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BOSTON UNIVERSITY
SCHOOL OF MEDICINE

Thesis

DEMENTIA CARE COORDINATION

by

TRACI AOKI

B.A., University of Southern California, 2011

Submitted in partial fulfillment of the
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DEDICATIONS PAGE

I dedicate this thesis to Gail Aoki, Dexter Aoki, and Robyn Aoki for their continuous support.

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DEMENTIA CARE COORDINATION

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Boston University School of Medicine, 2013

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ABSTRACT

Background: Dementia is a chronic, irreversible condition that currently affects millions of Americans. With increasing life expectancies and an aging population, it is predicted that this number will triple within the next fifty years, possibly affecting 16 million Americans by 2050. The majority of care for these patients is provided by informal caregivers, usually their spouses or children. However, studies have shown that most informal caregivers feel they need more information about the disorder and the services available to help them, as well as on how to effectively care for their family member. Caring for a dementia patient is more stressful and burdensome than caring for someone who is solely physically impaired. Dementia caregivers experience higher rates of anxiety and depression, less time for personal activities, and greater difficulties maintaining jobs. Thus, interventions that provide caregivers with support and train them to properly care for dementia patients can be beneficial for both the patients and their families by reducing the adverse effects caregiving has on the caregiver's mental and physical health while also improving the patient's quality of care.

Purpose: The purpose of this study is to evaluate the effects of the Alzheimer's Association's Dementia Care Coordination intervention on dementia patients and

their caregivers. This study will determine whether the intervention improves the qualities of life of patients and caregivers, lowering their depression and hospitalization rates while also reducing caregivers' levels of burden, distress, and anxiety.

Methods: 1500 patients and 1500 caregivers will be recruited into the study over three years. After completing a baseline questionnaire tracking such measures as caregiver and patient depression levels, hospitalizations, and doctor visits, the subjects will be randomly assigned to control or treatment groups. 1 of every 5 patient-caregiver pairs will be assigned to the control arm and every 4 of 5 will be in the treatment group. Those in the treatment group will be contacted by an Alzheimer's Association (AA) case manager, who will assess their needs and then provide them with individualized education and referrals to AA and community programs based on that assessment. Case managers also follow up with the family on a regular basis to provide continuous support. During their two years in the study, participants will complete two more questionnaires, at the end of Year 1 and at the end of Year 2. Measured patient outcomes include severity of neuropsychiatric symptoms, depression levels, quality of life, and resource utilizations. Measured caregiver outcomes include anxiety, distress, burden, depression, quality of life, and resource utilizations.

Predicted Results: In repeated-measures ANOVA models, participants demonstrated a main effect of group (intervention or control), but not of time, in caregiver anxiety, burden, depression, time spent caring for the patient, and

patient hospitalizations. Patient-caregiver pairs in the intervention group displayed a decrease in all five measures over the course of the two years, while those in the control group experienced an increase.

Discussion: Interventions that provide families with proactive case management, with personalized care plan recommendations and improved care coordination and communication between the AA, the referring clinician, and the family, can have a significant effect on the qualities of life of both dementia patients and their caregivers. While caregiver time, burden, depression, and anxiety generally tend to increase as the patient's dementia progresses, case management interventions can help to slow or halt this increase, even lowering their levels in many instances. Such interventions can also improve the quality of care received by patients, resulting in decreased utilization of various healthcare services by patients and thus, reduced healthcare costs for both the families and for society.

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ABBREVIATIONS

AA	Alzheimer's Association
AD	Alzheimer's Disease
BAI	Beck Anxiety Inventory
CBI	Caregiver Burden Inventory
CES-D	Center for Epidemiologic Studies Depression Scale
CSDD	Cornell Scale for Depression in Dementia
DLB	Dementia with Lewy Bodies
FTD	Frontotemporal Dementia
NPI-Q	Neuropsychiatric Inventory Caregiver Brief Questionnaire
QOL-AD	Quality of Life in Alzheimer's Disease
RUD	Resource Utilization in Dementia Questionnaire Version 3.2
VD	Vascular Dementia

INTRODUCTION

Alzheimer's disease (AD), the most common form of dementia, is a neurodegenerative condition currently affecting 5.4 million Americans. Other common types of dementia include vascular dementia (VD), dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). However, additional forms of dementia also exist. Dementia is a chronic, progressive, and irreversible disorder that can be unpredictable in both its rate of advancement and its symptoms. As the condition advances, it spreads to affect additional brain regions, leading to an increasing number of varied symptoms as well as increased severity of those developed symptoms. It also causes those affected to become increasingly dependent on others to complete daily activities (Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999). Patients generally develop a number of problematic symptoms such as: memory loss, poor judgment, uncharacteristic or inappropriate behavior, inability to reason, and difficulty planning and performing familiar tasks. In addition, the majority of patients with dementia exhibit at least one neuropsychiatric symptom, which has an impact on both patient and caregiver distress levels, during the duration of their disease. The most commonly exhibited of these are anxiety, depression, and apathy (Gauthier et al., 2010).

Dementia's impact on healthcare costs and utilizations

Due to increasing life expectancies and an aging population, America is experiencing a growth in the incidence of chronic disorders of aging such as

dementia. It is predicted that the number of patients with Alzheimer's disease or a related dementia will triple within the next fifty years, possibly affecting 16 million Americans by 2050. As a result, the cost of dementia care is expected to reach \$1.1 trillion by this time, significantly impacting the nation's healthcare system and resources (Zhao, Kuo, Weir, Kramer, & Ash, 2008).

Dementia patients cost Medicare three times as much as their cognitively healthy counterparts. They have significantly higher hospitalization rates, experience more co-morbid medical conditions, and generate greater health care costs (Phelan, 2012). In addition, approximately two-thirds of dementia patient hospitalizations are for potentially preventable conditions such as respiratory infections, urinary tract infections, and congestive heart failure. As a result, a number of intervention programs possessing such features as education and training for caregivers and improved coordination of the patient's care have been experimented with over the past couple of decades and studied for their effects on patient quality of care and health outcomes (Mittelman, 1996). It is hoped that by improving the quality of care of dementia patients, such programs could have an ameliorating effect on health care costs.

Caregivers may have knowledge deficits related to dementia, and often report a need for more information on how to properly care for their family member and deal with various symptoms such as problematic behaviors. Furthermore, patients frequently possess several medical problems, perhaps seeing multiple physicians who are unaware of each others' presence and

treatments due to a lack of proper care integration (Callahan et al., 2009). These doctors might prescribe incompatible medications or provide conflicting advice, leading to unfavorable results. For instance, some medications used to treat symptoms such as dizziness and urinary incontinence possess anti-cholinergic properties, while cholinesterase inhibitors are commonly used to treat dementia. If two different doctors unknowingly prescribe a patient both types of medications, this conflicting treatment may cause the dementia treatment to be ineffective (Schubert et al., 2006). Thus, dementia patients might benefit from interventions that educate caregivers, improve communication between physicians, and coordinate their care. The implementation of such programs may help to cut down the number of preventable hospitalizations and cost of dementia care to families as well as to society (Peikes, 2009).

Furthermore, many caregivers hope to avoid placing their family member in a nursing home for as long as possible, opting to care for the patient themselves. Programs providing them with education, training, and support will help them to achieve this goal. Studies have shown that interventions providing counseling and support for caregivers can postpone the placement of patients into nursing homes by a median of 329 days (Mittelman et al., 1996). This is beneficial not only to families, but also to society.

Indeed, studies have found evidence that interventions providing education, training, and support for caregivers, as well as coordination of patient care, have the potential to positively impact the physical health of patients and

possibly diminish healthcare costs (Vickrey et al., 2006). However, patients are not the only ones whose lives are significantly altered by dementia. Dementia is a devastating condition in that it has a profound impact on the lives of not only patients, but also their families and especially their primary caregivers.

