

Adherence to Home Exercise Program among Caregivers of Children with Cerebral Palsy

Serebral Palsili Çocukların Bakıcılarının Ev Egzersiz Programına Uyumları

Aynur BAŞARAN¹, Kiymet İkbal KARADAVUT², Şükran Özden ÜNERİ³, Özlem BALBALOĞLU⁴, Nuray ATASOY⁵

¹Clinic of Physical Medicine and Rehabilitation, Konya Beyhekim State Hospital, Konya, Turkey

²Clinic of Physical Medicine and Rehabilitation, Dr. Sami Ulus Pediatric Health and Research Hospital, Ankara, Turkey

³Clinic of Child and Adolescent Psychiatry, Dr. Sami Ulus Pediatric Health and Research Hospital, Ankara, Turkey

⁴Department of Physical Medicine and Rehabilitation, Bülent Ecevit University Faculty of Medicine, Zonguldak, Turkey

⁵Department of Psychiatry, Bülent Ecevit University Faculty of Medicine, Zonguldak, Turkey

Abstract

Objective: The objective of this study is to determine the factors that affect the adherence to home exercise programs among caregivers of children with cerebral palsy (CP).

Methods: The caregivers of 147 children with CP were recruited for the study. The adherence status of the caregivers to an exercise program was assessed by a survey. The sociodemographic data of both children and caregivers; family characteristics, CP type, and Gross Motor Function Classification System (GMFCS) level of the disabled child; and inventories related to mental health and burnout of the caregivers were evaluated to determine whether these data were related with the adherence status or not.

Results: Using statistically significant parameters in univariate tests [age, weight, and GMFCS level of the children and age and Maslach emotional exhaustion (EE) score of the caregiver], a logistic regression model was constructed to predict the adherence to exercise programs. GMFCS level and Maslach EE score were statistically significant independent factors that predicted the adherence to home exercise programs.

Conclusion: The severity of the functional limitation of children with CP seems to enhance the adherence of caregivers to home exercise programs, while the burnout of caregivers has a negative impact. Caregivers should be supported socially and medically for a successful home exercise program.

Key Words: Exercise, cerebral palsy, caregiver, mental health, burnout, self-report, adherence

Özet

Amaç: Bu çalışmanın amacı, Serebral Palsili (SP) çocukların bakıcılarının ev egzersiz programına uyumunu etkileyen faktörleri belirlemektir.

Gereç ve Yöntemler: Yüz kırk yedi SP'li çocuğun bakıcısı çalışmaya dahil edildi. Bakıcıların egzersiz programına uyumları bir anket ile belirlendi. Çocukların ve bakıcılarının sosyo-demografik verileri, aile özellikleri, çocukların SP tipi ve Kaba Motor Fonksiyon Sınıflandırma Sistemi (KMFSS) seviyeleri, bakıcıların ruh sağlığı ve tükenmişlik ölçeklerine ait verilerin tümünün bakıcıların uyum durumu ile ilişkili olup olmadığı araştırıldı.

Bulgular: Univariate testlerde istatistiksel olarak anlamlı verilerin [çocukların yaşı, ağırlığı, KMFSS seviyesi, bakıcıların yaşı ve Maslach emosyonel tükenme (EE) skoru] egzersiz programına uyumu tahmin gücünü belirlemek için lojistik regresyon modeli ile analiz edildi.

Sonuç: Serebral palsili çocukların fonksiyonel limitasyonlarının ciddiyeti bakıcıların ev egzersiz programına uyumlarını arttırırken, bakıcıların tükenmişlikleri uyumu olumsuz etkilemektedir. Bu nedenle bakıcıların sosyal ve medikal olarak desteklenmeleri başarılı ev egzersiz programları için gereklidir.

Anahtar Kelimeler: Egzersiz, serebral palsi, bakıcı, ruh sağlığı, tükenmişlik, özbildirim, uyum

Address for Correspondence / Yazışma Adresi: Aynur Başaran, MD, Konya Beyhekim Hospital, Clinic of Physical Medicine and Rehabilitation Yazır, Selçuklu 42250 Konya, Turkey Phone: +90 505 853 29 22 E-mail: aynurbasaran@hotmail.com

> Received/Geliş Tarihi: November/Kasım 2012 Accepted/Kabul Tarihi: August/Ağustos 2013 ©Telif Hakkı 2014 Türkiye Fiziksel Tıp ve Rehabilitasyon Derneği - Makale metnine www.ftrdergisi.com web sayfasından ulaşılabilir.

Introduction

Improvement of mobility and other functional abilities is mostly the primary goal of rehabilitation programs in physically disabled children. It is well known that the physical therapy for children with disabilities is beneficial (1-5).

