Mindfulness-Based Alzheimer’s Caregiving: A Randomized Controlled Trial
A Replication Report

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Prepared for the Virginia Department for the Aging and the US Department of Health and Human Services, Administration on Aging

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Throughout this project we have received assistance and support from many people. It would be impossible to list everyone who contributed, but we would like to acknowledge those who made it possible for us to complete this work.

We owe a debt of gratitude to the Alzheimer's Association Greater Richmond Chapter. In particular the efforts of the Chief Executive Officer, Sherry Peterson, and the Program Director, Mary Ann Johnson, were most helpful as we implemented our recruitment strategy. We couldn’t have had a more masterful social support intervention facilitator than Ms. Johnson. Her expertise and vast experience leading support groups certainly contributed to the positive results we were able to demonstrate through our data analyses.

Many other institutions also provided valuable help as well. From the beginning, Dr. Thelma Bland Watson (Executive Director, Senior Connections: The Capital Area Agency on Aging) and Ms. Mary Catharine Ginn Kolbert were most gracious in allowing our sessions to be conducted at the Senior Center, A Community Partnership. We can never adequately repay them for their accommodating generosity. We also want to acknowledge Brookland United Methodist Church for allowing our first sessions to be held there. We also appreciated the efforts of Lynne Seward, Executive Director of A Grace Place: Adult Care Center. Again, we were grateful for access to such an appropriate setting for our successful weekend retreat sessions. Reports from Ms. Seward and her staff at the Center indicate that our participants learned more about how well their loved ones adapted to a congregate, social setting.

Research is never accomplished without concerted effort from multiple project staff members, and we were delighted to engage the assistance of our most capable graduate research assistants and fiscal administrators. Ms. Shari Cordon was probably most instrumental in the formation of the original partnership between the VCU Department of Psychology and the Virginia Center on Aging when she brought the Principal Investigators together in the development of a training grant that was truly the genesis of our project. Suzzette M. Chopin, an enthusiastic collaborator, worked with Jessica M. Hellerstein and Ms. Cordon to manage essential aspects of the project, from screening potential participants to tracking the participants through the various phases of data collection. Of course, we also relied on Andrea Gordon, Financial Specialist in the VCU Department of Psychology, and Leland Waters, VCoA's Fiscal Administrator, who were always responsive when we required assistance with budgeting and accountability matters.

The recruitment challenge for this project was substantial. Our successful outreach was made possible through our work with the advertisers engaged (in no particular order): Senior Connections; FiftyPlus Magazine; Chesterfield Observer; Henrico Citizen; the Richmond Times Dispatch (and the local papers: the Midlothian Exchange; Goochland Gazette; Mechanicsville Local; and Powhatan Today); Hanover Herald-Progress; Style
Weekly; Richmond Magazine; The Richmond Voice; The Richmond Free Press; The Community Weekly; Skirt! Magazine; Ross Publishing, Inc.; and WRVA radio.

We would also like to acknowledge a few individuals who offered extraordinary assistance and support that was completely unexpected, but quite helpful along the way. Richard Burke, Extra Mile Printing (formerly The Brochure Place/XioPrint) provided much more consulting than would normally be expected in the development of our brochure and flyer. Craig Ross at Boomer Life Magazine seemed to take a special interest in our project and freely provided additional marketing advice. In memoriam, we want to recognize Rhonda Ellis of WCVE public radio who was instrumental in designing our radio advertisement in a way that was especially appealing and resulted in a superb response.

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Lastly, but most importantly, we dedicate this replication report to the family caregivers who attended the support group and mindfulness-based stress reduction sessions. Their commitment to find the time, when they had little time to give, and make the effort, even driving long distances, to participate in the programs is much appreciated. We are keenly aware of the extra burden imposed by their engagement in our study. Their willingness to share the challenges, joys, and sorrows of caregiving with others in the group enriched the experience for all involved. Ultimately, their efforts, as well as those of the entire project staff and project partners were intended to support Alzheimer’s caregivers everywhere who continue to faithfully and patiently go above and beyond, often sacrificing their own needs because of their steadfast dedication to honoring and protecting the dignity of others.

Every effort has been made to exclude the use of copyrighted material, and meticulously cite referenced material. If there have been any errors or omissions, we apologize and will be pleased to rectify these in any future editions.
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Brief Overview of Intervention Project

The majority of persons with Alzheimer’s disease (AD), particularly those in earlier stages of the disease, are cared for at home by family members, who have been shown to be vulnerable to a variety of psychological, physical, and relational problems. Caregiver burden can be detrimental for patients, caregivers, and society. As such, interventions that can reliably reduce AD caregiver burden are needed. In recent years, a number of interventions designed to address caregiver burden have been studied. An important finding to emerge from these studies is that existing caregiver interventions are not consistently effective in reducing burden in AD family caregivers. As such, there is a need to continue to study alternative interventions that may better address the complex intrapersonal and interpersonal stressors faced by AD caregivers. This project developed a novel intervention to specifically target a variety of AD family caregiver issues. In an 8-week, 2-arm randomized clinical trial, the project assessed mental health, physical health, and relationship outcomes for participants assigned to the novel mindfulness-based intervention or to an early stage support group operated through the Alzheimer’s Association. The study evaluated the immediate and longer-term efficacy of the intervention on measures of psychological symptoms and well-being, stress-related physiological functioning, and health-related quality of life in the caregivers, as well as caregiver-patient relationship quality. Thus, the intervention was designed to address an array of health, well-being, and relationship issues relevant to caregivers of persons with early stage AD. The project’s overarching goal was to assess the efficacy of a mindfulness-based intervention to reduce AD family caregiver burden. The use of established mindfulness interventions and outcome measures enhanced the potential for project success. Measures were assessed at baseline (pre-intervention), 8 weeks (post-intervention), and at a 3-month follow-up point.
I. Background

In the U.S., more than five million persons provide “informal” (i.e. in-home, unpaid) care for dementia patients, including ones with AD, a disorder characterized by progressive cognitive, functional, and behavioral decline. Relative to non-dementia care, AD caregiving has been associated with higher caregiver burden, which is a risk factor for a broad array of psychological and physical health problems. In addition, the majority of AD caregivers are family members (typically spouses, siblings, or children) who experience fractured relational bonds related to AD progression. The prevalence of AD is expected to increase dramatically during the next 25 years due to the rapid growth of the oldest age groups of the U.S. population. As such, the number of family caregivers who are affected will also increase. Thus, AD caregiving presents a widespread mental health challenge and an urgent need to develop and implement effective burden-reducing interventions for family caregivers.

Interventions to reduce AD family caregiver burden can be beneficial in several important ways. First, interventions targeting burden may reduce caregivers’ levels of stress, which have been shown to be a risk factor for negative health outcomes. In addition, less-stressed family caregivers may be able to provide home care longer for early stage AD patients, which is likely to increase quality of life. Finally, interventions reducing caregiver burden may allow family caregivers to perceive their relationships more positively. In recent years, researchers have acknowledged the need for special attention to AD caregivers and have designed interventions to address this need.

A. Existing Interventions for AD Caregivers

Because AD caregiving presents serious challenges to caregivers, interventions aimed at maintaining caregiver well-being are useful in several important ways. First, reducing family caregiver stress may successfully delay patient institutionalization by allowing family members to provide home care longer (Gaugler et al., 2000; Mausbach et al., 2007). Second, interventions that contribute to maintaining the mental and physical health of family caregivers can reduce the cost of their own healthcare and contribute to greater quality of life (Mittelman, 2005). Most important, interventions targeting caregiver burden can contribute to better psychological and physical functioning in caregivers. Recognizing this need, researchers have developed various interventions for AD caregivers, including psycho-educational programs, support groups, behavioral management programs, individual or family counseling, and multicomponent interventions (e.g., Akkerman & Ostwald, 2004; Mittelman, Roth, Coon, & Haley, 2004; Nichols et al., 2008). Interventions have been shown to reduce caregiver distress and psychological morbidity, and improve patients’ psychological well-being. However, numerous reviews have failed to identify a consistently effective method for reducing burden in AD caregivers (e.g., Bourgeois, Schulz, & Burgio,
There is also a need for interventions that address the needs of families dealing with dementia in the early stages before severe disease progression and more stressful caregiver conditions occur, and before caregivers develop physical and mental health problems that could interfere with their abilities to provide home-based support to relatives with AD.

B. Mindfulness-based Interventions

This study tested a mindfulness-based intervention as an alternative approach to effectively target AD caregiver burden. Mindfulness concerns ‘presence of mind’ – a receptive attentiveness to events and experiences occurring in the present moment, in contrast to a state of mind in which occurrences are habitually filtered through appraisals, evaluations, memories, and beliefs about events and experience (Brown, Ryan, & Creswell, 2007; Kabat-Zinn, 1994; Segal, Williams, & Teasdale, 2002). Over the past 25 years, mindfulness-based interventions have been increasingly incorporated into clinical interventions and wellness programs to teach individuals to better manage stress-related thoughts, emotions, and behavior (for reviews see Baer, 2003; Brown et al., 2007; Grossman, Niemann, Schmidt, & Walach, 2004).

Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1982), an 8-week, multi-component, manualized intervention, is the most frequently cited clinical application of mindfulness in the research literature. The intervention incorporates a variety of mindfulness techniques, including meditation training, yoga, dyadic exercises, and psycho-education to teach skills for managing stress and regulating emotions.

c. Effectiveness of MBSR

A growing body of evidence links MBSR with a wide range of salutary outcomes including reduced symptomatology in persons with medical disorders (Kabat-Zinn, Lipworth, & Burney, 1985; Reibel, Greeson, Brainard, & Rosenzweig, 2001), improved psychological functioning in psychiatric populations (Kristeller & Hallett, 1999; Teasdale et al., 2000), and improved immune functioning and overall well-being in both community and clinical populations (Carlson, Speca, Patel, & Goodey, 2003; Davidson et al., 2003; Williams, Kolar, Reger, & Pearson, 2001).

D. Mindfulness-based Intervention for AD Caregivers

Two pilot studies have examined the efficacy of a mindfulness-based intervention in alleviating AD caregiver burden (McBee, 2003; Pope et al., 2006). Although these studies lack the methodological rigor of randomized trial designs, the findings provide preliminary support for the utility of mindfulness training in reducing caregiver burden and improving their psychological well-being.

Our work has now extended this nascent line of research by employing more rigorous methodology in evaluating the efficacy of mindfulness training among
AD caregivers. Mindfulness training has been shown to facilitate emotional regulation and decrease stress (e.g., see reviews by Baer, 2003; Grossman et al., 2004), which has relevance for AD caregivers because caregivers with high expressed emotion tend to report higher levels of stress and depression, have more impaired mental health, less social support, and less effective coping strategies (Bledin, MacCarthy, Kuipers, & Woods, 1990; Zanetti et al., 1998). Our study rationale also drew logically from the understanding that the mindfulness-based intervention would successfully target AD caregiver burden in two important ways. First, existing interventions typically teach caregivers specific techniques to manage specific patient-related problems, which may become less useful over time as behaviors change. In contrast, mindfulness interventions teach a generic approach to stress management that can be adapted to various stressful situations. Second, by including the dyad, a mindfulness intervention can also address the relational aspect of caregiving.
II. Planning and Partnerships

A. Needs assessment results

Our intervention was grounded in the identification of the key psychological and interpersonal needs within the AD family caregiver population that a mindfulness-based program might help to address. Approximately one year prior to implementing the intervention, we conducted a web-based survey that would guide us in adapting the manualized and well-validated Mindfulness-Based Stress Reduction (MBSR) program (Santorelli & Kabat-Zinn, 2002) to an AD caregiver population. Before proceeding to such an intervention, however, we wanted to determine whether AD caregivers would have sufficient interest in mindfulness-based strategies for managing stress and improving relations with AD patients. By examining the interests and psychological needs of AD caregivers, we could determine the likelihood that a mindfulness-based program could be successfully implemented within the context of a randomized clinical trial. The specific input of caregivers on this assessment also helped us shape a mindfulness-based program that would better fit their needs and interests. We documented interest in specific mindfulness practices and practical issues (e.g., scheduling) and then used that information to design the format and content of the program. The study also allowed us to characterize the responding AD caregiver sample to roughly estimate the demographic composition of intervention program participants.

The survey (see Section VIII.C. Tools & Resources) was posted at the Comprehensive Virtual Center on Alzheimer’s Disease and the AlzPossible website (www.alzpossible.net). The Virginia Alzheimer’s Disease and Related Disorders Commission created this website to better fulfill their charge as an advisory commission in the executive branch of state government (http://www.vda.virginia.gov/alzcommission.asp). The web site infrastructure functions to facilitate the delivery of Alzheimer’s disease-relevant information and services.

The survey first described the various components and techniques to be included in the program, and asked for respondents to indicate how appealing the particular aspect would be to them. It then assessed their level of general interest in the program, and asked about the factors that would deter or facilitate their participation. Data from 65 family caregivers who responded to the survey prior to implementation of our program were encouraging. The vast majority of respondents were very (56%) or somewhat (34%) interested in the program.
Table 1. Results from caregiver needs assessment survey

The majority of participants were at least somewhat interested in each of the various components of the program (see Table 1). They were most enthusiastic about the consequences of participating in MBSR (e.g., responding more positively to stress, interacting in a more relaxed way with their care recipient (80-90% regarded the components as very much or extremely appealing). There was less enthusiasm for the guided meditation and gentle movement or exercise techniques that would lead to these consequences, however (less than half of participants thought these components were very much or extremely appealing).
Both respite care and transportation were important determinants of the respondents’ abilities to participate in the program. There was a great deal of variability with respect to the length and scheduling of classes, as well as the duration of the program. The majority of respondents were women (72.6%) and the average age was 57.6 years. The vast majority (92%) were White (not of Hispanic origin), and almost half (46.15%) were working full time (40 or more hours per week). Yet more than two-thirds (68.8%) were currently married or living with a partner, and 80% were in good or excellent health.

A. Adaptations to the original MBSR intervention/approach

The needs assessment results helped us design a mindfulness-based program that would better fit the needs and interests of our targeted caregivers. Intervention fidelity was balanced with the program modifications necessary to maximize program effectiveness. The MBSR program has built-in flexibility to accommodate different populations. So while the program was modified to suit the specific care and stress-related needs of the participants, program fidelity was not compromised.

Because the groups were homogeneous in terms of their shared stressful caregiving situations, the focus was not only on learning and experiencing their own individual relationships to mindfulness practices, but also on how they could be applied in dealing with challenges due to frustrations, guilt, or unwanted behavioral reactions. The tone of mutual support for one another as caregivers worked well in the unfolding of their positive and negative shared experiences about practicing mindfulness. For example, dealing with time constraints, facing difficulties in caregiving rather than avoiding them, over-reacting, and creating opportunities for loving connection or joy were all aspects of the experiences shared. Participants often reported that discovering this mutuality countered some of their feelings of isolation and loneliness. Learning a skill that could apply to all areas of their lives seemed revolutionary, given that the intervention focused on caregiving.

The commonly shared experiences also allowed the MBSR interventionist to adapt more specific language to address the caregivers’ experiences more directly. For example, guidance focused on paying more attention to guilt or anger, and its direct felt experience. Caregivers were also guided in addressing choices related to how they could cope more effectively with feelings in the midst of the painful situations they faced as responsible caregivers at home. The practice of mindfulness was modeled by the interventionist as everyday experiences were met in the moment with acceptance, compassion, and identification with more choices than previously known or experienced.

The core elements of the program deemed essential in maintaining fidelity were the mindfulness practices in class and as homework, and the social support offered through in-class discussion. No elements were compromised other than the unrealistic expectation that a full-day of retreat could be managed by the caregivers. The half-day format appeared to work well and the goal of providing a taste for a longer, more sustained focus and practice of mindfulness in silence.
and stillness was accomplished. The MBSR program is very flexible. Mindfulness is a quality of attention that can be applied to anyone with the cognitive capacity to sustain attention.

B. Establishing Successful Partnerships

1. Communicating program requirements

Early in the project, it was important to communicate the program requirements to our primary partners with the Alzheimer’s Association Greater Richmond Chapter. First, we shared the conditions of approval from the Virginia Commonwealth University (VCU) Office of Research Subjects Protection Institutional Review Board (IRB) protocol (see Appendix A) so the Chief Executive Officer (CEO) and Program Director (who served as the social support intervention facilitator) would be aware of the ethical obligations we were bound to uphold as investigators. We also shared the consent form (see Appendix B) and the Institutional Review Board protocol (see Appendix C). This documentation provided additional detail about the involvement of human subjects, including the recruitment and compensation plans, the consent process, and the privacy and confidentiality procedures for data safety and monitoring. It also gave them a better understanding of the project goal, specific aims, background and significance, research methods, and study design. In addition, the protocol specified the Chapter’s roles and responsibilities.

The PI and Co-PI, as well as the Virginia Center on Aging (VCoA) research assistant, Ms. Jessica Hellerstein, met with the CEO, Ms. Sherry Peterson, LCSW, under the auspices of the Virginia Department for the Aging. We presumed that this partnership would constitute our primary source for recruiting participants into the study. It was determined that the Chapter support group network, especially the early stage and younger onset groups, would yield the bulk of potential study participants. The CEO was forthright in her insistence that the researchers not have direct access to the support groups. We had previously presumed that we would be making arrangements with the individual support group facilitators to make on-site presentations about the opportunity to participate in the research. The CEO made it clear that the facilitators would only permit this if the group members were first consulted about their preference. Because it seemed like our initial plans presented an imposition and intrusion on the normal conduct of support group meetings, we deferred to the CEO and her staff to visit the support groups and engage the support group facilitators in promoting the research opportunity. To assist us in additional community-based recruitment efforts, the Chapter forwarded the contact information for the adult day care centers, assisted living facilities, home care agencies, and the offices of community physicians, psychiatrists, and neurologists in the Chapter territory.

We also wanted to explore how funding for respite care would be provided. Since the Chapter received funds for their on-going respite scholarship program under the same grant initiative that supported our research, we were interested in determining whether any of those funds would be available to the participants we
recruited for the study. It was important to come to a “meeting of the minds” regarding this issue at the outset, and a frank face-to-face discussion was the optimal way of reaching agreement. In the end, funds were allocated in the budget for our study to reimburse the Chapter for the respite care provided.

At the meeting with the Chapter we also discussed the definition of “early stage” being employed by the Alzheimer’s Association that was adopted for use in the present Alzheimer’s Disease Supportive Services Program (ADSSP) initiative through the U.S. Administration on Aging (AOA; see Appendix D). Communicating this critical criterion was an essential first step in making sure that we would not be turning away individuals who would otherwise qualify for participation but were ineligible because of the advanced stage of their care recipients (i.e., one or more deficits related to the activities of daily living (ADLs) or an inability to participate in a give-and-take dialogue). It was important for the Chapter to be clear that we could not accept any prospective participants whose care recipients were incapable of conversing or were compromised with respect to their ADLs. We needed our recruitment efforts to be proactively selective in order to avoid engendering disappointment among caregivers in need of our help, but unable to access it due to our particular constraints. We also made plans about how this should be incorporated into our determination of eligibility for the study through the use of the Functional Assessment Staging of Alzheimer’s Disease (FAST) instrument (Reisberg, 1988). We included this measure as part of the screening process because it could potentially allow us to control for the care recipients’ functional stage in our data analyses, but also because it served our purposes for applying the inclusion criterion related to our early stage focus.

