

ABSTRACT

PATTERSON, TARYN ROSE: African Americans and the Alzheimer's Caregiving Experience: Differential Intervention Efficacy within the Stress Process Model of Caregiving. (Under the direction of Jason C. Allaire, Ph.D.)

Over 20 years of caregiver intervention research has generated significant, clinically relevant outcomes and effective strategies for helping dementia family caregivers to optimize their own health and well-being in order to allow the care-recipient to age-in-place (Burgio et al., 2001). The Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention was designed to address the dearth of interventions addressing the multi-dimensional needs of caregivers. More specifically, REACH consists of intervention elements that address many domains of caregiver need, but can also be tailored to the unique needs of each caregiver, without sacrificing intervention efficacy.

The purpose of the present investigation was twofold: First, to examine the outcomes of REACH in North Carolina. Second, the investigation examined intervention outcomes using a developmental stress-process model (SPM) of caregiving. More specifically, the analyses utilized NC REACH data to examine the role of age, race, and rurality as mechanisms influencing burden and depression within a proposed stress process model inclusive of objective stressors, resources, and appraisals.

Analyses revealed that the regional translation of the REACH intervention to North Carolina yielded significant treatment group differences, with the intervention group incurring greater benefits as compared to the comparison group. Hierarchical regression models further revealed that although age and rurality did not moderate intervention effectiveness, there was a significant Age x Race interaction. Follow-up simple slope analyses for the association between change in burden and age were tested and revealed that

change in burden was more strongly related to age for Black caregivers than for White caregivers; older Black caregivers experienced a significant decrease in burden as compared to older White caregivers.

Findings are important both programmatically and theoretically. It could be argued that the next step in bolstering intervention outcomes might be a focus on understanding how intervention effectiveness differs based on differences in lifespan processes in context, such as differences in appraisals in the caregiving context, or based on interactions among demographic variables, such as age and race. Understanding if theories of lifespan development play a role in the caregiving process, particularly within an intervention context, may shed light not only on possible real-world application of such theories, but also on understanding why intervention elements are or are not effective.

© Copyright 2015 by Taryn Rose Patterson

All Rights Reserved

African Americans and the Alzheimer's Caregiving Experience: Differential Intervention
Efficacy within the Stress Process Model of Caregiving

By
Taryn Rose Patterson

A dissertation submitted to the Graduate Faculty of
North Carolina State University
in partial fulfillment of the
requirements for the Degree of
Doctor of Philosophy

Psychology

Raleigh, North Carolina

2015

APPROVED BY:

Jason C. Allaire
Committee Chair

Shevaun D. Neupert

Thomas Hess

Lucille Bearon

DEDICATION

For my family: Mom, Dad, Keith, Nana, and Gramps, all of whom have been caregivers in the best of times, and worst of times, and all the times in between.

I couldn't have done it without you.

BIOGRAPHY

“The best thing for being sad, replied Merlyn, is to learn something.

That’s the only thing that never fails.

You may grow old and trembling in your anatomies, you may lie awake at night listening to the disorder of your veins, you may miss your only love, you may see the world about you devastated by evil lunatics, or know your honour trampled in the sewers of baser minds.

There is only one thing for it then — to learn.

Learn why the world wags and what wags it.

That is the only thing which the mind can never exhaust, never alienate, never be tortured by, never fear or distrust, and never dream of regretting.

Learning is the only thing for you.

Look what a lot of things there are to learn!”

~The Once and Future King, T.H. White

ACKNOWLEDGEMENTS

It would be remiss of me not to acknowledge my first mentors, Marv Daehler, Sue Whitbourne, Tae Hart, and Mika Varma. You all gave me the foundation I needed to learn, make mistakes, grow, change course, and land on my feet, even stronger than when I first began.

I am indebted to my NC family: My ‘frens’ Tbelle and Gildy Lou, who are patient, kind, and searingly funny (Ellis Hotel 4 Eva); Dizz and Cary for Candlelight Confessions™ and all the laughs; Roo for her brilliant sense of humor, general brilliance, and domain-specific intelligence; Cbelles for her Type A-ness and spreadsheets that served as a colorful roadmap to fun; Dan for being a constant source of support, shenanigans, puns, and bandanas; Mams and D for summertime porch dinners and embracing me as a third wheel; and Seb for bike rides and day drinks and Bocce and Phish, for trips to Asheville with the gang, and all that other culture and humor that got me through. I learned so much from you all.

For my DAAS family: Sarah, Audrey, Heather and everyone else - Thank you for giving me the platform to apply my passions and skillset to the “real world”. I was so lucky to have landed there so many years ago. Additionally, thank you to financial and programmatic support via the Administration on Aging ADSSP Evidence-Based grant (90AE0325) without which I would not have been able to complete a dissertation and afford to eat.

To my new CFAR family: Felita, Linda, Natasha, Adrienne, Robyn, and Alisha. Thanks for the laughs, and incredible intelligence and passion I get to witness every day. You all have no idea how much I appreciate you.

To my committee: Jason Allaire, for always effectively sandwiching negative feedback between two positives, Shevaun Neupert for her positivity and thoughtful attention to detail, and Tom Hess, voice of reason's voice of reason. To Luci Bearon – thank you for understanding me when I didn't understand myself, for encouraging grounded creativity and non-linearity, and for your patience and unwavering enthusiasm along the entire journey.

And first and foremost for my family: To Jaime, Katie, Sarah, and Mollie for always being there for me when I need it most, and having patience with me when I withdraw into hibernation mode. For Keith and my favorite rugrats for reminding me what is really important in life. For Nana and Gramps. There's no amount of gratitude or musings that can be put on a page to cover how I feel about you. *Vi voglio bene. Voi fanno girare il mondo!* And for Mom and Dad, for letting me “do what I want” and always believing in my choices (even if they made you nervous). You are my best friends and I am so lucky.

TABLE OF CONTENTS

	Page
LIST OF TABLES	vii
LIST OF FIGURES	viii
Introduction	1
Review of the Literature	3
<i>Extant Caregiving Interventions</i>	3
Overview of the REACH intervention	4
Differential Success in Caregiving Interventions	6
Theoretical Approaches to Studying the Caregiving Context	7
<i>Stress Process Models of Caregiving</i>	7
Adult Developmental Theory and the Lifespan Perspective	10
Variables of Interest That Impact the Caregiving Experience	12
<i>Age</i>	12
<i>Race and Ethnicity</i>	13
<i>Rurality</i>	15
<i>Objective Stressors</i>	17
<i>Subjective Appraisals</i>	18
<i>Stress Appraisal</i>	18
<i>Health Appraisal</i>	20
<i>Perceived Social Support</i>	21
Summary	23
Research Questions	24
Method	27
Regional Translation of the REACH Intervention	27
Participants	28
Procedure	29
Measures	32
Results	37
Discussion	54
Limitations	59
Conclusions and Future Directions	61
References	62
Appendix	80
Appendix A: Detailed Overview of the REACH Intervention	81

LIST OF TABLES

	Page
Table 1. <i>Descriptive Statistics for NC REACH Intervention and Comparison Groups.</i>	32
Table 2. <i>Intercorrelations among Study Variables</i>	40
Table 3. <i>Two-Way Analysis of Variance Summary for Aim 1.....</i>	43
Table 4. <i>Caregiver and Care Recipient Characteristics for Study Variables</i>	44
Table 5. <i>Hierarchical Regression Model Predicting Change in Burden..... and Depression.</i>	51

LIST OF FIGURES

	Page
<i>Figure 1.</i> A Conceptual Model of Caregiver Stress (Pearlin, Mullan, Semple, & Skaff, 1990).	8
<i>Figure 2.</i> Proposed Stress-Process Model of Caregiving	10
<i>Figure 3.</i> Significant Change in Burden Depending on Intervention Group.....	43
<i>Figure 4.</i> Age x Race Interaction on Burden	50
<i>Figure 5.</i> North Carolina Counties with Persons Aged 0-17 as Compared to Persons Aged 60 and Older.	84
<i>Figure 6.</i> North Carolina Counties Currently Offering REACH	89

Introduction

An estimated 52 million caregivers, or 19% of the U.S. adult population, provide unpaid care to family and friends aged 18 years and older over the course of a year (Coughlin, 2010), with 14.9 million caring for an older adult with Alzheimer's Disease (AD) or related dementia (Alzheimer's Association Facts and Figures, 2012). The annual economic value of informal caregiving was estimated at \$450 billion in 2011 (The Economic Value of Family Caregiving, AARP Public Policy Institute, 2012), up from \$375 billion for 2007 (Houser & Gibson, 2008). The value of unpaid caregivers will likely continue to be the largest source of long-term care services in the U.S., and the aging population 65+ will more than double between the years 2000 and 2030, increasing to 71.5 million from 35.1 million in 2000 (Coughlin, 2010).

A large body of evidence exists regarding the health impacts incurred by assuming the role of a primary caregiver (Gitlin et al., 2003; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Beach, 1999). These findings in turn have generated intervention studies aimed at addressing the burden, distress, and health-related morbidity associated with caregiving. Recent trends within this area of research are aimed at innovations and interventions to divert long-term care expenditures, mainly by keeping individuals in their homes as long as possible. Over 20 years of caregiver intervention research has generated significant, clinically relevant outcomes and effective strategies for helping dementia family caregivers to optimize their own health and well-being in order to allow the care-recipient to age-in-place (Burgio et al., 2001). Evidence-based interventions have proven effective in mitigating issues such as caregiver depression, stress, family conflict and isolation,

reducing care-related illness, improving satisfaction with social supports, enhancing daily coping skills and delaying institutionalization without overburdening family members (Schulz et al., 2000; Burgio, Stevens, Guy, Roth, & Haley, 2003; Ducharme, Levesque, Giroux, & Lachance (2005); Schulz, Martire, & Klinger, 2005; Belle, Burgio et al., 2006; Mittleman, Hailey, Clay, & Roth, 2006).

However, there has been criticism that many family caregiver interventions are limited to a single-problem focus rather than the complex interplay of stress, depression, health risk and burden, and further, that many of the intervention studies lack scientific rigor (Belle et al. 2006). The overriding message is that caregiving presents multiple challenges that are not easily addressed. Due to the diversity of challenges inherent in the caregiving situation, interventions need to allow for some degree of tailoring of intervention components to meet the specific needs of the individual. Along the same lines, little attention has been paid to the role that lifespan theory, more specifically adult developmental theory, could play in evaluating and improving intervention outcomes. Applying what is known about socioemotional development (Carstensen, 1992; Carstensen, Fung, & Charles, 2003), social support, and appraisals across the lifespan (Okun & Keith, 1998; Ryff, Singer, & Palmersheim, 2004b; Seeman, Lusignolo, Albert, & Berkman, 2001; Uchino, Cacioppo, & Kiecolt-Glaser, 1996) may bolster efficacy by either providing a framework that capitalizes on age-related tendencies, or educates about the pitfalls of such tendencies within the caregiving context.

In North Carolina specifically, AD is the fifth leading cause of death (NC State Center for Health Statistics, 2011, leading causes of death by age group). Unlike some of the other causes of death, which have a relatively short course, dementia produces

progressive disability, often over a period of 10 years. The number of older North Carolinians with AD is projected to increase from 170,000 in 2010 to 210,000 in 2025. In 2010 alone, an estimated 430,000 AD and dementia caregivers provided more than 490 million hours of unpaid care in NC (North Carolina Alzheimer's Association, 2012). This would be equivalent to approximately 6 billion dollars in AD care in North Carolina in 2010 had it not been performed by an unpaid caregiver. The present investigation intends to examine if objective stressors, appraisals, and resources within the caregiving context vary by age and rurality. A greater theoretical understanding of how individuals react to the caregiving context, as well as how the caregiving experience may differentially impact individuals across the lifespan, has the potential to inform or modify interventions in order to address changing needs across the lifespan.

Review of the Literature

Extant Caregiving Interventions

Caregiver interventions can generally be divided into two major groups: (a) those aimed at reducing the objective amount of care provided by caregivers (respite, interventions to enhance the competence of the care receiver) and (b) those aimed at improving the caregiver's well-being and coping skills (e.g., psychoeducational interventions, support groups). Knight and colleagues (1993) suggested that a one-size-fits-all approach to assisting caregivers may not be useful because caregivers have vastly different needs. The Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention was designed to address this dearth of interventions addressing the multi-dimensional needs of caregivers. More specifically, REACH consists of intervention

elements that address many domains of caregiver need, but can also be tailored to the unique needs of each caregiver, without sacrificing intervention efficacy.

Such education and training programs strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques (Toseland & Smith, 2001). Studies assessing the effectiveness of skills training have produced equivocal and, at times, contradictory results. However, teaching specific caregiver skills that are clearly operationalized, practiced, and used to resolve real-life problems have been found to produce significant changes in outcome measures directly related to those skills (Bourgeois, Schulz, & Burgio, 1996; Gallagher-Thompson et al., 2000).

Overall, programs that offer a combination of counseling, support, and education services have been found to be especially effective. Mittelman, Ferris, Shulman, Steinberg, and Levin (1996) looked at the long-term effectiveness of a comprehensive support and counseling program for spouses and family members of patients with AD in postponing or preventing nursing home placement. The researchers found that a program of counseling and support not only can help prevent increased caregiver depression, but it can also substantially increase by up to 326 days over a 3 ½ year period the time spouses are able to care for Alzheimer's patients at home (as compared to the control group), particularly during the early and middle stages of dementia. The latter finding was particularly true for caregiving husbands.

Overview of the REACH Intervention

REACH I, a multi-site feasibility study launched in 1995, explored the effectiveness of different group-based interventions to reduce the burden and distress of

dementia caregivers in six participating sites: Birmingham, Alabama; Boston, Massachusetts; Memphis, Tennessee; Miami, Florida; Palo Alto, California; and Philadelphia, Pennsylvania. The interventions implemented across the six sites included: (a) Individual information and support strategies, (b) group support and family systems therapy, (c) psychoeducational and skill-based training approaches, (d) home-based environmental interventions, and (e) enhanced technology support systems. A unique aspect of the REACH intervention is that it is inclusive of a lifespan sample of individuals, both familial and non-familial (e.g. spouse, grandchild, niece/nephew, sibling, neighbor).

Built upon the findings of REACH I, REACH II was funded in 2001 to refine and test a multi-component psychosocial behavioral intervention to reduce burden and depression among caregivers of people with dementia conducted with the original six REACH I sites (for additional details regarding the REACH II intervention please see Belle et al., 2006; Elliott, Burgio, & DeCoster, 2010). The main objective of the REACH intervention is to address five potential areas of risk in caregiving: 1) Safety, 2) Social Support, 3) Problem Behaviors 4) Emotional Well-being, and 5) Self-Care and Preventive Health Behaviors. The intervention process involved a multi-step, person-centered approach, that begins with a pre-assessment of the caregiver and the caregiving context via a risk assessment tool. The interventionists, along with the caregiver, prioritized risk areas of greatest concern, and jointly addressed the risk across multiple domains. The intervention was based on a risk-appraisal approach in which five areas of risk – depression, burden, self-care, social support, and patient problem behaviors – are deemed central to the caregiver’s well-being and quality of life.

Such an approach allows for greater flexibility in addressing individual needs within the caregiving context (i.e. caregivers who have minimal problems with depression, but have substantial issues with safety of the care-recipient). They will receive only a small dose of the intervention component designed to enhance emotional well-being, paired with extensive training in how to make their living situation safer for the care recipient.

Differential Success in Caregiver Interventions

Upon review it is apparent that caregiving interventions differ in nearly all aspects, including recruitment procedures, targeted populations, targeted outcomes, and theoretical focus. Given these differences, evidence shows that the effects of interventions for caregivers are only small to moderate in size (Knight et al. 1993; Pinquart & Sorensen, 2006). More specifically, the same intervention can yield very different effect sizes depending on if it is administered in a group setting or an individual setting, and if the length of the intervention is greater or fewer than 8 weeks, with one-on-one interventions lasting longer than 8 weeks yielding the highest effect sizes. Effect sizes decrease even further when broken down by demographics. For example younger caregivers have smaller intervention effect sizes than older caregivers do, as do spousal caregivers and Alzheimer's caregivers. The fact that current interventions are not as effective for younger caregivers is particularly concerning given the fact that trends in the estimated number of younger adults caring for an older relative has been steadily increasing. If such a trend continues, care recipients in the near future will be even older than they are now, and caregivers will be younger (Levine, Hunt, Halper, Hart, Lautz, & Gould, 2005).

It has been suggested that in order to improve differential intervention outcomes and to generalize to diverse populations, caregiver interventions should be multidimensional, flexible (i.e. consumer-directed), and theory-based. This would allow for the identification of underlying mechanisms, such as family dynamics or age differences in appraisal, which more fully explain intervention outcomes, thus elucidating potential pathways to target and ultimately improve outcomes. Such an approach was utilized in the Miami site of the REACH I intervention. This site utilized family systems theory to tailor the intervention toward the family as the unit of analysis, and this approach lowered overall distress and burden throughout the intervention (Eisdorfer et al., 2003). Such a theoretical approach was relevant for that region specifically due to the emphasis placed on the family unit by Hispanic and Latino populations.