Effect of dementia on families and caregivers

With a growing population of dementia patients, the act of caregiving has become increasingly common (Schulz & Martire, 2004). However, caring for a dementia patient often requires a large commitment of time and energy, as well as money, sometimes for an extended period of time. Research has found that caring for an older adult with dementia is more stressful and burdensome than other types of caregiving, such as for someone who is solely physically-impaired. Dementia caregivers experience higher rates and levels of anxiety and depression, have far less time for personal activities, are more prone to feelings of social isolation, and face greater difficulties maintaining their jobs (Ory, Hoffman, and Yee, 1999).

Providing informal care for family members with dementia can take a significant toll on one's physical and mental health (Acton and Kang, 2001). When caring for a family member with dementia impinges on the caregiver's normal, daily activities, they often experience an increased sense of burden, as well as a higher likelihood of caregiver depression (Smith, Williamson, Miller, and Schulz, 2011). Furthermore, many researchers have found that caregivers exhibit a decreased health-related quality of life, and that caregiver depression

and emotional distress are both linked to an increased risk of cardiovascular disease and early mortality (Mausbach, Patterson, Rabinowitz, Grant, and Schulz, 2007).

Therefore, it is important to address the support needs of informal caregivers in order to improve the caregiver's own quality of life, along with the care dementia patients are receiving, and to delay placement of the patients in nursing homes. Research has shown that most informal caregivers of dementia patients feel they need more information about the disorder, available services, and advice on how to effectively care for their family member. They often lack sufficient caregiving training, and also feel they need more support, both physically and emotionally, in fulfilling their role and dealing with the associated burdens (Arno, Levine, & Memmott, 1999). Interventions that help to relieve this burden, including educational and training sessions, support groups, and services such as respite care and day care, could benefit caregivers (Luchetti et al., 2009).

Previous studies support this belief, showing that such intervention programs may indeed serve to decrease the depressive symptoms and perceived burden experienced by caregivers. Therefore, they may also help to improve the caregiver's quality of life, shielding them from the health problems associated with providing dementia patients over an extended period of time, such as increased rate of developing cardiovascular disease and early mortality (Mausbach et al., 2007). A six-month intervention study, conducted by Belle et

al. 2006, provided caregivers with both informational and emotional support. The program involved role-playing, skills training, and problem solving, as well as a customized care plan to improve the quality of care of the patient. It also included support group sessions via conference calling, to provide caregivers with additional emotional support. The study was successful in decreasing the caregivers' levels of depression and burden, while also improving their quality of life. It increased the caregivers' confidence in the abilities to care for the patient, and lowered their reported incidence of patient problem behaviors (Belle et al., 2006).

Interventions addressing caregiver quality of life, stress, burden, and depression are important not only because of their effects on the caregivers, but also because caregiver emotional health may impact the treatment and level of care received by the dementia patient. For example, studies have found that increased caregiver depression leads to decreases in quality of care. This may include less respectful behavior towards the patient, handling the patient roughly, yelling at them, and threatening to put them in a care home. Caregivers suffering from high levels of depression are also less likely to engage in behaviors of high quality care with their family member, such as spending time with them and treating them with respect as an adult (Smith et al., 2011). It is therefore important that intervention programs aiming to improve the lives of patients also address the needs of their caregivers.

One study that addressed this issue, conducted by Bass and colleagues, was a twelve-month intervention delivered via telephone. The Managed Care Demonstration provided families with information, support, and individualized care plans, tailored to their particular needs. Caregivers received ongoing support, with a care consultant calling them regularly to track progress and making any necessary modifications to the care plan. Besides improving the family member's caregiving abilities, the Managed Care Demonstration resulted in decreased depression levels and reduced strain in the caregiver's relationship with the dementia patient (Bass, Clark, Looman, McCarthy, & Eckert, 2003).

It is important that similar intervention programs give caregivers access to continuous support as the condition progresses and the demands on the caregiver increases. It is likewise essential that the interventions provide caregivers with customized care plans tailored to their individual needs. The support needs of caregivers are complex and may vary between different individuals or families. For instance, studies have shown that spousal caregivers often need more emotional support, whereas sons or daughters tend to need more information, such as about how to manage behavioral problems, and coordination of care (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Furthermore, dementia is unpredictable in both its rate of progression and in its resulting behavioral symptoms. Different dementia patients may display varying symptoms, and different caregivers may contrast in their reactions to

those symptoms and the burdens of caregiving and their abilities to deal with them.

The results of an intervention program headed by Kuzu et al. (2005) highlighted the importance of individualized care plans. Their intervention consisted of an educational component for caregivers, an informational booklet, and a customized component tailored to the patient's and caregiver's individual needs. Following participation, caregivers experienced decreased levels of depression and anxiety, along with an increased quality of life. They also reported fewer problems for both themselves and the patients. When asked which component they deemed most helpful, the majority favored the individualized component, especially the advice on how to deal with the patient's symptoms (Kuzu et al., 2005). In light of the findings of this and previous studies, it is essential that we develop a better, more comprehensive, approach to providing care for dementia patients, while also focusing on ways to alleviate caregiver stress, anxiety, and burden.

The Alzheimer's Association Dementia Care Coordination Project

The Alzheimer's Association is creating a new program that provides a higher level of care for dementia patients. This program involves better care coordination for dementia patients as well as increased education of, and support for, their caregivers.

Physicians will refer caregivers of dementia patients to the Alzheimer's Association, so that a trained care consultant can proactively contact the family.

The care consultant will provide families with informational literature on the condition and how to effectively care for the patient, while also creating individualized care plans and referring them to community-based programs based on their assessment of the family's needs. In addition, they will make follow-up calls to the caregiver, to provide continuous support to the family and to make any necessary adjustments to the care plan. They will also generate a report for the referring clinician, working to enhance coordination between the clinician, family, and Alzheimer's Association.

Purpose

The purpose of my thesis is to evaluate this integrated approach to care coordination and education of dementia patients and their caregivers, to determine the extent to which it benefits their lives. We believe that by improving the care coordination of patients and providing caregivers with increased education and support, patients will experience improved quality of life, as well as reduced levels of depression and number of potentially preventable hospitalizations. Meanwhile, caregivers will encounter decreased levels of distress resulting from patient's neuropsychiatric symptoms, along with reduced anxiety, depression, and burden. They will also experience higher qualities of life.

METHODS

Study Participant Recruitment

Patients and their caregivers will be recruited from three clinics: Beth Israel Deaconess Medical Center, Boston University Medical Center, and the VA Boston Healthcare System, all located in Boston, Massachusetts. In order to participate in the study, patients must be over the age of 50 with Alzheimer's disease or a related dementia, and must have a caregiver. Caregivers need to be over 18 years old. In total, 1500 patients and 1500 caregivers will be recruited over the course of three years (500 patients and 500 caregivers each year).

Intervention Procedure

The control group will receive the same standard of care that the Alzheimer Association currently offers to the community. Patients and family members are provided with the 24/7 Alzheimer's Association Helpline contact information, and can initiate a phone call if interested. An AA staff member (generally a layperson who has been trained to answer calls) is available to answer common questions, give advice, and refer callers to local services such as support groups, case managers, or long-term care facilities.

