

The Case for Exercise as a Therapeutic Modality for Home Caregivers of Dementia Patients

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Abstract

Background: The US healthcare system has become reliant upon family members to provide in-home care to ill relatives. Consequences from the stress of caregiving are well documented, with morbidity and mortality higher in caregivers of patients with dementia.

Purpose: Evaluate the potential for exercise as an intervention to improve the physical and psychological wellbeing of home-bound caregivers.

Aim: Identify exercise barriers to caregivers, investigate the effects of caregiver-specific exercise programs, and evaluate the viability of implementing such programs within the home.

Hypothesis: Caregivers of dementia patients may specifically benefit from interventions focused on fitness to improve strength and stamina while concomitantly ameliorating anxiety and depression. Moreover, the institutionalization of care recipients could potentially be delayed when cared for by more active and less despondent home providers.

Keywords: Caregiving; Alzheimer's disease; Chronic stress; Depression; Anxiety; Physical activity; Fitness; Quality of life

Background

The adverse effect of caregiving is well documented. Caregiver burden is now recognized as the psychosocial and physical reaction to the demands placed upon the caregiver. Caregivers who report the highest levels of burden tend to have limited personal time and financial resources, the least amount of outside assistance, and spend a longer period of time providing care [1]. Researchers continue to find that caregivers have a significantly lower self-described physical health status when compared with non-caregivers [2].

Recently, 60% of caregivers reported fair or poor health status, one or more chronic conditions, or at least one disability as compared to only 30% of non-caregiver peers [3]. Ho et al. also reported that caregivers were twice as likely as non-caregivers to report having heart disease, cancer, diabetes, or arthritis. In a meta-analysis, investigators noted that caregivers had 23% higher levels of stress hormones and 15% lower levels of antibody responses compared to non-caregivers [4]. This subsequent loss of immune function [5] has been shown to lead to recurrent infections [6], additional rates of cancer incidence [7], chronic heart disease [8], higher blood pressure [9], and elevated secondary stressors [10], such as sociodemographic factors including their financial standpoint and demands of care required for the situation; all of which leads to an increased risk of mortality [4,11,12].

The purpose of this review is to evaluate the potential for exercise as an intervention to improve the physical and psychological well-being of home-bound caregivers, leading to reduced morbidity and mortality rates. We aim to identify exercise barriers within the caregiver population, investigate the effects of caregiver-specific exercise programs, and evaluate the viability of implementing such programs within-the-home rather than a gym setting. We hypothesize that caregivers of dementia patients may specifically benefit from interventions focused on fitness to improve strength and stamina while concomitantly ameliorating anxiety and depression. Moreover, the institutionalization of care recipients could potentially be delayed when cared for by more active and less despondent home providers.

Introduction

The stress of caregiving is a multidimensional state [13] capable of influencing physical and mental health, family finances and time organization. These influences have been shown to adversely affect the caregivers of patients with dementia [14-16] in some cases to a greater degree than in the caregivers of non-demented patients due to the higher demands and chronic stress placed on dementia patient caregivers [17]. Moreover, caregiver burden is a multifactorial condition [18] in which various physical, psychological and personal factors interact and are interdependent [19]. Elements such as family and financial circumstances of the caregiver, their psychological resources, support system and training, along with the caregiver's satisfaction with their caregiving role and their relationship with the care recipient, all have an influence on the caregivers stress level [20]. In aggregate, these stressors all play an integrated role which may serve to negatively affect the overall health of caregivers.

Exposure to the chronic stress of caregiving, leading to an escalation in hypothalamic-pituitary-adrenal (HPA) axis activity and greater cortisol production, is associated with an increased risk of developing obesity [21], cardiovascular disease [22], hypertension [23] and type 2 diabetes [24]. Aberrant production of cortisol in caregivers is an indication of a dysregulated HPA axis and has been proposed as one physiological pathway mediating the link between the chronic stress of caregiving and the immunologic decline in caregivers [25].

The psychological and physical demands of caregiving for a spouse with a degenerative disease, e.g. dementia, are expected to last an average of 3-15 years [4]. Similarly, non-elderly caregivers of medically frail children have reported the psychosocial demands of caregiving extending into late adulthood [26]. Both older adults [4] and younger adult caregivers [27] report significant psychological morbidity associated with the caregiving experience. Additionally, findings have demonstrated dysregulation of the HPA axis [25] and immunologic defense mechanisms [28] in these populations.

