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Medication Non-Adherence in Community Dwelling Older Adults with Dementia: An
Educational Intervention for Family Caregivers

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partial fulfillment of the requirements for the Doctoral Degree of Science in Psychology with an
emphasis in Clinical Psychology

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Abstract

Older adults with neurocognitive disorders are at high risk for medication non-adherence, while being vulnerable to great injury from regimen deviations. Informal caregivers often aid in healthcare management for these individuals. The current study compared the efficacy of two online health education interventions designed to increase caregiver health related knowledge for use with care recipients. Women (N=35) assisting a cognitively impaired older person with medications, were randomly assigned to one of two online health education conditions (1) narrative vignettes depicting actors encountering common medication challenges, and written materials or (2) written materials and didactic video clips of information from medical experts. It was hypothesized that narrative group participants would show greater improvements in several domains of functioning when compared to didactic group participants. Results showed equivalent participant satisfaction between groups, and that caregivers did not improve differentially between condition, over time, in the domains of medication hassles, patient-provider communication, medication management adherence, or self-efficacy. There was no main effect of time on caregiver reported hassles, patient- provider communication or medication adherence. There was a significant main effect of time on caregiver self-efficacy for controlling upsetting thoughts about the caregiving situation $F(1, 33) = 8.07, p < .001, \eta_p^2 = .20$, achieved power = .79. Secondary analyses revealed that caregivers in the narrative vignette condition showed significant increases in overall self-efficacy for controlling upsetting thoughts, from pre-treatment ($M = 62.95, SD = 33.55$), to post treatment ($M = 72.38, SD = 31.27$), $t(17) = -2.53, p = .02$, as well as within several specific domains of self-efficacy for controlling upsetting thoughts. Future directions include replication of these findings, introducing a no-treatment control, and investigation of effective intervention components through dismantling trials.

Medication Non-Adherence in Community Dwelling Older Adults with Dementia: An Educational Intervention for Family Caregivers

The U.S. is experiencing an unprecedented shift in age demographics (U.S. Public Health Service, 2002). At present, 35 million older adults live in America, a number which will nearly double by the year 2030 (Centers for Disease Control and Prevention and The Merck Company Foundation, 2007). By that time older adults will comprise 18.6% of the population compared to 12.4% in 2000 (U.S. Census Bureau, 2004), representing one of the fastest growing groups in the country. Although the implications of these shifts for healthcare provision and policies have been discussed at great length, less attention has been allocated to medication specific concerns.

Medication non-adherence, defined as any deviation from a prescribed regimen capable of impacting intended effects, is a pressing behavioral health issue for older adults living in the community (Fine et al., 2009). On average, older adults are diagnosed with three to five chronic health conditions (e.g. diabetes, high blood pressure, arthritis) and manage these conditions with an average of 5 medications (Center for Disease Control and Prevention and the Merck Company Foundation, 2007). As a result, they are the largest population of medication consumers in the U.S. (Center for Disease Control and Prevention and the Merck Company Foundation, 2007). Although they comprise 13% of the population, they consume 34% of all prescription medications, and 30% of all over-the-counter medications. In a recent meta-analysis, over 90% of studies found increasing numbers of prescriptions to be associated with non-adherence (Vik, Maxwell, & Hogan, 2004). Accordingly, older individuals have more opportunities for non-adherence than other segments of the population (Ferinni & Ferrini, 2000).

Estimates vary slightly, but most projections indicate that over 50% of older adults in the community do not follow regimens as prescribed by medical personnel. One self-report study

found that approximately 53% of community dwelling older persons describe themselves as medication non-adherent. Because estimates based on patient self-report do not factor in the effects of poor insight and social desirability, a 53% level of non-adherence may represent an underestimation of true rates (Roth & Ivey, 2005). Recent meta-analytic studies that include multiple methods of estimation have placed non-adherence at an average rate of 64% in community dwelling older adults (Banning, 2009), with the highest estimates at 80% non-adherence (Center for Disease Control and Prevention and the Merck Company Foundation, 2007). Despite variance in prevalence rates, however, data suggest that medication non-adherence within older adults is alarmingly high.

The prevalence of non-adherence is especially concerning when understood in the context of negative health consequences, including adverse drug events (ADE). An ADE is defined as “any injury caused by/ or directly related to medication ingestion or errors in medication ingestion” (Institute of Medicine, 2007). These events include allergic reactions, fever, confusion, falls, renal failure, liver failure or death. Such non-adherence related ADEs are disquieting in light of age-related physical vulnerabilities (Fried & Walston, 2003). Unlike other populations, older adults have decreased homeostatic reserve; older bodies have more difficulty maintaining the physiological balance necessary to fight infections and, more importantly, overcome acute or chronic insults (Fried et al., 2003). Because homeostatic reserve is reduced by chronic health conditions, those who are taking the greatest number of medications for these conditions are the most vulnerable. As a result, even small errors in an older person’s medication regimen may have catastrophic consequences (Fried et al., 2003).

Decreased homeostatic reserve leads to more destructive bodily consequences in older adults than in younger adults. Older individuals are more susceptible to a host of injuries from

medications, including allergic reaction, renal/liver failure, excess disability (from frailty), injury from falls, death, delirium, depression, confusion, glucose fluctuations and memory impairment (Bates, 2007; Beery et al., 2010; Inouye, 2006; Murray & Callahan, 2003). Many of these consequences also have higher chronicity in older adults than younger adults (Bates, 2007; Beery et al., 2010; Inouye, 2006; Murray & Callahan, 2003).

It is important to note that polypharmacy in older adults combined with medication non-adherence, may increase the risk for ADEs and the severity of the events (Arnold, 2008). Mixing medications in ways other than prescribed may alter dose response as well as organ functioning (Arnold, 2008; Schmader et al., 2004). If the individuals taking multiple medications are not closely monitored, any side effects related non-adherence and polypharmacy will multiply as a function of the time between medication adjustments (Schmader et al., 2004). Further, the use of multiple medications, and problems adhering to a prescribed regimen, may increase the possibility of adverse medication related events (e.g. hospitalization); one study found that approximately 55% of older adults admitted to an ambulatory care setting had experienced at least one such instance (Gandhi et al., 2003).

In addition, older persons who are medication non-adherent to prescribed regimens have poorer global health outcomes than those who are more adherent (DiMatteo, Giordani, Lepper, & Croghan, 2002). Individuals who take medications as directed experience fewer disabilities, and enjoy improved chronic health conditions as quantified by changing cholesterol levels, blood pressure, glucose, and other objective measures (Banning, 2009; DiMatteo et al., 2002). Older adults who are not taking medications in the manner that they were prescribed can experience excess disability such as frailty, ambulatory problems, disability related to exacerbated health conditions, and objective decreases in positive indicators of health (Banning, 2009; Bates, 2007;

Beery et al., 2010). These non-adherent individuals also have shorter overall life expectancies (DiMatteo et al., 2002). One study demonstrated that older adults who were prescribed statins, a cholesterol lowering drug for diabetes mellitus, had a death rate which was doubled by medication non-adherence. Similarly, older adult patients who were non-adherent on the medication Clopidogrel, a drug used to prevent blood clotting while utilizing a drug eluting stent for diabetes, showed a death rate which was nine times greater than those who adhered to the prescribed regimen (Spertus et al., 2006).

With non-adherence and resulting ADEs, individuals can also incur high financial cost from increased emergency department admissions, elongated hospital stays, and added physician visits or medical testing (New England Healthcare Institute, 2009; Patel & Taylor, 2002). Approximately 30% of all hospital visits and 11.4% of emergency room admissions in older adults are linked to medication non-adherence (Col, Fanale, & Kronholm, 1990; Schlenk, Dunbar-Jacob, & Engberg, 2004). Additional costs may affect the families of non-adherent individuals. For instance, family members may suffer lost wages due to time spent addressing medical repercussions. On a macroscopic scale, medication non-adherence leads to costs paid by the federal government through taxpayer funds (Col et al., 1990; Schlenk et al., 2004). Improved medication management, however, could likely reduce these economic costs.

Medication Non-Adherence in Community Dwelling Older Adults with Progressive Neurocognitive Disorders

Older adults with Alzheimer's disease and other neurocognitive disorders are especially impacted by medication non-adherence. Quality of thinking and self-awareness, as well as memory and executive deficits can all play a role in medication management concerns.

Dementia, the primary symptom of many neurocognitive disorders, is defined broadly as

“significant cognitive decline from a previous level of performance in one or more of the following domains – complex attention, executive function, learning and memory, language, perceptual-motor or social cognition” (American Psychiatric Association, 2013). Dementing neurocognitive disorders are further specified with the following subtypes: Alzheimer’s disease, vascular disease, Lewy body disease, neurocognitive change due to a general medical condition, cognitive change due to HIV infection, cognitive change due to traumatic brain injury, Parkinson’s Disease with cognitive change, Huntington’s disease with cognitive change, Pick’s disease with cognitive change, cognitive change due to prion disease, substance induced persisting neurocognitive disorder, neurocognitive disorder due to multiple etiologies, frontotemporal lobar degeneration and unspecified neurocognitive disorder (American Psychiatric Association, 2013).

The most common subtypes of neurocognitive disorders present with a progressive disease process. Of the progressive types, Alzheimer’s disease, vascular disease, Lewy body disease and mixed etiologies of neurocognitive disorder are the most prevalent. Alzheimer’s disease comprises an estimated 60%-80% of all diagnosed cases and remains the most predominant neurocognitive disorder subtype (Alzheimer’s Association, 2012). Vascular disease accounts for an estimated 20-30% of cases while Lewy body disease is presents at a rate of 10-20% in older adult populations. Recent studies have shown a high prevalence of mixed etiologies for neurocognitive concerns, approximately 50%, upon autopsy (Alzheimer’s Association, 2012). In summary, it is estimated that well over three quarters of all diagnosed neurocognitive disorders are progressive in nature. Accordingly, the use of the terms “neurocognitive disorder,” and “dementia,” within this text will refer to the most common subtype, progressive, and its impact on medication adherence (Alzheimer’s Association, 2012).

In those with neurocognitive disorders the fundamental symptom of impaired cognition places these individuals at increased risk for medication non-adherence. A common measure of cognition, the Mini Mental Status Exam, is the current most frequently utilized evaluation in the literature base to gauge the level of this cognitive decline. Research indicates that community dwelling older adults scoring lower on the MMSE have significant difficulty with medication adherence. One study showed that MMSE scores predicted non-adherence in recently hospitalized older adults with multiple chronic health conditions (Gray, Mahoney, & Blough, 2001). Scores on the MMSE have also been shown to independently predict adherence to specific drugs such as anti-hypertensive medications (Salas et al., 2001). Thus, declining cognition has a well-documented relationship to decreased medication adherence in older adults.

When compared to older adults who do not exhibit cognitive decline, individuals with neurocognitive concerns demonstrate broadly worse levels of regimen adherence (Douglas, Letts, & Richardson, 2011). Persons with diagnosed neurocognitive disorders have been shown to lack basic fundamental knowledge regarding their medication regimens (Sela-Katz, Rabinowitz, Shugaev, & Shigorina, 2010). In one study, they evidenced significantly poorer knowledge of medication management than their unimpaired age-matched peers. Approximately 46.8% of those with a dementing illness lacked basic knowledge about their medication regimen while 6.9% of those without dementia lacked such knowledge (Sela-Katz et al., 2010). This study also found that basic knowledge regarding one's medication regimen declined over time as the neurocognitive disorder progressed. In research examining rates of adverse drug events and non-adherence in older adults, post-hoc analysis reveal that cognitive limitations are present in the majority of ADE cases (Field, Mazor, Briesacher, DeBellis, & Gurwitz, 2007). These unplanned deviations in prescribed regimens cause more accidental deaths than fires and

wandering in persons with dementia (Douglas et al., 2011). Taken together, this information highlights the potential for increased medication non-adherence in community dwelling older adults with neurocognitive disorders.

Medication non-adherence may also have more significant health consequences for those with neurocognitive disorders. In addition to the reduced homeostatic reserve of older adulthood, persons with dementing illnesses are more susceptible to episodes of delirium brought about by non-adherence (Fick et al., 2003; Inouye, 2006). Because dementia is a chronic injury to brain functioning, small physiological changes have a higher potential to cause injuries above and beyond what is the case for those who age without a dementing illness. Persons with neurocognitive diseases do not easily recover from such physiological insults. Individuals who suffer from delirium superimposed on dementia are at increased risk for accelerated cognitive decline, multiple re-hospitalizations, and often, death (Fick et al., 2003; Inouye, 2006).

Medication non-adherence in older adults with neurocognitive disorders becomes especially pressing in the context of the previously discussed demographics. At present, it is estimated that approximately 5.2 million Americans are affected by some form of dementia, most of which are progressive. By the year 2050, the number of seniors with irreversible and incurable dementias will increase to approximately 16 million (Alzheimer's Association, 2010). Thus, the problem of medication non-adherence in older adults with neurocognitive concerns will continue to grow.

Given the likelihood for high prevalence and additional health consequences, medication adherence in older adults with neurocognitive disorders is a critical behavioral health issue. Despite the need for data and interventions, however, the research in this field is in its infancy. What follows is a parallel review of interventions to improve medication adherence in all older

adults as well as those with dementia. The review of the broader older adult population shows a larger literature base which serves to highlight our lack of knowledge in those with neurocognitive concerns. The parallel structure also uses data available for older adults as a foundation for understanding possible interventions in community dwelling older adults with dementia. Overall, the current data points to the possible efficacy of interventions targeting informal caregivers of older adults.

Adherence Interventions in Community Dwelling Older Adults

Current literature shows that successful adherence interventions for older adults can be divided into two basic categories: those with behavioral components and those that provide psychoeducation. The more basic of these interventions, behavioral modifications, include pill package changes, alarms that cue for medication administration, self-monitoring of symptoms/side effects, self-monitoring of medication administration times, and over-the counter usage.

Packaging changes, or recommendations for this modification, are one of the most frequently used behavioral interventions. In these interventions patients are asked to utilize containers, such as pill boxes or blister packs, as opposed to their original pill bottles. The new containers provide a daily organization system and hold all medications to be taken on a given day or at a specified time within that day. Although few interventions use package changes as an exclusive intervention strategy, meta-analyses across medication types show large effect sizes (Cohen's $d = .67$) for interventions that discuss blister packaging or pill box organization (Conn et al., 2009). Mean effect sizes for interventions that do not include this behavioral component are relatively small (Cohen's $d = .30$; Conn et al., 2009). Despite the benefit of simplicity, however, these interventions have several drawbacks. They cannot account for wrong time errors nor do they aid in following medication specific administration instructions such as "take

with food” (Banning, 2009; Conn et al., 2009; Heneghan, Glasziou, & Perera, 2007). In order to counter difficulties in timing, reminder alarms are often utilized along with packaging changes. In these cases, meta-analyses show the average effect size of interventions without alarms to be small (Cohen’s $d = .30$), whereas interventions that discuss alarms systems with pill packaging show a large effect size (Cohen’s $d = 1.06$; Conn et al., 2009). The combination of these behavioral recommendations appears to be most effective in promoting medication adherence, and should be utilized in future health oriented intervention strategies.

Another promising behavioral intervention is symptom-monitoring and side-effect awareness, coupled with developing follow-up questions for medical staff (Conn et al., 2009). This intervention type requires that clients monitor and record their medication usage and that they monitor changes in health that may be medication related. The strategy teaches participants to record instances of medication taking behaviors on calendars or other logs, after each administration. Similarly, symptom monitoring requires patients to log positive and negative changes in health status which may relate to medication taking behavior (Conn et al., 2009). These techniques are typically used in parallel and have been associated with a large effect size (Cohen’s $d = 1.18$) compared to the low mean effect size (Cohen’s $d = .30$) for all interventions (Banning, 2009). This method, when used correctly, increases patient awareness of their current medication/health patterns and may subsequently change patterns of behavior by increasing the number and clarity of questions brought to treating personnel (Conn et al., 2009). These large effect sizes indicate that future interventions for medication adherence would best serve patients by providing tools to record medication related data, and teaching patients communication strategies and useful questions for medical staff.

The second class of successful adherence interventions in older adults without cognitive

impairment are psychoeducational, and are associated with a moderate effect size (Cohen's $d = .48$; Banning, 2009). This intervention type includes a detailed discussion about medication purposes, medication management strategies, problem solving surrounding adherence, a discussion of how to effectively communicate with medical personnel and recognizing when medication administration errors or adverse consequences have occurred (Conn et al., 2009). It is likely that when adherence interventions in older adults combine these psychoeducational components and behavioral modifications surrounding pill packaging changes, symptom monitoring and alarm systems, they may see increased efficacy (Conn et al., 2009).

Adherence interventions in older adults have been demonstrated as effective across multiple delivery formats. Personnel providing these interventions have included physicians, pharmacists, nurse practitioners, nurses, psychologists and social workers (Banning, 2009; Bouvy et al., 2003; Clifford et al., 2006; Conn et al., 2009). One aspect of these interventions that may be especially attractive is their flexibility in regards to setting of administration (Banning, 2009; Conn et al., 2009). They can be delivered on an inpatient or outpatient basis or during home visits and tele-health communications, all with equivalent efficacy (Banning, 2009). Delivering these interventions through tele-health mechanisms has been shown to reduce the high cost required to pay personnel for time of delivery, and is reported to be convenient for patients receiving care (Banning, 2009; Pew Research Center, 2011).

