emotional support tended to report lower depressive symptoms and higher positive affect as compare to those CGs with lower socio-emotional support. However, family disagreement regarding care was not correlated with any of the CG well-being indicators but was associated with CR-resistance; CGs with higher family disagreement tended to report higher occurrence of CR-resistance than did CGs with a few/no family disagreements.

When socio-emotional support was examined as a moderator through the HLM analyses, it did not play a significant moderating role, at either level: between “Person-Mean CR-resistance” and CG well-being variables, or between “Daily CR-resistance Fluctuation” and CG well-being variables. The lack of a significant moderating effect was understandable, considering the mixed findings in the extant literature (e.g., Miller et al., 2001). Perhaps having relatively high socio-emotional support influenced CG well-being in general, reflected in relatively low depressive symptoms and high positive affect. In regard to the buffering role for the impact from CR-resistance, socio-emotional support might not be an adequate universal resource for all family CGs.

Qualitative evidence from our interviews can help us understand the absence of socio-emotional support moderating effects, and that utilization of this specific resource might be highly dependent on individual CG preferences. In the qualitative interviews,

CGs discussed different types of strategies to deal with the emotional impact from CR-resistance on themselves.

Although it is notable that one of these different types of CG strategies was to utilize emotional support from close social network members, such as spouse and family, this strategy was one of several that worked for only specific CGs. Whereas a few CGs related in their interviews that they often made calls to their close friends or family members when they got emotionally upset from CR-resistance, others expressed that they preferred to deal with it by themselves in their prayers or journals, or by talking to other family CGs at support groups, CGs who share similar challenges.

Importantly, the qualitative thematic analysis identified that a critical factor for CG emotional well-being was that each CG had his/her own unique strategy in dealing with their emotional upset. Perhaps, for the particular sub-set of CGs who preferred sharing their emotional frustration with their close network members, socio-emotional support, assessed by the current instrument, may have worked as a buffer against the impact from CR-resistance on their emotional well-being. However, it is possible that the current instrument for socio-emotional support was too narrow for its sources, including spouse and family, or too general for the context in the way the questions were asked, caregiving in general. Therefore, the qualitative analyses could not adequately capture buffering effects of socio-emotional support.

Surprisingly, when the potential moderating effect of family disagreement regarding care was examined, the HLM analyses results revealed that frequent occurrence of this negative social network resource factor, family disagreement regarding care,

buffered the impact of “Daily CR-resistance Fluctuation” on CG emotional well-being, including depressive symptoms, feelings of benefits/gains, and positive affect.

Specifically, on days when CGs with relatively high family disagreement experienced an additional CR-resistance, they did not experience additional emotional impact whereas those CGs with relatively low family disagreement did.

Considering the significant positive correlation between CR-resistance and family disagreement regarding care, CGs with relatively high CR-resistance perhaps reached out to their family members for emotional support or advice when they faced CR-resistance, particularly on days when they faced more than the usual number of occurrences.

However, instead of receiving supportive comments from the family members, these CGs might have received criticism. As some examples in our individual interviews indicated, because these family members giving criticism were often not directly involved in daily care, they did not understand the CR’s condition and what exactly the CGs experienced with CR-resistance. One CG characterized this type of situation: “you get criticized, you know, by someone who doesn’t understand why you have to do what you ‘re doing....” These family members might not be aware of the severity of the CR’s condition and the CR-resistance incident, and thus they might give insensitive comments or inappropriate advice to the CGs with the conversation then devolving into an argument.

This unexpected positive influence, a buffering effect, of family disagreement regarding care on the impact from “Daily CR-resistance Fluctuation” on CG emotional well-being was one of the hardest results to interpret, especially with the contrasting results in the existing literature. Among limited numbers of existing studies that have

investigated the impact of family disagreement regarding care on CG health, there have been consistent results that care related family disagreement brought significant negative impact on CG emotional health (e.g., Deimling, Smerglia, & Schaefer, 2001; Scharlach, Li, & Dlv, 2006). Although our qualitative data did not yield direct evidence explaining this positive influence of family disagreement on CG emotional health, the combination of some themes that emerged in the qualitative analysis provides some hints.

Although the majority of our interview participants seemed to manage their caregiving demands in part by maintaining a good personal and social network, some CGs expressed that they had become very isolated from their family and social network since they had started their caregiving role. Among these CGs, a few were isolated by their own choice because they wanted to spend time alone with the CR, whereas others were isolated because they did not want to interact with family members whom they felt were unappreciative of their circumstances. Perhaps these isolated caregiving conditions could work to the CGs advantage by minimizing an additional stressor, such as family disagreement, when the caregiving demands were stable and not emotionally draining. However, when/if the CRs exhibited CR-resistance that could induce CG emotional upset, having someone to whom the CG could, in a timely fashion, express their frustration or hardship, particularly family members who share mutual background with the CR, could help the CG. Although these family members might initiate some disagreements, talking to them or having them present could help a CG recover from the impact of CR-resistance and/or maintain their emotional health instead of getting depressed by not having anyone with whom to talk.

In fact, one participant, who had been treated for her depression by a medical professional, commented in her interview that talking about her caregiving experiences in the interview itself helped her because she did not have anyone to talk to since she was caring for her husband whom she had married only several years earlier in their second marriage. Because as a couple, they had been close to neither the CG family nor the CR family, they have gotten further isolated from their family network since the CR started needing help. Based on our qualitative evidences, having no one to talk to seemed to be one of the hardest things when CGs face unusual and/or harsh behavior from their CRs and themselves get frustrated; this is particularly so for those CGs who face their own emotional and physical decline due to the care demands for their CRs and age-related changes. Perhaps the apparent positive buffering effect of family disagreement is due to the fact that the current family disagreement regarding care instrument inadvertently captured both CG experiences of family disagreement (its intended focus) and the availability of close family members to whom the CGs could call and talk with when they needed them the most. Because this interpretation was made on the basis of small pieces of individual CGs qualitative evidence, the role of family disagreement regarding care should be further examined in future research.

Community/Professional Service Utilization

The preliminary quantitative correlation analyses indicated that community service/support utilization was significantly correlated with only one CG well-being variable, physical health symptoms. CGs with high community service/support utilization tended to report a greater number of physical health symptoms. When community or

professional service utilization was examined as a moderator, the HLM results revealed that it played a significant moderating role at both person-mean and daily fluctuation levels: between “Person-Mean CR-resistance” and two of the CG well-being variables, physical health symptoms and feeling of benefits/gains, and “Daily CR-resistance Fluctuation” and feeling of benefits/gains.

At the mean level, community/professional services utilization, specifically health professional services based on the sub-scale analyses, played a significant buffering role in feelings of benefits/gains but played a significant exacerbating role in terms of physical health symptoms. Specifically, for CGs who had relatively high community/professional services utilization, regardless of their level of CR-resistance, these CGs had similar levels of feelings of benefits/gains; whereas for those CGs who had relatively low or no utilization, CGs who had higher levels of CR-resistance had significantly lower feelings of benefits/gains as compared to CGs who had lower CR-resistance. Surprising and contradictory results were found in the physical health symptoms; for CGs who had relatively high community/professional services utilization including all sub-types except CG service and assistant sub-type, CGs who had higher levels of CR-resistance reported significantly a greater number of physical health symptoms as compared to CGs who had lower CR-resistance, whereas for CGs who had relatively low or no community/professional service utilization, regardless of their level of CR-resistance, those CGs had similar relatively low levels of physical health symptoms.

Regarding feelings of benefits/gains, perhaps those CGs who effectively utilized their community/professional services , particularly health professional services, were able to balance caregiving demands and the CG's own emotional and social needs by fully utilizing their available resources even when they faced difficult caregiving demands, such as CR-resistance. In our qualitative thematic analysis as presented in the findings and interpretation section, two CG attitudes, being in charge and acceptance, were found to be key factors in CGs utilizing available resources. CGs who presented a being in charge attitude in their caregiving context as well as toward the CG's own needs, and who accepted his or her own abilities/limitations in meeting caregiving demands, often mentioned that they utilized available community/professional resources for balancing CR demands and the CG's own emotional and social needs.

