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INVESTIGATION OF CAREGIVER BURDEN AND OCCUPATIONAL THERAPY INTERVENTION IN DISABLED INDIVIDUALS IN COVID 19 TERM

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ABSTRACT

The aim of this study was to examine the caregiving burden of parents and activity participation of individuals with disabilities during COVID-19 period. The study sample consisted of 20 individuals who were studying in a private educational institution in Ankara. The study is a cross-sectional study. In the study, data were collected by face-to-face interview method. Individuals and their parents were allowed to fill out the COPM and ZBÖ for the second time, considering the same period of the year before the COVID-19 pandemic. The caregiving burden of the parents was evaluated with the Zarit Burden Interview (ZBI). Individuals' activity performance and satisfaction levels of daily living, productive activities, and leisure time activities were evaluated with the Canadian Occupational Performance Measure (COPM). The individual-centered occupational therapy intervention was applied as two sessions per week for twelve weeks. Post-intervention survey evaluations were made again. Wilcoxon paired two sample tests were used to compare the differences before and after the occupational therapy intervention. The mean age of the individuals was determined as 23.27±31.17 years. It was determined that 44.4% of caregivers had a medium level of care burden. When the care burdens were compared before and during the COVID 19 period, a statistically significant difference was obtained (p=0.008). The caregiving burden has increased during the COVID-19 term. In addition, there was a statistically significant difference between before and after occupational therapy intervention in terms of Zarit Burden Interview, activity performance and satisfaction scores (p=0.029, 0.002, 0.000, respectively). Activity performance and satisfaction scores increased, and but care burden scores decreased. We suggest that individual-centered activity-based occupational therapy interventions planned for individuals with disabilities during COVID-19 will increase the activity performance of individuals. More studies including assessment and intervention approaches related to caregiving burden in caregivers should be planned.

Key words: Caregiving burden, Occupational therapy, Leisure activities

COVID 19 DÖNEMİNDE ENGELLİ BİREYLERDE, BAKIM VEREN YÜKÜ VE ERGOTERAPİ MÜDAHALESİNİN İNCELENMESİ

ÖZ

Bu çalışma COVID 19 döneminde engelli bireylerde ebeveynlerin bakım veren yükünü ve bireylerin aktivite katılımını incelemek amacıyla yapılmıştır. Araştırmanın örneklemini Ankara'da özel bir eğitim kurumunda öğrenim gören 20 birey oluşturdu. Çalışma kesitsel bir çalışmadır. Çalışmada veriler yüz yüze görüşme yöntemiyle toplandı. Ebeveynlerinin COVID-19 pandemi öncesi yılın aynı dönemini düşünerek, COPM ve ZBÖ ikinci kez doldurmaları sağlandı. Ebeveynlerin bakım verme yükü, Zarit Bakım Yükü Ölçeği (ZBÖ) ile değerlendirildi. Bireylerin günlük yaşam, üretici aktivite ve serbest zaman aktivitelerine ait aktivite performans ve memnuniyet düzeyleri ise Kanada Aktivite Performans Ölçeği (KAPÖ) ile değerlendirildi. Birey merkezli ergoterapi müdahalesi 12 hafta boyunca 2 seans olarak uygulandı. Müdahale sonrası anket değerlendirmeleri tekrar yapıldı. Ergoterapi müdahalesi öncesi ve sonrası yapılan değerlendirme sonuçlarının karşılaştırılmasında Wilcoxon eşleştirilmiş iki örneklem testi kullanıldı. Bireylerin yaş ortalaması 23,27±311,77 yıl olarak belirlendi**.** Bakım verenlerin % 44,4'ünün bakım yükünün orta düzeyde olduğu belirlendi. COVID 19 dönemi ve öncesinde bakım yükleri karşılaştırıldığında istatistiksel olarak anlamlı bir fark elde edilmiştir (p=0.008). Bakım yükü COVID 19 döneminde artmıştır. Ergoterapi müdahalesi öncesi ve sonrası Zarit Bakım Yükü, aktivite performası ve memnuniyeti puanları karşılaştırıldığında istatistiksel olarak anlamlı fark bulundu (p=0.029) (p=0.002, p=0.000). Aktivite performası ve memnuniyeti puanları artmış, bakım yükü puanları ise azalmıştır. COVID 19 döneminde engelli bireyler için planlanan birey merkezli aktivite temelli ergoterapi müdahalelerinin, bireylerin aktivite performansını artıracağı düşünülmektedir. Bakım veren bireylerde bakım verme yükü ile ilgili değerlendirme ve müdahale yaklaşımlarını içeren daha fazla çalışma planlanması gerekmektedir.

Anahtar kelimeler: Bakım veren yükü, Ergoterapi, Serbest zaman aktiviteleri

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INTRODUCTION

Restrictive measures taken to prevent the spread of pandemics caused individuals to have difficulties in adapting their daily routines, habits, working styles, and some of their roles to this suddenly emerging situation (1-3). This situation has put people under more burden those with a family member who needs care (4-6). The difficulties experienced by family members who take care of a person affected by any disease in their family are generally defined as "caregiver burden" (7, 8). Having a person in need of continuous care in the family has a significant impact on the caregiver and other family members. It affects the daily work of caregivers and family members and may lead to conflicts and problems within the family. In particular, caregivers also face physical, emotional, social and financial difficulties (9-11). In addition, parents are also concerned about the interruption of their children's education in this process (12-14).