Two interventions of differing intensity demonstrate the efficacy of behavioral and psychoeducational interventions in flexible formats. The first study by Clifford and colleagues (2006) recruited cognitively unimpaired older adults ($N=410$) who had recently been prescribed a new medication and who had at least one chronic health condition. These participants were randomized to a treatment as usual group or the intervention group. The intervention group

received an initial consultation after obtaining their medications and a single phone call, two weeks later. When called, the intervention group was asked questions based on a semi-structured adherence interview. These questions inquired about client adherence patterns and addressed questions or difficulties they experienced in remaining adherent. Pharmacists were allowed to deviate from this interview as patients expressed individual concerns, but the most common area of consultation was behavioral modifications (reminder alarms and packaging changes), symptom monitoring, psychoeducation about side effects, and what questions to ask the prescribing professional. Overall, patients in the intervention group reported higher medication adherence ($p = .032$) and reported fewer medication related difficulties ($p = .021$) post-intervention. This intervention provided evidence that tele-health behavioral modification and psychoeducation may be an effective means for improving adherence.

The second psychoeducational intervention was a pharmacist led care plan spanning six months (Bouvy et al., 2003). This study included 152 older adult heart failure patients prescribed loop diuretics after a hospital visit. Patients with cognitive impairments were excluded from the study. When filling their prescriptions, patients in the randomized group received a semi-structured interview designed to problem solve around medication non-adherence. After this interview, the intervention group received 6 monthly consultation phone calls designed to answer patient medication questions and provide broadly based behavioral tips for adherence. The treatment as usual group did not receive interviews or phone calls. All patient adherence data was measured by a MEMS device assessing adherence to the diuretic regimen. Patients who received the intervention had significantly fewer days of non-adherence, 140/7656 days (1.8%), when compared to those who did not receive the intervention at 337/6196 (5.4%) days of non-adherence.

As such, the literature supports the efficacy of behavioral interventions, telecommunicated behavioral modification tips, and psychoeducation to increase medication adherence. Nevertheless, the current state of interventions for medication adherence in older adults demonstrates two critical weaknesses. First these techniques have only been utilized in cognitively unimpaired older persons. Second, the majority of these interventions lack clear theoretical underpinnings (Conn et al., 2009). As a result, this manuscript further reviews the relatively sparse data regarding medication adherence interventions in older adults with neurocognitive disorders. Afterwards, an intervention that includes explicit theoretical underpinnings and addresses weaknesses in present treatment strategies is described.

Adherence Interventions for Community Dwelling Older Adults with Progressive Neurocognitive Disorders

There is a dearth of literature for adherence interventions in community dwelling individuals with dementia. To date, only one study has implemented a medication adherence intervention for this population (Smith, Lunde, Hathaway, & Vickers, 2007). The study utilized a telephone reminder strategy to increase adherence and included those with both mild cognitive impairment (MCI) and dementia (N=14). The individuals received communications from a trained research assistant in the morning, at noon and before bed. The group receiving the intervention maintained medication adherence of approximately 80% while those who did not receive the intervention exhibited expected dementia related decline to adherence of 62%. There were no significant improvements between baseline medication adherence and post-intervention adherence rates.

This study represents a pioneering effort in an understudied population, but it demonstrated several substantial limitations to generalizability. Firstly, the majority of

individuals in the sample had a diagnosis of mild cognitive impairment. They did not qualify for a full neurocognitive disorder diagnosis as their cognitive declines did not yet impact daily functioning. The remainder of the sample included individuals in the beginning stages of Alzheimer's disease. This has two implications. These results may not hold for a true population of individuals with diagnosable neurocognitive disorders and this intervention type may not be helpful to those in latter stages of the disease process. Another limitation to generalizability is that the individuals with MCI were not divided into amnesic type or non-amnesic subtypes. This is important as amnesic individuals have a higher likelihood of conversion to full dementia (Alzheimer's Association, 2012). Thus, it is unclear what proportion of the MCI population had an increased potential for impairment. Because the majority of the sample included individuals with MCI, and because the authors did not assess for type of MCI, it is likely that study may not generalize to individuals in the community with full progressive neurocognitive concerns.

One study that supports this assumption of limited generalizability was designed by Insel and Cole (2005). This study implemented an individually tailored intervention designed to increase cues for medication memory in older adults and, thus, improve medication adherence (N=27). For example, if a coffee drinker prepared a pot of coffee in the morning and needed to take medication at that time, the pill bottles were placed next to the coffee maker. This was tailored to each individual. The primary outcome for this research was pill counts. This intervention increased medication regimen adherence in older adults across time from an initial level of 64.7% adherence to 78%. However, when they removed individuals scoring 1 SD below age norms on the MMSE (N=6), adherence rates began at 70.6% and were increased to 86%. Therefore, removing those who qualified for a dementia diagnosis caused improvement rates to

jump drastically. Taken together, this information implies that interventions focused solely on the person with dementia may see low efficacy. Considering the progressive nature of many dementias, this effect may be amplified with time.

The Role of Informal Dementia Caregivers in Medication Adherence

Informal caregivers, family, kin, and chosen family, are the most common source of assistance for older adults with cognitive limitations (Alzheimer's Association, 2011; Schulz & Martire, 2004). Approximately 70-80% of individuals with a dementing illness live in the community and of those individuals, 75% receive care from a family member or friend (Alzheimer's Association and National Alliance for Caregiving, 2004; Office for National Statistics, 2005; Schulz & Martire, 2004; US Census Bureau, 2005). A recent national survey completed by the Alzheimer's Association found that 43.5 million adult family/informal caregivers care for someone 50+ years of age and 14.9 million care for someone who has Alzheimer's disease or other dementia. (Alzheimer's Association, 2011). Medication management is a particularly complex task that frequently falls within the domain of caregiving (American Psychiatric Association, 2010; Arlt, Lindner, Rosier, & Rentelnkrus, 2008; Travis, Faan, Hsueh-Fen, Kao & Acton, 2005). Of the 14.9 million dementia family caregivers in the U.S., over half report aiding with medication management at some point in the care process (Alzheimer's Association, 2012; American Psychiatric Association, 2010; National Alliance for Caregiving in Collaboration with AARP, 2009; Travis, Kao, & Acton, 2005).

Although assuming such roles benefits both the patient and families in some ways (Hilgeman, Allen, DeCoster, & Burgio, 2007), many who become caregivers pay heavy psychological and physical tolls. (Graesel, 2002; Kam-Mei, & Au, 2011; Schulz, O'Brien, Bookwalla, & Fleissner, 1995). Overall, studies have found that these dementia family

caregivers are generally more distressed than caregivers of physically impaired elders (Ory, Yee, Tennstedt & Schulz, 2000). This distress includes high rates of clinical depression and/or depressive symptoms (Cassie, & Sanders, 2008; Schulz & Martire, 2004;), high rates of other negative emotions such as anger, frustration, burden, and fear (Ory et al., 2000), and other indices of distress, such as family conflict over caregiving, significant emotional strain, financial hardship, and reduced time for leisure pursuits (Ory et al., 2000; Pinquart & Sorensen, 2003). Physical tolls are also pervasive; Vitaliano et al. (2002) and Vitaliano, Young and Zhang (2004) found that caregivers had a greater prevalence of heart disease, high blood pressure and metabolic syndromes, than non-caregivers of the same age. Still other studies have found complaints of bodily aches and pains, greater prevalence of diabetes, allergies, and use of non-prescription pain medication to be common in dementia caregivers (Coon, et al., 2004; Pinquart & Sorenson, 2003). Approximately 17% of caregivers believe their health, in general, has gotten worse since assuming caregiving responsibilities and 17-35% of caregivers report their health as fair or poor (Feinberg, Reinhard, & Choula, 2011). Thus, the stress of the caregiving role, which frequently includes medication management, has the potential to produce negative mental health consequences in family caregivers.

Interventions targeting informal caregivers: General and medication related.

Numerous interventions have been developed to address the distressing effects of caregiving, but very few teach specific information for managing the elder's health and medication. Of the interventions published in the past decade, there have been multiple reviews support the efficacy of those designed to reduce stress or improve mood (Brodaty, Green & Koschera, 2003; Schulz, Martire & Klinger, 2005; Sorensen, Pinquart & Duberstein, 2002). A review by Gallagher-Thompson and Coon (2007) that used strict criteria for identifying psychosocial caregiver

interventions as evidence based, found that three categories could be so considered at the present time; psychoeducational skill-building programs (e.g., Coon, Thompson, Steffen, Sorocco & Gallagher-Thompson, 2003); psychotherapy (e.g., Gallagher-Thompson & Steffen, 1994); and multi-component interventions (those using several distinct types of treatment such as support groups plus family meetings and case management; e.g., Mittelman, Roth, Coon & Haley, 2004; Zarit & Zarit, 2007). Psychoeducational interventions, which derive from behavioral and cognitive theories and therapies (cf. Beck, Rush, Shaw & Emery, 1979; D’Zurilla, 1986; Lewinsohn, 1974; Lewinsohn, Munoz, Youngren & Zeiss, 1986) are often preferred by family members.

Despite the overall findings that psychoeducational and combination interventions are best suited to assuage caregiver stress, there are some components of the caregiving process that remain under-researched with a resulting lack of interventions. One such paucity exists in the realm of caregiver based medication management. Medication management is an especially critical component of the caregiving role, as it directly impacts care-recipient health. It can also result in hassles and increased caregiver strain (Thornton & Travis, 2003). Caregivers managing medications must be aware of scheduling logistics, timing of administration, safety issues, side-effects, knowing what to do in an emergency, issues of polypharmacy and information seeking when appropriate (Travis et al., 2005). If any of these processes are not well managed, it could result in negative physical consequences for the care-recipient as well as financial and emotional consequences for the caregiver (Bates, 2007; Beery et al., 2010; Inouye, 2006; Murray & Callahan, 2003).

Nevertheless, present literature searches reveal only one treatment study that sought to include informal caregivers as an intervention point for medication adherence in

neurocognitively impaired older adults (Kamimura, Ishiwata & Inoue, 2012). Participants were providing care to an older adult (≥ 65 years of age) who had a Clinical Dementia Rating Scale score ranging from 0.5 – 1 (N = 18). The analogue CDR is scored on a five-point scale that is meant to describe individuals without neurocognitive concerns (0) and with questionable (0.5), mild (1), moderate (2), and severe (3) neurocognitive difficulties. Caregivers were trained to program and fill an electronic pill planner, which included alarms and real-time pill dispensing, throughout the day. They were subsequently instructed to give minimal prompting to the older adult about managing their medications. The older adult's medication adherence was calculated for one week previous to this intervention and after three months of using the electronic pill planner, using ratio of total prescribed doses and total number of medication doses taken by the care-recipient (verified by pill count). Results showed that after 3 months of using this device, approximately 66% of the care-recipients in this study were taking all of their medication doses in a given day (Kamimura, Ishiwata & Inoue, 2012).

Although this study demonstrates the potential benefits of including caregivers in healthcare interventions, the findings lack generalizability to certain populations. Namely, this intervention only included older adults with questionable or mild cognitive impairment, and it is likely that individuals with greater cognitive impairment would demonstrate more difficulty in responding to electronic pill planners with reminders. Caregivers were also required to undergo substantial training by nursing staff in order to operate this device; education took place over three home visits. This preparation necessitates a sizeable time commitment for staff and caregivers. Not only is this approach costly, in terms of staff resources, but this may have limited external validity in a highly time-pressured caregiver population.

Despite the lack of adherence specific interventions, however, current review papers

suggest that all treatments designed to impact a care dyad, should include psychoeducation about effective communication strategies and education about cognitive impairment in those with neurocognitive disorders. These reviews show that interventions targeting specified dyadic problems produce decreased caregiver stress, higher satisfaction and greater intervention tolerability, when they teach effective interpersonal strategies (Moon & Adams, 2012).

Additional information, such as clear material describing the causes of confusion in the older adult, has the potential to increase ease of medication management and subsequent adherence (Alzheimer's Association, 2012; National alliance on Family Caregiving, 2009). It opens the door for continued dialogue between health professionals and caregivers/care-recipients, and may spur caregivers to seek outside support systems to aid in medication management, subsequently improving adherence (Alzheimer's Association, 2012; National alliance on Family Caregiving, 2009).

Overall, current research suggests that family caregivers may be the most useful primary point of contact when developing medication related interventions for those with dementia. Cognitive decline as a consistent predictors of medication non-adherence, (Gray et al., 2001; Sela-Katz et al., 2010) coupled with the hassles that caregivers experience when managing medication (Thornton & Travis, 2003), further underscore this group as the most impactful point of treatment. In addition, interventions that focus on the caregiver have potential to alleviate both caregiver strain, and may also positively impact the health of the care-recipient. Despite the need to support cognitively impaired older adults in managing medications, however, there are few interventions designed to help dyads achieve this goal, fewer that do so using caregivers as a point of intervention, and almost none that do so by developing an intervention with clear theoretical underpinnings.

Understanding Caregiver Medication Management from a Health Model Framework: Bandura's Theory of Self-Efficacy

Bandura's social cognitive theory attempts to explain the way in which individuals learn, and engage in new behaviors. This theory posits that people acquire a given behavior as a result of interactions between internal and external factors. Internal influences include cognitions, transient emotional states, past experiences, expectancies and goals. External influences refer to the context or the social and physical environment an individual inhabits while learning. Reciprocal determinism, or the interaction between the person, environment and behaviors, influences the manner in which an individual learns a given behavior (Bandura, 2001).

Social cognitive theory emphasizes the role of self-efficacy as one of the strongest internal states acting upon the acquisition of a new behavior. Bandura defines self-efficacy as the level of confidence one possesses that he/she can perform a given act (Bandura, 1977; Bandura, 1982; Bandura, 1997). It is a behaviorally specific construct that directly impacts one's ability to persist in tasks, despite obstacles. Self-efficacy also varies across domains; an individual can have high self-efficacy in one area and low self-efficacy in another. Finally, self-efficacy is influenced by environmental context (Bandura, 1977; Bandura, 1982; Bandura, 1994; Bandura, 1997).

Self-efficacy beliefs originate from several types of experiences. Firstly, they develop after performance accomplishments. Performance accomplishments occur when an individual successfully executes a behavior. The individual then believes that they can successfully perform future domain related behaviors (Bandura, 1982). Efficacy beliefs can also develop through vicarious experiences. In these cases, an individual observes someone else successfully completing a given activity. Vicarious experiences are most powerful when the model is a

similar other (Bandura, 1977; Bandura, 1982; Bandura, 1994). Verbal persuasion and physiological state changes are the final mechanisms for developing efficacy (Bandura, 1977; Bandura, 1982; Bandura, 1997). The most effective method for increasing self-efficacy is to engage in performance accomplishments (Bandura, 1997). Vicarious learning follows in power, whereas verbal persuasion and physiological state changes have the smallest impact on self-efficacy (Bandura, 1977; Bandura, 1982; Bandura, 1997).

Despite the largely domain specific nature of self-efficacy, however, there are five scenarios in which efficacy beliefs may generalize. The first scenario is when two tasks require similar sub-skills. Efficacy beliefs may also generalize when two skills were developed simultaneously or when cognitive meta-strategies learned for one skill apply to another. In addition, efficacy beliefs generalize to new experiences when the individual creates similar cognitive structures for learning a given behavior. Finally, one may experience a transformational restructuring of beliefs. For example, someone who undergoes a powerful mastery experience may gain the sense that they can overcome a broad array of challenges (Bandura, 1977; Bandura, 1982; Bandura, 1997).

Self-Efficacy Theory applied to medication management. Self-efficacy beliefs impact medication management and health related outcomes across multiple populations. In adults age 18-64, self-efficacy for medication management relates to increased ability to perform medication management behaviors. A study by Brus and colleagues (2000) examined the relationship between self-efficacy for adherence to sulphasalazine (a drug for rheumatoid arthritis) and a pill count measure of adherence. Logistic regressions classifying adults as adherent or non-adherent, with a cutoff of 80% adherence, showed self-efficacy was a significant predictor of adherence behavior. A similar study by Gifford and colleagues (2000) demonstrated

that levels of self-efficacy for managing two multidrug antiretroviral HIV regimens accurately classified individuals as having excellent adherence (100%), fair adherence (80-99%) and poor adherence (< 80%). It also showed that adherence and self-efficacy related to lower plasma concentrations of the HIV virus. In addition, self-efficacy is linked to adherence with other behavioral regimens recommended by physicians. In a recent study, (N=463) individuals with diabetes were shown to be more adherent to physician recommended diet and exercise when they reported high self-efficacy for following health related regimens, and higher self-efficacy for managing distressing emotions around these health based changes (King et al., 2010).