On the one hand, because those CGs who utilized social/professional services had set routines for their services, no matter how much the CRs exhibited CR-resistance or the CGs got exhausted from the CR-resistance, the CGs might be able to maintain their own routine activities for meeting their own needs, such as taking a break, socializing, and exercising, even with high incidents of CR-resistance. In other words, the set CR routines for obtaining community/professional services might encourage CGs to maintain their own routine activities for self maintenance. On the other hand, those CGs who did not or minimally utilized these services had difficulty in pursuing their daily routines without a set break from their caregiving responsibilities, particularly when/if they faced high frequency of CR-resistance. Those CGs who faced frequent CR-resistance were often emotionally and physically exhausted, so it was easy for them to give up or to not

consider doing non-urgent activities that could be important for maintaining CG emotional health.

In summary, our mean level results highlighted the important role of community/professional service utilization, particularly for maintaining CG emotional health. It is helpful to interpret this positive influence of community professional service utilization through the lens of Social Cognitive Theory and existing literature.

Community/professional services are vital resources for CG knowledge and abilities in managing their caregiving demands (e.g., McCallion, Toseland, Gerber, & Banks, 2004). Social Cognitive Theory would suggest that CGs who utilized community/professional support, as compared to other CGs who did not, with their increased knowledge and skills from the collective of their resources in the community, have higher levels of sense of efficacy with which they approach difficult caregiving demands, such as CR-resistance, while maintaining an optimistic attitude and manage those demands well. Moreover, Social Cognitive Theory would also add that, with the support from community/professional services, those CGs often sustained daily routines for meeting their own emotional and social needs, and a consequent better state of emotional health might have contributed to their relatively high sense of efficacy in managing occurrences of CR-resistance, as compared to other CGs who did not take advantage of available community/professional support.

At the daily level, having relatively low community/professional services utilization, specifically IADL services as based on the sub-scale analyses, played a significant buffering role in the link between “Daily CR-resistance Fluctuation” and

feelings of benefits/gains. Specifically, for CGs who had relatively low community/professional services utilization, on days when they faced more than usual CR-resistance, they experienced increased levels of feelings of benefits/gains whereas for CGs who had relatively high community/professional service utilization, on days when they faced more than usual CR-resistance, they maintained their relatively constant high level of feelings of benefits/gains regardless of their level of CR-resistance.

Interpreting these daily moderating effects of community/professional service utilization alongside the mean level results could help summarize the positive role and trends of community/professional utilization reflected in CG emotional and physical well-being in our data. On the one hand, those CGs who did utilize their community/professional services were likely to have relatively high positive perception of their caregiving context in general. This positive influence of community/professional service utilization seemed to be maintained regardless of CG experiences of both the mean level as well as the daily fluctuation of CR-resistance. In the course of routinely utilizing available community/professional services, perhaps CG are often encouraged to have and maintain their own routine activities for meeting their emotional and social needs. With the maintenance of optimal emotional and physical states, these CGs could manage at their potential difficult caregiving demands, including CR-resistance. On the other hand, CGs who did not or minimally utilized their community/professional services were likely to have chronically low levels of emotional health and decreased feelings of benefits/gains in general, especially for CGs who had relatively high CR-resistance. Perhaps with chronic demands from a high occurrence of CR-resistance, these CGs were

often emotionally and physically exhausted without any break from their caregiving responsibilities. However, for these same CGs, on days when they faced and managed more than a usual amount of CR-resistance, their feeling of accomplishment seems to *momentarily elevate* their feelings of benefits/gains.

Regarding physical health symptoms, the increased level of physical health symptoms for the group of CGs who had relatively high CR-resistance, as compared to CGs who had relatively low CR-resistance, could be caused by difficulty in keeping service appointments as a result of having to contend with difficult CR behavior, CR-resistance. As seen in our qualitative interview examples and as could be easily imagined, when CR-resistance was exhibited the time needed for carrying out routine daily activities, such as dressing, eating, and showering would be greatly extended. For CGs who utilized community/professional services, if their CRs exhibited relatively high frequency and intensity of CR-resistance, they often needed to expend more energy to carry out their routine CR caregiving activities with extra efforts in order to make their appointments. Perhaps accumulated physical and emotional extra demands due to this time strain impacted their physical health. Social Cognitive Theory also would add that these decreased CG emotional and physical states lowered CG sense of efficacy and negatively influenced not only their daily approaches to caregiving activities but also their physical health in general.

Additionally, the moderating results of CG physical health symptoms could be interpreted from the other side. CGs with more physical health symptoms, more aware of their own limits in providing care to their CRs, reached out to receive service/support in

the community, or these CGs with relatively high community service/support utilization were providing care to CRs with more severe conditions than other CRs. In fact, Toseland, McCallion, Gerber, and Banks (2002) reported that community/professional service utilization was predicted by CG objective stressors, including CR behavioral problems, functional declines, level of dementia, CG poor health, and CG perception that caregiving is negatively impacted one's health. Moreover, our qualitative data contained some evidence that when CGs experienced declines in emotional and/or physical health, they realized their own limitations in meeting caregiving demand by themselves, and this CG realization of their own limits caused them to reach out for community/professional services.

In summary. Overall, among key factors of CG well-being, sense of efficacy plays important role in CG emotional well-being reflected in all outcome variables (depressive symptoms, feelings of burden, feelings of benefits/gains, and positive affect). However, other key variables seemed to be associated with CG well-being in specific aspects. Pre-caregiving relationship quality was significantly associated with CG feelings of burden and feelings of benefits/gains whereas socio-emotional support was significantly associated with depressive symptoms and positive affect. Specifically on one hand, the influence of positive sense of efficacy reflected in lower feelings of burden and higher feelings of benefits/gains might be supported by better quality relationship with their CRs. A good quality relationship provided CGs an optimistic outlook and helped them view their caregiving role as an opportunity. This resulted in CG confidence in providing quality care. Therefore, these CGs could heighten gains rather than loss

(burdensome) in their caregiving role. On the other hand, the positive influence of sense of efficacy reflected in lower depressive symptoms and higher positive affects might be supported by higher socio-emotional support. Having available emotional support might be busted CG sense of collective efficacy in providing quality care, especially for foreseen caregiving needs and transitional events. It is also possible that actual interaction with other people rather than CRs could be helpful for the CG to have opportunities to get their frustration out and to take mind off from actual caregiving events.

As discussed by Miller and colleagues (2001), social support is one of the most complex constructs that involves many different kinds of support from different sources. Although certainly the immediate social network, including spouse, family members, and friends, could provide a critical role for family caregiving, perhaps, the most important and crucial sources of social support could be highly unique to the individual CG. In fact some studies that have investigated the role of social support for family CGs found that CG satisfaction with social support was more important factor in predicting CG emotional health than the types of social support that were utilized or provided (e.g., Savard et al., 2006).

Contradictory Quantitative Results and Qualitative Findings

The present study's results and findings derived from the two different methodologies— the quantitative reports on the 8-day daily survey and the semi-structured individual interviews, were complementary for the part. Each methodology provided uniquely meaningful information as well as supplemental evidence to the other. However, there were a few areas where there appeared contradictions or inconsistencies

within each method or between methods, specifically with respect to (a) CG report on CR-resistance and (b) influence of CG service utilization. These contradictory or inconsistent findings and results are discussed in the section that follows.

One of the major discrepancies was inconsistency in CG reports of their CR-resistance experience during individual interviews. At the time of phone screening and/or at the beginning of the follow-up interviews, about a half of the interview participants expressed that they had never experienced resistive behavior from their CRs, or they hardly had difficulties in dealing with their CRs. This roughly matched the proportion of CGs who reported that they did not experience CR-resistance in their original DUCS survey. However, these CGs' reports of no CR-resistance experiences were often revised toward to the end of each interview; nearly all participants remembered and discussed at least one incident of CR-resistance within the one to one and a half hour interview period.

These inconsistent CG comments regarding their CR-resistance experiences might have been partially caused by the fact that some CR-resistance incidents did not occur during daily personal care or assistance activities, and/or that CGs simply forgot the incidents because such incidents were rare. Our qualitative results provided some evidence that although most of CR-resistance incidents happened during routine care or assistance activities, particular types of CR-resistance, such as transitional or unusual/unfamiliar types of CR-resistance, could happen outside of this context. Perhaps, interview participants did not recall these rare incidents while they mainly discussed their typical caregiving days and routine in the early part of their interviews.

