

RESEARCH / ARAŞTIRMA

Impact of a Secondary Caregiver on the Well-Being of Primary Family Caregivers of People with Dementia: A Focus on Physical and Psychological Aspects

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ABSTRACT

Objective: The global number of people with dementia is rising, requiring caregivers from early disease stages. However, the effect of having a secondary caregiver on the primary caregiver's physical and psychological well-being is unclear. This study aimed to compare primary caregivers with and without a secondary caregiver in terms of physical and psychological parameters.

Material and method: This cross-sectional study included 61 primary family caregivers of people with dementia living in Izmir. Based on their caregiving arrangements, participants were categorized into two groups: those caregiving alone (n=26; 42.6%) and those caregiving with a secondary caregiver (n=35; 57.4%). Physical well-being was assessed using the Nordic Musculoskeletal Questionnaire (musculoskeletal disorders), International Physical Activity Questionnaire (physical activity), and Fatigue Severity Scale (fatigue). Psychological well-being was evaluated with the World Health Organization Quality of Life-Bref and Zarit Caregiver Burden Interview scales.

Results: No significant differences were found in psychological measures between groups. However, physical well-being differences were observed. Caregivers without a secondary caregiver spent a significantly higher percentage of their day sitting due to caregiving tasks (p=0.020). They also reported more musculoskeletal symptoms in the spine (p=0.05), upper limbs (p=0.046), and lower limbs (p=0.019) over the past week.

Conclusion: The presence of a secondary caregiver is linked to better physical well-being but does not significantly impact psychological well-being among caregivers of people with dementia. These results underscore the need to provide physical support to caregivers to maintain their well-being. These findings highlight the need for multi-faceted caregiver support programs, particularly in contexts where informal caregiving is culturally embedded.

Keywords: Caregiver, dementia, physical well-being, psychological well-being, secondary caregiver.

Demans Hastalarının Birincil Aile Bakıcılarının Sağlığı Üzerine İkincil Bakım Veren Etkileri: Fiziksel ve Psikolojik Yönlere Odaklanma

ÖZET

Amaç: Dünya genelinde demans hastası sayısı artmakta ve hastalığın erken dönemlerinden itibaren bakım verenlere ihtiyaç duyulmaktadır. Ancak, birincil bakım verenin yanında ikincil bir bakım verenin bulunmasının birincil bakım verenin fiziksel ve psikolojik sağlığı üzerindeki etkisi net değildir. Bu çalışma, ikincil bakım veren bulunan ve bulunmayan birincil bakım verenlerin fiziksel ve psikolojik parametreler açısından karşılaştırılmasını amaçlamıştır.

Gereç ve Yöntem: Bu kesitsel çalışma, İzmir'de bir üniversite hastanesinin nöroloji polikliniklerinden alınan 61 demans hastasının birincil aile bakıcısını içermektedir. Katılımcılar, bakım verme düzenlemelerine göre iki gruba ayrılmıştır: tek başına bakım verenler (n=26; %42,6) ve ikincil bir bakıcıyla birlikte bakım verenler (n=35; %57,4). Fiziksel sağlık, Nordic Kas-İskelet Sistemi Anketi (kas-iskelet sistemi bozuklukları), Uluslararası Fiziksel Aktivite Anketi (fiziksel aktivite) ve Yorgunluk Şiddeti Ölçeği (yorgunluk) kullanılarak değerlendirilmiştir. Psikolojik sağlık ise Dünya Sağlık Örgütü Yaşam Kalitesi Ölçeği-Kısa Formu ve Zarit Bakıcı Yüğü Ölçeği ile değerlendirilmiştir.