Studies have demonstrated that caregiver stress can elevate proinflammatory biomarkers, e.g IL-1 and IL-6, which have been implicated as physiological markers of the frailty syndrome [29]. Indeed, studies have linked the chronic stress of caregiving with accelerated aging of the immune system which increases susceptibility for age-related diseases. Kiecolt-Glaser et al. and Segerstrom and colleagues revealed that IL-6 levels were four times higher in elderly caregivers of dementia patients when compared with age-matched controls [30,31]. Consequently, the immune system precipitately declines in chronically stressed caregivers which fosters greater vulnerability for age-related diseases [30]. Miller et al. proposed glucocorticoid receptor desensitization on macrophages and the concomitant inability to terminate the inflammatory cascade as one possible physiological mechanism of immunologic disinhibition in the chronically stressed [32]. These findings suggest that the persistent stress of caregiving can escalate the typical, age-related increases in physiological markers of frailty through the hyperactive HPA axis.

Dysregulation of *in-vitro* markers of cellular immunity has also been demonstrated in elderly caregivers. These include proliferative response to mitogenic stimulation [33], mitogen-induced IL-1 secretion [34], NK cell activity [35], Th1-induced secretion of enriched Natural Killer cells [36], Th1 cytokine activity [37], and telomerase activity and telomere length [33]. In line with these findings, hyperactivity of the HPA axis in caregivers has been implicated as a possible physiological intermediary coupling the chronic stress of caregiving with the subsequent deterioration of cellular immunity [38]. Overall, these findings suggest that increased morbidity and mortality in caregivers may be the consequence of a chronic maladaptation of the HPA axis to the recurrent and protracted stress of long-term caregiving [39].

Methods

Regular participation in physical activity is one of the most effective ways to prevent obesity, cardiovascular disease and other morbidities as well as improve quality of life, increase functional independence and inhibit chronic depression in older adults with and without disabilities. In order to implement this behavior change, alternative, innovative, long-term, economically feasible interventions and therapeutic approaches are needed for individuals who are home-bound due to caregiving responsibilities. Research has demonstrated the positive outcomes of psychoeducational approaches, yet there is a scarcity of studies investigating the overall effect of an exercise program in caregiving populations.

No funding was received for this review. The Horvath Performance Laboratory of the Department of Exercise and Nutrition Sciences (University at Buffalo) is the Sponsor. Studies were selected according to the criteria outlined below. Study designs included randomized controlled trials (RCTs), including cluster RCTs, controlled (nonrandomized) clinical trials (CCTs) or cluster trials, interrupted time series (ITS) studies with at least three data points before and after the intervention, controlled before-after (CBA) studies, prospective and retrospective comparative cohort studies, and case-control or nested case-control studies. Cluster randomized, cluster non-randomized, or CBA studies included only if there are at least two intervention sites and two control sites. We excluded cross-sectional studies, case series, and case reports. Participants included studies examining the caregiving population (18 years or older). Literature search strategies developed using medical subject headings (MeSH) and text words related to caregiving and exercise. We searched MEDLINE (OVID interface, 1980 onwards) and Web of Science.

Results

The literature reveals there is no distinct, easily implemented and consistently effective method for achieving improved health in all caregivers [40]. A one-size-fits-all approach to supporting caregivers may not be useful as caregivers have a diverse array of needs and thus it cannot be assumed the same intervention will work among caregivers of different backgrounds and cultures [41]. As Knight and colleagues found in their meta-analysis, most interventions report some level of success and thus may provide valuable insight regarding different approaches for achieving positive results [40]. The group further found a strong consensus exists that all caregivers are likely to benefit from enhanced knowledge about their caregiving role, the care recipient's disease and locally available resources, as well as training in general problem-solving and behavior management skills or caregivers' emotional response to caregiving. Additionally, psychological interventions in caregivers of dementia patients have provided evidence of enhanced mental health [42,43]. Caregiver burden and depression have also been found to diminish [44] and quality of life improve [45] through telephone counseling, support groups and educational programs.

