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ASSOCIATION BETWEEN PHYSICAL ACTIVITY, GENERAL HEALTH AND BURDEN OF DEMENTIA CAREGIVERS

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ABSTRACT

Most caregivers do not engage in physical activity programs despite evidence that physical exercise improves general health and relieves symptoms of depression, anxiety and stress. The aim of the study is a) to investigate the amount of physical activity of caregivers in everyday life, b) to examine the reasons of limited participation in physical activities and c) to find out if limited participation in physical activity affects their general health. Fifty three (n=53) caregivers (59.04±12.76 yrs) were recruited by a Dementia Day Care Center. A caregiver questionnaire was designed to obtain information on basic demographics, living habits and current care details (hours of care, etc). The Greek version of PASE questionnaire was used to measure the amount of physical activity undertaken by caregivers. Caregiver burden was assessed via the Greek version of the validated Zarit burden interview and general health was investigated via the Greek version of General Health Questionnaire (GHQ-28). All data were analyzed by using SPSS, version 22. The majority of caregivers are daughters or wives. The current sample had a PASE mean score of 168.0±87.46. Differences in PASE score were found between occupational status (F=6.210, p=0.001) and living arrangements (F=3.882, p=0.05). No differences were found in PASE score between different levels of burden (F=1.058, p=0.376). PASE score was not related to GHQ28 scores. High correlations were found between ZBI and GHQ28 total (r=0.71, p=0.001) and ZBI and GHQ28 four subscales (somatic: r=0.62, p=0.001, anxiety-insomnia: r=0.66, p=0.001, social dysfunction: r=0.54, p=0.002, severe depression: r=0.44, p=0.003). ZBI was also correlated with years of care (r=0.38, p=0.004) and hours of care/day (r=0.40, p=0.003). The most frequent barriers to physical activity cited by caregivers were their living arrangements and their occupational status. In addition, burden was not cited as a significant barrier.

Contribution/Originality: This study is one of very few studies which have investigated the amount of physical exercise of dementia caregivers and connects it with other important aspects of caregiving, as general health and their burden. Additionally, this paper explores the possible reasons that caregivers do not engage in physical exercise.

1. INTRODUCTION

A number of longitudinal cohort studies (Hamer and Chida, 2009; Sofi *et al.*, 2011) and several meta- analyses (Norton *et al.*, 2014; Baumgart *et al.*, 2015) have focused on the protective role of physical activity in middle age against cognitive decline and dementia. Given the prevalence of dementia worldwide, due to the growth of elderly population (Prince *et al.*, 2015) governments must be prepared to address the health impact of affected patients and their caregivers. Caregivers are typically family members or friends who provide unpaid care to persons with dementia. The negative consequences of caring are well described (Joling *et al.*, 2010; Musich *et al.*, 2017). Research shows that caregivers suffer from depression, anxiety and poor physical health (Oyebode, 2003). Studies have revealed that caregivers of various patients are exposed to different risk factors for musculoskeletal disorders (Nelson *et al.*, 2006; Tinubu *et al.*, 2010; Sharan *et al.*, 2012). Although physical exercise has been found to reduce risk of cardiovascular disease, minimize falls and to improve balance, gait, endurance and general quality of life (Dubbert, 2002; Blake *et al.*, 2009) it has been shown that caregivers engage in less physical activity and participate in fewer formal physical activities compared with non-caregivers (Burton *et al.*, 1997; Fredman *et al.*, 2006). In general, despite recommendations by health professionals, it has been shown that elderly caregivers take part in few physical activities (Wilcox *et al.*, 2000) and do not engage in recommended physical activity levels (Gallant and Connell, 1997). The physical health of caregivers of people with dementia might be at high risk due to their reduced opportunities for physical exercise. Although many studies have been conducted examining the effects of caregiving on psychological health of caregivers, much less research is available on the impact of reduced physical activity.

Thus, the aim of the present study is a) to investigate the amount of physical activity of caregivers in everyday life, b) to examine and highlight the reasons of limited participation in physical activities and c) to find if limited participation in physical activity affects general health.

