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## Effects of a Telephone-Based Exercise Intervention for Dementia Caregiving Wives: A Randomized Controlled Trial

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### Abstract

Despite the importance of self-care for dementia caregivers, few interventions have included a focus on health behaviors. The current study reports outcomes of a telephone-based exercise intervention designed for women caring for a spouse with dementia. Caregivers (N = 137) were randomized to intervention or control conditions. Participants with at or below-median exercise scores at baseline had a significantly greater increase in exercise at six-month follow-up compared to their control counterparts. At 6 months, participants had greater reductions in perceived stress relative to controls. Participants also reported significantly greater increases in exercise self-efficacy than caregivers in the control group at both follow-up points. Results indicate that spouse caregivers are able to increase their physical activity and that a focus on exercise in multi-component interventions may be beneficial. Debate and discussion is needed to inform expectations for program impacts and their maintenance and to explore the interface between enhanced self-care and caregiving perceptions.

### Keywords

Alzheimer's disease; physical activity; self-care; self-efficacy; spouse

### Introduction

Engaging in regular physical activity has been associated with a long and growing list of positive outcomes among older adults, ranging from reduced risk of chronic illness to fewer functional limitations and less disability to improved mood and cognitive functioning (Center for the Advancement of Health, 2006; Centers for Disease Control and Prevention, 2007). Despite the growing evidence of the benefits of physical activity, just over one-fourth of adults between the ages of 65 to 74 years report regular exercise; by the age of 75, this figure drops to 20 percent (Federal Interagency Forum on Aging-Related Statistics, 2006). One group of older adults that faces unique barriers to initiating and maintaining an exercise regimen includes dementia caregivers (Burton, Newsom, Schulz, Hirsch, & German, 1997; King et al., 2000). Given the physical and mental health risks, chronic stress, and demands associated with the role (Schulz & Beach, 1999; Schulz & Martire, 2004) and the fact that

positive health behaviors, including exercise, may offset some of these negative outcomes (Connell & Gallant, 1999), sedentary behavior among this group is of particular concern.

Although several studies have concluded that caregivers are no more likely to be sedentary than non-caregivers (e.g., Castro et al, 2007; Fredman, Bertrand, Martire, Hochberg, & Harris, 2006), other studies show that caregivers have less time and opportunity to exercise as their role-related responsibilities increase (Bedini & Guinan, 1996; Lim & Taylor, 2005; Pinquart & Sorensen, 2003). Even if caregivers are as active as older adults in the general population, there is certainly room for improvement as the majority is either inactive or engage in insufficient levels of activity to achieve positive health outcomes (CDC, 2007).

Several benefits of physical activity may be especially relevant to caregivers. For example, regular exercise may increase the strength and stamina needed to perform the demanding physical tasks of the role; reduce depression, stress, anxiety, and fatigue; short circuit negative physiological responses to chronic stress (i.e., cardiovascular, immunologic, stress hormones, neurotransmitters); and enhance self-efficacy and personal control (Etkin, Prohaska, Connell, Edelman & Hughes, 2008; McAuley, Elavsky, Jerome, Konopack, & Marquez, 2005; Netz, Wu, Becker & Tenenbaum, 2005; Vitaliano, Zhang, & Scanlan, 2003).

To date, only a few physical activity interventions designed for dementia caregivers have been described in the literature. For example, a randomized controlled trial of a home-based exercise program reduced blood pressure in female dementia caregivers (King & Brassington, 1997). A physical activity and nutrition intervention designed for sedentary wives and daughters of family members with dementia decreased blood pressure reactivity, perceived stress, depression, and burden (Castro, Wilcox, O'Sullivan, Baumann, & King, 2002; King, Baumann, O'Sullivan, Wilcox, & Castro, 2002).

Several recent caregiver interventions that focus broadly on self-care have also been reported (e.g., Boise, Congleton, & Shannon, 2005; Teel & Leenerts, 2005), but the emphasis of this work has been on program and theory development, feasibility testing, and broad dissemination rather than on outcome evaluation. Thus, despite the growing interest in caregiver self-care, few interventions to date have been evaluated.

The current study reports on a randomized, controlled trial of "*Health First: Caregivers Take Time to Stay Active*" (*Health First*), a six-month telephone-based exercise intervention designed for female spouse dementia caregivers. This target group was selected because: a) spouse caregivers are particularly vulnerable to stress-related adverse health consequences compared to non-spouses (Schulz, O'Brien, Bookwala, & Fleissner, 1995), in part, because they are more likely to be older and to serve alone without back-up (Wolff & Kasper, 2006); b) female caregivers report higher levels of role-related distress compared to their male counterparts (Yee & Schulz, 2000); and c) women are less likely to exercise than men, both in samples of caregivers (King & Brassington, 1997) and among the general public (Robinson, 2007). Thus, older female spouse caregivers could be considered to be at "triple risk" for sedentary behavior.

The specific aims of this study are to assess whether, compared to baseline, participants in *Health First* showed greater improvements than the control group immediately following the intervention (i.e., 6 months from baseline) and six months later (i.e., 12 months from baseline and 6 months post-program). Outcome domains were selected to be consistent with the caregiver intervention literature, the theoretical framework upon which the intervention was based, and the expansive literature on the impact of physical activity on health outcomes. The domains included: exercise, self efficacy for exercise, self care, depression, perceived stress, and perceived caregiver burden.

