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THE ASSOCIATION BETWEEN ABILITY TO SUSTAIN PHYSICAL ACTIVITY AND QUALITY OF LIFE OF PRESCHOOL CHILDREN WITH CEREBRAL PALSY, AND PSYCHOSOCIAL STATUS OF CAREGIVERS

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ORIGINAL ARTICLE

ABSTRACT

Purpose: This study aimed to present the relationship between the ability to maintain physical activity in preschool children with cerebral palsy (CP) and quality of life, and the psychosocial status of caregivers.

Methods: Fifty-five children with CP and their caregivers were included in the study. The ability to maintain physical activity and quality of life were determined by the Early Activity Scale for Endurance (EASE) and Pediatric Outcomes Data Collection Instrument (PODCI), respectively. The psychosocial status of caregivers was assessed by Impact on Family Scale (IFS), Beck Depression Inventory (BDI) and State Trait Anxiety Inventory (STAI).

Results: The mean age of children (28 Female, 27 Male) and their caregivers (45 Female, 10 Male) was 46.96±14.66 months and 33.81±7.65 years, respectively. Significant correlations were found between EASE and PODCI sub-parameters ($p<0.05$). However, there were no significant correlations between EASE and the IFS, BDI and STAI ($p>0.05$). Statistically significant correlations were detected between PODCI-happiness and IFS ($p=0.042$, $r=-0.293$) and PODCI-transfer/mobility and BDI ($p=0.044$, $r=-0.273$).

Conclusion: This study suggests that the ability to sustain physical activity of preschool children with CP is closely related to their quality of life and the psychological well-being of caregivers is affected from the severity of impact of the disease on caregivers. The quality of life of preschool children with CP can be improved by holistic approaches aiming to improve the endurance for physical activity and psychological well-being of their caregivers.

Keywords: Anxiety; Caregivers; Cerebral palsy; Depression; Physical activity

OKUL ÖNCESİ SEREBRAL PALSİLİ ÇOCUKLARIN FİZİKSEL AKTİVİTEYİ SÜRDÜREBİLME YETENEĞİ VE YAŞAM KALİTESİ İLE, BAKIM VERENLERİN PSİKOSOSYAL DURUMU ARASINDAKİ İLİŞKİ

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Bu çalışmanın amacı okul öncesi serebral palsili (SP) çocuklarda fiziksel aktiviteyi sürdürebilme yeteneği ile yaşam kalitesi ve bakım verenlerin psikososyal durumları arasındaki ilişkiyi araştırmaktır.

Yöntem: Çalışmaya 55 SP'li çocuk ve bakım verenleri dahil edildi. Fiziksel aktiviteyi sürdürme yeteneği ve yaşam kalitesi sırasıyla Endurans için Erken Aktivite Skalası (EEAS) ve Pediatrik Veri Toplama Aracı (PVTA) ile belirlendi. Bakım verenin psikososyal durumu Aile Etki Ölçeği (AEÖ), Beck Depresyon Ölçeği (BDÖ) ve Durumluk-Sürekli Kaygı Envanteri (DSKE) ile değerlendirildi.

Sonuçlar: Çocukların (28 Kadın, 27 Erkek) ve bakım verenlerin (45 Kadın, 10 Erkek) yaş ortalaması sırasıyla 46,96±14,66 ay ve 33,81±7,65 yıl idi. EEAS ile PVTA alt parametreleri arasında anlamlı ilişkiler bulundu ($p<0,05$). Ancak, EEAS ile AEÖ, BDÖ ve DSKE arasında anlamlı ilişkiler bulunmadı ($p>0,05$). PVTA-mutluluk ile AEÖ ($p=0,042$, $r=-0,293$) ve PVTA-transfer/mobilite ile BDÖ ($p=0,044$, $r=-0,273$) arasında istatistiksel olarak anlamlı ilişkiler tespit edildi.

Tartışma: Bu çalışma, okul öncesi SP'li çocukların fiziksel aktiviteyi sürdürebilme yeteneğinin yaşam kalitesi ile yakından ilişkili olduğunu ve bakım verenlerin psikolojik iyilik hallerinin, hastalığın bakım veren üzerindeki etkisinin şiddetinden etkilendiğini düşündürmektedir. Okul öncesi SP'li çocukların yaşam kalitesi, endurans için fiziksel aktivite düzeyini ve bakım verenin psikolojik iyilik halini iyileştirmeyi amaçlayan bütünsel yaklaşımlarla geliştirilebilir.

Anahtar Kelimeler: Anksiyete; Bakım verenler; Serebral palsi; Depresyon; Fiziksel aktivite

INTRODUCTION

Cerebral palsy (CP) is a non-progressive neurodevelopmental condition characterized by abnormal muscle tone, impaired movement and postural development caused by damage to the immature brain. Sensory, cognitive communication and behavioral problems may also accompany these disorders. CP is known to be the most common group of childhood physical disorders with an incidence of 1.5 to 4 per 1000 births worldwide (1). Physical activity is defined as any physical movement that is generated by skeletal muscles and results in energy expenditure in daily life (2). Children with CP participate less in physical activity than their typically developing peers, and they have a greater period of inactivity during the day (3). Internal factors including postural disorders, pain, muscle tone changes, fatigue, nutritional problems (2) and external factors such as lack of parental support and environmental restrictions (3) can cause low physical activity levels and more sedentary time in these individuals. Increased sedentary time may result in social isolation and depression in children with CP (4). It is also emphasized that it is crucial to monitor the presence of problems related to the level of physical activity considering the recent evidence regarding the increasing prevalence of secondary problems such as stroke and heart problems in these individuals (5).