Bulgular: Gruplar arasında psikolojik ölçümler açısından anlamlı bir fark bulunmamıştır. Ancak, fiziksel sağlık açısından farklılıklar gözlemlenmiştir. İkincil bir bakıcısı olmayan bakıcılar, bakım verme görevleri nedeniyle günlerinin anlamlı derecede daha büyük bir bölümünü oturarak geçirmiştir (p=0,020). Ayrıca son yedi gün içinde omurga (p=0,05), üst ekstremiteler (p=0,046) ve alt ekstremitelerde (p=0,019) daha fazla kas-iskelet şikâyeti rapor edilmiştir.

Sonuç: İkincil bir bakımverenin varlığı, demans hastalarına bakan birincil bakımverenlerin fiziksel sağlığıyla ilişkilidir; ancak psikolojik iyi oluş üzerinde anlamlı bir etkisi bulunmamaktadır. Bu bulgular, bakımverenlerin sağlıklarını koruyabilmeleri için fiziksel destek sağlanmasının gerekliliğini vurgulamaktadır. Özellikle bakımın kültürel olarak aile içinde yürütüldüğü toplumlarda, çok yönlü bakımveren destek programlarına duyulan ihtiyacı öne çıkarmaktadır.

Anahtar Kelimeler: Bakım veren, demans, fiziksel sağlık, psikolojik iyilik hali, ikincil bakım veren.

1. Introduction

The number of people diagnosed with dementia is increasing globally due to rising average life expectancy and population growth. It is estimated that the worldwide population of people

with dementia (PwD), currently around 50 million, will reach 152 million by 2050 (1). Degeneration in various bodily systems and cognitive decline lead to impairments in daily living activities and a progressive loss of independence in PwD, beginning in the early stages of the disease. Consequently, caregivers are

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required to provide varying levels of support from the onset of symptoms (2, 3). In Türkiye, as in many countries worldwide, informal caregivers—unpaid family members, friends, or acquaintances—play a primary role in home care, despite the presence of formal caregivers (paid professionals) (4, 5).

Caring for a PwD at home poses numerous challenges (6-10). Therefore, caregivers have become a focal point in health-related research, with increasing attention to their needs and well-being (6-8). Caregiving is a demanding role that requires substantial time, energy, and financial resources, often leading to adverse health outcomes (9-11). Studies indicate that caregivers of PwD have higher rates of both pharmacological and non-pharmacological needs (12). Family caregivers frequently report caregiver burden, depression, anxiety, and chronic illnesses (12). However, findings regarding caregiver impact vary across studies, likely due to cultural, social, and individual differences in defining and perceiving these conditions (13). For this reason, studies conducted in different societies are essential.

Since there is currently no cure for dementia, the main focus of care is to provide support to patients, families, and caregivers and slow down the progression of the deterioration (8). It is common worldwide that in addition to the primary caregiver, two or more relatives are involved in the informal care of PwD (5). Most studies examining multiple caregivers focus on comparing the roles and impacts of primary and secondary caregivers (5, 14). Variables such as time spent in caregiving, disease stage, patient's age, caregiver's sex, education, and occupation significantly influence caregivers' physical and psychological well-being (4). However, the physical and psychological effects of the presence of a secondary caregiver on the primary caregiver remain unclear. To date, no studies have specifically examined how having a secondary caregiver influences the well-being of the primary caregiver. Therefore, this study aimed to compare primary caregivers with and without a secondary caregiver in terms of physical and psychological well-being parameters. The hypothesis of the study was that the presence of a secondary caregiver significantly affects the physical and/or psychological health of primary caregivers of individuals with dementia.

2. Material and Method

2.1. Study Design and Participants

This comprehensive cross-sectional study was conducted with caregivers of patients with dementia who were regularly followed up at the neurology clinic of Dokuz Eylül University Hospital. All participants provided written informed consents after receiving a detailed explanation of the study procedures.

The inclusion criteria were as follows: being the informal primary caregiver of a patient diagnosed with dementia (defined as multiple cognitive deficits with functional impairment), providing care for at least six months, volunteering to participate, being at least 18 years old, and having the ability to speak and read Turkish. The exclusion criteria were: being a paid caregiver and having any physical, psychological, or cognitive condition that would prevent completion of the questionnaires (4, 7). In line with the study's objective, participants were categorized into two groups based on the presence of a secondary caregiver: (1) caregiving alone, and (2) caregiving with a secondary caregiver.