People with disabilities are those who are at risk of chronic, physical, developmental, behavioral or emotional diseases and in need of health-related services. These individuals have occupational performance deficiencies due to their disabilities and have difficulties in daily life occupations (4,15-17). Therefore, the responsibilities of caring for an individual with disabilities put a serious burden on caregivers and cause stress (18,19).

The concept of degree of use is at the focal point of occupational therapy science and person-centered approach. It includes all activities that people do in their daily lives. According to the latest classification of the American Occupational Therapy Association (AOTA), there are nine areas of occupation (20). These areas are activities of daily living (ADL), assistive activities of daily living (AADL), health management, sleep and rest, education, work and productivity, play, leisure time and social participation (21).

People engage in many activities in many areas of occupation throughout their lives, and occupations are influenced by many life-related factors such as personal characteristics, environment, socio-cultural level and financial status. Occupations are linked to all roles of the person in life and include all activities and tasks (20,21). Occupational performance, on the other hand, is the selection, organization and realization of meaningful activities that the person performs for self-care, enjoyment of life, social and economic participation, and that are appropriate for his/her age and culture. An example of an occupational therapy intervention is helping a child with disabilities in school or social activities and ensuring his/her adaptation to life. With occupational therapy intervention, individuals and their environment can be well assessed and participation goals can be achieved. Communication, mobility, education, family life, leisure activities and social relationships are determinants of individual success in different life roles in their environment (22, 23). The interaction between the children’s emotional and social skills, communication skills, physical conditions, and cultural, physical and social environments in their performance domains can positively or negatively affect their performance in occupations (22, 23). Participation in recreational activities has many benefits such as increasing health and personal independence, skills and productivity, community integration and life satisfaction (24, 25).

Even if the COVID-19 pandemic ends in the near future, it is inevitable to say that the lives of individuals with disabilities will be hindered in terms of both social development and academic development, and therefore the process will be most negatively reflected on the parents who take care of disabled individuals (26). The number of research on difficulties experienced by individuals with disabilities and their parents due to COVID-19 is limited. To the best of our knowledge, no studies have investigated the relationship between the caregiving burden of parents of individuals with disabilities and the children's activity performance. The relevant literature shows that only the occupational participation of mothers and fathers and their caregiving burden related to children with special needs are mentioned (9, 27). Therefore, it is important to reveal the difficulties experienced by individuals with disabilities and their parents. In this study, unlike other studies, we aimed to determine the role of occupational therapy intervention during COVID-19 period on the caregiving burden in individuals with disabilities and to evaluate how it affects occupational performance and to contribute to the previously conducted and future studies on individuals with disabilities.

Hypothesis 0: Occupational therapy intervention has no effect on caregiving burden and occupational performance in individuals with disabilities.

Hypothesis 1: Occupational therapy intervention has an effect on caregiving burden and occupational performance in individuals with disabilities.

Materials and Methods

This was a cross-sectional study. Istanbul Aydın University Non-Interventional Clinical Research Ethics Committee approved the study on June 2nd, 2021, with number 2021/498. The study was carried out between June 4th, 2021 and September 4th 2021, in accordance with the Declaration of Helsinki.

A total of 20 individuals, eight (40%) girls and twelve (60%) boys attending a private educational institution participated in the study. Informed voluntary consent was obtained from the participants. All participants were informed about the purpose and procedure of the study before the evaluation. Before the study, all individuals and their families were informed about the study, and data were collected by face- to-face interview method. Socio-demographic information, including age, gender, educational status of parents, disability, economic status, and chronic diseases of all individuals participating in the study, were obtained.

The intervention was applied to the individuals for 12 weeks, two days a week for 40 minutes. At the end of the study, all participants were asked to answer the questionnaires again to determine the changes in the individual.

Inclusion Criteria

1. To be between the ages of eight and twenty-five,

2. To have a mild mental disability,

3. To accept the consent form,

4. To be able to communicate,

5. To volunteer to participate in the study,

6. Having needs in terms of making use of their daily occupation and free time,

7. comply with the instructions given

Exclusion Criteria

Individuals with a comorbid disease that may affect the outcome of the study

Approaches and methods

During the research, the data were collected face-to-face by an occupational therapist.

1. Socio-demographic information: For this study, a demographic information form was designed to collect socio-demographic data, information about the participant's daily routines, diagnosis, and information about any psychological and physical problems.

2. Surveys to be applied

1. Canadian Occupational Performance Measure (COPM): COPM is a standard measurement tool used to determine the individual's activity performance problems and to measure the individual's perception of performance change and satisfaction. There is also a Turkish validity and reliability study conducted on individuals with multiple sclerosis (28). Firstly, the individual determines the problematic activities in the areas of self-care, productivity, and leisure time activities that individuals do, wish to do, or are restricted from doing in their daily lives. Secondly, each activity in the areas determined by the individuals is given an importance value between 1-10 (1-Not at all important, 10-Very important). Thirdly, the individual chooses at least one and at most five activities that are most important to him/her and gives a performance and satisfaction score between 1-10 for each activity. Finally, average performance and satisfaction scores are calculated by summing and dividing them by the number of activities that the individual finds important (28).