Theoretical Approach to Studying the Caregiving Context

The Stress Process Model

Aside from the focus on clinical health outcomes, models of stress reactivity and coping are a predominant theoretical focus of caregiving interventions (Lazarus & Folman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). These models attend to individual differences in reactivity to the caregiving context, and identifying successful coping styles for optimal health outcomes.

One of the most widely used models of stress processes within the caregiving context is the Caregiver Stress Process Model (SPM) proposed by Pearlin and colleagues (1990). The fundamental concepts that comprise four main domains include: The background and context of the stress (i.e. socio-economic characteristics, caregiving history, family composition, etc.), primary and secondary stressors (i.e. cognitive status

of caregiver, behaviors of care recipient, ADL/IADL dependency of care recipient, available resources, etc.), the mediators of stress (e.g. coping), and the outcomes (See Figure 1).

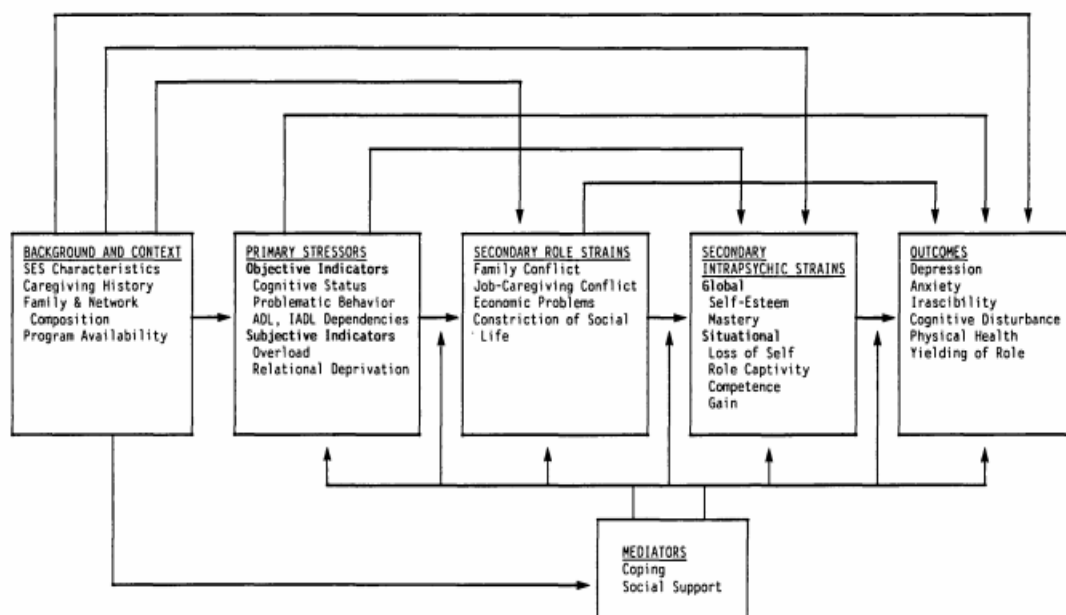


Figure 1. A conceptual model of Alzheimer's caregiver stress (Pearlin et al., 1990).

A few studies have examined portions of the Pearlin SPM as predictors of important caregiver outcomes such as health, emotional wellbeing, and desire to institutionalize (DTI) the care recipient. Dilworth-Anderson and Colleagues (2004) used the Pearlin model to guide their examination of the direct effects of background characteristics and stressors and the direct and mediating effects of resources (e.g. cultural justifications for caregiving, such as indicating that you are giving care because "It is my duty to provide care", "I was raised to believe care should be provided in the family", "It is what my people have always done", etc.) on psychosocial health and physical functioning. Hierarchical regression equations were used to analyze the psychosocial and physical functioning of the caregivers, and revealed that cultural

justifications for caregiving had a curvilinear effect on psychosocial health, with very weak and very strong cultural justifications for caregiving being predictive of poor psychosocial health.

Similarly, Hilgeman and colleagues (2009) utilized structural equation modeling to examine the overall Pearlin model fit, and built on the original model to include an examination of race or ethnicity. This is the only study to date that has tested the model in its entirety using secondary data drawn from the baseline assessment for the national REACH II (2004-2006) data. The researchers' analyses revealed that the original Pearlin model produced a satisfactory fit across race or ethnicity in the REACH II data, despite significant racial differences in each of the latent constructs. They found that race/ethnicity moderated the impact of resources on intrapsychic strain, defined as the infringement of the caregiving role into the caregiver's ability to maintain a sense of personal identity. Specifically, caregivers reported similar intrapsychic strain across race at lower levels of resources, but White caregivers reported more intrapsychic strain than Black or Hispanic/Latino caregivers when resources are higher.

The present study intends to examine age and rurality as potential moderating variables within a proposed adult developmental SPM (See Figure 2) based on the model by Pearlin and colleagues (1990), particularly with regard to how age and rurality might interact with objective stressors, resources, and appraisals to impact intervention outcomes.

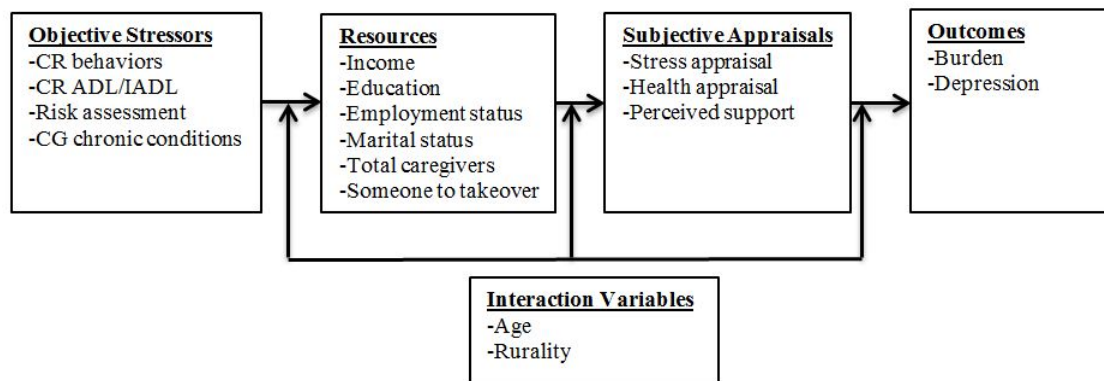


Figure 2. Proposed adult developmental stress process model of caregiving based on Pearlin and Colleagues' (1990) model.

Adult Developmental Theory and the Lifespan Perspective

Utilizing a lifespan developmental approach to examine caregiving outcomes revolves around the idea that development is life-long, is dependent on history and context, and is multidimensional and directional (Baltes, 1987). This perspective takes into account the fact that the caregiver experience is a dynamic process involving both gains and losses throughout the lifespan (Baltes, Staudinger, & Lindenberger, 1999). Depending on age, we might observe caregivers maximizing benefits or minimizing loss in domains of relative importance to them at that stage in their life. What is inherent in this is that the caregiving context might impact current and future developmental trajectories.

A lifespan perspective provides a framework for the study of constancy and change in caregiving behavior. The caregiving context provides a domain in which to examine the tenets of development across the lifespan, including the fact that development is a lifelong, multi-dimensional, and multidirectional process. Based on the pioneering work by Baltes, Reese, and Lipsitt (1980) on the influences on human development, the caregiving context could arguably cause intraindividual variability in

various developmental constructs based on whether or not it is considered an age-graded, history-graded, or a non-normative event. It can be argued that caregivers may gain new adaptive capacities at the expense of previous skills, capacities, behaviors or beliefs (Baltes, 1987). For example, many caregivers have difficulty asking for assistance from others, and taking time for themselves. In learning to do so, a caregiver's sense of self and identity may be challenged and redefined (Roberto & Jarrott, 2008).

Lastly, individuals have a capacity for differential behavior in response to different situations, including the diverse tasks and responsibilities one faces as a caregiver. Hilgeman, Allen, DeCoster, and Burgio (2007) found that there are limits on individuals' capacity for change. Analysis using the national REACH II data demonstrated that middle-aged and older caregivers who positively appraised the caregiving experience benefited to a greater extent from the intervention, but only daily levels of burden affected their tendency to find enjoyment in caregiving.

To date there has been no examination of rurality within the context of the SPM, which is arguably a factor with regard to resource access, specifically with regard to North Carolina. This specific variable was shown to significantly moderate program efficacy in the national REACH II demonstration, with intervention effectiveness being greater for urban caregivers as compared to rural caregivers, but only for burden (Burgio, et al., 2009), so it will be re-examined with the North Carolina translation REACH data as a potential moderator within the SPM.

Variables That Can Impact the Caregiving Experience

Age

According to lifespan developmental theory, a person's history affects his or her development (Baltes, Lindenberger, & Staudinger, 1998). Given that the most common desire is to remain in one's home into old age, to age in place, it is not surprising that the family unit can be considered the "backbone" of provisions of care (Wolf & Kasper, 2006).

Previous research has investigated the impact of both care recipient and caregiver age on caregiving outcomes, such as burden, depression, and health (Belle et al., 2006; Burgio et al., 2009; Schulz, Czaja, Lustig, Zdaniuk, Matire, & Perdomo, 2009). Some research has shown that caregiver age is negatively related to caregiver well-being (Rinaldi et al. 2005; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006), where advanced age of the caregiver is related to higher levels of depression and stress of the caregiver. This appears to hold true for midlife caregivers as well, with research by Covinsky and colleagues (2003) revealing that midlife dementia caregivers have higher rates of depression than their older counterparts. Other research, however, have noted that psychosocial development in middle adulthood is often marked by very positive processes, including reports of generativity in caregiving responsibilities (Peterson, 2002), meaning individuals, often women, report a greater impulse to reciprocate or fulfill a social responsibility. Therefore, they may report less caregiver burden. There is some research that shows the relationship between age and burden may depend on race, with White caregivers showing a positive relationship between age and burden and African-Americans showing a negative relationship (Cox, 1993; Lawton, Rajagopal,

Brody, & Kleban, 1992). A meta-analysis by Sorensen, Pinquart, and Duberstein (2002) concluded that interventions with older caregivers yielded greater improvements in the areas of burden, subjective well-being, ability/knowledge, and management of care-recipient symptoms than those with younger caregivers.

Race and Ethnicity

Racial and ethnic differences in the caregiving process have been well documented in the literature. The family caregiving literature consistently reports differences in burden between white and ethnic minority caregivers, with white caregivers typically reporting greater burden than other family minority groups (Adams, Aranda, Kemp, & Takagi, 2002). Potential explanations offered for these differences in the level of perceived burden include stronger feelings of family obligation and greater acceptance of the family of the care-giving situation among minority family members (Aranda & Knight, 1997; Connell & Gibson, 1997).

In a meta-analysis of caregiving research, Dilworth-Anderson, Williams, and Gibson (2002) found that African Americans' cultural beliefs helped explain caregiver health outcomes over 2 years; specifically, they found that higher levels of mastery were associated with poor health outcomes, a finding they attributed to African-American culture or socialization. For example, Whites were more likely than African-American to utilize only immediate family in caregiving and received more social services. Furthermore, African Americans had more members in their caregiving networks, were more likely to include friends and neighbors as resources, and were more likely to share caregiving responsibilities than were whites. African-American caregivers were also less likely to utilize formal supports than their white counterparts (Miller & Guo, 2000).

Similarly, Feld, Dunkle, and Schroepfer (2004) studied the support networks of black and white caregivers. Within both groups of caregivers, the presence of formal support was rare. However, black caregivers who relied solely on informal support were more likely to include members other than a spouse in their support network than white caregivers. The authors tied their findings to the presence of a more communal orientation within black communities, which may lead to lower levels of caregiver burden and depression among black compared to white caregivers (Pinquart & Sorensen, 2005).

The national REACH intervention found that behavior management skills training with care-recipients and problem-solving training with caregivers (Coon, Schulz, & Ory, 1999) resulted in a lower frequency of care recipient behavioral problems, reduced caregiver stress appraisals, and increased caregiver leisure activities. However, there was some evidence that interventions had differential impacts by race. African-American caregivers showed the greatest reductions in stressfulness appraisal following behavioral skills training, while white caregivers showed greater improvement after receiving only educational support. The REACH II intervention has been shown to improve caregiver quality of life for White, Hispanic, and African-American caregivers, however improvement for African-Americans was only observed for spousal caregivers (Belle et al., 2006).

Overall, there are similar negative effects of caregiving on different ethnic and racial groups, however there is a large amount of variance within dimensions of stress and coping models. For example, with regard to depression and burden, whites have been shown to report higher levels as compared to African-Americans, yet lower levels as

compared to Hispanic and Asian-American caregivers (Pinquart & Sorensen, 2005). With regard to physical health, whites fare much better than ethnic minorities in the caregiving context. Of course an obvious unresolved issue is whether or not this is specific to the caregiving context, or if it is reflective of health disparities between whites and ethnic minorities as a whole (Knight et al., 2007; Kim & Knight, 2008).

An additional difference among populations that could be largely explanatory of the aforementioned outcomes could be coping style. Ethnic minority caregivers tend to rely on cognitive and emotion-focused coping strategies more than whites, and factor structures for widely used assessments of coping may be variant across populations (Knight et al., 2007; Kim & Knight, 2008; Knight & Sayegh, 2010; Pinquart & Sorensen, 2005). Knight and Sayegh (2010) found that although the factor structure for the COPE and Brief COPE were invariant across white and African-American caregivers, there were in fact differences for Korean-Americans in that their factor structure included social support and acceptance factors, and no avoidant coping factor.

In general, results suggest that further work attending to the special needs of minority caregivers is important, particularly with regard to the differential impact of intervention elements depending on relationship to care recipient, coping styles, and ethnic and cultural preferences that can impact outcomes (Burgio et al., 2003; Knight & Sayegh, 2010).

Rurality

Another important factor to more fully understand within the caregiving context is the extent to which living in a rural versus urban area might impact intervention outcomes. Living in a rural area, termed “rurality” in the present study, can be associated

with poorer health, decreased access to community-based programs, health professionals, transportation, and mental health resources, as well as greater physical distance between available resources and social support outlets (Chwalisz, Buckwalter, & Talley, 2011; Coward, Kukulka, & Galliher, 1994).

Pearlin et al. (1990) noted that “virtually everything we are interested in learning about caregiving and its consequences is potentially influenced by key characteristics of the caregiver, we also consider access to and use of resources and programs as important contextual elements of the stress process” (pp. 585, 586). It can therefore be argued that the stress process of rural caregivers may be exacerbated by the aforementioned factors, and should be examined with the context of the SPM.

Research has revealed many challenges that rural caregivers could potentially face as compared to urban caregivers, with interventions yielding differential outcomes within domains of mental and physical health, and service and support utilization (Castro et al., 2007). Such findings have included poorer subjective health and subjective perceptions of stress (Davis, Gilliss, & Harper, 2011), and greater use informal supports by rural caregivers and care recipients than those in urban areas (Bedard, Koivuranta, & Stuckey, 2004; Coward, Cutler, & Mullins, 1990). Findings have also indicated that burden is positively associated with depression among rural caregivers (Butler et al., 2005; Rose et al., 2007). However, positive aspects of rural caregiving have also been observed, and this includes more positive appraisal of informal support networks as well as greater benefit-finding (Bishop, Martin, & Poon, 2006; Butcher, Holkup & Buckwalter, 2001; Litwin & Shiovitz-Ezra, 2006; Pinguart & Sorensen, 2000).

According to the 2010 U.S. Census Bureau's urban-rural classification, North Carolina is considered a rural state as compared to the rest of the United States, with approximately 30% of the population living in rural areas as compared to approximately 20% being the national average. As younger adults migrate to work and live along interstate highway corridors, this leaves many rural areas with increasingly elderly populations. These counties may experience a shrinking tax base which impacts resources, and access to services is further limited by the cost and reduced availability of transportation, whether they travel to the service or it is delivered to them (North Carolina Rural Economic Development Center, 2011).

When translating evidence-based programs to a regional population, it is important to examine how the unique demographic profile of the study population might impact intervention outcomes, particularly with regard to translation of programs that benefit individuals with AD. It will be important to examine rurality within the proposed SPM, given the fact that it has been shown to impact access to resources, utilization of supports, as well as perceptions of health and social support.

Objective Stressors

Objective, or primary, stressors tend to vary depending on the caregiving context and have been examined in many proposed models of the stress process (Hilgeman et al., 2009; Pearlin et al., 1990; Yates, Tennstedt, & Change, 1999). For the purposes of the current study, objective stressors are defined as measurable aspects of the caregiving context, such as counts and frequencies, and can include such things as the cognitive status of the care recipient, care recipient behaviors, and the number of activities, both daily (ADLs) and instrumental (IADLs), for which the care recipient is dependent on the

caregiver (Katz et al., 1963; Lawton & Brody, 1969). As noted, such stressors as are typically considered objective because they are based on measureable aspects of the care recipient, such as health, behavioral, and functional capabilities. Furthermore, from this kind of information inferences can be drawn to identify specific needs and possible solutions for both the caregiver and care recipient.