2.2. Assessments

Sociodemographic variables such as age, sex, height, weight, marital status, education, employment status, and exercise habits were obtained by questioning the participants. Caregiving-related factors, including the caregiver's relationship to the patient, duration of caregiving, weekly hours dedicated to care, and the presence of any additional caregivers, were collected. The patient's age, diagnosis, duration of diagnosis, and cognitive

level were recorded from the patient's file. The physical conditions (musculoskeletal disorders, physical activity level, and fatigue) and psychological conditions (quality of life and burden) were evaluated with questionnaires that were specific to each (8).

Musculoskeletal Disorders: The Nordic Musculoskeletal Questionnaire (NMQ) was used to assess musculoskeletal disorders. It included 27 items that investigated the presence of musculoskeletal symptoms in nine different parts of the body in the past seven days and 12 months. All answers are based on a binary response 'yes/no' (15). Based on a recent study conducted on caregivers, we classified this questionnaire as spinal disorders, upper limbs disorders, and lower limbs disorders (15, 16).

Physical Activity Level: The International Physical Activity Questionnaire - Short Form (IPAQ-SF) was used to assess the physical activity (PA) level. This form consists of seven questions and gives information about the time spent walking and moderate to vigorous activities over the past seven days. There is a separate section to evaluate sitting time. The frequency and duration of each activity are asked and based on the metabolic equivalent (MET) for each activity type a score as MET-minutes is obtained. Also, the weekly MET minutes are given as the total score (17). The World Health Organization (WHO) recommends doing at least 150 minutes of moderate to vigorous activities per week. Similar to the study of Jacob et al., in our study, the participants were dichotomized into those who do (≥ 150 min of moderate-to-vigorous PA per week) and do not (< 150 min = low PA) comply with the WHO PA recommendations (18).

In addition, PA were inquired by personal reports, such as what percentage of the total sitting times are for caregiving and how PA levels changed (decreased/same/increased) by caregiving (17).

Fatigue: The Fatigue Severity Scale (FSS) was used to measure fatigue. The FSS consists of nine items, and last week's fatigue level is evaluated on a scale of 1 to 7 points. According to this scale, the score range is 9-63, and an increase in score indicates severe fatigue. In some studies, the total score is divided by nine to determine the mean, and it can be further categorized into the following categories: mild/no fatigue (average score of less than 2), moderate fatigue (average score between 2.1 and 5), and severe fatigue (average score between 5.1 and 7) (19). Also, the participants were dichotomized into those who feel fatigued (average score ≥ 2.1) and do not (average score ≤ 2) (19).

Quality of Life: The World Health Organization Quality of Life-Bref (WHOQOL-BREF) scale was used to assess the quality of life (QoL) in four domains: physical health, mental health, social relationships, and environment. This questionnaire consists of 26 questions, and each question has a score from one to five. Scoring is calculated separately between 4-20 and 0-100. Getting a higher score indicates a higher QoL (20).

Burden: The Zarit Caregiver Burden Interview (ZCBI) was used to determine caregiver burden. ZCBI with 22 items evaluates the stress experienced by the caregiver. Each item is rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores ranging between 0-88. Higher scores indicate a greater burden. A score of 0-20 points translated as little or no burden, 21-40 meaning a mild to a moderate burden, 41-60 for a moderate to severe burden, and more than 61 for severe burden (21).

2.3. Statistical Analysis

The data analysis was made using the "SPSS 20.0 for Windows" statistical program. The normal distribution of the data was examined with the Shapiro-Wilk test and histogram graphics.