2. Zarit Burden Interview (ZBI): In order to assess caregiver burden in relatives of patients with dementia, the scale developed by Zarit et al. was also used in subsequent studies in families of patients with schizophrenia (29). In the Turkish validity and reliability study of the scale, in which the original version is consisted of 22 items, three items were removed, and the Turkish version consisted of 19 items.

The scale consists of the following subscales: 'Mental Tension and Deterioration of Private Life', 'Irritability and Restraint', 'Deterioration in Social Relationships', 'Financial Burden' and 'Dependency'. The scale consists of the following subscales:

The scale has a Likert-type rating ranging from 1 to 5, namely, "never," "rarely," "sometimes," "often," or "almost always." The minimum score that can be obtained from the scale is 19, and the maximum is 95. A high score on the scale indicates a high level of distress. For example, a score between 0-20 indicates "no care burden," 21-40 "light care burden," 41-60 "moderate care burden," and "61-88" indicates "heavy care burden" (29).

3. The semi-structured interview method was used for the assessments before the occupational therapy intervention. The information about the changes in activities of daily living before and after COVID-19 was recorded. There were questions about self-care skills, recreation and play

activities, reading status, and ability to meet literacy needs.

The following questions were asked in the interviews:

1.What is the reason for the difficulty in participating in the activity?

2.What are the factors that prevent you from doing the same activities?

3.What other factors support or prevent you from doing the leisure time activities you mentioned?

4. What are the attitudes/behaviors of your social circle, family, relatives, work, and social circle during your participation in the activity?

5. Which of these behaviors do you think hinders or supports you?

6. What physical environmental factors (such as physical conditions at home, outside the home, transportation) support or affect your participation in activities? Indicate the positive and/or negative factors.

Intervention: Our occupational therapy intervention was organized with a person-centered and holistic perspective. A problem - oriented, person - centered, problem – focused occupational therapy intervention program was planned and implemented by evaluating and analyzing the participation of individuals in daily life activities. Prior to the intervention, activity priorities and activities in which the individuals were restricted in participation were determined according to COPM, and the performance and satisfaction levels with these activities were examined. The intervention was planned based on the activities that the individuals stated that they were restricted according to COPM. We aimed to improve the occupational performance of the individual through activities of daily living and leisure time performance. The interventions focused on factors affecting activity performance:

Activity Training: Increasing the skills required for activity performance

1. Activities of Daily Living (ADL) Training: Intervention to the activity: Individuals who were dependent to others for ADL were trained on self-care, leisure time, and productive activities. When the problem areas in the activity performance of individuals were identified according to the COPM results, activity training was started. In case of identifying the problematic activity, activity training was given to improve the performance of that activity. Some individuals were dependent in two activities such as dressing and feeding activities, while others were dependent in a single activity. Individuals who were dependent in ADL were trained in activities related to self-care activities which they experienced problems. An example case: Eating activity: In the first assessment of the individual, he/she could not eat independently. In the first sessions with the individual, activities such as using a fork, knife, spoon and cutting bread, which are simple initial activity steps of eating activity, were practiced. No changes were made during the activity. The activity steps were practiced separately in each session. Then both steps were combined and the patient was asked to remember the steps. After each session, the duration was reduced. The family was also asked to encourage and support the individual. Towards the end of the intervention, the individual independently started, maintained and completed the eating

activity appropriately. The other individuals were analyzed using the same methods.

Training for Parents: All parents received information and awareness training. The following steps were used in this approach: Behavioral change: Parents were trained to support their child in order to increase his/her independence. Overprotective approaches were replaced with behavioral changes to improve independence. By using the therapeutic goal setting, practices were made on how parents should support their child's independent activities.

In our study, psycho-social approaches such as awareness training on the capabilities of individuals with disabilities, training on coping with stress, awareness training on the status of the individual with disabilities were given to parents. Parent education: The strengths of individuals, safety precautions, harms of protective behavior, the factors affecting activity performance, the concepts of occupational performance and social participation were explained to families.

Psycho-social skills training: Motivational interviewing: the aim of motivational interviewing was to identify and highlight intrinsic sources of motivation to achieve therapeutic benefit, build collaboration between the therapist, parent and individual, discuss alignment of expectations and goals, identify problem areas hierarchically and generate solutions in a step-by-step method. Parents who have lost their role were trained for stress management, coping and self-management to prevent stress/depression caused by not being able to fulfill their roles, habits and routines. They were also trained to increase awareness and skill-building on daily life performance skills that need to be strengthened. In addition, they were trained to reduce fatigue due to caregiving burden (e.g., energy conservation techniques, relaxation techniques, sleep hygiene training). Another training was given on patient transfer and joint protection techniques to reduce pain due to musculoskeletal problems following caregiving burden.

Statistical analysis

All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) for Windows 22 (IBM SPSS Inc., Chicago, IL). The conformity of the variables to the normal distribution was examined using visual (histograms and probability graphs) and analytical methods (Shapiro-Wilk tests). Descriptive analyzes were given using mean and standard deviation for normally distributed variables and median and maximum- minimum or interquartile range values for non-normally distributed variables. The correlations between normally distributed numerical variables were evaluated with the Pearson test, and the non-normally distributed variables were evaluated with the Spearman test. To investigate the efficacy of the application, the results obtained from of the two assessments were compared using the Wilcoxon Paired-Sample Test. The significance value was taken as 0.05.