Another possible reason for discrepancies in CG reports of CR-resistance experiences is that although many CGs had experienced CR-resistance in the past, they often figured out their own strategies for how to avoid or deal with the CR-resistance over time. Therefore, for some CGs, CR-resistance was no longer an issue or was an issue that they had left behind at an earlier phase of their caregiving career. These cases would likely apply to CGs who experienced two of the four types of CR-resistance, *a few specific activities* or *transitional* types of CR-resistance as discussed in the current qualitative analysis. As discussed in the qualitative findings and interpretation section, because of the predictable nature of these two types of CR-resistance, CGs who experienced these two types, as compared to other two types, often had more control over their situation by preparing and managing well and thus experienced less emotional impact. Therefore, those CGs, during the initial part of their interview period, did not recall incidents of CR-resistance.

Although the main focus of the present study, particularly in the quantitative phase, was trying to capture CG experiences of CR-resistance in the routine care situation, the discrepancy in CG reports regarding their CR-resistance experiences in the qualitative data (interviews) and the possible causes for discrepancy listed above highlight different dimensions in CG experiences of CR-resistance. CGs could experience different types of CR-resistance at different consistencies (rate and intensity) across different caregiving contexts, and CG experiences of CR-resistance and the emotional impact could change over a long-term caregiving career. This changeable nature of CR-resistance underlines Pearlin's (1990) point that family caregiving is not a

static state but that stressors and caregiving related circumstances change over time. The current study confirms that the CR-resistance feature of caregiving is not an exception and that CR-resistance poses changes in types and variabilities in frequency and magnitude at different levels: between-person, short-time within-person (e.g., daily change across different caregiving contexts), and long-term within-person during the caregiving career (e.g., changes in kinds of CR-resistance and emotional impacts). Although considering all the possible variability in CR-resistance is beyond the scope of the present study, this variability should be considered when professionals determine and provide support for the impact of CR-resistance on CG emotional and physical health.

The second main discrepancy in our findings was CG reports of community/professional service utilization between the quantitative results and the qualitative findings. The post-hoc sub-scales moderating analyses of community/professional service utilization yielded similar results with these of the original moderation analyses; community/professional service utilization played a significant buffering role in the link between CR-resistance and CG emotional well-being, specifically, for CG feelings of benefits/gains. However, one exception was found in the *CG service and assistance* sub-scale and that was that this particular service utilization did not play a significant moderating role. This non-significant finding was surprising because, in the qualitative interviews, about a half of the participants mentioned that, among available community/professional services, those for CG assistance that included CG support groups or counseling sessions were quite useful in

helping CGs manage the emotional impact from CR-resistance and other care related challenges.

As compared to other sub-scales of community/professional services, including IADL services, professional healthcare services, and daily services that provided mostly tangible kinds of services, *CG service and assistance* kinds of services such as support groups or counseling involved the more emotional aspects of CG support. Perhaps, as was similarly discussed in the socio-emotional support section, effectiveness of emotional support was highly dependent on individual preferences. Whereas some CGs seemed to get great benefits from professional CG services and assistance, others preferred to deal exclusively with family, or other family CGs who were in the same or similar situations. These kinds of professional CG services and assistance that were measured via this sub-scale might work well for a particular group of CGs but did not serve as a universal buffer for all CGs. Therefore, in the current quantitative analyses, this particular variable, CG service and assistance, did not appear to be a significant moderator.

Conclusion

The CG coping process involves "a complex and dynamic set of cognitive, affective, and behavioral responses that are aimed to regulate their emotions, solve, or improve the practical problems they face" (Gottlieb & Wolfe, 2002, p. 325). In order to enhance our knowledge in a small but critical piece of this complex family CG coping process phenomenon, the current study focused on one of the critical CG stressors, CR-resistance. We conducted a mixed methods study with 8-day quantitative survey data and

qualitative semi-structured individual interviews, exploring CR-resistance, its impact on CG emotional and physical health, and CG resource factors that were associated with CG strategies in dealing with CR-resistance and/or maintenance of their emotional and physical well-being. Our findings provide a unique contribution to the field in several ways.

First, with systematic documentation and detailed descriptions of CR-resistance, the current study identified *four different types of CR-resistance* that have unique characteristics in their (a) contexts, (b) occurrence patterns, and (c) emotional impact on CGs. Second, the current study determined whether *typical moderators* that have been identified in the extant literature and the theoretical frameworks were applicable for the current specific stressor, CR-resistance at two different levels: (a) Person-Mean CR-resistance and (b) Daily CR-resistance Fluctuation. Third, by highlighting the increased value of the transferrable and/or generalizable nature of CG cognitive resources, the qualitative thematic analyses revealed that CG cognitive resources, specifically CG knowledge, attitudes, and coping strategies helped CGs manage CR-resistance.

The current study revealed that the CG stressor--CR-resistance--was not a simple and universal phenomenon for the family CG. Because of the unique contexts and occurrence patterns of CR resistance, the impact on CG emotional well-being differed across four kinds of CR-resistance. The most *sudden and unpredictable* and the most *chronically demanding* CR-resistance were the two most difficult types for the CGs to deal with whereas the types of CR resistance associated with *a few specific activities* and *transitional events* were somewhat manageable. The main differences between these

difficult and manageable types of CR-resistance were characterized by their occurrence patterns: unpredictable vs. predictable and chronic vs. infrequent. For the former two difficult types, because of its unpredictable or chronic nature, CGs did not have control over how and when to manage the CR-resistance. These former two types could bring strong impact particularly on CG emotional health and sometimes on CG physical health. For the latter two manageable types, because of their predictable nature or infrequent occasion, CGs often had some control over how and when to manage the CR-resistance by balancing meeting CR care related demands as well as other CG life demands. Importantly, as discussed earlier, the current study documented the variability in the types and occurrences between CGs, within individual CGs, and over an individual CG caregiving career. This variability should be considered when professional help is sought to assist CGs to deal with their CR-resistance as well as to assist CGs in preparing for future events.

The current HLM analyses revealed that, for CR-resistance that could bring strong, emotional impact, typical CG resource factors, such as a sense of efficacy and socio-emotional support, seemed to not work in the same ways, for instance as a buffer, as for other CG stressors which have been found in the extant literature. The results highlighted possible differences in short-term (e.g., daily) and long-term (e.g., over months) CG moderators of the link between CG stressors and CG emotional and physical well-being, and the moderator would be different depending on the type of specific stressors. Additionally, the qualitative findings and quantitative results suggest that some effective moderators might be highly dependent on individual CG preference.

One typical CG personal resource, CG sense of efficacy, and one CG background factor, CG-CR relationship quality before caregiving, yielded similar results in that they were not found to be significant buffers of the link between CR-resistance and CG emotional and physical well-being at either the level of Person-Mean CR-resistance or Daily CR-resistance Fluctuation; based on the qualitative results, whatever buffering effect occurred was highly dependent on CG circumstances. The qualitative evidence to some degree showed that CG sense of efficacy might work to help minimize the unnecessary occurrence of CR-resistance, but once CR-resistance occurred, the initial emotional impact was not avoidable even for CGs with a relatively high sense of efficacy. Similarly, a high quality CG-CR relationship before caregiving also helped CGs minimize the unnecessary occurrence of CR-resistance. However, once CR-resistance occurs, relatively high CG-CR relationship quality before caregiving might exacerbate the emotional impact from the incident on the CG.

Analyses on the moderating influence of CG social network resources, socio-emotional support, family disagreement regarding care, and community/professional service utilization revealed interesting and somewhat more clear-cut results. Regarding support from the CG close network and family interaction, measured by the current disagreement regarding care scale, both were found to be a significant buffer of the link between “Daily CR-resistance Fluctuation” and CG emotional well-being whereas socio-emotional support from spouse and family was not found to be a moderator. Regarding support from the CG community, CG community/professional service utilization was

found to be a significant buffer of the link between “Person-Mean CR-resistance” for CG feelings of benefits/gains.

These social network resource results were, however, somewhat surprising given our qualitative evidence that some CGs expressed that socio-emotional support from a close network was one of the important factors for the CG maintaining emotional health in the face of CR-resistance; and several CGs also expressed that family disagreement regarding care caused them emotional stress, and, for a few CGs, such disagreement resulted in infrequent contact with those family members who had become involved in arguments. Moreover, although community/professional support utilization, as a whole, was found to be a significant buffer for CG emotional well-being, when the four subscales were separately examined in our quantitative analyses, the kind of community/professional support most frequently mentioned in the interviews--CG service and assistance, was not found to be a buffer. This was especially surprising since many CGs mentioned in their interviews that attending a CG support group and/or going to a therapy session helped them to overcome the difficulty of CR-resistance. These complex results regarding CG social network resources leave important questions to be explored in future research.