Objective stressors are an important element to include within a holistic examination of the caregiving context because they can exert both direct and indirect effects on caregiver outcomes. Objective stressors can be directly related to caregiver depression (Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999), and burden (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008), as well as moderated by additional factors such as perceived social support, stress appraisal, and resources (Pearlin et al., 1990; Hilgeman et al., 2009; Sun, Ong, & Burnette, 2012).

Subjective Appraisals

Stress Appraisal

Pinquart and Sörensen (2005) posit that not only is it important to consider the objective care recipient behaviors that are present, but the caregiver subjective appraisal of the behaviors as well. They found that higher levels of burden and stress appraisal are associated with worse mental and physical health outcomes. Similar findings reported by Schulz and Beach (1999) evidenced a higher risk of mortality for caregivers who appraised caregiving as stressful, as compared to non-caregivers and caregivers who did not report caregiving as stressful. Caregiver interventions have been shown to be successful at reducing negative appraisals of care recipient behaviors, even when the behavior is not itself reduced (Mittelman, Roth, Haley, & Zarot, 2004). Subjective

appraisals are highly predictive of caregiver emotional and physical health outcomes, and may have even greater predictive power than their objective counterparts (Gallagher-Thompson & Powers, 1997; Sun, Hilgeman, Durkin, Allen, & Burgio, 2009); there is little research, however, on the relationship between age and appraisal, specifically within the caregiving context and the SPM.

Drawing from the socioemotional selectivity theory (SST) as a framework, it could be hypothesized that older adults will evaluate their stress in a “less negative” light as compared to younger adults. The Strength and Vulnerability Integration (SAVI; Charles, 2010) model of emotional well-being in adulthood may predict a different age-related pattern of appraisal. The SAVI model posits that emotion regulation strategies in old age serve to avoid or limit exposure to negative stimuli, thus incurring greater emotional well-being. In situations that elicit high levels of sustained emotional arousal, however, there is greater age-related vulnerability. Drawing from the SAVI model, it could be hypothesized that due to the chronic nature of the caregiving context, older adults may actually have more negative appraisals.

There is some evidence of the aforementioned patterns in the stress reactivity and appraisal literature. Luong and Charles (2014) found that older adults reported less affective reactivity to interpersonal tensions than younger individuals, mainly due to differential endorsement of goals, less threatening appraisals, and more effective emotion regulation strategies. Throughout a controlled, lab-based, interpersonal stressor task, older adults generally exhibited less physiological reactivity to the task, and more pronounced positive and negative affect recovery following the task, than did younger adults. Older adults also appraised the task as more enjoyable, and more strongly

endorsed goals to perform well on the task, which mediated age differences in negative affect reactivity.

Similarly, the literature on daily hassles generally demonstrates that older adults appraise daily hassles less negatively and their affective reactivity to daily stressors is reduced when compared to younger adults (Charles & Almeida, 2007; Wrzus, Luong, Wagner, & Riediger 2014). This research, however, revealed that there are numerous factors that moderate this relationship, including situations of chronic stress rather than acute stress, feelings of personal control over the situation, as well as the type of stressor (chronic vs. acute, interpersonal vs. workplace, etc.). One way in which aging may affect emotional experience and reactivity is via changes in normative demands, phase-specific roles and developmental tasks (Almeida & Horn, 2004). These shifting demands and roles create different life contexts that can, in turn, buffer negative reactivity or reduce age-related differences in reactivity and appraisal.

Overall, the caregiving role provides an interesting context in which to examine lifespan patterns of stress appraisal. Most research has utilized predominantly White populations, and focused on acute stressors within an interpersonal domain. The present study intends to examine the role of appraisal in the stress process model of caregiving utilizing a sample of White and African-American Alzheimer's caregivers comprised of middle- and older-adults.

Health Appraisal

Health appraisal can be defined as an individual's subjective measure of his or her own health based on their perceptions. Physical health can play a critical role in determining the adaptive capacities available to individuals, which could arguably vary

across the lifespan depending on age (Bauer & Okun, 1986). Research comparing objective indicators of health and subjective appraisals, however, often show that discrepancies arise between the two (Hall, Chipperfield, Perry, Ruthig, & Goetz, 2006) particularly as individuals age, with older individuals tending to rate health more optimistically than younger individuals (Ferraro, 1980; Maddox & Douglas, 1973; Murray, Dunn, & Tarnopolsky, 1982; Stoller, 1984). Some argue that this discrepancy may reflect successful adaptation in the face of illness or disability (Rowe & Kahn, 1998).

Researchers have shown that, after controlling for objective health measures, self-rated health predicts mortality, with individuals who rate their health as poor having a greater risk of dying as those who rate their health as good or excellent (Idler & Benyamini, 1997; Idler & Benyamini, 1999). Furthermore, since poor health appraisal is arguably a source of stress, and given the fact that caregivers perceive themselves as less healthy than non-caregivers (Grafstrom et al., 1992), it is important to include health appraisal in models of caregiver stress, particular as a subjective appraisal.

Perceived social support

Due to the strength of the underlying theoretical literature that examines the relative importance of social ties and connectedness across the lifespan, as well as the obvious relevance between social ties and the caregiving context, perceived social support is an ideal domain to include in an adult development SPM of caregiving. Furthermore, similar to the domain of health and health appraisal, social support arguably has both objective and subjective aspects, and it is important to identify when

discrepancies may arise as such discrepancies may differentially impact intervention outcomes.

Numerous theoretical perspectives on social functioning across the lifespan lend themselves nicely to the present investigation. In particular, the understanding that as individuals age, there tends to be a decrease in number of social ties, yet increase in stability and centrality of these ties (Antonucci et al., 2001; Carstensen, 1992; Lang, 2001; Lang & Carstensen, 1994). Social relations and support have also been shown to foster a sense of efficacy within some contexts, which can then impact health and well-being (Antonucci & Jackson, 1987). Similarly, social support has been identified as a key element of perceived self-efficacy in the minority caregiving literature (Haley, et al., 1996; Kaufman, Kosberg, Leeper, & Tang, 2010; Kraemer, Wilson, Fairburn, & Agrad, 2002; Roth, Mittleman, Clay, Madan, & Haley, 2005).

Additionally, researchers have examined the underlying physiological substrates of social connectedness (Ong & Allaire, 2005), which has important implications in the caregiving context with regard to health outcomes. The caregiving context is often defined equally by positive and negative emotions and affect. Given the role of social support and connectedness in buffering physiological reactivity to stress and negative affect (Blascovich & Katkin, 1993; Cohen, Kaplan, & Manuck, 1994; Fredrickson & Levenson, 1998), it is important to examine this variable not only within the caregiving context, but across a lifespan sample of individuals sharing a similar context. Antonucci, Langahl, and Akiyama (2004) argued that, as individuals develop and change over time, so do their social relationships, and this dynamic relationship between situational characteristics, social relationships, and well-being is apparent when examined within a

caregiving context. In order to more fully understand health and well-being outcomes within the caregiving context, it makes sense to acknowledge the perceived support across the lifespan and within the caregiving context.

Summary

The national REACH intervention is unique in that it was designed to allow for flexibility in goal-setting as determined by the caregiver. In order to assess the variability in the needs of caregivers/care recipients, the REACH intervention uses a risk appraisal approach to determine how much emphasis is needed for each of the treatment components. Tailoring interventions to fit the expressed needs of caregivers is a novel and effective means of delivering cost-effective and efficacious interventions. Ideally, tailored interventions based on needs assessments, such as the REACH intervention, may be the most appropriate and efficient means of delivery.

Based on this shift in intervention design and delivery, it could be argued that the next step in bolstering intervention outcomes might be a focus on understanding how intervention effectiveness differs based on differences in lifespan processes in context, such as differences in appraisals in the caregiving context. Understanding if theories of lifespan development play a role in the caregiving process, particularly within an intervention context, may shed light not only on possible real-world application of such theories, but also on understanding why intervention elements are or are not effective.

To this end, the present study intends to investigate associations between objective stressors, resources, and appraisals (subjective stressors) of the SPM and subsequent impact on intervention outcomes. In addition, the present study will examine how intervention effectiveness is moderated by age and rurality. The outcome measures

included in the analyses will be residual change scores from baseline (pre-test) to 6-month follow-up (post-test) within the domains of depression and burden. Residual change scores, referred to as “base-free” measures of change (Tucker, Damarin, & Messick, 1966), are viewed as superior to simple pretest – posttest difference scores (Veldman & Brophy, 1974), particularly when pre-test scores are highly correlated to post-test scores (Prochaska, Velicer, Nigg, & Prochaska, 2008).

Present Study

Research Questions

The current study investigated 4 specific research questions:

Research Question 1: *Does the REACH intervention demonstrate efficacy in North Carolina?*

In order to understand overall program effectiveness and to adhere to a key tenant of translation of an evidence-based program (Glasgow, Klesges, Dzewaltowski, Bull, & Estabrooks, 2004; Green & Ottoson, 2004; Green & Glasgow, 2006), it is necessary to examine success in replicating targeted outcomes of the original REACH II intervention. These targeted outcomes include decreased caregiver burden and decreased levels of depression, with comparisons occurring between individuals in the active intervention group and the comparison group.

Research Question 2: *Do age and rurality, with race as a covariate, predict intervention effectiveness with respect to burden and depression?*

In order to understand if age and rurality have differential impacts on change in the outcomes, these variables will be included as predictors in model, with race as a covariate. It is hypothesized that greater intervention effectiveness within the domains of

burden and depression will be observed for older caregivers, and those residing in urban areas.

Research Question 3. *Does intervention effectiveness, with respect to burden and depression, vary for individuals with greater objective stressors, fewer resources, and more negative appraisals (subjective stressors)?*

The second aim of this study is to extend the Pearlin and colleagues' SPM (Pearlin, 1999; Pearlin, Menaghan, Lieberman, & Mullan, 1981). The SPM provides a conceptual framework for analyzing the role of objective stressors, subjective appraisals, and resources, as mechanisms influencing the outcomes of depression and burden.

Similar to Dilworth-Anderson et al. (2004), Hilgeman et al., (2009), and Lee et al., (2010), the current study built on the Pearlin SPM to examine the role of objective stressors (care recipient behaviors, care recipient ADL/IADLs, risk assessment score, number of chronic conditions), subjective appraisals (health appraisal, perceived social support, stress appraisal), and variables that can impact caregiver access to important support-related resources (income, education, employment and marital status, total paid and unpaid caregivers, and whether they identified an individual who is available to take over caregiving responsibilities if needed) in predicting changes in intervention outcomes (depression and burden).

It is hypothesized that greater reported objective stress, fewer reported resources, and greater negative appraisals will result in lower outcome improvement within the domains of depression and burden.

Research Question 4. *Do age and rurality moderate the relationships between objective stressors, resources, appraisals, and intervention effectiveness within the domains of*

depression and burden?

As part of the present examination, age and rurality will be examined as moderators of the proposed SPM. Caregiver stressors and lack of informal social support have previously been identified as predictors for institutionalization (Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993; Gaugler et al., 2000). Based on previous research, perceived social support was included in the SPM as a subjective appraisal, and it was hypothesized that there would be a significant relationship between age and outcomes (Dilworth-Anderson, Pierre, & Hilliard, 2012; Kaufman, et al., 2010; Lee, et al., 2010).

Previous research has shown that the age of both the care recipient and caregiver is related to overall well-being, with older caregivers and care recipients reporting lower levels of well-being and high levels of depression (Belle et al., 2006; Burgio et al., 2009; Schulz et al., 2009). This has typically been attributed to the fact that with age come greater health-related co-morbidities, which can lead to greater burden. Additionally, previous research has shown that age can impact intervention outcomes, with older caregivers typically incurring greater improvements within all targeted domains (Knight et al. 1993; Pinquart & Sorensen, 2006; Sorensen et al., 2002).

Building on research by Hilgeman and colleagues (2009) that found differential effectiveness of the REACH intervention depending on race, race was included as a covariate in the proposed SPM.

It was hypothesized that main effects of rurality and age will be observed, with lower outcome improvement for rural and younger caregivers. It was hypothesized that a significant interaction between age and objective stressors, resources, and appraisals

emerge, as well as significant interactions between rurality and resources, and rurality and appraisals.

Method

Regional Translation of the REACH Intervention

In October 2009, the North Carolina Division of Aging and Adult Services (DAAS) received a three-year Alzheimer's Disease Supportive Services Program (ADSSP) grant to implement the evidence-based intervention, REACH II through the Aging Services Network and partner organizations. Through federal grant funds as part of the Older Americans Act (OAA), DAAS translated the clinically-tested REACH intervention for feasible and effective use at the community level (see Appendix A for full details regarding the translation of the REACH intervention to North Carolina).

The OAA specifies that its funds should be directed to “older individuals with greatest economic need and older individuals with greatest social need with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas” (Older American's Act, Section 305 (a)(2)(E)). Of North Carolinians age 60+, 19% are members of ethnic minority groups, but unlike many other states, most are African-American (16%, compared to 8% nationally; US Census Bureau. 2007-2011 American Community Survey, Sex by Age; Black or African American alone), with only 3% belonging to other groups, including American-Indians, Hispanic, and Asians. Although the state has seen an increase in the Hispanic/Latino population in the past decade, most are younger than 60, so just over 1% of older adults belong to that

ethnic group (US Census Bureau. 2007-2011 American Community Survey, Sex by Age; Hispanic or Latino).

One of the primary aims of the present study was to examine REACH outcomes in North Carolina, with particular focus on the unique racial and rural make-up of the state. A vital measure of the strength of an intervention is arguably its ability to be successfully translated to different contexts without fear of decreased efficacy, and understanding why differences exist is the lynchpin of translational science. In order to more fully understand the effects of the intervention, the North Carolina REACH translation included a comparison group that received only educational materials pertaining to Alzheimer's caregiving, but did not receive any components of the active intervention. Due to limited sample size, the present study was guided by the analytical techniques employed by Dilworth-Anderson and colleagues (hierarchical regression) rather than Hilgeman and colleagues (Structural Equation Modeling).

Participants

Recruitment activities focused on brochure dissemination, presentations to local family caregiver groups, and recruitment through currently enrolled Project C.A.R.E. (Caregiver Alternatives to Running on Empty) clients, Project C.A.R.E clients on the waiting list, and eligible clients enrolled in the Family Caregiver Support Program (FCSP). Eligible participants were individuals providing care for someone with Alzheimer's or a related dementia, and who was actively considering placement as determined by the 6 – item DTI assessment. In 2011 REACH intervention eligibility was broadened to include any eligible individual, regardless if they were receiving services via Project C.A.R.E. or FCSP. Additionally, in 2011 with guidance from Lou Burgio,

PhD, co-investigator of the original REACH II intervention, North Carolina transitioned from the REACH II intervention to REACH OUT. Intervention components remained the same, however participants are considered to be “completers” when they complete 6 sessions with the interventionist rather than 12 sessions. This programmatic change was made after receiving input from the interventionists and caregivers via the post-test satisfaction survey, and the yearly participatory program evaluation. The present study treated both REACH II and REACH OUT participants as having received the same intervention, however, number of sessions was examined initially as a potential variable contributing to overall program effectiveness. For the remainder of the document the author will refer to the intervention at NC REACH, rather than REACH II or REACH OUT.

The NC REACH sample currently consists of 170 community-dwelling adults (50 comparison group; 120 treatment group). Thirty-one participants enrolled in the intervention but withdrew prior to completion (an attrition rate of approximately 15%). Reasons for withdrawing included not having enough time, death of the care recipient, or placement of the care recipient. The mean age is 64 years old ($SD = 13.23$; $range = 18 - 87$ years), with 56% of the sample living in a rural location. Additionally, 87.5% are female, 47% report having a high school degree or less, and the mean yearly income is \$28,500 ($SD = \$17,000$; $range = < \$5,000 - > \$55,000$). The race breakdown is as follows: 48% African-American, 16% American Indian, and 36% White.

Procedure

Recruitment

Outreach strategies revolved around the existing Alzheimer's Disease supportive service network including the Alzheimer's Association, Project C.A.R.E., Area Agencies on Aging, Aging and Disability Resource Connections (ADRC's) and Mecklenburg County Department of Social Services. Recruitment was accomplished through program announcement flyers and brochures distributed at health fairs, workshops, and other public awareness events. Informational packets were mailed to community centers, memory assessment clinics, physicians, pharmacies, hospitals, churches, senior centers, provider agencies and other key organizations serving the target population.

REACH referrals were primarily received through a state-funded service for dementia caregivers called Project C.A.R.E. Project C.A.R.E. provided a limited amount of respite care in conjunction with individualized family consultant services by trained staff in case management of dementia care. Because of their frequent contact with families who are coping with Alzheimer's, Project C.A.R.E. Family Consultants serve as a primary referral source for this project. The Family Caregiver Support Program also served as a referral source.

Intervention Delivery

The NC REACH intervention is delivered by certified interventionists with at least a bachelor's degree, occurring over 6 months, and including 6-12 sessions (the original REACH model consisted of 12 sessions; the REACH OUT model consists of 6 sessions). Interventionists are allowed to supplement at-most 2 in-home visits with telephone calls at their discretion. They are required to document which visits were telephone calls on the schedule.