According to the absence hypothesis, the correlation coefficient was 0.7, the correlation coefficient between the ZBI and the activity participation was 0.548, the sample calculation was made with the correlation test at 80% power and 0.05 significance level, so that a total of 20 individuals were found to be sufficient for this study.

Results

A total of 20 individuals, eight (40%) girls and twelve (60%) boys attending a private educational institution participated in the study**.** Those that developed a disability at a later stage of their lives constituted 88.8% of the participants and 55.6% of the participants had mild mental disabilities. The mean age of the individuals was 23.27 ± 31.1 As seen in Table 2, 39.2% of the individuals were illiterate. Half of them (50%) had intellectual disability, 15% had dyslexia, 15 % had cerebral palsy, 10.0% (15%), going to the movies (10%), shopping (10%), visiting (10%), handicrafts (10%), talking on the phone (10%) ,traveling (5%), worshiping (5%), doing homework (5%), going to the party (5%), dancing (5%) (Table 2).

During COVID-19 period, the most preferred activities by children were "recreational activities" [watching TV (55.6%), playing games (26.7%), doing puzzles (22.2%), playing computer (22%)]; followed by "talent activities" [music/painting/handicrafts (27.8%)], pectively (Table 2). Most difficult activities were stated as meeting with friends and relatives (45%),had autism, 5% had Fragile syndrome, 5% had experienced head trauma. While the playing on a computer (30%), taking a bath (25%), painting (25%), music/painting/crafts (15%), walking weekly activity duration was 3.27 ± 2.56 hours before COVID-19, it reduced to 2.77 ± 3.00 hours during the COVID-19 period, howing that, the time devoted to activity has decreased during COVID-19. The number of activities decreased during COVID-19 period (from 3.55±0.92 to 2.44±1.14).

Table 1. Descriptive Characteristics of Individuals

	n	**%**
Gender		
Woman	8	40
Man	12	60
Degree of intellectual disability		
Mild intellectual disability(IQ 75-90)	9	45.0
Moderate intellectual disability(IQ 45-75)	1	5.0
Financial situation of the family		
Good	2	5.6
Average	14	72.2
Poor	4	22.3
The reason for the difficulty inparticipation in the activity		
COVID-19 pandemic	13	72.2
Financial difficulties	4	22.3
Difficulty accessing to the activity area	2	11.2
Lack of support of family to participate in activities	2	11.2
Inability to find the strength to do activities	2	11.2
Health problems	2	11.2
Lack of suitable places for activities	4	22.3
Using assistive device	2	11.2

Table 2. Activities of Individuals

	Recreational activities Before COVID-19 Term		Recreational Activities in the COVID-19	
	n	**%**	**n**	**%**
Painting	4	22.2	4	22.2
Making puzzles	4	22.2	4	22.2
Playing computer	4	22.2	4	22.2
Playing with toys	3	16.7	3	16.7
Playing games	4	22.2	4	22.2
Watching TV	10	55.6	10	55.6
Taking a walk	1	5.6	1	5.6
Social activities				
Going to the cinema	3	16.7	0	
Going to a party	2	11.1	0	
Getting together with friends	3	16.7	3	16.7
Talking on the phone	3	16.7	3	16.7
Talent activities				
Music/painting/crafts	5	27.8	5	27.8
Dancing	2	11.1	2	11.1
Self-improvement				
Engaging in religious worship	2	11.1	2	11.1

The ZBI scores showed that the lowest score for caregivers was four and the highest was 35 before COVID-19, while the mean score was 18.45±11.38. However, during COVID-19, the lowest ZBI score was six and the highest was 45, while the mean score was 23.30 ±12.01 (Table 2). The results of pre-COVID-19 ZBI showed that thirteen individuals scored between 0 and 21, and seven individuals scored between 21 and 40. After COVID-19, nine individuals scored between 0-21, and ten individuals scored between 21-40. Only one person scored above 41. The mean scores of the caregiving burden items revealed that the families adopted an overprotective approach (Table 3).

The caregiving burden of the individuals before and during COVID-19 period was significantly different (p=0.008). The caregiving burden showed an increment in COVID-19 period (Table 3). While the caregiving burden with a child with autism was 34 points before COVID-19, it was 45 points during the COVID-19 period and had the highest score compared to other diagnostic groups.

The caregiving burden of the individuals before and during COVID-19 period was significantly different (p=0.008) (Table 3).

There was statistically significant difference between activity performance and satisfaction scores before and during the COVID-19 period (p=0.000) (Table 3).

The comparison of ZBI scores before and after the intervention showed a statistically significant difference (p=0.029) (Table 4).

There was a statistically significant difference between activity performance and satisfaction scores before and after the intervention (p=0.002, p= 0.000). After occupational therapy training, activity performance scores for COPM performance (COPMp) (p=0.002, t=- 3.584) and COPM satisfaction (COPMs) (p=0.000 t=-19.00) increased, and the difference was statistically significant (Table 4).