As discussed by Miller (2001), social support is one of the most complex constructs that involves many different kinds of support from different sources. Although certainly the immediate social network, including spouse and family members, could play a critical role in supporting family caregiving, perhaps, as previously discussed, the actual selection and use of critical sources of social support could be highly dependent on

individual CG preferences. In fact some studies that have investigated the role of social support for family CGs have found that CG satisfaction with social support was an important factor for predicting CG emotional health rather than types of social support that were utilized or provided (e.g., Savard et al., 2006). Perhaps, social network measures that attempt to capture CG needs and satisfactions could provide more meaningful information regarding the complex role of social networks for individual CGs than can measures that focus more exclusively on types.

Finally, our qualitative thematic analyses closely examined individual CG experiences of CR-resistance from the CG perspective, and the thematic analysis revealed several CG cognitive resources that played important roles in dealing with CR-resistance. These findings not only confirm some results in the existing qualitative literature (Farran et al., 2004), they also present possible origins and roles of these CG cognitive resources.

Specifically, particular CG attitudes, such as the *family oriented caregiving value* and *respect for the CR* provided CGs a positive outlook in their caregiving situation that helped CGs approach their caregiving demands with optimism. In general, their optimistic approach often helped CGs provide quality care to their CRs, and thus it also helped minimize the occurrence of unnecessary CR-resistance. For those CGs with these attitudes—family oriented caregiving value and respect for the CR, two other critical CG attitudes for CG survival, *acceptance* and *being in charge*, were often given. Those CGs who *accepted* their current caregiving condition, such as the CR's diseases, the caregiving arrangement, the CG support system, and the CG's own limitations in meeting CR demands, were able to efficiently deal with their caregiving challenges, including

CR-resistance, without excessive emotional upset or frustration. Moreover, CGs who presented a *being in charge attitude* over caregiving demands proactively assessed foreseeable demands and actively searched for solutions, and thus, these CGs also often effectively managed CR-resistance. Additionally, CGs who possessed a being in charge attitude also over their own emotional and physical health, often maximally utilized available community and social resources that enabled them to balance caregiving demands and their own needs. This confirms results in another qualitative study that skillful CGs seemed to reach out for and to utilize available resources better as compare to other CGs who are not so skillful (Farran et al., 2004).

Lastly, two types of CG knowledge played critical roles for CG management of CR-resistance: disease-specific information and CR personal information, including information about the CR's personality and preferences in daily activities. Specifically, knowing disease-specific symptoms and behavior, CGs were often able to appropriately attribute the cause of CR-resistance to the disease rather than to emotional upset at the CGs. This helped CGs efficiently manage CR-resistance. Although CG informational support has not typically been highly evaluated in the review literature (e.g., Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007), perhaps basic disease related knowledge provides solid foundation for CG sense of efficacy and should not be lightly eliminated from interventions. The current findings further highlighted an additional important knowledge that knowing CR personality and preferences in daily activity also helped CGs manage their CR-resistance by developing a workable strategy specific to their CRs. Additionally, the thematic analysis further revealed that the combination of

particular CG knowledge and CG enactable skills--knowing exactly how to implement CG knowledge in a specific situation--were important factors for CGs to maximally utilize their personal resources.

Importantly, the thematic analyses also highlighted the patterns whereby *particular CG transferred and/or generalized knowledge, attitudes, and coping experiences* from past CG work experiences and personal challenges seemed to influence overall CG emotional resiliency under caregiving demands. Transferred and/or generalized CG knowledge, attitudes, and coping experiences provided CGs additional confidence that they could deal with CR-resistance and other care related challenges and also helped CGs position themselves on the positive side of the caregiving role, such as in maintaining feelings of benefits/gains. Those CGs who had relatively high confidence in their ability and positive attitudes, with their increased level of efficacy often effectively and efficiently managed CR-resistance and other care related challenges by maintaining their own emotional health.

Implications and Recommendations for Research and Practice

The results and findings of the present study indicate that CR-resistance is a complex CG stressor that varies in type, occurrence, and impact on CG emotional and physical well-being. Even with typical CG resources, such as social emotional support and CG sense of efficacy, some emotional impact from CR-resistance seemed to be hard to avoid. Based on detailed descriptions of CG experiences, the findings have implications for content and goals of future intervention. and research for promoting well-being of family CGs.

Developing a CR-resistance instrument/checklist that assesses types of CR-resistance could be the first important step for developing appropriate support systems for CGs in dealing with CR-resistance. As described in the results section, each of the four types of CR-resistance has unique characteristics and poses different types of demands on CGs. At minimum, this instrument could screen the most vulnerable CGs who are facing the most difficult types of CR-resistance, such as the chronic and unfamiliar/unpredictable types. If public resources allow, CGs with different types of CR-resistance should be referred to support that will allow them to develop appropriate coping strategies depending on the CG's needs.

Second, developing a checklist that captures the CG's preferred method for emotional support would help professionals efficiently prepare CGs for foreseeable needs and refer CGs to a best fitted service when needs arise. Our results and findings suggest that some CR-resistance could induce CG emotional reactions. However, there is no one universal emotional strategy for all CGs; but each CG needs to develop his/her own unique strategies in dealing with emotional impact. Importantly, although some may prefer more private self-contained strategies over those involving others, our results also suggest that not having anyone could be the worst situation when/if CGs face unexpected strong emotional upset. It is ideal for all CGs to prepare by having some ways of getting emotional support when they face unusual CR-resistance or other care-related incidents that induce emotional upset. Perhaps, for those CGs who prefers privacy, having a hotline number or regular check calls from a social worker or volunteer veteran CGs might work as a safety net in case they face a sudden unexpected incident.

Third, it would be useful to develop a mapping tool by which CGs could identify their existing (transferable) knowledge, skills, and strengths from their work and personal experiences that are applicable to their caregiving context. Although our thematic analyses found great positive influence of these transferable/generalizable CG cognitive resources on CG emotional resiliency, this area needs further exploratory studies in order for professionals to develop efficient and applicable tools. Perhaps, as a pilot project, it would be useful to develop an instrument to catalogue individual CGs' different kinds of transferable/generalizable strengths and also enable CGs to highlight their own best strengths and what they regard as the positive side of their caregiving role.

Finally, the last two notes for developing future projects and intervention programs come from the reflections of the principal investigator/interviewer of the present study. Although to develop effective interventions, it is important and helpful to highlight CG successful stories with successful strategies, *CGs ongoing efforts and struggles in the process of finding their own survival strategies* should not be overlooked or denied. A majority of our interview participants were relatively successful survivors of family caregiving. Even though several of them expressed that they had experienced significant emotional and physical symptoms due to caregiving related stress, they fought through by finding *their own unique ways to maintain their health* throughout their caregiving career. At the time of the individual interviews, most of them presented themselves as having relatively good emotional and physical health. In their interviews, many of them had good and positive things to say about their caregiving experiences.

However, none of the participants said it was easy. In fact, many of them said it was quite hard at times.

This way to CG success reminded me of what is called “coping modeling” in Bandura’s observational learning (1997). According to Bandura, there were two types of effective observational learning, masterly modeling and coping modeling; masterly modeling is learning from those who “perform calmly and faultlessly,” whereas coping modeling is learned from those who “gradually overcome their difficulties by determined coping efforts” (p. 99). These were both successful methods, but coping modeling can boost efficacy beliefs in observer learners who are unsure of themselves in their role more so than can masterly modeling. As evidenced in our participant’s comment, “it was... gradual...I kinda grew into myself as he was growing into his elder age I was growing into the caregiver thing,” many of family CGs were not master CGs to begin with, and, during a long-time caregiving career, they often learned and grew into masterly ones. Highlighting these ongoing and persistent CG efforts that often lead to their success should be important information for CG intervention programs. Perhaps veteran or still struggling CGs should be utilized as important assets for intervention programs.