However, research findings emphasizes the need to consider exercise as well, not only as a caregiving intervention, but also as a key lifestyle modification [46,47]. Dementia patient caregiving is in many ways a "vocation," and a key aspect of this conceptualization is the recognition of various transitions that can occur for family caregivers during the course of dementia care [44,48]. By moving beyond exercise as an intervention and instead considering it as a transition, the current body of research demonstrates that exercise offers benefits to the caregiver long after caregiving has ended. Indeed, approaches that promote health both during and after arduous dementia patient caregiving may offer similar benefits to those caring for elderly relatives with other less demanding chronic diseases [49]. Hence beyond the standard benefits the population at large can stand to gain from participating in habitual exercise, senescent caregivers of dementia patients can specifically benefit from interventions focusing on physical fitness.

While existing research has reliably demonstrated the positive effects of psychosocial and educational approaches [50,51] there is a

paucity of compelling studies investigating the overall effect of an exercise program in caregivers. Hirano and colleagues intervened exclusively with exercise prescription, offering neither counseling nor educational services [46]. They found significant improvements in caregiver burden, fatigue frequency and sleep quality. Additionally, King and Brassington reported that a significant proportion of caregivers rated "improving their physical activity levels" more desirable than "stress management" or other types of health promotion programs (e.g. nutrition, weight control) [52].

Discussion

The benefits of exercise have been thoroughly explored in both healthy and diseased states. Increased physical activity levels are known to contribute to the prevention of coronary artery disease and reduce symptoms in patients with established cardiovascular disease [53]. Habitual exercise has also been shown to reduce the risk of other chronic diseases, including obesity [54], osteoporosis [55], type 2 diabetes [56], depression [57], breast [58] and colon cancer [59], as well as decreasing overall mortality rate [60]. Conversely, it has been reported that lower levels of physical activity increase the risk of cardiovascular disease [61], hypertension [62], various cancers [63], type 2 diabetes [63] and depression [64]. Additionally, individuals with higher physical activity levels have greater sleep quality compared to those with lower physical activity [65]. This is notable given that family caregivers as a group tend to suffer from poor sleep patterns [66]. Moreover, the mortality rate of sedentary individuals is significantly higher than that of physically active individuals [67].

Despite encouragement by government and private agencies to exercise regularly, it has been shown that senescent caregivers take part in limited leisure time physical activities [68]. Indeed, the burden of caregiving has been associated with reduced levels of physical activity because strained caregivers have little time to engage in exercise [69,70]. More recently, von Kanel and colleagues corroborated previous studies showing that caregivers, when compared to noncaregivers, are physically less active and show greater cardio-metabolic risk [71]. Not all studies find caregivers are less physically active than non-caregivers. Lack of opportunity to engage in exercise may depend on caregiver burden, the extent of social support, severity of stress exposure, and health of the care recipient. However, taken together, both the physical health and psychological well-being of aging caregivers may be at increased risk due to an overall reduced opportunity for regular exercise. Consequently, interventions aimed at increasing physical activity in caregivers seem warranted as a feasible means to possibly reduce caregiver morbidity and mortality rates to a level seen in their non-caregiving counterparts. In light of the physical and psychological challenges of caregiving, coupled with the complementary benefits of exercise and caregivers' interest in improving their fitness, the need for developing exercise interventions aimed specifically for caregivers is incontrovertible.

Under the President's Council on Fitness, Sports and Nutrition Program, exercises requiring moderate muscular and aerobic strength and endurance (such as walking, cycling and gardening) as well as balance and stretching activities are all endorsed and promoted [72]. While such moderate-intensity physical activity (3-6 METS) may not show appreciable increases in standard measures of fitness (e.g. a treadmill exercise test), an increasing number of studies demonstrate that exercise stimulus of a more modest level can result in significant health benefits irrespective of changes in VO₂ max or other fitness parameters [52,73-75]. Typically, higher exercise intensities result in greater benefits. Yet such intensities may be unachievable when the target population is of an older demographic. Various low to moderate-intensity physical activity approaches (e.g. Tai Chi and Yoga) have been shown to be effective at improving measures such as balance, coordination, reaction time and function [76,77]; as well as mood [78],depression [79],anxiety [80],blood pressure [77], physical pain [81] and cortisol levels [78,81]. These results highlight not only the appropriateness, but the physical and psychological efficacy of such modest exercise interventions when specifically tailored to the situational constraints of older, homebound caregivers. In sum, these data suggest that low to moderate-intensity physical activity modalities have the potential of ameliorating the correlative maladies widely documented in chronically stressed caregivers.