The relationship between self-efficacy and medication adherence extends across age groups. In a population of older adults who experienced a transient ischemic attack (TIA) or stroke, those who reported higher self-efficacy for controlling thoughts about medication management showed greater levels of medication adherence. Level of self-efficacy and adherence related to a higher likelihood of meeting target glucose/cardiac outcomes (Ireland, Arthur, Gunn, Oczkowski, 2010). Similarly, older adults with high self-efficacy demonstrate greater ability to manage osteoporosis medications and exhibit improved medical outcomes (Resnick, Wehren, & Orwig, 2003). Additional data demonstrate that self-reported medication adherence is significantly associated with self-efficacy for remembering to administer medication (McDonald-Miszczak, Maris, Fitzgibbon, & Ritchie, 2004).

Finally, numerous studies show that self-efficacy relates to medication management, across cultures. Lewis (2011) demonstrated that low income African Americans with high self-efficacy for positive medication related behaviors and high self-efficacy for managing emotions surrounding health conditions, exhibited greater adherence and better overall communication with medical providers. HIV positive patients recruited from a hospital in Hong Kong, who

reported higher self-efficacy for their medication regimen, also demonstrated higher self-reported medication adherence (Mo, & Mak, 2009). Israeli patients managing oral and injected medications for diabetes exhibited the same pattern: higher self-efficacy related to increased ability to manage medications (Mishali, Omer, & Heymann, 2010). Lastly, medication adherence efficacy in Taiwanese organ transplant patients predicted higher levels of medication adherence post-transplant (Weng, Dai, Huang, & Chiang, 2009).

Social Cognitive Theory and a caregiver based intervention. At present, no other model exists which reliably predicts improved medication management across age groups and ethnicities (Bandura, 2004; Conn et al., 2009; Jackson, 2011). Further, self-efficacy based interventions are easily tailored to individual concerns. Bandura (2004), notes that each individual has a unique level of pre-existing efficacy as well as a unique set of obstacles and a differing course of progress. He also explains that this model allows for interventions administered in a variety of modalities (Bandura, 1998; Bandura, 2004). As a result, interventions based in self-efficacy theory allow for flexibility in content and administration. These facets may be highly beneficial to informal dementia caregivers.

The Current Study: Specific Aims and Hypotheses

The primary aims of this study were to examine the efficacy of a web based intervention that utilized Bandura's theory of self-efficacy and targeted dementia family caregivers. In this study, a multimedia health education condition based on enacted true-to-life vignettes was predicted to increase caregivers' medication management self-efficacy through observational learning of similar others. The same information and suggestions delivered in traditional voice and written text of experts formed the didactic comparison condition. Expert testimony has been demonstrated to be far less effective in shaping self-efficacy beliefs and effective behaviors

(Bandura, 1997), while interactive vignettes maximize participants' engagement with the online educational materials (Epstein, Collins, Thomson, & Pancella, 2007; Epstein & McGaha, 1999; Epstein, Thomson, Collins, & Pancella, 2009). Because women are disproportionately likely to provide medication assistance to aging family members, this intervention focused on female caregivers (U.S. Bureau of the Census, 2005).

This intervention utilized an internet based modality that encompassed the psychoeducational and behavioral content areas previously highlighted as effective in the older adult, cognitively impaired older adult, and caregiver literature. This internet modality was selected because tele-health interventions demonstrate high efficacy for improving medication related behaviors and may be particularly well suited to the busy schedules of informal caregivers (Steffen & Mangum, 2003). In addition, internet-based services create access for underserved rural caregivers (Steffen & Mangum, 2003). Finally, the internet has become an important source of health information, with eighty percent of internet users, and fifty-nine percent of the US population, searching online for health material (Pew Research Center, 2011). The proportion of adults aged 65 and older who use the internet to search for information has grown to 53%; of these, 70% report going online daily (Pew Research Center, 2011). Thus, the internet is a viable and convenient medium for providing flexible and accessible health education; such flexibility is linked to the success of recruitment and retention in health education and intervention research (Coday et al., 2005).

Specifically, the goals of this online health education intervention were to increase positive behaviors associated with effective medication management strategies by women caring for a cognitively impaired older relative/friend and to decrease medication-related caregiving hassles. The hypotheses that were examined are as follows:

Compared to participants in the traditional online health education condition, dementia caregivers assigned to the narrative vignette condition would:

- 1). Report higher levels of satisfaction with the intervention at the post-intervention assessment (1 month).
- 2). Show a greater pre to post-intervention decrease in medication refill and administration hassles.
- 3). Show a greater pre to post-intervention increase in self-reported positive communication behaviors with medical providers.
- 4). Show a greater pre to post-intervention decrease in medication non-adherent behaviors for care-recipient medication regimens.
- 5) Show greater pre to post-intervention increases in self-efficacy for controlling upsetting thoughts related to the caregiving situations.

Methods

Participants

Eligible participants were (a) women aged 18 years and older, who (b) assisted a community-dwelling biological or “chosen” earlier-generation relative by (c) accompanying/providing transportation to a medical appointment of this relative at least once in the past year and who (d) were engaging in at least one of the following caregiving activities related to prescription drugs: Ordering, retrieving, organizing or administering medication, routinely reminding the older adult to take medications, or sharing in decision-making with care recipient and physician to begin, hold, increase, decrease, or discontinue a medication and who (e) endorsed a score of 2, “somewhat distressed,” or more, on two items of the Family Caregiver Medication Administration Hassles Scale (Travis et al., 2003). Similar criteria have been used

successfully in research on medication administration by family members of older adults (Travis et al., 2003). This definition of caregivers is culturally sensitive to women who provide significant care for non-relatives from a previous generation (e.g., caring for “fictive kin,” neighbors, and church members in African American communities, as well as for older gay men and lesbians who may not have access to support from biological family members).

Care-recipients were required to have a caregiver reported diagnosis of dementia. Additional inclusion criteria for the care recipient were no lifetime reported history of (b) schizophrenia, (c) bipolar disorder, (d) suicide attempts, (e) Huntington’s Disease, (f) Korsakoff’s Disease, (g) Multiple Sclerosis, (h) HIV, (i) traumatic brain injury or (j) drug/alcohol dependence.

Recruitment. All assessment and intervention tasks were conducted online (with available telephone technology support), which allowed for local and nationwide recruitment, using a variety of strategies. The project advertised on the electronic newsletters and websites for local and national agencies serving older adults (e.g., Family Caregiver Support Programs of Area Agencies of Aging) and family caregivers (e.g., National Family Caregiver Association, Alzheimer’s Association TrialMatch research registry, online family caregiver chat rooms and groups). This study also utilized the lab’s *Constant Contact* (online newsletter service) database generated during a prior Express Scripts measurement development study, for individuals who indicated interest in receiving information about other research. In addition, the lab created an active Facebook page and twitter account which advertised the link for the screening survey. Only “followers” or “friends” on these social media sites were able to see these messages to minimize non-caregiver responses to the screening survey. Followers of these social media sites

exclusively included nationwide agencies for aging individuals (e.g. Alzheimer's Association chapters across multiple states).

In addition to these electronic methods for recruitment, lab members advertised this study in-person during the St. Louis, St. Charles, Edwardsville and Rolla Walk to End Alzheimer's events. This study also provided recruitment materials at all Alzheimer's Association Care and Conquer talks. In addition, presentations were made about the study to Alzheimer's Association Faith Ambassadors in the St. Louis area as well as to staff at the St. Louis College of Pharmacy. Alzheimer's Association Respite Care Families were also mailed recruitment flyers.

Study Participants

Flow of participants through the study. A total of 467 individuals were screened before entry into this study and of those 467 individuals, 54 (11.56%), were eligible for the intervention. One individual was removed before randomization due to a non-working email and only initials given for the name. Thus, 53 individuals, 11.35%, were randomized to the experimental narrative vignette treatment condition, or the comparison didactic condition. Of the 53 caregivers randomized, 25 were assigned to the comparison didactic condition (47.17%) and 28 (52.83%) were assigned to the experimental condition (Table 1).

As shown in Table 1, caregivers who were enrolled in the intervention, at pre-treatment, ranged in age from 26 to 56 ($M = 53.43$, $SD = 9.88$). These individuals identified as primarily White (75.5%), followed by African American (15.1%), Multiracial (7.5%), and Latina (1.9%). The large majority of these caregivers stated that they were caring for a parent (88.6%). Marital status was approximately evenly divided, with 56.6% stating that they were married or living as married. This sample of caregivers was well educated, with the average years of education equivalent to a bachelor's degree ($M = 16.01$, $SD = 2.44$). About 34% of this sample earned

between \$10,000 - \$50,000 a year, while the remaining 66% earned over \$50,000 each year. Individuals entering the intervention reported caring for their loved one for an average of 3.52 years ($SD = 2.40$). These caregivers reported that, at the time of the survey, they provided about 72% of all of their loved one's total care.

As shown in Table 2, participants entering the intervention were providing care to individuals who demonstrated moderate levels of impairment on the IADL, ADL and CDR (IADL: $M = 1.06$, $SD = 1.42$; ADL: $M = 3.02$, $SD = 2.46$; CDR: $M = 1.45$, $SD = .80$). The most common neurocognitive diagnosis was Alzheimer's disease (47.2%), however many individuals did not know the exact diagnosis of the older adults cognitive difficulties (37.7%). Approximately 9.4% of participants reported caring for someone with vascular dementia. These caregivers endorsed managing an average of about 7 prescription medications and 4 over the counter medications (Rx Meds: $M = 7.37$; $SD = 3.66$; OTC Meds: $M = 3.51$, $SD = 1.89$). The most common medical conditions in the care-recipient group, aside from dementia, were high blood pressure (69.8%) and arthritis (45.3%).

No demographic differences in caregiver age, years of education, level of involvement, numbers of medicines managed, the relative risk of medicines managed, or current mental health status, emerged when comparing narrative vignette participants to didactic group participants, at the initial assessment time point (Tables 1 and 2). Similarly, care-recipients were equivalent on all demographic variables, including types of medical diagnoses, level of impairment and living arrangements, as reported by the caregiver. Although no demographic differences between groups reached significance, some non-significant trends emerged. Overall, the narrative experimental group showed a lower ratio of enrolled African American participants, at 7.1%, compared to 24% in the comparison control group ($p = .10$). In addition, caregivers in the

experimental group reported that they were caring for individuals with slightly higher levels of functionality in IADLs, ($p = .17$; Control $M = .80$, $SD = 1.15$; Experimental $M = 1.29$, $SD = 1.61$). Nevertheless, these groups were equivalent on all examined demographic variables.

In order to further assess the equivalency of these two groups on primary outcome variables, independent t-test were run to compare the narrative vignette and comparison didactic conditions on initial levels of hassles, self-efficacy, medication adherence behaviors and patient-provider communication (Table 3). Several significant differences emerged in the data. Caregivers in the comparison didactic group reported that they were experiencing overall higher number of hassles than those assigned to the narrative vignette condition (didactic $M = 37.40$, $SD = 26.21$; narrative vignette $M = 27.57$, $SD = 17.76$; $p = .01$; Cohen's $d = .51$). When examined based on subscales, independent t-tests found that two areas of hassle were driving this overall difference. Caregivers in the didactic comparison condition reported that they were significantly more hassled in the areas of Safety (didactic $M = 7.36$, $SD = 6.42$; narrative vignette $M = 4.68$, $SD = 3.94$; $p = .01$; Cohen's $d = .44$) and polypharmacy (didactic $M = 6.04$, $SD = 4.30$; narrative vignette $M = 3.43$, $SD = 2.91$; $p = .03$; Cohen's $d = .72$) but not in the domains of information seeking or scheduling logistics. Caregivers did not show any significant differences between the narrative vignette condition and comparison didactic on initial levels of Self-Efficacy for Controlling Upsetting Thoughts, medication adherence as measured by the Morisky Medication Adherence Scale, or caregiver communication with medical providers.

Table 1.

Pre-intervention Caregiver Demographic Characteristics; Total and Comparison of Conditions.

Variable	Total (N = 53)	Intervention Group		Intervention Group Comparison	
		Didactic (n = 25)	Narrative (n = 28)	F or χ^2	P Value
Age (M, SD)	53.43 (9.88)	53.92 (9.05)	53 (10.7)	.92	.34
Years of Education (M, SD)	16.01 (2.44)	15.84 (2.09)	16.17 (2.75)	.91	.35
DASS 21 score (M, SD)					
Depression	4.89 (4.24)	4.68 (3.72)	5.00 (4.73)	.90	.35
Anxiety	2.89 (3.19)	2.80 (3.41)	2.90 (3.03)	.04	.84
Stress	7.24 (4.64)	7.60 (4.62)	6.93 (4.73)	.30	.59
Total Time as Caregiver in years (M, SD)	3.52 (2.40)	3.94 (2.06)	3.32 (2.58)	.91	.35
What Percent of Total Care Provided (M, SD)	72.28 (29.02)	77.56 (26.53)	69.17 (29.12)	.47	.50
Ethnicity n, %				6.35	.10
Caucasian	40 (75.5%)	15 (60%)	25 (89.3%)		
African American	8 (15.1%)	6 (24%)	2 (7.1%)		
Latina	1 (1.9%)	1 (4%)	0		
Multiracial	4 (7.5%)	3 (12%)	1 (3.6%)		
Married/ Living as married n, (%)	30 (56.6%)	13 (52%)	17 (60.7%)	.93	.37
Relationship to Care Recipient n (%)				3.27	.52
Daughter	47 (88.6%)	23 (92%)	24 (85.7%)		
Granddaughter	3 (5.7%)	2 (8%)	1 (3.6%)		
Aunt/ Uncle	1 (1.9%)	0	1 (3.6%)		
Close Friend	2 (3.8%)	0	2 (7.1%)		
How Caregiver Helps with Healthcare, n (%)					
Order Medications	48 (90.6%)	24 (96%)	24 (85.7%)	.31	.58

Pick Up Medications	49 (92.4%)	24 (96%)	25 (89.3%)	.85	.37
Drive to Medical Appointment	52 (98.1%)	25 (100%)	27 (96.4%)	.91	.34
Help Organize Meds	51 (96.2%)	25 (100%)	26 (92.9%)	1.87	.17
Help Decide When to Change Dose	44 (83%)	22 (88%)	22 (78.6%)	.83	.37
Help Decide When to Start Med	46 (86.8%)	23 (92%)	23 (82.1%)	1.11	.29
Actually Give the Medications	44 (83%)	22 (88%)	22 (78.6%)	.83	.37
Participate in Medical Appointments	52 (98.1%)	25 (100%)	27 (96.4%)	.91	.31
Income, n (%)				9.02	.53
Less than \$5000	0	0	0		
\$5,000 - \$9,999	0	0	0		
\$10,000 - \$14,999	3 (5.6%)	1 (4%)	2 (7.1%)		
\$15,000 - \$19,999	3 (5.6%)	1 (4%)	2 (7.1%)		
\$20,000 - \$29,999	4 (7.5%)	2 (8%)	2 (7.1%)		
\$30,000 - \$39,999	8 (15.1%)	5 (20%)	3 (10.7%)		
\$40,000 - \$49,000	5 (9.5%)	1 (4%)	4 (17.9%)		
\$50,000 - \$59,000	5 (9.5%)	3 (12%)	2 (7.1%)		
\$60,000 - \$69,999	5 (9.5%)	3 (12%)	2 (7.1%)		
Over \$70,000	20 (37.7%)	9 (36%)	11 (39.4%)		
Employment Status, n (%)				1.27	.74
Retired	10 (18.9%)	4 (16%)	6 (21.4%)		
Working Full Time	25 (47.2%)	12 (48%)	13 (46.4%)		
Working Part Time	6 (11.3%)	2 (8%)	4 (14.3%)		
Unemployed	12 (22.6%)	7 (28%)	5 (17.9%)		

* = $p < .05$.

Table 2

Pre-intervention Care-Recipient Demographic Characteristics; Total and Comparison of Conditions.