2. METHODS

2.1. Participants

All fifty three (n=53) participants (59.04±12.76 yrs) were caregivers of elderly people diagnosed with dementia and were attending the Dementia Day Care Center's programmes. The study was approved by the Ethics committee of the Greek Alzheimer Association, and all caregivers provided their written informed consent after a detailed description of the study.

2.2. Assessment of Caregivers

Three assessment tools were used:

1). The Greek version of PASE questionnaire, which is a validated 12-item self- administered document that is designed to measure the amount of physical activity undertaken by people over the age of 65. The PASE assesses the types of activities typically chosen by older adults such as walking, recreational activities, housework and caring for others. It uses frequency, duration and intensity level of activity over the previous week to assign a score, ranging from 0-400, with higher scores indicating greater physical activity (Washburn *et al.*, 1993; Kriska and Caspersen, 1997; Schuit *et al.*, 1997; Loland, 2002).

2).The Greek version of the ZBI which consists of 22 questions about the impact of the patient's disabilities on the caregiver's life (Zarit *et al.*, 1980). Total score ranges from 0 to 88, with higher scores indicating greater caregiver's burden. According to Karlikaya *et al.* (2005) zero to 20 points indicates little or no burden, 21 to 40 points, mild to moderate burden, 41 to 60 points, moderate to severe, and finally 61 to 88, severe burden, and

3). The Greek version of General Health Questionnaire (GHQ-28) which investigates general health (Garyfallos *et al.*, 1991). The response is in a 4-point scale. It consists of four 7 item scales: 1. somatic symptoms, 2. anxiety and insomnia, 3. dysfunction and 4. severe depression. For each item, four answer possibilities are available (- not at all, 2-no more than usual, 3-rather more than usual, 4-much more than usual). The higher scores indicate poorer caregiver psychological well-being (Nagyova *et al.*, 2000). The caregivers' questionnaire was designed to obtain information on basic demographics, living habits and current care details.

2.3. Statistical Analysis

Data were analyzed using the Statistical Package for Social Sciences (IBM 22, USA). Descriptive statistics were carried out for all variables. All data were reported as Mean ± SD. Median was used for GHQ-28 score (Willmott *et al.*, 2004). The Independent sample T-test was used to examine differences between groups. Pearson's correlations coefficient was computed to estimate the association between variables. A one-way analysis of variance (Anova) was used to determine the relationship between dependent variables (PASE, GHQ-28, ZBI) and independent variables (age of carers, education, sex etc). Statistical significance was set at $p<0.05$.

3. RESULTS

Demographic profile of 53 caregivers of the study is shown in Table 1.

Table-1. Demographical description of caregivers (Mean±sd , %)

Variables	**Mean±sd , %**
Description of caregivers	
Age	59.04±12.77
Sex	
Female	67.9% (n=36)
Male	32.1% (n=17)
Years of education	
1-12	34% (n=18)
+ 12	43.4% (n=23)
Employment	
Full- time	22.6% (n=12)
Part-time	17% (n=9)
Retired	34% (n=18)
Unemployed	22.6% (n=12)
Other	3.8% (n=2)

The characteristics of care and patients' profile are presented in Table 2.

Table-2. Characteristics of care (Mean, SD, %, n)

Variables	**Mean, SD, %, n**
Caregiver status	
Primary	73.6% (n=39)
Secondary	26.4% (n=18)
Relationship to care-recipient	
Children	49.1% (n=26)
Spouses	41.5% (n=22)
Brother/Sister	5.7% (n=3)
Other	3.8% (n=2)
Paid caregivers	
Yes	22.6% (n=12)
No	77.4% (n=41)
Type of dementia	
Alzheimer	54.7% (n=29)
Vascular	11.3% (n=6)
Other type	13.2% (n=7)
Stage of dementia	
Early	15.1% (n=8)
Middle	67.9% (n=36)
Late	17% (n=9)
Years of disease	4.6±2.9
Years of care	3.9±2.4
Hours of care/day	10.3±8.9
Living arrangements	
Lives with care recipient	67.9% (n=36)
Lives alone	32.1% (n=17)