Non-adherence to the prescription of exercise in older individuals can often make it difficult to estimate the net effect of exercise. A previous study where participants were allowed to evaluate the intensity of their exercise during telephone counseling showed no significant improvement in self-reported physical activity; however, 50% of caregivers reported increased "total minutes" and 42% reported increased "moderate minutes" of physical activity from pre- to postintervention [74]. While studies that combine physical activity with counseling have shown decreased caregiver burden [52,73] another study using a similar paradigm revealed negative effects on caregivers' sense of burden [82]. This may be due to the specific stress associated with their caregiving role remaining fundamentally unchanged upon returning home from exercising. Hill et al. postulated that the accompanying stress experienced after leaving a care recipient at home to participate in a physical fitness program elsewhere may increase overall burden and feelings of guilt within the itinerant caregiver [82]. Hence alternative, innovative, long-term, economically feasible exercise interventions and approaches are needed in order to successfully implement this behavioral change.

Although many exercise programs are coached in group settings, it has been reported that exercising on one's own is more appealing [52]. The challenge has been to develop methodologies which provide the continuous instruction, supervision and feedback that have been shown to be principal determinants of program adherence [83] while still allowing individuals the flexibility to choose how and when to exercise. The development of home-based approaches has demonstrated promise in facilitating long-term exercise adherence with a minimal amount of direct contact. Originally tested with cardiac patients [84], this approach has been utilized in a variety of populations, including the obese [85], the middle-aged [86] and samples of older adults [87]. Results have provided credible evidence of the effectiveness and safety of home-based physical activity regimens.

The few exclusively in-home exercise interventions designed for caregivers vary in the time commitment. King and colleagues showed promising results diminishing stress-induced blood pressure reactivity with concomitant improvements in rated sleep quality through the use of exercise videos and indoor stationary cycling [88]. However, this 12month protocol required at least four 30- to 40-minute exercise bouts per week, which may not be feasible for caregivers of dementia patients given their extensive health care obligations. Consequently, Connell and Janevic encouraged a group of dementia patient caregivers to exercise in shorter sessions, supplying videotapes of low-impact aerobic dance appropriate for individuals with limited mobility [89]. Rather than advocating a "cookie cutter" approach to exercise prescription, individualized goals were set, resulting in enhanced exercise self-efficacy and decreased perceived stress. While most

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physical activity interventions have asked caregivers to exercise continuously for 30-minute bouts, a recent study by Marquez and colleagues found dementia patient caregivers preferred exercising in multiple 10-minute sessions when compared to non-caregivers in order to meet physical activity guidelines [90]. Therefore, it is hypothesized that this type of flexible exercise prescription is more appropriate for strained caregivers of dementia patients who often describe limited time as a barrier to exercise [71]. Investigating the efficacy of such programs in the caregiving population, who have unequivocal time constraints and elevated levels of burden, is the next logical phase in this area of research.

Conclusion

As the number of individuals with dementia increases, so too will the number of caregivers. The need for physical activity interventions in the caregiving population is exhibited by their low levels of exercise, poor mental health, significantly greater stress, anxiety, depression and deleterious physical condition. Furthermore, caregivers have lower exercise self-efficacy, social support to exercise and greater perceived barriers to exercise than non-caregivers [90].

Regular exercise may increase the strength and stamina needed to perform the demanding physical tasks of caregiving while reducing stress, anxiety, depression and fatigue. Additional studies are necessary to evaluate the viability of implementing these interventions through the use of modern technology to bring in-home, truncated bouts of exercise to today's overburdened caregivers. Feasibility and costeffectiveness studies are also needed to evaluate the role of caregiver physical activity relative to other interventions as they apply to the health of the care recipient. Caregivers with compromised physical and emotional welfare are less likely to provide quality care due to their own ailing health [91-93]. Therefore, the institutionalization of elderly care recipients could potentially be delayed when that care is administered by more active, healthier and less despondent providers. Consequently, there is a clinical, economic and moral imperative to develop physical fitness interventions with specific strategies for overcoming the recognized exercise barriers and underlying obstacles to improve the aggregate health and quality of life of family caregivers.

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