The initial in-home session serves to orient participants to the study, provide relevant educational materials, and to begin tailoring the intervention to their needs via the Risk Assessment and Coping Goals. During the first visit, all baseline measures are administered, basic information on the importance of self-care to improve healthy behaviors is reviewed, and caregivers receive a “health passport,” a booklet that provided reminder information about health maintenance activities (such as annual physical examinations) and a tool to record health information and health appointments for both themselves and the care recipients.

The goal of the remaining intervention visits is to develop the caregiver's ability to assess and manage care recipient problem behaviors and manage their own stress and emotional wellbeing. The interventionist and caregiver engage in a problem-solving process (including defining problems in specific and objective terms, translating problems into objective goals, and generating specific action-oriented steps to solve the problems) to find effective and workable solutions to problem behaviors identified.

Skill training for managing burden is integrated into the process as well, and includes strategies such as taking a break from caregiving activities, and Behavioral Activation techniques for stress management, including breathing exercises, listening to music, and stretching exercises. Caregivers also received training and practice in mood management techniques and strategies for increasing involvement in designated pleasant events.

For individuals enrolled in the original REACH II intervention, post-test assessments are administered at visit 12, or whenever participation is terminated. If participants completed at least 9 sessions they are considered to have completed the

intervention. For individuals enrolled in REACH OUT, post-test assessments are administered at visit 6, or whenever they decide to terminate participation. If participants completed at least 4 sessions they are considered to have completed the intervention.

Measures

Demographics

Caregiver and care recipient demographics for the North Carolina REACH intervention are collected via the division-wide DAAS – 101 Client Registration Form and DAAS 101 Supplemental Form. Of the caregivers in the NC REACH intervention, 80% are female, 43% are African-American, 52% are rural, 50% are married, 27% are working full-time or part-time, 15% are below the poverty level, 70% of care recipients are living in the same household as the caregiver, and 40% are spousal caregivers. For demographic comparisons of the intervention groups, see Table 1 below.

Table 1

Descriptive Statistics for NC REACH Intervention and Comparison Groups

	<i>N</i>	CG Age Mean (SD) Range	CR Age Mean (SD) Range	BurdenPre Mean (SD) Range	BurdenPost Mean (SD) Range	Income Mean (SD) Range
Intervention	129	62.92 (13.17) 40-97	80.19 (9.17) 52-99	23.02 (9.10) 2-45	19.50 (9.93) 0-44	\$27,229 (\$16,679) \$0-\$72,000
Comparison	51	55.56 (15.92) 40-90	76.02 (10.30) 59-91	22.22 (9.55) 4-42	22.04 (7.93) 4-40	\$29,769 (\$18,074) \$1,800-\$56,400

Caregivers were coded as either “spouse” or “non-spouse” for the final analyses based on the importance of this distinction in the caregiving literature (e.g., Miller & Guo, 2000).

Objective Stressors

ADL and IADL Assistance

The seven item ADL scale (Katz et al., 1963) assessed the care recipient's ability to perform basic tasks of daily functioning independently (e.g., bathing, dressing, toileting, eating, grooming, transfer). Similarly, the eight-item IADL scale (Cronbach's $\alpha = .76$ for IADL and $.81$ for ADL; Lawton & Brody, 1969) assessed the assistance needed to perform higher-level tasks such as shopping, operating the telephone, preparing meals, doing housework or laundry, and managing finances or medications. Total level of assistance needed for ADLs and IADLs were summed separately, with higher scores indicating more functional impairment.

Risk Assessment

Risk was assessed with a 23-item questionnaire (Czaja, et al., 2009) with scores ranging from 0 to 23 (with lower scores indicating less risk). Caregiver risk refers to risk in the domains of health, safety, and well-being of both the caregiver and care recipient (for example, "*Do you ever leave the care recipient alone or unsupervised in the home?*", "*In the past month has it been hard to eat healthy or well-balanced meals on a regular basis?*", "*How often in the past month have you felt like screaming or yelling at the care recipient because of the way he/she behaved?*", "*Providing help to the care recipient has made me feel good about myself*"). Three social support items assessed perceptions of help and emotional support, and whether the caregiver had someone to take over care if needed. For the purpose of the present study, these three social support items will be used as part of the "subjective appraisals" within the SPM. Cronbach's $\alpha = .67$.

Care Recipient Behaviors

The Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992) assessed the presence of 24 problem behaviors that the care recipient may have exhibited in the past week (e.g., trouble remembering recent events, asking the same question over and over). The caregiver indicated if the behavior occurred or not (yes/no). A sum score reflects the total number of behaviors reported by the caregiver. Cronbach's alpha = .93.

Number of Chronic Conditions

As noted, caregiver and care recipient demographics for the North Carolina REACH intervention are collected via the division-wide DAAS – 101 Client Registration Form and DAAS 101 Supplemental Form. The supplemental form asks caregivers to report all officially diagnosed (and self-identified) chronic conditions for themselves and the care recipient. The present analyses used a total count of chronic conditions as an indicator of objective stress.

Subjective Stressors

Stress Appraisal

The Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992) assessed the presence of 24 problem behaviors that the care recipient may have exhibited in the past week along with an appraisal of how stressful each behavior was to the caregiver. In the presence of a problem behavior caregivers reported how upset they were by each behavior using a 5-point scale from 0 = not at all to 4 = extremely (Teri et al., 1992). The conditional “appraisal” score was calculated by dividing the sum scores by the total frequency of behavior problems (Gitlin et al., 2005). The final score had a

range from 0 to 4, with higher scores indicating greater bother. This scale is well validated and highly reliable. Cronbach's $\alpha = 0.90$.

Subjective Health Appraisal

Caregivers' self-reported health was measured by creating a composite of the following items, taken from the 23-item Risk Assessment (Czaja et al., 2009), with lower scores indicating better health:

- “In general would you say your health is...” responses range from 0 (Excellent) to 4 (Poor).
- “During the past month, have you had trouble falling asleep, staying asleep, or waking up too early?” Responses range from 0 (Never) to 2 (Often).
- “Have you cut back on physical activities, like exercise and walking, because of caregiving?” Responses range from 0 (No) to 1 (Yes).
- “In the past month, has it been hard to eat healthy or well-balanced meals on a regular basis?” Responses range from 0 (never) to 3 (very often).

Perceived Social Support

The present study intends to examine perceived social support as a subjective stressor within the SPM using the following three items from the Risk Assessment that reflect the proposed social support domains included in the Pearlin SPM of instrumental and expressive support: “In the past month, how satisfied have you been with the comfort, interest, and concern you have received from others” (Expressive; 0 = Not At All 3 = Very), and “If you were unable to care for the CR or for yourself, do you have someone who could take over?” (Instrumental; Yes/No).

Resources

A central focus in examinations of the Pearlin SPM is caregiver “resources”. Depending on the researchers, this construct has included variables such as caregiver knowledge and religious coping strategies (Hilgeman et al., 2009; Lee et al., 2010), caregiving mastery and cultural justification (Dilwirth-Anderson et al., 2004), or social support and resilience (Lee et al., 2010; Milkie, 2010). The current study utilized factors that typically relate to access, availability, and use of support-related resources, including income, education, employment status (working/un-employed/retired), marital status, total number of paid and unpaid caregivers, and whether they identified an individual who is available to take over caregiving responsibilities if needed (yes/no). Given the rural nature of North Carolina, an exploration of access to resources will be a novel interpretation to the traditional examination of resources within the SPM.

Moderators of the SPM

At the baseline interview, caregivers provided their date of birth, which was used in conjunction with the date of the baseline interview to determine age at the time of intervention delivery. They additionally indicated if they currently reside in an urban, rural, or suburban setting. Individuals who indicated that they were residing in a suburban setting (N = 5) were included in the “urban” group.

Outcome Measures

In order to examine how caregivers responded to the REACH intervention (i.e. intervention effectiveness), and how this might vary depending on age and rurality, residual change scores were calculated for burden and depression using pre-test (baseline) and post-test (six-month) scores for these outcome assessments.

Burden

Zarit Caregiver Burden Inventory (Zarit, Orr, & Zarit, 1985; Bedard et al., 2000). The 12-item abbreviated version of the Zarit Caregiver Burden Inventory was used to assess the present study's primary outcome, burden associated with caregiving (e.g., not enough time for oneself, not as much privacy). Caregivers rated each item on a 5-point scale from 0 (*never*) to 4 (*nearly always*). Scores range from 0 to 48, with higher scores indicating higher reported caregiver burden. Cronbach's alpha = .80.

Depression

Caregiver depression was assessed with the 9-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001), with scores ranging from 0-27. Higher scores indicate greater levels of depression. Cronbach's alpha = .83.

Results

Due to the fact that there were too few caregivers between the ages of 18 and 40 to comprise a "young adult" category (N = 10), analyses examined potential moderating effects using age groupings of middle-age (40 – 59) vs. older adults (60+). Approximately 50% of participants are in the middle-age (N = 70) and older adult age groups, respectively (N = 88). The age-group delineations were chosen in part due to the number of individuals that comprised each age-group, as well as the fact that programs funded by the Older Americans Act require that individuals be aged 60 and older. Due to the fact that 96% of the caregivers in the current dataset reported providing care ranging from 1 to 12 years, an additional two individuals who indicated providing 21 years of care were removed from the analyses.

Prior to testing possible moderating effects of age and rurality, chi-square tests of independence were performed to examine the relationship between race and rurality, and race and relationship to care recipient. Results revealed a non-significant relationship for race and rurality $\chi^2 (1, N = 155) = 1.20, p = 0.16$, and a significant relationship for age and relationship to care recipient $\chi^2 (7, N = 153) = 41.50, p = 0.01$, with 71% of middle-aged caregivers being daughters/daughter-in-laws, and 43% of older caregivers being wives. All data will be from the pre-test assessments, except the outcome measures (burden and depression) will reflect residual change scores between pre- and post-test assessment.

Missing values were handled according to the REACH Intervention guidelines (Schulz, Burgio, Stevens, Burns, Czaja, Gallagher et al., 2005). Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004: User Guide and General Instructions. Inter-university Consortium for Political and Social Research). For cases missing less than 25% of items on a given scale, means were used from the relevant group to replace the missing value. If a caregiver missed more than 25% of items on any one of the measures, the data were excluded. Participants in the NC REACH intervention rarely opted out of completing a measure; so missing data were not an issue for the current study. The one exception to this was a protocol change that occurred early on in the translation of the NC REACH; completing the PHQ-9 at post-test was not required unless the participant scored at or above the clinical severity threshold for moderate depression at pre-test (10 or more out of a total of 27), or if the caregiver was showing signs of depression. For this reason, several early NC REACH participants were missing the PHQ-9 post-test (including the entirety of the comparison group). A total of 56

participants were dropped from the PHQ analysis for this reason, and burden was the only outcome domain able to be examined for Aim 1 of the present study. A total of 31 participants were excluded from the analyses due to attrition at pre-test.

Prior to testing results, all assumptions were tested, including plotting variables to assess normality and identify any outliers, and any violations of assumptions are reported in the following section. Intercorrelations among study variables are presented in Table 2. The following independent variables were highly correlated ($>.30$): Age and employment status, CR IADLs and CR ADLs, CR behaviors and CG stress appraisal, income and social support satisfaction, and change in burden and change in depression. The collinearity statistics (i.e., Tolerance greater than 0.1 and VIF less than 10) were within marginal limits for the aforementioned variables, so the assumption of multicollinearity was not stringently met (Coakes, 2005; Hair et al., 1998).

Table 2

Intercorrelations among Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Race	1	-.16	-.09	-.04	.20	.08	-.05	.28	.02	.12	-.02	.16	-.13	-.08	.02	-.04	-.34†	-.09
2. Age	--	1	.04	.08	-.02	-.07	-.16	.20	.11	-.23	.50†	.30*	.13	-.23	-.07	-.12	.04	.12
3. Rurality	--	--	1	.09	-.01	.20	.15	-.22	.14	-.20	-.04	-.24	.12	-.01	.30*	.25	-.03	.33
4. CR IADLs	--	--	--	1	.38†	.02	-.01	-.04	-.06	-.15	.17	.05	.01	-.01	-.01	.12	-.03	-.10
5. CR ADLs	--	--	--	--	1	.09	.09	.02	.07	.14	-.13	-.12	-.01	-.02	.05	.23*	-.11	-.02
6. CR Behaviors	--	--	--	--	--	1	.22*	-.04	.20	-.10	.05	-.14	.01	.05	.70†	.23*	.02	.02
7. Total Risk	--	--	--	--	--	--	1	-.16	.17	.13	-.10	-.30*	-.12	.36†	.33†	.63†	.12	.03
8. Yrs. Caregiving	--	--	--	--	--	--	--	1	.01	.15	.15	.37†	-.03	-.01	-.07	-.27	-.17	-.25
9. Chronic Conditions	--	--	--	--	--	--	--	--	1	.08	.19	.08	.05	.04	.15	.28	-.07	.08
10. Education	--	--	--	--	--	--	--	--	--	1	-.02	.12	-.01	.14	-.07	.11	-.05	-.28
11. Employment	--	--	--	--	--	--	--	--	--	--	1	.20	.04	-.06	-.07	-.02	.12	.14
12. Income	--	--	--	--	--	--	--	--	--	--	--	1	-.08	-.37†	-.22	-.16	-.31*	-.10
13. Marital Status	--	--	--	--	--	--	--	--	--	--	--	--	1	-.03	-.09	-.01	-.10	.06
14. Soc. Supp. Appraisal	--	--	--	--	--	--	--	--	--	--	--	--	--	1	.09	-.15	.04	-.09
15. Stress Appraisal	--	--	--	--	--	--	--	--	--	--	--	--	--	--	1	.31*	.09	.05
16. Health Appraisal	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	1	.20*	.26*
17. Change in Burden	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	1	.44†
18. Change in Depression	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	1

Notes: All measures are from pre-test assessment. All measures are of caregiver (CG) unless noted as care recipient (CR). Race was coded White = 0; Black/African American =1).

* $p < .05$

† $p < .001$

All test variables were normally distributed with the exception of IADLs being negatively skewed, years of caregiving slightly positively skewed, and stress appraisal at pretest slightly positively skewed, none of which warranted transformation. For Aim 1 analyses, sphericity cannot be assessed because there are only two levels of the repeated measure. Therefore, homogeneity of variances will be reported to gauge equality of variance for the group.

Aim 1: Does the REACH intervention demonstrate efficacy in North Carolina?

The first goal of this study was to examine the efficacy of the NC REACH intervention. To test this first aim, a two (treatment condition: intervention vs. comparison,) by two (time, pretest v. posttest) repeated measures analysis of variance (RM-MANOVA) was tested (See Table 1 for descriptive statistics) using caregiver burden as the primary outcome. Caregiver depression is not able to be examined in Aim 1 due to the fact that the in years 1 through 3 of the North Carolina REACH translation, the PHQ-9 was not required at post-test, rather used as a tool to indicate the presence of depressive symptomology. This led to incomplete pre-post data within the depression outcome.

The Box's Test of Equality of Covariance Matrices revealed that there was a violation of the assumption of homogeneity of covariance between the groups (Box's $M = 27.15, p < .001$). This indicated that there were significant differences between the covariance matrices, largely due to unequal sample sizes between the comparison and intervention groups ($N=51$ and $N=129$, respectively). To correct for this violation, Pillai's Trace will be reported to protect against inflated Type I errors due to unequal sample sizes. Levene's Test for equality of variances indicated that there was not a violation for pre-test burden scores between

groups $F(1,178) = .159, p = .70$, however there was a marginal violation for post-test scores $F(1, 178) = 2.92, p = .05$.

Initial multivariate results (See Table 3) indicated there was a statistically significant Time X Group interaction $F(1,177) = 6.20, p < .05$; Pillai's Trace = 0.034, $\eta^2_p = 0.034$ (See Figure 3). More specifically, burden scores for the intervention group significantly decreased from pre-test to post-test ($F(1,129) = 27.65, p < .001$), whereas there was no change in burden scores for the comparison group ($F(1, 51) = 0.09, p = .80$).

Due to the fact that North Carolina transitioned from REACH II (12 sessions over 6 months) to the abbreviated REACH OUT intervention (6 sessions over 6 months), intervention type was examined as a covariate, and results indicated that there was no main effect of intervention type on burden ($F(1,177) = .35, p = .38$; Pillai's Trace = 0.002, $\eta^2_p = .002$). The 6-session REACH intervention was as effective as the 12-session REACH intervention. It should be noted, however, that the comparison group did have lower pre-test scores as compared to the intervention group (See Table 1), although this difference was not significant. All subsequent analyses utilized the intervention group only.