## Design and Methods

### Recruitment and Randomization

*Health First* participants were recruited from the Michigan Alzheimer's Disease Research Center (MADRC) and local chapters of the Alzheimer's Association (AA) in Michigan and Ohio. Eligible participants were primary caregivers for a spouse with dementia, living with their spouse at home, and interested in increasing their physical activity. Letters describing the study were sent to 742 female caregivers whose husbands had been evaluated at the MADRC and who were interested in participating in research. Of these, 244 were ineligible (primarily because the patient was deceased or no longer lived at home); 201 caregivers could not be reached; and 39 indicated that they preferred not to be contacted. Thus, of the 742 MADRC-affiliated caregivers who were contacted initially, 258 were potential participants; 94 enrolled in the study. In addition, 4,427 flyers describing the project were distributed by the AA resulting in telephone calls from 74 eligible caregivers; 63 enrolled. Thus, the two recruitment sources yielded a total of 157 wives who entered the study.

Following a baseline telephone interview, participants were randomized to intervention ( $n = 86$ ) or control ( $n = 71$ ) groups. Because more withdraws were expected from the intervention group due to the time demands of participation, the next eligible caregiver was assigned to this group when a participant withdrew to ensure overall balance in the study design. Follow-up interviews were administered at approximately 6 and 12 months from baseline.

### Health First – Theory, Format, and Curriculum

*Health First* draws on two theoretical bases -- social cognitive theory (SCT; Bandura, 1986) and "motivational interviewing" (Miller, 1996), both of which have informed the design of behavior-change interventions for older adults (King et al., 2000; Netz et al., 2005). According to SCT, self-efficacy can be enhanced through incremental achievement of behavioral goals, modeling of the desired behaviors by similar others, and verbal persuasion (Strecher, DeVellis, Becker, & Rosenstock, 1986). Each of these efficacy-enhancing techniques was incorporated into *Health First*. For example, rather than promoting a "one size fits all" exercise regimen, individualized goals were set by participants in conjunction with a telephone counselor to maximize the likelihood of success. This type of flexible exercise "prescription" was thought to be particularly suitable for dementia caregivers, who often face time demands and schedule constraints associated with their role (Castro et al., 2002). Consistent with principles of motivational interviewing, participants were encouraged to assume responsibility for working toward their goals, while the counselor provided feedback in a manner that increased self-efficacy and the likelihood of successful change (Miller, 1996).

Participants received the following materials: a) a *Health First* video featuring spouse caregivers discussing strategies for fitting physical activity into their daily routine as a way to model desired behavior; b) a choice of exercise videos; one featured low impact exercises appropriate for caregivers with limited mobility, the other featured low impact aerobic dance and movement, c) a copy of the booklet "Pep Up Your Life", distributed by the AARP, which contains information on flexibility, strength and balance exercises for older adults; d) a *Health First* workbook that explained each step of the program and included forms for participants to keep track of their weekly goals and progress toward their long-term goals; and e) two "motivational" newsletters, one mailed at five months from baseline and the second mailed two months after the completion of the program.

The telephone-based format of the program was chosen to circumvent two primary barriers to participation that dementia caregivers often face -- the inability to leave their spouse

home alone and not having sufficient time to exercise due to their caregiving responsibilities. To address the first barrier, all data collection and program elements were designed to be completed at home. No contact with program staff was required.

Several program features were designed to address the potential or perceived conflict between the time demands of caregiving and participation in *Health First*: a) telephone counseling calls were scheduled at the participants' convenience; b) counselors were trained to help participants problem solve in the event that participants reported that they had difficulty finding the time to exercise; c) participants were encouraged to exercise in shorter and more frequent sessions if they could not spare a longer block of time on a particular day; and d) program materials emphasized that one of the benefits of participating in *Health First* was realizing how important it was to claim time for self-care as an investment in the long-term ability to continue to provide care for their spouse.

*Health First* participants received 14 telephone calls from trained behavior-change counselors over a 6-month period (weekly for 2 months; biweekly for 2 months, monthly for 2 months). Counselors participated in a day-long training session to address program fidelity that included opportunities for role-playing and performance feedback to promote appropriate and accurate delivery of the program (for additional discussion of program fidelity, see Gitlin et al., 2000). During the first two telephone calls, participants were directed to complete daily activity logs (to establish baseline levels of physical activity) and to set a realistic long-term exercise goal that specified the type of exercise (i.e., strengthening, flexibility, aerobic) as well as duration and frequency. Participants were encouraged to set a goal that consisted of a minimum of 30 minutes of low-to-moderate intensity aerobic exercise at least three times a week, supplemented by stretching and strength training. Examples of what constituted "low" (e.g., slow walking) and "moderate" (e.g., brisk walking) activity were provided in the participant workbook. During all subsequent calls, participants set specific short-term goals for exercise, after evaluating success in reaching the previous short-term goal in collaboration with the counselor. A problem-solving process was used to address any barriers to goal attainment. Short-term goals were intended to be "stepping stones" toward the long-term goal and could be repeated for subsequent weeks. During the final phone session, the counselor and participant together reviewed progress and then set a new long-term goal for the participant to accomplish on her own over the next six months. To further address program fidelity, the project manager monitored several calls made by each counselor to confirm that the intervention was being delivered correctly and uniformly.

Study participants assigned to the control group did not receive the intervention but completed the baseline and follow-up telephone interviews and received written materials about physical activity at the end of the study period.