The continuous variables were expressed as mean \pm standard deviation and the categorical variables as numbers and percentages (%). The student's t-test was used to compare the normally distributed variables and the Chi-square test or Fisher's exact test, where appropriate, was used to compare the categorical data. A p-value of less than 0.05 was considered to show a statistically significant result.

The required sample size was calculated using the G*Power software (v.3.1.9.7, Heinrich Heine University, Düsseldorf, Germany). Since no similar study was available in the literature, we estimated that a minimum of 102 participants would be needed to achieve 80% power with an effect size of 0.50. However, due to practical constraints related to the clinical follow-up schedule—where participants attended routine six-month check-ups—the data collection period was limited to six months. During this time, 61 family caregivers who met the inclusion criteria were recruited.

A post hoc power analysis was performed using data from these 61 participants. The calculated effect size for the difference in sitting time between groups (Cohen's $d=0.63$) yielded a statistical power ($1 - \beta$) of 0.78, suggesting that the study had sufficient power to detect meaningful differences in this parameter.

2.4. Ethical Aspects of the Research

Ethical approval was obtained from the Non-Interventional Research Ethics Board of Dokuz Eylül University (approval number: 2018/05-08). All procedures were conducted in accordance with the principles outlined in the Declaration of Helsinki.

3. Results

A total of 64 participants initially agreed to participate in the study; however, 3 did not complete the required forms. Consequently, data from the remaining sixty-one participants were (43% caregiving alone) included in the analysis. Sociodemographic variables of caregivers, caregiving information, and patient characteristics are presented in Table 1. The mean age and mean care duration (hours/week) were statistically higher in caregivers without a secondary caregiver. Both groups were statistically different in terms of relationship with the patient and employment status ($p<0.05$) (Table 1).

Most participants in each group did not have exercise habits, and both groups were similar in terms of exercise habits. In caregivers without a secondary caregiver, the percentage of sitting time in a day for caregiving was statistically higher, and most of their sitting time was for caregiving ($p=0.020$). Both groups were similar in terms of other PA evaluations (PA level, PA change, compliance with WHO recommendation, etc.) ($p>0.05$). While both groups had similar descriptions of long-term musculoskeletal disorders, statistically more musculoskeletal disorders in the spine, upper limbs, and lower limbs are observed in the caregiving alone group in the last seven days ($p=0.05$, $p=0.046$, $p=0.019$ respectively) (Table 2).

Both groups were similar in terms of QoL and caregiver burden which we examined under the heading of psychological parameters ($p>0.05$) (Table 3).

4. Discussion

In our study, we aimed to compare primary caregivers with and without a secondary caregiver in terms of physical and psychological well-being. It seemed that they are similar in terms of psychological parameters, but there are some differences in terms of physical parameters. In caregivers without a secondary caregiver, the percentage of sitting time in a day for caregiving was higher, and they had more musculoskeletal disorders in the spine, upper limbs, and lower limbs in the last seven days.

PA is an important physical well-being aspect that was evaluated within the scope of our study. We hypothesized that the distribution of daily activities may be affected by caregiving responsibilities and that the presence of a secondary caregiver could influence the level of PA. Regardless of having a secondary caregiver, participants in both groups reported changes in their PA levels. However, most caregivers did not meet the World

Table 1. Sociodemographic variables of caregivers, caregiving information, and patient characteristics