The treatment arm differs from the control arm in four main ways. First, a case manager from the Alzheimer's Association proactively contacts the families, rather than requiring the caregiver to initiate the contact. Case managers will make up to three attempts at contact. Second, the same case manager will call the family back after each contact is made, to assure that issues are followed up on and that the family has followed through with recommendations. Third, the

Alzheimer's Association staff members calling these families are licensed social workers, whereas in the control group the caller may be a trained layperson. Finally, the licensed social worker Care Consultant generates a report after each contact. This report is sent to the referring clinician and may be incorporated into the patient's medical record for follow up during the patient's next appointment with the physician. The Alzheimer's Association will work to enhance coordination between the clinician, family, and Alzheimer's Association. No such report is generated for the control group.

Patients and caregivers assigned to the treatment group are referred to the Alzheimer's Association at time zero, whereas those in the control group are not referred for another two years (and will then begin to receive the same services as the treatment group) (Figure 1). Once the Alzheimer's Association receives the referral, an AA Care Consultant will proactively contact the family within three business days, assessing their needs and providing individualized education and referrals to both Alzheimer's Association and community-based programs based on that assessment. The Care Consultant provides family caregivers basic information such as a list of adult day health programs and support groups, as well as any necessary advice including how to manage the patient's behavioral issues or wandering. Following this initial call, the Care Consultant will send the caregiver a care plan along with additional literature, such as information on Alzheimer's disease or other relevant disorder, communication strategies, wandering, driving evaluation programs, the

Alzheimer's Association, medical alert bracelets, and a calendar of caregiver education programs. In addition, family caregivers will receive ongoing follow-up calls so that the Alzheimer's Association can continue to support the family and make adjustments to the care plan as the condition progresses. The Alzheimer's Association will also track service usages by families, as well as their satisfaction with the Association services.

Evaluation Procedure

A trained research clinician at each of the three medical centers will refer patients and caregivers for the study, while a trained research assistant will recruit and consent them. Their information will then be sent to the research site, where four out of every five pairs (caregivers and patients) will be randomly assigned to the treatment group, and one of five will be assigned to the control group. The group assignment of the pair will only be known to the clinician at the research site – all research assistants will be blinded to group assignment.

Written questionnaires will then be mailed to caregivers (regardless of the assigned group), who are given the choice of answering them either on paper or on-line. The questionnaires are designed to evaluate caregiver stress and quality of life, patient symptoms and quality of life, and resource utilizations by both the patient and caregiver. Participants will be given a personal code to be used on envelopes and questionnaires so that all information is de-identified. Two weeks after receiving the questionnaires, participants will receive a phone call from the research assistant inquiring if they have any questions about filling

out the questionnaires and politely reminding them to complete and return them. This will occur three times over the course of the study: at the beginning (time 0), at the end of year 1, and at the end of year 2 of the study (Figure 2).

Data Collection and Measurement

Questionnaires for patients and caregivers will be administered three times: after first recruitment (baseline), at the end of year 1, and at the end of year 2. Participants have the option of filling out either written or online versions of these questionnaires.

Caregiver anxiety will be ascertained using the Beck Anxiety Inventory (BAI; Beck and Steer, 1990), a 21-item self-reported symptom rating scale. Caregivers will indicate how much they have been bothered by each symptom during the past month. Each item is ranked on a 4-point scale, with “0” = *not at all*, “1” = *mildly*, “2” = *moderately*, “3” = *severely*.

Patient neuropsychiatric symptoms and their effect on caregivers will be measured with the Neuropsychiatric Inventory Caregiver Brief Questionnaire (NPI-Q; Cummings et al., 1994). The NPI-Q is a 12-item clinical instrument, where caregivers rate the severity of each symptom displayed by the patients within the past month, and then rate the distress they (the caregivers) experience because of the patient’s symptom. Symptom severity is ranked on a 3-point scale, with “1” = *mild*, “2” = *moderate*, and “3” = *severe*. Caregiver distress is ranked on a 6-point scale, with “0” = *not distressing at all*, “1” = *minimal*, “2” = *mild*, “3” = *moderate*, “4” = *severe*, “5” = *extreme*.

Caregiver burden will be assessed using the Caregiver Burden Inventory (CBI; Novak and Guest, 1989), which measures burdens in various aspects of the caregiver's life, including in social relationships, physical health, and emotional health. Caregivers rank such statements as "I feel embarrassed over his/her behavior" and "I feel that I am missing out on life" on a 5-point scale, where "0" = *never*, "1" = *rarely*, "2" = *sometimes*, "3" = *quite frequently*, "4" = *nearly always*.

Caregiver depression will be measured using the Center for Epidemiologic Studies Depression scale (CES-D; Weissman et al., 1977). The CES-D is a 20-item self-reported depression symptom scale, requiring caregivers to indicate how often they have experienced certain symptoms during the past week. Caregivers rank statements such as "I was bothered by things that usually don't bother me" on a 4-point scale, where "0" = *rarely or none of the time (<1 day)*, "1" = *some or a little of the time (1-2 days)*, "2" = *occasionally or a moderate amount of time (3-4 days)*, "3" = *most or all of the time (5-7 days)*.

Patient depression will be ascertained with the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, and Young, 1988). The CSDD involves caregivers retrospectively rating the severity of the patient's depressive symptoms within the past week on a 3-point scale, with "0" = *absent*, "1" = *mild or intermittent*, "2" = *severe*.

Caregiver and patient quality of life will be assessed with the Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon et al., 1999) questionnaires. The

caregiver will first rank various aspects of his or her own life, such as physical health, energy, and living situation, on a 4-point scale, where “1” = *poor*, “2” = *fair*, “3” = *good*, and “4” = *excellent*. The caregiver will then rank the same quality of life aspects as they apply to the patient, using the same rating scale.

Caregiver and patient resource utilizations will be assessed using the Resource Utilization in Dementia Questionnaire version 3.2 (RUD) (Wimo et al., 1998). The RUD gathers data on both caregivers and patients, on frequency and duration of hospitalizations, usage of social services, unscheduled contacts with health care professionals, medication management, and amount of time the caregiver spends caring for the patient and missing work.

Data Analysis

Our primary outcome measure will be the Resource Utilization in Dementia Questionnaire (RUD), with an emphasis on caregiver time. Secondary outcomes, which will all be measured by caregiver survey, include caregiver stress and depression, caregiver burden, patient depression, patient neuropsychiatric symptoms and their effect on caregivers, and caregiver and patient quality of life.

Once we receive the completed questionnaires, we will compare caregiver responses at baseline and after treatment, and will also compare these responses with the non-intervention group as a control measure, in order to determine whether the intervention is indeed decreasing caregiver stress and

anxiety, improving caregiver understanding of effective caregiving techniques, and improving patient quality of life while also reducing healthcare expenditures.

For this thesis, my emphasis will be on caregiver anxiety, burden, and depression, along with patient hospitalizations and caregiver time. Because we have only just started collecting data, and the study will not be completed for another three years, we have generated predicted results for the purpose of this thesis. This generated data is based on the means and standard deviations from prior related studies, with added noise using SPSS to produce more realistic data.

PREDICTED RESULTS

Caregiver Anxiety

A repeated-measures ANOVA was conducted using a between-subjects factor of group (intervention or control) and a within-subjects factor of time (Baseline, Year 1, and Year 2), in order to examine the level of anxiety experienced by caregivers of dementia patients. Using our idealized data, we predict that participants will demonstrate a main effect of group ($F(1,1498) = 50.448, p < 0.001, \eta^2 = 0.033$), but not of time. We also predict that there will be a significant interaction between group and time ($F(2,2996) = 19.77, p < 0.001, \eta^2 = 0.017$), with the level of reported anxiety by caregivers increasing over the two years for those in the control group and decreasing for those in the intervention group. The idealized data used for this purpose was based on findings of Kuzu et al. (2005) (Figures 3 and 4).