Moreover, the present study highlighted that CGs have their own preferred ways to deal with their unique caregiving demands. This finding underscores the existing literature as to how intervention should be tailored to the specific problems of individual CGs (e.g., Brodaty, Hoffman, Kleban, & Schoonover, 1994; Selwood et al., 2007), and further suggests that interventions should also be flexible with different options for CGs to choose their own workable/preferred ways they feel comfortable enough with to

actually utilize. As evidenced in the intervention literature, improving CG knowledge itself does not easily buffer the impact of caregiving demands on CG well-being (e.g., Selwood et al., 2007). The current study highlighted that other CG cognitive resources and particular attitudes would play important roles in how those CGs efficiently and effectively utilize their available resources. Our findings suggest that some CGs would find their own uniquely effective strategies by taking their own pathways in their own time, for example by trying their own coping strategies by themselves first before utilizing other options. Perhaps, intervention options should be tailored to the particular CG's attitudes or preferences. For instance, for CGs with a being in charge attitude, providing a wide range of options from which the CG could choose might work well, whereas for other CGs, more directly assertive or didactic advice from professionals would be best.

Limitations

The findings from this study must be interpreted in light of the study's limitations. First, there was a long time-lag, five to six years, between the original DUCS quantitative survey and the follow-up individual interviews. This time-lag limited the number of the follow-up interview participants and might have caused discrepancies between the CGs' original survey reports and interview descriptions. It is possible that CGs had different perspectives on their CR-resistance experiences when they recalled experiencing CR-resistance five years previous as compared to whatever their perspectives were at the time of resistance, regardless of their caregiving status. Five years later, the CGs should be

more experienced and mature, and have had time to retrospectively reflect on their experiences.

There were several methodological limitations regarding the quantitative part of the study. First, because of the sample size, sub-group analyses for ethnic or cultural background, CG gender, and CR disease type could not be conducted. These sub-groups might have different patterns in the occurrence of CR-resistance, its impact on CGs, and the possible moderating factors. Second, CGs may have been unsure of, or confused about, the meaning of the term “resistant” in the measure of CR-resistance in the quantitative daily survey. CGs were asked about their CR-resistance experience in each caregiving care/assistance item as follows: "Was R (CR) resistant to your assistance?". The word "resistant" might have been unclear and/or some CGs may have been unwilling to report some of their CR-resistance experiences. Third, because the current quantitative study utilized the existing DUCS data set, there were limited numbers of instruments that could be used for the current HLM analyses. For instance, we did not have instruments that measured (a) CR-resistance both within and outside of the context of routine personal care, (b) CG routine activities outside of caregiving for maintaining CG health, or (c) CG additional cognitive resources. Instruments that measure the latter three constructs could have expanded our quantitative analyses and allowed for further comparisons and contrasts with our qualitative findings. Fourth, although the original DUCS daily survey was implemented as an 8-consecutive day daily survey and captured CGs experiences of CR-resistance for a typical week including week days and weekends, as noted earlier, CG experiences of CR-resistance could change over time. Although it

could bring additional burden on participant CGs, a longer-term daily survey is ideal to capture both daily and long-term changes in CR-resistance and CG experiences.

There were also a few specific limitations that were associated with the qualitative part of study. First, our sample included CGs from various phases of their caregiving career; we interviewed CGs who continued to provide care for their CR at home, CGs whose CRs had passed away, and a CG whose CR had transferred into a nursing home. Although the thematic analysis did not identify patterns based on CG status, the participants' reflections on their experiences could have been partially influenced by their caregiving phase. For example, it is possible that those participants who are no longer serving actively in the CG role reflected back on their experiences more positively than ongoing CGs. It is also possible that different CG cognitive resources (e.g., attitudes, knowledge) could have different priorities across different caregiving phases. Second, as compared to those individuals who did not agree to participate in the interviews, the interview sample might contain more skillful CGs who managed their challenges well although quantitative group comparison analyses did not identify significant background differences between the 63 original DUCS survey participants and the 19 follow-up interview participants. Our interview participants might have more positive things to say about their caregiving experiences. Thus, our qualitative study may only reflect the reality of a somewhat selective, more successful group of CGs rather than that of the average experiences of the original CGs and the family CG population in general.

Future Directions

Some of the present study limitations could be improved in future projects. First, although the current PI conducted a thorough qualitative thematic analysis in the present study, the themes that emerged from the interviews have not been validated by study participants via a member check. A member check with selected participants, confirming the accuracy with which these themes represent their caregiving experiences or what they meant to express in their qualitative interviews, would be an important next step before making firm conceptual conclusions. Second, although the present study was designed based on the extant literature and theoretical frameworks, it is possible that the assumed causal association in the model (i.e., that CR-resistance impacts CG emotional and physical well-being) could be reversed--CG emotional and physical well-being might influence the occurrence of CR-resistance, perhaps indirectly through the impact of CG well-being on CGs' approach to their caregiving demands and CRs. This reversed model should be further explored. Third, although the quantitative analyses were done by controlling for CG gender because of the limited sample size in the current study, the PI noticed possible differences between the female and male CG responses during the qualitative interviews. Perhaps, using a qualitative comparative analysis, gender as well as other CG characteristic differences could be further explored in the future projects.

APPENDIX A: INTRODUCTION RECRUITMENT LETTER

May XX, 2009

(Name)

(Address)

Tucson, AZ Zip



Daily Understanding of Caregiver Study

Dear Mr./Ms. (Name),

My name is Yumi Shirai, and I am a doctoral student in the Division of Family Studies and Human Development at the University of Arizona. I am currently conducting a study for my dissertation about family caregivers' experiences, with a special focus on elders' resistance to receiving help and assistance from caregivers in day-to-day activities.

You are receiving this letter because you participated in our previous study, Daily Understanding of Caregiver Study (one yellow survey and 8 blue daily surveys), conducted by Dr. Susan Silverberg Koerner (my academic advisor). Thank you very much for your participation in that study. Your effort provided valuable information for professionals (e.g., researchers, service providers, community program developers) to better understand daily family caregiver experiences. I hope that this letter finds you doing well.

In order to learn more about your experiences of caregiving (either current or past), we would like to implement a follow-up survey and an individual interview with those individuals who participated in our earlier research.

In about a week, I will contact you via phone and explain more about this follow-up study and the possibility of your participation. You may participate in the follow-up portion of the study whether or not you are still providing care for your relative.

We look forward to learning more about your caregiving experiences. Please keep in mind that your participation is very important to the success of this project and ultimately to the improvement of programs/services available to older adults and family caregivers in the community.

If you have any questions about this project or if your telephone number is no longer xxx-yyyy, please contact me by phone or email at the numbers listed below.

Looking forward to talking with you.
Sincerely,

Yumi Shirai, M.S.
Research Associate
Division of Family Studies and Human Development
University of Arizona
(520) 331-3448
yumish@email.arizona.edu

APPENDIX B: PHONE CONVERSATION

Daily Understanding of Caregiving Study: Follow-Up Study Recruitment Phone Conversation Guide

1. Introduction

- Call is from the Daily Understanding of Caregiving Study at the University of Arizona. I am Yumi Shirai, one of DUCS research associates and I am pursuing a dissertation research project that is a follow-up to the earlier study.
- Whether the caregiver received reminder letter.
- As mentioned in the letter, I am calling to describe the follow-up study and to find out whether you would be interested in participating.

2. Current caregiving status

- When the caregiver participated in our previous caregiving study, he/she was providing care for a family member. Is he/she still providing care for the same person?

Yes_____

No_____

If no, when did he/she stop providing care for the person

Reasons why he/she stopped

Does he/she provide care for somebody else?

Yes _____ for Whom? _____

No _____

3. Purpose of the study

- To follow up on the caregivers who participated in the DUCS project to find out about their current caregiving status and health condition.
- To learn more about caregivers' experiences with a special focus on those times when relatives resist receiving help and assistance from caregivers in day-to-day activities.
- To learn how that resistance may influence the life and well-being of the caregiver.

4. Participation options

All DUCS participants are eligible to participate to this follow-up portion of study regardless of their current caregiving status (i.e., continuing caregiver and discontinued caregiver).

- They can choose to complete a follow-up survey or, if possible to complete a follow-up survey and participate in an interview.

5. Voluntary participation

Free to (a) choose not to participate, (b) not answer any questions they do not feel comfortable with, or (c) to withdraw from the study, at any time.

6. Steps of the study

a) Survey Only Group:

- Receive a packet of materials including an instruction cover letter, the follow-up survey, a consent form, and two pre-addressed, pre-paid envelopes.
- Consent Form:
 - Read the consent form.
 - Ask questions regarding the study if you have any (PI's phone number will be provided).
 - Sign the consent form.
 - Send consent form back in the pre-addressed, prepaid envelope.
 - Receive a copy of the consent form via mail.
- Follow-Up Survey:

The survey will ask you questions about your current life circumstances, caregiving situation, and personal well-being.