Variables	Caregiving alone (n=26)	Caregiving with a secondary caregiver (n= 35)	p
	Mean \pm SD or n (%)	Mean \pm SD or n (%)	
Sex, male/female (%)	12(46.2)/14(53.8)	17(48.6)/18(51.4)	0.852
Age (yrs)	64.19 \pm 12.20	55.77 \pm 15.58	0.026*
BMI (kg/m ²)	26.85 \pm 4.25	26.33 \pm 4.83	0.667
Educational Background			
Literate	0(0)	1(2.9)	
Primary school	5(19.2)	1(2.9)	
Secondary school	5(19.2)	3(8.6)	0.063
High school	5(19.2)	9(25.7)	
University	11(42.3)	21(60)	
Employment Status			
Employed	2(7.7)	12(34.3)	0.010*
Not employed	15(57.7)	17(48.6)	
Retired	9(34.6)	6(17.1)	
Relationship			
Spouse	19(73.0)	11(31.4)	
Child	6(23.1)	20(57.1)	0.024*
Child-in-law	0(0)	2(5.7)	
Another	1(3.8)	2(5.7)	
Marital Status			
Married/Single (%)	21(80.8)/5(19.2)	24(68.6)/11(31.4)	0.284
Care duration (hours/week)	55 \pm 33.05	36.93 \pm 35.35	0.048*
Patient's age (yrs)	70 \pm 7.67	74.49 \pm 10.92	0.078
Diagnoses			
AD	14(53.8)	21(60)	
Parkinsonism	4(15.4)	2(5.7)	
FTD	3(11.5)	3(8.6)	0.836
LBD	1(3.8)	2(5.7)	
Undiagnosed	4(15.4)	7(20)	
Patient's MMSE	18.67 \pm 7.73	18.27 \pm 5.39	0.831
Diagnosis duration (yrs)	3.40 \pm 2.76	3.53 \pm 2.67	0.859

Note: Values are expressed as means (and standard deviations) or numbers (and percentages). * $p<0.05$
 BMI: Body mass index, AD: Alzheimer's disease, FTD: Frontotemporal dementia, LBD: Lewy body dementia, MMSE: Mini mental state examination

Health Organization (WHO) recommendations for PA. The similarity in exercise habits between the groups suggests that the presence of a secondary caregiver does not significantly impact structured exercise behavior. Our findings also indicate that a large proportion of total daily sitting time in both groups was attributed to caregiving tasks such as attending to and supporting the person with dementia. This proportion was significantly higher among those without a secondary caregiver. Although PA data vary across countries, studies consistently show that PA levels in the general adult population often fall short of WHO guidelines (22).

While caregiving might intuitively seem associated with higher PA due to its physically demanding nature, previous studies have demonstrated that caregivers typically have lower PA levels and face a greater risk of sedentary behaviour compared to non-caregivers (18, 23, 24). Some research suggests that the absence of a secondary caregiver—such as a family member or friend—may hinder caregivers' ability to engage in PA, whereas supportive interventions can offer promising alternatives (8). Within the scope of our study, caregivers of PwD appear to be a particularly vulnerable group regarding PA, due to both their low PA levels and the substantial proportion of sedentary time related to caregiving responsibilities. The absence of a

secondary caregiver exacerbates this issue. Our comprehensive assessment of PA in this context provides a meaningful contribution to the literature. Furthermore, we believe that efforts to improve PA among caregivers should be integrated into public health policies, given its broad implications for overall well-being.

Table 2. Comparison of physical parameters

Variables	Caregiving alone (n=26)	Caregiving with a secondary caregiver (n= 35)	p
	Mean \pm SD or n (%)	Mean \pm SD or n (%)	
Exercise Habit No/Yes (%)	14(53.8)/12(46.2)	22(62.9)/13(37.1)	0.479
Sitting time for caregiving (Percentage of total sitting time) (%)	54.81 \pm 22.47	38.86 \pm 27.95	0.020*
PA Same/Changed (%)	9(34.6)/17(65.4)	17(48.6)/18(51.4)	0.276
PA Change More active Less active No change	6(23.1) 11(42.3) 9(34.6)	6(17.1) 12(34.39) 17(48.6)	0.313
Complying on PA recommendation No/Yes (%)	21(80.8)/5(19.2)	26(74.3)/9(25.7)	0.552
IPAQ _{Total} (MET-Min/Week)	1895.40 \pm 2203.76	1958.67 \pm 2717.01	0.923
Spine symptoms in the last 12 months No/Yes (%)	5(19.2)/21(80.8)	9(25.7)/26(74.3)	0.552
Spine symptoms in the last 7 days No/Yes (%)	9(34.6)/17(65.4)	21(60)/14(40)	0.05*
Upper limbs symptoms in the last 12 months No/Yes (%)	12(46.2)/14(53.8)	13(37.1)/22(62.9)	0.479
Upper limbs symptoms in the last 7 days No/Yes (%)	12(46.2)/14(53.8)	25(71.4)/10(28.6)	0.046*
Lower limbs symptoms in the last 12 months No/Yes (%)	7(26.9)/19(73.1)	13(37.1)/22(62.9)	0.400
Lower limbs symptoms in the last 7 days No/Yes (%)	10(38.59)/16(61.5)	24(68.6)/11(31.4)	0.019*
FSI	3.38 \pm 1.23	3.34 \pm 1.69	0.920
Fatigue No/Yes (%)	5(19.2)/21(80.8)	8(22.9)/27(77.1)	0.732