To follow up on the significant interaction between group and timepoint, we conducted one-way ANOVAs to examine group differences at each timepoint. For caregiver anxiety outcomes, there was no significant difference at the initial timepoint. However, at both the Year 1 and Year 2 timepoints, the intervention group reported significantly lower anxiety levels than did the control group (Y1: $F(1,1499) = 26.110, p < 0.001$; Y2: $F(1,1499) = 90.290, p < 0.001$).

Caregiver Burden

In order to examine the degree of burden experienced by caregivers, we conducted a repeated-measures ANOVA using a between-subjects factor of group (intervention or control) and a within-subjects factor of time (Baseline, Year 1, and Year 2). Based on our idealized data, we predict that participants will demonstrate a main effect of group ($F(1,1498) = 64.10, p < 0.001, \eta^2 = 0.041$), but not of time. We also predict that there will be a significant interaction between group and time ($F(2,2996) = 30.48, p < 0.001, \eta^2 = 0.020$), with the level of burden experienced by caregivers increasing over the two years for those in the control group and decreasing for those in the intervention group. The generated data used for this purpose was based on findings of Luchetti et al. (2009). (Figures 5 and 6).

To follow up on the significant interaction between group and timepoint, we conducted one-way ANOVAs to examine group differences at each timepoint. For caregiver burden outcomes, there was no significant difference at the initial timepoint. However, at both the Year 1 and Year 2 timepoints, the intervention

group reported significantly lower burden levels than did the control group (Y1: $F(1,1499) = 50.934, p < 0.001$; Y2: $F(1,1499) = 129.338, p < 0.001$).

Caregiver Depression

In order to examine the level of depression experienced by caregivers, we conducted a repeated-measures ANOVA using a between-subjects factor of group (intervention or control) and a within-subjects factor of time (Baseline, Year 1, and Year 2). Using our idealized data, we predict that participants will demonstrate a main effect of group ($F(1,1498) = 96.65, p < 0.001, \eta^2 = 0.061$), but not of time. We also predict that there will be a significant interaction between group and time ($F(2,2996) = 36.88, p < 0.001, \eta^2 = 0.024$), with the degree of depression experienced by caregivers increasing over the two years for those in the control group and decreasing for those in the intervention group. The idealized data used for this purpose was based on findings of Belle et al. (2006) (Figures 7 and 8).

To follow up on the significant interaction between group and timepoint, we conducted one-way ANOVAs to examine group differences at each timepoint. For caregiver burden outcomes, there was no significant difference at the initial timepoint. However, at both the Year 1 and Year 2 timepoints, the intervention group reported significantly lower burden levels than did the control group (Y1: $F(1,1499) = 28.035, p < 0.001$; Y2: $F(1,1499) = 178.881, p < 0.001$).

Caregiver Time Outcomes

A repeated-measures ANOVA was conducted using a between-subjects factor of group (intervention or control) and a within-subjects factor of time (Baseline, Year 1, Year 2), to examine time spent caring for the patient. Using our idealized data, we predict that participants will demonstrate a main effect of group ($F(1,1498) = 16.63, p < 0.001, \eta^2 = 0.011$), but not of time. We also predict that there will be a significant interaction between group and time ($F(2,2996) = 8.48, p < 0.001, \eta^2 = 0.006$), with the amount of time required to fulfill caregiving duties increasing over the two years for those in the control group and decreasing for those in the intervention group. The idealized data used for this purpose was based on findings of Kuzu et al. (2005) (Figures 9 and 10).

To follow up on the significant interaction between group and timepoint, we conducted one-way ANOVAs to examine group differences at each timepoint. For caregiver time outcomes, there was no significant difference at the initial timepoint. However, at both the Year 1 and Year 2 timepoints, the intervention group reported lower caregiver time than did the control group (Y1: $F(1,1499) = 4.1, p < 0.05$; Y2: $F(1,1499) = 28.331, p < 0.001$).

Patient Hospitalization Outcomes

In order to examine the number of hospitalizations of the dementia patients in our study more closely, we conducted a repeated-measures ANOVA using a between-subjects factor of group (intervention or control) and a within-subjects factor of time (Baseline, Year 1, and Year 2). Using our idealized data,

we predict that participants will demonstrate a main effect of group ($F(1,1498) = 62.43, p < 0.001, \eta^2 = 0.040$), but not of time. We also predict that there will be a significant interaction between group and time ($F(2,2996) = 64.69, p < 0.001, \eta^2 = 0.041$), with the number of patient hospitalizations increasing over the course of the study for those in the control group and decreasing for those in the intervention group. The generated data used for this purpose was based on findings of Wimo et al. (2005) (Figures 11 and 12).

To follow up on the significant interaction between group and timepoint, we conducted one-way ANOVAs to examine group differences at each timepoint. For patient hospitalization outcomes, there was no significant difference at both the initial timepoint and Year 1. However, at the Year 2 timepoint, the intervention group reported significantly lower burden levels than did the control group (Y2: $F(1,1499) = 261.450, p < 0.001$).

DISCUSSION

Due to the fact that we have just started collecting data and the study will not be completed for another three years, we have generated predicted results based on previous studies, for the purpose of this thesis. This generated data is based on the means and standard deviations from prior related studies, with added noise using SPSS to produce more realistic data.

This study is examining the effects of care coordination on the quality of life and health outcomes of both dementia patients and their caregivers. The

intervention will provide families with proactive case management from the Alzheimer's Association, personalized care plan recommendations, and improved care coordination and communication between the Alzheimer's Association, the referring clinician, and the family. Our primary hypothesis is that the care coordination intervention will result in decreased utilization of various healthcare resources and related services by both patients and caregivers. Our secondary hypothesis is that patients will experience an improved quality of life and reduced levels of depression, while caregivers will encounter lower levels of distress, anxiety, depression, and burden, as well as a higher quality of life. However, for the purpose of this thesis, I will be focusing solely on caregiver anxiety, burden, and depression, along with patient hospitalizations and caregiver time. Furthermore, for the full analysis, we might want to use age, gender, and education level as covariates when examining at the data.

Patient Hospitalizations Outcomes

We predicted that the information and training provided by care consultants would help caregivers to provide higher quality care to their family members, which would serve to decrease the incidence of hospitalizations for potentially avoidable conditions that are often common amongst dementia patients. Our predicted results demonstrated this effect, showing a significant difference between control and treatment participants for number of patient hospitalizations in Year 2. However, unlike the other measures we analyzed, this significant difference was not also present at Year 1. This reflects the fact that

for certain metrics, it may require a longer period of time to see a significant effect of the intervention on the patient and caregiver participants.

Caregiver Time Outcomes

We predicted that the Care Coordination intervention would reduce the amount of time caregivers needed to spend caring for the patients. Our results supported this belief, exhibiting a significant difference in caregiver time between control and intervention participants, for both Year 1 and Year 2. Caregivers in the intervention group displayed a significant decline in time spent caring for their family members over the two years, whereas those in the control group experienced an increase in time.

As dementia progresses, patients suffer a rise in cognitive deterioration. As a result, they become increasingly dependent on their caregivers in order to partake in their normal daily activities. This progressive decline in the patient's abilities in activities of daily living results in a corresponding rise in caregiving hours, the amount of time the caregiver must devote to caring for the patient. Therefore, intervention components that help to promote the patient's abilities in activities of daily living, as contained in this intervention, should also serve to decrease the time caregivers must devote to caring for the patient.

Caregiver Burden, Depression, and Anxiety Outcomes

We predicted that the Dementia Care Coordination program would curtail the levels of depression, anxiety, and burden of the caregivers in our study. Our results strongly supported this prediction, with caregivers in the intervention

group experiencing a statistically significant decrease in anxiety, burden, and depression over the course of the two-year study. There was also a significant difference in these measures between Time 0 and Year 1, as well as between Time 0 and Year 2. Meanwhile, caregivers in the control group displayed an increase in anxiety, burden, and depression over the course of the two years, as the patient's condition progressed.