3.1. Outcome Measures

The current sample has a mean PASE score of 168.0±87.46. Male caregivers had 141.6±66.85 and female 180.5±93.9. No differences were found between male and female. The majority of caregivers (69.8%) had a high (206.41±75.40) PASE score (> 122). The PASE score was analyzed by age and sex of caregivers, level of education, years of care, hours of care/day, type and stage of dementia and no differences were observed. Figure 1 and Figure 2 show the differences in PASE score between different occupational status (F=6.210, p=0.001) and living arrangements (F=3.882, p=0.05). No differences were found in PASE score between different levels of burden (F=1.058, p=0.376). The PASE score was not related to GHQ28 scores.

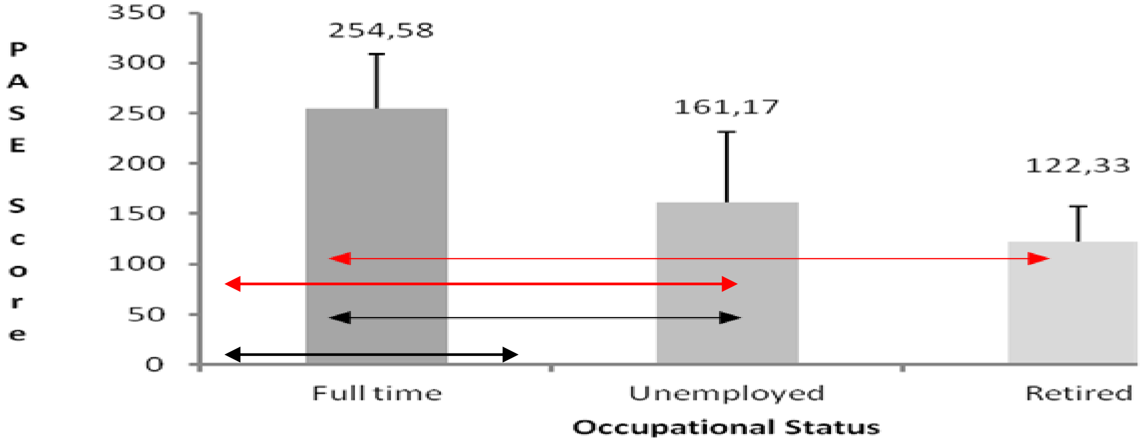

Figure-1. PASE score by occupational status

↔ Indicated difference between full time to retired p= 0.001
↔ Indicated difference between full time to unemployed p= 0.001