2. Determining how partners can best be involved
   a) UVA Mindfulness Center

   The Mindfulness-Based Stress Reduction trainer, Ms. Allie Rudolph, LCSW, was engaged directly based on Co-PI Brown’s previous contacts with the University of Virginia (UVA) Center for Mindfulness, which provides mindfulness training services to UVA patients and central Virginia community members throughout the year (http://www.medicine.virginia.edu/clinical/departments/medicine/divisions/general-med/the-mindfulness-center). Until her recent retirement just before the project began, Ms. Rudolph was a mindfulness trainer in the Center for 12 years. As such, Ms. Rudolph was contracted for the current project independently, and buy-out from her services to the Center was not required. Early in our relationship with Ms. Rudolph, there arose a clear, shared interest in adapting the MBSR program to test the promise of this intervention for family caregivers of those with Alzheimer’s Disease and other dementias.

   b) Senior Connections: The Capital Area Agency on Aging

   Another partnership was also important from the beginning of the project. VCoA has a long history of working with Senior Connections: The Capital Area Agency
on Aging (AAA), and PI Google had worked with their Caregiver Support Services Manager for a number of years through the Richmond Area Caregiver Coalition. Composed of diverse leaders in the field of aging services, this group was established in 2004 under Title III-E in the Older Americans Act pertaining to the National Family Caregiver Support Program (NFCSP). By conducting the evaluation of a Respite Care Incentive Grant project under the direction of the AAA, with state-level funding from the state unit on aging (Virginia Department on Aging), the PI became well aware of these services offered by the AAA to help family caregivers (i.e., direct payments and scholarships to help family caregivers use adult daycare, in home personal care, and transportation to services). VCoA was also involved in a community foundation grant that supported development of the CareCompass initiative (http://www.seniorconnections-va.org/Portals/0/CareCompassIntro.pdf) and the EmployedCaregivers.org web resources (http://www.seniornavigator.org/www.employedcaregivers.org/). VCoA ultimately created the replication report for the Workplace Partners for Eldercare project (http://www.vcu.edu/vcoa/index/workplace_partners.pdf). All of these efforts were made possible through the staff support position created under the NFCSP, so we were happy to continue our collaboration through this new initiative focusing on Alzheimer’s caregivers.

The RTI International report on the relationship between the Alzheimer’s Disease Demonstration Grants to States (ADDSG) program (now the ADSSP) and the NFCSPs in multiple states describes how these two programs have complemented each other and outlines the benefits that have resulted from the collaboration in a number of states (Brown & Wiener, 2008; www.adrctae.org/tiki-download_file.php?fileId=29109). In Virginia, we assumed that this inter-relationship would be helpful as we recruited program participants. The Senior Connection’s Caregiver Support Services Manager began by disseminating our recruitment information to members of the Richmond Area Caregiver Coalition (n=30). In this way we were able to get the word out to a diverse group of service providers in the community. In addition to the adult day service and home care administrators, word of our project reached the American Red Cross, the American Hospice Foundation, and Jewish Family Services. The NFCSP staffer vigorously disseminated brochures and flyers throughout the duration of the project at all of the agency’s caregiver events (education sessions, health fairs, etc.). This utilization of the NFCSP infrastructure promised to provide us with a remarkable opportunity to identify, refer, enroll and serve the caregivers targeted in our ADSSP project. Unfortunately, our analysis of Referral Sources from the phone calls received was not indicative of this. Only a few of our callers could be tied to referral sources related to the AAA.

c) Senior Center, A Community Partnership

We also approached the AAA when we were looking for an appropriate site to conduct the MBSR intervention. Senior Connections had recently partnered with the Junior League of Richmond when the Senior Center of Richmond, established in 1957, dissolved. The resulting entity, the Senior Center, A Community Partnership, seemed a natural choice for our program site, since they already offered a Caregiver Resource Center and sponsored a Pathways
Program, providing focused activities for older adults with mild to moderate cognitive disabilities. It was located centrally in the City, with easy access and parking, and as a long-lasting establishment, it was well known. They agreed to provide the space for our program free of charge. Unfortunately, we soon learned that there were plans to move the Senior Center to a new location out of the City. This was ultimately fortuitous, however, as the new location was more proximal to the Alzheimer’s Association offices and more convenient, not only for the Social Support group facilitator, but also for the University of Virginia interventionist who traveled weekly to conduct the MBSR sessions. More importantly, the new site proved to be an ideal setting for the MBSR sessions. We enjoyed a large glassed-in space and a light, airy environment with beautiful views of the wooded grounds, and well-maintained paths circling a sparkling lake with geese and ducks. This created a highly conducive environment for the session work being conducted there.

In addition, our initial intake sessions were conducted on the VCU campus, but learned that participants would prefer to avoid the congested urban university environment with its traffic and parking issues. As a consequence, we subsequently made arrangements for all of the intake sessions to be held at the Senior Center (see Intake Invitation Letter in Section VIII.A. Tools & Resources). This was advantageous because participants learned the driving directions at intake and were even further oriented by the intervention start dates. Ultimately, the Senior Center agreed to provide space for the Social Support sessions, as well as the MBSR sessions.

We also worked with the Pathways Program coordinator, to enroll their participants in the study. Although this was not as successful as we had hoped, a relationship was established that could prove helpful in the future as we seek to sustain our initiative.

d) Adult Day Services

The MBSR program includes a ‘retreat day’ in which participants are given the opportunity to deepen and further develop their understanding and application of the stress-reduction practices taught in the weekly classes (see Section VIII.A. Tools & Resources). In consideration of caregiving and respite care demands, we decided to conduct a half-day (four-hour) retreat. Again, our partnership with the Alzheimer’s Association was helpful in the arrangements for this event. The Social Support facilitator with the Chapter worked with the CEO of an adult day services center as a site for the retreat. The CEO had a long history of serving on the Chapter’s Board of Directors with the project PI. By using the Center as the retreat site, participants could be accompanied by their care recipients. The Center provided programming for the care recipients in the special care unit, while the caregivers engaged in their retreat. A Grace Place: Adult Care Center has a well-developed memory support program that focuses on reminiscence therapy and Eden Alternative principles. They also have an established creative arts program, and we knew that this would be a stimulating way to engage the care recipients. So, an experienced art instructor and art therapist became another important community partner brought in to facilitate our study.
We also worked with other reputable adult day services centers in the area. They received our mailed information (cover letter, project summary, brochures, and posters) using the list provided by the Alzheimer’s Association. The community liaison at one center was particularly interested in helping us get the word out to their caregivers, and at least one of the participants we enrolled was recruited through our affiliations with the adult day services network in our area.

e) Home Care Agencies, Assisted Living Facilities, Physicians, Psychiatrists, etc.

Our mailing to home care agencies was also productive to some extent. By talking directly with the agency heads we obtained a commitment that they would cull their lists of clients for individuals who met our particular criteria. They would then make arrangements to forward our brochures to the appropriate caregivers. It was encouraging to realize that even after the recruitment phase ended, the home care agencies were calling to see if they could still offer our program to their families.

We knew that the Chapter had good relations with the assisted living facilities and they were strong supporters with respect to the Chapter’s programming and fundraising efforts. So, it was a surprise that our efforts to establish partnerships did not yield the desired result in terms of our recruiting. They were receptive when approached about helping with the recruitment for our study, and yet the established alliances were not fruitful.

Our outreach to physicians, psychiatrists, physiatrists, and neuropsychologists was also not as productive as we originally hoped. Again, a number of the physicians who received our mailings had close ties to the Chapter, and several had served with the project PI on the Chapter’s Board of Directors or had been colleagues in other respects. But the referrals did not materialize as we expected. A few related connections within the University were also promising, but ultimately unproductive. We posted flyers in the Primary Care and Neurology clinics at VCU Medical Center, and the Geriatric Care Manager in the division of Geriatric Services at the VCU Medical Center vigorously promoted our opportunity, and the Chair of the Division of General Internal Medicine informed his House Calls team of physicians and nurse practitioners. This innovative, but well-established, intensive home-based medical services program serves approximately 275 patients with multiple chronic conditions each month. Unfortunately, the only referral we screened was not qualified for the study due to the advanced condition of the care recipient. We were also able to work with the Richmond Veteran’s Affairs Medical Center and the Southeast Parkinson’s Disease Research, Education and Clinical Center to engage their Richmond support group members in our study.

Although most of these partnerships generated calls, ultimately many were generally unsuitable due to our restrictive inclusion criterion. Our conclusion was essentially the same as our original presumption. In the absence of a formal, grant-supported relationship with a memory disorders clinic that strictly applies
the study’s specific inclusion and exclusion criteria prior to referral, recruitment of potential participants becomes much more challenging. Although we reached out to the neurologist that staffs the University’s dementia clinic, and directly requested help from the Nurse Practice Manager in Neurology who schedules the clinic, our partnership with the more active and well-established memory disorders clinic at the University of Virginia, would have allowed us to better target the recruitment of caregivers of those with early stage dementia. Due to the distance potential participants would need to travel each week to attend our programs however; the potential productivity of this partnership was severely limited.

3. Leveraging trust through community advocates using a top-down approach

Our top-down approach to leverage trust was accomplished primarily through our partnerships with the Alzheimer’s Association Chapter and the AAA. Because the trust-worthy reputations of these two key partners was an exceptional advantage in the recruitment process as described above, our start-up for the project would have been much more difficult without the assistance we were provided. As we began to explore sites for our programs, the Chapter immediately determined that the Support Group intervention would occur in one of the typical settings that have been established for their network of monthly support groups, i.e., churches and long term care or assisted living facilities. The Chapter’s Program Director, Mary Ann Johnson, MA, quickly determined the best location for the intervention that she would be facilitating and made the arrangements needed. But we requested her assistance in helping us explore venues for the MBSR intervention. We assumed, and she confirmed, that cold calls from us to the churches would not likely be successful. We knew that the Ms. Johnson’s graduate degree in Christian Education and her established reputation in the ecumenical community would be useful when approaching members of the clergy to secure their cooperation. Several sites were identified and she made initial inquiries about the availability of space that would be suitable for our needs. The MBSR group needed more open space than is required for the support groups, so more was being asked of the churches in this instance. For example, rather than a small multipurpose room with tables and chairs, we were interested in fellowship halls. Yet, these inquiries on our behalf were considered because of the trusting relationships previously established between the church community and the Chapter staff.

Ultimately, as described above, we were able to situate the MBSR interventions at the Senior Center. When funds were first granted, the Executive Director of the AAA was also directing the Senior Center. Because of our close collaborations in the past, we turned to them in our quest for appropriate space. Although we were easily able to negotiate an arrangement that would suit our purposes, a new Director of the Senior Center was soon appointed. The new director was a past president of the Junior League of Richmond and a prominent community leader. We had not established a relationship with her previously, but were able to rely on the AAA to pave the way for us. As a consequence, a
trusting relationship soon developed and, as we have described above, this new connection was fortuitous indeed.

4. Clearly specify benefits to participants so partnering organizations can accurately communicate them

When discussing the program with our partnering organizations, we were careful to emphasize the proven benefits of our interventions for the participants. We developed the following explanation of the MBSR intervention to concisely and clearly communicate our intention as follows:

To develop and test the efficacy of a mindfulness-based intervention model for teaching coping skills to the caregivers of persons with Alzheimer’s Disease.

Mindfulness concerns ‘presence of mind’ – a receptive attentiveness to events and experiences occurring in the present moment, in contrast to a state of mind in which occurrences are habitually filtered through appraisals, evaluations, memories, and beliefs about events and experience.

For 25 years mindfulness-based interventions have been incorporated into clinical interventions and wellness programs to teach individuals to better manage stress-related thoughts, emotions, and behavior.

To date, only two pilot studies have examined the efficacy of a mindfulness-based intervention in alleviating AD caregiver burden. Although these studies lack the methodological rigor of randomized trial designs, the findings provide preliminary support for these kinds of interventions.

The practice of mindfulness meditation has grown exponentially over the past thirty years both in the U.S. and across the globe. Indeed, it has been suggested that mindfulness and morality are found at the intersection of science and spirituality, and that science, rather than religious institutions, may come to provide answers about what it means to lead both a compassionate and happy life (Stiles, 2007). But we knew that the concept would not be familiar to everyone. So our first challenge was to provide an immediately understandable definition. Then we had to unequivocally relate the well-established literature supporting the evidence base for MBSR. Finally, because our application was innovative, we had to assert the preliminary evidence and in the process imply the rationale for our controlled experimental design. The above explanation suited all of these purposes.

5. Make sure that partnering agencies understand the benefit to them as well

Successful collaborative partnerships provide benefits to everyone involved. They fit within the mission of the partners, expand reach, or provide new tools and understanding that complement existing programs. Throughout the process of establishing our partnerships and determining how the various organizations
could best be involved, we were always cognizant of how the collaborations
could be mutually beneficial. We've mentioned the synergy between our ADSSP
funded project and the AAA's NFCSP initiative. Our program also became an
additional resource in the arsenal of assistance provided by the AAA's Caregiver
Support Services Manager. The same is true for the Care Coordinators in the
field, as well as the Case Managers who made referrals to our program. The
Alzheimer's Association was also happy to have another option for the families
that they support. The Program Director reports that those who participated in
her social support intervention bonded so thoroughly that they are continuing to
meet independently. There is a chance that the group may request the
involvement of a support group leader who has been trained by the Chapter.
The Chapter also had the opportunity to participate in its first research project
specifically targeting caregivers of those in the early stages of the disease. In
addition, the support group leaders were able to provide a local opportunity for
their members who are always interested in participating in Alzheimer's research.
The Senior Center advanced its mission to promote mental, physical, and
emotional health. The new partnership also helped strengthen their ever-
expanding ties to the community. The same is true of the Adult Day Services
Center. The MBSR retreat helped to advance their mission to provide resources
and information designed to educate and enrich family members who care for
individual's with Alzheimer's disease and other dementias. We were especially
gratified by the number of caregivers who brought their care recipients to the
MBSR retreat at the Adult Day Services Center. If they were previously unaware
of the socialization advantages available in this kind of group setting, they
certainly became enlightened. They are also now aware of this respite option, as
they continue their individual journeys as caregivers.
III. **Reach: Recruiting Participants**

A. Recruitment and Retention

In the initial phase of the project, the plan for engaging research subjects and the recruitment materials were developed. Modes of communication to recruit participants included state and local newsletters, magazines, newspapers, e-mails, and internet ads. Later the radio was used as a productive marketing approach. Project staff compiled a list of print media outlets that targeted caregivers could be expected to read (e.g., relevant magazines, special sections of newspapers) and in which we planned to advertise the study (see Section VIII.B. Tools & Resources). In addition, brochures and flyers, based on the wording approved by the VCU IRB (see Section VIII.B. Tools & Resources), were disseminated throughout the community at churches, assisted living facilities, physicians’ offices, congregate retirement communities, and other venues.

1. Take the program to where the people are

Recruiting caregivers of family members who had early stage Alzheimer’s disease or other dementias began as soon as possible. In the recruitment process, it works best to go where the people are already seeking services. Our community partnership with the Alzheimer’s Association was central in this regard. Their ability to reach the specific early stage subgroup within the target population of Alzheimer’s caregivers was superb. The Table below shows that we received at least eight calls from support group members.

<table>
<thead>
<tr>
<th>Heard About Study</th>
<th>Count (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Radio</td>
<td>29 (17.0%)</td>
</tr>
<tr>
<td>Fifty Plus</td>
<td>15 (8.8%)</td>
</tr>
<tr>
<td>Friend/Care Provider</td>
<td>13 (7.6%)</td>
</tr>
<tr>
<td>Richmond Times Dispatch</td>
<td>12 (7.0%)</td>
</tr>
<tr>
<td>Boomer Life</td>
<td>10 (5.8%)</td>
</tr>
<tr>
<td>Flyer Posted</td>
<td>10 (5.8%)</td>
</tr>
<tr>
<td>The Community Weekly</td>
<td>9 (5.3%)</td>
</tr>
<tr>
<td>Support Group</td>
<td>8 (4.7%)</td>
</tr>
<tr>
<td>Age in Action Mass Email</td>
<td>7 (4.1%)</td>
</tr>
<tr>
<td>Alzheimer’s Association/Chapter Newsletter</td>
<td>7 (4.1%)</td>
</tr>
<tr>
<td>Connect Richmond</td>
<td>7 (4.1%)</td>
</tr>
<tr>
<td>Other ListServs (Sr. Resource Digest, VCUHS)</td>
<td>5 (2.9%)</td>
</tr>
<tr>
<td>Style</td>
<td>5 (2.9%)</td>
</tr>
<tr>
<td>Brochure from Daycare/ALF</td>
<td>4 (2.3%)</td>
</tr>
<tr>
<td>Doctor’s office</td>
<td>4 (2.3%)</td>
</tr>
<tr>
<td>Richmond Mag/Skirt!</td>
<td>4 (2.3%)</td>
</tr>
<tr>
<td>Richmond Voice/Free Press</td>
<td>2 (1.2%)</td>
</tr>
<tr>
<td>Senior Connections Mature Life/AAA</td>
<td>2 (1.2%)</td>
</tr>
<tr>
<td>Web Ad</td>
<td>2 (1.2%)</td>
</tr>
<tr>
<td>Clear Channel</td>
<td>1 (0.6%)</td>
</tr>
<tr>
<td>Did not say/did not recall</td>
<td>15 (8.8%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>171 (100%)</td>
</tr>
</tbody>
</table>
Brochures and posters were mailed directly to adult day care centers (n = 15), assisted living facilities (n = 60), home care agencies (n = 54), and the offices of community physicians, psychiatrists, and neurologists (n = 30). These lists were provided by the Alzheimer’s Association Greater Richmond and contact information was entered into a database that could be used to generate personalized cover letters modified appropriately for each of the four target groups (see Section VIII.B. Tools & Resources). The mailings also included a more detailed summary of the project (see Section VIII.B. Tools & Resources). We were able to document four calls from caregivers who learned of our project when they made visits to their “doctors,” and at least that many from those who saw our promotional materials at an adult day services center or assisted living facility.

We knew that our recruitment success would depend to some extent on our choice of location for the programs. When we initially started recruiting, we hadn’t yet determined our program location sites and wanted to choose them based on what would be the most convenient for the participants recruited. However, this strategy was misguided because callers wanted to know where they would have to travel to each week before committing to participate. Once we had determined our program locations, participants could factor this into their decision about whether or not to participate. As time went on, we learned how having as much information as possible to give to potential participants facilitated the recruiting process. Ultimately we used a church where one of the Alzheimer’s Association’s monthly support groups met for the Social Support intervention group, and the Senior Center for the MBSR intervention group. Both of these locations had ample free parking and were convenient for people coming from different regions within the Greater Richmond Area. For the second series of sessions, all programs were held at the Senior Center.

Geography and the location of our program sites were also important considerations when developing our advertisement plan. In our advertising for the second series of sessions, we tried to hone in on a specific subgroup of Richmond newspaper readers who lived within certain geographic areas of the city. We tailored print advertising efforts to maximally take advantage of the Senior Center’s location. We added additional print media sources, including the Richmond Skirt!, a popular monthly magazine targeted to women. We explored the use of local inserts in the major daily newspaper, the Richmond Times Dispatch (RTD), tailored for the specific counties and areas surrounding the City (Chesterfield, Midlothian, Goochland, Powhatan, and Mechanicsville). In addition, our ad appeared as part of those local inserts included in The Community Weekly pages (sponsored by Richmond Area Businesses). This publication was sent to homes in seven zones of one county (Chesterfield) and all zones of another (Powhatan) that are proximal to the Senior Center.