Exercise programs in cerebral palsy (CP) are lifelong activities that are prescribed for home. Exercise in CP facilitates the children to learn how to use their remaining potential to compensate for the movements that could not have been performed. Regular and appropriate home exercise programs and participation of the caregiver are crucial for the rehabilitation of disabled children. Rehabilitation professionals agree that caregiver involvement is cost-effective for more comprehensive rehabilitation. Programs involving the caregivers has been shown to accelerate the success of the rehabilitation goals and to improve motor function of disabled children (2,6-8). For this reason, teaching exercises to family members and assessing follow-up for adherence are very important components of treatment. Furthermore, to maximize outcomes, rehabilitation professionals should assure the parents about the effectiveness of caregiver incorporation into rehabilitation.

Current literature about the factors affecting the adherence to conventional home exercise programs is incomplete. Regarding childhood, physical activity and keeping on physiotherapy often decrease in adulthood (9-11), and lack of beneficial effects and loss of motivation are some of the causes reported (9). It has been estimated that the rate of non-adherence to prescribed therapeutic regimens is almost as high as 50% (2). In fact, causes of failure to adhere to the recommendations about the interventions and home programs have not been well documented and well understood (2,7). Resumption of the treatment requires awareness of the factors that lead to interruption. Thus, as parental involvement is a crucial component, it is important to evaluate the parental adherence to home programs and the reasons of non-adherence.

In this study, we aimed to assess the adherence ratio and factors that affect the adherence to conventional home exercise programs in children with CP.

Material and Methods

Patient selection

The caregivers of 147 children with CP (male: 56.5% (n=83) and female: 43.5% (n=64)) were recruited for the study. Three of the participants refused to participate to the study. Eleven participants were excluded from the study, because of they did not complete the questionnaires due to lack of time. As for the questionnaires given by face to face interview, there has been no failure for the completed ones.

The participants were included in the study according to the following inclusion criteria: (1) the primary caregiver of a child of 2-18 years old, (2) the child had a diagnosis of CP, and (3) the caregiver was instructed on a daily home exercise program. All the children were attending a state-funded regional children's rehabilitation center two or three times weekly.

Study protocol

To assess the adherence status, the researchers designed an adherence survey. The form included three close-ended questions. The purpose of these questions was to assess the level of adherence to the instructed home exercise program and the causes related with poor adherence expressed by the caregivers (Table 1). Caregivers who carried out the daily home exercise program at least once daily were considered adherent to therapy, while the others were poorly adherent.

The socio-demographic data of both children and caregivers and family characteristics have been documented. The cerebral palsy type and functional level of the disabled child have been determined. Mental status of the caregiver was evaluated with the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI), and burnout of the caregivers was evaluated by Maslach Burnout Inventory (MBI). The compiled data were evaluated to determine whether these data were related with the adherence status or not.

Gross Motor Function Classification System (GMFCS)

The functional level of the child was determined based on the GMFCS. GMFCS is a classification system specifically devised for children with CP in which children younger than 12 years of age are classified into 5 groups according to gross motor movements, such as spontaneously initiated movements, sitting, and gait. Because the motor functions in children are dependent on age, for each level, functions are defined according to 4 different age groups: <2 years, between 2 and 4 years, 4 to 6 years, and 6 to 12 years. The aim is not to establish the quality of the movements and developmental potential but to determine the present GMFCS status of the child (12). Lower levels, such as 1 and 2, indicate better functions in the GMFCS evaluation. In this study, the functional level of children older than 12 were evaluated as if they were 12.

Table 1. Adherence survey

Have you been instructed to follow a daily home exercise program?
a) Yes

often were vou able

2. How often were you able to carry out the home exercise program? (If you are able to carry out the home exercise program at least once daily, do not answer question 3.)

a) No, never

- b) No, I was carrying out at the beginning, but no more
- c) Yes, sometimes, but less than once a day
- d) Yes, I am carrying out regularly, at least once daily

3. What is the reason not to carry out the home exercise program according to you?

- a) I think that attending a state-funded regional children's rehabilitation center is sufficient
- b) I think that it is not helpful
- c) I think that I carry out enough
- d) I have no more time
- e) I feel burned out

b) No

Başaran et al.				
Adherence to Home Exercise Program in CP				

The Beck Depression Inventory (BDI) was used to evaluate the symptoms of depression of the caregivers. BDI is a 21-item scale that gathers information on different symptoms of depression. Each item on the scale is scored from 0 to 3 points. It provides information both on the presence and severity of depression and on somatic, emotional, cognitive, and motivational dimensions. Higher scores imply the presence of more depression. A score of 11-17 indicates mild depression, a score of 18-23 indicates moderate depression, and a score greater than 24 indicates severe depression (13). A validity and reliability study of the Turkish version of the BDI was performed by Hisli (14).