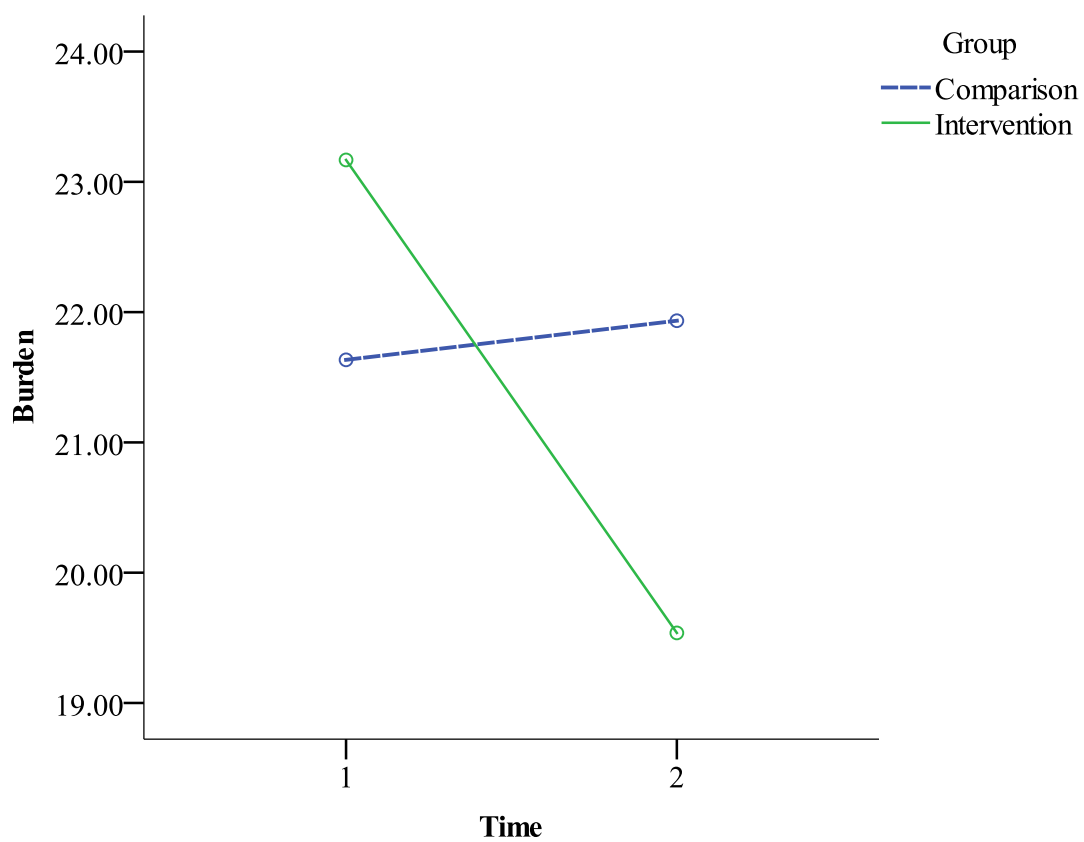


Figure 3. Significant change in burden depending on intervention group.

Table 3

Two-way Analysis of Variance Summary for Aim 1

	SS	df	MS	F	η^2_p
Time	47.02	1	47.02	2.10	0.01
Time x Intervention Type	7.91	1	7.91	0.35	0.002
Intervention Group	6.72	1	6.72	2.09*	0.11
Time x Intervention Group	139.64	1	139.64	6.20*	0.03

* $p < .05$

Aim 2: Do age and rurality, with race as a covariate, predict intervention effectiveness with respect to burden and depression?

The second goal of the study was to examine age and rurality as predictors of change in the outcomes of burden and depression, while controlling for race. Prior to running analyses for aims 2-4, comparison group participants were removed. Caregiver/care recipient characteristics for all study variables are presented in Table 4.

The current study utilized residual change scores to reflect changes in each outcome across the intervention. Residual change scores use standardized residuals and are obtained by regressing post-test scores on pre-test scores to provide a change score adjusted for baseline variance and to correct for regression to the mean. In other words, regression is used to predict post-test scores from pre-test scores for each outcomes. The difference between the predicted and the observed post-test scores are the residuals, and are used as the outcome in all subsequent analyses. Negative scores would reflect a decrease in burden at post-test, whereas positive scores would reflect an increase.

Table 4

Caregiver and Care Recipient Characteristics for Study Variables

	Black/African American (<i>n</i> = 61)	White/Caucasian (<i>n</i> = 68)
CG Characteristics	<i>M (SD)</i> <i>Range</i>	<i>M (SD)</i> <i>Range</i>
Age	61.15 (12.09) 43-87	65.18 (12.27) 40-97
Total Risk	14.08 (3.72) 6-23	14.50 (4.04) 7-27
Yrs. Caregiving	6.81 (5.27) 2-21	4.53 (2.71) 1-12
Chronic Conditions	2.11 (1.66) 0-7	2.04 (1.73) 0-7

Table 4 Continued

Income	\$30,460.87 (\$16,591.12) \$0-\$72,000	\$24,985.68 (\$17,389.22) \$0-\$60,000
Social Support Appraisal	3.48 (1.84) 0-6	3.74 (1.59) 0-6
Stress Appraisal	18.52 (15.20) 0-62	17.98 (13.63) 0-52
Change in Burden	-0.33 (0.99) -3.00-1.32	.32 (0.82) -1.59-1.77
Change in Depression	-0.14 (1.19) -2.00-2.98	0.05 (0.86) -1.89-2.59
	<i>n (%)</i>	<i>n (%)</i>
Location		
Rural	9 (37.5%)	21 (67.7%)
Urban	15 (62.5%)	10 (32.3%)
Employment Status		
Full-time	14 (23.7%)	9 (13.6%)
Part-time	2 (3.4%)	6 (9.1%)
Quit due to Caregiving	5 (8.5%)	7 (10.6%)
Not working	15 (25.4%)	21 (31.8%)
Retired early due to Caregiving	0	3 (4.5%)
Retired	23 (38.9%)	19 (43.9%)
Lost job due to caregiving	0	1 (1.5%)
Education		
<High school	0	1 (3.2%)
Some High School	3 (12.5%)	1 (3.2%)

Table 4 Continued

High School graduate	5 (20.8%)	10 (31.3%)
Some College/ Vocational	7 (29.2%)	12 (38.7%)
College graduate	8 (33.3%)	7 (21.9%)
Graduate School	1 (4.2%)	0
Marital Status		
Single (never married)	14 (26.2%)	7 (10.4%)
Married	36 (59.0%)	46 (68.7%)
Single (divorced/widowed)	11 (18.0%)	14 (20.9%)
CR Characteristics	<i>M (SD)</i> <i>Range</i>	<i>M (SD)</i> <i>Range</i>
CR IADLs	7.62 (0.97) 2-8	7.55 (0.89) 3-8
CR ADLs	4.21 (1.83) 0-6	3.17 (2.13) 0-6
CR Behaviors	11.63 (5.66) 3-29	10.84 (4.99) 0-27

Notes: ADL = activities of daily living; IADL = instrumental activities of daily living; CG = caregivers; CR = care recipient.

Separate hierarchical regression models were run for each outcome. For the model examining burden, race was entered as a covariate in step 1. In step 2, mean-centered age and location (urban vs. rural) were entered as predictors. Results revealed that race (dummy coded as White=0; Black/African American =1) significantly contributed to the model and accounted for 20% of the variance in change of burden, $F(1, 37) = 9.22, p < .05, R^2\Delta = .20$. However, the inclusion of age and rurality in the model as predictors did not significantly

contribute to the variance in change in burden, and accounted for an additional 2.2% of the variance, $F(2, 35) = .50, p = .61, R^2\Delta = .02$. Improvements within the burden domain depended on whether a caregiver was African American or White. Burden decreased to a greater extent for African Americans as compared to Whites, $\beta = -.46, t(56) = 3.04, p < .005$.

For the model examining depression, race was once again entered in step 1 as a covariate, followed by age and location in step 2 as predictors. Results revealed that neither race ($F\Delta(1, 25) = 1.95, p = .17, R^2\Delta = 0.07$), nor age and rurality ($F\Delta(1, 23) = 0.49, p = .62, R^2\Delta = 0.04$) contributed significantly to the variance within the domain of depression, nor were there any main effects of race, age, or rurality.

Aim 3: Does intervention effectiveness, with respect to burden and depression, vary for individuals with greater objective stressors, fewer resources, and more negative appraisals?

The next goal of the study was to examine a proposed Stress Process Model (SPM) of NC REACH. To do so, a hierarchical regression model was used to test the relations among the constructs in the SPM (objective stressors, resources, appraisals) for the intervention group and subsequent changes in the targeted outcomes (burden and depression) while controlling for age, race, and rurality.

In step one of the burden regression, race, age, and rurality were entered as covariates. Next, objective stressor variables (CR behaviors, CR ADL/IADL assistance, CR behaviors, total risk, years of caregiving, and number of CG chronic conditions) were added. In step three, resource variables were entered (household income, education, employment status, and CG marital status). Step four included the subjective appraisal variables (stress appraisal, health appraisal, and perceived social support). Lastly, the final aim of the present

study was to include a fourth step which included the addition of a moderating interaction term, Age x Race.

Model results for depression were non-significant, so although the test statistics will be reported below in Table 6, they will not be discussed further.

In step 1, the covariates race, age, and rurality did not significantly explain variance in the change in caregiver burden $F(3, 16) = 2.45, p = .11, R^2 = 0.24$. However, race was revealed to be the only significant predictor of change in burden, with African American caregivers incurring greater decreases in burden as compared to Whites (See Table 5). With the addition of objective stressor variables in step 2, race was no longer significant, nor did any of the objective stressors significantly predict change in burden ($F\Delta(6,10) = 0.83, p = .57, R^2\Delta=0.25$). Additionally, none of the individual stressor variables were significant in step 2.

The model summary for step 3 (the addition of resource variables to objective stressors and covariates) significantly accounted for an additional 43% of the variance in change in caregiver burden, $F\Delta(4,6) = 8.20, p=.01, R^2\Delta =.43$. With the addition of resource variables in the third step, CG age, CR IADL assistance, total baseline risk, number of self-reported CG chronic conditions, CG education, and household income all became significantly predictive of change in burden. As indicated by the resulting beta-weights, lower age, greater reported CR IADL assistance, a greater number of reported CG chronic conditions, lower levels of baseline risk, lower levels of CG education, and lower household income were all significantly related to decreases in burden (see Table 5). Race and rurality remained non-significant, as did CR ADL assistance, CR behaviors, total years of caregiving, employment status, and marital status.

The addition of the subjective appraisal variables in the fourth step was non-significant overall, $F\Delta(3,3) = 1.38$, $p = .40$, $R^2\Delta = .04$. Social support satisfaction, stress appraisal, and health appraisal were not significantly related to decreases in burden. The only observed changes with the addition of subjective appraisal variables were that baseline risk and CG education were no longer significantly related to greater burden reduction. Age remained significant, as did CR IADLs, chronic conditions, and income.

Aim 4: Do age and race moderate the relationships between objective stressors, resources, appraisals (subjective stressors), and intervention effectiveness within the domains of depression and burden?

Lastly, step five significantly explained an additional 3% of the variance in change in burden, $F\Delta(1,2) = 21.53$, $p = .04$, $R^2\Delta = .03$, and revealed a significant age x race omnibus interaction (See Figure 4). Follow-up simple slope analyses (Aiken & West, 1991) for the association between change in burden and age were tested and revealed that change in burden was more strongly related to age for Black caregivers ($b = -.22$, $SE_b = .02$, $T = -12.41$, $p < .0001$) than for White caregivers ($b = .02$, $SE_b = .02$, $T = 1.18$, $p = .24$). This relationship was in the opposite direction for Black caregivers as for White caregivers; older Black caregivers experienced a significant decrease in burden as compared to White caregivers who did not experience a change in burden regardless of age.

Additional findings from step 5 include that with the addition of the interaction term, CR IADL assistance, CG chronic conditions, and household income remained significant in the model, with greater reported CR IADL assistance, a greater number of reported CG chronic conditions, and higher household income significantly related to decreases in burden

It should be noted that after step five, no additional modifications to the model could be made. The model was no longer free to vary, and additional interaction effects added to step 5 could not explain any additional variance.

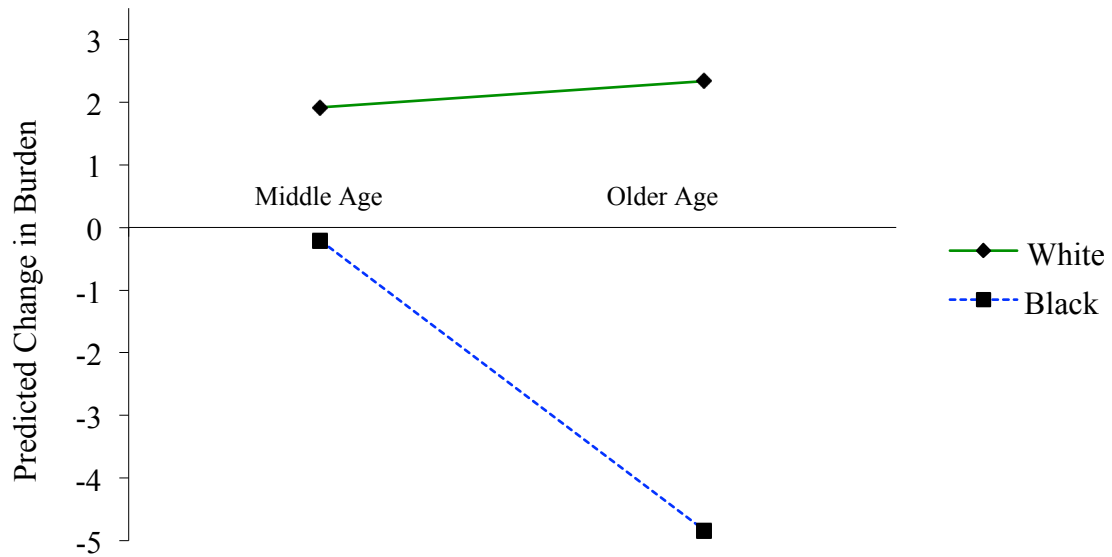


Figure 4. Interaction of caregiver age \times race on burden.

Table 5

Hierarchical Regression Model Predicting Change in Burden and Depression.

Predictors	Burden						Depression					
	R^2	ΔR^2	b	β	t	p	R^2	ΔR^2	b	β	t	p
Step 1:	0.24	0.24					0.09	0.09				
Covariates												
Race			-0.99	-0.51	-2.23	0.04*			-0.72	-0.27	-1.00	0.33
Age			0.01	0.21	0.91	0.38			-0.01	-0.07	-0.24	0.81
Rurality			-0.28	-0.14	-0.57	0.58			0.30	-0.03	0.30	0.42
Step 2:	0.49	0.25					0.24	0.15				
Covariates												
Race			-0.68	-0.35	-1.25	0.24			-0.13	-0.05	-0.10	0.93
Age			0.02	0.32	1.02	0.33			-0.03	-0.35	-0.56	0.60
Rurality			0.01	0.005	0.31	0.44			0.21	0.45	0.44	0.57
Objective Stressors ¹												
CR IADLs			-0.34	-0.18	-0.60	0.56			-1.27	-0.21	-0.36	0.73
CR ADLs			-0.03	-0.05	-0.20	0.88			0.18	0.30	0.70	0.51
CR Behaviors			0.05	0.26	1.10	0.31			-0.41	0.13	0.31	0.77
Total Risk			0.06	0.23	0.87	0.41			0.11	0.06	0.10	0.79
Yrs. Caregiving			0.09	0.27	0.95	0.37			0.16	0.35	0.48	0.65
Chronic Cond			-0.29	-0.50	-1.58	0.15			-0.74	0.36	0.77	0.47
Step 3:	0.92*	0.43					0.17	0.6				
Covariates												
Race			0.51	0.26	1.32	0.23			2.67	1.01	1.84	0.16
Age			0.05	0.78	3.32	0.02*			-0.11	-1.10	-1.43	0.25
Rurality			0.20	0.06	0.02	0.34			-0.03	-0.47	-0.33	0.30
Objective Stressors												
CR IADLs			-2.34	-1.21	-4.94	0.03*			-1.27	-0.68	-0.36	0.38
CR ADLs			-0.01	-0.014	-0.089	0.932			0.18	0.21	0.60	0.59

Table 5 Continued

CR Behaviors	0.056	0.31	1.91	0.104	-0.41	-1.15	-1.67	0.19
Total Risk	0.10	0.38	2.73	0.03*	0.11	0.32	0.65	0.56
Yrs. Caregiving	0.09	0.27	1.78	0.13	0.16	0.34	0.55	0.62
Chronic Cond	-0.30	-0.50	-3.10	0.02*	1.10	1.15	1.68	0.19
Resources ²								
Education	0.37	0.42	2.97	0.03*	-0.74	-0.56	-1.66	0.20
Employment	0.11	0.25	1.16	0.29	1.01	1.74	2.03	0.14
Income	0.001	-1.33	-5.33	0.02*	-0.00	-0.44	-0.94	0.42
Marital Status	-0.31	-0.22	-1.51	0.18	-0.68	0.38	0.97	0.41
Step 4:	0.97	0.05			1.00	.		
Covariates								
Race	0.71	0.36	1.92	0.15	3.14	1.20	.	.
Age	0.05	0.71	3.09	0.04*	-0.07	-0.70	.	.
Rurality	0.10	0.51	0.22	0.21	-0.25	-0.04	.	.
Objective Stressors								
CR IADLs	-1.97	-1.02	-3.91	0.03*	-1.61	-0.86	.	.
CR ADLs	-0.12	-0.23	-1.24	0.30	-0.22	-0.26	.	.
CR Behaviors	0.04	0.21	0.97	0.40	-0.57	-1.61	.	.
Total Risk	0.08	0.31	0.69	0.54	0.74	2.10	.	.
Yrs. Caregiving	0.05	0.15	0.84	0.46	-0.48	-0.99	.	.
Chronic Cond	-0.33	-0.54	-3.43	0.04*	0.10	0.10	.	.
Resources								
Education	0.32	0.37	2.60	0.08	0.26	0.20	.	.
Employment	0.09	0.20	0.80	0.48	1.53	2.64	.	.
Income	-0.009	-1.24	-5.26	0.01*	0.001	-1.19	.	.
Marital Status	-0.15	-0.11	-0.56	0.62	1.61	0.89	.	.
Appraisals ³								
Social Supp.	-0.15	-0.27	-1.03	0.38	-1.54	-1.20	.	.
Stress	0.01	0.16	0.60	0.59	-0.17	-0.20	.	.
Health	0.33	0.19	0.47	0.67	-2.72	-1.18	.	.