We continued to advertise with the RTD, this time with our advertisement appearing in the section for caregiver news and information. We used a variety
of different print advertisements including monthly, bi-monthly, weekly, and special publications. For the daily paper, we placed ads in the regular section devoted to aging-related issues and resources. But when there was a specialty publication for caregivers, we were able to reach 450,000 readers. Because this resulted in only one call, we turned our focus to other publications. We chose those that were cost effective and renewed our contract with certain publications (such as Boomer Life and Fifty Plus) because of the steady number of calls generated from those two publications. Boomer Life is a widely circulated bimonthly print magazine that is available for free at area grocery stores, medical offices, vending boxes, restaurants, and professional office buildings. Another popular senior publication, Fifty Plus is also a widely circulated monthly newspaper available for free at approximately 400 locations in the greater Richmond area, including grocery stores, malls, and libraries. Another popular publication sold on the newsstand in the Richmond area was not as helpful. Although the advertising rate was comparable to those in the daily paper, the response was not nearly as good. With at least five calls documented, we had somewhat better luck with the free and well-established Style Weekly, Greater Richmond's alternative newsweekly.

We also took advantage of the freely available advertising available. Our announcement was featured prominently in the newsletter produced by the state unit on aging (VDA) and the VCoA (see Section VIII.B. Tools & Resources). Age in Action has a target audience of professionals in the field of aging - gerontologists, geriatricians, health professionals and administrators, adult home and community professionals, and others interested in geriatrics and gerontology education and research in the Commonwealth of Virginia. The Alzheimer's Association Greater Richmond agreed to include our ad in the Chapter Newsletter (14,500 printed with 13,900 mailed each quarter), and Senior Connections (the AAA) also ran the ad in their publication, Mature Life. An e-mail advertisement to recruit study participants was sent to all of the employees in the Medical College of Virginia hospitals. This latter method of outreach was singularly unproductive. But since our programs were not tailored to suit the needs of working caregivers, this lack of response is not so surprising in retrospect.

Recruitment efforts also included internet advertisements. In support of our project, Boomer Life offered to create and post a banner on the home page of their on-line magazine free of charge. When viewers click on the banner they are directed to the full ad included in the magazine (see Section VIII.B. Tools & Resources). We also worked with a fellow faculty member in the Department of Gerontology to post a prominently placed ad in the Central Virginia Section of the National Caregivers Library (see Section VIII. B. Tools & Resources). The National Caregivers Library was created by FamilyCare America, Inc. and is the largest single source of information and tools for caregivers and seniors in the country. It makes its resources available to caregivers for free through alliances with professionals, businesses and other organizations who serve seniors and
their caregivers with a variety of products and services. Caregivers who click on the homepage banner ad are led to the advertisement and a fuller description of the project. We were surprised to learn that we could not document a single referral from this latter source.

Since a few of our participants had been recruited via the internet, we also pursued an additional online source and arranged for multiple announcements through the Virginia Center on Aging listserv, as well as the Senior Resources Digest listserv, and expanded to reach the larger ConnectRichmond community. The Senior Resources Digest affinity listserv at ConnectRichmond engages individuals and agencies involved with serving the needs of senior citizens and their caregivers in Central Virginia. It is a forum that facilitates awareness, discussion and collaboration on programs, funding, events, conferences, employment opportunities, and research on relevant issues affecting older adults and family caregivers. Because selling, advertising or fundraising is prohibited, this site is a popular mechanism for promoting events that benefit the nonprofit community. The Senior Resources Digest is a more selective listserv that engages exclusively those in the aging services community. In November, we also worked with SeniorNavigator, Virginia’s premier online resource for health and aging information. In addition to posting our advertisement on the “In the News” section of their website (see Section VIII.B. Tools & Resources), they sent a special e-mail announcement to their listserv of Richmond area caregivers. All of this internet advertising was free. The listservs allowed us to directly reach a mass audience and resulted in at least seven calls each in response to the Age in Action and ConnectRichmond posts, with five additional contacts in response to the other sources.

By the time we began recruiting for the second series of sessions, we decided that our budget would allow us to make use of the radio to reach a broader audience. We had the choice of advertising with a popular Clear Channel talk radio station that commands a large segment of the baby boomer and older population, the public radio station, and a smaller talk radio station. We ultimately decided to advertise with the two larger stations due to the broader audiences we would be able to reach. The smaller station had a mixed racial demographic of listeners with a target audience of 35-54, but the size of the listenership was our primary consideration at this time. The commercial talk station allotted us a 30-second script and the public station used a 40-word script (See Section VIII.B. Tools & Resources). Our decision proved to be effective, generating 30 calls. This amounted to approximately 17% of all the calls we received (n=30/171). We broadcast the 30-second advertisement six times during the 7am-8am time period from 12/14-12/18 for a total of one call. The 40-word message on the local public radio station was broadcast 7 times during the “News and Information” programs and 21 times during the “Music and Variety” programs during the following dates resulting in a total of 29 calls: 12/14-12/18; 12/21-12/25; 12/28-1/1; 1/4-1/8; 1/11-1/15; and 1/18-1/19. After the first week, we decided to continue advertising on public radio exclusively due to a
significantly higher response rate in comparison with the more conservative radio station. Although the commercial station was thought to appeal to an older audience, we were surprised at how few calls came in during the first week of radio advertising. For our purposes, public radio was the best avenue for generating the most calls.

2. Recruiting for diversity

We were surprised to realize the lack of diversity among participants in the first series of sessions. All 14 of the participants were women, with only two African American group members. We were determined to address this for the second series of sessions, and decided to advertise with The Richmond Voice and Richmond Free Press, two local newspapers with items of particular appeal to African-American and other minority community audiences, to enhance our outreach to minority populations. This advertising only generated three documented calls, but the demographics for the second series of sessions were substantially more diverse than that of the first session. By reaching a broader audience via radio advertising and continued efforts to broaden our advertising demographic we were able to recruit a more diverse cohort for the second series of sessions.

<table>
<thead>
<tr>
<th>Race/Cohort</th>
<th>First Series of Sessions</th>
<th>Second Series of Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>White non-Hispanic women</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Black women</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>White non-Hispanic men</td>
<td>--</td>
<td>4</td>
</tr>
<tr>
<td>Black men</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Hispanic men</td>
<td>--</td>
<td>1</td>
</tr>
<tr>
<td>Race not indicated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>14</strong></td>
<td><strong>23</strong></td>
</tr>
</tbody>
</table>

3. Recruitment barriers

Because of our focus on caregivers dealing with the early stages of dementia, this screening criterion was included on our advertising materials. It is likely that a number of potential caregivers were not responding because they assumed they were not eligible due to the advanced progression of the disease in their loved one. It is likely that omitting this criterion from the recruitment documents and relying exclusively on our use of the Functional Assessment Staging of Alzheimer’s Disease (Reisberg, 1988) instrument would have aided recruitment by increasing the number of calls received. Over the first year of the project, however, 26.5% of potential participants (n = 13/49) who were screened according to the FAST criteria, could not be included in the study. This early stage screening still had the unfortunate consequence we were trying to avoid. Caregivers in need of the program were turned away because their care
recipients’ dementia was too far advanced. But our decision to be specific about the early stage focus in our advertising may have prevented this difficult situation from being more frequent than it ultimately was. Our effort to be precise and clearly targeted in our recruitment did not have the desired effect of eliminating inappropriate calls. And it may have had the undesirable consequence of deterring appropriate calls.

To test this assumption, we decided to go with a more generalized description of the radio advertising. The 30-second and 40-word live read advertisements did not specifically communicate the early stage focus. Overall, 41.3% of potential participants (n = 50/121) who were screened according to the FAST criteria did not qualify for the study due to the advanced progression of the disease in their care recipient. All in all, almost one-third (29.2%) of the calls we received (50/171) were from individuals who were not screened as potential participants for the programs. Either they didn’t meet the inclusion criterion or were excluded due to the exclusion criteria.

Use of the FAST instrument (Reisberg, 1988) also presented some additional challenges. We included this measure as part of the screening process because it allowed us to control for the care recipients’ functional stage in our data analyses. But it was difficult at times to determine if care recipients had ADL deficits as a consequence of conditions unrelated to AD. For example in the absence of other limitations, it was necessary to make an attribution about the genesis of urinary continence. If a care recipient experienced a fall, as another example, there were ADL deficits related to that physical decline and this complicated attributing the incapacity to the progression of dementia. Funding limitations and practical considerations prohibited us from engaging a neuropsychiatrist or similar medical profession who could have made a definitive diagnosis. So we considered the “big picture” and did our best to judge when someone was ineligible due to advanced dementia given complicating conditions. When caregivers were rejected for this reason, we were apologetic and asked if we could retain their contact information for a later date, should we be able to run the study on a larger scale when the focus was not so limited. Also, we were able to refer them to the resources available through the local Alzheimer’s Association Chapter and provided them with the contact information if they were not already aware. We also suggested that they contact us in the future if there was anything that we might be able to do to help them.

Another recruitment barrier involved the struggle with our choices regarding program format. It was always disappointing for us when someone was unable to participate because of their unavailability during the day. Overall, 8.2% of all callers expressed the need for evening classes due to daytime conflicts (n = 14/171). Daytime programs proved to be particularly problematic for working caregivers. For example, we documented 57.1% of caregivers (n = 8/14) who couldn’t attend daytime classes because of work conflicts. Although it is undocumented, work may have also been the conflict for the remaining 42.9% of
caregivers (n = 6/14) who could not attend daytime classes. We seriously considered having evening programs for the second series of sessions, but due to the hesitancy of older drivers to travel at night in the wintertime, and the lack of comparability with the format for the first series of sessions, we decided to keep uniformity across the two series.

Still another challenge was related to our inability to include the Alzheimer’s Association logo on our recruitment materials. We delayed printing our brochures and posters while we waited for permission from the national organization, and even though the request came from the Chapter's CEO, we were ultimately unable to secure approval.

Of course, we also needed to counter the stigma associated with accepting mental health services. Although the study was concerned with the psychological states of Alzheimer’s caregivers, reluctance was reduced by the focus on stress reduction programs. We wanted caregivers to be able to express their psychological needs in a safe space where confidentiality was stressed. All of our efforts, from choice of location to the informed consent process, facilitated this goal.

4. Retention of participants

Because we were employing a randomized controlled design, we knew at the outset that there would be some sensitivity or even apprehensiveness with regard to program assignment on the part of those we were recruiting. We were insistent that both programs would be beneficial. We assured them that both were designed to help deal with caregiver stress, but used different methods to accomplish that result. When we did the screening initially, our plan was to recruit the participants first, and then conduct the random assignment procedures. By doing this, we weren’t able to give participants all of the information up front. We have found that it works best to pre-randomize for intake so that participants can be informed of which of the two sessions they will be assigned to at the end of the first phone screening. Along this line, it’s important to have as much information as possible ready for the caregivers upon the initial phone call including intake dates and session dates, as well as the program focus. We also learned that it was best if participants assigned to the Social Support Group had a different intake date than participants in the MBSR Group. By keeping the groups separate, we precluded the possibility of participants in the different conditions interacting and sharing information about the two programs.

We kept in touch with participants who screened in for the first series of sessions but could not attend (n=13), and a few were able to be participants for the second series (n = 3). We also made follow-up calls to participants before the sessions began to clearly communicate the date and time. Calls to participants to remind them of saliva collection times facilitated data collection, as well as retention (see
the Protocol and Strategy for Pursuing Follow-Up Data via Phone Calls in Section VIII.A. Tools & Resources). Participants often needed to be reminded as to why they were giving us saliva samples. Many participants were unable to remember why the saliva collections were important or wanted further clarification about the purpose of the samples in the study. At intake, some participants showed some hesitancy to give saliva samples, but this was remedied with an explanation of how we wanted a physiological measure of the participant’s response to stress. Although no one asked specifically, they may have simply needed reassurance that we were not using the saliva to test their genetic risk for acquiring the disease. Returning the samples promptly through the intended service was imperative to maintaining the condition of saliva samples. Some participants also needed reminder calls to explain that FedEx was the method of shipping we were using. Despite explicit instructions at the intake, there was confusion among some participants as to which shipping method to use. So that our samples would not degrade in the mail, we took extra measures in the form of follow up phone calls and emails to remind participants of the difference between FedEx, UPS, and USPS.

When participants first approached us about participating in the program, we emphasized that by enrolling in the study, they were making a commitment to attend every session. Of course, we couldn’t demand that people attend every session, or that they strive to be punctual, but we emphasized how important it was for enhanced learning and preserving group cohesiveness. We related how this was especially important in small groups, where even one person missing affects group discussions. We also thought that it was valuable to talk one-to-one with anyone who showed a pattern of being late or absent. We encouraged them to attend for the benefit of learning what was being accomplished in each session and for the sake of the other group members, who may have come to rely on each other’s presence each week.

5. Finessing Advertising and Printing Media

The project team researched a number of printing companies to determine the most cost-effective way of reproducing the recruitment brochures and posters (see Section VIII.B. Tools & Resources for a graphic representation of the variables and other important considerations when Choosing Print Media Coverage). Our spreadsheet of advertisers also included the printers we were considering so information could be easily compared (see the sample spreadsheet in Section VIII.B. Tools & Resources). Of course, cost was a critical factor in the decisions. It was also important to ask for a rate card from
potential advertising sources. A rate card gives a small visual of how the advertisement will look on the page. It also has information about the size and price of the advertisement. We found it helpful to print rate cards for quick reference about the printer. When making the initial spreadsheet, it is helpful to note the demographic target, the medium (magazine, newspaper, electronic), circulation, size of the ad, the price (including any discounts), and the timeline for publication. Some print publications are monthly; others are quarterly, weekly, or special (as in the Caregiver's Section of the daily paper, the RTD). Flyers and brochures are usually a one time expense. In the spreadsheet for these items, we suggest that there are columns for a contact person, phone number, quantity and/or size of the advertisement, amount or frequency, description, and print deadlines.

We found that telling advertisers we were a non-profit organization aided in our success with discounted advertising. Negotiating with printers or advertisers also proved to be fortuitous. Telling the advertiser about other discounts we had already negotiated often helped us obtain a lower price. Explaining that we had a limited budget also helped us negotiate lower rates. For example, by working with the Community Weekly we were able to get a 68% discount. We also requested discounts for advertising with a certain publisher more than once. Creating a relationship with the advertiser, whichever medium you choose, is valuable. We found that a strong relationship with the advertisers led to further assistance in advertising. One (Craig Ross of Boomer Life) helped us brainstorm about other avenues for advertising. He helped connect us with a sister company (of Boomer Life) for online advertising (Seniors Guide Online). Establishing a good relationship with our printer (XIOPrint) also helped us get the most for our money with the flyers and brochures. Getting to know the contacts and establishing good relationships was an invaluable strategy for our recruitment plan.

Because we didn’t have access to special graphic design programs (like Photoshop, etc.), it was difficult to get the dimensions exactly to size for some of the publications using the computer programs we could access (i.e., Microsoft Word and Microsoft Publisher). When possible, it is best to get assistance from advertisers. It was very helpful to have a printer who had a graphic artist free of charge. If we sent an advertisement to a printer who had a graphic designer, the graphic designer would resize the ad for us to fit the specific dimensions of the publication. Often times, the graphic artist improved the aesthetic appearance of our ad free of charge! (See Section VIII.B. Tools & Resources for a sample of our advertisement in *Boomer Life* that was designed by their graphic artist).

**B. Maximizing Reach**

The only cost for participating was the time commitment required to complete the study. The program was free and participants were offered $100 to compensate them for the time required to complete the study. We
emphasized this in recruitment efforts. We also emphasized that participants would receive a personalized report describing their individual psychological and physiological responses in the study (see Section VIII.B. Tools & Resources for the Personalized Research Report Form and Cover Letter).

1. Facilitating access

If needed, professional respite care was provided so that participants could attend the stress reduction programs. Respite was offered to all participants, and in some cases this was the essential element that facilitated the participation of caregivers. The Alzheimer’s Association provided us with vouchers for respite care for the person with Alzheimer’s disease or other dementia. These were distributed to participants at the intake sessions with instructions that they be forwarded to the agency engaged to provide the respite care. One participant needed child care so that she could attend the sessions, and others were required to travel extensively in order to get to the programs. In these cases, we offered additional compensation to facilitate their participation. Our decision to schedule programs to avoid night driving for older adults may have also maximized our reach.

2. Effective Marketing to Establish Trust

As mentioned previously, the Chapter staff promoted our program to support group leaders who could then recommend participation to their group members. The Alzheimer’s Association Greater Richmond requested 1,000 brochures and 50 posters to use in their recruitment efforts on our behalf. Because of the good reputation enjoyed by the Chapter, we were confident that their solicitations would be productive. Brochures were displayed at all of the Chapter’s health fairs and at all three memory walks held in the Chapter territory. The opportunity was also discussed at Chapter workshops and at educational symposiums held in the branch areas. In addition, we participated in the Chapter’s annual education conference, and distributed brochures in cooperation with three different exhibitors.

Marketing assistance from Senior Connections surely helped us establish trust. They distributed brochures and posters to their Care Coordinators, who field calls and make home visits throughout the territory to arrange for services through the agency’s Care Coordination Program. As trusted individuals in the community, their promotion of the program was most likely productive. Senior Connections also aided recruitment through family caregiver training sessions. Again, since the area agency aging enjoys their reputation as a dependable and reliable provider of services in the community, their assistance likely increased confidence in the benefits of the program we were offering. The opportunity to enroll in our stress reduction programs was promoted by presenters at the sessions and brochures were included in the participant packets distributed.
Word-of-mouth recommendation from program participants was probably one of the most powerful recruitment methods operating over the course of our project. Those involved in the first series who also attended regular monthly support groups encouraged others in their groups to enroll in second series. Well after the programs ended, monthly support group members were still sharing their experiences with the program and encouraging others to consider participating.

Trust was also engendered by our procedures during the orientation sessions. We could introduce the Chapter’s Program Director as the facilitator for the Social Support intervention, emphasizing her affiliation with the Alzheimer’s Association, her graduate degree in Christian Education, and her extensive experience in leading support groups. Noting the effectiveness of this procedure during the first series of sessions, we also involved the MBSR facilitator at the intake meeting with those who were assigned to her program during the second series of sessions. We were able to emphasize her credentials as a licensed clinical social worker, as well as her certification in MBSR and 15 years of experience providing MBSR programs. In this way we maximized our reach before the programs officially commenced, and assured potential participants that they would be receiving the highest quality of programming.
IV. Effectiveness

A. Intended impact

The *Mindfulness-Based* intervention model served 20 family dyads (a caregiver and a care recipient). An additional 20 caregivers were referred to conventional family support groups. Each group was assessed to determine the short- and long-term impact of the interventions in helping them deal with the stress of caregiving to see which model provided the most impact.

B. Data collection

The project succeeded in recruiting 40 caregiving dyads to enroll in the study, and providing almost 300 units of respite services to 18 persons with early stage dementia through the services of 14 providers. Data collection allowed for the comparison of a variety of measures of caregiver well-being and other key outcomes. Assessment measures were collected at baseline (pre-intervention), 8 weeks (post-intervention), and at a 3-month follow-up point. This last data collection point was particularly important and we emphasized this in the letter that accompanied the our mailing of the follow-up measures (see Section VIII.A. Tools & Resources).

C. Screening Measures

A number of measures were used to screen potential participants and ensure the recruitment of early stage family caregivers of individuals with AD or other dementia (see Section VIII.C. Tools & Resources). First participants taking antidepressant or anxiolytic medications needed to have been on a stable medication regimen for 8 weeks prior to enrollment. Exceptions were made for individuals taking sedative-hypnotic medications for sleep, low-level psychotropic medications for pain management, or beta-blockers for heart conditions.

Use of the Functional Assessment Staging of Alzheimer’s Disease (FAST) instrument (Reisberg, 1988) allowed us to determine whether or not the persons with dementia were in fact in the early stage of AD as defined for the present AOA initiative by the Alzheimer’s Association. Essentially, we screened to insure that the persons with dementia retained the ability to participate in daily activities and participate in a give-and-take dialogue.