Table 3. Activity Performance, Zarit Burden Interview, Before and COVID-19 Term

	Before COVID-19 Mean (SD)	Min-max	During COVID-19 Mean (SD)	Min-max	p	t
ZBI	18.45 (11.38)	4-35	23.30 (12.01)	6.00-45.00	0.008	-2.954
COPMp	7.10 (2.14)	8-10	6.20 (2.30)	2.00-10.00	0.00*	-13.07
COPMs	6.30 (1.89)	6-10	5.35 (1.98)	2.00-9.00	0.00*	-19.00

t: Paired sample t-test; COPM: Canadian Occupational Performance Measure; COPMp: COPM performance; COPMs: COPM satisfaction

Table 4: Comparison of Activity Performance and Zarit Burden Interview Scores Before and After Intervention

	COVID-19 Pre-intervention Mean(SD)	Min-max	COVID-19 Post-intervention Mean (SD) Minmin-max	Min-max	p	t
ZBI	23.30 (12.01)	6.00-45.00	19.40 (10.98)	7.00-40.00	0.029	-2.367
COPMp	6.20 (2.30)	2.00-10.00	6.75 (1.88)	3.00-9.00	0.002	-3.584
COPMs	5.35 (1.98)	2.00-9.00	6.30(1.89)	3.00-9.00	0.000	-19.000

t: Paired sample t-test; COPM: Canadian Occupational Performance Measure; COPMp: COPM performance; COPMs: COPM satisfaction

DISCUSSION

As a result of the study, we determined that most of the caregivers perceived caregiving burden at a moderate level. In addition, individuals' ADL and leisure time occupational performances increased after the intervention. Many previous studies have reported that caregivers of disabled individuals perceive care as a moderate burden (9, 30). These findings are in parallel with the findings of our study. In addition, some studies have reported that caregivers had a light (31) and heavy (27, 29, 32-34) perception of caregiving burden.

In the study in which light caregiving burden was reported, it has been stated that the support of family members to the caregiver contributed largely. In a study conducted in families with children with Down syndrome, caregiving burden was found to be at moderate level (35). In one study (29), which was found to be high compared to our study, most of the parents tried to meet all the care needs of their children with cerebral palsy without allowing them to take responsibility. As the responsibilities of the caregiver increase, the caregiving process may become a one-way, dependent and intense commitment that puts the caregiver's life at risk. In addition to the role of caregiver, the burden of caregiving increases due to the woman's inability to fulfill her other responsibilities such as mother, wife, fiancée and child.

A recent study has found that self-esteem decreased in mothers with children with intellectual disabilities due to increased caregiving burden (36). Sari et al., in their article on the burden of parents with children with intellectual disabilities, pointed out that parents with children with intellectual disabilities were experiencing emotional, social, financial and physical burdens (37). Therefore, the presence of a person with disability in the family affects the relationship and life of the parents with all family members. Regardless of the disability of the child, psychological effects of the parents, financial difficulties, problems related to the care, treatment and education of the child, changes in the lifestyle of the parents (social culture and leisure time activities, etc.), problems in relations with the family and social environment and concerns about the future of the child create difficulties (38, 39).

In our study examining the effect of occupational therapy intervention on occupational performances in individuals with disabilities, we observed that the individuals' ADL and leisure time occupational performances increased. In our intervention, which was applied with a person-centered and holistic approach, we examined the changes in occupational performance, and showed that personal, environmental and occupation-related factors could affect occupational performance. One previous publication has stated that a one-point improvement in the COPM offers a good level of development and reflects a serious change in the views of disabled people and their families (40). According to the results of the COPM, there was an increase of 0.40 and 0.95 points, respectively, in individuals' occupational performance and satisfaction scores after the intervention. In our study, we showed that effective change can be achieved in the occupational performance and satisfaction status of individuals with disabilities with person-centered ADL and leisure time occupation-based intervention approach. It is an expected result that the physical burden of the family will decrease when the individual starts to meet his/her eating, personal hygiene, clothing and cleaning needs independently. Previous reports have emphasized that families experience difficulties and need help in the areas of food preparation and feeding, personal care of the child, use of medications, body hygiene, protection from danger and prevention of harmful behaviors, dressing, dental care, use of bathroom, diaper changing, tantrums, use of stairs and wheelchair (36). Therefore, it was determined that the burden of care would decrease with the intervention made to the parents. Similarly, it has been shown that planned education led to a decrease in the anxiety of caregivers and indirectly to a significant decrease in the perceived caregiving burden (41, 42).

In our study, we did not find any correlation between individuals' daily life occupational performance scores and caregivers' caregiving burden scores, whereas other studies have found a weak and moderate negative relationship. One study has demonstrated a weak relationship between children's daily life occupation level and caregiving burden of parents (34), while other studies have found a moderate relationship, which does not support previous finding. Based on these results, as the performance levels of the individual increase, the level of caregiving burden experienced by caregivers decreases. As the performance levels of individuals with disabilities increase, they are able to fulfill their own responsibilities better and participate more actively in their activities, thereby significantly reducing the burden of caregivers. Many studies in the literature support this finding (43, 44). Especially in people with disabilities such as cerebral palsy, in which the person is severely disabled, and the level of independence is low, the burden of care becomes more of a physical burden, whereas on the other hand, it has been found that the burden of care is higher in people with cognitive impairment (44-46).

It has been reported that 84% of parents were able to meet the physical mobility demands of their disabled children before the pandemic, and nothing had changed during the pandemic, while 36% stated that they were not able to meet the mobility needs of their children when the pandemic started (47). The COVID-19 pandemic has limited the ability of many individuals, especially children, to engage in physical activity. Restriction of movement due to COVID-19 has led to increased time spent at home, and online education has restricted the movement of children with special needs, leading to problems such as the development or progression of chronic diseases and weakening of muscle strength (48).