Beck Anxiety Inventory (BAI) scale was used to evaluate the anxiety of caregivers. The BAI measures the frequency of anxiety symptoms. It consists of 21 items, scored on a Likert-type scale from 0 to 3, as "not at all" (0); "mildly; it did not bother me much" (1); "moderately; it was very unpleasant, but I could stand it" (2); and "severely; I could barely stand it" (3). Higher scores indicate an increased level of anxiety. According to the 1993 Revision of the BAI manual, total scores of 0-7 reflect "a minimal level of anxiety;" 8-15 "mild anxiety;" 16-25 "moderate anxiety;" and 26-63 "severe anxiety" (15). It is, as well, a very reliable and well-validated scale (16). The validity and reliability of the Turkish version was confirmed by Ulusoy et al. (17).

The Maslach Burnout Inventory (MBI) consists of 22 items and provides a measurement of the degree of burnout in terms of three subscales: emotional exhaustion, depersonalization, and personal accomplishment. The first subscale consists of nine questions and measures emotional exhaustion (EE), described as being overextended and exhausted by one's work. The fiveitem depersonalization (DP) scale assesses the extent to which a respondent feels uncaring toward recipients of care or service. The final scale, consisting of eight items, assesses feelings of personal accomplishment (PA) and success from work. Each of the 22 items is rated for frequency. The frequency rating ranges from 1 (a few times a year) to 6 (every day). The respondents may also indicate whether the feeling or attitude is never experienced (0). It is a reliable and well-validated scale (18,19). The validation of the Turkish version has been done by Ergin (20). During validation, the 7-point rating scale was decided to be inappropriate for the Turkish culture, and the rating scale was reduced to a 5-point rating scale. In the Turkish version, the Likert-type scale ranged from 0 to 4 for each question: '0 Never,' '4 every day.'

A written informed consent was obtained from all the participants. This study was approved by the ethical committee of a university hospital.

Statistical Analysis

Chi-square and Fischer's exact tests were used for nominal variables. Kolmogorov-Smirnov test was used to assess normal distribution of continuous variables. Mann-Whitney U-test was used for ordinal and nonparametric continuous variables. A binary logistic regression model was constructed to determine the independent contributions of statistically significant variables and also to assess the effectiveness of the model to predict the adherence to home exercise programs. In order to detect an odds ratio of 2.0 that causes a change in the probability from 0.20 to 0.33, 102 patients are required, with beta equal to 0.20 and alpha equal to 0.05. Additionally, to detect a correlation of 0.30 between GMFCS and patient compliance required 84 patients at the same alpha and beta levels. PASW for Windows 18.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analyses. The statistical significance level was set at 0.05.

Results

The distribution of adherence according to the survey was as follows: No, never: 6.8% (n=10); No, I was carrying out at the beginning, but no more: 8.2% (n=12); Yes, sometimes: 19.7% (n=29); Yes, I carry out regularly, at least once daily: 65.3% (n=96). The good adherence ratio was 65.3% (n=96). A total of 51 caregivers (34.7%) were poorly adherent to the home exercise program. The causes related with the poor adherence expressed by the poorly adherent caregivers were 'I think attending a state-funded regional children's rehabilitation center is sufficient': 39.2% (n=20); 'I think that it is not helpful': 5.9% (n=3); 'I think that I carry out enough': 3.9% (n=2); 'I have no more time': 29.4% (n=15); and 'I feel burned out': 21.6% (n=11).

The sociodemographic data of both children and caregivers and family characteristics and comparisons between the adherent and poorly adherent groups are documented in Table 2. Mental health and burnout of caregivers and comparisons between the adherent and poorly adherent groups are documented in Table 3.

Using statistically significant parameters in univariate tests (age, weight, and GMFCS of the children and age and Maslach EE score of the caregiver), a logistic regression model was constructed to predict the adherence to exercise. This model correctly classifies the 87.5% of the participants who had good adherence to the exercise program. On the other hand, only 52.9% of the participants were correctly classified in the poorly adherent group. Therefore, using the responses to parameters of age, weight, and GMFCS of the children and age and Maslach EE score of the caregiver, we can classify participants with a sensitivity of 87.5% (95% CI=79.4%-92.7%) and a specificity of 52.9% (95% CI=39.5%-66.0%). With the binary logistic regression model, GMFCS and Masclach EE score were found to be significant independent predictors, with an odds ratios of 1.50 (95% CI 1.11-2.03) and 0.92 (95% CI 0.87-0.98), respectively (Table 4).