The FAST assesses stage of AD and dementia through care provider report. The FAST has demonstrated reliability, validity, and progressive ordinality as an assessment technique for evaluating functional deterioration in AD patients throughout the entire course of the illness (Reisberg, 1988; Reisberg, Ferris, de Leon, & Crook, 1982; Sclan & Reisberg, 1992). It has also been validated in community residing patients with probable AD in a five-year prospective study to
document the association of temporal and clinical changes over time (Reisberg et al., 1996). This staging procedure has several advantages over other dementia assessments (Auer & Reisberg, 1997). It encompasses the entire range from normal aging to very severe, end-stage, immobile AD. It also embodies universal functions, and information can be obtained retrospectively (and even postmortem) via telephone contact. Most importantly for our purposes, the FAST staging procedure has diagnostic and differential diagnostic relevance.

The FAST scale is composed of seven major functional levels (1 through 7). These levels have been enumerated to be optimally concordant with the corresponding global level of cognition and functional capacity on the Global Deterioration Scale (GDS; Reisberg et al., 1982). In addition, the FAST enumerates 11 substages corresponding to GDS Stages 6 and 7. These substages are enumerated with letters 6a to 6e and 7a to 7f, and the methodology for scoring each of the 16 FAST levels has been documented in detail (Reisberg, 1988). For our purposes caregiver dyads were included if the FAST stage was rated as 5 or lower, even though this criterion for ‘early stage’ is slightly different from the FAST cut-off.

Participants were excluded from the study with respect to the following psychiatric disorders or history thereof: major depression with psychotic features; psychosis; lifetime history of schizophrenia, bipolar disorder, organic brain syndrome, or mental retardation; and alcohol or substance abuse within the previous year.

Anticipating that some caregivers would be older adults with possible cognitive impairment; the Telephone Interview for Cognitive Status (TICS) was employed as part of the screening (Brandt, Spencer, & Folstein, 1988). The instrument is acceptable to respondents and has a sufficient range to be useful in field research studies of AD and other disorders. An 11-item instrument with a maximum score of 41, modeled after the Mini-Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975), the TICS successfully discriminates even mildly AD cases from health controls. It has high predictive value and reliability for the detection of cognitive impairment, similar to the MMSE.

D. Outcome Measures

The study evaluated the immediate and longer-term efficacy of the interventions on measures of psychological symptoms and well-being, stress-related physiological functioning, and physical morbidity in the caregivers, as well as caregiver-patient relationship quality.
1) Demographics (see Section VIII.C. Tools & Resources)

Participants provided information related to key demographic (e.g. age, gender, marital status, race/ethnicity) and caregiving variables (e.g., years or months spent caregiving, weekly hours spent in caregiving activities).

2) Mental Health

   a. Caregivers' perceived stress was assessed with the Perceptions of Stress Scale (PSS-10; Cohen, Kamarck, & Mermelstein, 1983), a one-factor, 10-item scale that measures the degree to which situations occurring over the last month are felt to be stressful. Items are designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The PSS-10 is commonly used in caregiver studies, has demonstrated strong psychometric properties, including internal consistency ($\alpha = .75$), test-retest reliability, and construct validity (Cohen et al., 1983; Cole, 1999) and has modestly correlated with other measures of appraised stress (Cohen & Wills, 1998).

   b. Caregiver burden was measured with the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980), a 22-item scale measuring the degree to which caregivers perceive their caregiving responsibilities as having an adverse effect on their health, personal and social life, psychological well-being, and finances. The ZBI is the most commonly used measure of caregiver burden and has demonstrated robust psychometric properties, including internal consistency ($\alpha = .91$), test-retest reliability = .71, and construct validity (Gallagher, 1989; Pratt et al., 1987).

3) Relationship Quality.

The caregivers' relationship appraisal was measured with the Caregiver-Care Recipient Mutuality Measure (CGM; Archbold, Stewart, Greenlick, & Harvath, 1992), a 15-item instrument measuring the caregiver's perception of connectedness and reciprocity in the caregiver-care recipient relationship. Scores reflect the interactive nature of relationship quality, including dimensions of reciprocity, love, shared pleasurable activities, and shared values. The CGM has demonstrated good psychometric properties in previous research with caregiver populations, including internal consistency ($\alpha = .91-.95$), and construct validity (Archbold, Stewart, Greenlick, & Harvath, 1992; Carter et al., 1998).
4) Biological Marker of Stress

Of key interest to this study was the Hypothalamic-Pituitary-Adrenocortical (HPA) axis, a neuroendocrine pathway known to be centrally involved in stress reactions (Lovallo, Thomas, Cacioppo, Tassinary, & Berntson, 2000). HPA-axis based responses provide key objective markers of stress in social contexts that have implications for long-term physical health (e.g., Dickerson & Kemeny, 2004). Cortisol is a commonly used marker of HPA-axis activation. When stress occurs, the hypothalamus produces corticotrophin-releasing hormone, which then stimulates the pituitary gland to secrete adrenocorticotropic hormone (ACTH), and consequently stimulates the adrenal cortex to release cortisol into the bloodstream.

Daily salivary cortisol was obtained through Salivettes (Sarstedt AG & Co., Numbrecht, Germany), which are small pieces of tubular-shaped cotton packaged in a plastic tube. Four pre-labeled Salivettes were given to participants during the: 1) pre-intervention assessment; 2) last intervention class session; and 3) post-intervention assessment. Participants were asked to collect their samples at home and refrain from ingesting antihistamines or alcohol during the 24 hours preceding assessment days. Cortisol follows a diurnal slope, with levels peaking in the morning and decreasing throughout the day. For this reason, it was necessary to measure cortisol throughout waking hours. Participants were instructed to collect saliva at six time points (upon waking; 45 minutes later, 2.5 hours after awakening, 8 hours after awakening, 12 hours after awakening, and at bedtime) by placing the cotton in their mouth and chewing it for two minutes before returning the cotton to the plastic tube. Participants received verbal instructions at each assessment session, and also received written instructions and an activity log to complete along with the Salivettes (see Section VIII.A. Tools & Resources).

5) Secondary Measures

Information was also collected to assess important baseline characteristics that might moderate intervention effects or be indicative of actual intervention effects.
a. Mindful Attention Awareness Scale (see Section VIII.C. Tools & Resources)

Mindfulness was assessed at a trait level using the Mindful Attention Awareness Scale (MAAS; Brown & Ryan, 2003). Past research has shown that mindfulness, as assessed via the MAAS, is related to a variety of self-reported indicators of psychological well-being. It includes 15 statements such as, “I find it difficult to stay focused on what's happening in the present.” The MAAS is measured on a 6-point Likert scale ranging from “Almost Always” to “Almost Never” and is computed as a mean score of all 15 items. The MAAS is well validated and has excellent reliability, $\alpha = .82$ (Brown & Ryan, 2003; MacKillop & Anderson, 2007), as well as a very good internal consistency ($\alpha = .91$).

b. State Anxiety

The Profile of Mood States (POMS; McNair & Lorr, 1964) is intended to measure how participants are feeling at the present moment (emotional state). It is composed of six mood scales that were developed using clinical populations (tension, depression, anger, vigor, fatigue, and confusion). Respondents are scored on a 5-point Likert scale, ranging from “Not at all” to “Extremely”, across a set of 58 adjectives. The POMS is well-validated in several populations and shows good reliability across studies (McNair, Lorr, & Droppleman 1971; Albrecht & Ewing, 1989).

c. The Short Form-36 health survey (SF-36; Ware & Sherbourne, 1992) was derived from the General Health Survey of the Medical Outcomes Study (Stewart, Hays, & Ware, 1988). It is one of the most widely used generic measures of health-related quality of life and has been shown to discriminate between subjects with different chronic conditions, as well as subjects with different severity levels of the same disease. The SF-36 has been psychometrically and clinically validated (McHorney, Ware, & Raczek, 1993), and has demonstrated sensitivity to significant treatment effects in a variety of patient populations. It generates eight subscales and two summary scores corresponding to the mental and physical health components. The eight subscales are: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of
physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions.

d. Acceptance and Action Questionnaire (AAQ)

The theory of experiential avoidance (Hayes et al., 1996; Blacklege & Hayes, 2001) underlies Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999). The central aim of ACT is to enhance the ability to become more fully aware of present behavior, self-endorsed values, and then to commit to behaviors that are consistent with those values (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Inherent in mindfulness is an acceptance of, or willingness to be with what is, in contrast to states of mind that involve avoidance, control, and the investment of personal well-being in altering circumstances or attaining goals. The AAQ is a 32-item questionnaire designed to assess a high need for emotional and cognitive control, avoidance of negative private events, inability to take needed action in the face of private events, and forms of cognitive entanglement, such as excessively negative evaluations of private experiences or negative self-references (Hayes et al., 2004). Mindfulness has been defined as an acceptance skill (Linehan, 1994) and the relation between the two constructs as well as the MBSR and ACT interventions has been clearly articulated (Brown, Ryan, Creswell, 2007). The AAQ measure was employed here to help elucidate the processes of adopting a non-judgmental or accepting orientation and obtaining insight among Alzheimer’s caregivers.

B. Results

Patient Characteristics

As a whole, the sample of 38 participants (MBSR n = 23; SS n = 15) was predominantly female (84.2%) and most were Caucasian (75.7%); the remainder were African American (21.6%) or Hispanic/Latino (2.7%). The average age of participants was 61.14 years of age (SD = 10.41, range = 39 to 88 years). Most individuals were married (65.8%); the remainder (34.2%) were widowed, separated, divorced or never married. The sample was generally well-educated, with most having attended college (32.4%) or earned a college degree (35.1%). An additional 29.7% had graduate school training. Only one (2.7%) had just a
high school education. Among those who reported household income (n = 9 missing) the annual median was $60,000 (range $19,000 - $120,000). The MBSR and SS groups did not significantly differ on these demographic characteristics (gender, age, ethnicity, civil status, income), all ps > .21.

**Treatment Effects on Self-Reported Mental Health, Physical Functioning, and Caregiving Outcomes**

Preliminary t-tests revealed no differences between the MBSR and SS conditions in self-reported mental health, physical functioning, and caregiving variables at baseline, all ps > .10. Random effects multilevel models (REML) were used to test for changes over time (pre-intervention, post-intervention, and 3-month follow up), and condition differences in these changes over time on all continuous self-reported outcome measures. Both MBSR and SS groups reported significant improvements over time in MAAS mindfulness (p = .0003), PSS perceived stress (p = .001), AAQ experiential avoidance (p = .0002), and all of the subscales of the POMS: tension (p = .0003), depressive symptoms (p = .006), anger (p = .009), vitality (p = .03), fatigue (p = .001), and confusion (p = .02). There were also significant declines in reported ZBI caregiver burden (p = .02) but no improvements in the caregiver – care recipient relationship (p = .90), nor SF-36-reported physical or mental functioning (ps = .07 and .32, respectively). There were no condition × time effects on any of the self-report outcomes, all ps > .13.

**Treatment Effects on Diurnal Cortisol Response**

At pre-intervention, post-intervention, and 3-month follow up, diurnal cortisol was assessed 6 times during the day (from waking to bedtime). After log-transformation to correct non-normality in this diurnal cortisol data, REML was used to test for group main effects and group × diurnal time effects at each measurement point separately (pre-intervention, post-intervention, and 3-month follow up). No group differences in the diurnal cortisol slopes were found at each of the measurement points (all ps > .05). There were also no group × time effects in the cortisol slopes at any of the three measurement points (all ps > .05).
V. Adoption

A. Incorporation under the NFCSP

Amendments to the Older Americans Act in 2006 included caregivers for persons with Alzheimer’s disease under the NFCSP. As mentioned previously, the RTI International report (Brown & Weiner, 2008) describes the plans that states had in place to incorporate ADDGS (now ADSSP) services into the NFCSP. Most states had plans to continue ADDGS programs in this way at the conclusion of the grant support. But few had readily identifiable streams for additional funding. In Virginia additional support would be required, but the MBSR program would need to expand throughout the Commonwealth in order to justify the application of state-level support. A more likely option would be to find a way that the MBSR program could be adopted by the AAA. Community grant funding could be applied to complement the NFCSP funding in a way that would allow the research to continue. Perhaps an additional position focused on the engagement of Alzheimer’s caregivers could be supported to complement the position filled by the Senior Connection’s Caregiver Support Services Manager. Although RTI International found few barriers to cooperation between NFCSP and ADDGS programs, the lack of focus on dementia caregivers at the AAA was a disadvantage in our recruitment efforts, and might also present a philosophical deterrent to collapsing the two programs under a single effort.

B. Inclusion under Virginia Department for the Aging’s Respite Care Incentive Grant

For the last 10 years, the Virginia Department for the Aging’s Respite Care Grant Program, with General Fund Appropriations from the Commonwealth of Virginia, has supported the development, expansion, or start-up operations of respite care services to family caregivers of older adults. Significant flexibility is granted in an effort to encourage innovative and creative strategies for the development and provision of services. It seems that the MBSR intervention would qualify for continuation through this grant program. The focus on dementia would address a recommendation made by the Virginia Commission on Alzheimer’s Disease and Related Disorders (ADRD) in 2008. Essentially, the Commission asked the Department for the Aging to incorporate a greater focus on Virginians with Alzheimer’s disease as a targeted group for receiving respite services through the Respite Care Incentive Grant program. This recommendation was never acted upon, and since that time funding for the Respite Care Incentive Grant program was suspended beginning in FY 2010 and continuing in FY 2011 & 2012. There may be some saving grace however, since Virginia’s Four-Year Plan for Aging Services ([http://www.vda.virginia.gov/pfdocs/FourYearPlanForAgingServices-RD461-2009.pdf](http://www.vda.virginia.gov/pfdocs/FourYearPlanForAgingServices-RD461-2009.pdf)), that was mandated in 2008 by the Virginia General Assembly, calls for
restored funding ($177,287) to maintain the Respite Care Incentive Grant and develop new public and private funding for services to assist caregivers in all regions of the Commonwealth.

C. Inclusion under Virginia Department for the Aging’s Respite Care Initiative

The ADRD Commission also focused on respite care in its short term recommendations to the Governor and Secretary of Health and Human Resources. State level funds are also provided to the Virginia Department for the Aging to support a Respite Care Initiative that enables a caregiver of an individual with dementia to have a temporary rest from the caregiver role. Funding fell from the maximum annual allocation of $600,000 to $483,044, with an additional $53,672 reduction this year, but some of the remaining monies might be diverted to propagate the MBSR intervention. The program clearly constitutes an innovative and effective method for achieving the respite goal. When the Commission last approached the Governor in 2008 to preserve the fund after an initial cut however, there were 264 families on the waiting list for respite services. The appeal was met with still further cuts, and the program remains vulnerable given the budgetary constraints faced by the Commonwealth.

D. Adoption through the Alzheimer’s Association Chapter

The Chapter’s Program Director could be called into service to facilitate the adoption of the MBSR intervention. Her involvement could be exclusively through the Chapter or she could help with implementation of the program as a kind of adjunct to the Pathways Program to the Senior Center or the Memory Support Program at the adult day services center that participated in our project. The Program Director attended a session at the Joseph and Kathleen Bryant Alzheimer’s Disease Research Center annual conference presented by Jeffrey Brantley, M.D., Director of the MBSR program at Duke University. Dr. Brantley completed the MBSR professional training program at the University of Massachusetts Medical School. Mindfulness interventions for caregivers are receiving attention throughout the Alzheimer’s Association network. Richard Sears, Psy.D., the Director of the Center for Clinical Mindfulness and Meditation affiliated with the Union Institute and University Psy.D. Program in Clinical Psychology, for example, was a keynote speaker at the Greater Cincinnati Chapter’s 2010 Education Conference. And the Alzheimer’s Association, Mid-South Chapter promotes the benefits of mindfulness for professional caregivers. But the Chapters primarily depend on grants to fund these kinds of initiatives, and although the Greater Richmond Chapter has certainly had success in securing foundation support, without additional funding their ability to continue with this respite option is uncertain.
E. Ancillary Pathways Program

Because of the one-to-one attention devoted by the staff to those in the Pathways Program, it was not as well-developed as it might have been at the time of our study. Our hope was that by collaborating with the Senior Center, our study might be useful in a reciprocal way (i.e., by boosting future enrollment in the Pathways Program). To accomplish this anticipated benefit, the MBSR program for caregivers might be offered simultaneously with the activities scheduled for older adults with early stage. The early stage support group for Alzheimer’s caregivers offered through the Greater Richmond Chapter is organized precisely in this manner. Programming for the care recipients is provided, while the caregivers attend their support group meetings. If a community grant is sought to allow the MBSR program to be included under the NFCSP with the addition of a position at the AAA focused on the engagement of Alzheimer’s caregivers, that role could be expanded to include the recruitment of participants for the Pathways Program as well. Alternatively, a position could be created at the Senior Center to engage the family caregivers of those in the Pathways program in an MBSR program. Since our program ended, the Senior Center has begun offering Falun Gong classes twice a week. Perhaps an enhanced version of this offering that incorporated the MBSR component could be established specifically for family caregivers of loved ones with dementia.

F. Adult Day Services Center Ancillary Program

The Alzheimer’s Association presents monthly workshops for the caregivers of members who participate in the Adult Care Center’s Memory Support Program at A Grace Place. Because it addresses their mission, an MBSR intervention group could be easily be implemented as an additional ancillary program. Of course, the limiting factor in this kind of adoption rests with the availability of a trained MBSR interventionist.

A recruitment effort could be undertaken to identify an appropriate instructor in the immediate area. As long as three minimum criteria are applied, the recruitment effort could be quite successful. First, the interventionist must be competent. That is, they must have the requisite training from the Center for Mindfulness in Medicine, Health Care and Society at the University of Massachusetts Medical Center, the Duke Center for Integrative Medicine, or another reputable provider of certification. Second, the interventionist must have the ability to effectively communicate with older adults, as well as a certain level of cultural competence. Finally, the interventionist must exhibit a caring and compassionate nature.
VI. Implementation

A. Manualized intervention

To help ensure the success of the caregiver intervention, it is important that it be manualized and validated, as is the case with the MBSR program, which has 30 years of research support and a “probably efficacious” designation from the National Institutes of Health. The table of contents for the manualized intervention (Santorelli & Kabat-Zinn, 2002) is included in Section VIII.A. Tools & Resources. Note: the manual is copyrighted and only available to Professional Training Program Graduates of the Oasis Professional Education and Training who have become certified by the University of Massachusetts Medical School Center for Mindfulness in Medicine, Health Care, and Society (CFM) to teach MBSR (see Section VIII.A. Tools & Resources). The intervention also included utilization of four self-recorded CDs distributed to MBSR program participants. The CDs are similar to the 8-week MBSR CD sets available through the CFM (http://www.umassmed.edu/Content.aspx?id=41288&linkidentifier=id&itemid=41288). (see Section VIII.A. Tools & Resources for an order form).

In his forward to Teaching Mindfulness: A Practical Guide for Clinicians and Educators (McCown, Reibel, & Micozzi, 2010), Jon Kabat-Zinn describes how one of the critical challenges when mindfulness is taught has been maintaining the level of mastery and integrity necessary to insure fidelity as the content is transmitted through the large cadre of well-trained, highly competent, and skilled mindfulness teachers. Integrity of the MBSR curriculum is tantamount and needs to be protected as teachers face the desire to enrich the program when they make the lesson plans their own. He adds that the desire to add additional pedagogical material is admirable in some cases, and necessary if teachers are to have ownership of their programs. There is an inner logic for conserving the 8-week long format and MBSR curriculum, but teaching in varied contexts and new venues requires a certain amount of spontaneous creativity. So while modifications and innovations are absolutely necessary, teachers must strive to maintain the essence as they respond to cultural differences or particular community constituents. Sensitivity and flexibility are constant demands, but Kabat-Zinn advises teachers to look for authentic responses within their own hearts and “find a way to be real within the container of the MBSR curriculum, and bring it to life in the face of life unfolding and expressing itself in the human beings you are working with, and in yourself, of course.” (p. xxii).