Previous studies have stated that environmental factors, social groups and occupation-roles that hinder occupational performance have been identified as major problems (29). Similarly, the indoor and outdoor activities of 77.7% of disabled children was affected during the COVID-19 period, and about 35.4% of the responses showed that the child's mobility was affected more negatively. About 39.2% of the children had problems in motor activity, approximately one-third of children needed help to move indoors and 36.2% of them needed help to move outdoors. Approximately half of the parents stated that their child had mobility problems outdoors during COVID-19 (49). In our study, 72.2% of the children stated that their performance was limited in their participation in occupation due to COVID-19. We determined that the occupational performance and social occupation participation of individuals with disabilities decreased significantly during COVID-19. Environmental factors that increase the occupational performance of individuals were found to require the most attention. The care of a disabled person covers a very wide area. This includes health care (pharmacological treatment, rehabilitation), education, and personal care (basic and assisted activities of daily living). We showed that a person-centered intervention approach can provide effective change in the performance of disabled people's activities of daily living and leisure time occupation. In our country, the care provided by family members and parents often poses difficulties for the family (50). The parents who participated in our study reported different caregiving burden problems. These findings are similar to the psycho-social problems reported in the literature. In our study, we applied psycho-social approaches such as awareness training about the capabilities of parents, coping with stress, and the status of the disabled person.

After the 12-week intervention, most of the individuals showed a positive improvement in their psycho-social status. We suggest that the person-centered occupational therapy intervention based on ADL and leisure time occupational therapy and the training given to caregivers improved the psycho-social problems related to the burden of care.

CONCLUSION

We found that training caregivers of individuals with disabilities reduces the caregiving burden perceived by caregivers. In other words, it is possible to prevent the increasing pressure of parents under care burden. In order to achieve this, parents need to be supported in terms of care. As a result, this study showed that the caregiving burden of parents decreased as the child's literacy performance increased. Further socialization of individuals with disabilities and the development of literacy performance skills may be effective in both reducing the caregiving burden of parents and preventing chronic pain, depression and fatigue that may occur in parents as a result of caregiving burden. We believe that this is a public health problem and research is needed to raise awareness among parents. Occupational therapists can suggest training programs while assessing children with disabilities, taking into account the needs of parents. Within the scope of these programs, parents can be more active and motivated in the care and rehabilitation of children with physical and mental disabilities. Future studies that evaluate the awareness of parents caring for children with disabilities will contribute to the literature.

Our study has some limitations. First, the study was limited to parents and their children who were educated in a private educational institution in Ankara city center. In addition, there was no specific disease, the time elapsed after the disease was not examined, the gender and education level of the caregivers were not investigated, the psychological status of the caregiver parents was not evaluated and environmental factors were not examined. We suggest that, in future studies, the treatment goals of the child and caregivers should be examined in terms of specific diseases and gender. We believe that it is necessary to include specific diagnoses and disease-specific assessments of children and to evaluate the degree of caregiving burden according to the current physical, psychological and mental levels of children.

We recommend:

- Occupational therapists should counsel caregivers about providing social support to alleviate the caregiving burden. They should first assess the family, inform them in line with their needs, provide support when necessary and refer them for professional help.

- Support systems should be increased by raising awareness in the parents providing home care services to reduce the caregiving burden

- A holistic approach should be preferred in the implementation of person-centered treatment programs

- Family-centered trainings should be organized that involve all family members in care.

- Families should be informed, campaigns should be organized to increase social awareness, the level of knowledge of caregivers about the disease should be measured and then practical trainings should be provided in order to provide early education to minimize the child's dependence level.

- During occupational therapy, the importance of socialization and productivity coupling should be explained to caregivers.

- In order to reduce the burden of caregivers, treatment programs targeting development of socialization in individuals with neurological diseases should be organized

- Families should be provided with regular, systematic and continuous health care, psychological and social support and these families should be prioritized for services.

- Support programs should be organized in such a way that families should care for their children at home or in institutions on certain days of the week so that families can allocate time for themselves to socialize.

-For the intervention programs to be prepared for the solution of the problems, the strengths and weaknesses of the social relations of the families should be identified.

- The problems of individuals experiencing caregiving burden should be identified, and training programs can be organized for them, which can be helpful for coping with these problems.

- The experiences of parents due to caregiving stress should be identified and "coping with stress" trainings should be provided to help them cope with stress

- Factors affecting the caregiving burden should be studied in different populations

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Declaration of conflicting interests

The authors confirm that there is no conflict of interest.

Declaration of Ethical Code

İstanbul Aydın University Non-Interventional Clinical Research Ethics Committee approved the study on June 2nd, 2021, with number 2021/498.