## Measures

Sociodemographic variables included age (in years), highest level of education (high school or less, some college, college degree or higher), race/ethnicity (African American, Hispanic/Latino, Asian/Pacific Islander, White, American Indian, Other), and employment status (employed full-time, retired, homemaker, disabled).

Self-rated physical health was assessed with a single item, "Overall, how would you rate your physical health?" (poor, fair, good, very good, excellent). A count of chronic conditions was obtained by summing positive responses to questions about the following illnesses: arthritis, high blood pressure, heart disease, chronic lung disease, diabetes, cancer, and stroke. A subscale of the Medical Outcomes Study (MOS) Short-Form General Health Survey (Ware & Sherbourne, 1992) was used to assess physical functioning. Caregivers

were asked whether their health has limited them (not at all, a little, or a lot) in eight areas ranging from vigorous activities to walking to bathing and dressing. Possible scores range from 8 to 24, with higher scores indicating better functioning. Respondents were also asked whether they engaged in regular physical activity defined as vigorous enough to work up a sweat for at least 20 minutes 3 times/week.

Objective caregiving burden was assessed by the total number of problems reported on the Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992). The RMBPC assesses upset or burden with the presence of 24 memory and behavior problems and was used in this study as an indicator of symptom severity of the care recipient. Possible scores range from 0 to 24, with higher scores indicating more problem behaviors.

Exercise behavior was measured as time spent in aerobic exercise (“physical activities such as brisk walking, swimming, dancing and stationary bicycling that are vigorous enough to work up a sweat or get your heart thumping”) stretching (“exercises to increase your flexibility”), and strengthening (“such as using weights”) over the past week (Lorig et al., 1993). Response options for each category included: none, less than 30 minutes, 30 to 60 minutes, 1 to 3 hours, and more than 3 hours. In all analyses, time spent in the three domains was summed to yield a total exercise/week score because participants were directed to include all three types of exercise in their individualized regimen. Higher scores on this ordinal scale indicate more physical activity.

Exercise self-efficacy was measured by nine items developed for dementia caregivers (King & Brassington, 1997). Respondents rated their level of confidence that they could exercise when faced with barriers (e.g., being tired, hectic schedule) using a 1 to 10 scale (not at all confident to very confident). The ratings were averaged across items for a total exercise self-efficacy score. Cronbach’s alpha in the current sample was .87.

Self-efficacy for self-care was assessed by the single item, “How confident do you feel in being able to take care of yourself?” (Gallant & Connell, 1998). Response choices ranged from “not confident at all” to “very confident” using a 5-point scale.

Depressive symptoms were measured with the 11-item Iowa short form of the Center for Epidemiologic Studies Depression Scale (CES-D; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993). Respondents were asked the frequency with which they experienced symptoms in the past week (hardly ever or never, some of the time, or much or most of the time). Possible scores range from 0 to 22; higher scores are associated with more symptoms. Cronbach’s alpha was .88. Perceived stress was measured with the 14-item Cohen Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). Respondents rate the degree to which events in the last month were perceived as stressful using a 5-point scale ranging from “never” (0) to “very often” (4). This measure was originally computed by summing all items, after reverse scoring the positive items and eliminating cases with a missing value for any item. However, after it became evident that this procedure resulted in a loss of more than 20% of cases when calculating the perceived stress change score (baseline-Month 6), the strategy was changed such that the mean value of answered scale items was computed instead. It should be noted that no case had more than three missing values for this scale at any time point, and the majority of cases with any missing values had only one such value. Cronbach’s alpha for this sample was .86. Subjective caregiving burden was assessed by responses to the “bother/upset” questions asked as part of a modified version of the RMBPC Form (Gitlin et al., 2003). For each item, caregivers indicated “How bothered or upset were you by this (memory or behavior problem in the care recipient)?” Responses ranged on a 5-point scale from “not at all” to “extremely.” Responses were summed for an overall

subjective burden score, with possible scores ranging from 0 to 96. Higher scores are associated with being more bothered or upset by the care recipient's problem behaviors.

## Data Analysis

Descriptive statistics were calculated for all study variables at baseline. Means and standard deviations were then calculated for each outcome at the three data collection points. Next, independent-sample t-tests and contingency table analyses were conducted to compare intervention and control group scores for study variables at each time point. In all analyses, an alpha level of .05 was used to determine statistical significance.

Next, hierarchical linear regression was used to assess the impact of the intervention on the outcomes of interest after controlling for covariates. For all models, the dependent variable was the change score for each outcome (i.e., 6 month score–baseline score or 12 month score–baseline score). Change scores were used because they were more normally distributed than the raw follow-up scores and thus better met the assumptions of linear regression.

The change score for each outcome was first regressed on its respective baseline value, age, count of chronic illnesses, and objective caregiver burden. Next, intervention group status (1 = intervention group, 0 = control group) was added to the model. Following this step, an interaction term (baseline value by intervention group status) was added to the model to determine whether the effect of the intervention varied with the baseline score of each outcome. If the interaction term did not add significantly to the explained variance (based on the significance of the F-test for the incremental increase in  $R^2$ ), it was dropped. Otherwise, the final model was re-estimated after centering the baseline value of the outcome on its mean, a technique used to reduce the effect of multicollinearity (Aiken & West, 1991). In addition, standardized effects sizes were calculated for each outcome by squaring the semi-partial correlation coefficient for the intervention group from the multiple regression models of program effect (as per Cohen's recommendations, 1988). The resulting effect sizes represent the proportion of variance explained by participation in *Health First*, controlling for all model covariates. Effect sizes, then, provide a standardized, multivariate measure of program effect.