Variable	Total (N = 53)	Intervention Group		Intervention Group Comparison	
		Didactic (n = 25)	Narrative (n = 28)	<i>F</i> or χ^2	<i>P</i> Value
Age (<i>M, SD</i>)	83.02 (8.05)	83.00 (6.83)	83.03 (9.12)	1.71	.20
Years of Education (<i>M, SD</i>)	12.39 (2.53)	12.08 (2.66)	12.68 (2.41)	.01	.94
Care Recipient IADL score (<i>M, SD</i>)	1.06 (1.42)	.80 (1.15)	1.29 (1.61)	1.98	.17
Care Recipient ADL score (<i>M, SD</i>)	3.02 (2.46)	2.96 (2.58)	3.07 (2.40)	.64	.43
Care Recipient CDR Score (<i>M, SD</i>)	1.45 (.80)	1.44 (.79)	1.46 (.81)	.03	.86
HBLQ Score (<i>M, SD</i>)	3.87 (1.36)	4.08 (1.32)	3.69 (1.39)	.60	.44
Total Number of Rx Medications (<i>M, SD</i>)	7.37 (3.66)	7.76 (3.91)	7.03 (3.47)	1.20	.28
Total Number of OTC Medications (<i>M, SD</i>)	3.51 (1.89)	3.32 (1.84)	3.68 (1.94)	.18	.67
Gender, n (%)				.05	.82
Male	12 (22.6%)	6 (24%)	6 (21.4%)		
Female	41 (77.4%)	19 (76%)	22 (78.6%)		
Medical Problem, n (%)					
Arthritis	24 (45.3%)	13 (52%)	11 (39.3%)	.86	.35
Spinal/ Back Problems	7 (13.2%)	2 (8%)	5 (17.9%)	1.12	.29
Diabetes	13 (24.5%)	7 (28%)	6 (21.4%)	.31	.58
High Blood Pressure	37 (69.8%)	18 (72%)	19 (67.9%)	.11	.74
Other Cardiovascular	17 (32.1%)	8 (32%)	9 (32.1%)	.00	.99

Cancer	1 (1.9%)	1 (4%)	0	1.14	.29
Pulmonary	7 (13.2%)	4 (16%)	3 (10.7%)	.32	.70
Vision	17 (32.1%)	8 (32%)	9 (32.1%)	.00	.99
Heavy Alcohol Use	3 (5.7%)	1 (4%)	2 (7.1%)	.24	.62
Depression	21 (39.6%)	10 (40%)	11 (39.3%)	.00	.96
Anxiety	16 (30.2%)	6 (24%)	10 (35.7%)	.86	.35
				2.31	.51
Living Arrangement, n (%)					
With Caregiver	24 (45.3%)	13 (52%)	11 (39.3%)		
In Own Home, Alone	13 (24.5%)	6 (24%)	7 (25%0		
In own Home, with other	13 (24.5%)	4 (16%)	9 (32.1%)		
With Another Relative	3 (5.7%)	2 (8%)	1 (3.6%)		
Care Recipient Dementia Subtype, n (%)				4.99	.41
Don't Know	20 (37.7%)	7 (28%)	13 (46.4%)		
Alzheimer's Disease	25 (47.2%)	14 (56%)	11 (39.3%)		
Vascular	5 (9.4%)	3 (12%)	2 (7.1%)		
Lewey Body	2 (3.8%)	1 (4%)	1 (3.6%)		
Parkinson's Disease	1 (1.9%)	0	1 (3.6%)		

* = $p < .05$.

Table 3

Pre-intervention Comparison between Conditions on Primary Outcome Variables

Variable	Didactic (n = 25)	Narrative (n = 28)	<i>F</i>	<i>P</i> Value	Cohen's <i>d</i>
Hassles: Information Seeking Subscale (<i>M, SD</i>)	13.04 (9.80)	10.25 (7.53)	1.70	.98	.32
Hassles: Scheduling Logistics Subscale (<i>M, SD</i>)	11.00 (8.22)	9.21 (7.31)	.56	.48	.23
Hassles: Safety Subscale (<i>M, SD</i>)	7.36 (6.42)	4.68 (3.94)	8.24	.01*	.51
Hassles: Polypharmacy Subscale (<i>M, SD</i>)	6.04 (4.30)	3.43 (2.91)	4.85	.03*	.72
Hassles: Total (<i>M, SD</i>)	37.40 (26.21)	27.57 (17.76)	6.75	.01*	.44
Self-Efficacy for Controlling Upsetting Thoughts: Total (<i>M, SD</i>)	61.37 (26.25)	63.23 (33.76)	3.32	.074	.06
Morisky Medication Adherence (<i>M, SD</i>)	2.80 (1.58)	2.14 (1.60)	.01	.92	.42
Stanford Patient Communication (<i>M, SD</i>)	3.54 (.95)	2.96 (1.31)	1.74	.19	.51

* = $p < .05$.

Analysis of Participant Dropout. Individuals who did not complete the post-intervention assessment ($n = 2$), those who never logged into the intervention website ($n = 11$), and those who did not log in and did not complete the second assessment ($n = 5$), were considered treatment non-completers (Table 4). Of the total participants randomized to the control didactic condition ($n=25$), 72% ($n = 17$) were categorized as treatment completers using the aforementioned criteria. A total of 61% ($n = 18$) of all participants randomized to the experimental narrative vignette condition ($n = 28$), were considered to be treatment completers. No significant differences in dropout rates emerged between the didactic and narrative vignette conditions $\chi^2(1, N = 53) = 0.75, p = .38$.

Using independent sample t-tests and Chi Square tests of independence, treatment completers and treatment non-completers, were compared on several demographic variables and primary outcome measures (Table 5). Several significant differences arose. Participants who dropped out of treatment were caring for individuals who were less impaired than those who completed treatment, as shown by caregiver reported CDR scores ($p < .001$; Completers $M = 1.59, SD = .90$; Non-Completers $M = 1.19, SD = .46$), and caregiver reported ADL scores ($p = .05$; Completers $M = 2.68, SD = 2.58$; Non-Completers $M = 3.67, SD = 2.14$). Participants who dropped out of treatment were reporting poorer medication management adherence than caregivers who completed the intervention ($p = .02$; Completers $M = 2.40, SD = 1.38$; Non-Completers $M = 2.56, SD = 2.03$). Those who dropped out of treatment were also reporting higher overall level of medication related hassles ($p = .04$; Completers $M = 31.54, SD = 24.31$; Non-Completers $M = 33.56, SD = 18.99$). Specifically, treatment non-completers endorsed more difficulty on the hassle subscale associated with polypharmacy than treatment completers ($p < .001$; Completers $M = 4.62, SD = 4.31$; Non-Completers $M = 4.72, SD = 2.74$). There were no

additional differences between treatment completers and non-completers on other demographic variables, such as caregiver age, level of education, mental health symptomatology, level of care provided, total years providing care, ethnicity, income, employment status or complexity of the medication regimen they managed. There were no other differences between treatment completers and non-completers on primary outcome variables, including self-efficacy for controlling upsetting thoughts or patient provider communication. To visually review this description of participant flow through the study, see Figure 1 below.

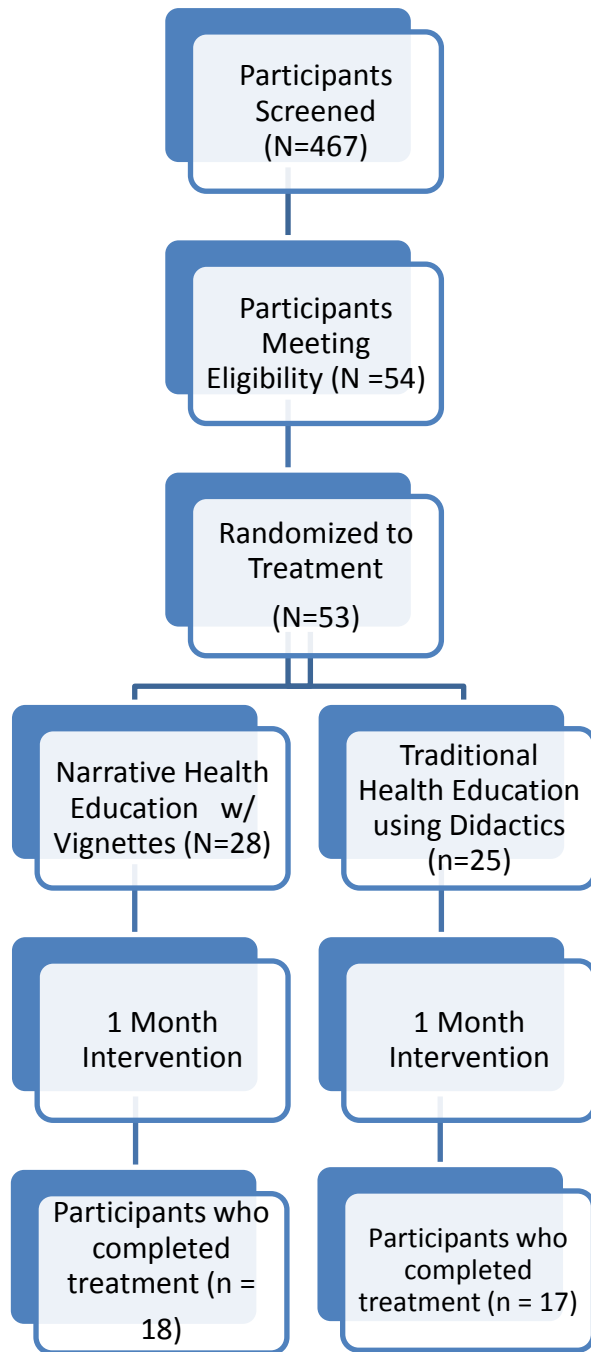


Figure 1. Flow of Participants through the Intervention

Table 4

Frequency Table of Participant Dropout by Type of Non-Completer Status

	Participants who Entered Website	Participants who Did not Enter Website
Participants who Completed Post-assessment	35	11
Participants who did not Complete Post-assessment	2	5

Table 5

Pre-intervention Comparison of Treatment Completers and Treatment Non-Completers

Variable	Treatment Completers (n = 35)	Treatment Non-Completers (n = 18)	F or χ^2	P Value
Caregiver Age (<i>M, SD</i>)	53.49 (9.53)	53.33 (10.80)	.06	.81
Caregiver Years of Education (<i>M, SD</i>)	16.14 (2.61)	15.78 (2.13)	.10	.75
Caregiver DASS 21 score (<i>M, SD</i>)				
Depression	4.37 (4.47)	5.78 (3.70)	.00	.99
Anxiety	2.49 (3.01)	3.56 (3.48)	.57	.45
Stress	6.51 (4.33)	8.67 (5.02)	.99	.32
Total Time as Caregiver in years (<i>M, SD</i>)	3.69 (2.29)	3.13 (2.66)	.05	.82
Percent of Total Care Provided by Caregiver (<i>M, SD</i>)	72.43 (30.04)	72.00 (27.76)	.54	.67
Caregiver Hassles: Information Seeking Subscale (<i>M, SD</i>)	11.06 (8.88)	12.56 (8.49)	.71	.40
Caregiver Hassles: Scheduling Logistics Subscale (<i>M, SD</i>)	9.97 (8.07)	10.22 (7.25)	1.80	.19
Caregiver Hassles: Safety Subscale (<i>M, SD</i>)	5.89 (5.62)	6.06 (5.03)	.83	.37
Caregiver Hassles: Polypharmacy Subscale (<i>M, SD</i>)	4.62 (4.31)	4.72 (2.74)	10.10	.00**
Caregiver Hassles: Total (<i>M, SD</i>)	31.54 (24.31)	33.56 (18.99)	4.27	.04*
Self-Efficacy for Controlling Upsetting Thoughts: Total (<i>M, SD</i>)	61.72 (30.78)	63.69 (29.80)	.12	.73
Caregiver Morisky Medication Adherence (<i>M, SD</i>)	2.40 (1.38)	2.56 (2.03)	5.80	.02*

Care-recipient HBLQ Score (<i>M, SD</i>)	4.11 (1.23)	3.39 (1.50)	2.31	.14
Care-Recipient CDR score (<i>M, SD</i>)	1.59 (.90)	1.19 (.46)	18.51	.00**
Care-Recipient IADL score (<i>M, SD</i>)	.94 (1.28)	1.28 (1.67)	1.09	.30
Care- Recipient ADL score (<i>M, SD</i>)	2.68 (2.58)	3.67 (2.14)	4.04	.05*
Caregiver Ethnicity, n (%)			1.17	.76
Caucasian	25 (71.43%)	15 (83.33%)		
African American	6 (17.14%)	2 (11.11%)		
Latina	1 (2.85%)	0		
Multiracial	3 (8.58%)	1 (5.56%)		
Relationship to Care Recipient n %			4.62	.33
Daughter	32 (91.43%)	15 (83.33%)		
Granddaughter	1 (2.86%)	2 (11.11%)		
Aunt/ Uncle	0	1 (5.55%)		
Close Friend	2 (5.71%)	0		
Caregiver Income, n (%)			9.71	.46
Less than \$5000	0	0		
\$5,000 - \$9,999	0	0		
\$10,000 - \$14,999	1 (2.86%)	2 (11.11%)		
\$15,000 - \$19,999	1 (2.86%)	2 (11.11%)		
\$20,000 - \$20,999	4 (11.43%)	0		
\$30,000 - \$39,999	5 (14.28%)	3 (16.67%)		
\$40,000 - \$49,000	4 (11.43%)	2 (11.11%)		
\$50,000 - \$59,000	4 (11.43%)	1 (5.56%)		
\$60,000 - \$69,999	4 (11.43%)	0		
Over \$70,000	12 (34.28%)	8 (44.44%)		
Caregiver Employment Status, n (%)			6.01	.11
Retired	5 (14.29%)	5 (27.78%)		
Working Full Time	18 (51.43%)	7 (38.89%)		
Working Part Time	2 (5.71%)	4 (22.22%)		
Unemployed	10 (28.57%)	2 (11.11%)		

* = $p < .05$, ** = $p < .001$

Procedures

Women who responded to advertised information about the project, or who directly obtained the screening assessment link through the aforementioned sources, were directed to an online screener. Before completing the online screening assessment, participants were asked to provide informed consent for the study. The consent form emphasized participation as voluntary and explained that participation could be withdrawn at any time without prejudice to the person or the care recipient. Participants were offered a \$25 gift card for each of their 2 completed online assessments (intake and post-intervention). This project was reviewed by the University of Missouri-St. Louis IRB, with approval given before initiating data collection.

Those who met study criteria and provide informed consent for the study, and who agreed to be enrolled in the intervention, were then sent an email containing the link to complete the pre-intervention assessment, and were entered into a study tracking log to monitor completion dates for assessments and timeline for further contacts. In order to reduce survey fatigue, the initial assessment was broken into four smaller surveys so that participants could complete them across multiple sittings. Participants were given one week to complete these surveys, after which they were sent a reminder email to finish the pre-intervention assessment. Average time to complete the pre-assessment was one week, with zero reminders.

After completion of the pre-intervention assessment, participants were randomly assigned to one of the two treatment conditions, the narrative vignette treatment program or the comparison didactic condition. Block randomization occurred after the pre-intervention assessment as the present study was part of a larger experiment that included both dementia and non-dementia caregivers. Thus, in order to separate these types of caregiver into two groups, and evenly balance those in the control and experimental conditions, the project coordinator was

required to view care-recipient dementia status in the pre-assessment. Although random assignment was not blind to project coordinator, this individual was required to access only one of the four initial surveys in order to determine the care-recipient's dementia status. Of note, all intervention materials and contact points were pre-determined and thus there was not possibility of differing participant assignment based on project coordinator knowledge of intervention condition.

To ensure true random assignment, participants were given an ID number in ascending order as they entered the study. An online random number generator was used to evenly divide ID numbers into two groups (narrative and didactic) before the study began. A lab member, unaffiliated with the project, placed the randomly assigned condition type into sealed envelopes with the ID number on the front. Once an individual was determined to be in the dementia group, the envelope with the correct participant number in the group was opened, and the individual was placed in the condition identified inside the envelope.

Once randomized by condition, individuals were sent "Email 1," which contained instructions for using the website as well as a login ID and password. On a weekly schedule, thereafter, participants were given access to new website materials via internal website stepped programming. Using this same weekly schedule, participants were emailed and notified that their access level had been increased, and that they could view more materials. After four total weeks viewing materials, participants were sent the link to the online post-intervention assessment. Once again, to reduce fatigue, these interventions were broken into four smaller pieces. All email contacts throughout the study were standardized – they were identical between groups, with the exception of brief details provided about the intervention in "Email 2" (e.g. describing

what participants would see when they entered the website). See Appendix A to review of the email contact and website access timelines.

In order to ensure the quality of online data collected, steps were taken to guarantee that participants were providing thoughtful responses. The length of time a participant took to fill out each assessment was measured and compared to median response times of other participants as well as time taken by pilot participants and project research assistants, to complete the measures. Those who completed the surveys in significantly less time than other participants would not be included in data-analysis in order to protect the quality of data. The average time it took participants to complete the pre-assessment and post-assessment was approximately 60 minutes and 45 minutes, respectively. The average time it took pilot participants and project research assistants to complete the pre-assessment and post-assessment, was 40 minutes and 30 minutes, respectively. No participants took less than 30 minutes to complete the pre or post-intervention assessment, and thus, no participants were excluded based on this quality management, time-based criteria.

Experimental Conditions

Four health education areas, described in detail below, were developed to address specific caregiving concerns related to managing medications for an older adult. All four content areas were included in both treatment conditions. Throughout this study, both groups viewed the same online interface – a website entry page with four clickable content areas. During the four weeks of their participation, all participants were sent weekly emails to notify them that their access level to the website had been increased. Each participant was assigned a week 1, week 2, week 3 and week 4 pre-programmed access level, that was increased by the project coordinator at the start of that week. So, with each passing week in the intervention study, information was

added, but never taken away.

Although the two interventions were identical in the type of information and suggestions provided, they varied significantly in the presentation of the material. In both groups, week 1-4 access levels contained identical didactic handouts across condition, but additional narrative video vignettes were only included in the experimental narrative vignette treatment. All participants were free to choose which branches to view and how much time to spend with the material throughout the intervention period.

Comparison didactic group. Participants entering the comparison didactic condition website first encountered a still screen shot with four clickable content areas. When participants entered any content area, they saw another screen containing one column. This column was titled “resources” and contained PDF didactic handouts with information about that content area, and a single video of an “expert” (pharmacist, nurse, psychologist or social worker) providing brief supplementary information. All material available for a given week appeared as white clickable links; materials that were to become available in following weeks were grey and visible but not yet clickable as a link. Materials from previous weeks remained available as participants progressed through the intervention.