Note: Values are expressed as means (and standard deviations) or numbers (and percentages). *p<0.05
PA: Physical activity, IPAQ: International physical activity questionnaire, FSI: Fatigue severity impact

Musculoskeletal health is an important aspect of physical well-being, and current evidence suggests that caregivers are at increased risk for musculoskeletal symptoms and injuries, potentially due to the physical demands of caregiving duties (16). Providing care for PwD often requires 24/7 responsibility. Studies have shown that caregiving for a person with dementia is more physically and emotionally demanding than caring for someone with only a physical disability (12).

Notably, even being a partner of someone with dementia—without necessarily serving as the primary caregiver—has been associated with musculoskeletal and psychological problems. Recent research has also shown an increased number of medical consultations among such individuals due to these issues (10). Regardless of whether care is formal or informal, Figueiredo et al. reported that musculoskeletal symptoms are highly prevalent among caregivers of older adults, with incidence rates reaching up to 63%. These caregivers frequently experience pain on most days of the week (16). Informal caregivers, in particular, provide care without employment

protections, regulated working hours, or regular breaks—factors that likely contribute to worse physical outcomes and a higher risk of musculoskeletal injuries (16). In line with these findings, our results show that musculoskeletal complaints were significantly more common among caregivers who did not have a secondary caregiver. This supports existing literature and underscores the physical burden associated with sole caregiving responsibilities.

Table 3. Comparison of psychological parameters

Variables	Caregiving alone (n=26)	Caregiving with a secondary caregiver (n= 35)	p
	Mean \pm SD or n (%)	Mean \pm SD or n (%)	
ZCB	31.69 \pm 14.78	31.09 \pm 13.44	0.868
No	7(26.9)	6(17.1)	0.964
Mild	11(42.3)	21(60)	
Moderate Severe	7(26.9) 1(3.8)	7(20) 1(2.9)	
QoL-physical health	70.19 \pm 17.05	72.04 \pm 15.91	0.665
QoL- mental health	77.08 \pm 13.50	71.43 \pm 16.08	0.152
QoL- social relationship	61.54 \pm 25.17	67.14 \pm 21.86	0.357
QoL- environment	74.36 \pm 14.60	72.78 \pm 14.24	0.673

Note: Values are expressed as means (and standard deviations) or numbers (and percentages). *p<0.05
ZCB: Zarit Caregiver Burden Interview, QoL:Quality of life