Author contribution

Concept, Design, Supervision, Critical Review, Review: A.G
Resources, Data Collection and/or Processing, Literature Review, Analysis and Comment, Written by: AG, DB

REFERENCES

1. Akoğlu G, & Karaaslan BT. Possible Psychosocial Effects of COVID-19 and the Isolation Process on Children, İzmir Katip Çelebi University Faculty of Health Sciences Journal. 2020;5(2), 99-103
2. Duan L, Zhu G. Psychological interventi ons for people affected by the COVID-19 epidemic. Lancet Psychiatry. (2020);7(4): 300–2.
3. Xiang Y-T, Yang Y, Li W, Zhang L, Zhang Q, Cheung T, et al. Timely mental health care for the 2019 novel coronavirus outbreak is urgently needed. The Lancet Psychiatry. 2020;7(3), 228-9.
4. Willner P, Rose J, Kroese BS, Murphy GH, Langdon PE, Clifford C, Hutchings H, Watkins A, Hiles S, & Cooper V. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. Journal of Applied Research in Intellectual disabilities. 2020;33(6), 1523-1533.https://doi.org/10.1111/jar.12811.
5. Silverman A. People with intellectual disabilities may be denied lifesaving care under these plans as coronavirus spreads [Press release]. https://www.propublica. org/article/people-with-intellectual-disabilities-may-be-denied-lifesaving-care-under-these-plans-as-coronavirus-spreads. Google Scholar. 2020
6. Courtenay K, & Perera B. COVID-19 and people with intellectual disability: Impacts of pandemic. Irish Journal of psychological Medicine. 2020; 37(3), 231– 236.

7. Asbury K, Fox L, Deniz E, Code A, & Toseeb U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? Journal of Autism and Developmental Disorders 2020;51,1772–1780

8. Zarit SH, Reever KE. and Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. The Gerontologist.1980;20, 649-655.

9. Emir A, Tarakcı D, Doğan S. Investigation of Caregiver Burden and Compassion Fatigue in Mothers of Children with Special Needs. Halic Uni J Health Sci. 2020; 3(3), 153-160.

10. Homan KJ, Greenberg JS, Mailick MR. Generativity and Well-Being of Midlife and Aging Parents With Children With Developmental or Mental Health Problems. Res Aging. 2019;42(3-4), 95-104.

11. Yıldırım S, Yalçıner N. & Güler C. Caregiver burden in chronic mental ıllness: A systematic review. Journal of Psychiatric Nursing. 2017; 8(3),165–171.

12. Coyne LW, Gould E R, Grimaldi M, Wilson K G, Baffuto G, & Biglan A. First things first: Parent psychological flexibility and self-compassion during COVID-19. Behavior Analysis in Practice. 2020; 14,1092–1098.

13. Karip E. COVID-19: School Closure and After. Accessed August 12, 2020, https://tedmem.org/vurus/covid-19-okullarin-kapatilmasi-ve-sonrasi-Ataman, A. Reasons for Needing Special Education. A. In Ataman, Children with Special Needs and Introduction to Special Education, Ankara: Gündüz Education. 2020.

14. Atila-Demir S, Keskin G. Difficulties Encountered by Mothers with an Intellectually Disabled Child- A Qualitative Study, The Journal of Academic Social Science Studies. 2018; 66, 357-372.

15. Arlington VA. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). American Psychiatric Publishing 2013.

16. Balcı S, Kızıl H, Savaşer S, Dur Ş, Mutlu B. Determining the difficulties and family burden of families with mentally retarded children J Psychiatric Nurs. 2019; 10(2),124-130.

17. Akı E, Tanrıverdi N, Şafak Y. The Effect of Individual-Centered Occupational Therapy Program on Participation in Activities of Daily Living in Individuals with Schizophrenia Journal of Occupational Therapy and Rehabilitation. 2014; 2(2), 83–90

18. Wijesinghe CJ, Cunningham N, Fonseka P. et.al. Factors Associated With Caregiver Burden Among Caregivers of Children With Cerebral Palsy in Sri Lanka. Asia Pac J Public Health. 2015; 27 (1), 85-95.

19. Barros ALO, de Gutierrez GM, Barros AO, Santos M. Quality of life and burden of caregivers of children and adolescents with disabilities. Spec Care Dentist. 2019;39, 380–388.

20.American Occupational Therapy Association. Occupational therapy scope of practice. The American Journal of Occupational Therapy, 2021; 75 (Supplement_3) 7513420020.

21.Romli, MH, Wan Yunus F, & Mackenzie L. Overview of reviews of standardised occupation-based instruments for use in occupational therapy practice. Australian Occupational Therapy Journal. 2019; 66(4), 428-445.

22. Pituch E, Rushton PW, Ngo M, Heales J & Arguin AP. Powerful or Powerless? Children's, Parents', and Occupational

Therapists' Perceptions of Powered Mobility. Physical & Occupational Therapy In Pediatrics. 2019; 276-291

23.Pavão SL, Ferreira Rocha NAC. Sensory processing disorders in children with cerebral palsy Infant Behav Dev. 2017;46,1-6.

24. Håkansson C, Lissner L, Bj€orkelund C, et al. Engagement in patterns of daily occupations and perceived health among women of working age. Scand J Occup Ther. 2009;16(2),110–117.

25.Håkansson C, Bj€orkelund C, Eklund M.Associations between women's subjective perceptions of daily occupations and life satisfaction, and the role of perceived control. Aust Occup Ther J. 2011;58(6), 397–404.

26. Koçbeker Eid BN, Karamuklu ES. Investigation of Difficulties and Emotions of Mothers with Special Needs Children during the COVID-19 Epidemic Research Article. National Education.2022;51, 233, 419-442

27**.** Yıldırım M, Düken ME, Dağ YS, Yayan EH. Comparison of Care Burden of Mother and Fathers of Children with Cerebral Palsy. Research Artıcle. CBU-SBED. 2020; 7(2),130 -135.