Narrative vignette condition. Participants entering the experimental condition’s website also encountered a still screen shot with four clickable content areas. In the center of the page, they saw a clickable section titled “introduction.” Upon clicking the introduction link, a video appeared, introducing the main narrator of the video vignettes. This actor also briefly described the types of information that one would expect to see in the coming weeks. When participants entered any content area, they saw another screen containing two columns. As with the comparison condition, one column was titled “resources” and contained PDF didactic handouts

with information about that content area, and a single video of an “expert” (pharmacist, nurse, psychologist or social worker) providing brief supplementary information.

The narrative vignette condition also included a second column, not present in the control condition, titled “Story.” This column included brief video episodes, each less than four minutes in length, showing ethnically diverse care dyads encountering various medication related challenges as the weeks progressed. Caregivers were directed to the PDF handouts to review methods for solving the concerns faced by dyads in the videos. A new episode and a new set of handouts were available to the caregivers each week. Basic medication management information and suggestions were interspersed throughout these video narratives; the vignettes were designed for “real life” relevance to caregiving experiences. The episodes began by demonstrating problem solving in “easy” scenarios and progressed in a graduated manner to more difficult problem solving scenarios, as is suggested by Bandura’s framework for building self-efficacy. All content in these videos was taken directly from content in the PDF handouts available in both conditions. The material available for a given week appeared as white clickable links; materials that were to become available in following weeks were grey and visible but not yet clickable as a link. Materials from previous weeks remained available as participants progressed through the intervention. See Appendix B for a summary of resources available in each content area, over time.

Health Education Content Areas across Conditions

Managing medications. This content area included a discussion of adverse events linked to medications (e.g., falls, delirium, nursing home placement, negative health outcomes), and provided information about the most effective ways to manage scheduling of doses and refills. This module also included psychoeducation about the role a pharmacist can play in

medication management problem solving, as well as a list of basic and advanced questions that can be used to help improve medication management and organizational skills. The module provided further information about the benefits of assessing interaction effects of over-the-counter medications with prescriptions that the care-recipient already takes; pharmacy staff consultation was highly encouraged.

Talking together. This content area focused on developing communication skills between the caregiver and care-recipient. Caregivers were given instruction on how to use basic communication strategies such as eye contact, tone, and “I” language in everyday medication management interactions. This content area also provided examples of medication-related conflict between the caregiver and care recipient, and provided suggestions for effective communication strategies when negotiating these disagreements. In addition, caregivers were encouraged to use these communication skills to think about the future with their older loved one, and were given resources on housing, financial planning, driving and healthcare plans as they may relate to an older loved one’s physical health conditions. This module also addressed legal and HIPAA requirements for full communication between family members and healthcare professionals.

Signs of confusion. Given that caregivers of persons with thinking problems may not know the strengths and weaknesses of their loved one’s thinking abilities, as they pertain to medication management, this content area provided participants with information about the signs and symptoms of delirium and dementia, as well as ways to distinguish the two. Caregivers were given information about the high rates of undiagnosed delirium and dementia in community dwelling older adults and the benefits of medical evaluation and diagnosis. Further information was presented about the process for obtaining a diagnosis for a progressively dementing

neurocognitive illness, including material about brief cognitive screens and neuropsychological testing, as well as the domains of thinking measured in these evaluations.

Healthcare visits. This content area provided caregivers with information about how to prepare for healthcare visits that they attend with their loved one. Caregivers were given a list of example questions they could ask the medical providers about current medications, newly prescribed medications, over the counter medications, and side-effects. This module also addresses legal and HIPAA barriers to full communication between family members and healthcare professionals. The content area explained the need for signed releases on file in the patient's chart to allow these conversations and provided an example of a nationally-available form for durable power of attorney for healthcare (*Five Wishes*).

Measures

At intake and post intervention (four weeks later), caregivers completed the following assessments. All measures were present at both time points, with the exception of the demographic questions, which were only assessed at pre-intervention, and self-reported satisfaction with the intervention, which was only assessed in the post-intervention assessment.

Primary outcome measures.

User Satisfaction regarding the Use of the Computer Program Questionnaire (USUCPQ). This User Satisfaction Questionnaire (Ponpaipan et al., 2010) is an 8-item measure that assess user satisfaction with online health-based interventions. This measure is based on a 7-point Likert scale (0 = Very Unsatisfied, 7 = Very Satisfied), with higher scores indicating greater levels of satisfaction. The original scale was first utilized in a population of middle aged Taiwanese caregivers, to explore their satisfaction with an online study to promote increased exercise and healthful eating among their older loved ones. Although this original study reported

good distribution in the data ($N = 26$ caregivers), no further psychometrics were reported. This scale was selected due to its similarity in user population and function in assessing caregiver satisfaction with an online health based intervention. The measure explored the following domains of caregiver satisfaction regarding the intervention a) convenience b) entertainment c) how interesting the content was d) speed of the modules e) usefulness f) practicality g) tolerability and h) how much information was presented. There are no subscales for this measure, rather a maximum of 56 points can be obtained, creating a total satisfaction score. This 8-item scale demonstrated excellent internal consistency in the current study ($\alpha = .96$). Results revealed that the USUCPQ was kurtotic and slightly negatively skewed (Table 6). One univariate outlier was identified on this measure, within the experimental treatment condition ($z > 3.29$). This individual was not removed from analyses due to the small sample size. Instead, mean value substitution was utilized to replace the individual's satisfaction score. No transformation was completed to allow for greater interpretability of the main analyses.

The Family Caregiver Medication Administration Hassles Scale. This measure consists of 24 items that reflect concerns over keeping prescription medications filled, scheduling logistics, safety issues, and information seeking (Travis et al., 2003). Higher scores on this measure indicate greater levels of perceived hassle. It is a self-reported instrument with four subscales. The first subscale, Information Seeking/ Information Sharing, is comprised of 9 items that describe education and communication based hassles. The second subscale, Scheduling and Logistics, contains 7 items and asks about medication management and administration hassles. The 5-item Safety Issues subscale asks about medication errors and adverse drug effects, while the 3-item Polypharmacy subscale measures hassles related to interactions with multiple prescribing providers and managing tasks related to multiple medications. Caregivers are

instructed to rate each of the items on a scale from 0 = “not a hassle” to 5 = “one of the worst of all hassles.” Scoring is completed by creating a total summed score of all items and total summed scores for the subscales. The overall reliability of this instrument in initial psychometric studies $\alpha = 0.95$, with subscale reliabilities of the following: Information Seeking/Information Sharing ($\alpha = .92$), Safety Issues ($\alpha = .83$), Scheduling Logistics ($\alpha = .90$), and Polypharmacy ($\alpha = .80$). Test retest reliability was .84. The overall reliability of this instrument was excellent in the current study ($\alpha = .97$), similar to the scale’s original findings. The hassle subscales had the following internal reliability scores: Information Seeking/Information Sharing ($\alpha = .92$), Safety Issues ($\alpha = .89$), Scheduling Logistics ($\alpha = .86$), and Polypharmacy ($\alpha = .83$). As seen in Table 6, the safety issues subscale was slightly positively skewed. All other subscales and totals were within normal limits for measures of normality. As such, no transformations were completed. There was no evidence of outliers on this measure.

Morisky Medication Adherence Scale. This is an 8-item self-report measure that describes the medication adherence patterns in a given individual. These items require “yes” or “no” self-reported responses, where a “yes” response is scored as a one, indicating a non-adherent behavior, and a no is scored as a zero, indicating good medication adherence. Higher scores on this measure, indicate poorer medication adherence. Individuals with summed scores of 0 fall in the “high adherence” range, those with a 1-2 fall in the “medium adherence” range and those who score greater than 2 fall in the “low adherence” range. This measure has been developed and evaluated for use with low-literacy patients, and has been reported as demonstrating high criterion validity with medication monitoring devices (Morisky et al., 2008). In the original literature, this measure demonstrates good internal reliability ($\alpha = .83$). In the

current study, this measure was modified such that the caregiver managing medications answer the questions about the care recipient's level of adherence. Present results show this measure was within the low range of acceptability for internal reliability ($\alpha = .60$). This measure demonstrated adequate response normality, with little kurtosis and skew (Table 6). No outliers were identified and no transformations of the data were completed for responses on this instrument.

Stanford Patient Communication with Physicians. This measure consists of 3 self-reported items that describe patient behaviors while speaking with a medical provider (Lorig et al., 1996). The instrument instructs patients to rate each of their behaviors on a 5-point Likert scale from 0 = never to 5 = always. A total score for this measure is obtained by computing the average of these three items. Higher scores indicate better patient-provider communication. The overall internal reliability of this instrument is 0.73, with test retest reliability at .89. This instrument demonstrated good internal consistency in the current study ($\alpha = .70$). As seen in Table 6, the measure was within normal limits for kurtosis and skew. As such, no transformations were completed. Similarly, there was no evidence of outliers on this measure, and no data points were removed.

Revised Scale for Caregiving Self-Efficacy: Self Efficacy for Controlling Upsetting Thoughts. The Revised Scale for Caregiving Self-Efficacy is a 5-item instrument that asks caregivers to report their overall confidence from 0% to 100% in successfully controlling upsetting thoughts related to their caregiving situations (Steffen et al., 2002). A 0% confidence indicates that they believed they could not do the specified task under any circumstances, 50% confidence indicates that if they gave it their best effort, chances are about 50-50 that they could perform the activity, and a 100% confidence indicates that they are certain they can perform the

given task. Upsetting thoughts include thinking about unpleasant aspects of the caregiving situation, viewing the caregiving situation as unfair, thinking about how much they have lost, thinking about how much they are missing/giving up, and worrying about future problems. Internal reliability for this measure is good ($\alpha = .80$) and test-retest reliability has been shown to be adequate ($r = .76$). The internal consistence of this measure, within the current study, was excellent ($\alpha = .96$). Skew and Kurtosis in this sample were within normal limits, indicating acceptable normality of the data. One multivariate outlier was identified within the experimental group; mean values of self-efficacy for controlling upsetting thoughts were substituted for this participant's responses, in order to maintain the highest possible sample size.

Covariate and demographic measures: Caregivers

Caregiver demographics. For descriptive purposes, caregivers provided information about their age, ethnicity, marital status, household income, level of education and employment outside of the home. They were also required to provide information about their relationship to the care recipient, the number of years they have been caregiving, the amount of the care recipient's total care that they personally provide, as well as the specific ways in which they help the older adult manage medications.

Depression Anxiety Stress Scale (DASS) – 21 item short form. The Depression Anxiety Stress Scale - 21, is a 21-item measure that asks participants to describe their current level of distress within the domains of depression, anxiety and stress (Lovibond & Lovibond, 1995). Responses are scored on a 4-point Likert scale where 0 = Never and 3 = Almost Always. Higher total scores in each domain, represent greater levels of subjective distress. The measure is broken into three domains of function, Depression, Anxiety and Stress, which each contain 7 items. Each subscale is calculated by summing the responses in that domain; cutoff score descriptions

within each field range from normal, to extremely severe, with total possible scores on each subscale ranging from 0-21. This scale has demonstrated good internal reliability; Depression $\alpha = .94$, Anxiety $\alpha = .87$ and Stress $\alpha = .91$. The DASS has also been shown to have good convergent validity with other measures of depression and anxiety (BAI and BDI), and is psychometrically sound across multiple populations both clinically and non-clinically based (Antony, Bielig, Cox, Enns, & Swinson, 1998; Lovibond & Lovibond, 1995). In the current study, the DASS-21 demonstrated good to excellent levels of internal consistency: Depression $\alpha = .92$, Anxiety $\alpha = .80$ and Stress $\alpha = .90$. Additionally, results revealed that the Depression Subscale of the DASS was slightly positively skewed and kurtotic, while the Stress scale was slightly positively kurtotic (Table 6). There was no evidence of outliers. No transformations were completed to allow for greater interpretability of the main analyses.

Intervention Dosage: Login Access. The intervention website included an administrative option that tracked the number of times an individual caregiver logged into the site using their unique login ID and password. Using the “Slimstats” function within the administrative access portion of the website, the total number of logins was found for each individual participant. Only those caregivers who had logged into the intervention website, a minimum of one time, were included in final analyses as treatment completers. Those who never logged into the intervention website were considered treatment non-completers.

Intervention Dosage: Didactic Resource Access. The intervention website also tracked whether or not an individual downloaded a handout or didactic video, how many times this occurred, and at what time. Each PDF handout and didactic video was reviewed for usage statistics and tied to an individual participant, using the “slimstats” function within the administrative access portion of the website. The total number of times an individual

downloaded each type of resource was summed. Thus, an individual could view a single PDF or didactic video multiple times, and each occurrence was counted as a discrete event for that resource. These viewing events were then summed within the four content areas to describe the number of resource downloads/ views within the domains of “Medication Management,” “Talking Together,” “Signs of Confusion, “ and “Healthcare Visits.”

Intervention Dosage: Narrative Video Access. Similar to the aforementioned usage measures, the intervention website tracked whether or not an individual in the experimental condition downloaded a narrative video, how many times this occurred, and when. Each narrative video was reviewed for usage statistics and tied to an individual participant, using the “Slimstats” function within the administrative access portion of the website. The total number of times an individual downloaded each type of video was summed. Each viewing occurrence was counted as a discrete event for that video resource. These viewing events were then summed within the four content areas to describe the number of episode views within the domains of “Medication Management,” “Talking Together,” “Signs of Confusion, “ and “Healthcare Visits.”

Covariate and demographic measures: Care recipients

Care recipient demographics. Caregivers were asked to provide several pieces of information about the older adult for whom they provide care. Caregivers described the care recipient’s current living arrangements, race/ethnicity, category of neurocognitive diagnosis and were asked to check boxes with medical diagnostic categories that matched the concerns of their care-recipient. Caregivers also reported the total number of prescription medications that their care-recipient was prescribed, as well as the total number of over-the-counter medications this individual utilized. Participants were not asked about the function of these medications, specific

names of the medications or dosages, in order to preserve care-recipient confidentiality for care-recipient protected health information.

HbLq Medication Risk Questionnaire. This 8- item measure is designed to assess medication regimen complexity as well as risk for adverse drug events in older adults (ADEs). Individuals are asked to report on various aspects of medication complexity and risk, by selecting a “yes” or “no” response for each of the 8 risk factors for an ADE. A “yes” response is coded as a one, while a “no” is coded as a zero. Item scores are summed to create an overall medication complexity and risk score, with higher numbers indicating greater risk. The scale contains questions regarding number of medications, number of prescribing physicians, number of medical problems and pharmacies (Levy, 2003). This scale demonstrates adequate internal consistency in original psychometrics studies ($\alpha = .69$), with high test-retest reliability ($\kappa > 0.6$). The current study demonstrates similar levels of internal consistence ($\alpha = .70$) and is normally distributed with minimal kurtosis and skew (Table 6). No outliers were identified and no transformations were made based on the already normally distributed nature of the data.

Analogue Clinical Dementia Rating Scale (CDR). This measure was originally developed as a structured clinical interview. The analogue CDR is scored on a five-point scale that is meant to describe individuals without neurocognitive concerns (0) and with questionable (0.5), mild (1), moderate (2), and severe (3) neurocognitive difficulties. The overall CDR score is determined by a complex algorithm that takes into account items in six domains of functioning: memory, orientation, judgment and problem solving, involvement in community affairs, involvement at home and in hobbies, and personal care. In its original format, clinicians score each domain of functioning, and are instructed to score each functional domain independently from the others. Original levels of inter-rater reliability for this measure were high, with all

domains ranging from .75 - .94. This scale was modified for the current study: all items were given with the exact same instructions, but the caregivers were asked to rate their own perceptions of the care-recipient's level of impairment. Internal reliability of the measure administered in this new format for the current study, was excellent ($\alpha = .93$). Responses on this measure demonstrated a normal distribution with minimal kurtosis and skew (Table 6). No outliers were identified. As such, no transformations were made to the data and no data points were removed.

Activities of Daily Living Form. Caregivers were asked to report on the current functional deficits of the identified family member, using the Katz Activities of Daily Living Form (ADL; Katz et al., 1963). This questionnaire asks caregivers whether care-recipients are able to independently bathe, eat, toilette etc. Scores on this measure range from 0 to 6 with 0 being the highest level of impairment in ADLs (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963). This instrument was originally designed to be rated by a healthcare professionals but has since been shown to be reliable ($\alpha = .78-.94$) and valid when completed by family caregivers (Sikkes, et al., 2010). This measure demonstrated excellent internal reliability in the current study ($\alpha = .91$), but was negatively skewed (Table 6). No outliers were identified and to maintain interpretability of the results, no transformations of the data were completed.

Independent Activities of Daily Living. Caregivers were asked to report on their care-recipient's ability to perform independent activities of daily living as measured by the Independent Activities of Daily Living Scale (IADL; Lawton, Moss, Fulcomer & Kleban, 1982). This is a 31 item measure which assesses 8 domains of functioning: Ability to use the telephone, shopping, food preparation, housekeeping, laundering, obtaining transportation, responsibility for own medications and finances. Scores on this measure range from 0 to 8, with a score of 0

indicating the greatest level of impairment. This instrument was originally designed to be rated by a healthcare professionals but has since been shown to be reliable ($\alpha = .78-.90$) and valid when completed by family caregivers (Sikkes, et al., 2010). This measure demonstrated acceptable levels of internal reliability in the current study ($\alpha = .64$), but was positively skewed and kurtotic (Table 6). No outliers were identified and to maintain interpretability of the results, no transformations of the data were completed.