The curriculum outline employed here (see Section VIII.A. Tools & Resources) is indicative of the way in which mindfulness is a present-centered process that must unfold naturally in the curriculum. The 8-week sessions that were conducted as part of this innovative study, cannot be replicated fully. In his book review, Joshua Felver-Gant (2010) relates how teaching mindfulness is “a process that inherently cannot be fully prescribed, and is therefore “empty” of any
specific content. To be authentic to mindfulness practice the content of mindfulness curricula cannot be detailed beforehand. There is a paradoxical dualism involved in “teaching mindfulness” in explicit detail and urging teachers to mindfully follow general guidelines. Our curriculum reveals the path we followed and provides examples as guidance, but those who intend to replicate our results will inevitably find themselves developing their own modifications and innovations.

B. Consultations

The MBSR interventionist consulted with the local Alzheimer’s associations and also with Lucia McBee, L.C.S.W. who has worked extensively with elderly patients and their caregivers both family and institutional. She is a MBSR teacher in New York City and has taught mindfulness to patients with dementia and their caregivers for many years. She was extremely helpful through the resource of her book, *Mindfulness-Based Elder Care* (McBee, 2008), her generous sharing of curricula from her teaching experience, and also as a consultant by telephone when questions arose.

The interventionist has also trained with Dr. Gregory Kramer, who teaches a form of meditation practice, which is interpersonally oriented. His approach involves bringing the tranquility attained in meditation directly into interactions with other people. It involves interacting with a partner as a way of accessing a profound kind of insight that can then be taken into everyday human interactions (Kramer, 2007).

Poetry was also used in the class and other inspirational readings most often copied and given out as handouts to the participants (Kabat-Zinn 1990, 1994, 2005; Jack Kornfield, 1993). Other teaching opportunities came from the participants themselves as they contributed relevant stories, situations, and current events that related to the mindfulness practices shared in the classes. Walking meditation sometimes occurred out of doors as weather permitted and often experiences of nature, weather, and woodland creatures added to the awareness practices.

C. Space, Equipment, and Group Size Considerations

This group-based intervention has minimal space and equipment requirements. Group sizes generally range from 10-20 persons. This upper limit is considered important to ensure adequate opportunity for individual members’ input during class discussions. The room in which the classes are held should be sufficient in size to accommodate a circle of seated participants and permit participants’ use of yoga mats for floor-based mindful movement exercises. For the present MBSR classes, the Senior Center of Richmond provided rooms well-suited to these requirements.
D. Timeline Considerations

Our experience with the program suggests that several considerations regarding the intervention timeline must be borne in mind to ensure successful implementation. First, as with all group-based interventions, the speed with which recruitment is conducted will determine the starting dates of the intervention. Weather considerations are also important to the completion timing of the intervention. In Central Virginia, where snow and other inclement weather can impede travel during the winter months, it may become necessary to cancel one or more classes, as was the case with one of the present MBSR courses, held January to March, 2010. This delayed the completion of the 8-week program. Thus, it is recommended that program courses be held in non-winter months if possible. The absence of the Social Support interventionist (and her participants!) to attend the annual Alzheimer’s Association education conference, for example must also be considered in fostering consistent implementation of the intervention.

E. On-going Site Management

Finally, successful implementation of the intervention should be facilitated by participant class attendance record-keeping and weekly practice logs (see Section VIII.A. Tools & Resources). For the present MBSR and SS interventions, participant absences and lateness were recorded for each class, which helped the interventionists to follow up with late and/or missing participants to resolve difficulties with (timely) attendance. We had a tracking system for attendance in the form of an initial sign-in sheet and attendance logs that were kept throughout each series (see Section VIII.A. Tools & Resources). The Attendance Record logs allowed the group facilitators to indicate for each participant whether they were present or absent, arrived late (and how many minutes), left early (and how many minutes), and whether the participant was subsequently contacted to discover if there were any issues that could be addressed to make sure that there were no attendance problems in the future. Facilitators identified the reasons for any absences and disseminated the application of session resources to returning participants in order to facilitate retention. Anecdotal reports from the interventionists suggest that such follow up efforts helped to foster higher intervention completion rates.
VII. Maintenance
   A. Individual Level

   1. Three month follow-up

Both MBSR and SS groups reported significant improvements over time in MAAS trait mindfulness as measured by the *Mindful Attention Awareness Scale*. Essentially this result provides evidence of the interventions’ ability to increase a unique quality of consciousness that is related to and predictive of, a variety of emotion regulation, behavior regulation, interpersonal, and well-being phenomena. There was also evidence that the interventions were capable of inducing sustained coping strategies related to psychological inflexibility and experiential avoidance. Participants learned to avoid negative evaluations of their thoughts or feelings and to make behavioral adjustments when confronted with difficulty. Significantly, it appeared that caregivers became increasingly capable of interpreting their negative evaluations as distinct from objective fact. These abilities likely contributed to the development of more effective coping processes, such as cognitive reappraisal.

Decreases in stress and burden were also documented. Results related to the *Perceptions of Stress Scale* were indicative of the degree to which situations occurring over the last month are felt to be stressful. It appeared that even three months after the interventions, participants were continuing to experience the benefits imparted initially. It was particularly gratifying to note continued improvements measured by the *Zarit Burden Interview*. The interventions were shown capable of decreasing the degree to which caregivers perceived their caregiving responsibilities as having an adverse effect on their health, personal and social life, psychological well-being, and finances.

Finally, the results supported improvements over time with respect to all of the subscales of the *Profile of Mood States* questionnaire. We were able to document statistically significant changes in levels of tension, depressive symptoms, anger, vitality, fatigue, and confusion. It can be concluded that the interventions were robust in influencing the mood of participants as well as their response to the current life situation.

The interventions were not found to be effective in improving physical or mental functioning as measured by the *Short-Form Health Survey*, however. Because the interventions were not specifically designed to globally change health-related quality of life, this result is not so disconcerting. We did hope for changes in the quality of the relationship between caregivers and their care recipients though, and the failure to demonstrate results in this respect is more of a cause for concern. The *Caregiver-Care Recipient Mutuality Measure* provides an indication of a caregiver’s perception of connectedness and reciprocity in the
caregiver-care recipient relationship. We were unable to document improvements in the nature of the relationships with respect to reciprocity, love, shared pleasurable activities, and shared values. However, effects might have been noted at a follow-up point further in the future, or may be documented at later stages of the disease process, when relational aspects become more critical.

Dispositional mindfulness has been shown to predict reduced brain activity in areas pertaining to emotional reactivity and increased activity in areas related to emotion regulation (Creswell, Eisenberger, & Lieberman, 2008). Recent research indicates that these central nervous system changes have a direct downstream relation to HPA axis activation (Herman, Ostrander, Mueller, & Figueiredo, 2005). Therefore, HPA axis-based response was of particular interest in this study.

Unfortunately we were unable to document group differences with respect to this measure at any of the time-points considered. Clearly, the assessment of both emotional and biological aspects of the stress response can provide a more complete understanding of the variability in stress resilience. But others have also found this incongruence in psychological and physiological stress responses when mindfulness interventions are assessed (Galantino, Baime, Maguire, Szapary, & Farrar, 2005). This may be due to a true lack of physiologic effect of the MBSR program among Alzheimer's caregivers or a need for more specific and sensitive measures of stress. Research shows other markers to be more sensitive to the relaxation response, such as salivary immunoglobulin A or α-amylase (Takai et al., 2004). Cortisol is only one of several interconnected chemical mediators of the stress response, and the addition of still other measures that may be responsive to stress reduction interventions (e.g., dehydroepiandrosterone, catecholamines, cytokines, and the other glucocorticoids) may contribute to a more comprehensive understanding of the body's response when coupled with self-report data to assess MBSR interventions (Matousek, Dobkin, & Pruessner, 2010).

2. Confidence in lasting benefit

A longer term follow-up would be informative. There are a number of questions that remain unanswered in the absence of additional data. It’s important to remember that our intervention was specifically applied to caregivers dealing with Alzheimer’s disease in the early stages. Given progression of the disease, it is difficult to predict how long the documented benefits might persist. But will the MBSR techniques continue to be as effective in reducing stress, and improving well-being or emotional/behavioral regulation? It is likely that the MBSR practice would need to be stepped up to cope with increasing stress over time as the disease progressed. As the challenges become more difficult, one or more booster sessions might be warranted to promote the extension of practice.

There is also the question of the extent to which caregivers in the MBSR condition continue to employ techniques learned, or whether participants who
were not already involved in the Chapter’s monthly support groups sought to be subsequently engaged.

Our research in this area would be enhanced by the addition of longitudinal data beyond the three month follow-up of our measures. Of course, data at more remote time points would be advantageous, and it would be helpful to pinpoint the factors that contribute to long-term maintenance of our stress reduction results. But there is also reason to further explore differences between the two interventions. For example, the social support facilitator has suggested that the participants in her group would have an advantage over MBSR Group participants in their preparation to access community resources as they become needed. The sharing among group members in a problem-solving context would naturally lead to specific suggestions about supports available in the community. The extent to which being knowledgeable in this regard contributes to long-range stress reduction deserves to be investigated in further research.

There is also merit especially in extending the research to determine if the results we obtained with our focus on early stage caregivers would also be obtained from caregivers who are further along in the journey. Would our approach be even more useful as the caregiver burden increases and participants are required to cope with more difficult and challenging behaviors? As we were required to turn away caregivers when their loved ones’ disease was too far progressed, we were especially dismayed when contemplating the probable benefits that could have been afforded. Logic suggests that the intervention would be at least equally effective, but this presumption needs to be tested in further trials.

B. Institutional Level

1. Sustainability

Recruitment efforts in the future should be facilitated by a remarkable confluence of events that have resulted in the appointment of a new Chair for the Department of Neurology at VCU. James P. Bennett, Jr., M.D., Ph.D. recently assumed this position after more than 10 years as a Professor of Neurology and Psychiatric Research at the University of Virginia. He has established a comprehensive Parkinson’s Disease and Movement Disorders Multidisciplinary Research and Treatment Center at our University. This should also accelerate activities in the Department of Neurology’s dementia clinic.

Another development that will surely be of assistance in our future recruitment efforts is the receipt of a 2010 Clinical and Translational Science Award from the National Center for Research Resources at the National Institutes of Health. The VCU Center for Clinical and Translational Research has joined the national consortium of medical research institutions that is transforming the way in which communities become engaged in research. The
consortium has generated resources to enhance the efficiency and quality of clinical research. For example, a Web-based national recruitment registry is now available for us to connect with volunteers interested in participating in clinical studies.

We would also like to continue and enhance our cultural outreach efforts by applying what we learned during the June 2009 ADSSP Technical Assistance call that included the PowerPoint presentation on investigating diversity in caregiving by David W. Coon, Ph.D. Of course we will also draw from our own past successful effort funded by AoA (Google, 2002, 2004; Google & Churcher, 1996; Google & Finley, 1994), but there will be a concerted intention to apply the tools since developed and available through AoA’s ADSSP National Resource Center (e.g., ADDGS Lessons Learned in Cultural Outreach http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/docs/ADDGS_Lessons_Learned.doc), the ADDGS Program: Cross-State Report on Initiatives Targeting Limited English-Speaking Populations and African American Communities http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/docs/Minority%20Cross-site%20Paper--5-07--Final.pdf, and the ADSSP toolkit on Serving African American Families: Home and Community based Services for People with Dementia and their Caregivers http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/docs/Toolkit_4_Serving_African_Americans.pdf) will all be helpful in identifying and addressing the cultural and organizational obstacles to extending the reach of our dementia-focused intervention.

This research can also be expanded in other additional directions, however. A geographical replication involving additional Chapters and perhaps a rural out reach component is certainly worth considering. Given the MBSR interventionist’s affiliation with the Mindfulness Center in the University of Virginia School of Medicine, it would be advantageous to connect our program with the School of Nursing’s Southeastern Rural Mental Health Research Center to promote a community-based collaboration with the Central and Western Chapter of the Alzheimer’s Association.

2. Systems Integration

We have discussed how funding to continue program activities might be forthcoming through the adoption of our intervention by any number of engaged partners (see Section V Adoption). Some kind of integration into NFCSP seems the most likely however. The Virginia Department for the Aging could encourage the AAAs to consider how their NFCSP funding could be leveraged to encompass this opportunity to offer MBSR programming. The advantage of this approach rests with the benefits that can be afforded when the ADDGS piloted innovative approaches to accomplish outreach and support become merged with the well-established NFCSP. As was the case in North Carolina however
(Brown, Siebenaler, & Wiener, 2006), the Department has yet to develop a proposal detailing how this kind of jointly-funded arrangement could be structured.

The relationships developed through implementation of grant-funded projects often continue to function after the grant cycles have concluded. Our case is no different. The partnerships discussed in the first section of the report continue to be productive, and so there should be further opportunities to collaborate in the future either through private foundation or local government funding. The effort could also be supplemented by employing a fee for service sliding scale strategy. We have noted how the ADDGS grant activities in North Carolina were extended through collaboration with the States’ Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services. We may find a similar opportunity in Virginia with another federally funded initiative.

There is also the possibility of leveraging our pilot data to obtain research funding sufficient to support a larger scale intervention. We are also supportive of federal legislation that is providing states with continuation funds through the ADSSP. We would like to leverage those funds to gain state funding to expand our efforts. Our data concerning organizational benefits and program effectiveness should be helpful in this regard.
References


VIII. Tools & Resources

A. Intervention
   1. Intake Invitation Letter
   2. Salivette Schedule and Activity Log
   3. MBSR Intervention Curriculum
   4. Initial Sign-In Sheet
   5. Attendance Record
   6. Weekly Practice Log
   7. Retreat Information Flyer
   8. Three-Month Follow-Up Letter to Participants
   9. Protocol and Strategy for Pursuing Follow-Up Data by Phone

B. Recruitment
   1. Sample spreadsheet of printers and advertising sources
   2. Brochure
   3. Flyer
   4. IRB-approved newsletter, internet, and e-mail wording
   5. Personalized Research Report Form and Cover Letter
   6. Considerations when Choosing Print Media Coverage
   7. Sample Letter Requesting Recruitment Material Dissemination
   8. Project Summary Included with Letters Requesting Dissemination of Recruitment Materials
   9. Program Advertisement Created by Boomer Life Graphic Designer
   10. Program Advertisement Featured in Age in Action Newsletter
   11. Internet Banner on Boomer Life Magazine Home Page (Top) and Internet Ad Appearing at Boomer Life Magazine Online (Bottom)
   12. Internet Ad--Central Virginia Section of the National Caregivers Library
   13. Advertisement posted on the Senior Navigator website
   14. 30-Second and 40-Word Radio Scripts

C. Self-Devised Research Instruments
   1. Needs Assessment Questionnaire
   2. Phone Screening Inclusion-Exclusion Questionnaire
   3. Background Information
   4. Mindful Attention Awareness Scale (MAAS)
A. Intervention
A.1. Intake Invitation Letter
January 13, 2010

Dear Participant,

Thank you for your interest in joining us for a Stress Reduction Program for family care providers of those with Alzheimer’s Disease or other dementias. We hope this experience will be a very helpful and enriching one for you.

As you discussed recently with one of our staff, we would like to have an introductory meeting with you on Wednesday, January 27th from 2:00-4:00 pm to present the program and the research study and give you opportunity to ask any questions about your involvement. If you agree to join the project, we will ask you to complete some preliminary research questionnaires at this initial meeting. If you decide to join, you will be in the Stress Reduction group that will meet each Wednesday from 2:00 to 4:00 pm from February 3rd to March 24th.

Both the introductory meeting and the Stress Reduction group will meet at the Senior Center, 4200 Innslake Drive, Suite 101, Glen Allen, VA 23294; ph 804-353-0061. The Center has ample free parking in front. A large sign out front of the building reads, “Virginia Hospital and Health Care Association.” The group facilitator’s name is Ms. Allie Rudolph; she can be reached at 434-293-6607 if you would like to discuss anything before the group begins.

**To get to the Senior Center:**

From the East:
Take I-64W to the W Broad St/US-250 E via Exit 178B.  
Turn Left onto Cox Rd.  
Turn Right onto Innslake Dr.  
Follow Innslake Dr all the way around until you pass over Cox Rd again. After you re-cross Cox Rd, 4200 Innslake Dr. will be on your Right.

From the West:
Take I-64E to the W Broad St/US-250 E via Exit 178B.  
Turn Left onto Dominion Blvd.  
Turn Right onto Innslake Dr.  
4200 Innslake Dr. is on your Left.

From the North:
Take I-64W to the Nuckols Rd South exit via Exit 51B.  
Merge onto Nuckols Rd.  
Turn slight Left onto Cox Rd.  
Turn Right onto Innslake Dr.  
4200 Innslake Dr. is on the Right.

From the South:
Please use the “From the East” or the “From the West” directions above, according to what is most appropriate for you.
Please note that part of Innslake Drive forms a loop off of Cox Road, so don’t be confused if your directions have you turn onto Innslake Dr. from Cox Rd. and then you cross Cox Rd again. See map below. Please call the Senior Center at 804-353-0061 if you have trouble finding the address.
A.2. Salivette Schedule and Activity Log
**Salivette Schedule**

Please collect your saliva samples in the salivettes provided to you on the following schedule. Please try to adhere as closely as possible to the schedule:

1) Immediately upon awakening (before getting out of bed)
2) 45 min after awakening
3) 2.5 h after awakening
4) 8 h after awakening
5) 12 h after awakening
6) At bedtime

**Activity Log**

At bedtime tonight (date), please complete this log on today’s activities.