28.Torpil B. Turkish Cultural Adaptation, Validity and Reliability of Canadian Activity Performance Measurement in Individuals with Multiple Sclerosis. Ankara: Hacettepe University. 2017.

29. Werner S, Hochman Y, Holler R, Shpigelman CN. Burden and Growth during COVID-19: Comparing Parents of Children with and without Disabilities Journal of Child and Family Studies, J Child Fam Stud. 2022;31(6),1535-1546.

30.Wijesinghe CJ, Cunningham N, Fonseka P. et. al. Factors Associated With Caregiver Burden Among Caregivers of Children With Cerebral Palsy in Sri Lanka. Asia Pac J Public Health. 2015; 27 (1), 85-95.

31.Demiral B. Determining the Care Burden of the Mothers of Children with CP Before and After Orthopedic Intervention, Master Thesis, Bahçeşehir University, Istanbul. 2016.

32.Turan Gürhopur, FD and İşler Dalgıç A. Family Burden Among Parents of Children With Intellectual Disability Journal of Psychiatric Nursing. 2017;8(1),9–16.

33.Çalışır H, Karabudak SS, Karataş P, Meşealan İ, Tosun AF. Family Burden and Hopelessness Levels of Mothers with Children with Cerebral Palsy. 2018; 11(2), 147-156.

34. Gündede E, Şenocak E, Yıldız Özer A. The Relationship Between Care Burden, Psychological Status, and Quality of Life in Parents Who Have a Child Diagnosed with Cerebral Palsy Ahı Evran Medıcal Journal Ahi Evran Med J. 2022; 6(3), 290-296 .

35. Van Riper M. Living with Down Syndrome: The family experience, Down Syndrome Quarterly. 1999; 4(1), 1-7.

36. Argyrakouli E, Zafiropoulou M. Self-esteem of Greek mothers of children with intellectual disabilities. International Journal of Disability, Development and Education. 2003; 50(2),181-195.

37. Yellow HY. Family loading in families with mentally handicapped children C.Ü Hem High School Der. 2007; 11(2),1-7.

38. Yıldız E, Yücel H, Yağcı F. Relationship Between Stress Coping Strategies and Activity-Role Balances of Families with Children Having Special Needs in the Quarantine Situation Because of Covid-19. Journal of Occupational Therapy and Rehabilitation. 2022; 10(2), 63-72.

39. Espinosa F, Metko A, Raimondi M, Impenna M, & Scognamiglio E. A model of support for families of children with autism

living in the COVID-19 lockdown: Lessons from Italy. Behavior Analysis in Practice. 2020;13, 550–558.

40. Law M, Polatajko H, Pollock N, Mccoll MA, Carswell A, & Baptiste S. Pilot Testing of the Canadian Occupational Performance Measure: Clinical and Measurement Issues. Canadian Journal of Occupational Therapy. 1994;61(4), 191-197.

41. Uğur Ö, Fadıloğlu ZÇ. The Effect of Planned Education Applied to Caregivers of Cancer Patients on Caregiver Burdens, Cumhuriyet Nurs J. 2012;53-58

42. Çulhacik GD, Durat G, Eren N. Effects of activity groups, in which art activities are used, on resilience and related factors in families with disabled children. Perspect Psychiatr Care. 2021; 57(1),343-350.

43. Gómez-de-Regil L, Kwapil TR, Barrantes-Vidal N. Predictors of expressed emotion, burden and quality of life in relatives of Mexican patients with psychosis. J Psychiatr Ment Health Nurs. 2014;21,170–9.

44. Şen G, Aytar A. The Relatıonshıp Between The Functıonalıty Of Chıldren Wıth Dısabılıtıes And Its Effects On Parents Durıng The COVID-19 Pandemıc Process, Turk J Physiother Rehabil. 2022; 33(2),23-31.

45. Vergili Ö, Oktaş B, Koçulu E. Investigation of the effect of a disabled child's independence level on their caregivers in terms of health-related quality of life. Hacettepe University Faculty of Health Science Journal. 20151(1):1-7.

46. Javalkar K, Rak E, Phillips A, Haberman C, Ferris M, Van Tilburg M. Predictors of Caregiver Burden among Mothers of Children with Chronic Conditions. Child (Basel, Switzerland,2020) [Internet].

47.Y ersel BÖ, Akbaş A, Durualp E. Daily Life Activities of Children with Special Needs During the Pandemic Process.2021; 1, 126 -145.

48. Narzisi A. Handle the autism spectrum condition during coronavirus (COVID-19) stay at home period: Ten tips for helping parents and caregivers of young children. Brain Sciences. 2020;10(4), 207.

49. Zahaika D, Daraweesh D, Shqerat S, Arameen D, and Halaweh H. Challenges Facing Family Caregivers of Children With Disabilities During COVID-19 Pandemic in Palestine J Prim Care Community Health. 2021; 12, 1–8.

50. Atagun M, Balaban O, Atagun Z, Elagoz M, Ozpolat A. Caregiver Burden in Chronic Diseases. Psikiyatr-CurrApproaches Psychiatry. 2011;3,513-552.