Table 6

Psychometric Properties of Study Variables (n = 35 User Satisfaction; N = 53 other Variables)

Variable	Mean	SD	Range	SE of Skew	Skew	SE of Kurtosis	Kurtosis	alpha
User Satisfaction	43.97	9.50	8-56	.40	-1.80	.78	4.90	.96
Medication Administration Hassles Subscale:								
Information Seeking Subscale:								
Safety Issues Subscale:								
Scheduling Logistics Subscale:								
Polypharmacy	4.66	3.83	0-13	.33	.67	.64	-.86	.83
Morisky Medication Adherence Scale	2.45	1.61	0-7	.33	.65	.64	-.06	.60
Stanford Patient Communication Scale	3.24	1.81	0-5	.33	-.73	.64	.50	.70
Self-Efficacy For Controlling Upsetting Thoughts	62.35	30.18	0-100	.33	-.49	.64	-.95	.96
DASS: Depression	4.85	4.25	0-21	.33	1.32	.64	2.67	.92
DASS: Anxiety	2.89	3.12	0-11	.33	.99	.64	-.01	.80
DASS: Stress	7.24	4.64	0-21	.33	.98	.64	1.13	.90
Medication Risk HBLQ	3.87	.19	1-7	.33	-.13	.64	-.41	.70
Clinical Dementia Rating Scale	1.45	.80	.5-3	.33	.75	.64	-.58	.93
Activities of Daily Living	3.02	3.47	0-6	.33	.01	.64	-.70	.91
Independent Activities of Daily Living	1.06	1.41	0-6	.33	1.74	.64	2.80	.64

Data Analytic Strategy

Independent sample t-tests were used to evaluate between group differences in satisfaction with each treatment strategy, post-intervention. A repeated measure MANOVA assessed Condition * Time effects and the main effect of time on participant self-reported hassles. Similarly, repeated measure ANOVA analyses assessed Condition * Time effects and the main effect of time for the following dependent variables; patient-provider communication, medication adherence and self-efficacy for controlling upsetting thoughts.

In order to achieve power of 0.80 for the primary analyses, at an alpha of .05, with a large effect size ($d = .80$), a minimum of 26 participants were required at pre and post-intervention, in each treatment group (Cohen, 1992). Thus, of the initially planned data analyses, the largest sample size necessary was $N = 52$. This study is considered underpowered for testing mean differences in scores ($N = 35$), due to attrition of the initially enrolled 53 participants. Because the analyses were not modified to accommodate this small sample size, Cohen's d and η_p^2 were utilized in unison with p values to assess for statistical significant differences between groups scores. Further, p value corrections for type one error were not utilized due to the underpowered nature of this study.

No missing values were present in this data set. All responses to primary measures in the pre-assessment and post-assessment were marked in the survey software as "required" items, due to the anticipated difficulty in obtaining participants who qualified for the study, as well as the potential dropout. As described above, all data were screened for high quality of responses. No participants were removed due to low response quality, as all individuals fell within the estimated highest on lowest time range of assessment completion. All data was checked for

normality; no transformations were completed in order to allow for ease of interpretability. Independent sample t-tests and chi square analyses were completed to assess for pre-treatment equivalence, as described above. The narrative vignette and comparison didactic group were approximately equivalent on all initially gathered demographic variables, but the comparison didactic group began the intervention reporting a greater level of medication administration hassles. In instances where outliers were identified, mean value substitution was utilized to replace outlying values. Mean insertion based upon outlier data was infrequent and occurred in less than 3% of cases.

Intervention Website Usage

In order to describe website usage patterns, resource access statistics were downloaded and sorted by type of resource viewed (i.e. content area of resource) and the format of the resource viewed (narrative video or didactic resource). Each participant's resource usage was coded using the cumulative number of views for each individual didactic video and narrative resource, as opposed to a binary "viewed" or "not viewed" system. All participants who logged into the intervention website, including those who did not complete assessment time point two, were included in website usage analyses (control $n = 19$; experimental $n = 18$).

As shown in Table 7, when compared across treatment conditions, didactic comparison group caregivers and narrative vignette caregivers, viewed approximately equivalent numbers of didactic resources in the following intervention topic areas: "Medication Management," "Talking Together," and "Causes of Confusion." Caregivers in the narrative vignette group viewed a greater number of PDF and expert video resources within the "Healthcare Visits" content area than did comparison didactic group participants (didactic $M = 1.84$, $SD = .2.17$; narrative vignette $M = 2.39$, $SD = 2.68$; $p = .04$; Cohen's $d = .23$). A trend arose, but did not reach

significance, when comparing the total number of PDF and didactic video resources viewed between comparison didactic and narrative vignette group participants; narrative group participants showed a non-significant trend toward viewing a greater total number of didactic resources than the comparison didactic group (didactic $M = 12.05$, $SD = 10.60$; narrative $M = 14.22$, $SD = 13.21$; $p = .07$; Cohen's $d = .19$). As described above, the PDF and expert video didactics were available in both conditions. When caregivers were compared by treatment condition on their total usage of all resources, including both didactic resources and narrative video episodes (only available to the experimental group), caregivers in the experimental condition showed a greater number of total views for all website resources (didactic $M = 12.31$, $SD = 10.99$; narrative $M = 27.00$, $SD = 23.64$; $p < .001$; Cohen's $d = .83$.)

Caregiver narrative video usage was also examined for descriptive purposes. As reported in Table 8, participants in the narrative vignette condition showed the highest number of narrative video views in the "medication management" content area ($M = 3.44$, $SD = 3.20$), followed by "Talking Together" ($M = 2.89$, $SD = 2.87$), "Causes of Confusion" ($M = 2.67$; $SD = 2.81$) and "Healthcare Visits" ($M = 2.39$, $SD = 2.59$).

Table 7

Number of Didactic Resource Views (PDF + Didactic Video) and Total Resources Viewed (PDF + Didactic Videos + Narrative Videos) per Content Area, across Conditions

Variable	Didactic (n = 19)	Narrative (n = 18)	F	P Value	Cohen's d
Number of Didactic Resource views; "Medication Management" (<i>M</i> , <i>SD</i>)	3.00 (3.53)	4.39 (4.31)	.44	.51	.36
Number of Didactic Resource Views; "Talking Together" (<i>M</i> , <i>SD</i>)	3.00 (2.92)	3.22 (3.51)	2.32	.14	.07
Number of Didactic Resource Views "Causes of Confusion" (<i>M</i> , <i>SD</i>)	4.21 (3.43)	4.22 (3.69)	1.24	.27	0.0
Number of Didactic Resource Views; "Healthcare Visits" (<i>M</i> , <i>SD</i>)	1.84 (2.17)	2.39 (2.68)	4.78	.04*	.23
Total Didactic Resources Viewed (<i>M</i> , <i>SD</i>)	12.05 (10.60)	14.22 (13.21)	3.61	.07	.19
Total number of All Resources Viewed, Any Type (<i>M</i> , <i>SD</i>)	12.31 (10.99)	27.00 (23.64)	17.46	.00**	.83

* = $p < .05$., ** = $p < .001$

Table 8

Description of Total Narrative Episode Viewing Incidents per Content Area

Content Area	M	SD
“Medication Management”	3.44	3.20
“Talking Together”	2.89	2.87
“Causes of Confusion”	2.67	2.81
“Healthcare Visits”	2.39	2.59

Results

Primary Outcomes

Hypothesis one. Independent samples t-tests were used to test the hypothesis that participants in the narrative vignette condition would report higher levels of satisfaction with the intervention than participants in the comparison didactic group. As seen in Table 9, analyses revealed that there were no significant differences between the narrative vignette and comparison didactic condition on total intervention satisfaction scores (Control $M = 45.33$, $SD = 7.81$; Experimental $M = 44.68$, $SD = 6.75$; $p = .46$, Observed power = .08). Similarly, no significant differences were found between groups on satisfaction levels with the intervention's level of convenience, level of interest it provoked, pace, tolerability or amount of information that was presented. Although non-significant, a trend emerged with narrative group participants reporting slightly higher levels of satisfaction with the intervention entertainment value (Control $M = 5.11$, $SD = 1.28$; Experimental $M = 5.19$, $SD = 1.09$; $p = .15$, Observed power = .08)

Table 9

Comparison of Participant Intervention Satisfaction across Treatment Conditions

Variable	Didactic (n = 18)	Narrative (n = 17)	F	P Value	Cohen's d	Power
Satisfaction Total (<i>M</i> , <i>SD</i>)	45.33 (7.81)	44.68 (6.75)	.56	.46	.09	.08
Satisfaction: Convenience (<i>M</i> , <i>SD</i>)	5.94 (1.11)	5.75 (1.00)	.23	.63	.18	.13
Satisfaction: Entertainment (<i>M</i> , <i>SD</i>)	5.11 (1.28)	5.19 (1.09)	2.17	.15	.07	.08
Satisfaction: Interesting (<i>M</i> , <i>SD</i>)	5.50 (1.15)	5.75 (.93)	1.24	.28	.24	.17
Satisfaction: Fast (<i>M</i> , <i>SD</i>)	5.71 (1.07)	5.63 (1.09)	.02	.89	.07	.08
Satisfaction: Useful (<i>M</i> , <i>SD</i>)	5.67 (1.24)	5.50 (1.10)	.31	.58	.15	.11
Satisfaction: Practical (<i>M</i> , <i>SD</i>)	5.94 (.94)	5.56 (1.10)	.86	.36	.37	.28
Satisfaction: Tolerable (<i>M</i> , <i>SD</i>)	5.72 (.90)	5.60 (1.03)	1.25	.27	.12	.10
Satisfaction: Information (<i>M</i> , <i>SD</i>)	5.72 (1.45)	5.75 (1.00)	1.51	.23	.02	.06

* = $p < .05$.

Hypothesis two. A repeated measures two-group, Time * Condition MANOVA, was used to test the hypothesis that narrative vignette group participants would report greater decreases in medication management hassles than participants in the comparison didactic condition from pre-treatment to post-treatment (for variable means see Table 10). Results indicate that the composite dependent variable, comprised of the change in four hassles subscales from pre-treatment to post-treatment, was not significantly affected by treatment condition $F(4, 30) = 1.63, p = .19, \eta_p^2 = .18$, achieved power = .44 (Table 11). Intervention dosage, as measured by total number of discrete didactic and narrative resource viewing events, was examined as a covariate in this model, but was not retained. Univariate analyses found non-significant results across tested subscales associated with small portions of the variance in change: Hassles of Information Seeking $F(1, 33) = .08, p = .78, \eta_p^2 = .00$, Observed Power = .06; Hassles of Scheduling $F(1, 33) = 1.25, p = .27, \eta_p^2 = .04$, Observed power = .19; Hassles of Safety $F(1, 33) = .01, p = .93, \eta_p^2 = .00$, Observed power = .05; Hassles of Polypharmacy $F(1, 33) = .3.66, p = .07, \eta_p^2 = .11$, Observed Power = .46. Similarly, this analysis revealed a non-significant main effect of time on caregiver reported medication administration hassles $F(4, 30) = .89, p = .48, \eta_p^2 = .11$, achieved power = .25 (Table 11). Based on these results, hypothesis two was not supported.

Hypothesis three. A repeated measures two-group, Time * Condition ANOVA, was used to test the hypothesis that narrative vignette group participants would report a greater increase in positive patient – provider communication behaviors, than participants in the comparison didactic condition from pre-treatment to post-treatment. Results showed that caregiver communication behaviors, from pre-treatment to post-treatment, were not significantly

affected by treatment condition $F(1, 33) = 2.74, p = .11, \eta_p^2 = .08$, Achieved power = .36 (Table 11). Based on initial group differences, the total medication administration hassles score was examined for inclusion in this model as a covariate, but was not retained as a significant covariate in the model. Similarly, intervention dosage, as measured by total number of discrete didactic and narrative resource viewing events, was examined as a covariate in this model, but not retained. This analysis also revealed a non-significant main effect of time on patient-provider communication $F(1, 33) = .22, p = .65, \eta_p^2 = .01$, Achieved power = .07 (Table 11). Overall, there was no evidence to suggest that caregiver communication behavior was impacted differently by treatment condition over time. Thus, hypothesis three was not supported.

Hypothesis four. A repeated measures two-group, Time * Condition ANOVA was used to test the hypothesis that narrative vignette group participants would report a greater improvement in medication adherence behaviors related to the care-recipients regimen, than participants in the comparison didactic condition from pre-treatment to post-treatment. Results showed that medication non-adherence, from pre-treatment to post-treatment, was not significantly affected by treatment condition $F(1, 33) = 2.83, p = .10, \eta_p^2 = .08$, Achieved power = .37 (Table 11). Based on initial group differences, pre-treatment total hassles score was examined for inclusion in this model as a covariate, but was not retained as significant. Similarly, intervention dosage, as measured by total number of discrete didactic and narrative resource viewing events, was examined as a covariate in this model, but was not retained. Overall, there was no evidence to suggest that caregiver adherence to prescribed regimens was impacted differently by treatment condition over time. This analysis also revealed a non-significant main effect of time on caregiver medication management $F(1, 33) = .96, p = .34, \eta_p^2 = .03$, Achieved power = .16 (Table 11). As a result, hypothesis four was not supported.

Hypothesis five. A repeated measures two-group, Time *Condition ANOVA was used to test the hypothesis that experimental treatment condition participants would report a greater increase in self-efficacy for controlling upsetting thoughts about the caregiving situation, than participants in the control didactic condition from pre-treatment to post-treatment. Results showed that self-efficacy for controlling upsetting thoughts, from pre-treatment to post-treatment, was not significantly affected by treatment condition $F(1, 33) = .09, p = .76, \eta_p^2 = .00$, Achieved power = .06. Based on initial group differences, the total pre-treatment medication administration hassles score was examined for inclusion in this model as a covariate, but was not retained, due to non-significance. Similarly, intervention dosage, as measured by total number of discrete didactic and narrative resource viewing events, was examined as a covariate in this model, but was not retained. This analysis did, however, reveal a significant main effect of time on caregiver self-efficacy for controlling upsetting thoughts about the caregiving situation $F(1, 33) = 8.07, p < .001, \eta_p^2 = .20$, Achieved power = .79. Examination of pre/post-treatment means and standard deviations reveal this change occurred in the direction of improved self-efficacy for controlling upsetting thoughts over time.

Hypothesis five exploratory analyses. Due to the apparent increase in self-efficacy for controlling upsetting thoughts in both groups, over time, exploratory analyses were used to assess the significance of these within group changes, and to determine whether one or both groups was driving the significant result. Paired sample t-tests were computed to determine if there was a change in Self-Efficacy for Controlling Upsetting thoughts within comparison didactic group participants from pre-treatment to post treatment (Table 12). Results indicate that the overall caregiver self-efficacy for controlling upsetting thoughts score did not change significantly within the didactic group between pre-treatment and post-treatment. Although

participants in the comparison didactic condition show marginal increases in total levels of Self-efficacy for controlling upsetting thoughts, as well as individual areas of self-efficacy (i.e., controlling thoughts about unpleasant aspects of care, fairness, their previous life, things they have given up and worries about the future), these changes did not reach statistical significance.

Similarly, paired sample t-test were used to compare narrative vignette group participants on self-efficacy for controlling upsetting thoughts at pre-treatment and post-treatment (Table 13). Results indicate that caregiver self-efficacy improved significantly within the narrative vignette group from pre-treatment to post-treatment. Caregivers in the narrative condition showed a significant overall increase in self-efficacy for controlling upsetting thoughts from pre-treatment ($M = 62.95, SD = 33.55$) to post treatment ($M = 72.38, SD = 31.27$), $t(17) = -2.53, p = .02$. Specifically, participants in the narrative condition significantly increased in their self-efficacy for controlling upsetting thoughts about unpleasant aspects of the caregiving situation (pre-treatment $M = 63.17, SD = 32.74$; post treatment $M = 72.47, SD = 31.71, t(17) = -2.18, p = .04$; Cohen's $d = .30$) thoughts about caregiving being unfair (pre-treatment $M = 62.23, SD = 36.00$; post treatment $M = 73.11, SD = 33.95, t(17) = -2.11, p = .05$; Cohen's $d = .32$) and worries about the future (pre-treatment $M = 53.59, SD = 33.76$; post treatment $M = 62.17, SD = 33.57, t(17) = -2.11, p = .05$; Cohen's $d = .26$). Although it did not reach statistical significance, there was a trend toward improvement in controlling upsetting thoughts about the "how good life was before caregiving," (pre-treatment $M = 66.12, SD = 37.88$; post treatment $M = 75.56, SD = 33.45, t(17) = -2.04, p = .06$; Cohen's $d = .27$). Overall, caregivers in the experimental group demonstrated improved total self-efficacy for controlling upsetting thoughts, as well as improved self-efficacy for controlling upsetting thoughts in several individual domains.