Discussion

Non-adherence to home exercise programs is documented as one of the factors affecting treatment outcomes (2,21,22). Unfortunately, adherence to home exercise programs is low for many caregivers who have a disabled child. In the study by Rone-Adams (2), 66% of the caregivers declared varying levels of non-adherence to their program. For our study, the poor adherence ratio was 34.7%. However, as the results of these studies were based on statements of the caregivers, the honesty of the caregivers while answering the questions about adherence

Başaran et al. Adherence to Home Exercise Program in CP

Table 2. Sociodemographic and family characteristics and

comparisons between the good and poor adherent groups				
Patient (disabled child) characteristics	Poor adherence (n=51)	Good adherence (n=96)	р	
Age (yr)	11.0±3.8 (2.5-18.0)	7.4±4.1 (2.5-18.0)	<0.001*	
Gender				
Male	27 (52.9%)	56 (58.3%)	0.53	
Female	24 (47.1%)	40 (41.7%)		
Body weight	29.1±12.4 (10.0-56.0)	19.3±9.4 (7.0-50.0)	<0.001*	
CP type				
Spastic Diplegia	19 (37.3%)	35 (36.5%)	0.14***	
Spastic Hemiplegia	18 (35.3%)	21 (21.9%)		
Spastic Quadriplegia	13 (25.5%)	37 (38.5%)		
Other	1 (2.0%)	3 (3.1%)		
GMFCS	2.6±1.5 (1-5)	3.2±1.4 (1-5)	0.02*	
Level I	19 (37.3%)	18 (18.8%)		
Level II	6 (11.8%)	15 (15.6%)		
Level III	12 (23.5%)	20 (20.8%)		
Level IV	5 (9.8%)	19 (19.8%)		
Level V	9 (17.6%)	24 (25.0%)		
Presence of associated condi	tions			
None	11 (21.6%)	25 (26.0%)	0.55	
Present	40 (78.4%)	71 (74.0%)		
Intellectual impairment	24 (47.1%)	48 (50.0%)	0.73	
Speech impairment	22 (43.1%)	50 (52.1%)	0.77	
Seizures	21 (41.2%)	26 (27.1%)	0.08	
Hearing problems	5 (9.8%)	8 (8.3%)	0.30	
Visual impairment	24 (47.1%)	33 (34.4%)	0.13	
Bladder and bowel problems	24 (47.1%)	51 (53.1%)	0.48	
Gastrointestinal problems and malnutrition	14 (27.5%)	23 (24.0%)	0.64	
Respiratory dysfunction	14 (27.5%)	33 (34.4%)	0.39	
Caregiver characteristics				
Caregiver			0.13**	
Mother	46 (90.2%)	93 (96.9%)		
Father	1 (2.0%)	2 (2.1%)		
Other	4 (7.8%)	1 (1.0%)		
Age of caregiver (yr)	36.7±8.0 (23-57)	31.6±6.6 (20-51)	<0.001*	
Educational status				
Illiterate	5 (9.8%)	3 (3.1%)	0.06*	
Literate	2 (3.9%)	1 (1.0%)		

Primary school	30 (58.8%)	56 (58.3%)	
Secondary school	8 (15.7%)	15 (15.6%)	
High school	5 (9.8%)	18 (18.8%)	
University	1 (2.0%)	3 (3.1%)	
Marital status			0.75**
Single	-	3 (3.1%)	
Married	46 (90.2%)	89 (92.7%)	
Divorced/widow	5 (9.8%)	4 (4.2%)	
Employment			
Employed	4 (7.8%)	9 (9.4%)	1.00
Unemployed	47 (92.2%)	87 (90.6%)	
Family characteristics			
Size of family			0.95
Nuclear family	39 (76.5%)	73 (76.0%)	
Extended family	12 (23.5%)	23 (24.0%)	
Health insurance			0.86
Absent	3 (5.9%)	5 (5.2%)	
Present	48 (94.1%)	91 (94.8%)	
Total family income			
Poor	27 (52.9%)	57 (59.4%)	0.49**
Middle class	22 (43.1%)	36 (37.5%)	
High income	2 (3.9%)	3 (3.1%)	
Number of siblings			
None	1 (2.0%)	10 (10.4%)	0.10*
1	6 (11.8%)	24 (25.0%)	
2	22 (43.1%)	36 (37.5%)	
3 and more	22 (43.1%)	26 (27.1%)	
Presence of siblings <3 years	4 (7.8%)	12 (12.5%)	0.39
Presence of siblings with CP	5 (9.8%)	3 (3.1%)	0.13
Presence of anybody else in need of care	10 (19.6%)	12 (12.5%)	0.25
Presence of a helpmate for the care of children	14 (27.5%)	37 (38.5%)	0.18

CP: cerebral palsy; GMFCS: gross motor function classification system. *Mann-Whitney U-test was used to compare groups.