## Study Withdrawals

Over the project period, 15.9% of the original sample ( $n = 26$ ) was lost to follow-up; 20 women (13 intervention, 7 control) dropped out prior to the 6-month follow-up; 6 (4 intervention, 2 control) dropped out before the 12-month follow-up. One additional caregiver was missing a 6-month interview and was not included in this analysis. Nine women in the intervention group stopped participating in prescribed activities before the end of the program, primarily because they reported being "too busy." Because they completed at least two telephone counseling sessions and by this time, had received all program materials and established a long-term exercise goal, all 9 were retained for analyses. Thus, the final sample consisted of 137 caregivers at 6 months and 130 caregivers at 12 months. Study participants who withdrew from the study or died ( $n = 25$ ) were compared with those who completed the study on baseline variables; no significant differences were discovered ( $p \leq .05$ ).

## Results

### Baseline Characteristics of Sample

The baseline sociodemographic, physical health, and caregiving characteristics of study participants are presented in Table 1. Average age of the sample was 66.8 years ( $SD = 9.4$ ).

The majority of women had at least some education beyond high school (65.7%) and described themselves as White/Caucasian (92.7%). About one-fifth (21.9%) of the sample was employed part- or full-time.

The average physical health self-rating was 3.1 (SD = 0.9), or slightly better than “good”; this rating is identical to that reported by spouse caregivers in a population-based study (Schulz et al., 1997). Participants reported an average of 1.6 (SD = 1.1) chronic illnesses. The prevalence of specific conditions in the current sample was comparable to national trends for women over 65, with arthritis and hypertension reported by about 50% and heart disease by about 25% (data not reported; Robinson, 2007).

Overall, physical functioning was high (M = 21.0, SD = 3.2), indicating that study participants experienced little impairment in daily activities. One-fifth (20.4%) reported that they engaged in physical activity “vigorous enough to work up a sweat” for at least 20 minutes, three times a week; this percentage is almost identical to that reported for the general population of older women (Robinson, 2007).

### Means of Study Outcomes across Time Points

The means of all study outcomes at baseline, 6 months, and 12 months are presented in Table 2. At baseline, there was a significant between-group difference in depression scores (intervention group M = 9.4, SD = 2.9; control group M = 7.9, SD = 2.8). At 6 months, significant between-group differences were discovered in weekly exercise scores (intervention group M = 7.0, SD = 2.7, control group M = 5.8, SD = 2.7) and in exercise self-efficacy (intervention group M = 5.8, SD = 2.1, control group M = 5.0, SD = 2.2). At 12 months, the significant between-group difference in exercise self-efficacy remained (intervention group M = 5.5, SD = 2.3, control group M = 4.7, SD = 2.2).

### Multivariate Analysis of Program Effect

Regression coefficients for the effect of *Health First* on change in exercise-related outcomes from baseline to 6-month follow-up are displayed in Table 3. At six months, program participation had a significant, positive effect on the change in total exercise from baseline to post-intervention follow-up ( $p < .01$ ). Women in the intervention group had, on average, an increase in total exercise score that was 1.3 units greater than among women in the control group, adjusting for baseline exercise score and caregiving characteristics.

In addition, there was a significant interaction between baseline weekly exercise and intervention group status ( $p < .05$ ). To determine the nature of this interaction, the sample was stratified according to baseline activity level, with women who had activity levels at or below the median (5.0 or less) compared to those with levels above the median (greater than 5.0). Results (not shown) indicate that the immediate post-intervention effect was significant ( $p < .01$ ) only among women who had a baseline weekly exercise score at or below the median. More specifically, this subgroup of *Health First* participants increased their average exercise levels in each category (i.e., aerobic, stretching, strengthening) from a range between “none” and “less than 30 minutes” to a range between “less than 30 minutes” and “30 to 60 minutes.”

Program participation also resulted in a significant increase in exercise self-efficacy at six months (see Table 3). Caregivers in the intervention group showed greater increases in their exercise self-efficacy score compared to caregivers in the control group, after adjusting for covariates ( $p < .01$ ). No significant interaction between treatment group and baseline self-efficacy for exercise was observed.

At six months, no effect of the intervention on self-efficacy for self-care was observed. In addition, there was no evidence of an interaction between self-efficacy for self-care and treatment group status.

At 12 months, no significant differences in change scores were observed between the intervention and control participants for total weekly exercise or self-efficacy for self-care after adjusting for covariates (see Table 4). For exercise self-efficacy, however, caregivers in the intervention group increased their scores from baseline by an average of .96 points more than did caregivers in the control group, after adjusting for covariates ( $p < .01$ ). No significant interactions between the baseline values of these variables and intervention group status were observed.

The main effect of group assignment on change in depressive symptoms from baseline to 6 months approached significance ( $p < .10$ ); women in the intervention group reported a greater average decline in depressive symptoms than those in the control group (see Table 3). For perceived stress, no between-group difference was found at the 6-month follow-up in univariate analyses. After controlling for covariates, however, results indicated that the intervention significantly reduced perceived stress, such that the adjusted mean score for caregivers in the intervention group decreased by an average of .16 points more than among the control group ( $p < .05$ ). No significant interactions between intervention group status and baseline values of depression or perceived stress were observed. At 12-month follow-up, no significant effect of the intervention on either change in depression or perceived stress was evident (see Table 4). Finally, participation in *Health First* did not impact subjective caregiving burden at either 6 or 12 months (see Tables 3 and 4).