Table 10

Pre and Post-Intervention Scores on Primary Outcome Measures across Treatment Condition

Variable	Didactic (n = 18)		Narrative (n = 17)	
	Pre- Treatment	Post- Treatment	Pre-Treatment	Post- Treatment
Omnibus Test: Medication Hassles Information Seeking (<i>M, SD</i>)	11.83 (10.06)	10.83 (8.20)	10.23 (7.67)	13.00 (7.70)
Scheduling (<i>M, SD</i>)	10.83 (8.31)	9.50 (7.09)	9.06 (7.96)	8.76 (8.68)
Safety (<i>M, SD</i>)	6.77 (6.57)	4.72 (4.10)	4.94 (4.39)	6.41 (4.03)
Polypharmacy (<i>M, SD</i>)	6.00 (4.77)	3.83 (4.16)	3.17 (3.32)	3.11 (3.52)
Omnibus Test: Stanford Patient Communication Scale (<i>M, SD</i>)	3.83 (.86)	3.52 (1.15)	2.90 (1.20)	3.09 (1.40)
Omnibus Test: Morisky Medication Adherence (<i>M, SD</i>)	2.56 (1.65)	2.11 (1.64)	2.23 (1.03)	2.35 (1.17)
Omnibus Test: Self- Efficacy for Controlling Upsetting Thoughts (<i>M, SD</i>)	62.67 (27.21)	70.28 (28.82)	62.95 (33.55)	72.38 (31.27)

* = $p < .05$.

Table 11

*Repeated Measures Multivariate and Univariate Analysis of Variance for Primary Outcome**Variables*

Variable	df	MS	<i>F</i>	<i>p</i>	η_p^2	Observed Power
Omnibus Test:						
Medication Hassles						
Time	4	12.06	.89	.48	.11	.25
Condition * Time	4	35.11	1.63	.19	.18	.44
Omnibus Test:						
Patient Communication						
Time	1	.08	.22	.65	.01	.07
Condition * Time	1	1.06	2.74	.11	.08	.36
Omnibus Test:						
Medication Adherence						
Time	1	.47	.96	.34	.03	.16
Condition * Time	1	1.38	2.83	.10	.08	.37
Omnibus Test: SECUT						
Time	1	1268.49	8.07	.00**	.20	.79
Condition *Time	1	14.36	.09	.76	.00	.06

Note: SECUT = Self Efficacy for Controlling Upsetting Thoughts. * = $p < .05$; ** = $p < .001$.

Table 12

Secondary Analyses: Within Subjects Comparison of Didactic Group Participants on Pre-treatment and Post-treatment Self-Efficacy (n = 18)

Outcome	Pre-Treatment		Post-Treatment		95% CI for Mean Difference	t	df	p	Cohen's d
	M	SD	M	SD					
SECUT: Total	62.67	27.21	70.28	28.82	-17.41, 2.18	-1.64	17	.12	.28
SECUT: Unpleasant Aspects of Care	70.78	25.43	76.27	24.62	-18.16, 7.67	-.92	17	.37	.23
SECUT: Unfair	68.00	28.87	74.67	27.58	-17.03, 3.73	-.35	17	.19	.24
SECUT: Previous life	61.78	31.78	69.27	34.20	-19.04, 4.03	-1.37	17	.19	.23
SECUT: Gave up for care	62.83	31.51	69.72	31.26	-18.71, 4.93	-1.23	17	.24	.23
SECUT: Worries about Future	49.94	33.62	61.44	34.68	-26.79, 3.79	-1.56	17	.13	.35

Note. SECUT = Self- Efficacy for Controlling Upsetting Thoughts, * = $p < .05$

Table 13

Secondary Analyses: Within Subjects Comparison of Narrative Group Participants on Pre-treatment and Post-treatment Self-Efficacy (n = 17)

Outcome	Pre-Treatment		Post-Treatment		95% CI Mean Difference	t	df	p	Cohen's d
	M	SD	M	SD					
SECUT: Total	62.95	33.55	72.38	31.27	-17.32, -1.52	-2.53	16	.02*	.30
SECUT: Unpleasant Aspects	63.17	32.74	72.47	32.71	-18.34, -.241	-2.18	16	.04*	.36
SECUT: Unfair	62.23	36.00	73.11	33.95	-19.81, .05	-2.11	16	.05*	.32
SECUT: Previous life	66.12	37.88	75.76	33.45	-19.68, .04	-2.04	16	.06	.27
SECUT: Gave up for care	61.64	36.97	68.71	35.86	-15.99, 1.87	-1.68	16	.11	.23
SECUT: Worries about Future	53.59	33.76	62.17	33.57	-17.22, .04	-2.11	16	.05*	.26

Note. SECUT = Self- Efficacy for Controlling Upsetting Thoughts, * = $p < .05$

Discussion

Summary of Results

This study assessed the efficacy of two differing online health education interventions. Both conditions were designed to improve medication management and related healthcare behaviors in informal caregivers of older persons with dementia. The didactic comparison condition contained a series of downloadable PDF “Handouts” with information about managing medications, attending a healthcare visit, causes of confusion in older adults, and communication with the older loved ones. Each section included one video of an expert providing information in traditional didactic voice. The narrative vignette condition included the same content as above, with additional web episode storylines that showed caregivers interacting with their loved one, and problem solving concerns in each of the aforementioned domains. The current study introduced one of very few health oriented interventions targeting informal dementia caregivers (George & Steffen, 2015; Kamimura, Ishiwata & Inoue, 2012).

Although this study presented with challenges, such as limited sample size and correspondingly low power, several significant findings emerged in the data. Firstly, caregivers in the narrative vignette condition showed more thorough usage of materials on the intervention website than those in the didactic condition. Participants in the narrative condition viewed more didactic resources (PDF + expert video) in the area of “Healthcare Visits,” than the comparison didactic group. Although there were more total resources available in the experimental group, the data suggests that caregivers in this condition fully utilized this additional information; narrative group participants viewed more available links, in total, than those in the comparison didactic group. Finally, a non-significant trend emerged, suggesting that caregivers in the narrative condition might view more didactic resources, overall, than individuals in the

comparison condition.

Primary analyses revealed that there were no significant differences between the narrative vignette and comparison didactic groups on their reported levels of satisfaction with the intervention, after treatment was completed. In addition, there were no Time * Condition effects on medication hassles, communication with healthcare providers, medication management adherence, or self-efficacy for controlling upsetting thoughts. Analyses revealed a significant main effect of time on self-efficacy for controlling upsetting, across condition. Nevertheless, the primary hypotheses were not supported.

Secondary analysis for this study revealed a number of significant results. Within group comparisons of narrative vignette participants showed that this group improved significantly in their self-efficacy for controlling upsetting thoughts about the caregiving situation from pre-intervention to post-intervention. Although trends existed, comparison didactic group participants did not see the same significant within-group gains on self-efficacy, over time. These points are considered below, in detail, and the study is reviewed for current strengths, limitations and future directions.

Sample Description

This sample of caregivers was comprised of predominately Caucasian, middle-aged women, caring for a parent who was diagnosed with Alzheimer's disease. Of note, approximately 38% of caregivers knew that their loved one was diagnosed with a dementing illness, but did not know the exact diagnosis related to this impairment. Caregivers in this sample were managing an average of 11 medications as a part of the care-recipient's daily regimen. These individuals were highly educated, middle class, and caring for moderately impaired older adults, and were reporting a moderate level of hassles related to managing the

care-recipient's medications.

The current study sample exhibits a number of strengths and areas for growth. In general, caregivers in this data set accurately represented overall demographics for caregivers in the U.S. in the domains of age and care-recipient diagnosis (Alzheimer's Association and National Alliance for Caregiving, 2004). One area of growth in this study, as well as the majority of caregiver research, is obtaining a more ethnically diverse sample of participants (Reinhard, Given, Petlick, & Bemis, 2008). Despite high effort to recruit non-white caregivers, with particular recruitment attention given to the African American community, the majority of caregivers in this study were Caucasian. Similarly, over half of the caregivers reported a household income above \$50,000 per year, and the majority had completed the equivalent of a college degree. It is possible that caregivers in lower income communities with differing levels of education may perceive the online nature of the study as a barrier, despite the growing trend toward increased internet access in these communities (Cohen & Adams, 2009). Thus, although this recruitment difficulty is consistent in the literature (Reinhard, Given, Petlick, & Bemis, 2008) it presents limitations to the generalizability of these results to non-white, lower income and differently educated communities.

Pre-Treatment Group Equivalence. Narrative vignette and comparison didactic group participants were approximately equivalent on all pre-treatment demographic variables. Both groups were similar in regards to symptom presentations on primary outcome measures, with the exception of three significant differences. Caregivers in the comparison didactic condition began the intervention with higher levels of self-reported medication management hassles; they reported hassles approximately 10 points above those of caregivers in the experimental group, out of a possible 120 points (Travis, Kao, & Acton, 2005). Didactic group caregivers reported

more polypharmacy related concerns at time one, such as keeping multiple prescriptions filled and managing prescriptions by multiple providers. They also endorsed being more hassled by medication issues related to safety, such as recognizing adverse side effects in the care recipient and knowing how to give the medication safely. These initial discrepancies could have impacted the ability to detect between-group differences. Because caregivers in the didactic condition reported higher initial levels of hassles, they had greater room for improvement during the intervention study. Conversely, the experimental group would experience a “floor effect,” and have significantly lower room for improvement throughout the intervention. This failure in group equivalency may have reduced the ability of the study to find significant between group differences on changing levels of hassle pre and post-intervention.

Analysis of Dropout. Participant dropout in the current study was approximately 34% across both treatment conditions. No significant differences arose in the number of participants who dropped out of treatment between the comparison didactic condition and the narrative vignette condition. Similarly, there were no differences in ethnicity, income, level of education, level of care provided, or on the multiple indicators of subjective distress between the treatment completers and non-completers. Thus, the intervention exhibited a strength in that once participants were enrolled in the study, the treatment was tolerated equivalently well across multiple caregiver demographic groups.

Significant differences were found in participant dropout on care-recipient levels of impairment. Those who dropped out of treatment were providing care to persons who were less impaired than those who completed the intervention study, as measured by the analogue CDR and ability to complete ADLs. One hypothesis for this discrepancy is differing caregiver perceptions about level of need for treatment, between those providing care for more impaired

and less impaired elders. Multiple behavioral health models, such as the Health Belief Model and the Protection Motivation Theory, postulate, and have shown good evidence, that intervention participants must first believe that they are at risk for a particular concern, before they are effectively able to consider it as a relevant problem, and engage in treatment for this difficulty (Abraham & Sheeran 2004; Norman, Boer & Seydel, 2005). It is possible that caregivers providing aid to those with more impairment saw the intervention as more relevant to their current problems, whereas those providing care to an older adult with less impairment did not see the intervention as germane to their current difficulties. If true, this is unfortunate, as most neurocognitive disorders are progressive (Alzheimer's Association, 2012). By the very nature of neurocognitive illness, care-recipient level of impairment will increase over time and topics that were initially less applicable may rapidly become necessary areas of focus for the caregiver.

Lastly, it is important to note that caregivers who were expressing a greater degree of medication related hassles and poorer medication management adherence were more likely to drop out of treatment. If primary analyses had found significant differences between treatment groups on these outcome variables, further examination would be required to ensure that differential dropout did not occur between conditions, and artificially indicate treatment efficacy that could be attributed to dropout. As noted below, between group differences did not arise, however, thus negating the need for this inquiry. In addition, this finding raises concern of intervention tolerability for individuals that are most in need of treatment. Although the intervention was tolerated well by multiple demographic groups, it may have been more difficult to complete for individuals with a higher severity of medication related concerns.

Hypothesis 1 Discussion

Hypothesis one postulated that participants in the narrative vignette condition would show greater levels of satisfaction with the intervention, than participants in the didactic comparison condition, at the post-treatment assessment. No significant differences were found between group levels of satisfaction. Intervention related satisfaction scores were high for both conditions, in the mid-forties, out of a total of 56 possible points. On average, participants reported that they were “satisfied,” or “very satisfied,” in most domains of the intervention, including the tolerability of treatment. The tolerability of an intervention is a critical variable in influencing participant retention in psychological and behavioral health related interventions, as well as participant treatment engagement (Epstein, Thomson, Collins, & Pancella, 2009). It is especially noteworthy that both groups found the interventions to be equally tolerable, as the narrative condition contained a greater number of available video resources for treatment. Thus, participants in the narrative condition viewed larger numbers of treatment materials and reported similar satisfaction levels with the intervention, indicating that the increased level of materials may not have been a significant burden on caregiver time. This is relevant in the current caregiver population, as these individuals typically report being pressed for time, especially members of a sandwich generation, who provide care for both children and older loved ones (Steffen et al., 2002).

Hypothesis 2 Discussion

Hypothesis two posited that caregivers in the narrative condition would show greater decreases than the comparison didactic group on medication administration hassles, over time. There was no significant Time * Condition effect on caregiver self-reported hassles, nor was there a significant main effect of time on this variable. There are a number of possible reasons

for this finding. As mentioned above, the groups did not begin at an equivalent level of medication administration hassles; the comparison didactic group initially reported greater levels of hassle, thus widening the range of possible change scores, and decreasing the possibility that the narrative group could show greater levels of change on this variable. Once again, this study was also somewhat underpowered. Although every effort was made to obtain the initially proposed sample size of $N=53$, only 35 participants successfully completed the study. To find any significant differences, regardless of directionality, the effect size would have to be within the “large” categorization of current statistical recommendations (Cohen, 1992). Analyses of the total medication administration hassles and hassles subscale changes across group never reached an effect size that would be considered “large.” As a result, it is unlikely that current statistical analyses would have the power to find a significant result. Lastly, it is also possible that this was a correct acceptance of the null hypothesis, that treatment condition did not differentially impact caregiver medication administration hassles over time.

Hypothesis 3 Discussion

Hypothesis three predicted that the narrative group participants would show a greater increase in self-reported positive communication behaviors with medical providers, compared to the comparison didactic condition, over time. There was no significant Time * Condition effect or main effect of time on this variable. Once again, possible reasons for these results include the low power available for study, due to a small sample size. Effect size analyses revealed only a small η_p^2 for this result, and an observed power of .36, indicating a 36% likelihood of detecting statistical significance and correctly rejecting the null hypothesis if $p < .05$.

In addition, it is also possible that neither treatment group had the opportunity to re-assess their current communication behaviors with medical providers, in real medical

appointments, within the month-long time period of the study. As such, there may not have been an opportunity for caregivers to notice a change in their behaviors within this context. Of course, the final possibility remains that this study correctly accepted the null hypothesis, that there was no differential intervention group impact on patient-provider communication over time.

Hypothesis 4 Discussion

Hypothesis four predicted that narrative group participants would show greater improvements in medication adherence behaviors for care-recipient medication regimens, compared to didactic group participants, over time. Analyses revealed that there was no significant Time * Condition effect nor was there a main effect of time on medication adherence behaviors. Once again, this analysis suffers from the same low statistical power and small effect size as was present in previous analyses. The corresponding difficulty in finding statistically significant results remains a consideration in this analysis (Cohen, 1992). As mentioned above, for hypothesis 3, it is also possible that the month-long intervention progression did not provide caregivers with adequate time to have re-adjusted their medication management behaviors and to report on said adjustments. This might be especially true in cases where caregivers exhibited the majority of their resource views in the final week of the intervention. Again, the final possibility also remains that this study correctly accepted the null hypothesis, that there was no differential intervention group impact on caregiver medication adherence behaviors, over time.

Hypothesis 5 Discussion

Hypothesis five postulated that narrative group participants would show greater increases in self-efficacy for controlling upsetting thoughts related to the caregiving situations, compared to didactic group participants, over time. Analyses revealed a non-significant Time * Condition effect on self-efficacy, but a significant main effect of time on caregiver self-efficacy for controlling upsetting thoughts. Thus, the composite improvement scores in both groups' level of

self-efficacy, was found to be significant. Once again, however, it is possible that due to the small sample size, the correspondingly low power and the small effect sizes observed for this analysis, the study did not have the power necessary to be able to detect statistically significant differences between groups. This assertion may be correct, as trends in the data suggest that although both groups show increased self-efficacy for controlling upsetting thoughts over time, the narrative condition exhibits greater trends in this direction.

Secondary analyses for hypothesis 5 revealed a significant within-group effect in the narrative condition; caregivers receiving this treatment showed significant increases in total levels of self-efficacy for controlling upsetting thoughts from pre-intervention to post-intervention. Specifically, participants in the narrative condition reported improved ability to control upsetting thoughts about “how unfair the caregiving situation is,” “unpleasant aspects of the caregiving situation,” and “worries about the future.” Based on these findings, it is possible that caregivers in the narrative group were effectively able to build self-efficacy through vicarious experiences of similar others in the narrative web episodes (Bandura, 1977; Bandura, 1982; Bandura, 1994). This is a promising finding, as improved self-efficacy has been linked to one’s ability to persist in tasks despite obstacles, and to learning new behaviors (Bandura, 1982; Bandura, 1994; Bandura, 1997). As a result, this increase in self-efficacy may correlate with other long-term improvements in health management domains of caregiving.