As previously mentioned, by reducing caregiving hours by means that include providing information on how to improve the patient's abilities in activities of daily living and referring caregivers to services such as adult care, the intervention is also predicted to lower levels of caregiver burden. Other ways in which this intervention will target caregiver burden include training caregivers to provide higher quality care, which can decrease the frequency of patient behavioral disturbances, teaching them how to manage such problematic behaviors, and helping caregivers to develop coping strategies, if necessary.

General Discussion

Targeting patient behavioral disturbances is of particular interest because of the major influence the intensity of problem behaviors has on caregiver burden, as well as on caregiver anxiety. This intervention is important because by reducing caregiver burden, caregivers are able to care for patients at home for a longer period of time, rather than placing them in a nursing home. In addition, degree of caregiver burden is correlated with patient quality of care as well as quality of life.

Aside from providing caregiver training and information that should improve outcomes for both patients and their caregivers, the simple presence of the care consultants adds to the caregivers' support systems, perhaps helping to reduce the sense of social isolation caregivers often report experiencing (Bass et al., 2003). This additional support and lowered isolation may help to diminish caregiver depressive symptoms, as might support groups that the care consultants will refer caregivers to if they feel they would benefit from this service. Thus, we have reason to believe that this intervention will serve to reduce depression levels in caregivers who are demonstrating depressive symptoms.

It is important to remember that dementia is an irreversible and progressive disorder, with symptoms worsening over time. There are currently no treatments capable of changing this fact. Thus, it may happen that once this study is complete and we have gathered all of the actual data, we will see the ratings of patients and caregivers in the treatment group worsening over time rather than improving as in our generated idealized data. However, this is not necessarily a sign of the intervention not working. Rather, it may be that while the intervention is not completely fixing the situation, it is slowing the rate of their progressive worsening, and therefore still benefiting the participant.

Prior research has suggested that there may be a correlation between time spent fulfilling caregiving duties and the level of burden reported by caregivers. Even attending services meant to help caregivers, such as support

groups or informational sessions, may actually end up increasing their sense of burden by taking away some of their personal time. In order to address this unintended effect, it may be beneficial to modify the ways in which some of these services are offered. For example, Guided Care was an in-person intervention, an educational program with seminars and workshops for caregivers, as well as caregiver support groups. However, these programs were poorly attended, which participants reported was due to the timing, location, and duration of the sessions. The study produced no statistically significant effects on caregiver depression, strain, or work productivity (Wolff et al., 2010).

In comparison, REACH, an intervention that occurred either at the patient's home or via telephone, produced much more successful results. This intervention involved information, role-playing, problem solving, and skills training, and occurred at the caregivers' homes as well as over the phone. It even contained support group session via telephone conference calling. Caregivers receiving this intervention treatment reported increased quality of life, as well as reduced burden and depression levels (Belle et al., 2006).

In-home interventions are more convenient for caregivers, and are likely to have more positive and significant results. Because caregivers are not required to travel and can participate in from the comfort of their own homes, the interventions are less likely to be viewed as an additional burden. Indeed, according to a study by Luchetti et al. (2009), when the intervention program infringes even more on the caregiver's personal time, it ends up increases the

sense of burden they experience instead of ameliorating it. Therefore, interventions should aim to be as convenient as possible for caregivers, taking up a minimal amount of time and being readily accessible. Improving the accessibility of services such as adult day care or respite care to patient-caregiver pairs may also be beneficial, as may be increasing the number of venues by which the various intervention components are available to participants. For example, certain informational components might be available via pamphlets, telephone, and online.

Based on the findings of previous related studies, it appears that those that were most successful shared many similar attributes. Following a caregiver assessment that occurs either at the caregiver's home or via telephone, care consultants will create a customized care plan that is tailored to the caregiver's and patient's individual needs. This might include information on proper caregiving techniques such as managing the patient's problematic behaviors, as well as referral to services and community resources they could benefit from such as support groups or adult day care. Both the intervention and the recommended services should be as convenient and non-time intrusive as possible, so as not to add to the caregiver's burden or stress. The care consultant will also initiate follow-up calls or visits, providing the caregiver with ongoing support and training. This also allows them to re-assess the caregiver's and patient's situation, determining if any changes or additions need to be made to the initial care plan.

There are several ways in which our study and analyses could be improved in the future. In order to strengthen the analysis of the study's data, we might want to consider adjusting for such variables as baseline ratings, gender, age, education level, and relationship with the patient (ie: spouse, son, daughter). Studies have found that the level of burden caregivers reported feeling was significantly affected by their gender, with female caregivers reporting much greater amounts of burden. Furthermore, both female and spousal caregivers are more likely to experience increased psychological distress (Luchetti et al., 2009). In addition, if caregivers report low baseline levels of measures such as anxiety, burden, and depression, as well as low patient hospitalizations at time 0, it is unlikely that they will experience a significant improvement in these measures over the course of the two-year intervention since there is not much room for improvement.

When examining caregiver measures, we may also want to consider whether the participant shares caregiving duties with other family members, or if they are the sole caregiver. Caregivers in the study provide varying amount of assistance to the patients, and some of the questionnaire measures are more applicable to certain caregivers than to others. For instance, prior studies have found that caregivers who devote 14 or more hours of their week to caring for their family member report higher levels of depression, strain, and productivity loss at Time 0 (Wolff et al., 2010). We may also want to take note of whether the caregiver has an outside job that they need to balance caregiving duties with, as

well as whether the patient lives with the caregiver and whether the caregiver attends informational or support groups, or utilizes adult day care or any related services.

It is important to consider the impact of other medical conditions the patient may have, as this could affect many of the measures we are examining. Moreover, caregivers might have health conditions of their own which might have an impact on their ratings. Finally, it may also be useful to gather more detailed information in regards to the patients' memory struggles and their progression over time, as well as how and if the program changes the level of communication between the clinicians, caregivers, patients, and Alzheimer's Association.

Based on the findings of prior related studies, interventions such as the Alzheimer's Association Dementia Care Coordination have the potential to be extremely beneficial to both dementia patients and their caregivers, improving their physical as well as psychological health, in addition to improving their own relationship.