1. What time did you awaken today?   ________ am / pm (circle one)
2. Hour many hours of sleep did you get last night? ________
3. Please list all food and beverages that you consumed today, including the approximate amount of each:
   1. ______________________________
   2. ______________________________
   3. ______________________________
   4. ______________________________
   5. ______________________________
   6. ______________________________
   7. ______________________________
   8. ______________________________
   9. ______________________________
   10. ______________________________
4. If you did some form of exercise today, please indicate the activity/activities and the duration:
   Type: ___________________________ Duration: ________ minutes
   Type: ___________________________ Duration: ________ minutes
5. If you consumed one or more alcoholic beverages today, please indicate how many of each:
   _____ glass(es) of wine
   _____ beer(s)
   _____ drink(s) of hard liquor
6. If you smoked one or more cigarettes or cigars today, please indicate how many:
   _____ cigarette(s) / cigar(s) (circle one)
7. If you experienced symptoms of a (possible) illness today, please list those symptoms:
   1. ______________________________
   2. ______________________________
   3. ______________________________
8. If you took any medications today, please list them and the amount of each:
| Medication 1: _____________________ | Dosage: ______ mg |
| Medication 2: _____________________ | Dosage: ______ mg |
| Medication 2: _____________________ | Dosage: ______ mg |

**Women only**

9. Were you menstruating today?   Yes   No   (circle one)

10. If you used an oral contraceptive today, please indicate what type:
________________________________
A.3. Intervention Curriculum
MINDFULNESS-BASED STRESS REDUCTION
PROFESSIONAL TRAINING RESOURCE MANUAL

Integrating Mindfulness Meditation into Medicine and Health Care

Compiled and Edited by
Saki F. Santorelli, Ed.D And Jon Kabat-Zinn, Ph.D.
©2002

Contents

Program Mandala of the Center for Mindfulness in Medicine, Health Care, and Society

I. About the Center for Mindfulness in Medicine, Health Care, and Society and the Stress Reduction Clinic
   - The Pull of the Soul Toward the Possible: The Emerging Vision and Work of the Center for Mindfulness
   - A Review of Programs and Activities 1979-2000

II. MBSR Curriculum Guide and Supporting Materials
    - Guidelines for Representing This Work
    - MBSR: Qualifications and Recommended Guidelines for Providers
    - MBSR: Standards of Practice
    - Curriculum: Outline MBSR-8 Week Program
    - MBSR Curriculum Content: Describing MBSR for HMO’s and the Medical Record

III. Evaluation Instruments
     - Instruments Used in Various Studies 1979 – 2002
     - Pre-Program Assessment Form
     - Post-Program Assessment Form

IV. Select Chapters and Monographs on MBSR
    - MBSR Teacher Readiness & On-Going Development:
      An Interview with Saki Santorelli
      Indra’s Net at Work: The Mainstreaming of Dharma Practice in Society
      Intervention Elements
      Meditation
      A Teaching Mandala of MBSR
      Catalyzing Movement
      Mindfulness & Mastery in the Workplace
      Mindfulness Meditation Ancient

V. The Contemplative Mind in Medicine: An MBSR Program for First & Second Year Medical Students

VI. MBSR Programs We Know About

VII. Some General References of Meditation and Mindfulness
Becoming an MBSR Teacher

Teaching Mindfulness-Based Stress Reduction (MBSR) requires the capacity to meet our own suffering and that of others with attention, resilience, transparency, and compassion.

For most people, cultivating these qualities is both cumulative and non-linear. Therefore, we encourage you to proceed through Oasis training programs slowly and thoroughly, allowing time to integrate your learning into your life and your teaching.

It is not necessary for you to become certified by the Center for Mindfulness (CFM) to teach MBSR. However, before beginning to teach, we strongly encourage you to participate in one or both of the Oasis Foundational Training Programs - MBSR in Mind-Body Medicine and/or Practicum in MBSR. In addition to participating in Oasis foundational training programs, dedication to the ongoing exploration of the following interconnected pathways of study and personal development is essential:

Personal psychological development

Your ongoing commitment to learning as much as possible about your own personality and patterns of relating is necessary if you hope to teach MBSR. Such knowledge requires ongoing self-inquiry and inner work.

Meditation training, including silent retreat attendance

Because wonder and inquiry into the nature of the self and reality is an essential practice for MBSR teachers, your engagement in a daily practice of mindfulness meditation and on-going participation in silent, teacher-led retreats is critically important. We recommend attendance at retreat centers that emphasize Theravadan Buddhist teachings because the spirit, practices, and attitudes of MBSR are reflective of this tradition. Other consciousness disciplines that include many days of silence, interaction with a meditation teacher, and practice in a style of meditation that encourages spaciousness and introspection may be acceptable.

Yoga or other bodywork training

Recognition of the body as a vehicle for mindfulness is essential. We recommend that you practice and train in mindful hatha yoga, or in some other form of body-centered awareness practice.
Professional training and graduate degree in a related field

Teaching MBSR requires an intellectual understanding of the scientific, medical, and educational roots of MBSR, and the capacity to articulate these aspects of the teaching. For that reason, it is essential to pursue a graduate degree in a field connected to MBSR. Psychology, education, and medicine are typical fields of study, but any program that emphasizes an understanding of the mind and body, and includes service as a component, may be acceptable. You do not have to have a graduate degree to teach MBSR, but if you wish to receive certification, you must have completed your graduate program.
**Center for Mindfulness in Medicine, Health Care and Society**  
University of Massachusetts Medical School  
55 Lake Ave. North  
Worcester, MA 01655  
Fax: 508-856-1977  Phone: 508-856-2656  
Federal Identification Number 04-3108190  

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**THE ABOVE MANUALS ARE ONLY AVAILABLE TO PROFESSIONAL TRAINING PROGRAM GRADUATES**

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10% discount on orders of 10 sets or more  
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10% CD DISCOUNT | $0.00 |

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*Paperwork must be submitted prior to order processing*

**EXPEDITED SHIPPING (Overnight or Second day) = $40.00**
Mindfulness Curriculum for Alzheimer’s Caregivers

“Mindfulness is paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.”
Compassion and letting go of judgment are equally important aspects of the practice of mindfulness.”
Class One

- Welcome
- Intro to Mindfulness/ What is MBSR and Mindfulness practice?
- Go around in-group to meet each other/what are their circumstances? What most want from course?
- Suffering/Stress of being human
- Stress and Caregiving talk
- Noticing the moments in internal/external phenomena
- Formal/informal practice
- Introduction to Breath and body awareness
- Formal practice: Body Scan exercise
- Diaphragmatic breathing (Breath as anchor point)
- Compassion/Loving kindness and letting go of judgment

Themes: Group sharing a common human experience of caregiving. Need for self-care/self help trusting this can help others. Present moment awareness is a constant companion that can support the way we perceive situations. The goal is to learn new and different coping patterns, grow in the ever-abundant challenges of acceptance and changing that which can be changed.

Homework
- Practice mindful breathing in different situations
- Practice the body scan each day (using CD for guidance)
- Choose one routine activity in your daily life and make a deliberate effort to bring moment–to-moment awareness to that activity each time you do it. Possibilities include waking up in the morning, brushing your teeth, showering, drying your body, getting dressed, preparing food, washing dishes, shopping, waiting in lines, etc.
- Read Mindfulness and Mastery (copyrighted reprint, Saki F. Santorelli, M.A., University of Massachusetts Medical Center©)
- Do “The 9 Dots” (Full Catastrophe Living) and “Two Faces” exercises.
Class Two

- Begin with some silence, settling in, breathing
- Raisin exercise (establishes interconnectedness, beginner’s mind)
- Group check-in, how did the week go? Perception exercises? Body scan? Awareness?
- Formal practice: Body Scan on floor or chair
- Attitudes of Mindful practice
- Small groups exercise/large group (Discuss body scan just experienced also how it went during the week, how it was to make time for it, problems/obstacles, how it worked with them or not.) OR…..
- Whole group discussion
  - Everyday mindfulness/Walking

**Themes:** Attitudes to be cultivated in Mindfulness
- Doing vs. Being mode
- Curiosity/Non-judgment
- Thoughts and emotions that block care-giving
- Interpretation of Events (old lady/young lady, walking down the street)
- Perception and creative responding: Not the stressors so much as the way they are handled

**Homework**
- Practice Mindfulness using the body scan or sitting CD for guidance.
- Read the *Mindful Eating* article
- Practice eating mindfully at least once a day.
- Do Pleasant Events Calendar (and bring to next class to discuss together)
  - What was the pleasant experience (Monday – Sunday)?
  - Were you aware of the pleasant feelings while the event was happening?
  - How did your body feel, in detail, during this experience?
  - What moods, feelings, and thoughts accompanied this event?
  - What thoughts are in your mind now as you write this event?
- Mindfulness of one routine activity
Class Three

- Formal practice: Sitting/breathing meditation
- Pause Relax Open exercise (dyad work for generating compassion)
- Homework: How it went, how class is going for them
- Formal practice: Stretching
- Introduction to Formal practice: Walking
- Dyads

Themes: Relaxing the Body/Mind in Stretching and Walking, Expanding awareness of phenomena through sustained attention to the Body/Mind practices, Informal application of Mindfulness in daily routines and living, Pleasure and power in being present for unfolding moments and it relates to care giving.

In any moment, we can take refuge in awareness and love. When we get lost we need only pause, relax and open to what is here, and re-arrive in the natural presence that is our true home.

---Tara Brach

HOMEWORK
- Practice Mindfulness using the body scan, stretching, or sitting on your own or with the CDs for guidance.
- Practice eating mindfully at least once a day.
- Do Unpleasant Events Calendar (and bring to next class to discuss together)
  - What was the unpleasant experience (Monday – Sunday)?
  - Were you aware of the unpleasant feelings while the event was happening?
  - How did your body feel, in detail, during this experience?
  - What moods, feelings, and thoughts accompanied this event?
  - What thoughts are in your mind now as you write this event?
- Mindfully brush your teeth one morning or evening
- Practice Self-Compassion each day.
Class Four

- Formal practice: Breathing
- Formal practice: Stretching
- Formal practice: Mindful Walking: Begin standing, with awareness focused to the soles of the feet. Expand to body in stillness and begin walking slowly
- Dyads: What are the thoughts and emotions that block caregiving??

**Themes:**
Attitudes starting with non-judging
Pause/Relax/Open
Bare attention: See things clearly as they are (like it is). How are you? Fine. How is it now? See it for what it is and relate wisely. Or listening carefully to the truth of the moment
To Be Here in the present moment
Everything is constantly changing
Noticing the moment without commentary (or a judging mind)
Curiosity/Non-Judging
Doing vs. Being

**Homework**
- Practice Mindfulness everyday, with the body scan, stretching, or sitting on your own or with the CDs for guidance.
- Practice eating mindfully at least once a day.
- Compassion for Self and Loved One each day
- Remember to pause often into daily routines, finding your breath and body awareness to support relaxation and coming home to the moment.
- Read the articles:
  - “Non-Judging” (Jon Kabat-Zinn Full Catastrophe Living, Chapter 2, pp. 33-34))
  - “The Pause” (Gregory Kramer, Meditating Together, Speaking from Silence: The Practice of Insight Dialogue)
  - excerpt from Jack Kornfield’s “A Path with Heart (Part 1).
Class Five

- Meditation of body sensations/ breath/thoughts as thoughts
- Bare attention
- Reaction vs. Responding
- Dyads: Stressful Situation….. Practice speaking/listening while exploring difficult emotions that come up in caregiving
- Loving Kindness for self and other
- Guided compassion practice

**Themes:** Communication in presence and dyads interpersonal practice. Mindful speaking and non-verbal presence in communication i.e. what gets communicated. Compassion and loving kindness as practice for self and loved one.

**Homework**
Making arrangements for the Saturday Retreat
Practice Mindfulness everyday, with the body scan, stretching, or sitting on your own or with the CDs for guidance.
- Read “Relax” (Gregory Kramer, Meditating Together, Speaking from Silence: The Practice of Insight Dialogue) and reflect on the moments of letting go
- Read Jack Kornfield’s excerpt from A Path with Heart (Part 2)
- Compassion for Self and Loved One each day (adapted from Christina Feldman, Compassion: Listening to the Cries of the World)
- Remember to Pause and Relax often into daily routines, finding your breath and body awareness to support relaxation and coming home to the moment.
MBSRP RETREAT DAY

WELCOME

Intro to the Day
Thanks to all who came, sacrifice for many, unknown, unusual to take this kind of time for self

• Teachers
• Taking care of Self (self permission to honor own needs) (walking, sitting, stretching, lying down, bathrooms, breaks, )
• Tea and water
• Custody of the eyes   No talking/eye contact (helps deepen practice, use energy for mindfulness)
• Use whole time for practice… suggest not to read during lunch or distract self
• Moment to moment practice
• Time for non doing  (Suspending usual ways of being/talking, projects, radio, moving around, doing things like cleaning, shopping…By suspending these things, a lot of feelings will be noticed that are usually suspended because we’re caught up in doing…

Allow whatever might emerge, physical or emotional pain, boredom, guilt, frustration, irritation,
Simply accept them, feelings and experiences in the moment

• Silence and no eye contact will support process of looking into and accepting ourselves
• Just practice being with things the way they are not trying to feel a certain way… just letting things unfold.
• Invitation to drop expectations including having a pleasant day

Sit/Yoga and Stretching
Body Scan
Walking Inside and Outside
Sit/Tea
Lunch
Readings/ Loving Kindness/Reconnecting with Loved Ones
Class Six

- Sitting/Stretching in Chairs?
- Discussion of Retreat Day
- Forgiveness Meditation
- Dyads in communication/Pause Relax Open
- Closing compassion
- May I be well. Safe from harm. Happy. At Ease.

Themes: Working with Pause/Relax/Open for individual and interpersonal skill building in mindfulness. Self-awareness in behavior patterns as relates to stressful situations and reactivity in difficult encounters. Role-playing mindful response vs. reactivity in encounters with others.

**Homework**

- Alternate stretching and the body scan, (CD’s or handout sheets or on own)
- Read “OPEN” (Gregory Kraemer – Insight Dialogue) and reflect on the moments of PAUSE, RELAX, OPEN
- Practice compassion meditation for Self and Loved One each day
- Do the mindful communications calendar instructions each day.
- Practice mindfulness informally every day remembering at any moment: in work, play, transitions, you can bring awareness to your body and breathing.
- Practice Compassion on own or with CD
Class Seven

- Stretch/Body Scan
- Work with Communication exercise from the week
- Forgiveness Meditation
- Dyads in communication: How it is being with my family member with compassion for self and them
- Tea
- Closing compassion/forgiveness
- May I be well, Safe from harm, Happy, At Ease

Themes:
Continuing to explore communications with loved ones using mindfulness practices/Reacting vs. Responding to stressful situations/ Coping strategies for problems areas currently experiencing at home.

Homework
- Alternate stretching and the body scan (CD’s or handout sheets or on own)
- Practice mindfulness informally every day remembering at any moment: in work, play, transitions, you can bring awareness to your body and breathing.
- Read and contemplate handouts
  - Stress Reaction Cycle diagram
  - Stress Hardiness (Suzanne C. Kobasa)
    - American Journal of Community Psychology, 7, 413-423.
  - Coping with Stress: Responding vs. Reacting
- Practice Compassion (on own or with CD)
Class Eight

- AoA research data collection: 10-15 minutes
- Review of Formal Practices
  - Stretching, Body Scan, Walking
- Tea (Kindness Poem)
- Listening/Speaking Sharing Circle
- What learned, will take with them,
- Continuing Practice Individual, reading, sangha etc
- Loving Kindness Meditation to close
- *Hokusai Says* (poem by Roger Keyes)

**Themes:** Review/Continuation of practice after class, both formal and informal/Resources for support

**Homework:** Practice for rest of life/ Practice in caregiving with Mindfulness

**Handouts:** Reading List Resources, Poems from Class
A.4. Initial Sign-In Sheet
<table>
<thead>
<tr>
<th>Date:</th>
<th><strong>Type of Support Group</strong> (please select one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>County Where Support Group Is Held:</td>
<td>Early Stage: ☒ Other:</td>
</tr>
<tr>
<td>Name of Support Group:</td>
<td>Caregiver: ☐</td>
</tr>
<tr>
<td>Facilitator(s):</td>
<td>Bereavement: ☐</td>
</tr>
</tbody>
</table>

**Sign-In Instructions (all information will be kept in the strictest confidence):**
- **All attendees** please provide your name, address, county of residence and e-mail so we may contact you regarding news and additional educational opportunities.
- Please also provide us with some additional information about the person with dementia that you care for and the type of respite service you are using to attend these program sessions. Your cooperation is **completely voluntary and the data will only be used in aggregate form for grant reporting purposes.**

Name: _______________________________ City: ____________________________
Address: _____________________________ Zip: ______
County of Residence: _________________ Phone: ______________________________
Email Address: _____________________________________
Add to Newsletter List? ______ Notify of Advocacy Issues? ______ (must provide e-mail address)
Age of person with disease_________ Race/ethnicity of person with disease ______
Gender of person with disease_________ Zip code of person with disease_________
Respite use: Home Health Care______ Adult Day Center_______ Companion Care_______ None_______

How much do you believe this 8-week program will benefit you (please circle one number):

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
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<td>2</td>
<td>3</td>
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</table>
A.5. Attendance Record
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<td>Julia</td>
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</tbody>
</table>

Additional Notes:
A.6. Weekly Practice Log
Mindfulness-Based Stress Reduction for Caregivers

Weekly Practice Log

Date today: ___ / ___ (mo / day)

Instructions: Please be honest in your responses to the following questions. Please answer according to what really reflects your experience, rather than what you think your experience should be.

**Sitting Meditation** Practice Experiences **Within the Last Week**

1. How many **days** did you practice sitting meditation in the *last week*?
   
   ________ days

2. How many **practice sessions** of sitting meditation did you have in the *last week*?

   ________ sessions

3. How many **minutes** did you practice sitting meditation during the *average session this past week*?

   ________ minutes

**Body Scan** Practice Experiences **Within the Last Week**

1. How many **days** did you practice body scan in the *last week*?

   ________ days

2. How many **practice sessions** of body scan did you have in the *last week*?

   ________ sessions

3. How many **minutes** did you practice body scan during the *average session this past week*?

   ________ minutes
Yoga Practice Experiences Within the Last Week

1. How many **days** did you practice yoga in the *last week*?
   _______ days

2. How many **practice sessions** of yoga did you have in the *last week*?
   _______ sessions

3. How many **minutes** did you practice yoga during the *average session this past week*?
   _______ minutes

Informal Meditation Practice Experiences Within the Last Week

1. How many **days** did you do informal meditation practice in the *last week*?
   _______ days

2. How many informal meditation practice **sessions** did you have in the *last week*?
   _______ sessions

3. How many **minutes** did you do informal meditation practice during the *average session this past week*?
   _______ minutes
A.7. Retreat Information Flyer
MBSR Caring for Caregivers Retreat Day
Saturday March 20, 2010
Time 10 am – 2 pm

Grace Place Adult Care Center
8030 Staples Mill Road, Richmond, VA 23228
Phone: 804.261.0205

We look forward to providing a special day designed to help you care for yourself while care is provided for your loved one.

Lunch and refreshments will be provided for both you and your family member.

Please dress in warm, comfortable clothing that will allow for gentle stretching on the floor. Yoga mats will be provided. Also please bring shoes and jacket for walking outside (if weather permits).

Respite Care for Your Loved One

A highly trained and experienced leader from the Alzheimer’s Association, Ms. Lynne Seward, will facilitate the respite care, along with staff helpers. Ms. Seward is the owner and founder of Grace Place, a top adult care center in the Richmond area. An experienced art instructor and art therapist, Ms. Theodora Merry, will also contribute to group activities. Respite attendees will be fully occupied with enjoyable activities for the duration of your retreat time. Food and drink will be provided and, of course, you will have opportunity to check in with your loved one at any time during the retreat day.

Directions to Grace Place

Please see specific directions on the following pages. If you have any trouble at all locating Grace Place, please feel free to call the center at the phone number given above.
A.8. Three-Month Follow-Up Letter to Participants
Virginia Commonwealth University  
Stress Reduction Programs  

February 23, 2010

Dear [name],

The entire study team would like to thank you for your participation in our research on stress reduction programs for caregivers of family members with Alzheimer’s Disease and other dementias. Your efforts to date have truly made a difference and we have enjoyed our time together.

As you may remember, this study involves three separate time points at which we collect the necessary research data from each of our study participants. When you finished the stress reduction classes last November, you completed the second of these time points. **We are now at the third and final time point of data collection. The data we receive now is just as important as what you’ve provided previously, and may turn out to be the most important aspect of our project.**

This last collection is very similar to the previous ones and simply involves your completion of a short questionnaire packet and a single day of saliva collection (to assay for cortisol). In a few days we would like to give you a call to discuss a best day that works for you to do your saliva collection. Then we will send you a FedEx box with the questionnaire packet, saliva collection vials, and storage bottle, along with another FedEx box for the return of these materials after you complete them.