In terms of effect sizes, the .15 for total exercise at 6 months is considered (per Cohen, 1988) between “medium” and “large”; the effect on exercise self efficacy at both time points is between “small” and “medium”, as is the effect for perceived stress at six months (see Table 3). The only effect size of note at 12 months is for exercise self-efficacy (see Table 4). Although these interpretations of the effect sizes (as “small” and “medium”) are useful only as general guidelines, they support the general conclusion that the intervention was modestly successful in the short run in selected areas.

## Discussion

*Health First*, one of the few physical activity programs designed specifically for dementia caregivers, increased exercise behavior among less-active participants and enhanced exercise self-efficacy and decreased perceived stress immediately following the intervention. By 12-month follow up, however, only the positive effects on exercise self-efficacy were still apparent. As for the impact of the program on exercise outcomes, these results are not totally unexpected. A variety of interventions designed for older adults have increased physical activity in the short term but few have been able to show long-term maintenance effects (van der Bij, Laurant, & Wensing, 2002) and it is estimated that less than half of those that initiate exercise will continue, no matter what type of program they participate in (Marcus et al., 2006). Other hypothesized outcomes related to the *Health First* content or approach and based on previous research were unaffected at both follow-up points by program participation, including self-efficacy for self-care, depressive symptoms, and perceived caregiver burden.

This study brings several strengths to the small but growing literature on self-care interventions designed for dementia caregivers. First, study outcomes were assessed both immediately after the conclusion of the program and at six months post-program. As with all behavior-change interventions, this longer-term follow-up is useful when attempting to



assess whether program effects can be sustained over time (van der Bij, Laurant, & Wensing, 2002). In the case of dementia caregivers, this may be especially important because the demands of caregiving are likely to change as the care recipient's disease progresses. Second, the study design included a comparison group that did not receive an educational or psychosocial intervention, increasing the possibility that program effects can be isolated. Finally, eligible caregivers were randomized to the two study arms, increasing confidence in the between-group comparisons in outcomes.

At the conclusion of *Health First*, program effects were strongest on measures related to physical activity. At initial follow-up, a significant interaction between intervention group and baseline exercise revealed that *Health First* participants who were fairly inactive when they started the program had increased their total amount of exercise per week to a greater extent than did their counterparts in the control group. The finding of a program effect on exercise behavior only among those participants who were less active to begin with is not unprecedented in the literature on exercise interventions for older adults (see, e.g., Jarvis, Friedman, Heeren & Cullinane, 1997), nor is it altogether surprising, given that a ceiling effect may have been present for the more active women. Because the majority of older female caregivers in the general population are not currently exercising at recommended levels, however, even modest increases in exercise among sedentary older adults can have important health benefits. In this way, a program like *Health First* might fill a niche for older women who find it difficult to participate in other types of physical activity programs with more structured requirements, including those that cannot be individually tailored and used at home. For participants who were already active, participation in *Health First* did not lead to significant increases in physical activity over the program period. Program effects on exercise outcomes may have been greater if *Health First* recruited only sedentary participants, an approach that has been adopted in a number of physical activity interventions (e.g., Castro et al., 2002; King & Brassington, 1997). Caregivers who were engaging in regular exercise when they agreed to participate in the program may have done so to maintain rather than increase their activity level; thus, creating a ceiling effect for the exercise measure. Although an interest in increasing physical activity level was one of the study criteria, as a practical matter, the counselors encouraged participants to either achieve or maintain a moderate amount of exercise in the face of caregiving demands that are likely to grow more onerous over time.

In an effort to investigate the possibility of a maintenance effect at post-intervention follow-up, the mean change in total weekly exercise was calculated among women in each experimental condition whose exercise levels were above the median at baseline. Results indicated that the exercise levels of this subset of *Health First* participants were essentially unchanged from baseline, while those in the control group decreased slightly. Although this difference did not reach statistical significance, it suggests that *Health First* may have prevented the slight decrease in exercise over the six-month study period that was observed in the control group. By 12 months, however, this trend was not apparent as exercise levels in both groups declined.

Exercise maintenance was further examined in a separate analysis (Connell & Janevic, 2007). At six months after the completion of the program, participants who reported that they were exercising the same or more than they did during the program were compared to those who reported exercising less. In contrast to those who were able to maintain the exercise level they achieved during the program, the "exercising less" group reported significantly lower self-efficacy for exercise, for self-care, and for taking care of their spouse; higher levels of stress and depressive symptoms; and poorer self-rated physical health. A content analysis of responses to an open-ended question about what was helpful in maintaining their exercise routine and what got in the way revealed two major barriers –