Fatigue is another critical physical parameter to monitor in caregivers of PwD, as it can negatively impact QoL, increase medical symptoms, and eventually lead to caregiver burnout. These caregivers are responsible not only for managing the patient's daily activities but also for coping with emotional and behavioral challenges such as forgetfulness, emotional outbursts, and wandering. Due to such mental, emotional and physical demands, caregivers of PwD are expected to experience high levels of fatigue (25). Despite its importance, fatigue remains an underexplored topic among caregivers of PwD. While many factors influence fatigue, individual perceptions and experiences—such as personal mastery and the positive aspects of caregiving—have been associated with a lower perception of caregiver-related fatigue (25–27). In a study by Riska and Mansoor, initial feelings of fatigue and negative emotions reported by caregivers evolved over time into more positive experiences as participants found meaning in their caregiving roles (28). In contrast, a qualitative study by Ozcan and Akyar presented a participant in the early stage of caregiving who stated, “I am not tired yet, but I will be in the future” (8), reflecting anticipatory fatigue. Our study provides an important contribution to the literature by addressing fatigue among caregivers of PwD. We observed that the majority of caregivers—regardless of the presence of a secondary caregiver—reported experiencing moderate levels of fatigue. Based on these findings, we believe that implementing structured support and interventions aimed at managing caregiver fatigue could significantly improve their daily functioning and overall well-being.

The loss of functional abilities and the progression of communication disorders in PwD impose constant demands and stress on caregivers, significantly limiting their personal freedom and leading to feelings of burnout as well as various health problems (11). It has been reported that over 60% of caregivers of PwD living at home experience significant caregiver burden (1, 29). When caregivers of patients with various conditions were compared, caregiver burden was found to be specifically associated with dementia (30). Thus, providing care for a PwD can be considered an intrinsic risk factor for caregiver burden. Regarding caregiver interventions, studies indicate that the effectiveness of such interventions on reducing

caregiver burden tends to diminish over time (7). For instance, one study showed that despite increased disease awareness and improved coping strategies following a psycho-educational program, no significant reduction in caregiver burden was observed (31). Similarly, although positive aspects of caregiving exist, primary caregivers often report a greater burden (5). Consistent with these findings, our study demonstrated that the presence of a secondary caregiver did not significantly affect caregiver burden, as a large proportion of caregivers in both groups experienced similar levels of burden. Furthermore, despite comparable overall QoL scores, the higher average score in the spiritual sub-dimension among caregivers who cared alone may reflect the role of spirituality in coping with caregiving stress.

QoL, defined as an individual's perception of their position in life within the context of their values and culture, is regarded by healthcare providers, researchers, and policymakers as a multidimensional concept encompassing physical, social, and mental well-being (32). Caregivers' QoL varies depending on numerous factors related to both the patient and the caregiver, and there are controversial results in the literature on this issue (33). Reduced leisure activities among caregivers have been associated with increased emotional stress, depression, and lower life satisfaction. One study reported that caregivers who engaged in activities beyond caregiving were less adversely affected (34), while another found that greater social support corresponded to better QoL perceptions (33). Although both groups in our study exhibited similar overall QoL scores, caregivers without a secondary caregiver showed lower scores in the social dimension, reflecting this phenomenon. Interventional studies on caregiver QoL often report effects limited to the short term, with multi-component long-term interventions failing to sustain improvements over time (32). The perception of caregiving is also influenced by cultural context; in Turkish society, as in many Asian cultures, caregiving is largely voluntary and imbued with spiritual meaning (8, 35). This spiritual perception may contribute to the relatively positive psychological outcomes observed in both groups in our study, as evidenced by above-average QoL subscale scores and the predominance of moderate or no caregiver burden.

It is important to note that, unlike many studies reporting psychological differences between caregivers, our study did not find significant differences in psychological well-being, caregiver burden, or QoL between caregivers with or without a secondary caregiver. This finding may be partly explained by cultural factors specific to Turkish society, where caregiving is often viewed as a familial duty imbued with spiritual meaning, potentially buffering psychological distress, especially in the earlier stages of caregiving (8, 35). Additionally, the relatively short duration of diagnosis and caregiving among our participants may have limited the manifestation of psychological differences. These contextual factors highlight the need for culturally sensitive interpretations of caregiver experiences and suggest that physical health effects may precede psychological impacts in this population.