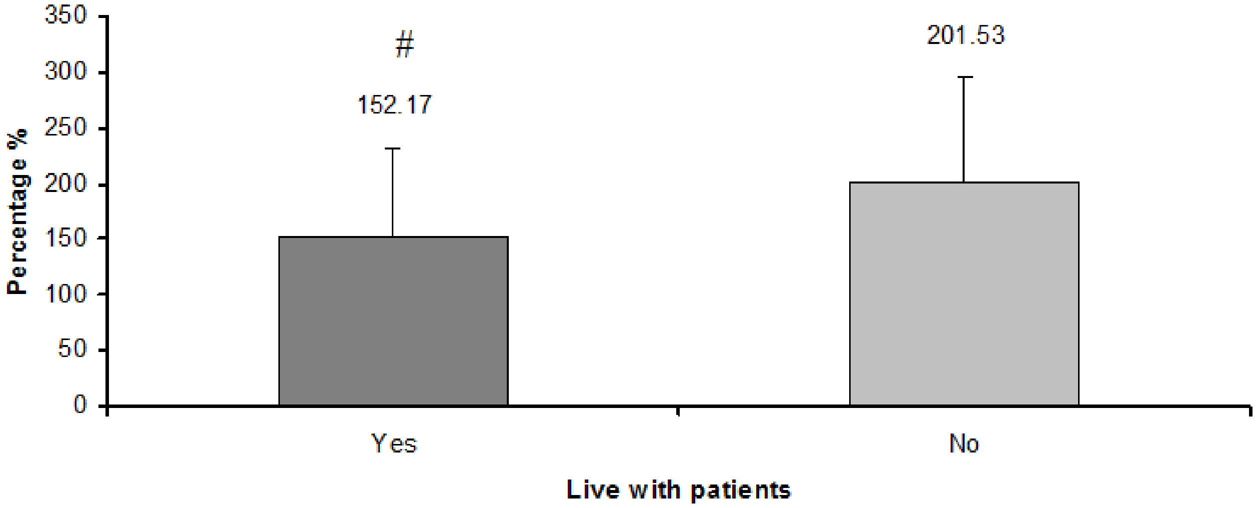

Figure-2. PASE score by living arrangements

indicated difference between those living with patients and those who do not (p=0.05)

The mean ZBI score was 41.8 (±13.8). Although female caregivers had higher scores (44.06±13.8) than their counterparts (37.12±13.13), no statistical significance was found. Most caregivers reported mild to moderate burden (43.4%) or moderate to severe (37.7%) (Figure 3). High correlations were found between ZBI and GHQ28 total (r=0.71, p=0.001) and ZBI and GHQ28 four subscales (somatic: r=0.62, p=0.001, anxiety-insomnia: r=0.66, p=0.001, social dysfunction: r=0.54, p=0.002, severe depression: r=0.44, p=0.003). ZBI was also correlated with years of care (r=0.38, p=0.004) and hours of care/day (r=0.40, p=0.003).

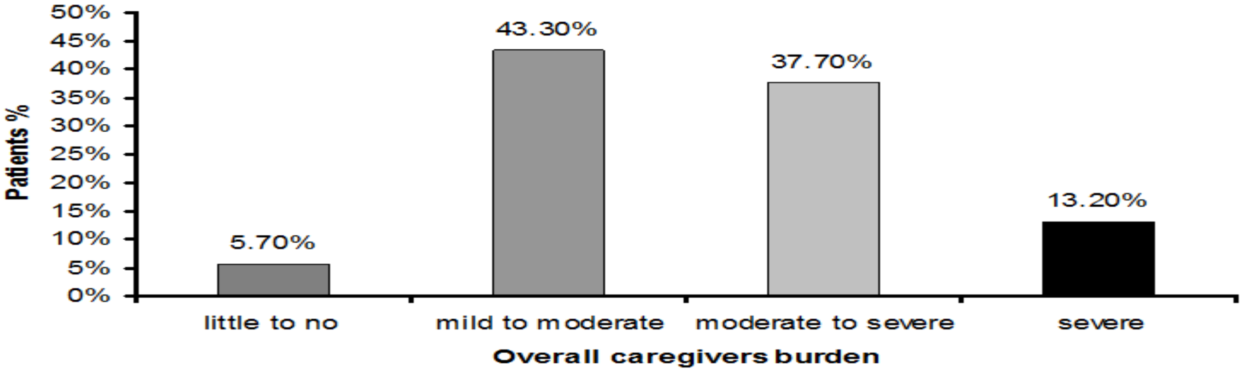

Figure-3. Caregivers burden divided into categories (%)

The GHQ-28 total and subscale scores of caregivers are presented in Table 3. Almost half of caregivers (50.9%, n=27) scored well in health status. 49.1% (n=26) scored more than 4 points. No differences were found in GHQ-28 total and subscale scores when analyzed by age and sex of caregivers, level of education, years of care, hours of care/day and type of dementia. In subscale scores caregivers who looked after patients of middle and later stage of dementia, had higher scores of anxiety-insomnia compared to those in early stage of dementia (F=4.280, p=0.019). Additionally, caregivers living with middle and later stage dementia patients reported high levels of anxiety and social dysfunction (F=4.308, p=0.04 and F=11.700, p=0.001, respectively). GHQ-28 was correlated with years of care (r=0.28, p=0.04), hours of care/day (r=0.43, p=0.001) and hours of care/week (r=0.27, p=0.05).