**For our research to be successful, this final collection is particularly important because it will provide information about how the possible benefits of the stress reduction programs may be maintained over time.**

It is also important to realize that we need to know about your current stress level and other experiences **regardless of how much benefit you feel you have gained over time.** Your participation in this final phase of the project will be invaluable to help us determine which stress reduction programs are most effective for family caregivers like yourself. After all, our goal is to develop helpful stress management strategies, and that’s what we’ve been working toward over the course of your participation in the project. It would be a shame if we were unable to follow through to the end.

We appreciate your willingness to partner with us in this endeavor and want to remind you that once this final phase of the project is completed, we’ll be sending you a check for $100 as well as a personalized report showing how your psychological states and cortisol levels have changed from the beginning of the program until now.

Please feel free to contact us if you have any questions or concerns. We’ll be in touch soon.

Respectfully yours,

*The VCU Stress Reduction Study Team*

Kirk Warren Brown, PhD  804-828-6754 kwbrown@vcu.edu  
Connie Coogle, PhD  804-828-1525 ccoogle@vcu.edu  
Jessica Hellerstein  804-828-1525 hellersteijm@vcu.edu
A.9. Protocol and Strategy for Pursuing Follow-Up Data via Phone Calls
AoA Time 3 Reminder Calls

1. We need to call these people Thursday or Friday at latest.

2. On the spreadsheet ("passed screen" tab), type your name next to the people you will call (in the “Who is calling” column; see Sue's example). Call only those people showing a 'yes' in the “Follow-up” column.

3. If you get voicemail, be sure to leave a callback number on which you can be reached easily anytime b/c we need to speak with them ASAP.

4. When you get the person live on the phone,
   
   i) Ask: Did you get the letter we sent out earlier this week?
   
   ii) Just a reminder that this is the final saliva collection and questionnaire packet of the project. *We are doing this one more time as it's important to determine how our stress reduction participants are doing now in their day-to-day lives, some time after the program has finished.*
   
   iii) Just a reminder that your payment will be processed and personalized report prepared after this final set of measures are completed.
   
   iv) Ask: What day would you like to do your final saliva collection? Choices are Tue Mar 9, Wed Mar 10, Sun Mar 14, Mon Mar 15, Tue Mar 16, or Wed Mar 17. [Note: Once you have their date, add it to the google doc in the column called "T3 saliva collection day.”]
   
   v) Say that in the next few days you will receive a Fed Ex box containing all the saliva collection materials and the final, brief questionnaire packet. There will also be a Fed Ex box enclosed inside the shipment to send everything back to us.
   
   vi) I just want to remind you of the saliva collection schedule:
       
       Vial # 1 when they first wake up (sitting up in bed).
       
       Then use Vial # 2, 3, etc up to Vial 6 for the rest of the day using the schedule that will be included in the box.
   
   vii) To remind you: As you complete each saliva collection, put the swab back in the vial & put the vial in the storage bottle. Remind them to *only open the bottle to put in the 6 vials.*
   
   viii) After the 6th saliva collection is in the bottle at bedtime, wrap the bottle in the newsprint included in the box.
   
   ix) Put the bottle and the completed questionnaire packet in the Fed Ex box that box has Dr. Brown's name and address on it.
   
   x) Put the sealed box in a FedEx drop box the next morning.

5. If Sue/Shari/Jessica have any questions, call Kirk ASAP. If its after 5 pm, please call his cell phone: 804/687-9235. Please don’t wait to call. We need to move quickly on this shipment.
B. Recruitment
B.1. Sample spreadsheet of printers and advertising sources
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<th>Company</th>
<th>Contact</th>
<th>phone</th>
<th>quantity</th>
<th>amount</th>
<th>description</th>
<th>print deadlines</th>
<th>pub date</th>
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<td>Elizabeth Bolka</td>
<td></td>
<td>3000</td>
<td>$998.00</td>
<td>brochure on 100# gloss</td>
<td>n/a</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>4000</td>
<td>$1,045.00</td>
<td>brochure on 100# gloss</td>
<td>n/a</td>
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</tr>
<tr>
<td>Printing Services, Inc.</td>
<td>Nita Doolin</td>
<td></td>
<td>3250</td>
<td>$811.25</td>
<td>brochure on 100# gloss</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>FedEx Kinko's</td>
<td>Cheryl Pryor</td>
<td>866-926-8641</td>
<td>3250</td>
<td>$576.55</td>
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<td></td>
<td></td>
<td>int'l biz fee</td>
<td></td>
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<tr>
<td>FiftyPlus Magazine</td>
<td>Lisa Fracker, Mark Fetter</td>
<td>673-5203 work</td>
<td>1/8 page</td>
<td>$279.00</td>
<td>monthly magazine</td>
<td>second Friday of month before pub.</td>
<td>Sept, Oct, Nov</td>
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<tr>
<td>Chesterfield Observer</td>
<td>Carol McCracken</td>
<td>545-7502</td>
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<td></td>
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<td>business card size</td>
<td>$175.00</td>
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<tr>
<td>Henrico Citizen</td>
<td>Tom Lappis</td>
<td>262-1700</td>
<td>1/4 page</td>
<td>$285.00</td>
<td>newspaper</td>
<td>deadline 1&amp;3 Monday for run on 1&amp;3 Thursday</td>
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</tbody>
</table>
B.2. Brochure
Who are the Study Investigators?
Dr. Kirk Warren Brown, PhD
Department of Psychology
Virginia Commonwealth University

Dr. Connie Google, PhD
Virginia Center on Aging
Virginia Commonwealth University

What is the purpose of this study?
Dr. Kirk Warren Brown and Dr. Connie Google, nationally recognized researchers of stress and dementia, are conducting a study investigating the beneficial effects of two Stress Reduction Programs for Alzheimer’s and dementia family care providers.

This study seeks to understand how these programs can help family care providers feel better and relate better to their care recipients. If you are interested in stress reduction and in helping us learn more about caregiving persons with Alzheimer’s Disease and other dementias, please consider joining our study!

Who can participate in this study?
You may qualify to participate if you can:
- Attend an 8-week stress reduction course (one evening per week), complete study measures, and meet the following criteria:
  - At least 18 years of age and providing care to a spouse, sibling, parent, or other relative of someone with early stage Alzheimer’s Disease or other dementia
  - Free of major, uncorrected sensory impairments and cognitive deficits
  - Free of a psychiatric disorder or history thereof.
  - If taking certain medications, will be on a stable regimen for at least 8 weeks prior to enrollment.

What would I do as a participant in this study?
- Enroll in an 8-week stress reduction course that meets once evening per week for 2 hours.

- Complete a 30 minute packet of psychological questionnaires at 3 times – right before and after the course, and 3 months after the course.
- Collect saliva samples at the same time points to assess physiological responses.

Participation is voluntary and all responses will remain strictly confidential. The study does not require the use of medication.

If needed, professional respite care during each weekly class will be provided at no cost.

Who will have access to my study information?
We will take all reasonable efforts to protect your privacy. We will not share with anyone the information you give us; however, information from the study and information from your research records may be looked at for research or legal purposes from authorized agents of Virginia Commonwealth University. However, your identity will not be publicly disclosed.

Where will the study take place?
Stress reduction classes will be held at a local, easily accessible community location.

Interviews will be held in a quiet, modern laboratory at VCU.
What benefits will I receive for participating?

- You will receive a stress reduction course for free.
- You will be paid $100 for completion of the study.
- You will have the option to receive a personalized report describing your psychological and physiological responses in the study.
- If needed, professional respite care during each weekly class will be provided at no cost.

There are NO costs for participating in this study except the time commitment for completing the study.

How do I get started?

For questions or enrollment information, please contact us at 828-1525. If you reach the voicemail, please leave your name and telephone number. We will promptly return your call. All inquiries will remain confidential.
B.3. Flyer
At times, care providers all experience *stress*...

Are you providing care to a family member with Alzheimer’s Disease or other dementia?

Whether you have a little or a lot of stress, Virginia Commonwealth University invites you to participate in a research study on two Stress Reduction Programs.

**Caring for Care Providers**

*Eligible participants will be:*
- At least 18 years of age and providing care to a family member with early stage Alzheimer’s Disease or other dementia
- Free of major, *uncorrected* sensory impairments and cognitive deficits
- Free of a psychiatric disorder or history thereof
- If taking certain medications, will be on a stable regimen for at least 8 weeks prior to enrollment

To learn more about the study please call us at **(804) 828-1525**

Participants will receive one of two 8-week programs for free, a personalized report, and up to $100 for completing the study.
B.4. Newsletter, Internet, and E-mail Ad
ARE YOU A CARE PROVIDER TO A FAMILY MEMBER WITH ALZHEIMER’S DISEASE OR OTHER DEMENTIA?

Virginia Commonwealth University invites you to participate in a research study investigating two Stress Reduction Programs.

VCU investigators seek to understand how these stress reduction programs can help family care providers feel better and relate better to their care recipients.

*Caring for Care Providers*

Eligible participants will be:

- At least 18 years of age and care provider to a spouse, sibling, parent, or other relative of someone with early stage Alzheimer’s Disease or other dementia
- Free of major, *uncorrected* sensory impairments and cognitive deficits
- Free of a psychiatric disorder or history thereof
- If taking certain medications, will be on a stable regimen for at least 8 weeks prior to enrollment

Participants will receive an 8-week (one evening/week) stress reduction course for free, up to $100 for completion of the study, and a personalized report of study responses.

If needed, professional respite care during each 2-hour class will be provided at no cost. The study does not require the use of medication.

For more information, please call us at 804-828-1525.

This research is funded by the U.S. Administration on Aging.

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**VIRGINIA COMMONWEALTH UNIVERSITY**

www.vcu.edu

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Approved

3-18-09

Created on 03.12.09
B.5. Personalized Research Report Form and Cover Letter
PERSONALIZED REPORT OF THE STUDY RESULTS

Please indicate by checking the category below whether you want to receive a personalized report on your psychological and physiological responses in this study.

☐ I would like to receive a personalized report on my psychological and physiological responses in this study. Please write your name and contact information below (e-mail address OR mailing address is acceptable).

☐ I do not want a personalized report from this study. No further action on this page is required.

Please note that your name and contact information will not be linked with your survey responses, nor will we share your name or contact information with anyone for any reason. The only individuals who will have access to the data are trained study personnel.

Please also note that if you request a personalized report, it is your responsibility to let the study investigator know if your e-mail or street address changes. The study investigator’s contact information is in the informed consent form you received (under the “Questions” section).

First Name __________________________________________

Last Name __________________________________________

Email Address ________________________________________

Street Address ________________________________________

Apt/Suite ____________________________________________

City ____________________________________________ State ______

Zip Code ____________________________________________

APPROVED

3-18-09/ER/JR

March 12, 2009
[Date]

Stress Reduction for Family Caregivers of Persons with Alzheimer’s Disease and Other Dementias
Personalized Research Report

Dear [Mr./Ms. ________],

In [month] [year] you participated in the “Stress Reduction for Family Caregivers of Persons with Alzheimer’s Disease and Other Dementias” research study hosted by Virginia Commonwealth University. At that time you indicated that you would like to receive a personalized report describing your psychological and physiological responses during the study, and this report is enclosed here. The report presents a summary of what we believe are some of the most important and interesting information you provided, over the course of the study. The report has three main elements: The first describes each psychological and physiological measure and explains what the scores on each one mean. The second part presents your actual scores on these measures. The third part provides scores showing how the ‘average’ adult has responded on these measures, as reported in published research.

If you have any questions about this report, or any lingering questions or concerns about the study or your participation in it, please feel free to contact me. I can reached as follows:

Kirk Warren Brown, PhD
Virginia Commonwealth University
808 W. Franklin Street
P.O. Box 982018
Richmond, VA 23284
Telephone: 804-828-6754
E-mail: kwbrown@vcu.edu

I want to thank you again for being part of this research project. Our primary goal for the project is to help to enhance the well-being of care providers like yourself, and you’ve made an important contribution to that end. I hope that in some fashion your participation in the project, and this report, serves the same end in your own life.

Yours,

Kirk Warren Brown, PhD
Principal Investigator

APPROVED
3-18-09/ER/JR

March 12, 2009
B.6. Primer/Decision Tree for Choosing Print Media Coverage
Choosing Print Media Coverage

**Medium**
- Brochures and Flyers
  - Price/Quantity
  - Shipping Costs
- Print/Magazine
  - Circulation
  - Advert Size
  - Price
  - Graphic Designer

**Variables**
- Price/Quantity
- Shipping Costs

**Considerations**
- Graphic design adjustments
- Will they ship directly to separate addresses?
- Frequency of ad
- ½ page, ¼ page, etc.
- Discount for non-profit
- Make own ad
- Get free graphic design adjustments

**Frequency of Ad**
- Bimonthly/Monthly
- Weekly
- Special
B.7. Sample Letter Requesting Dissemination of Recruitment Materials
June 24, 2009

Dear ________,

The Virginia Center on Aging and the Department of Psychology at Virginia Commonwealth University (VCU) are conducting a study of the beneficial effects of two stress-reduction programs for family caregivers of those with Alzheimer’s disease or related dementias. The goal of the research project is to understand how family caregivers can feel better and relate better to their care recipients. Enclosed is a more detailed summary description of the project. This project is funded by the Virginia Department for the Aging under the Alzheimer’s Disease Supportive Services Program of the U.S. Administration on Aging, Department of Health and Human Services.

The success of our project will depend in part on the goodwill and cooperation of trusted leaders in the Greater Richmond service provider community. We can only do this with your kind assistance! We are looking to you to help us recruit caregivers who could benefit by participating in our study, and are asking for your assistance in promoting this opportunity among the caregivers you serve. Also please share this information with colleagues who, in your estimation, could contribute to our effort.

We hope that you will post the enclosed flyer and distribute the brochures we’ve provided. But we would appreciate any other support you might offer, such as:

- Sending an email communication to caregivers.
- Placing an advertisement in your regular publications that might reach caregivers.
- Post an internet announcement on your website.

We’ve enclosed VCU-approved documents (VCU IRB #HM12070) to be used in these dissemination efforts.
We will gratefully recognize your support of this work in our final project report. Just notify us of your efforts. Moreover, we will be happy to share the results of the study with you.

If we can answer any questions about this project, please contact Connie Coogle, PhD (804-828-1525; ccoogle@vcu.edu) or Kirk Warren Brown, PhD (804-828-6754; kwbrown@vcu.edu). We hope you will join us in implementing this innovative project and look forward to hearing from you.

With our many thanks,

Constance L. Coogle, Ph.D.  
Project Co-Director

Kirk Warren Brown, Ph.D.  
Project Co-Director

cc: project summary; brochures; flyers; newspaper, e-mail & internet ad text
B.8. Project Summary Included with Letters Requesting Dissemination of Recruitment Materials
Stress Reduction Programs for Alzheimer’s Caregivers

Providing care for family members with Alzheimer’s disease (AD) or other dementias presents serious challenges to caregivers. Methods that effectively address caregiver burden can contribute to better psychological and physical functioning. There is a need for programs that focus on the needs of families before severe disease progression and more stressful caregiver conditions occur, and before caregivers develop physical and mental health problems that could interfere with their abilities to provide support to relatives with AD.

The current research project is offering AD family caregivers the opportunity to enroll in either an 8-week Mindfulness-Based Stress Reduction (MBSR) program or an 8-week Social Support program. In accord with the ‘gold standard’ of clinical research practice, participants will be randomly allocated to one of the two programs. The MBSR program will train participants in mindfulness, or ‘presence of mind’ – a receptive attentiveness to events and experiences occurring in the present moment, in contrast to a state of mind in which occurrences are habitually filtered through appraisals, evaluations, memories, and beliefs about events and experience. Over the past 25 years, mindfulness-based programs have been increasingly incorporated into clinical trials and wellness programs that teach individuals to better manage stress-related thoughts, emotions, and behavior. The technique incorporates a variety of mindfulness techniques, including meditation training, yoga, dyadic exercises, and psycho-education to teach skills for managing stress and regulating emotions. The Support Program is intended to reduce caregiver stress by exploring techniques to manage specific problems that arise. Both programs will focus on the relational aspect of caregiving and are designed to address an array of key health, well-being, and relationship issues relevant to caregivers. The project will determine the benefits of each program by assessing the mental health, physical health, and relationship outcomes for each participant.

We anticipate that the first set of program sessions will be held on a Monday or Wednesday beginning the last week in September at a time and location most suitable for the majority of program participants. The sessions will be repeated in January. Enrollment in the study is currently underway. For questions or enrollment information please call the Virginia Center on Aging at 804-828-1525. All inquiries will remain strictly confidential.
B.9. Program Advertisement Created by Boomer Life Graphic Designer
ALZHEIMER’S OR DEMENTIA
FAMILY CAREGIVERS

VCU invites you to participate in a research study on two
STRESS REDUCTION PROGRAMS.

Participants will receive one of two 8-week programs for free, a personalized report, and up to $100 for completing the study.

For more information, call 804-828-1525

Eligible participants will be:
- At least 18 years of age and providing care to a family member with early stage Alzheimer’s Disease or other dementia
- Free of major, uncorrected sensory impairments and cognitive deficits
- Free of a psychiatric disorder or history thereof
- If taking certain medications, will be on a stable regimen for at least 6 weeks prior to enrollment

ADAG
ADMINISTRATION ON AGING
B.10. Program Advertisement Featured in Age in Action
At times, care providers all experience stress...

Are you providing care to a family member with Alzheimer's Disease or other dementia?

Whether you have a little or a lot of stress, Virginia Commonwealth University invites you to participate in a research study on two

Stress Reduction Programs
Caring for Care Providers

Eligible participants will be:
• At least 18 years of age and providing care to a family member with early stage Alzheimer’s Disease or other dementia
• Free of major, uncorrected sensory impairments and cognitive deficits
• Free of a psychiatric disorder or history thereof
• If taking certain medications, will be on a stable regimen for at least eight weeks prior to enrollment

To learn more about the study, please call us at (804) 828-1525. Participants will receive one of two eight-week programs for free, a personalized report, and up to $100 for completing the study.
B.11. Internet Banner on Boomer Life Magazine Home Page (Top) and Internet Ad Appearing at Boomer Life Magazine Online (Bottom)
CENTERSTAGE
The Wait is over

BILL BEVINS
Blues Talk with Lil’ Ronnie
September 20, 2009
CD and DVD Jam
Read More...

DANIEL NEMAN
Silver Screen:
Film School 101
To buy, or not to buy; that's the question.
Read More...

Volunteer!
Make a difference.
Volunteer Now

Your Boomer Life
January 20, 2010
Glatt’s Table

View our current issue online

http://boomerlifemagazine.com/ver2/
ALZHEIMER'S OR DEMENTIA FAMILY CAREGIVERS

VCU invites you to participate in a research study on two STRESS REDUCTION PROGRAMS.

Participants will receive one of two 8-week programs for free, a personalized report, and up to $100 for completing the study.

For more information, call 804-828-1525.

Eligible participants will be:
- At least 18 years of age
- Family members or caregivers of those with Alzheimer's Disease or other dementia
- Black or Hispanic participants
- Present health or mood problems may not interfere with participation.
- Offer a relevant or unrelated stressor.
- If taking certain medications, consult with a health care provider or pharmacist to implement.

ADA - American Diabetes Association

de 9/30/2009
Welcome to Our Caregivers Library

You are in the Central Virginia Section of the National Caregivers Library - one of the most extensive libraries for caregivers that exist today. Hundreds of articles, forms, checklists and links to external resources are organized into logical categories, which appear on the side of this page. Click any category for a list of sub-categories, articles and resources. Simply continue “drilling down” until you find what you need.

IMPORTANT NOTE:
These resources are copyrighted and are for personal use only. Any copying or use for organizational or commercial purposes is strictly prohibited. If you are interested in these resources for commercial or organizational use, please contact us at (804) 327-1111 for permission.