issues related to their caregiving role and to their own health. These results confirm that older caregivers face challenges to maintaining an exercise routine that are both typical of older adults and also unique to their caregiving role, demonstrating the need for a more nuanced approach to the measurement and interpretation of maintenance effects in future research. A modest effect of *Health First* on exercise self-efficacy was also observed, both immediately following program participation and six months later. Even at 12 months, caregivers who participated in *Health First* retained the increases (from baseline) in exercise self-efficacy, compared to the control group. This finding suggests that the *Health First* curriculum enhanced participants' confidence that they could exercise when faced with commonly reported barriers (e.g., feeling tired, facing a hectic schedule). Some researchers consider a program's ability to increase physical activity related self-efficacy an important intervention goal unto itself, because this construct has been shown to be a strong predictor of physical activity (King et al., 1992; King et al., 2006; Sallis & Owen, 1999). It is interesting to speculate about why a maintenance effect for exercise self-efficacy was discovered but not for exercise. The self-efficacy measure may be more sensitive than the exercise measure. Alternatively, self-efficacy for a particular behavior may be more robust and less prone to diminishing over time than the actual behavior. By emphasizing the link between overall self-care and the ability to take care to their spouse in program materials and by providing opportunities for setting and achieving realistic exercise goals, it was anticipated that *Health First* would increase self-efficacy for self-care; however, no effect was found. It is very possible that the single-item measure of self-efficacy for self-care used in this study did not adequately capture this construct. Also, scores on this measure were high at baseline ( $M = 4.1$  on a 5-point scale,  $SD = 9$ ), creating a ceiling effect and making it difficult to assess change over time. Additional research is needed to understand how self-efficacy beliefs in one domain can "transfer" to other domains or to a more global sense of control and how best to help caregivers build self-efficacy for self-care.

*Health First* had a small but statistically significant effect on perceived stress in the expected direction immediately following the intervention, but this effect was not maintained by 12-month follow-up. Reducing negative affect has been a stated goal of both exercise and caregiving interventions. In general, the former appear to have stronger and more consistent positive effects on psychological outcomes than the latter (Blumenthal & Gullette, 2002). In fact, the psychological benefits of participation in an exercise intervention appear to be relatively robust regardless of program format or type of exercise, and range from improving mood to reducing anxiety and depression (Blumenthal & Gullette, 2002; Netz et al., 2005). Most importantly, the finding that participation in *Health First* resulted in a reduction in perceived stress corroborates findings reported by King and Brassington (1997) that dementia caregivers can reap significant psychological benefits from exercise (King et al., 2002). The next step, though, is to identify how interventions can help caregivers to sustain the short-term benefits of participation over time, even when their caregiving situation and demands of the role change (King et al., 2002).

One goal shared by a wide variety of caregiver interventions, including support groups, psychoeducational programs, and respite care, is to alleviate caregiver burden and stress. The bulk of the evidence suggests, however, that dementia caregiver interventions have only infrequently had a significant and long-term effect on commonly-used measures of burden (Acton & Kang, 2001; Sorensen, Pinquart, & Duberstein, 2002). Consistent with this pattern, *Health First* did not impact subjective caregiver burden although it could be argued that exercise might mitigate feelings of being upset by caregiving tasks via improved psychological state. Additional research is needed to examine the interface between self-care practices among caregivers and perceptions of the caregiving experience.

## Limitations

Several study limitations should be noted. First, the *Health First* sample is unlikely to be representative of the general population of female spouse dementia caregivers. Among the portion of the sample that was recruited from a clinical database, about one-third of eligible caregivers agreed to participate. It is difficult to compare this to an “average” response rate in caregiver intervention research because most comparable studies recruit participants on a voluntary basis (e.g., via service organizations or local media) and thus do not have clear sampling frames from which to base a response rate.

The generalizability of results is also limited by the fact that the *Health First* study sample was overwhelmingly White and well-educated and entirely female and English-speaking. The extent to which this program would be appropriate and efficacious among diverse groups of caregivers is unknown. Because the telephone format of the intervention has the potential to reach caregivers in a wide variety of settings and of diverse ethnicities (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006) and the content and approach can be tailored to accommodate a range of abilities and goals, testing a program like *Health First* among more varied groups of caregivers should be a high priority.

An additional limitation is related to the measurement of exercise behavior. Physical activity was measured with a self-reported one-week recall of time spent on three types of exercise. Although this approach has been used successfully in past intervention research with older adults (Lorig et al., 1993; Lorig et al., 1996; Lorig et al., 1999; Lorig et al., 2005; Lorig et al., 2006; Lorig et al., 2008; Lorig et al., 2008), it may offer a less accurate picture of changes in physical activity over the project period than, for example, exercise stress tests, pedometers, or measures of strength and flexibility. More rigorous and sensitive measures of moderate-intensity physical activities favored by older adults should be developed for future research, balanced with the need to limit respondent burden (for additional discussion of this issue and examples of measures developed specifically for older adults, see van der Bij et al., 2002).

A behaviorally-specific approach to the measurement of self-efficacy for self-care is also recommended for future research, as per social cognitive theory (Bandura, 2001). It is very possible that caregivers might report high levels of self-efficacy for one aspect of self-care (e.g., eating nutritiously) but low levels of self-efficacy for other aspects (e.g., managing stress). One such measure that reflects the multi-dimensional nature of self-care and was designed with caregivers in mind may provide a more sensitive test of the ability of a behavioral intervention to impact efficacy beliefs (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). A final caveat relates to the individually-tailored approach incorporated in the *Health First* curriculum. Participants were encouraged to set their own goals and to select activities that were realistic and appealing. For some participants, an appropriate long-term goal might be to walk around the block twice a day; for others, it might mean adding a stretching component to an already rigorous cardiovascular workout routine. In this way, it is likely that no two caregivers in the study followed exactly the same exercise regimen during the project period, making it more challenging to quantify program success. On the other hand, individually-tailored exercise programs have been highly recommended because they can be responsive to the unique barriers faced by older adults, particularly those that serve as a primary caregiver (Brawley, Rejeski, & King, 2003).