Table-3. GHQ-28 and subscales scores of caregivers (n=53, median, %)

Variables	Scores (median, %)
GHQ-28 total score	3 (20.8%)
GHQ-28 score < 4	50.9% (n=27)
GHQ-28 score > 4	49.1% (n=26)
GHQ-28 subscales	
Somatic symptoms	0 (50.9%)
Anxiety-Insomnia	1 (18.9%)
Social dysfunction	1 (24.5%)
Severe depression	0 (79.2%)

4. DISCUSSION

A lot of research has been devoted to the impact of dementia caregiving. To our knowledge much less research is available on associations of physical activity with demographic characteristics, general health and burden. The purpose of the present study was to investigate the physical activity levels of dementia caregivers and the association between levels of physical activity, general health, and caregiver burden. A number of interesting findings were revealed from our study.

The majority of caregivers in the current study, as in previously published works (Tang *et al.*, 2013; Andreakou *et al.*, 2016; Shim *et al.*, 2016) were female daughters or wives living with individuals with dementia (Rodríguez *et al.*, 2012; Andreakou *et al.*, 2016).

The mean physical activity score suggested that males were not significantly more active than females, in contrast to other studies (Logan *et al.*, 2013). Previous research (Logan *et al.*, 2013) has investigated the relationship between physical activity, as measured by the PASE, and health parameters. Our study sample compared to the results of previous studies (Chad *et al.*, 2005; Hagiwara *et al.*, 2008; Logan *et al.*, 2013) has higher PASE scores. A possible explanation is that our participants are younger. We also found that physical activity scores were the same between caregivers who experienced limited, moderate or severe sense of burden. With respect to caregiving characteristics, we found a relationship between physical activity and employment. Caregivers who work full time have higher levels of physical activity compared with unemployed and retired caregivers. A possible explanation may be that the PASE questionnaire measures, physical exercise, also housework, yard work and caring for other people, and it is expected caregivers who work full time, as they are younger, to spend a significant time in both physical exercise and other activities. Older people generally prefer to spend more time in light activities such as housework or gardening. On the other hand, people who are unemployed, probably because of the financial difficulties they are facing, follow lower cost activities such as walking or yard work.

The total mean score on the ZBI questionnaire of caregivers of this study (Zarit *et al.*, 1980; Wang *et al.*, 2008; Tang *et al.*, 2013) is higher compared to ZBI scores of previous studies. A number of factors are associated with burden such as gender, age, disease progression, educational level and ethnicity (Chan and Chiu, 2005). In our study, participants were young (59.04±12.76yrs) and mostly female (n=36), and higher levels of burden are associated with these two conditions (Lévesque *et al.*, 1999; Gallicchio *et al.*, 2002).

Furthermore, no difference was revealed in general health between those who reported lower or higher amounts of physical activity. According to past reviews, between 18% and 35% of caregivers perceive their health as fair or poor (Schulz *et al.*, 1995). Two meta-analyses found that caregivers have poorer physical health than non-caregivers both by perceived or objective measures (Pinquart and Sorensen, 2003; Vitaliano *et al.*, 2003). Based on our results, it seems that general health is affected more by burden and characteristics of care (years of care, hours of care/day or /week) than levels of physical activity. Several studies have strongly suggested that physical health of caregivers deteriorated due to longitudinal burden (Epstein-Lubow *et al.*, 2008).

4.1. Limitations and Future directions

Some limitations of the present study should be noted. Firstly, the study included mainly caregivers who make use of the services (such as non pharmacological interventions) provided by the Dementia Day Care Centres to their care-recipients. Secondly, the present study did not include objective measures of physical activity such as a pedometer that could improve accuracy and reduce recall bias. Thirdly, our study population age was under 65yrs, and the PASE questionnaire is designed to measure the amount of physical activity undertaken by individuals over the age of 65yrs. Thus, our results should be generalized with caution.

In the next phase of research, more objective measures should be obtained, for example body composition measures, heart rate, flexibility and strength measures etc. in the caregivers's sample who benefit from Day Care Centres services.

4.2. Conclusions

This study highlights the fact that caregivers do not participate in physical activity more because of their living arrangements and occupational status, rather than because of the burden. From our results, it is evident that burden is associated with caregiving characteristics. Thus, a better understanding of caregivers needs could help us design better interventions, both for them and their patient-recipients.

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