Table 5 Continued

Step 5:	.99*	0.03	
Covariates									
Race	2.23	1.14	6.32	0.02*	
Age	0.07	1.04	9.57	0.01*	
Rurality	0.21	0.21	0.37	0.56	
Objective Stressors									
CR IADLs	-1.80	-0.93	-9.81	0.01*	
CR ADLs	-0.13	-0.25	-3.77	0.06	
CR Behaviors	0.009	0.05	0.56	0.63	
Total Risk	-0.13	-0.50	-2.10	0.17	
Yrs. Caregiving	-0.50	-0.15	-1.51	0.27	
Chronic Cond	-0.32	0.34	-9.40	0.01*	
Resources									
Education	0.20	0.23	3.92	0.06	
Employment	0.06	0.14	1.52	0.27	
Income	-0.007	0.00	-11.0	0.08*	
Marital Status	-0.30	-0.20	-2.82	0.12	
Appraisals									
Social Supp.	0.30	0.56	0.48	0.68	
Stress	0.23	0.39	3.64	0.07	
Health	1.13	0.65	3.71	0.07	
Interaction ⁴									
Age X Race	-1.14	-1.03	-4.64	0.04*	

Note: All measures are from pre-test assessment. All measures are of caregiver (CG) unless noted as care recipient (CR).

* $p <$

Discussion

This study addressed two primary aims: 1) to test the overall efficacy of the NC REACH intervention, and 2) to examine a proposed stress process model predicting change in the outcomes of burden and depression.

To address the first aim, a repeated measures MANOVA was used to test the overall efficacy of NC REACH. Results indicated that there was a significant Time X Group interaction. Burden scores for the intervention group significantly decreased from pre-test to post-test, whereas there was no change in burden scores for the comparison group. These results confirmed the overall efficacy of the REACH intervention in reducing caregiver burden. Additionally, there was no difference in intervention efficacy depending on number of sessions; the truncated REACH OUT intervention consisting of 6 sessions was just as effective in reducing caregiver burden as the original 12-session REACH intervention. From an economic and sustainability perspective, this is an important finding to inform state-level programming.

To address the second aim, a stress process model was proposed based on previous REACH literature (Hilgeman & Colleagues, 2009), and separate hierarchical regression models were run for each outcome. None of the regression steps yielded significant findings within the depression domain, so the primary focus of the present study has been on burden.

The initial step in the regression yielded non-significant findings for rurality and age, but race was found to be significantly related to changes in burden. Next, similar to Hilgeman et al. (2009) and Gallagher-Thompson and Powers (1997), objective stressors alone did not significantly predict the outcome (Step 2). This may suggest that a focus on objective stressors alone, when subjective factors such as CG depression and stress may be of

primary concern to the CG, will not yield optimal results. Due to the fact that many of the objective stressor variables examined in the present study, as well as extant REACH literature, relate to CR characteristics and behaviors, it may be that reducing CR-related assessments would allow for a greater focus on more significant CG factors, and subsequently improve outcomes and program sustainability. Interestingly, CR IADLs and CG chronic conditions remained significant in each of the subsequent regression steps, and speaks to the potential need to target these specific objective factors within the caregiving context.

Although the present study utilized considerably different variables within the resources domain as compared to previous research, the addition of this step of variables (step 3) resulted in a significant impact on outcomes, similar to Hilgeman et al. (2009) and Dilworth-Anderson and colleagues (2005). Research that examines CG resources tends to employ a more subjective approach, examining coping styles, religiosity, and social support satisfaction (Hilgeman et al, 2009; Piquart & Sörensen, 2005; Dilworth-Anderson et al., 2005). It could be that objective resources, such as those that contribute to one's overall advantage or cumulative disadvantage in society, may be just as important.

Contrary to anticipated results, the addition of the subjective appraisal variables in step 5 did not account for a significant amount of variance in the outcomes. It's hypothesized that this finding is due to the lack of validated assessments of these constructs within the current study. In an attempt to replicate previous stress process models inclusive of subjective stressors, the current analyses had to create two composite scores: one consisting of 3-items to reflect social support appraisal, and one consisting of 4-items to reflect health appraisal. Both composites were created from assessments that were not developed to

measure social support or health. Additionally, the stress appraisal measure was a subscale of the Memory and Behavior Problem Checklist. The appraised stress was not a global appraisal, but rather specific to the reported CR behavior problems. Although it could be argued that domain-specific stress is more important to target within the caregiving context as opposed to global stress, due to the aforementioned findings that objective stressors (including CR problem behaviors) were not significant predictors of change in burden (Step 2), perhaps this domain-specific approach to examining stress appraisal was not optimal.

Lastly, an exploratory analysis examined an Age x Race interaction (Step 5). Although rurality was originally hypothesized to be the primary moderator as opposed to race, due to the non-significant findings with regard to rurality and the significant relationship of race, race was further examined as a potential moderator. The resulting significant Age x Race interaction adds to the existing body of research that racial and ethnic differences significantly moderate numerous factors within the caregiving context. The family caregiving literature consistently reports differences in burden between White and ethnic minority caregivers, with White caregivers typically reporting greater burden than other family minority groups (Adams, Aranda, Kemp, & Takagi, 2002). Potential explanations offered for these differences in the level of perceived burden include stronger feelings of family obligation and greater acceptance of the family of the caregiving situation among minority family members (Aranda & Knight, 1997; Connell & Gibson, 1997).

The national REACH intervention found that behavior management skills training with CRs and problem-solving training with CGs (Coon, Schulz, & Ory, 1999) resulted in a lower frequency of care recipient behavioral problems, reduced caregiver stress appraisals, and increased caregiver leisure activities. However, there was some evidence that

interventions had differential impacts by race. African-American caregivers showed the greatest reductions in stress appraisal following behavioral skills training, while White caregivers showed greater improvement after receiving only educational support. Furthermore, Hilgeman and colleagues (2009) found that REACH outcomes differed depending on the interaction between race and resources, and Lee and colleagues (2010) found that outcomes depended on the interaction between race and coping strategy.

In a meta-analysis of caregiving research, Dilworth-Anderson, Williams, and Gibson (2002) found that African Americans' cultural beliefs and behaviors within the caregiving context helped explain better outcomes in many domains. For example, Whites were more likely than African-Americans to utilize only immediate family in caregiving and received more social services. Furthermore, African Americans had more members in their caregiving networks, were more likely to include friends and neighbors as resources, and were more likely to share caregiving responsibilities than were Whites. African-American CGs were also less likely to utilize formal supports than their White counterparts (Miller & Guo, 2000). Taken together, such patterns may explain the finding that Black CGs in the current study decreased overall burden across the intervention, whereas White CGs did not.

Similarly, Feld, Dunkle, and Schroepfer (2004) studied the support networks of Black and White CGs. Within both groups of caregivers, the presence of formal support was rare. However, Black CGs who relied solely on informal support were more likely to include members other than a spouse in their support network than White CGs. The authors tied their findings to the presence of a more communal orientation within Black communities, which may lead to lower levels of burden and depression among Black compared to White CGs

(Pinquart & Sorensen, 2005). Although the present study did not have a measure of social network size or composition, it can be posited that this is one explanation.

Overall, there are similar negative effects of caregiving on different ethnic and racial groups, however there is a large amount of variance within dimensions of stress and coping models. For example, with regard to depression and burden, Whites have been shown to report higher levels as compared to African-Americans, yet lower levels as compared to Hispanic and Asian-American caregivers (Pinquart & Sorensen, 2005). Along the same lines, Hilgeman et al. (2009) found that White or Caucasian CGs experienced significantly greater intrapsychic strain than Black or African Americans and Hispanic or Latinos. With regard to physical health, Whites fare much better than ethnic minorities in the caregiving context. Of course an obvious unresolved issue is whether or not this is specific to the caregiving context, or if it is reflective of health disparities between Whites and ethnic minorities as a whole (Knight et al., 2007; Kim & Knight, 2008).

An additional difference among populations that could be explanatory of the aforementioned outcomes could be coping style. Previous research has shown that African-American and Hispanic caregivers often endorse more emotion-focused coping, mainly religious coping, as compared to White caregivers (Cox, 1993; Navaie-Waliser et al., 2001; Lee et al., 2010; Picot, Debanne, Namazi, & Wykle, 1997), which tend to have more negative outcomes depending on domain, particularly health domains (Knight et al., 2007; Kim & Knight, 2008; Knight & Sayegh, 2010; Pinquart & Sorensen, 2005).

In general, these results suggest that race of the caregiver is an important component of the model. Race and ethnicity has been shown to impact the perceived intensity of caregiver stressors, the availability of resources, and coping processes (Hilgeman et al., 2009;

Pinquart & Sörensen, 2005). Furthermore, these differences have been linked to numerous differences in caregiving outcomes (e.g., Pinquart & Sörensen, 2006).

Limitations

Several limitations need to be addressed within the present study. The decision to use residual change scores as the dependent variable was based on previous research with REACH data (Lee et al., 2010). Residual change scores use the standardized residuals from linear regressions of follow-up scores on baseline measures to provide a change score adjusted for baseline variance (Tucker et al., 1966). Such scores are viewed as superior to pretest-posttest difference or gain scores because they do not correlate highly with the pretest scores and contain less error (Dimitrov & Rumrill, 2003; Veldman & Brophy, 1974; Zimmerman & Williams, 1982). However, there are limitations as well, primarily due to potential difficulty with statistical interpretation, as well as the process of predicting change scores based on pre-test scores being conceptually confusing.

Additional limitations include that there was only one follow-up assessment, which makes it difficult to assess the long-term effects of the intervention. The limited sample size and constrained pool of assessments meant that a limited range of variables had to be utilized in the model. There was a conscious attempt to take a theoretically-guided approach when selecting variables. This was primarily based on proposed structures of stress process models, as well as what variables extant literature suggests might be important in the caregiving context. It is possible that other variables and moderators, such as additional care recipient characteristics or subjective appraisals, are equally important to explore. Additionally, future studies may want to test a modified model by removing non-statistically significant

indicators or those with low R^2 values. After the addition of the final step in the present analysis, the model was no longer free to vary.

Lack of adequate data within racial and ethnic groups, and a mid-intervention protocol change contributed to issues with inadequate data collection. Due to the fact that the REACH intervention allows for adaptive regional translation, a protocol change in North Carolina contributed to incomplete PHQ-9 data collection, which subsequently limited the data's inclusion in the present examination. Also, due to low frequency, non-Black ethnic minority caregivers were removed from the data. Future studies, particularly within North Carolina, should oversample Hispanic/Latino and Native American CGs to better understand the pattern of outcomes across more diverse races/ethnicity.

Lastly, the non-significant findings may be due to the adaptive nature of the intervention. The REACH intervention is tailored to the needs of the CG using a risk appraisal (Belle et al., 2006). For example, if health is a primary area of risk, and identified as a primary goal by the CG, health is targeted via the use of practice-based activities such as pleasant events, meditation, exercise, a health passport etc. Due to the fact that the present study found a greater number of chronic conditions to be significantly related to greater reductions in burden, and that worse health at baseline was related (albeit non-significantly) to greater reductions in burden, this could indicate that over the course of the intervention caregivers improved health behaviors, including how to manage health conditions and employ effective stress management techniques. Follow-up analyses revealed that there was indeed a significant improvement in health from pre- to post test ($t(128) = 3.80, p < .001$). The adaptive, tailored approach to the intervention could mean that it is difficult to generate significant effects due to this variable nature of the examined constructs.

Conclusions and Future Directions

Overall, one of the most interesting findings that emerged from the current study was from the exploratory examination of race within the stress process model. The significant interaction that emerged between race and age revealed that change in burden was more strongly related to age for Black caregivers than for White caregivers; older Black caregivers experienced a significant decrease in burden as compared to White caregivers, who did not incur a significant change in burden across the intervention. This is particularly important programmatic and planning information, particularly for rapidly aging states, and states with increasing proportions of non-white residents.

Future directions will be to include an examination of caregiving priorities, or goals, within the context of the REACH intervention. The NC REACH is unique in that it allows caregivers to identify 3-5 coping goals to which to tailor the intervention. Given the significant interaction between age and race, and the breadth of literature of differing coping styles and goals across age and race, it will be important to utilize this information to more fully understand how the NC REACH intervention can be further tailored to improve caregiver outcomes.

REFERENCES

- Adams, B., Aranda, M.P., Kemp, B., & Takagi, K. (2002). Ethnic and gender differences in distress among Anglo American, African American, Japanese American, and Mexican American spousal caregivers of persons with dementia. *Journal of Clinical Geropsychology, 8*, 279-30.
- Almeida, D. M., & Horn, M. C. (2004). Is daily life more stressful during middle adulthood? In O. G. Brim, C. D. Ryff, & R. C. Kessler (Eds.), *How healthy are we? A national study of well-being at midlife* (pp. 425-451). Chicago: University of Chicago Press.
- Alspaugh, M. E., Stephens, M. A., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging, 14*, 34-43.
- Antonucci, T. C., & Jackson, J. S. (1987). Social support, interpersonal efficacy, and health: A life course perspective. In L. L. Carstensen & B. A. Edelstein (Eds.), *Handbook of clinical gerontology* (pp. 291-311). Elmsford, NY: Pergamon Press.
- Antonucci TC, Langfahl ES, Akiyama H. Relationships as outcomes and contexts. In: Lang FR, Fingerman KL, editors. *Growing together: Personal relationships across the life span*. Cambridge
- Antonucci, T. C., Akiyama, H., & Merline, A. (2001). Dynamics of social relationships in midlife. In M. E. Lachman (Ed.), *Handbook of midlife development* (pp. 528-570). Chichester, UK: Wiley.
- Arnett, J.J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469-80.
- Aranda, M.P. & Knight, B.G. (1997). The influences of ethnicity and culture on the caregiver

- stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37, 342–354.
- Baltes, P. B. (1987). Theoretical propositions of life span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology*, 23, 611-626.
- Baltes, P. B., Lindenberger, U., & Staudinger, U. M. (1998). Life-span theory in developmental psychology. In R. M. Lerner (Ed.), W. Damon (General Ed.), *Handbook of child psychology: Vol. 1. Theoretical models of human development* (5th ed., pp. 1029-1043). New York: Wiley.
- Baltes, P. B., Staudinger, U. M., & Lindenberger, U. (1999). Life span psychology: Theory and application to intellectual functioning [Review]. *Annual Review of Psychology*, 50, 471-507.
- Baltes, P.B., Reese, H.W., and Lipsitt, L.P. (1980). Lifespan developmental psychology. *Annual Review of Psychology*, 31, 65-110.
- Bauer, P. A., & Okun, M. A. (1983). Stability of life satisfaction in later life. *The Gerontologist*, 23, 261-265.
- Bédard, M., Koivuranta, A., & Stuckey, A. (2004). Health impact on caregivers of providing informal care to a cognitively impaired older adult: Rural versus urban settings. *Canadian Journal of Rural Medicine*, 9(1), 15-23.
- Bédard, M., Pedlar, D., Martin, N. J., Malott, O., & Stones, M. J. (2000). Burden in caregivers of cognitively impaired older adults living in the community: Methodological issues and determinants. *International Psychogeriatrics*, 12, 307-332.
- Belle , S. H. , Burgio , L. , Burns , R. , Coon , D. , Czaja , S. J. , Gallagher- Thompson, D. , et