Despite the possibility that this improvement may be attributable to the intervention, it is also possible that internal threats to validity, such as maturation, regression toward the mean and repeated assessment, have impacted this finding (Kazdin, 2003). It is difficult, without further data, to attribute this finding exclusively to the impact of the intervention. A “no-treatment” or waitlist control would be beneficial in further exploring this result.

Evaluation of Research Methodology

Strengths. This study included several novel components that served as strengths and useful contributions to the present state of caregiving literature. Firstly, the intervention developed for this manuscript was one of very few health education treatments that focused on care dyads of a person with cognitive impairment (Banning, 2009; Conn et al., 2009). Current studies meeting these criteria, often lack clear theoretical underpinnings in their intervention development, and only include older adults with minimal cognitive concerns (Banning, 2009; Conn et al., 2009). The present intervention, however, has clear theoretical groundings in Bandura's Social Cognitive Theory, while including caregivers of more impaired elders. In addition, this is the first randomized health education intervention developed to focus largely on caregivers. The majority of current studies focus on healthcare modifications for the cognitively impaired older adult, while entirely neglecting the likelihood that there may be an involved informal care partner (Kamimura, Ishiwata & Inoue, 2012).

In addition, the current intervention is the first health education treatment available to caregivers in an online format. This is beneficial, as the number of individuals using online resources, across generations, continues to increase (Cohen & Adams, 2009; Pew Research Center, 2011). Those in lower income communities also report increasing access to technology and the internet through the use of smart phones (Cohen & Adams, 2009), and most individuals who seek out healthcare information use online searches, at some point during the process (Pew Research Center, 2011). Finally, many studies show that caregivers have increased time-constraints when compared to similar non-caregiving individuals (Schulz & Martire, 2004). The online availability of interventions may decrease the time investment necessary for caregivers to easily obtain aid.

Another strength of the intervention is the flexible content approach. Caregivers in this study were able to log into the website at any time of day and spend as much time as they believed necessary on the intervention website. In addition, they were able to select any content area and any video or PDF resources that interested them as a part of their own individualized treatment program. The tailored and individual specific nature of this intervention is a significant asset, as psychological treatment literature suggests that this is linked to increased retention of participants as well as improved outcomes (Epstein, Thomson, Collins, & Pancella, 2009; Epstein, Collins, Thomson, & Pancella, 2007; Epstein & McGaha, 1999).

Limitations & Future Directions. The present study also had several limitations. In general, the sample size was lower than necessary to obtain power sufficient for detecting statistically significant changes between groups. In addition, secondary analyses lack a comparison group, such as a no-treatment control or a waitlist control. Although this study included a narrative condition and comparison didactic condition, there was no way to discern if within group changes would have occurred without any form of intervention from the researchers. It is difficult to positively attribute within-group changes over time to an intervention effect rather than to threats to internal validity such as multiple assessment or maturation. Further, many of the currently measured medication and healthcare related behaviors may be low base-rate events and as such, ideal measurement of change should occur over a period of time that is greater than one month. Future studies that seek to replicate and explore these findings through longitudinal measurement and may wish to include a third, no treatment control group, or waitlist control group that can be used as a comparison.

In addition, this study may have reduced external validity in caregivers who are non-white, lower income or who demonstrate lower educational attainment. It is possible that the

decreased level of recruitment for these individuals reflects a bias in these communities for lower access to technological resources (Pew Research Center, 2011), or it may reflect the traditional pattern of these underserved populations to show lower general engagement with healthcare and health related interventions, based on historical interactions with healthcare communities (Commission on Social Determinants of Health, 2008; Office of Minority Health, 2011). Future studies may benefit from anticipating these potential recruitment barriers, and remedy this by singularly targeting individuals in these underserved communities. Similarly, future studies may explore the current barriers to technological access and eliminate these by providing other avenues to internet resources (i.e. library cards or rented tablets).

Other areas for growth may include attempts to utilize this intervention in spousal caregivers, caregivers of persons without dementia, and exploring intervention response between rural and urban caregivers. It would also be beneficial to identify the most salient intervention components contributing to caregiver improvement over time. As is traditional with the trajectory of most early intervention trials, future studies should seek to establish effectiveness, rather than efficacy, in larger populations that includes a broader swath of caregivers (Kazdin, 2003). Dismantling trials, after establishing efficacy of the intervention, may be useful in determining the “active ingredients,” involved in producing positive caregiver change (Kazdin, 2003). Because this study occurred over a relatively brief time frame (1 month), future research may further benefit from extending the amount of follow-up contact and assessment points as well as including a qualitative component regarding caregiver’s experiences during the intervention trial.

Clinical Considerations. The current finding that narrative intervention participants saw improved self-efficacy for controlling upsetting thoughts, has several clinical implications. This

noted increases in self-efficacy could have benefits related to improved mood management in caregivers (George & Steffen, 2015), increased ability to tolerate distress in the caregiving situation, ability to persist in learning new behaviors, (Bandura, 1977; Bandura, 1982; Bandura, 1994), and may be linked to other positive health management behaviors for the older loved one. Improving caregiver self-efficacy for controlling upsetting thoughts may have other unforeseen positive consequences, such as reduced need for caregiver utilization of psychotropic medications (George & Steffen, 2015). Clinical access points for caregiver introduction to this intervention, may include Emergency Departments, which often serve as primary care for underserved populations (Commission on Social Determinants of Health, 2008) or primary care clinics, the first contact point for older adults and caregivers who are noting cognitive concerns (Boise, Neal, & Kaye, 2004; Forester & Oxman, 2003).

Conclusions

This study investigated the efficacy of an online health education intervention, designed to improve caregiver medication management of a cognitively impaired care-recipient's medication regimen. Women caring for an older generation, cognitively impaired loved one, were randomized to one of two treatment conditions; the narrative vignette group or the didactic comparison condition. Participants in this study were asked to complete pre-assessment measures assessing caregiver medication administration hassles, patient-provider communication, medication management adherence, and self-efficacy for controlling upsetting thoughts. Afterwards, they engaged in a 1-month online health education intervention, and filled out similar post-assessment questionnaires directly following completion of the intervention. Strengths of this study include targeting a novel population for medication management in older adults with dementia, creation of a flexible online format that allowed caregivers to explore

health education content areas of most interest to them, and a theoretical basis in Social cognitive theory.

The findings of this study were mixed and require further future exploration. Although the didactic and narrative treatment groups did not differ from one another on improvement in the aforementioned areas, there was a significant main effect of time on caregiver self-efficacy for controlling upsetting thoughts. Participants in the narrative vignette condition, specifically, showed significant overall improvement in self-efficacy for controlling upsetting thoughts, over time. There were no differences in intervention group levels of satisfaction at post-treatment, suggesting similar levels of tolerability between conditions.

Overall, this study provides the groundwork necessary implementation of health education interventions in care dyads. Future research should seek to replicate these findings, while including a no-treatment or waitlist control for comparison to the already developed treatment conditions. In addition, future studies would benefit from exploring the external validity of this intervention in underserved populations, broadening the possible treatment populations, and completing dismantling studies to determine the effective components of the present health education treatment.

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Appendix A.

Contact Timeline for Intervention Groups

Narrative Group Contact Timeline	Didactic Group Contact Timeline
<ul style="list-style-type: none"> Participant completes screening assessment. Assessment program emails project coordinator that someone has qualified for project. 	<ul style="list-style-type: none"> Participant completes screening assessment. Assessment program emails project coordinator that someone has qualified for project.
<ul style="list-style-type: none"> Project Coordinator Sends “Email 1/ Introductory assessment email ” Record date email was sent in the participant tracking form. 	<ul style="list-style-type: none"> Project Coordinator Sends “Email 1/ Introductory assessment email ” Record date email was sent in the participant tracking form.
<ul style="list-style-type: none"> The 4th pre-assessment survey generates an automatic email when completed. 	<ul style="list-style-type: none"> The 4th pre-assessment survey generates an automatic email when completed.
<ul style="list-style-type: none"> Send email 2 “Introduction to intervention with login ID and password: Experimental Condition” In sandwichgenerationdiner.com assign login ID, password and User Level one for narrative condition. 	<ul style="list-style-type: none"> Send email 2 “Introduction to intervention with login ID and password: Control condition” In sandwichgenerationdiner.com assign login ID, password and User Level one for didactic condition.
<ul style="list-style-type: none"> One week later, send “email 3, after one week” Increase Participant access level to week 2 of narrative condition. 	<ul style="list-style-type: none"> One week later, send “email 3, after one week” Increase Participant access level to week 2 of didactic condition.
<ul style="list-style-type: none"> One week later send “email 4 after 2 weeks” Increase participant access level to week 3 of narrative condition. 	<ul style="list-style-type: none"> One week later send “email 4 after 2 weeks” Increase participant access level to week 3 of didactic condition.
<ul style="list-style-type: none"> One week later send “email 5 after 3 weeks” Also Send the “5 wishes email” Increase participant access to week 4 (final level) of narrative condition. 	<ul style="list-style-type: none"> One week later send “email 5 after 3 weeks” Also Send the “5 wishes email” Increase participant access level to week 4 (final level) of didactic condition
<ul style="list-style-type: none"> One week later, a total of 4 weeks after the login ID email, send the “post-test assessment” email 	<ul style="list-style-type: none"> One week later, a total of 4 weeks after the login ID email, send the “post-test assessment” email
<ul style="list-style-type: none"> The 4th survey in this group generates an automatic email when completed. 	<ul style="list-style-type: none"> The 4th survey in this group generates an automatic email when completed.

Appendix B

Treatment Condition Content Areas

Week	Narrative condition	Didactic Condition
1	<p>Medication Management</p> <ul style="list-style-type: none"> • Organizing Meds (PDF) • Introduction (Dyad Video) • Organizing Meds (Dyad Video) <p>Talking Together</p> <ul style="list-style-type: none"> • Basic Communication Tips (PDF) • Introduction (Dyad Video) • Basic Communication (Dyad Video) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Causes of Confusion (PDF) • Causes of Confusion (Expert Video) • 10 Warning Signs (PDF) • Introduction (Dyad video) • Causes of Confusion (Dyad Video) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Getting Ready for a Healthcare Visit (PDF) • Introduction (Dyad Video) • Getting Ready (Dyad Video) 	<p>Medication Management</p> <ul style="list-style-type: none"> • Organizing Meds (PDF) <p>Talking Together</p> <ul style="list-style-type: none"> • Basic Communication Tips (PDF) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Causes of Confusion (PDF) • Causes of Confusion (Expert Video) • 10 Warning Signs (PDF) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Getting Ready for a Healthcare Visit (PDF)
2	<p>Medication Management</p> <ul style="list-style-type: none"> • Ask Your Pharmacist (PDF) • Ask Your Pharmacist (Expert Video) • Ask Your Pharmacist (Dyad Video) <p>Talking Together</p> <ul style="list-style-type: none"> • Handling Minor Disagreements (PDF) • Minor Disagreements (Dyad Video) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Why get a Diagnosis (PDF) • Getting a Diagnosis Step 1 (Dyad Video) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Learning about Meds (PDF) • Learning about Meds (Dyad Video) 	<p>Medication Management</p> <ul style="list-style-type: none"> • Ask Your Pharmacist (PDF) • Ask Your Pharmacist (Expert Video) <p>Talking Together</p> <ul style="list-style-type: none"> • Handling Minor Disagreements (PDF) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Why get a Diagnosis (PDF) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Learning about Meds (PDF)
3	<p>Medication Management</p> <ul style="list-style-type: none"> • Over the Counter Meds (PDF) • Taking Time for More Questions (PDF) 	<p>Medication Management</p> <ul style="list-style-type: none"> • Over the Counter Meds (PDF) • Taking Time for More

	<ul style="list-style-type: none"> • Taking Time for More Questions (Dyad Video) <p>Talking Together</p> <ul style="list-style-type: none"> • Handling Major Disagreements (PDF) • Major Disagreements (Dyad Video) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Getting a Diagnosis (PDF) • AD8 (PDF) • Getting a Diagnosis Step 2 (Dyad Video) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Release Forms (PDF) • Side Effects (PDF) • Side Effects (Expert Video) • Release Forms and Side Effects (Dyad Video) 	<p>Questions (PDF)</p> <p>Talking Together</p> <ul style="list-style-type: none"> • Handling Major Disagreements (PDF) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Getting a Diagnosis (PDF) • AD8 (PDF) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Release Forms (PDF) • Side Effects (PDF) • Side Effects (Expert Video)
4	<p>Medication Management</p> <ul style="list-style-type: none"> • Fine Tuning Questions For Your Pharmacist (PDF) • Fine Tuning (Dyad Video) <p>Talking Together</p> <ul style="list-style-type: none"> • Planning for the Future (Expert Video) • Housing Plans (PDF) • Transportation Plans (PDF) • Healthcare Plans (PDF) • Long Term Plans (PDF) • Financial Plans (PDF) • Values and Plans (Dyad Video) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Following a Dementia Diagnosis (PDF) • Following a Dementia Diagnosis (Dyad Video) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Affording Meds (PDF) • Affording Meds (Dyad Video) 	<p>Medication Management</p> <ul style="list-style-type: none"> • Fine Tuning Questions For Your Pharmacist (PDF) <p>Talking Together</p> <ul style="list-style-type: none"> • Planning for the Future (Expert Video) • Housing Plans (PDF) • Transportation Plans (PDF) • Healthcare Plans (PDF) • Long Term Plans (PDF) • Financial Plans (PDF) <p>Signs of Confusion</p> <ul style="list-style-type: none"> • Following a Dementia Diagnosis (PDF) <p>Healthcare Visits</p> <ul style="list-style-type: none"> • Affording Meds (PDF)

Appendix C

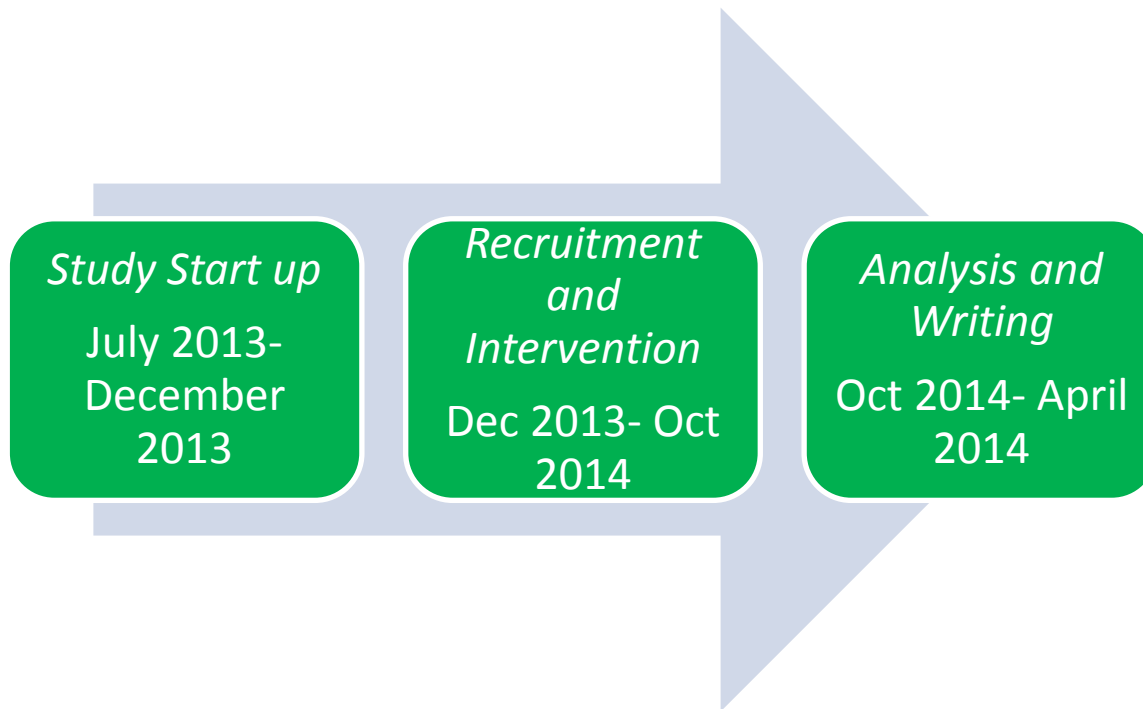
Timeline for Project

Study Start up – July 2013 → Dec 2013

Recruitment- December 2013 → October 2014

Intervention- December 2013 → October 2014

Analysis and Writing- October 2014 → April 2015



Appendix D

Student Duties

Startup

- Time investment: 20- 40 hours per week
- Creation of Intervention
 - Create all Didactic Handouts
 - Provide outlines for script writers detailing narrative vignette content areas based in self-efficacy theory
 - Revise script
 - Consult with healthcare professionals about didactic content
 - Consult with web designers about layout of intervention website and issues of online measurement and assessment/ screener set-up
- Measure Selection
- Create and Submit IRB for Intervention
- Create all online assessments and screens through Qualtrics

Recruitment

- Time investment: 20-40 hours per week
- Perform all recruitment duties and project management

Intervention

- Time investment: 20-40 hours per week
- Monitor each individual's intervention progress
- Send reminder emails for individual participation
- Direct participant financial compensation
- Provide Tech Support

Analysis and Writing

- Perform all duties related to dissertation analysis and writing