Fischer's exact test was used after grouping. *Chi-Square test was used ignoring the "other" group.

Values are presented as mean±standard deviation (minimum-maximum) or frequency (percentage).

must have been influential. A probable overestimation of adherent behavior for participant self-reports has also been reported (2,23). Therefore, the actual rate of poor adherence by caregivers was greater than the results documented (2). This means that poor adherence is probably higher than our findings.

Previous studies were conducted to determine the factors that influence adherence. The factors, including age, marital status, socioeconomic status, and family size, have been studied. However, similar to our study, none of them has been found to be an independent factor for predicting non-adherence (2). In

comparisons between the good and poor adherent groups			
Psychiatric scale	Poor adherence (n=51)	Good adherence (n=96)	р
BDI	13.8±8.7 (0-35)	13.6±8.9 (0-41)	0.83
Minimal	19 (37.3%)	43 (44.8%)	
Mild	17 (33.3%)	28 (29.2%)	
Moderate	7 (13.7%)	10 (10.4%)	
Severe	8 (15.7%)	15 (15.6%)	
BAI	16.2±7.9 (3-34)	13.0±6.8 (0-31)	0.62
Minimal	16 (31.4%)	26 (27.1%)	
Mild	20 (39.2%)	35 (36.5%)	
Moderate	8 (15.7%)	24 (25.0%)	
Severe	7 (13.7%)	11 (11.5%)	
MBI			
EE	16.2±7.9 (3-34)	4.3±4.2 (0-18)	0.02
DP	22.2±5.3 (8-32)	13.0±6.8 (0-31)	0.28
PA	3.4±3.6 (0-14)	22.0±5.8 (3-32)	0.96

Table 3. Mental health and burnout of caregivers and

* Mann-Whitney U-test was used to compare the groups.

BDI: The Beck Depression Inventory; BAI: Beck Anxiety Inventory; MBI: Maslach Burnout Inventory; EE: Emotional exhaustion; DP: Depersonalization; PA: Personal accomplishment.

Table 4. Logistic regression analysis of study parameters predicting patients' adherence					
Parameter	Odds	95% CI	р		
Age	0.94	0.78-1.15	0.57		
Weight	0.95	0.89-1.01	0.11		
GMFCS	1.50	1.11-2.03	0.01		
Age of caregiver	0.95	0.89-1.02	0.16		
MBI EE score	0.92	0.87-0.98	<0.001		

GMFCS: Gross motor function classification system; MBI: Maslach Burnout Inventory; EE: Emotional exhaustion

our study, educational status and employment of the caregiver and total family income related with the socioeconomic status were non-predictive of adherence. Duration of the disability has been one of the factors that decrease adherence (2,7). The child's age may be a factor affecting adherence; as the child grows, the duration also increases. In our study, the age and the weight of the children were statistically significant in univariate tests but were not found to be independent predictors in the logistic regression model, in which the adherence to exercise was used as a binary outcome. Having a son is important for a traditional family in Turkish culture. We thought that caregivers who have a son will be more adherent. Contrary to our expectations, gender of the children was also non-predictive. Similarly, due to the instinctive nature of motherhood, we expected mothers to be more adherent, but the adherence did not differ among caregivers, either (Table 2).

The physical limitations were reported among the predictors of adherence to home exercise programs, suggesting that if a caregiver refused to accept the child's physical limitations, his or her level of adherence may be low (2). Our study has demonstrated that children who are classified to have more impairment have caregivers who are more adherent, relative to the caregivers of children who are classified as having less impairment. In other words, the severity of the functional limitation of children with CP seems to enhance the adherence of caregivers to home exercise programs. Besides, neither the type of CP nor the associated conditions (such as seizures, hearing problems, respiratory problems, etc.) have been found to be predictive of non-adherence (Table 2).

Stress is reported as an influential factor of adherence. The relationship between stress and adherence has been documented in the literature. Increased stress is prevalent among families caring for a disabled child (2,24). Even though breeding and rearing a nondisabled child may be stressful for the mothers (25), it is inevitable for the mothers of children with disabilities to experience greater stress and emotional demands (26). Studies revealed that parents of disabled children had significantly higher levels of psychiatric symptoms and were more likely to indicate higher levels of depression and anxiety symptoms, compared with controls (26-28). In the study by Rone-Adams et al. (2), the results reveal that there is a statistically significant relationship between stress and adherence, suggesting that a caregiver's level of adherence can be predicted by the intensity of the experienced stress. In our study, almost two-thirds of the caregivers had mild to severe depression (62.7% of non-adherent, 55.2% of adherent) and mild to severe anxiety (68.6% of non-adherent, 71.9% of adherent). Nevertheless, no significant associations with either BDI or BAI have been documented, suggesting that neither depression nor anxiety of the caregivers had a significant effect on the adherence status.