Additional research and reflection is needed to best determine the appropriate outcome measures for caregiver interventions, the amount of behavior change required to conclude that a program is successful, and the time frame that is optimal to capture program effects. What is the benchmark for success of caregiver interventions that focus on self-care (i.e., physical activity, nutrition, sleep hygiene)? Should results be compared to other similar

behavior-focused interventions designed for older adults in general or for other non-dementia caregiving populations? Or, should results be compared to other dementia caregiver interventions that aim to reduce stress and burden or to other interventions designed for spouse caregivers? Is it feasible to expect long-term program impacts when the demands and responsibilities of the caregiving role can change (sometimes suddenly and dramatically) over time? More discussion of these issues would help to inform next steps for future caregiver interventions and to maintain realistic expectations for possible intervention outcomes (Marcus et al., 2006; Sorensen et al., 2002).

In conclusion, results from this study suggest that a telephone-based exercise intervention for older women caring for a spouse with dementia may be effective at increasing physical activity in the short-term, especially among sedentary caregivers, and may also help reduce stress. *Health First* was also successful in increasing self-efficacy for exercise even six months after the program had ended. Although a cost-benefit analysis was beyond the scope of this study, the telephone modality is relatively inexpensive (see, for example, Marcus et al., 2006) and may be delivered by a variety of existing community-based groups (e.g., local chapters of the Alzheimer's Association). Therefore, a program like *Health First* may be a valuable addition to the current complement of support groups, educational programs, and respite opportunities currently offered by health and social service providers to families caring for a loved one with dementia.

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**Table 1**  
 Baseline sociodemographic, physical health, and caregiving characteristics of study sample<sup>a</sup>

Variable	Total sample (N=137)		Intervention (N=74)		Control (N=63)		Test Statistic (df)	P value
	M (SD) or %		M (SD) or %		M (SD) or %			
Age in years (range 40–87)	66.8 (9.4)		66.0 (9.8)		67.7 (9.0)		t (135) = 1.06	0.29
Education								
High school or less	34.3%		27.0%		42.0%		$\chi^2$ (2) = 4.72	0.10
Some college	41.6%		43.2%		39.7%			
College degree or higher	24.1%		29.7%		17.5%			
Race (% White)	92.7%		91.9%		93.7%		$\chi^2$ (1) = 0.16	0.76
Employed full/part-time	21.9%		18.9%		25.4%		$\chi^2$ (1) = 0.84	0.24
Self-rated physical health (1=poor, 5=excellent)	3.1 (0.9)		3.0 (0.9)		3.2 (0.9)		t (135) = 1.26	0.21
Number of chronic health conditions (range 0–5)	1.6 (1.1)		1.6 (1.1)		1.6 (1.0)		t (135) = -0.10	0.92
Physical functioning scale (range 8–24)	21.0 (3.2)		20.9 (3.1)		21.1 (3.4)		t (127) = 0.46	0.65
Engages in regular physical activity <sup>b</sup>	20.4%		16.2%		25.4%		$\chi^2$ (1) = 1.76	0.13
Objective caregiver burden (range 0–24)	9.3 (3.8)		9.0 (3.8)		9.7 (3.9)		t (135) = 0.93	0.36

<sup>a</sup> Sample includes participants who provided both baseline and 6-month follow-up data.

<sup>b</sup> Activity vigorous enough to work up a sweat for at least 20 minutes, 3 times/week.



**Table 2**

Means and standard deviations of study outcomes at baseline, 6 months, and 12 months<sup>a</sup>

	Baseline (n=137)			6 months (n=137)			12 months (n=130)					
	Intervention (n= 74)	Control (n= 63)	t (df)	P value	Intervention (n= 74)	Control (n= 63)	t (df)	P value	Intervention (n=69)	Control (n=61)	t (df)	P value
Total exercise/week score <sup>b</sup>	5.2 (2.2)	5.4 (2.6)	0.50 (133)	0.62	7.0* (2.7)	5.8 (2.7)	-2.57 (131)	0.01	6.1 (2.5)	5.9 (2.8)	-0.33 (124)	0.74
Self-efficacy for exercise	5.0 (2.2)	5.2 (1.8)	0.59 (135)	0.56	5.8* (2.1)	5.0 (2.2)	-2.24 (135)	0.03	5.5* (2.3)	4.7 (2.2)	-2.04 (128)	0.04
Self-efficacy for self-care (1=low, 5=high)	4.0 (1.0)	4.3 (0.8)	1.56 (133)	0.12	4.3 (0.9)	4.3 (0.7)	-0.31 (134)	0.98	4.4 (0.9)	4.4 (0.8)	0.26 (127)	0.79
Depressive symptoms (0 = low, 22 = high)	9.4* (2.9)	7.9 (2.8)	-2.99 (131)	0.00	8.1 (3.0)	8.3 (2.9)	0.39 (120)	0.21	8.5 (2.8)	7.7 (2.7)	-1.62 (127)	0.11
Perceived stress (0 = low, 4 = high)	1.9 (0.5)	1.8 (0.5)	-0.70 (135)	0.48	1.7 (0.6)	1.8 (0.6)	1.17 (135)	0.24	1.8 (0.6)	1.7 (0.6)	-0.63 (128)	0.53
Subjective caregiver burden (0 = low, 120 = high)	14.7 (11.5)	14.4 (9.1)	-0.16 (135)	0.88	12.9 (10.9)	13.4 (10.0)	0.27 (121)	0.79	13.2 (12.8)	13.4 (11.9)	0.10 (106)	0.92

<sup>a</sup>Baseline and 6 month samples include everyone with baseline and 6-month data; 12-month sample includes everyone with baseline and 12-month data. All intervention group participants completed at least two program sessions;

<sup>b</sup>Sum of aerobic, stretching, and strengthening exercise per week.