Figures

Figure 1. AADCC Procedure

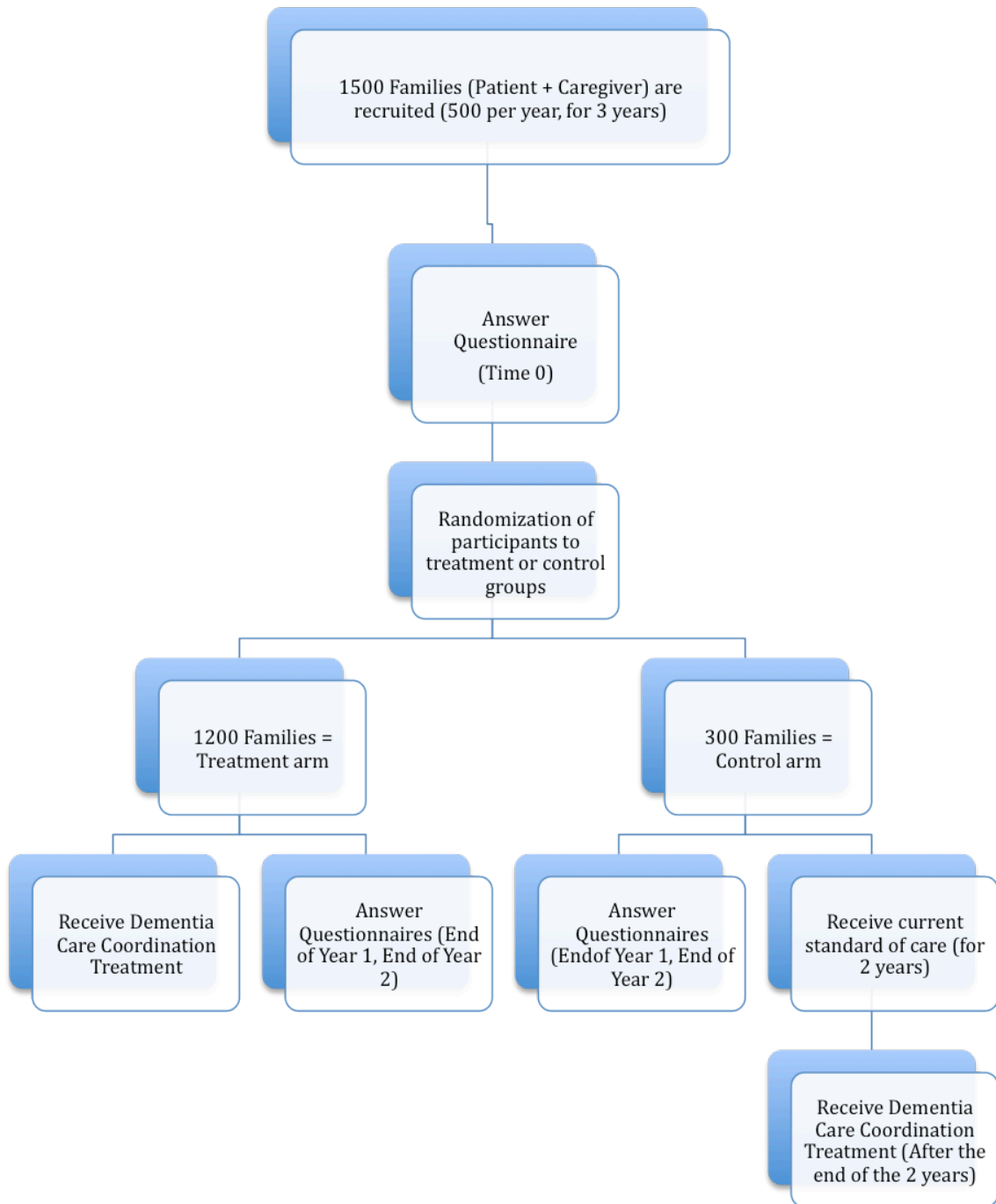


Figure 2. Evaluation Procedure

	Pre-Baseline	Time 0	End of Year 1	End of Year 2
Clinic identifies patient & consents patient + caregiver	X			
Clinic obtains list of current medications of both the patient & caregiver (via questionnaire)		X	X	X
Clinic obtains list of outpatient & inpatient visits during the past year for the patient & caregiver (via questionnaire)		X	X	X
Clinic refers patient & caregiver to research staff		X	X	X
Research staff administers questionnaires		X	X	X
Research staff randomly refers 4 out of 5 patients + caregivers to the Alzheimer's Association (Treatment Group)		X		
4 out of 5 patients + caregivers receive Dementia Care Coordination (Treatment arm)		X	Cont.	Cont.
Research staff refers the remaining 1 out of 5 patients + caregivers (Control Group) to the Alzheimer's Association				X
The remaining 1 out of 5 patients + caregivers receive Dementia Care Coordination				X

Figure 3. Caregiver Anxiety (Idealized Data)

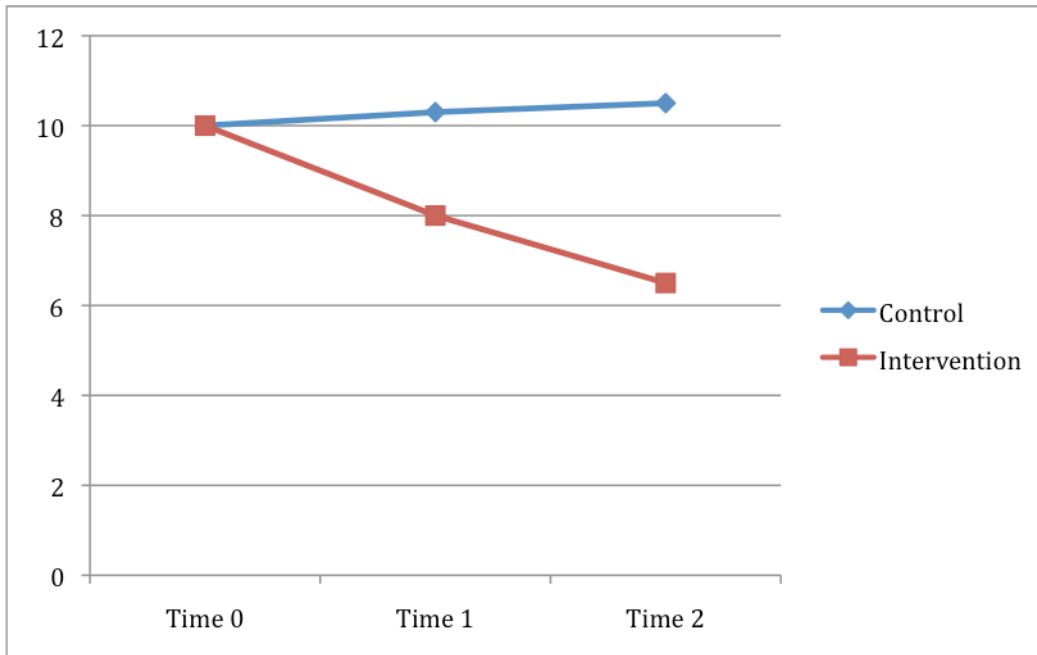


Figure 4. Caregiver Anxiety (Data with Added Noise)

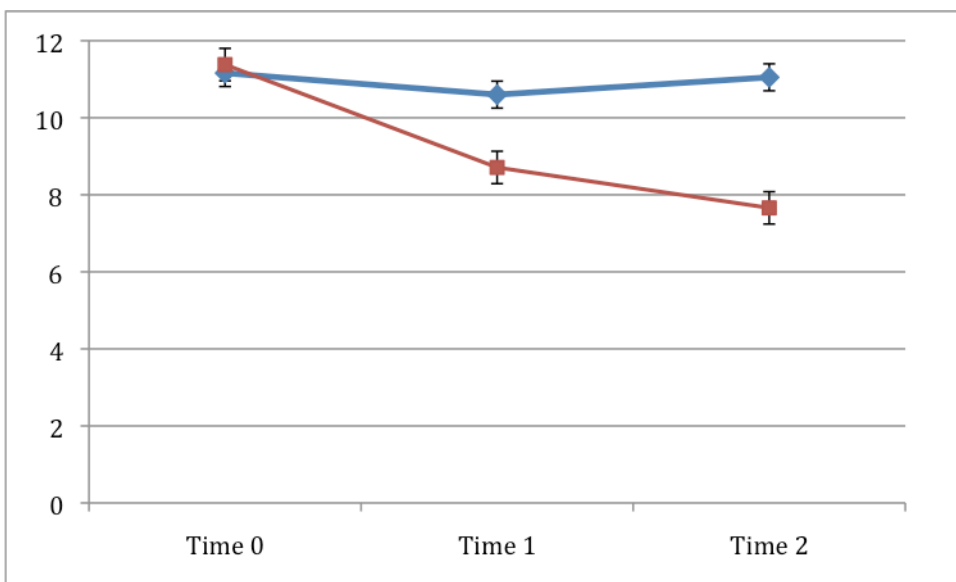


Figure 5. Caregiver Burden (Idealized Data)