However, caregivers of disabled children usually fail to cope with stress, and eventually, most of them get burned out. Lack of motivation, tiredness, and disappointment are inevitable during the course of treatment. These adverse conditions may lead to exhaustion and burnout. The need for adherence to prolonged interventions, financial problems, special housing modifications, equipment needs, social isolation, and grieving reactions can contribute to the stress (2,29) and may increase the exhaustion. According to natural course of CP, rate of improvement decreases throughout childhood, and maintaining functional status may not be possible; moreover, with aging, there can be a modest decrease in function, as there is for the general population (30). A number of studies have noted that about one-third of participants report modest to significant decreases in walking or self-care tasks (11,31-34). This deterioration after long and tiring years may increase burnout. The caregivers eventually may become ineffective and inefficient, no matter how hard they tried to accomplish their responsibilities. There are some studies documenting the burnout level of a mother/caregiver of a disabled child (35-37). In this study, the effect of burnout level to adherence was studied. The EE score of MBI of the poorly adherent group was higher, indicating a higher level of burnout.

The logistic regression model demonstrated that the Maslach EE score of the caregiver predicted poor adherence. These results revealed that the caregivers do not give up home programs even if they are in depression or anxiety. However, when they have difficulty in overcoming stress and experience exhaustion, they fail to show adherence to treatment.

The caregivers of children with CP should overcome the difficulties and complications arising from their children's impairments. It is often time-consuming and may be stressful for the caregivers and leads to burnout (35-39). It can be predictable that any factor increasing the demands on caregivers will make it difficult to adhere to the home exercise program. Therefore, we have analyzed the factors (number of the siblings, presence of siblings younger than 3 years old, presence of other siblings with CP, presence of anybody else in need of care) that are supposed to increase the demand on caregivers and determined whether they are associated with the adherence or not. In contrast, the presence of a helpmate for the care of the children is thought to decrease the load on caregivers, which, in turn, helps to adhere. But, none of them was statistically significant in our study.

According to self-reports, 21.6% (n=11) of the poorly adherent caregivers expressed that they feel burned out. The expression of the poorly adherent caregivers that "I think that attending a state-funded regional children's rehabilitation center is sufficient" at a rate up to 39.2% (n=20) is interesting. Unfortunately, this result is compatible with our observations, which is mentioned commonly by the poorly adherent caregivers during clinical practice. But, the reasons and consequences of such an attitude should be argued. Today's modern family-centered treatment paradigms require involvement of the family in every single step of the rehabilitation program. Achievement of this goal requires a thorough assessment of the effectiveness of rehabilitation centers.

Various factors have an effect on the adherence to home programs of disabled children and, thus, the outcome. Here, some factors possibly affecting the adherence have been argued. In order to reduce exhaustion and increase the adherence, features of each case should be considered.

Healthcare professionals should focus on how the caregiver can be supported and rendered less exhausted. Interventions, such as counseling and relaxation techniques, may help to achieve better lifestyles both for themselves and their child (2,40). Education about the prognosis, aging with a disability, and expectations of an exercise program are important in order to prevent frustration and to keep their expectations reasonable (41).

Additionally, incorporating the home program into the daily routine might lead to less exhaustion and thus better adherence (2). In the study by Allen et al. (41), enjoyment was a key benefit of the strength-training program for adults with CP (9), which is a factor that can promote adherence and persistence. As discussed above, greater adherence is seen in the more functionally impaired groups. This may be, in some way, due to the children being more passive recipients of their parent's care, whereas the more able children, especially as they get older, may choose not to do their exercises, regardless of what their caregivers try. This non-adherent manner may cause additional exhaustion for the caregiver. An enjoyable exercise program will provide higher adherence and less stress and consumption.

When instructing a home exercise program, rehabilitation professionals should consider the caregiver's emotional needs and mental health to enable adherence. Additionally, supporting the caregivers in coping stress is an important consideration (2).

Finally, healthcare professionals should reevaluate the effectiveness of rehabilitation centers, and the necessary training and supervision should be provided in accordance.