Scale values: 1 = none, 2 = < 30 min., 3 = 30–60 min., 4 = 1–3 hours; 5 = >3 hrs,

\* p < 0.05

Table 3

Unstandardized regression coefficients and standard errors for the final regression model examining the effect of participation in Health First at 6 months on study outcomes

Outcome	Age	Illness count	Objective burden	Baseline outcome	Intervention group	Baseline outcome X Intervention group		F value	Treatment effect size <sup>a</sup>
						Model R <sup>2</sup>			
Total weekly exercise (n= 131)	-0.00 (0.02)	-0.40 <sup>^</sup> (0.21)	0.04 (0.06)	-0.32 <sup>***</sup> (0.12)	1.33 <sup>**</sup> (0.43)	-0.49 <sup>**</sup> (0.18)	0.32	9.86 <sup>***</sup>	.15 <sup>b</sup>
Exercise self-efficacy (n= 137)	-0.03 (0.02)	-0.26 (0.16)	0.08 (0.04)	-0.52 <sup>***</sup> (0.08)	0.94 <sup>**</sup> (0.32)	--	0.31	11.79 <sup>***</sup>	.04
Self-efficacy for self-care (n=134)	-0.00 (0.01)	-0.07 (0.06)	-0.00 (0.02)	-0.71 <sup>***</sup> (0.13)	0.07 (0.13)	--	0.41	17.8 <sup>***</sup>	.00
Depressive symptoms (n= 119)	-0.02 (0.03)	0.41 (0.23)	0.00 (0.07)	-0.54 <sup>***</sup> (0.09)	-0.88 <sup>^</sup> (0.49)	--	0.31	10.2 <sup>***</sup>	.02
Perceived stress (n= 137)	0.00 (0.00)	-0.00 (0.04)	-0.01 (0.01)	-0.28 <sup>***</sup> (0.08)	-0.16 <sup>*</sup> (0.08)	--	0.14	4.08 <sup>**</sup>	.03
Subjective caregiver burden (n=123)	-0.04 (0.08)	1.49 <sup>*</sup> (0.72)	0.29 (0.28)	-0.44 <sup>***</sup> (0.10)	-0.71 (1.46)	--	0.20	6.10 <sup>***</sup>	.00

Note. For each model, an intervention group by baseline value of outcome interaction term was added as a final model-building step; where this did not result in a significant incremental increase in R<sup>2</sup>, it was omitted from the final model. Where this term was significant (i.e., total exercise/week), the model was re-estimated with the baseline total exercise centered on its mean;

<sup>^</sup> p < 0.10,

\* p < 0.05,

\*\* p < 0.01,

\*\*\* p < 0.001.

<sup>a</sup> Treatment effect size is represented by squared semipartial coefficients for the treatment group.

<sup>b</sup> Calculated for the group of participants who scored at or below the median total exercise score at baseline; n=80.

Table 4

Unstandardized regression coefficients and standard errors for the final regression model examining the effect of participation in Health First at 12 months on study outcomes

Outcome	Age	Illness count	Objective burden	Baseline outcome	Intervention group	Baseline X Intervention group	Model R <sup>2</sup>	F value	Treatment effect size <sup>a</sup>
Total weekly exercise (n= 124)	-0.01 (0.02)	-0.07 (0.20)	-0.00 (0.06)	-0.42*** (0.10)	0.34 (0.43)	--	0.16	4.40**	.00
Exercise self-efficacy (n=122)	-0.02 (0.02)	-0.24 (0.16)	0.07 (0.04)	-0.36*** (0.08)	0.96** (0.33)	--	0.21	6.57***	.05
Self-efficacy for self-care (n=119)	-0.00 (0.01)	-0.01 (0.07)	-0.01 (0.02)	-0.61*** (0.09)	-0.03 (0.14)	--	0.32	11.1***	.00
Depressive symptoms (n= 117)	0.00 (0.02)	0.06 (0.20)	-0.09 (0.06)	-0.44*** (0.08)	-0.09 (0.44)	--	0.27	8.81***	.00
Perceived stress (n= 122)	0.00 (0.33)	-0.01 (0.04)	-0.00 (0.01)	-0.19* (0.08)	0.01 (0.08)	--	0.06	1.54	.00
Subjective caregiver burden (n= 108)	-0.05 (.12)	0.74 (1.1)	0.19 (0.45)	-0.60*** (0.16)	-1.0 (2.2)	--	0.23	6.12***	.00

Note. For each model, an intervention group by baseline value of outcome interaction term was added as a final model-building step; where this did not result in a significant incremental increase in R<sup>2</sup>, it was omitted from the final model. Where this term was significant (i.e., total exercise/week), the model was re-estimated with the baseline total exercise centered on its mean.;

\* p < 0.05,

\*\* p < 0.01,

\*\*\* p < 0.001.

<sup>a</sup>Treatment effect size is represented by squared semipartial coefficients for the treatment group.