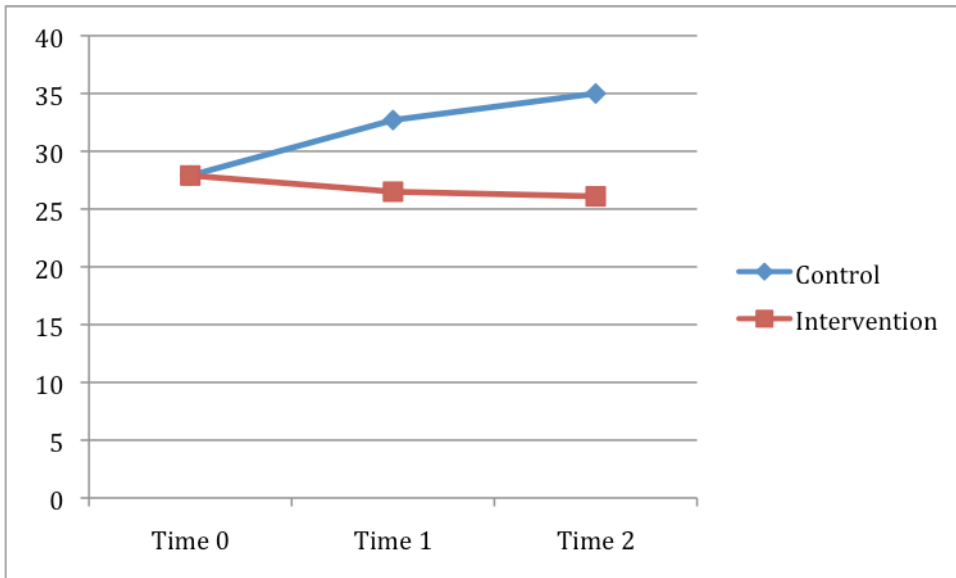


Figure 6. Caregiver Burden (Data with Added Noise)

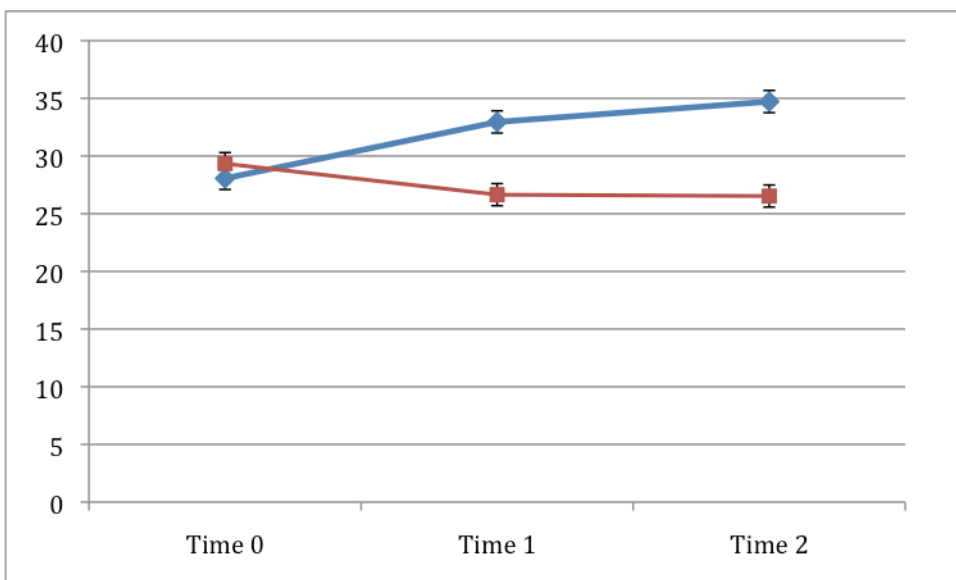


Figure 7. Caregiver Depression (Idealized Data)

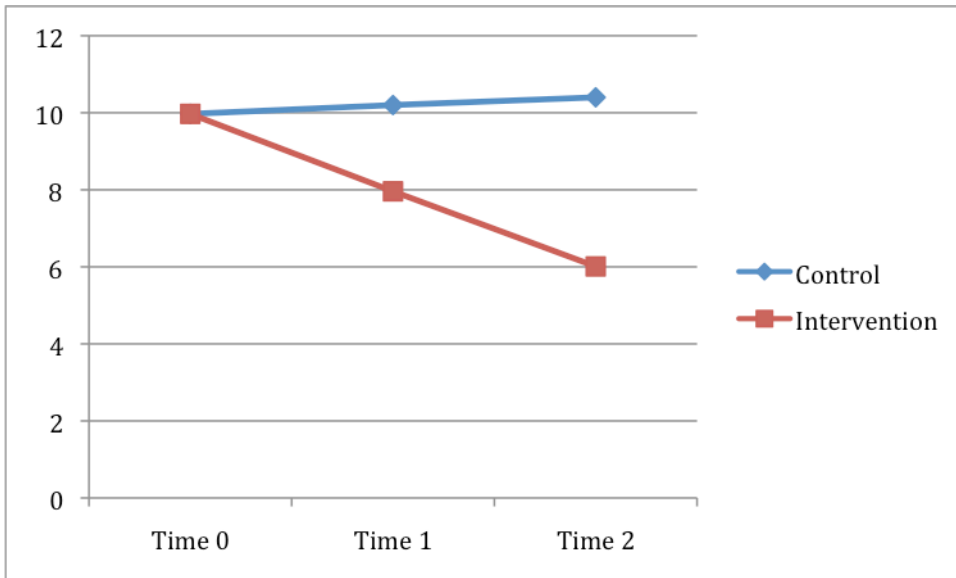


Figure 8. Caregiver Depression (Data with Added Noise)

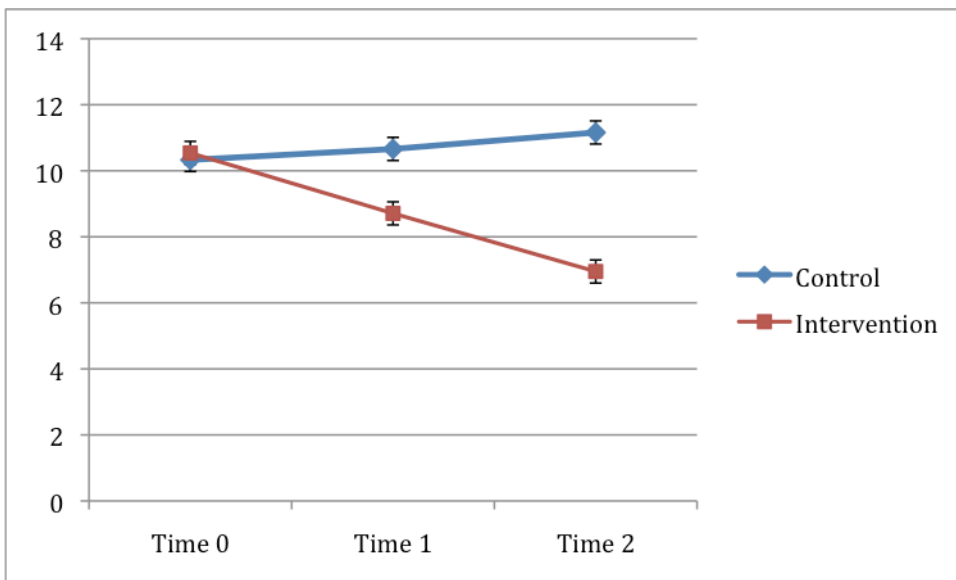


Figure 9. Caregiver Time (Idealized Data)