Conclusion

The severity of the functional limitation of children with CP seems to enhance the adherence of caregivers to home exercise programs, while the exhaustion and burnout of caregivers have a negative impact. Coaching of the caregivers and consideration of the psychological status and expectations related to their children's future are important to achieve the best results in rehabilitation programs.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Bülent Ecevit University Educational and Research Hospital Ethics Committee. (05.07.2007-2007/07).

Informed Consent: Written informed consent was obtained from patients who participated in this study.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept - A.B.; Design - A.B., K.İ.K., Ş.Ö.Ü., N.A.; Supervision - A.B., K.İ.K.; Funding - A.B., K.İ.K.; Materials - A.B., K.İ.K.; Data Collection and/or Processing - K.İ.K., Ş.Ö.Ü., Ö.B.; Analysis and/or Interpretation - A.B.; Literature Review - A.B., K.İ.K., Ö.B.; Writing - A.B.; Critical Review - K.İ.K., Ş.Ö.Ü., N.A.

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study has received no financial support

Etik Komite Onayı: Bu çalışma için etik komite onayı Bülent Ecevit Üniversitesi Uygulama ve Araştırma Hastanesi Etik Kurulu'ndan alınmıştır (05.07.2007-2007/07).

Hasta Onamı: Bu çalışmaya katılan hastalardan yazılı onam alınmıştır

Hakem değerlendirmesi: Dış bağımsız.

Yazar Katkıları: Fikir - A.B.; Tasarım - A.B., K.İ.K., Ş.Ö.Ü., N.A.; Denetleme - A.B., K.İ.K.; Kaynaklar - A.B., K.İ.K; Malzemeler - A.B., K.İ.K.; Veri toplanması ve/veya işlemesi - K.İ.K., Ş.Ö.Ü., Ö.B.; Analiz ve/veya yorum - A.B.; Literatür taraması - A.B., K.İ.K., Ö.B.; Yazıyı yazan - A.B.; Eleştirel İnceleme - K.İ.K., Ş.Ö.Ü., N.A. Çıkar Çatışması: Yazarlar çıkar çatışması bildirmemişlerdir.

Finansal Destek: Yazarlar bu çalışma için finansal destek almadıklarını beyan etmişlerdir.

References

- Ekenberg L, Erikson A. Physiotherapy for young people with movement disorders: factors influencing commencement and duration. Dev Med Child Neurol 1994;36:253-62. [CrossRef]
- Rone-Adams SA, Stern DF, Walker V. Stress and compliance with a home exercise program among caregivers of children with disabilities. Pediatr Phys Ther 2004;16:140-8. [CrossRef]
- Verschuren O, Ketelaar M, Takken T, Helders PJ, Gorter JW. Exercise programs for children with cerebral palsy: a systematic review of the literature. Am J Phys Med Rehabil 2008;87:404-17. [CrossRef]
- Odman PE, Oberg BE. Effectiveness and expectations of intensive training: a comparison between child and youth rehabilitation and conductive education. Disabil Rehabil 2006;28:561-70. [CrossRef]
- Dodd KJ, Taylor NF, Graham HK. A randomized clinical trial of strength training in young people with cerebral palsy. Dev Med Child Neurol 2003;45:652-7. [CrossRef]
- Gross AM, Eudy C, Drabman RS. Training parents to be physical therapists with their physically handicapped child. J Behav Med 1982;5:321-7. [CrossRef]
- Law M, King G. Parent compliance with therapeutic interventions for children with cerebral palsy. Dev Med Child Neurol 1993;35:983-90. [CrossRef]
- Piggot J, Paterson J, Hocking C. Participation in home therapy programs for children with cerebral palsy: a compelling challenge. Qual Health Res 2002;12:1112-29. [CrossRef]
- Sandström K, Samuelsson K, Oberg B. Prerequisites for carrying out physiotherapy and physical activity - experiences from adults with cerebral palsy. Disabil Rehabil 2009;31:161-9. [CrossRef]
- Hilberink SR, Roebroeck ME, Nieuwstraten W, Jalink L, Verheijden JM, Stam HJ. Health issues in young adults with cerebral palsy: towards a life-span perspective. J Rehabil Med 2007;39:605-11. [CrossRef]
- Bottos M, Feliciangeli A, Sciuto L, Gericke C, Vianello A. Functional status of adults with cerebral palsy and implications for treatment of children. Dev Med Child Neurol 2001;43:516-28. [CrossRef]
- Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39:214-23. [CrossRef]
- Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961;4:561-71. [CrossRef]
- Hisli N. Beck Depresyon Envanteri'nin üniversite öğrencileri için geçerliliği, güvenilirliği. Turk J Psychol 1989;7:3-13.
- Beck AT, Stern RA. Beck Anxiety Inventory Manual. San Antonio, TX: The Psychological Corporation Harcourt Brace & Company; 1993.
- Beck AT, Epstein N, Brown G, Steer RA. An inventory for measuring clinical anxiety: psychometric properties. J Consult Clin Psychol 1988;56:893-7. [CrossRef]
- Ulusoy M, Sahin N, Erkmen H. Turkish version of the Beck Anxiety Inventory: Psychometric properties. J Cogn Psychother 1998;12:163-72.
- Maslach C, Jackson SE. The measurement of experienced burnout. Journal of Occupational Behaviour 1981;2:99-113. [CrossRef]
- Donohoe E, Nawawi A, Wilker L, Schindler T, Jette DU. Factors associated with burnout of physical therapists in Massachusetts rehabilitation hospitals. Phys Ther 1993;73:750-6.
- Ergin C. Burnout in physicians and nurses and adaptation of the Maslach Burnout Scale. VIIth National Congress of Psychology,