- al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, 145, 727-738.
- Berwick, D.M. (2003). Disseminating innovations in health care. *Journal of the American Medical Association*, 289, 1969-75.
- Bishop, A. J., Martin, P., & Poon, L. (2006). Happiness and congruence in older adulthood: A structural model of life satisfaction. *Aging and Mental Health*, 10(5), 445-453.
- Blascovich, J. & Katkin, E. (1993). *Cardiovascular reactivity to psychological stress and disease*. American Psychological Association; Washington, DC.
- Bourgeois, M. S., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. *International Journal of Aging and Human Development*, 43, 35-92.
- Bruce, J. M., McQuiggan, M., Williams, V., Westervelt, H., & Tremont, G. (2008). Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia and geriatric cognitive disorders*, 25(4), 385-390.
- Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., et al. (2001). "Come talk with me": Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist*, 41, 449-460.
- Burgio, L., Stevens, A. B., Guy, D., Roth, D. L., & Haley, W. E. (2003). Impact of two interventions on White and African-American family caregivers of individuals with dementia. *The Gerontologist*, 43, 568-579.
- Burgio, L.D., Collins, I.B., Schmid, B., Wharton, T. McCallum, D. & Decoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging

- personnel: the REACH OUT program. *Gerontologist*, 49(1), 03-116.
- Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23(1), 33–55.
- Butler, S. S., Turner, W., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work*, 46(1), 47-63.
- Carstensen, L. L. (1992). Social and emotional patterns in adulthood: Support for socioemotional selectivity theory. *Psychology and Aging*, 7, 331-338.
- Carstensen, L. L., Fung, H. H. & Charles, S. T. (2003). Socioemotional selectivity theory and the regulation of emotion in the second half of life. *Motivation Emotion*, 27, 103-23.
- Castro, C. M., King, A. C., Housemann, R., Bacak, S. J., McMullen, K. M., & Brownson, R. C. (2007). Rural family caregivers and health behaviors: Results from an epidemiologic survey. *Journal of Aging and Health*, 19(1), 87–105.
- Charles, S. T. (2010). Strength and vulnerability integration: A model of emotional well-being across adulthood. *Psychological Bulletin*, 136, 1068–1091.
- Charles, S.T., & Almeida, D.M. (2007). Genetic and environmental effects on daily life stressors: More evidence for greater variation in later life. *Psychology and Aging*, 22, 331-340.
- Chwalisz, K., Buckwalter, K. C., & Tally R. C. (2011). Caregiving in rural America: A matter of culture. In R. Talley, K. Chwalisz, and K. Buckwalter (Eds.), *Rural Caregiving in the United States: Research, Practice, Policy*. Rosalyn Carter Institute

- Caregiving Book Series. New York: Springer.
- Cohen, S., Kaplan, J. R., & Matthews, K. A. (1994). Social support and coronary heart disease: Underlying psychological and biologic mechanisms. In S. A. Shumaker & S. M. Czajkowski (Eds.), *Social support and cardiovascular disease* (pp. 195-211). New York: Plenum.
- Connell, C. M., & Gibson, G. D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*, 37, 355-364.
- Coon, D. W., Schulz, R., & Ory, M. (1999). Innovative intervention approaches for Alzheimer's disease caregivers. In D. Biegel & A. Blum (Eds.), *Innovations in practice and service delivery across the lifespan* (pp. 295-325). New York: Oxford University Press.
- Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. *Outcomes & Insights in Health Management*, 2(1), 1-7.
- Covinsky, K. E., Eng, C., Lui, L. Y., Sands, L. P., Sehgal, A. R., Walter, L. C., Wieland, D., Eleazer, G.P., & Yaffe, K. (2003). Reduced employment in caregivers of frail elders: Impact of ethnicity, patient clinical characteristics, and caregiver characteristics. *Journals of Gerontology: Medical Sciences*, 56A, M707-M713.
- Covinsky, K.E., & Johnston, C.B. (2006) Envisioning better approaches for dementia care. *Annals of Internal Medicine*, 145, 780-1.
- Coward, R.T., Bull, C., Kukulka, G., & Galliher, J. (1994). *Health services for rural elders*. New York: Springer.
- Coward, R. T., Cutler, S. J., & Mullens, R. A. (1990). Residential differences in the

- composition of the helping networks of impaired elders. *Family Relations*, 44-50.
- Cox, C. (1993). Service needs and interests: A comparison of African-American and White caregivers seeking Alzheimer assistance. *American Journal of Alzheimer's Disease*, 3, 33-40.
- Czaja, S. J., Gitlin, L. N., Schulz, R., Zhang, S., Burgio, L. D., Stevens, A. B., ... & Gallagher-Thompson, D. (2009). Development of the risk appraisal measure: a brief screen to identify risk areas and guide interventions for dementia caregivers. *Journal of the American Geriatrics Society*, 57(6), 1064-1072.
- Davis, L. L., Gilliss, C. L., & Harper, M. S. (2011). Family Caregiving: Implications for Rural Practice, Policy, Education, and Research. In *Rural Caregiving in the United States* (pp. 19-31). Springer New York.
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist*, 42, 237-272.
- Dilworth-Anderson, P., Goodwin, P. Y., & Wallace Williams, S. (2004). Can culture explain the physical health effects of caregiving over time among African American caregivers? *Journal of Gerontology: Social Sciences*, 59B, S138-S145.
- Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 60(5), S257-S262.
- Dilworth-Anderson, P., Pierre, G., & Hillard, T.S. (2012). Social justice, health disparities, and culture in the care of the elderly, *The Journal of Law, Medicine, & Ethics*, 40(1),

26-32.

- Dimitrov, D. M., & Rumrill, P. D. (2003). Pretest-posttest designs and measurement of change. *Work-Andover Medical Publishers Incorporated*, 20(2), 159-165.
- Ducharme, F., Levesque, L., Giroux, F., Lachance, L. (2005). Follow-up of an intervention program for caregivers of a relative with dementia living in a long term care setting: are there any persistent and delayed effects? *Aging & Mental Health*, 9(5), 461-469.
- Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Arguelles, S., Mitrani, V.B., et al. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist*, 43, 521-31.
- Elliott, A.F., Burgio, L.D., & DeCoster, J. (2000). Enhancing caregiver health: findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention. *Journal of the American Geriatrics Society*, 58, 30-7.
- Feld, S., Dunkle, R.E., & Schroepfer (2004). Race/ethnicity and marital status in in IADL caregiver networks. *Research on Aging*, 26, 531-558.
- Ferraro, K. F. (1980). Self-ratings of Health Among the Old and the Old-Old." *Journal of Health and Social Behavior*, 21, 377-83.
- Fredrickson, B.L., Levenson, R.W. (1998). Positive emotions speed recovery from the cardiovascular sequelae of negative emotions. *Cognition and Emotion*, 1998, 12, 191-220.
- Gallagher-Thompson, D., Arean, P., Coon, D., Menendez, A., Takagi, K., Haley, W., et al. (2000). *Development and implementation of intervention strategies for culturally diverse caregiving populations*. In: Schulz, R., editor. *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*. New York: Springer,

p. 151-185.

- Gallagher-Thompson, D., & Powers, D. V. (1997). Primary stressors and depressive symptoms in caregivers of dementia patients. *Aging & Mental Health, 1*, 248-255.
- Gaugler, J. E., Edwards, A. B., Femia, E. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2000). Predictors of institutionalization of cognitively impaired older adults: Family help and the timing of placement. *Journal of Gerontology: Psychological Sciences, 55B*, P247-P256.
- Gitlin, L. N., Roth, D. L., Burgio, L. D., Loewenstein, D. A., Winter, L., Nichols, L., ... & Martindale, J. (2005). Caregiver appraisals of functional dependence in individuals with dementia and associated caregiver upset psychometric properties of a new scale and response patterns by caregiver and care recipient characteristics. *Journal of Aging and Health, 17*(2), 148-171.
- Gitlin, L.N., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S., Hauck, W. (2003). Effects of the home environmental skill-building program on the caregiver/care-recipient dyad: Six-month outcomes from the Philadelphia REACH initiative. *The Gerontologist, 43*, 532-546.
- Glasgow, R., Lichtenstein, E., Marcus, A. (2003). Why don't we see more translation of health promotion research to practice? Rethinking the efficacy-to-effectiveness transition. *American Journal of Public Health, 93*, 1261-1267.
- Glasgow, R. E., Klesges, L. M., Dzewaltowski, D. A., Bull, S. S., & Estabrooks, P. (2004). The future of health behavior change research: What is needed to improve translation of research into health promotion practice? *Annals of Behavioral Medicine, 27*, 3-12.

- Grafstrom, M., Fratiglioni, L., Sandman, P. O., & Winblad, B. (1992). Health and social consequences for relatives of demented and non-demented elderly: A population based study. *Journal of Clinical Epidemiology*, *45*, 861-870.
- Green, L.W., & Glasgow, R.E. (2006). Evaluating the relevance, generalization, and applicability of research: issues in external validity and translation methodology. *Evaluation of Health Professions*, *29*, 26-53.
- Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A., Collins, R. P., & Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in Black and White family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology*, *64*, 121-129.
- Hall, N. C., Chipperfield, J. G., Perry, R. P., Ruthig, J. C., & Goetz, T. (2006). Primary and secondary control in academic development: gender-specific implications for stress and health in college students 1. *Anxiety, stress, and coping*, *19*(2), 189-210.
- Hilgeman, M., Allen, R., DeCoster, J., & Burgio, L. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and Aging*, *22*, 361-371.
- Hilgeman, M. M., Durkin, D. W., Sun, F., DeCoster, J., Allen, R. S., Gallagher-Thompson, D., & Burgio, L. D. (2009). Testing a theoretical model of the stress process in Alzheimer's caregivers with race as a moderator. *The Gerontologist*, *49*, P248-P261.
- Houser, A., & Gibson, M. J. (2008). *Valuing the invaluable: The economic value of family caregiving 2008 update*. Washington, DC: AARP Public Policy Institute.

- Idler, E.L., & Benyamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38*, 21-37.
- Idler, E. L., & Benyamini, Y. (1999). Community studies reporting association between self-rated health and mortality. *Research on Aging, 21*, 392-401.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL, a standardized measure of biological and psychosocial function. *Journal biological and psychosocial function Journal of the American Medical.*
- Kaufman, A. V., Kosberg, J. I., Leeper, J. D., & Tang, M. (2010). Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. *Journal of Gerontological Social Work, 53*(3), 251-269.
- Kim, J., & Knight, B.G. (2008). Effects of caregiver status, coping styles, and social support on the physical health of Korean American caregivers. *The Gerontologist, 48*, 287-299.
- Knight, B.G., Lutzky, S.M., & Macofsky-Urban, F. (1993). A meta analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist, 33*, 240-248.
- Knight, B.G., Flynn Longmire, C.V., Dave, J., Kim, J.H., & David, S. (2007). Mental health and physical health of family caregivers for persons with dementia: A comparison of African American and white caregivers. *Aging & Mental Health, 11*, 538-546.
- Knight, B.G., & Sayegh, P. (2009). Cultural values and caregiving: Updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences, 69*(6), 1-

10.

- Kraemer, H.C., Wilson, T., Fairburn, C.G., Agras, W.S. (2002). Mediators and moderators of treatment effects in randomized clinical trials. *Archives of General Psychiatry*, 59,877–83.
- Kroenke, K., Spitzer, R.L., & Williams, J.B.W. (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16, 606-613.
- Labouvie-Vief, G. (1998). Cognitive-emotional integration in adulthood. In K. W. Schaie & M. R. Lawton (Eds.), *Annual review of gerontology and geriatrics: Vol. 17* (pp. 206-237). New York: Springer.
- Lachman, M.E. (2004). Development in midlife. *Annual Review of Psychology*, 55, 305-331.
- Lang, f., & Carstensen, L.L. (1994). Close emotional relationships in late life: Further support for proactive aging in the social domain. *Psychology and Aging*, 9, 315-324.
- Lang, F. R. (2001). Regulation of social relationships in later adult hood. *Journal of Gerontology: Psychological Sciences*, 56B, P321-P326.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people; self-maintaining and instrumental activities of daily living. *Gerontologist*, 9, 179-186.
- Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among Black and White families. *Journal of Gerontology: Social Sciences*, 47, S156-S164.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lee, C. C., Czaja, S. J., & Schulz, R. (2010). The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver social support, and religious coping on the

- effectiveness of a multicomponent psychosocial caregiver intervention, in three racial ethnic groups. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 65B, 185-194.
- Levine, C., Hunt, G., Halper, D., Hart, A.Y., Lautz, J. & Gould, D. (2005). 'Young Adult Caregivers: A First Look at an Unstudied Population'. *American Journal of Public Health* 95(11), 2071-5.
- Litwin, H., & Shiovitz-Ezra, S. (2006). Network type and mortality risk in later life. *The Gerontologist*, 46(6), 735-743.
- Luong, G. & Charles, S. (2014). Age differences in affective and cardiovascular responses to a negative social interaction: The role of goals, appraisals, and emotion regulation. *Developmental Psychology*, 50(7), 1919-1930.
- Maddox, G. L. & Douglas, E.B. (1973). Self-assessment of Health: A Longitudinal Study of Elderly Subjects. *Journal of Health and Social Behavior* 14, 87-93.
- Milkie, M. A. (2010). The Stress Process: Some Family-Level Considerations. In *Advances in the Conceptualization of the Stress Process: Essays in Honor of Leonard I. Pearlin*, edited by W. R. Avison C. S. Aneshensel, S. Schieman, and B. Wheaton. New York: Springer.
- Miller, B., & Guo, S. (2000). Social support for spouse caregivers of persons with dementia. *Journal of Gerontology: Social Sciences*, 55B, S163-S172.
- Mittelman, M.S., Ferris, S.H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer disease. *Journal of the American Medical Association*, 276, 1725-31.
- Mittelman, M.S., Haley, W.E., Clay, O.J., & Roth, D.L. (2006). Improving caregiver well-

being delays nursing home placement of patients with Alzheimer disease.

Neurology, 67, 1592-1599.

- Mittelman, M.S., Roth, D.L., Haley, W.E., Zarit, S.H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: results of a randomized trial. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 59, P27-P34.
- Murray, J., Dunn, G., & Tarnopolsky, A. (1982). Self-assessment of health: An exploration of the effects of physical and psychological symptoms. *Psychological Medicine*, 12, 371-378.
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis A. N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. *The Gerontologist*, 41, 733-741.
- Okun, M. A., & Keith, V. M. (1998). Effects of positive and negative social exchanges with various sources on depressive symptoms in younger and older adults. *Journal of Gerontology: Psychological Sciences*, 53B, P4-P20.
- Ong, A. D., & Allaire, J. C. (2005). Cardiovascular intraindividual variability in later life: The influence of social connectedness and positive emotions. *Psychology & Aging*, 20, 476-485.
- Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, 177-185.
- Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social behavior*, 337-356.

- Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 38, 583-594.
- Peterson, B. E. (2002). Longitudinal analysis of midlife generativity, intergenerational roles, and caregiving. *Psychology and Aging*, 17, 161-168.
- Picot, S. J., Debanne, S. M., Namazi, K. H., & Wykle, M. L. (1997). Religiosity and perceived rewards of Black and White caregivers. *Gerontologist*, 37, 89-101.
- Pinquart, M., & Sörensen, S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychology and aging*, 15(2), 187.
- Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving for older adults: A meta-analysis. *The Gerontologist*, 45, 90-106.
- Pinquart, M., & Sorensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 1-19.
- Prochaska, J. J., Velicer, W. F., Nigg, C. R., & Prochaska, J. O. (2008). Methods of quantifying change in multiple risk factor interventions. *Preventive medicine*, 46(3), 260-265.
- Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M.C., et al. (2005). Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. *International Journal of Geriatric Psychiatry*, 20, 168-74.
- Roberto, K.A., & Jarrott, S.E. (2008). Family caregivers of older adults: A life span

- perspective. *Family Relations*, 57, 100-111.
- Rose, J. H., Bowman, K. F., O'Toole, E. E., Abbott, K., Love, T. E., Thomas, C., & Dawson, N. V. (2007). Caregiver objective burden and assessments of patient-centered, family-focused care for frail elderly veterans. *The Gerontologist*, 47(1), 21-33.
- Roth, D.L., Mittelman, M.S., Clay, O.J., Madan, A., & Haley, W.E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging*, 20, 634-644.
- Rowe, J. W., & Kahn, R. L. (1998). *Successful aging*. New York: Pantheon/ Random House.
- Ryff, C.D., Singer, B.H. & Palmersheim, K.A. (2004b). Social inequalities in health and well-being: The role of relational and religious protective factors, in O.G. Brim C.D. Ryff and R.C. Kessler (eds.), *How Healthy are We?: A National Study of Well-Being at Midlife* (University of Chicago Press, Chicago, IL), pp. 90–123.
- Schaie, K.W., Willis, S.L., 2002. *Adult development and aging*, 5th ed. Prentice-Hall, New York.
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist*, 35, 771–791.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282, 2215–2260.
- Schulz, Richard, ed. (2000). *Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers*. New York: Springer

- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martinez, L. M., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist, 42*, 589–602.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L.N., & Mahoney, D. (2003). Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions. *The Gerontologist, 43*, 514–520.
- Schulz, R., Martire, L.M., & Klinger, J.N. (2005). Evidence-based caregiver interventions in geriatric psychiatry. *Psychiatric Clinics of North America, 28*, 1007–38.
- Schulz, R., Czaja, S.J., Lustig, A., Zdaniuk, B., Matire, L.M. & Perdomo, D. (2009). Improving the quality of life of caregivers of persons with spinal cord injury: A randomized controlled Trial. *Rehabilitation Psychology, 54*(1), 1-15.
- Seeman, T.E., Lusignolo, T.M., Albert, M., Berkman, L. (2001). Social relationships, social support, and patterns of cognitive aging in healthy, high-functioning older adults: MacArthur studies of successful aging. *Health Psychology, 20*, 243-55.
- Serrano-Aguilar, P.G., Lopez-Bastida, J., Yanes-Lopez, V. (2006). Impact on health related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. *Neuroepidemiology, 27*, 136-142.
- Shifren, K (2009). *How Caregiving Affects Development: Psychological Implications for Child, Adolescent and Adult Caregivers*. Washington, DC: American Psychological Association.
- Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*, 356-372.