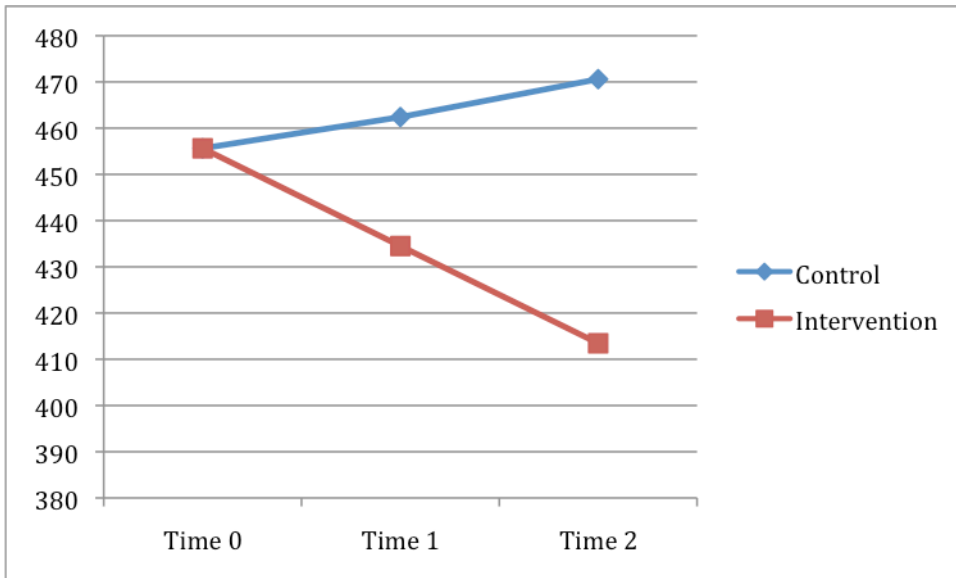


Figure 10. Caregiver Time (Data with Added Noise)

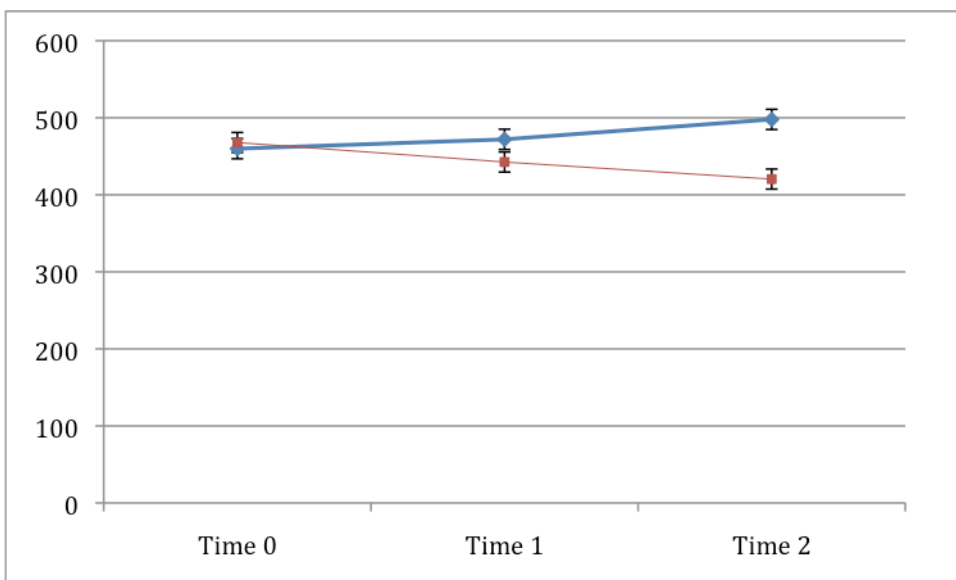


Figure 11. Patient Hospitalizations (Idealized Data)

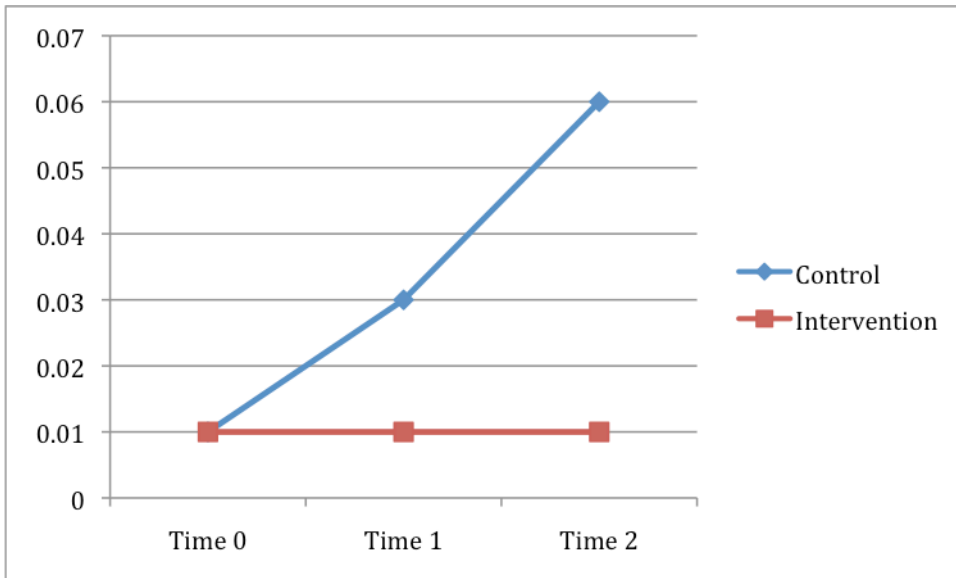
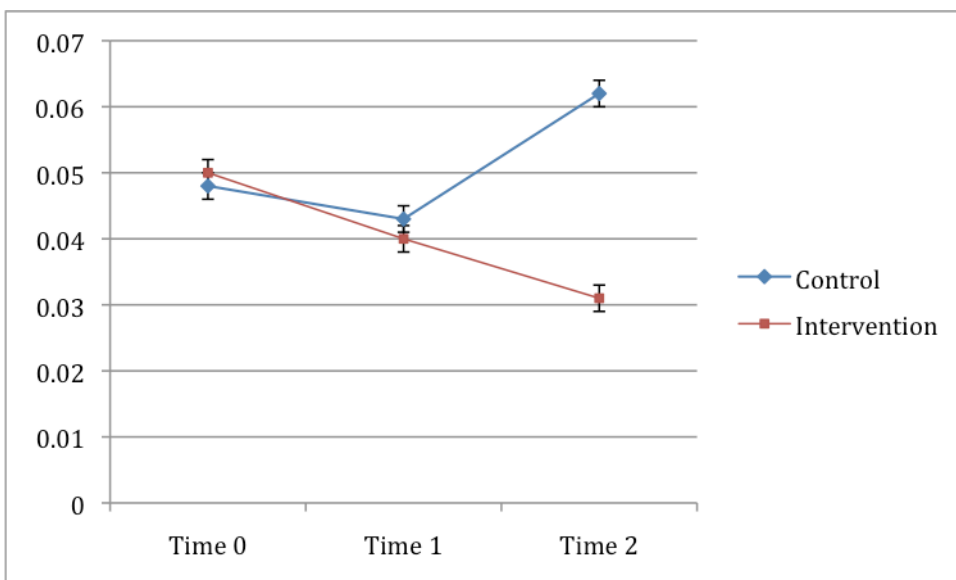


Figure 12. Patient Hospitalizations (Data with Added Noise)



LIST of JOURNAL ABBREVIATIONS

JAMA

Journal of the American Medical Association

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