Scientific Studies and Publication of Turkish Psychologs Associations; 22-25 September; Ankara 1992. p. 143-54.

- Mayo NE. The effect of a home visit on parental compliance with a home program. Phys Ther 1981;61:27-32.
- Major DA. Utilizing role theory to help employed parents cope with children's chronic illness. Health Educ Res 2003;18:45-57. [CrossRef]
- Marston MV. Compliance with medical regimens: a review of the literature. Nurs Res 1970;19:312-23. [CrossRef]
- Rimmerman A, Stanger V. Parental stress, marital satisfaction and responsiveness to children: a comparison between mothers of children with and without inborn impairment. Int J Rehabil Res 2001;24:317-20. [CrossRef]
- Naerde A, Tambs K, Mathiesen KS, Dalgard OS, Samuelsen SO. Symptoms of anxiety and depression among mothers of pre-school children: effect of chronic strain related to children and child caretaking. J Affect Disord 2000;58:181-99. [CrossRef]
- Smith TB, Innocenti MS, Boyce GC, Smith CS. Depressive symptomatology and interaction behaviors of mothers having a child with disabilities. Psychol Rep 1993;73:1184-6. [CrossRef]
- Carpiniello B, Piras A, Pariante CM, Carta MG, Rudas N. Psychiatric morbidity and family burden among parents of disabled children. Psychiatr Serv 1995;46:940-2.
- Altındag Ö, Iscan A, Akcan S, Koksal S, Ercin M, Ege L. Anxiety and Depression Levels in Mothers of Children with Cerebral Palsy. Turk J Phys Med Rehab 2007:22-4.
- Saloviita T, Itälinna M, Leinonen E. Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX Model. J Intellect Disabil Res 2003;47:300-12. [CrossRef]
- Turk MA, Logan LR, Kanter D. Aging With Pediatric Onset Disability and Diseases. 4th ed. Alexander MA, Matthews DJ, editors. New York: Demos; 2010.
- 31. Turk MA, Geremski CA, Rosenbaum PF, Weber RJ. The health status of women with cerebral palsy. Arch Phys Med Rehabil 1997;78:S10-7. [CrossRef]
- Strauss D, Ojdana K, Shavelle R, Rosenbloom L. Decline in function and life expectancy of older persons with cerebral palsy. NeuroRehabilitation 2004;19:69-78.
- Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. Dev Med Child Neurol 2001;43:76-82. [CrossRef]
- Ando N, Ueda S. Functional deterioration in adults with cerebral palsy. Clin Rehabil 2000;14:300-6. [CrossRef]
- Karadavut KI, Uneri SO. Burnout, depression and anxiety levels in mothers of infants with brachial plexus injury and the effects of recovery on mothers' mental health. Eur J Obstet Gynecol Reprod Biol 2011;157:43-7. [CrossRef]
- Bilgin S, Gozum S. Reducing burnout in mothers with an intellectually disabled child: an education programme. J Adv Nurs 2009;65:2552-61. [CrossRef]
- 37. Richardson M, West P. Motivational management: coping with burnout. Hosp Community Psychiatry 1982;33:837-40.
- Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics 2005;115:626-36. [CrossRef]
- Blacher J. Sequential stages of parental adjustment to the birth of a child with handicaps: fact or artifact? Ment Retard 1984;22:55-68.
- 40. Hernandez NE, Kolb S. Effects of relaxation on anxiety in primary caregivers of chronically ill children. Pediatr Nurs 1998;24:51-6.
- Allen J, Dodd KJ, Taylor NF, McBurney H, Larkin H. Strength training can be enjoyable and beneficial for adults with cerebral palsy. Disabil Rehabil 2004;26:1121-7. [CrossRef]