Are you a caregiver to someone with Alzheimer's?

Hurry.
Sign up has begun and participation is limited.

Click here for details.
B.13. Advertisement on Senior Navigator Website
Richmond Area Caregivers: Participate in An Important Research Study

ARE YOU A CARE PROVIDER TO A FAMILY MEMBER WITH ALZHEIMER’S DISEASE OR OTHER DEMENTIA?

Virginia Commonwealth University (VCU) invites you to participate in a research study investigating two Stress Reduction Programs.

VCU investigators seek to understand how these stress reduction programs can help family care providers feel better and relate better to their care recipients.

Caring for Care Providers

Eligible participants will be:

- At least 18 years of age and care provider to a spouse, sibling, parent, or other relative of someone with early stage Alzheimer’s Disease or other dementia
- Free of major, uncorrected sensory impairments and cognitive deficits
- Free of a psychiatric disorder or history thereof
- If taking certain medications, will be on a stable regimen for at least 8 weeks prior to enrollment

Participants will receive an 8-week (one evening/week) stress reduction course for free, up to $100 for completion of the study, and a personalized report of study responses.

If needed, professional respite care during each 2-hour class will be provided at no cost.

The study does not require the use of medication.

For more information, please call us at 804-828-1525.

This research is funded by the U.S. Administration on Aging.

Sincerely,

Constance L. Coogle, PhD, Virginia Center on Aging, VCU, ccoogle@vcu.edu
Kirk Warren Brown, PhD, Department of Psychology, VCU, kwbrown@vcu.edu

Source: Virginia Center on Aging
Last Review: Monday, November 16, 2009
B.14. 30-Second and 40-Word Radio Scripts
Mindfulness-Based Stress Reduction for Alzheimer’s Caregivers

Radio advertisements

THIRTY SECOND
Often caregivers don’t realize the toll that providing care can take on them. If you are providing care for a family member with Alzheimer’s Disease or another dementia, you may be eligible to participate in free stress reduction programs offered by Virginia Commonwealth University researchers. For more information on enrolling in this research, call 804-828-1525. Again, that’s 804-828-1525.

FORTY WORD
Are you providing care for a family member with Alzheimer’s Disease or another dementia? You may be eligible to participate in free stress reduction programs offered by Virginia Commonwealth University researchers. For information on this study, call 804-828-1525. That’s 828-1525.
C. Self-Devised Research Instruments
C.1. Needs Assessment Questionnaire
New Support Program for Alzheimer’s Disease Caregivers: Needs Assessment Questionnaire

1) Are you the main person providing care for someone with Alzheimer’s Disease (AD)?
   ___ Yes
   ___ No

2) Where does this person live?
   ___ Their home
   ___ Your home
   ___ Assisted living facility
   ___ Nursing home
   ___ Other (please specify)_________________________

   2a) If this person does not live in your home, how far from you does this person live? _____ miles

   2b) If this person lives in your home or in their home, do you have some type of help with the caregiving responsibilities?
      ___ Yes, always
      ___ Yes, often
      ___ Yes, occasionally
      ___ No, never

   2c) If you have assistance, how helpful do you find it to be?
      ___ Not at all helpful
      ___ A little helpful
      ___ Somewhat helpful
      ___ Very helpful
      ___ Extremely helpful

3) How is this person with AD related to you? (Check ONE)
   ___ Friend, neighbor, or other non-relative
   ___ Spouse/partner
   ___ Mother/father
   ___ Mother-in-law/father-in-law
   ___ Grandparent
   ___ Other relative (please specify) ________________

4) How long have you been providing care for this person? _____ years _____ months

5) Approximately how long has this person been experiencing memory-related problems? _____ years _____ months

6) On average, how many days per week do you provide care for this person?
   ___ less than 1 day per week
   ___ 1-2 days per week
   ___ 3-4 days per week
   ___ 5-6 days per week
   ___ 7 days per week
7) On the days that you provide care for this person, on average, how much care do you provide?
   __ < 1 hour per day
   __ 1-5 hours per day
   __ 5-10 hours per day
   __ 10-15 hours per day
   __ 15-24 hours per day

8) Overall, to what extent does this person depend on you for activities of daily living, such as bathing, dressing, preparing meals, shopping, etc?
   __ Not at all
   __ A little
   __ Somewhat
   __ Very much
   __ Extremely

9) Overall, how burdened do you feel in caring for this person?
   __ Not at all
   __ A little
   __ Somewhat
   __ Very much
   __ Extremely

10) What are the problems you experience as a consequence of caring for this person? (Check all that apply)
    __ It affects my relationship with this person in a negative way
    __ It affects my relationship with other family members or friends in a negative way
    __ It affects my health in a negative way
    __ It affects my stress in a negative way
    __ It affects my job/work in a negative way
    __ It affects my finances in a negative way
    __ I don’t have enough time for myself
    __ I don’t have enough time for my family and friends
    __ Other (please specify) ____________________________

11) Do you have outside emotional support for yourself? (Check all that apply)
    __ Individual, family, or couples counseling
    __ Psychotherapy or psychiatric treatment
    __ Support groups
    __ Family
    __ Friends
    __ Other (please specify) ____________________________
12) Where do you get your information about resources for caregivers of Alzheimer’s Disease patients? (Please indicate your top THREE sources.)

___ Alzheimer Association  
___ Social Services agency  
___ Area Agency on Aging  
___ Other organization for older adults. Which one(s)? ______________________  
___ Friends or neighbors  
___ Family  
___ Co-workers  
___ Physicians  
___ Other health care professionals. Which one(s)? ________________________  
___ Telephone book  
___ Internet  
___ TV/Radio  
___ Newspaper/magazines. Which one(s)? _______________________________  
___ Religious organizations. Which one(s)? ______________________________  
___ Civic or community organizations. Which one(s)?______________________  
___ Other sources. Which one(s)? ___________________________________

13) Are you getting the information you need?  
___ Yes  
___ No  Explain  _____________________________________________________

14) How much would you say that you know about the services that are available through the Alzheimer’s Association?  
___ A lot  
___ Some  
___ A little  
___ Nothing at all

15) The following questions concern a new, supportive program currently under development for caregivers of individuals with AD. This new program will emphasize stress management for AD caregivers as well as techniques to interact more effectively with care recipients. The following elements are being considered for this new program. Please indicate how helpful you think each component would be.

15a) Stress management techniques like (non-religious) guided meditation and yoga.

___ Very helpful  
___ Somewhat helpful  
___ Neutral  
___ Somewhat unhelpful  
___ Very unhelpful

15b) Techniques to interact in a more relaxed, less stressful way with a person with AD.

___ Very helpful  
___ Somewhat helpful  
___ Neutral  
___ Somewhat unhelpful  
___ Very unhelpful
15c) Techniques to help me deal with my emotions (e.g., sadness or anxiety).
___ Very helpful
___ Somewhat helpful
___ Neutral
___ Somewhat unhelpful
___ Very unhelpful

15d) Techniques to make me more aware of myself and enhance my personal growth.
___ Very helpful
___ Somewhat helpful
___ Neutral
___ Somewhat unhelpful
___ Very unhelpful

15e) Learning stress management and effective caregiving through focused discussion with other AD caregivers in a supportive group.
___ Very helpful
___ Somewhat helpful
___ Neutral
___ Somewhat unhelpful
___ Very unhelpful

16) If this program were offered to you with these components, to what extent would you be interested in participating? In answering this question, assume that you had opportunity to learn more about the program beforehand and that the class scheduling was appropriate for you.
___ Very interested
___ Somewhat interested
___ Neutral
___ Somewhat uninterested
___ Very uninterested

17) Which factor(s) would determine your ability to participate in the supportive program? (Check as many as apply to you)
___ If respite care for my care recipient is provided during classes
___ If transportation to and from classes is provided
___ If classes are no more than ________ hours in length
___ If classes are no more than ________ weeks in duration
___ If classes are scheduled between ______ am/pm and ________ am/pm
___ Other (specify) ___________________________________________

18) Is there anything else you can tell us about your interest in the supportive program?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Finally, here are a few important closing questions to help us better understand the responses to this survey. Please remember that your responses are anonymous and cannot be used to identify you personally.

19) Gender
   ___ Male
   ___ Female

20) Age ___ years

21) Race/ethnicity (Check all that apply)
   ___ White (not of Hispanic origin)
   ___ Hispanic/Latino(a)
   ___ African American/Black
   ___ Asian/Pacific Islander
   ___ American Indian/Alaskan Native
   ___ Other _________________

22) Marital Status
   ___ Married/living with partner
   ___ Divorced/separated
   ___ Widowed
   ___ Single (never married)

23) Employment
   ___ Full-time (40 or more hours per week)
   ___ Part-time, ____ hours per week
   ___ Retired, but working part-time
   ___ Other (please explain) ______________________________

24) How would you describe your general physical health?
   ___ Excellent
   ___ Good
   ___ Fair
   ___ Poor

25) Where do you currently live?
   Town/City/County ___________________
   State __________

   Thanks for your time in completing this survey!
C.2. Phone Screening Inclusion-Exclusion Questionnaire
Phone Screening Inclusion-Exclusion Questionnaire

1. First, ask the potential participant how they became aware of the study. This is important so we can track the recruitment efforts. Check one:
   
   ___ Chapter newsletter
   ___ Age in Action (VCoA) newsletter
   ___ Boomer Life
   ___ FiftyPlus
   ___ Style
   ___ RTD
   ___ Richmond mag
   ___ Other; specify: ___________________________

   “In brief, let me tell you that there are two stress reduction programs that will begin in January and run for 8 weeks, ending in mid-March. We are trying to choose a time and location that is best for the majority of the group.

2. Ask for availability. What days of the week work best for you? Afternoons or Evenings?
   ___ Mon Aft/Eve    ___Tues Aft/Eve    ___Wed Aft/Eve    ____Thurs Aft/Eve    ____Fri Aft/Eve

   “This study will include measurements of psychological states and several saliva samples to assess physiological responses, and so we want to identify factors which may affect these responses during the investigation. I’d like you to please answer the following questions. Before beginning, I want to emphasize that all information that you provide will remain confidential, and feel free not to answer any questions that you feel uncomfortable in answering. If you have any questions as you go along, please ask me to clarify. Ok, ready?”

3. Are you 18 years of age or older?

   Yes   No

4. Do you provide care to a family member with AD or other dementia?

   Yes   No

   a. [If yes] what is your relationship to that person? ______________________________

5. Administer the FAST care recipient stage questionnaire. Preface with the following explanation:

   “Our federal funding source is focusing our project on care recipients whose conditions have progressed to a particular stage in the process. For this reason, we need to find out about the skills and deficits you are dealing with as you provide care.”
   [stop interview if ‘Yes’ response at stage 6 or above].
6. Are you taking any antidepressant or anti-anxiety medications at this time?
   Yes  No
   
   a. [If yes] has your medication dosage been stable for at least the past two months?
   Yes  No

7. I will read a list of medical conditions, and when I come to the end I’d like you to answer yes if you have any of them. You do not need to indicate which of these conditions you have, just answer yes if anything on the list applies to you. If you do not have any of these conditions, please answer no.

   Yes  No

   ______ Current or past major depressive disorder with psychotic features.
   ______ Current or past psychosis
   ______ Current or past schizophrenia disorder.
   ______ Current or past bipolar disorder.
   ______ Current or past organic brain syndrome.
   ______ Diagnosed mental retardation.
   ______ Alcohol or substance abuse condition within the past year.

8. Administer the TICS. (Preface with, “Finally, we need to complete a brief, simple measure of sensory and cognitive functioning to ensure that the classes will be appropriate for you.”)

Exclude if ANY of the following have the answers below:
Q3:   No
Q4:   No
Q6a:  No
Q7:   Yes
FAST: Stage 6 or above.
TICS: Score 30 or below.
Interviewer recruitment action taken:

_____ Prospective participant fails to match one or more criteria as specified above. Inform them that,

“Unfortunately, you did not meet one (or more) of the criteria for the study, namely [criteria/ion to be named here], and this may complicate our interpretation of the study findings. So unfortunately we cannot invite you to participate in the study.”

[Note: If they are deemed ineligible because of the advanced progression of their care recipient’s disease, you should also tell them:]

“We intend to use the data from this study to secure a larger grant and we hope that funding will not be as restrictive in terms of the care recipient’s stage in the disease. May we contact you again at a later date?”

_____ Yes  _____ No

[Tell everyone the following]

“I want to thank you for your interest in the study and for taking the time to speak to me today.”

_____ No exclusion criteria met. Proceeded to schedule Time 1 appointment with the following:

“Let me tell you a little about the study. The purpose of the study is to understand how two Stress Reduction Programs can help family caregivers feel better and relate better to their care recipients. If you decide to be in this research study, you will be randomly assigned (like flipping a coin) to participate in one of two stress reduction programs: the Mindfulness-Based Stress Reduction (MBSR) group or the Social Support (SS) group. Both programs have been proven effective. They just employ different methods to accomplish the same result which is stress reduction. Both groups involve a series of classes and activities that you will be asked to participate in. I just want to emphasize that by enrolling in the study, you are making a commitment to attend every session. Each group will meet at an easily accessible location in the community. You will not be asked to come downtown. We will try to choose a location that is best for the majority of those participating in each program. One group will also have one half-day session on a Saturday during the time that it runs. Both groups are designed to help you take better care of yourself and your care recipient.

Aside from participating in a stress reduction program, we will ask you to complete a relatively brief packet of questionnaires about your psychological and caregiving experiences before the start of the program, at the end of it, and once more 3 months after your program ends. At those same time points, we’ll also ask you to collect several small saliva samples over the course of one day to assess physiological responses to the stress reduction programs.”
“Do you have any questions at this point?”

[Once those are addressed]
We will be calling you to set up an appointment time
where you will meet with Dr. Kirk Warren Brown in the Psychology Department at VCU
on W. Franklin St. He’ll talk more with you about the study and give you a chance to ask
questions before you consent to participate. If you do, we’ll complete our first packet of
questionnaires and give you the devices for the first saliva collection. We’ll also give you
some details on the stress reduction program you’ll participate in, including the location,
time, and so on.”

“Can we go ahead and set up an appointment for you?”

Date and time of Time 1 appointment: ___ /_____ /_____ @ ______ am or pm
C.3. Background Information
**BACKGROUND INFORMATION**

**Instructions:** To close, we would like some background information to help us interpret the questionnaires you just completed. Please remember that all of your responses will be anonymous and confidential.

Section A. General Demographics

1. What is your gender?  
   ___ Male  
   ___ Female

2. What is your age?  ___ years

4. What is your racial/ethnic origin? (check one)  
   ___ White or Caucasian  
   ___ Black or African American  
   ___ Hispanic or Latino  
   ___ Asian  
   ___ Native American  
   ___ Other

5. What is your current marital status? (check one)  
   ___ Married  
   ___ Widowed  
   ___ Separated  
   ___ Divorced  
   ___ Single (never married)

6. What is the highest level of education you attained? (check one)  
   ___ Some grade school  
   ___ Completed grade school  
   ___ Some high school  
   ___ Completed high school  
   ___ Some college  
   ___ Completed college degree  
   ___ Some graduate education  
   ___ Completed graduate degree

7. What is your current yearly household income from all sources?  _________ dollars

Section B. Caregiving Experiences

1. Are you the main person providing care for someone with Alzheimer’s disease (AD) or other
1. Does this person have Alzheimer’s disease or dementia?
   ( ) Yes
   ( ) No

2. Where does this person live?
   ( ) Their home
   ( ) Your home
   ( ) Assisted living facility
   ( ) Nursing home
   ( ) Other (please specify) ____________________

3. If this person lives in your home or in their home, do you have some type of help with the caregiving responsibilities?
   ( ) Yes, always  ( ) Yes, often  ( ) Yes, occasionally  ( ) No, never

4. If you have assistance, how helpful do you find it to be?
   ( ) Not at all helpful
   ( ) A little helpful
   ( ) Somewhat helpful
   ( ) Very helpful
   ( ) Extremely helpful

5. How is this person with AD or dementia related to you? (Please check ONE)
   ( ) Friend, neighbor, or other non-relative
   ( ) Spouse/partner
   ( ) Mother/father
   ( ) Mother-in-law/father-in-law
   ( ) Grandparent
   ( ) Sister/brother
   ( ) Other relative (please specify) ____________________

6. How long have you been providing care for this person?
   Years ______  Months ______

7. Approximately how long has this person been experiencing memory-related problems?
   Years ______  Months ______

8. On average, how many days per week do you provide care for this person?
   ( ) less than 1 day  ( ) 1 – 2 days  ( ) 3 – 4 days  ( ) 5 – 6 days  ( ) 7 days

9. On the days that you provide care for this person, on average how much care do you provide (in hours)?
10. Overall, to what extent does this person depend on you for activities of daily living, such as bathing, dressing, preparing meals, shopping, etc?

( ) Not at all  ( ) A little  ( ) Somewhat  ( ) Very much  ( ) Extremely

11. Overall, how burdened do you feel in caring for this person?

( ) Not at all  ( ) A little  ( ) Somewhat  ( ) Very much  ( ) Extremely

12. What are the problems you experience as a consequence of caring for this person? (Check all that apply)

( ) It affects my relationship with this person in a negative way
( ) It affects my relationship with other family members or friends in a negative way
( ) It affects my health in a negative way
( ) It is stressful for me
( ) It affects my job/work in a negative way
( ) It affects my finances in a negative way
( ) I don’t have enough time for myself
( ) I don’t have enough time for my family and friends
( ) Other (please specify) ________________

13. Do you have emotional support from any of the following? (Check all that apply)

( ) Individual, family, or couples counseling
( ) Psychotherapy or psychiatric treatment
( ) Support groups
( ) Family
( ) Friends
( ) Church/Synagogue/Mosque/Temple/etc
( ) Other (please specify) ________________
C.4. Mindful Attention Awareness Scale
Instructions: Below is a collection of statements about your everyday experience. Using the 1-6 scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what really reflects your experience rather than what you think your experience should be. Please treat each item separately from every other item.

1 2 3 4 5 6
Almost Always Very Frequently Somewhat Frequently Somewhat Infrequently Very Infrequently Almost Never

I could be experiencing some emotion and not be conscious of it until some time later. 1 2 3 4 5 6

I break or spill things because of carelessness, not paying attention, or thinking of something else. 1 2 3 4 5 6

I find it difficult to stay focused on what’s happening in the present. 1 2 3 4 5 6

I tend to walk quickly to get where I’m going without paying attention to what I experience along the way. 1 2 3 4 5 6

I tend not to notice feelings of physical tension or discomfort until they really grab my attention. 1 2 3 4 5 6

I forget a person’s name almost as soon as I’ve been told it for the first time. 1 2 3 4 5 6

It seems I am “running on automatic,” without much awareness of what I’m doing. 1 2 3 4 5 6

I rush through activities without being really attentive to them. 1 2 3 4 5 6

I get so focused on the goal I want to achieve that I lose touch with what I’m doing right now to get there. 1 2 3 4 5 6

I do jobs or tasks automatically, without being aware of what I’m doing. 1 2 3 4 5 6

I find myself listening to someone with one ear, doing something else at the same time. 1 2 3 4 5 6
Almost Always  Very Frequently  Somewhat Frequently  Somewhat Infrequently  Very Infrequently  Almost Never

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>I drive places on ‘automatic pilot’ and then wonder why I went there.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I find myself preoccupied with the future or the past.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I find myself doing things without paying attention.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I snack without being aware that I’m eating.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

**MAAS Scoring**

To score the scale, simply compute a mean of the 15 items. Higher scores reflect higher levels of dispositional mindfulness.