In our study, caregivers without a secondary caregiver spent significantly more hours per week on caregiving (mean=55±33.05 h) compared to those with a secondary caregiver (36.93 ± 35.35 h). This extended caregiving duration may have contributed to increased sedentary behavior, as indicated by a higher percentage of daily sitting time attributed to care tasks within this group. Research suggests that prolonged caregiving duration can be associated with negative physical well-being outcomes, including musculoskeletal symptoms and sedentary lifestyles, especially among older caregivers (36, 37). In line with this, our findings demonstrate that caregivers without a secondary caregiver reported more musculoskeletal complaints over the past seven days. These

results suggest that the absence of a secondary caregiver might contribute to poorer physical well-being outcomes through increased caregiving time and related sedentary behavior, with age possibly acting as an important interacting factor. These group differences underscore the need for statistical control in future analyses, such as regression models or ANCOVA, to isolate the independent effect of secondary caregiver presence with a larger sample size.

4.1. Limitation

Consistent with these findings, our study demonstrated that the presence of a secondary caregiver did not significantly affect caregiver burden, as a large proportion of caregivers in both groups experienced similar levels of burden. Furthermore, despite comparable overall QoL scores, the higher average score in the spiritual sub-dimension among caregivers who cared alone may reflect the role of spirituality in coping with caregiving stress. One limitation of our study is the relatively small sample size, which was constrained by the clinical follow-up schedule and the six-month data collection period. However, post hoc power analysis indicated a statistical power of 77%, which is close to the commonly accepted threshold of 80%. This suggests that the study had sufficient power to detect meaningful effects, though future studies with larger samples are warranted to confirm and extend these findings. Additionally, as this was a cross-sectional descriptive-comparative study conducted at a single neurology outpatient clinic, causal relationships cannot be established, and the findings cannot be generalized to all caregivers of people with dementia in Türkiye. The cultural, social, and healthcare system differences across regions may influence caregiving dynamics, and thus multi-center studies with larger and more diverse samples are needed to enhance the external validity of the results. These limitations should be taken into account when interpreting the findings and planning future research.

5. Conclusion and Recommendations

In conclusion, the presence of a secondary caregiver appears to be associated with better physical well-being, as indicated by reduced musculoskeletal symptoms and less total sitting time. However, no significant differences were observed between groups in terms of psychological well-being, caregiver burden, or QoL. This lack of psychological differences may reflect cultural factors specific to Turkish society, where caregiving is often regarded as a spiritual and familial duty, potentially buffering psychological distress in the earlier stages of caregiving. Additionally, the relatively short duration of diagnosis and caregiving in our sample might also contribute to these findings. Nevertheless, the observed variability in caregiver burden highlights the need for tailored support interventions for both caregivers and patients with dementia.

Considering the unique characteristics of the Turkish healthcare system and cultural context, where family members traditionally assume caregiving roles with limited formal support, it is essential to develop accessible and culturally appropriate home care services. Strengthening the primary healthcare infrastructure to provide regular physical and psychological support for caregivers, along with public awareness campaigns that recognize and value informal caregiving, could improve overall caregiver well-being. Furthermore, integrating caregiver support into existing social and health policies will promote sustainability and enhance the quality of care for people with dementia.

6. Contribution to the Field

This study contributes to the field by specifically examining the impact of a secondary caregiver on the physical and psychological well-being of primary family caregivers of people with dementia. Our findings highlight that the presence of a

secondary caregiver is associated with better physical well-being but does not significantly affect psychological well-being, underscoring the complex dynamics of caregiving. These insights can inform tailored interventions and support strategies aimed at improving caregiver well-being and QoL.

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Conflict of Interest

There is no conflict of interest with any person and/or institution.

Authorship Contribution

Concept: EF, HYÖ, SÖ; Design: EF, HYÖ, SÖ, GY; Supervision: None; Funding: None; Materials: None; Data Collection/Processing: EF, HYÖ, GY; Analysis/Interpretation: EF, HYÖ; Literature Review: EF, HYÖ; Manuscript Writing: EF, HYÖ; Critical Review: SÖ.

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