 - Read the cover page of the survey for instructions
 - Ask questions regarding the survey if you have any.
 - Complete the survey
 - for a continuing caregiver, it will take about 40 minutes; and
 - for a discontinued caregiver, it will take about 10 minutes.
 - Send the completed survey back in the pre-addressed, prepaid envelope.

b) Survey-and-Interview Group:

- Schedule an interview place and date during this phone conversation.
 - The interview can take place in the caregiver's preferred location (at his/her home or at a private office on the UA campus) at a time convenient to him/her.

At home prior to the interview date:

- Receive a packet of materials including an instruction cover letter, the follow-up survey, and a consent form.
- Consent Form:
 - Read the consent form.
 - Ask questions regarding the study if you have any (PI's phone number will be provided).
 - Sign the consent form.

- Follow-Up Survey:

The survey will ask about your current life circumstances, caregiving situation, and personal well-being.

- Read the cover page of the survey for instructions.
- Ask questions regarding the survey if you have any.
- Complete the survey
 - for a continuing caregiver, it will take about 40 minutes; and
 - for a discontinued caregiver, it will take about 10 minutes.

On the interview date:

- Bring the signed consent form and completed survey.
- Ask questions regarding the study if you have any.
- Interview:

Will be asked about your caregiving experiences with a focus on care-recipient resistance during care assistance (e.g., how often this occurs/occurred, why you think it happens/happened, what you do/have done when it does happen).

- Conducted by me (the PI)
- Last about one hour
- Audio recorded

- Follow-up call: About 1-3 months after the interview, a few randomly selected interviewees will get a call to check on how accurately I have interpreted the interview responses - how well I've made sense of the interviews; whether my interpretations match your experiences.

7. Confidentiality.

- No names will appear on the survey or on the interview transcripts.
- Code numbers will be used for each participant.
- A master list linking names with code numbers will be secured in locked files with access restricted to the principal investigator of the DUCS project (Dr. Koerner), the current PI (Shirai), and designated project assistants.
- Completed surveys and computer files (i.e., interview audio files, data files, and transcriptions) will be kept in a secured area with access limited to the DUCS principal investigator, the current PI, and designated project assistants.

8. Any questions to be answered.

9. Participation preference

a) Follow-up survey only _____

b) Survey-and-interview _____

****Encourage the caregiver to choose place and time where and when he/she would be most likely to have privacy.****

Interview date _____ time _____

place_____

Preferred method of interview reminder

c) No follow-up _____

10. For further information or questions:

Contact the PI,

Yumi Shirai

(520) 331-3448

yumish@email.arizona.edu

APPENDIX C: CONSENT FORM

SUBJECT'S CONSENT FORM

APPROVED BY UNIVERSITY OF ARIZONA
THIS STAMP MUST APPEAR ON ALL
DOCUMENTS USED TO CONSENT SUBJECTS.
DATE: 6-18-09 EXPIRATION: 6-17-10

Daily Understanding of Caregiving Study:
Follow-Up Study (Survey and Interview)

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to better understand some of the factors associated with care-recipient (dependent family elder) resistance during care assistance and how care-recipient resistance may influence the life and well-being of caregivers. The success of this study will provide valuable information for professionals (e.g., researchers, service providers, community program developers) ultimately to the improvement of programs/services available to older adults and family caregivers in the community.

WHY ARE YOU BEING ASKED TO PARTICIPATE?

You are being invited to participate in this follow-up study because you already completed questionnaires in a previous Daily Understanding of Caregiving Study (DUCS).

HOW MANY PEOPLE WILL BE ASKED TO PARTICIPATE IN THIS STUDY?

All sixty-three caregivers who completed the previous DUCS survey will be asked to participate in this follow-up phase of the DUCS project.

WHAT WILL HAPPEN DURING THIS STUDY?

Your follow-up study participation will involve a) completing a follow-up survey and b) participating in an individual interview.

a) Completing a follow-up survey:

Your survey participation will involve completing one of two follow-up surveys (continuing caregiver survey or discontinued caregiver survey) at your home prior to the interview date. During our phone conversation, you let us know your current caregiving status – that is, whether you are a **continuing caregiver** who continues to provide care for the same relative from the previous DUCS survey, or a **discontinued caregiver** whose caregiving responsibility for the same relative from the previous DUCS survey has ended. Based on your current caregiving status, a relevant survey was sent to your home. If you are a continuing caregiver, the survey will take about 40 minutes to complete, and will ask you questions about your current life circumstances, caregiving situation, and personal well-being. If you are a discontinued caregiver, the survey will take about 10 minutes to complete, and will ask you questions about your current life circumstances and personal well-being.

b) Participating in an individual interview:

Your interview participation will involve answering questions in an interview with the principal investigator (Yumi Shirai). The interview will take place at a location of your preference which you chose during the recruitment phone conversation (e.g., your home, one of the private offices at the McClelland Park Building on the University of Arizona campus). In the individual interview, you will be asked about your experiences around care-recipient resistance during care assistance (e.g., the factors associated with care-recipient resistance, how care-recipient resistance may influence your life and well-being). The interview will take approximately an hour of your time. Approximately one to three months after the interview, you may be randomly selected to participate in a brief phone interview to check the accuracy of the PI's analysis/interpretation of the interview data. In this phone interview, the PI will ask you whether the themes that emerged in the PI's analysis of the data are an accurate reflection of your caregiving experiences.

ARE THERE ANY RISKS TO ME?

Although no risks to the participants are expected in this study, your participation may involve some minor risks. For example, certain questions might lead to temporary feelings of sadness or distress for you. Although strong feelings of sadness and/or distress are rare, there will be a referral list of agencies and behavioral/mental health professional available to you should these feelings occur. If at any time you find a survey or an interview question to be stressful or upsetting, you can decline to answer that question and/or terminate your participation. If the researchers suspect any abuse, neglect, or exploitation, they are legally required to make a referral to the appropriate state or county agencies.

ARE THERE ANY BENEFITS TO ME?

There are no immediate benefits to you personally as a result of participating in this study. However, your participation will allow scientists to better understand some of the factors associated with care-recipient resistance during care assistance and how care-recipient resistance may influence the life and well-being of caregivers.

WHAT ARE THE ALTERNATIVES FOR PARTICIPATING IN THIS STUDY?

The alternative is to complete the follow-up survey only without participating in an individual interview. You can request a change in your participation by contacting the Principal Investigator, Yumi Shirai, at (520) 331-3448.

WILL THERE BE ANY COSTS TO ME?

There is no cost to you for participating, except your time.

WILL I BE PAID TO PARTICIPATE IN THE STUDY?

As compensation for your time, and to thank you for your participation, you will receive a \$30 check upon completion of the survey and the interview.

WILL VIDEO OR AUDIO RECORDINGS BE MADE OF ME DURING THE STUDY?

We will make an audio recording during the interview so that we can be certain that your responses are recorded accurately only if you check the box below:

- ☐ I give my permission for an audio recording to be made of me during my participation in this research study.
- ☐ I do not give my permission for an audio recording to be made of me during my participation in this research study.

WILL THE INFORMATION THAT IS OBTAINED FROM ME BE KEPT CONFIDENTIAL?

The only persons who will know that you participated in this study will be the research team members: the Principal Investigator (Yumi Shirai), her advisor (Dr. Susan Silverberg Koerner), and trained DUCS research assistants. Steps will be taken to ensure confidentiality: (a) no names will appear on the interview transcripts; (b) no names will appear on the surveys; (c) names will be replaced with ID numbers on all research material; and (d) a master list linking names with ID numbers will be secured in locked files with access restricted to the research team members. The results of this project may be published at a later date or presented at educational seminars and lectures; however, under no circumstances will any identifying information be used.

MAY I CHANGE MY MIND ABOUT PARTICIPATING?

Your participation is completely voluntary, and you are free to withdraw from the project at any time without causing bad feelings. You may choose to not answer some/any of the questions during the course of the study.

WHOM CAN I CONTACT FOR ADDITIONAL INFORMATION

You can obtain further information from the Principal Investigator, Yumi Shirai, Ph.D. candidate, at (520) 331-3448. If you have questions concerning your rights as a research subject, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. If you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator; or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office. If you would like contact the Human Subjects Protection Program via the web (this can be anonymous), please visit <http://www.irb.arizona.edu/contact/>.