- Stoller, E.P. (1984). Self-assessments of health by the elderly: The impact of informal assistance. *Journal of Health and Social Behaviors*, 25, 260.
- Sun, F., Hilgeman, M. M., Durkin, D. W., Allen, R. S., & Burgio, L. D. (2009). Perceived income inadequacy as a predictor of psychological distress in Alzheimer's caregivers. *Psychology and Aging*, 24, 177-183.
- Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving a review of empirical studies on Chinese Americans. *American journal of Alzheimer's disease and other dementias*, 27(1), 13-22.
- Talley, R.C., & Crews, J. E. (2007). Caring for the most vulnerable: Framing the public health of caregiving. *American Journal of Public Health*, 97, 224-228.
- Teri, L., Truax P., Logsdon R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist (RMBPC). *Psychology and Aging*, 7(4), 622-31.
- The Economic Value of Family Caregiving, AARP Public Policy Institute, 2012.
- Thompson, E. H., Futterman, A. M., Gallagher-Thompson, D., Rose, J. M., & Lovett, S. B. (1993). Social support and caregiving burden in family caregivers of frail elders. *Journal of Gerontology*, 48(5), S245-S254.
- Toseland, R. W., & Smith, T. (2001). *Supporting caregivers through education and training*. Administration on Aging, National Family Caregiver Support Program, Washington, DC.
- Tucker, L.R., Damarin, F., & Messick, S. (1966). A base-free measure of change. *Psychometrika*, 3, 457-473.

- Uchino, B. N., Cacioppo, J. T., & Kiecolt-Glaser, J. K. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychological Bulletin, 119*, 488-531.
- Veldman, D. J., & Brophy, J. E. (1974). Measuring teacher effects on pupil achievement. *Journal of Educational Psychology, 66*(3), 319.
- Wolff, J.L., & Kasper, J.D. (2006). Caregivers of frail elders: updating a national profile. *Gerontologist, 46*, 344-356.
- Wrzus, C., Luong, G., Wagner, G.G. & Riediger, M. (2014). Can't Get It Out of My Head: Age Differences in Affective Responsiveness Vary With Preoccupation and Elapsed Time After Daily Hassles. *Emotion*.
- Yates, M. E., Tennstedt, S., & Chang, B.-H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Psychological Sciences, 54B*, P12-P22.
- Zarit, S.H., Orr, N.K., & Zarit, J.M. (1985). *Families under stress: Caring for the patient with Alzheimer's disease and related disorders*. New York: New York University Press.
- Zimmerman, D. W., & Williams, R. H. (1982). Gain scores in research can be highly reliable. *Journal of Educational Measurement, 19*(2), 149-154.

APPENDIX

Appendix A

Detailed Overview of the REACH Intervention

History

REACH I, a multi-site feasibility study launched in 1995, explored the effectiveness of different group-based interventions to reduce the burden and distress of dementia caregivers in six participating sites: Birmingham, Alabama; Boston, Massachusetts; Memphis, Tennessee; Miami, Florida; Palo Alto, California; and Philadelphia, Pennsylvania. The interventions implemented across the six sites included: (a) Individual information and support strategies, (b) group support and family systems therapy, (c) psychoeducational and skill-based training approaches, (d) home-based environmental interventions, and (e) enhanced technology support systems. Although the interventions were derived from diverse theoretical frameworks, they are all consistent with basic health-stress models in which the goal is to change the nature of specific stressors (e.g., problem behavior of the care recipient), their appraisal, and/or the caregivers' response to the stressors.

The original REACH intervention had some of the features of a traditional multi-site randomized controlled clinical trial (e.g., random assignment of participants to treatment and control conditions, common database and outcome measures, and identical measurement intervals across sites), however it differed on one key dimension—the interventions varied across sites. REACH was designed to examine the feasibility and outcomes of multiple different intervention approaches, rather than to provide definitive information on the efficacy of one specific intervention strategy for enhancing caregiver outcomes. The strength of this approach is that it yields information about the effectiveness of different approaches to

caregiving as well as the combined effects of active treatment versus controls (Schulz, Burgio, Burns, Eisdorfer, Gallagher-Thompson, Gitlin, & Mahoney, 2003).

The pooled results of the original REACH interventions indicated that among all caregivers combined, active interventions were superior to control conditions in reducing caregiver burden, interventions that emphasized active engagement of caregivers had the greatest impact in reducing caregiver depression, women and those with less education who were in active interventions reported reduced burden compared with similar individuals in control conditions. Additionally, caregivers in active interventions who were Hispanic, those who were nonspouses, and those who had less than a high school education reported lower depression scores than those with the same characteristics who were in control conditions (Schulz et al, 2002; Coon et al., 1999; Gitlin et al., 2003; Schulz et al., 2004; Wisniewski et al., 2003).

These components included education, skills to manage troublesome care-recipient behaviors, social support, cognitive strategies for reframing negative emotional responses, and strategies for enhancing healthy behaviors and managing stress. Methods used in the intervention include didactic instruction, role-playing, problem-solving tasks, skills training, stress management techniques, and telephone support groups.

REACH II has been successfully adapted to use in the community (e.g. by personnel in local Area Agencies on Aging) and it has also been effectively adapted for use with family caregivers of persons with acquired physical disabilities, such as spinal cord injury (Burgio, et al, 2009; Schulz, Czaja, Lustig, Zdaniuk, Matire, & Perdomo, 2009).

Original Intervention Elements

The REACH intervention is multi-component, involving various treatment modalities and a range of strategies and techniques to address five potential areas of risk in caregiving: 1) Safety, 2) Social Support, 3) Problem Behaviors 4) Emotional Well-being, and 5) Self-Care and Preventive Health Behaviors. REACH uses a risk assessment to determine how much emphasis to place on each of the intervention components. Thus, the intervention is standardized with respect to the components available, but varies with respect to the dosing or depth of treatment delivered for each component. The tailoring of the intervention is guided by the findings of the risk assessment. For example, caregivers who have minimal problems with depression, but have substantial issues with safety of the care-recipient, they will receive only a small dose of the intervention component designed to enhance emotional well-being, but will receive extensive training in how to make their living situation safer for the care recipient. This enables the interventionists to concentrate on those areas where risk factors are higher. In a sense, the REACH model emphasizes a “consumer-directed” approach.

Regional Translation of the REACH Intervention

Background

North Carolina (NC) ranks 10th nationally in total population, 9th in the size of the population age 60 and older, and 11th in the population 85 and over (US Census Bureau. 2007-2011 American Community Survey). Between now and 2030, the North Carolina population age 65 and over (65+) will increase from 1.9 million to 3.0 million. Furthermore, by 2025, 86 of the 100 counties are projected to have more people over age 60 than under age 18 (see figure 5).

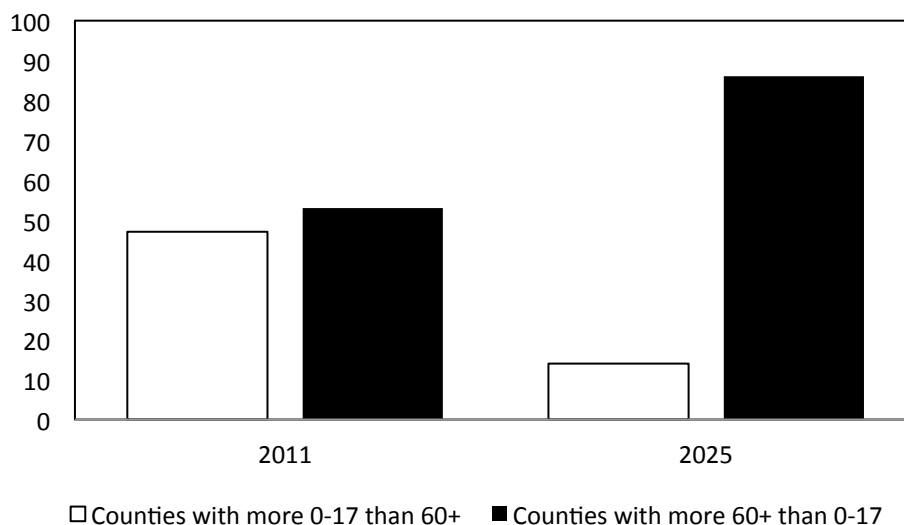


Figure 5. North Carolina counties with persons aged 0-17 as compared to persons age 60 and older.

Population projections show that by 2025, when the youngest baby boomers (born between 1946 and 1964) are age 60 and older, and are eligible for Older Americans Act (OAA) services, baby boomers will account for nearly 25% of the state’s population (North Carolina Aging Services Plan, 2011-2015). Congress passed the OAA in 1965 in response to concern by policymakers about a lack of community social services for older adults. The original legislation established authority for grants to states for community planning and social services, research and development projects, and personnel training in the field of aging. Today, the OAA is considered to be the major vehicle for the organization and delivery of social and nutrition services to older adults and their caregivers.

The OAA specifies that its funds should be directed to “older individuals with greatest economic need and older individuals with greatest social need with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural

areas” (Older American’s Act, Section 305 (a)(2)(E)). Of North Carolinians age 65+, 19% are members of ethnic minority groups, but unlike many other states, most are African-American (16%, compared to 8% nationally; US Census Bureau. 2007-2011 American Community Survey, Sex by Age; Black or African American alone), with only 3% belonging to other groups, including American-Indians, Hispanic, and Asians. Although the state has seen an increase in the Hispanic/Latino population in the past decade, most are younger than 60, so just over 1% of older adults belong to that ethnic group (US Census Bureau. 2007-2011 American Community Survey, Sex by Age; Hispanic or Latino).

As elsewhere in the nation, heart disease is the leading cause of death among people age 65+ in North Carolina, with cancer and respiratory disease being second and third. Alzheimer’s Disease (AD) is the fifth leading cause of death in North Carolina (NC State Center for Health Statistics, 2011, leading causes of death by age group). Unlike some of the other causes of death, which have a relatively short course, dementia produces progressive disability, often over a period of ten years. The number of older North Carolinians with Alzheimer’s disease is projected to increase from 170,000 in 2010 to 210,000 in 2025. In 2010 alone, an estimated 430 thousand AD and dementia caregivers provided more than 490 million hours of unpaid care in NC (North Carolina Alzheimer’s Association, 2012). This would be equivalent to approximately 6 billion dollars in AD care in North Carolina in 2010 had it not been performed by an unpaid caregiver.

The significance of this unique racial demographic profile is important when translating evidence-based aging programs to a regional population, particularly with regard to translation of programs that benefit individuals with AD. Particular attention must be paid to populations that are of high risk or predisposition to Alzheimer’s disease. Older minority

populations, particularly African Americans, are at greatest risk for developing Alzheimer's Disease, largely due to the higher prevalence of health-related risk factors for Alzheimer's disease such as obesity, hypertension, diabetes, and stroke, in African-American populations (Kivipelto, Helkala, Laakso, Hänninen, Hallikainen, and Alhainen et al., 2001). Despite being more at risk for Alzheimer's disease, older African Americans are diagnosed much later in the disease process than older Whites and, as a result, face significantly higher dementia-related morbidity and health care costs (Husaini, Sherkat, Moonis, Levine, Holzer, and Cain, 2003). Although this clearly points to underlying systemic and cultural factors with regard to diagnosis and prevention, community-based alternatives to placement for individuals with Alzheimer's Disease will be imperative in light of increasing minority and old-old populations, and decreasing economic resources, in North Carolina and the entire United States alike.

Evidence-Based Translation

In recent years there have been calls to expand the dissemination of research and to document its translation into practice (Green & Stoto, 1997; Zerhouni, 2005). This movement has been driven by the recognition that research findings should benefit the public as rapidly as possible, yet it is challenged by the often lengthy lag time between development and application of research discoveries (Berwick, 2003; Glasgow, Lichtenstein, & Marcus, 2003). Efforts to address this delay in research translation have gained heightened visibility from public health, medical care, and aging services networks.

Related to this issue is the concurrent demand to move caregiver interventions into public health practice (Covinsky & Johnston, 2006). This focus would yield systematic reviews of caregiver programs, and help identify the current state of caregiver programs and

the conditions under which they are likely to be most effective. Such examinations should ideally be inclusive of programmatic elements, regional barriers, and participant characteristics to get a holistic understanding of differential program effectiveness depending of the aforementioned elements. Additionally, this would facilitate a broader understanding of the translation processes necessary to make effective programs more accessible, affordable, and widespread.

Family caregivers remain the backbone of the health and social service system in the US; and the role of the family will continue to expand with the growth of the over 85 year old population. Caregivers of persons with dementia are particularly vulnerable, experiencing higher levels of anxiety and depression and expressing lower quality of life. There is a large literature on interventions to support caregivers; and there is substantive evidence about what works in improving outcomes for caregivers.

Many scholars are focusing on implementation and dissemination, yet uptake in practice is still limited and evidence-based interventions have not been translated for delivery in different care settings. Clearly, treatment development and adaptation work must move to implementation and dissemination work to institutionalize the years of research on this critical topic to widespread community-based practice.

The ultimate objective is to reach more people with effective evidence-based programs, and to improve the health and quality of life of caregivers and their families. The need to better understand how to move caregiver interventions rapidly into practice presents challenges and opportunities for the field of public health and caregiving (Talley & Crews, 2007).

North Carolina Resources for Enhancing Alzheimer's Caregiver Health

The Alzheimer's Disease Supportive Services Program (ADSSP) is administered by the Administration on Aging (AoA)/Administration for Community Living (ACL), within the U.S. Department of Health and Human Services. The ADSSP mission is to expand the availability of community-level supportive services for people with dementia and their caregivers with a focus on serving hard to reach and underserved areas such as low-income, rural and minority communities. In collaboration with the Aging Network and a variety of state and community-level partners, the ADSSP supports efforts to create and maintain responsive, integrated and sustainable service delivery systems by delivering support services, translating evidence-based research, and linking public and nonprofit institutions that develop and operate community-based services.

In October 2009, the North Carolina Division of Aging and Adult Services (DAAS) received a three-year ADSSP grant to implement the evidence-based intervention, REACH II through the Aging Services Network and partner organizations. Through federal grant funds, DAAS intends to fully translate the clinically-tested REACH intervention for feasible and effective use at the community level. Outcomes will be demonstrated against the core elements of REACH II.

As part of the process of translation, the REACH II intervention was initially offered to caregivers served by Project C.A.R.E. (Caregiver Alternatives to Running on Empty). Project C.A.R.E. was originally a program designed and funded as part of a federal demonstration grant in 2001 to develop systems and design services that support individuals with AD and their caregivers. Additional federal funds were secured in 2008 to expand the program to counties beyond the original four rural counties and two urban counties, and to

strengthen community-state partnerships. In 2008, Project C.A.R.E. transitioned from a federally funded demonstration program to an established state-funded program with an annual budget of approximately \$500,000. Over the past 10 years, Project C.A.R.E. has proven successful in targeting and reaching low-income, rural and minority families caring for a person with dementia at home. Adding the REACH II intervention to the menu of service options for Project C.A.R.E. clients has strengthened state efforts to address disparities in the quality, access, choice and use of dementia-specific support services for caregivers.

The REACH intervention is currently being offered in five program sites and three satellite offices, serving a total of 43 counties (see Figure 6): 1) Boone (Alleghany, Ashe, Avery, Mitchell and Yancey counties); 2) Franklin (Cherokee, Clay, Graham and Macon counties); 3) Hendersonville (Buncombe, Cleveland, Jackson, Haywood, Henderson, Madison, McDowell, Polk, Rutherford, Swain and Transylvania counties); 4) Pembroke (Bladen, Columbus, Cumberland, Hoke, Richland, Robeson, Sampson and Scotland counties); 5) Winston-Salem (Davie, Forsyth, Surry, Stokes and Yadkin counties); and 6) Washington (Beaufort, Bertie, Gates, Halifax, Hertford, Hyde, Martin, Northampton, Pitt and Washington counties). In North Carolina, interventionists called ‘Family Consultants’ deliver the REACH intervention. With the growing need for the program, DAAS intends to expand the program’s reach to all 100 counties by the end of 2013.



Figure 6. North Carolina counties currently offering the REACH intervention.