YOUR SIGNATURE

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

Name (Printed)

Participant's Signature

Date signed

STATEMENT BY PERSON OBTAINING CONSENT

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

Name of study personnel

Study personnel Signature

Date signed

APPENDIX D: CR-RESISTANCE SCALE (ASSISTANCE WITH DAILY TASKS)

ASSISTANCE WITH DAILY TASKS

INSTRUCTIONS:

5. On the next few pages, we will be asking you whether you have assisted R with a variety of personal, household, and organizational tasks in the past 24 hours. Below is an example (with example responses) of the questions you will see on the next few pages. Please read this example carefully, and then complete the pages that follow thinking back to the past 24 hours.

EXAMPLE TASK	Did you assist R with this task in the <u>past 24 hours</u> ?	IF YES, please answer the questions to the right.	How many times ?	About how many minutes each time?	Was R resistant to your assistance?	How stressful was assisting for you? Circle: 0 = not at all 1 = a little 2 = somewhat 3 = very
Showering or bathing	Yes No	→			Yes No	0 1 2 3

TASK	Did you assist R with this task in the <u>past 24 hours</u> ?	IF YES, please answer the questions to the right.	How many times ?	About how many minutes each time?	Was R resistant to your assistance?	How stressful was assisting for you? Circle: 0 = not at all 1 = a little 2 = somewhat 3 = very
Showering or bathing	Yes No	→			Yes No	0 1 2 3
Dressing or undressing	Yes No	→			Yes No	0 1 2 3
Taking medications	Yes No	→			Yes No	0 1 2 3
Grooming (e.g., brushing teeth, shaving, washing face)	Yes No	→			Yes No	0 1 2 3
Grooming (e.g., brushing/combining hair; cutting /filing nails)	Yes No	→			Yes No	0 1 2 3
Getting in/out of bed, or on/off chair	Yes No	→			Yes No	0 1 2 3

TASK	Did you assist R with this task in the <u>past 24 hours</u> ?	IF YES, please answer the questions to the right.	How many times ?	About how many minutes each time?	Was R resistant to your assistance?	How stressful was assisting for you? Circle: 0 = not at all 1 = a little 2 = somewhat 3 = very
Feeding self	Yes No	→			Yes No	0 1 2 3
Using toilet (e.g., wiping, flushing) or changing diaper/pad	Yes No	→			Yes No	0 1 2 3
Cleaning after bowel or bladder accident	Yes No	→			Yes No	0 1 2 3
Walking around or using wheelchair	Yes No	→			Yes No	0 1 2 3
Preparing meal / food	Yes No	→			Yes No	0 1 2 3
Shopping for food, clothes, or other essentials	Yes No	→			Yes No	0 1 2 3

TASK	Did you assist R with this task in the <u>past 24 hours</u> ?	IF YES, please answer the questions to the right.	How many times ?	About how many minutes each time?	Was R resistant to your assistance?	How stressful was assisting for you? Circle: 0 = not at all 1 = a little 2 = somewhat 3 = very
Doing laundry	Yes No	→			Yes No	0 1 2 3
Housecleaning	Yes No	→			Yes No	0 1 2 3
Using telephone	Yes No	→			Yes No	0 1 2 3
Handling finances (e.g., writing check, Social Security, bank)	Yes No	→			Yes No	0 1 2 3
Handling health-related matters (e.g., doctor appointments, ordering medications, insurance)	Yes No	→			Yes No	0 1 2 3

TASK	Did you assist R with this task in the <u>past 24 hours</u> ?	IF YES, please answer the questions to the right.	How many times ?	About how many minutes each time?	Was R resistant to your assistance?	How stressful was assisting for you? Circle: 0 - not at all 1 = a little 2 = somewhat 3 = very
Transportation (driving R somewhere)	Yes No	→			Yes No	0 1 2 3
Arranging for in-home or out of home services	Yes No	→			Yes No	0 1 2 3
Supervising or checking up on service providers	Yes No	→			Yes No	0 1 2 3
Other:	Yes No	→			Yes No	0 1 2 3
Other:	Yes No	→			Yes No	0 1 2 3

APPENDIX E: DEPRESSIVE SYMPTOMS AND POSITIVE AFFECT SCALE

My Feelings

1. Using the following scale, indicate to what extent you have felt these emotions in the past 24 hours.

	Not at All	Just a Little	Somewhat	Very Much
I felt very critical of others.	1	2	3	4
I lacked enthusiasm for doing anything.	1	2	3	4
I became easily annoyed or irritated.	1	2	3	4
I felt bored or had little interest in things.	1	2	3	4
I had temper outbursts I couldn't control.	1	2	3	4
I cried easily or felt like crying.	1	2	3	4
I got angry over things that are not important.	1	2	3	4
I felt down-hearted or blue.	1	2	3	4
I felt tense or keyed up.	1	2	3	4
I felt slowed down or low in energy.	1	2	3	4
My feelings were hurt easily.	1	2	3	4

	Not at All	Just a Little	Somewhat	Very Much
I felt happy.	1	2	3	4
I felt strong.	1	2	3	4
I felt enjoyment or fun.	1	2	3	4
I felt alert.	1	2	3	4
I felt pleased.	1	2	3	4
I felt joyful.	1	2	3	4

APPENDIX F: CG FEELINGS OF BURDEN SCALE

Caregiving Ups and Downs

2. Please read each of the items listed below and indicate how much you felt that way in the past 24 hours.

<i><u>IN THE PAST 24 HOURS,</u></i> <i><u>HOW MUCH DID YOU FEEL...</u></i>	NOT at All	A Little	SOME- WHAT	VERY MUCH
...THAT BECAUSE OF THE TIME YOU SPENT WITH R YOU DIDN'T HAVE ENOUGH TIME FOR YOURSELF?	1	2	3	4
...PULLED BETWEEN CARING FOR R AND TRYING TO MEET OTHER RESPONSIBILITIES (WORK/FAMILY)?	1	2	3	4
...ANGRY WHEN YOU WERE AROUND R?	1	2	3	4
...THAT R AFFECTS YOUR RELATIONSHIP WITH FAMILY MEMBERS OR FRIENDS IN A NEGATIVE WAY?	1	2	3	4
...STRAINED WHEN YOU ARE AROUND R?	1	2	3	4
...THAT YOUR HEALTH SUFFERED BECAUSE OF YOUR INVOLVEMENT WITH R?	1	2	3	4
...THAT YOU DON'T HAVE AS MUCH PRIVACY AS YOU WOULD LIKE BECAUSE OF R?	1	2	3	4

<i>IN THE PAST 24 HOURS, HOW MUCH DID YOU FEEL...</i>	NOT AT ALL	A LITTLE	SOME- WHAT	VERY MUCH
...THAT YOUR SOCIAL LIFE SUFFERED BECAUSE YOU ARE CARING FOR R?	1	2	3	4
...THAT YOU HAVE LOST CONTROL OF YOUR LIFE SINCE R'S ILLNESS / DISABILITY?	1	2	3	4
...UNCERTAIN ABOUT WHAT TO DO ABOUT R?	1	2	3	4
...YOU SHOULD BE DOING MORE FOR R?	1	2	3	4
...YOU COULD DO A BETTER JOB IN CARING FOR R?	1	2	3	4

APPENDIX G: PHYSICAL HEALTH SYMPTOMS SCALE

PHYSICAL HEALTH

7. IN THE PAST 24 HOURS, DID YOU EXPERIENCE ANY OF THE FOLLOWING PHYSICAL SYMPTOMS? *CHECK (✓) ALL THAT APPLY.*

___ HEADACHE	___ HEART POUNDING
___ CONSTIPATION OR DIARRHEA	___ NAUSEA OR STOMACH ACHES
___ MUSCLE SORENESS	___ HOT OR COLD FLASHES
___ SHORTNESS OF BREATH	___ CONGESTION
___ TIGHTNESS IN CHEST	___ POOR APPETITE
___ TREMBLING OR SHAKING	___ SORE THROAT
___ BACKACHE	___ DIZZINESS
___ COLD OR FLU SYMPTOMS	___ OTHER:

APPENDIX H: FEELINGS OF BENEFITS/GAINS

MORE FEELINGS

3. Some caregivers experience positive feelings or reactions to caregiving. For others this is not the case. There are no "right" or "wrong" answers. Please indicate how much you felt each of the following in the **PAST 24 HOURS** as a result of providing help to your relative.

<i>"PROVIDING HELP TO MY RELATIVE..."</i>	Not at All	Just a Little	Somewhat	Very Much
made me feel more useful	1	2	3	4
made me feel good about myself	1	2	3	4
made me feel needed	1	2	3	4
made me feel important	1	2	3	4
made me feel strong and confident	1	2	3	4
gave more meaning to myself	1	2	3	4
enabled me to learn more skills	1	2	3	4
enabled me to develop a more positive attitude toward life	1	2	3	4
strengthened my relationship with my relative	1	2	3	4
gave me a sense of comfort	1	2	3	4

APPENDIX I: CG SENSE OF EFFICACY SCALE

CAREGIVING BELIEFS AND ATTITUDES

24. Let us know how much you agree or disagree with each of the

following statements.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I am usually certain about what to do in caring for R.	SD	D	A	SA
No matter what I do as a caregiver, it never seems to be enough.	SD	D	A	SA
In general, I am able to handle most problems in the care of R.	SD	D	A	SA
I am <i>not</i> doing as well as I would like as a caregiver.	SD	D	A	SA
I feel that I have a great deal of influence over the things that happen in caregiving.	SD	D	A	SA
I believe I am mastering most of the challenges in caregiving.	SD	D	A	SA
I have lost some control of my life since caring for R.	SD	D	A	SA

APPENDIX J: CG-CR RELATIONSHIP QUALITY BEFORE CAREGIVING

SCALE

RELATIONSHIP WITH YOUR RELATIVE BEFORE CAREGIVING

27. Think about the quality of your relationship with your relative BEFORE you got involved in his/her care. Read each statement and decide how well it described your relationship.

	Not at All	A Little	Somewhat	Very Much
I liked him/her.	1	2	3	4
I had a hard time being honest with him/her.	1	2	3	4
I enjoyed spending time with him/her.	1	2	3	4
I cared about his/her feelings.	1	2	3	4
I didn't get along with him/her very well.	1	2	3	4
I respected him/her.	1	2	3	4
I felt close to him/her.	1	2	3	4
I still loved him/her even when we argued or disagreed.	1	2	3	4
I felt tense or upset when I spent time with (or spoke to) him/her.	1	2	3	4
I openly showed affection toward him/her.	1	2	3	4


Relationship With Your Relative Before Caregiving (Continued)

	Not at All	A Little	Somewhat	Very Much
He/she liked me.	1	2	3	4
He/she had a hard time being honest with me.	1	2	3	4
He/she enjoyed spending time with me.	1	2	3	4
He/she cared about my feelings.	1	2	3	4
He/she didn't get along with me very well.	1	2	3	4
He/she respected me.	1	2	3	4
He/she felt close to me.	1	2	3	4
He/she still loved me even when we argued or disagreed.	1	2	3	4
He/she seemed to be tense or upset when he/she spent time with (or spoke to) me.	1	2	3	4
He/she openly showed affection toward me.	1	2	3	4


APPENDIX K: SOCIO-EMOTIONAL SUPPORT SCALE

FAMILY AND FRIENDS


25. Please read and respond to each of the following social support items.

	Not at All	A Little	Some-what	Very Much
How much do your family members (not including your spouse or partner) understand the way you feel about things?	1	2	3	4
How much do they really care about you?	1	2	3	4
How much can you rely on them if you have a serious problem?	1	2	3	4
How much can you open up to them if you need to talk about your worries?	1	2	3	4
	Never	Rarely	Some-times	Often
How often do your family members (not including your spouse or partner) criticize you?	1	2	3	4
How often do they make too many demands on you?	1	2	3	4
How often do they let you down when you are counting on them?	1	2	3	4
How often do they get on your nerves?	1	2	3	4

Family and Friends (Continued)

	Not at All	A Little	Some-what	A Lot
How much do your friends understand the way you feel about things?	1	2	3	4
How much do they really care about you?	1	2	3	4
How much can you rely on them if you have a serious problem?	1	2	3	4
How much can you open up to them if you need to talk about your worries?	1	2	3	4
	Never	Rarely	Some-times	Often
How often do your friends criticize you?	1	2	3	4
How often do they make too many demands on you?	1	2	3	4
How often do they let you down when you are counting on them?	1	2	3	4
How often do they get on your nerves?	1	2	3	4

Family and Friends (Continued)

If you have no spouse or partner, move to Question #26 on the next page.	Not at All	A Little	Some-what	A Lot
How much does your spouse/partner understand the way you feel about things?	1	2	3	4
How much does he/she really care about you?	1	2	3	4
How much can you rely on him/her if you have a serious problem?	1	2	3	4
How much can you open up to him/her if you need to talk about your worries?	1	2	3	4
	Never	Rarely	Some-times	Often
How often does your spouse/partner criticize you?	1	2	3	4
How often does he/she make too many demands on you?	1	2	3	4
How often does he/she let you down when you are counting on him/her?	1	2	3	4
How often does he/she get on your nerves?	1	2	3	4

APPENDIX L: FAMILY DISAGREEMENT REGARDING CARE

FAMILY DISAGREEMENTS

4. Below is a list of issues that family members sometimes disagree about. Indicate whether any of the following disagreements occurred between you and anyone in your family in the past 24 hours.

	Was there any disagreement in the past 24 hours?		If YES, how stressful was the disagreement for you? 1 = Not at all 2 = A little 3 = Somewhat 4 = Very			
What should (or should not) be done for your relative	Yes	No	1	2	3	4
How much (or how little) <u>they</u> are involved in your relative's care	Yes	No	1	2	3	4
The way you care for your relative	Yes	No	1	2	3	4

APPENDIX M: COMMUNITY/PROFESSIONAL SERVICE UTILIZATION

COMMUNITY SERVICES & ASSISTANCE

28. Please place a check mark (T) next to those services that you've
used in the past 12 months to assist in caregiving for your relative.

- ☐ Home-delivered meals (e.g., Meals-on-Wheels)
- ☐ Congregate meals
- ☐ Legal services
- ☐ Transportation (e.g., VanTran)
- ☐ Senior center activities (e.g., adult day care)
- ☐ Home health aide
- ☐ Visiting nurse services (in-home)
- ☐ Counseling
- ☐ Financial advice or financial planning
- ☐ Homemaker services (e.g., housecleaning)
- ☐ Shopping help
- ☐ Respite care
- ☐ Nursing care (visiting nurse services)
- ☐ Support groups
- ☐ Treatments or therapy (occupational, speech, physical, etc.)
- ☐ Companion / friendly visiting service
- ☐ Information and referral service
- ☐ Case management (case aide service)
- ☐ Other _____(describe)
- ☐ Other _____(describe)
- ☐ NONE, I haven't used any services

APPENDIX N: INTERVIEW QUESTION TOPICS

Daily Understanding of Caregiver Study: Follow-Up Study

Semi-Structured Interview Topics (CR-Resistance)

What kind of help does/**did** R need?

Has/**had** R ever resisted to your assistance?

When/where/how often does/**did** the caregiver (CG) experience care-recipient resistance (CR-resistance)?

****Give me a specific example****

****Could you describe what you mean by...?****

Behavior: How do/**did** you overcome resistance?

Response: How do/**did** you respond to his/her resistance?

Predict:

How much/often can/**could** the CG predict the occurrence of CR-resistance?

What does the CG think about why CR-resistance happens?

Prevent:

What has/**had** worked for preventing the CR-resistance?

Thinking back to times of CR-resistance, what does the CG think would work to prevent or lessen CR-resistance?

Emotion:

How stressful is/**was** CR-resistance to the CG?

What (which kind of resistance) bother(**ed**) you the least? Why?

What bother(**ed**) you the most?

Why?

How does/**did** the resistance make you feel?

How long does/**did** the feeling last?

How much does/**did** the feeling influence your life?

Has/**had** this CG experience of CR-resistance changed over time?

Does/**did** anybody help the CG to deal with the CR-resistance?

What kind of assistance/information does/**did** the CG think would help the CG to better deal with CR-resistance? **Any recommendation to other CGs?**

Although these questions will be the primary guides during the interview, participants will be allowed and encouraged to elaborate on their answers in order to gather rich insights into their specific experiences with CR-resistance.

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