The ability to sustain physical activity in children with CP is an important parameter that affects an individual's social participation (6). This has led to a growing interest in development and implementation of interventions aimed at increasing the predisposition to be physically active for children with CP in recent years (6,7). Thus, it is necessary to determine the physical activity levels in this group. However, considering the age criteria of the limited number of current measurement methods regarding physical activity (8,9), such methods are not suitable for determining the level of physical activity of preschool children with CP. Therefore, it is thought that determining the capacity of children with CP aged 2 to 5 years to sustain physical activity may help predict their physical activity levels during school-age years and adolescence (6), allowing for early interventions and guidance (10).

CP causes many musculoskeletal problems and affects the daily life of children and their families (11). Previous studies have reported that caregivers of children with CP are significantly affected physically and psychologically (1, 11) and that parents often experience problems such as psychological anxiety, financial problems, and restriction in social and cultural activities. This brings along a burden of care that affects all caregivers (11). Families of children with CP cope with many circumstances such as diagnostic process and its acceptance, provision of adequate care and fulfilling expectations. While some families can adapt to this process and go through successfully, some families have difficulty coping with these problems and experience high levels of depression (12). A meta-analysis study reports that depressive disorders were more common in mothers of children with CP than in mothers of healthy children (13). In addition, the burden of caring for mothers of children with CP exceeds the time requirements of the typical family and leads to additional pressure due to their efforts to meet the continuous care requirements (11, 14). Therefore, it is argued that mothers of children with CP who have lower functional level experience more stress and have lower quality of life. As a result, it has been reported that programs targeting children with CP and their caregivers have started to gain importance in recent years to maintain long-term mental and physical health in children with CP and their caregivers (14).

Caregiver stress and psychological distress may affect the quality of care provided and limit the child's participation in rehabilitation and social activities. Therefore, coping with caregiver stress is crucial not only for the well-being of the caregiver, but also for the healthy development of the child. Even though many studies have been conducted on the psychosocial state of the families of the individuals with disability, that the lack of studies which investigate the impact of the physical activity of the individuals with disability on caregiver and psychosocial state of caregivers have been reported (15). The objective of this study is to contribute to the development of holistic approaches by addressing a gap in the existing literature and elucidating the factors associated with the ability to sustain physical activity in preschool children with CP and the effects of these factors on their caregivers. Karatekin et al. also suggested that the behavioral aspects of the children with CP affect caregivers physically and psychologically, and children and their families should be evaluated together in future studies (16). The purpose of the study was to investigate the relationship between the ability to sustain physical activity in preschool children with CP and quality of life, and the psychosocial status of their caregivers.

METHOD

This cross-sectional study was conducted in collaboration with Hacettepe University Faculty of Physical Therapy and Rehabilitation and Yozgat Bozok University Sarikaya School of Physiotherapy and Rehabilitation. The study protocol was approved by the Non-Interventional Clinical Research Ethics Committee of Yozgat Bozok University under the decision no. 2017-KAEK-189_2022.07.28_01. The study was carried out between August 2022 and December 2022, based on the Declaration of Helsinki. Written consents were obtained from the caregivers who participated in the study.

Participants

This study was conducted with children aged between 2 to 5 years who were diagnosed with CP by a pediatric neurologist, and their literate caregivers. Children who underwent orthopedic surgery or diagnosed with a metabolic disease or a neuromuscular or severe respiratory disease in addition to CP, or whose caregivers had communication problems were excluded from the study.

The sample size of the present study was determined based on the assessment results of the study conducted by Bjornson et al. (17). Statistical power values for each statistical significance test were obtained using the G*POWER program. The effect size was calculated as 0.616, and it was found that a minimum of 32 children should be included for a power of 80.6% and a significance level of 5%. The study was completed with the inclusion of 55 children with CP and their caregivers.

Assessments

Descriptive Information and Functional Status Assessment

Age (month), height (cm), weight (kg), body mass index (kg/m2), gender and CP type of children; and age (year), education levels and professions of the caregivers were recorded in the study.

Functional levels of the children were identified by the Gross Motor Function Classification System (GMFCS). Revised in 2007 and shown to be valid for children with CP in Turkish by El et al., the GMFCS evaluates the ability to perform the defined daily functions at a certain level in 5 levels between Level 1 to Level 5, of which Level 1 indicates the highest, and Level 5 shows the lowest functional level (19).

Assessment of the Ability to Maintain Physical Activity

The ability to sustain physical activity in children with CP was assessed by the Turkish version of the Early Activity Scale for Endurance (T-EASE) which was recently found as valid and reliable in the Turkish preschool children with CP.

The original instrument was developed by McCoy et al. in 2012, and it has been shown to be valid and reliable in determining the endurance for physical activity of preschool children with CP aged between 2 to 5 years (19). The T-EASE consists of 10 questions and takes approximately 10 minutes to complete, and each item is scored between 1 to 5. For items 1, 2, 3, 4, 5, 7, 8 and 9, the caregiver chooses the option that is most suitable for the child among “always, usually, sometimes, rarely, never”, depending on the activity asked. Items 6 and 10 include selection of the most accurate duration depending on the maximum time the child spends in the specified directive. A score of 1 to 5 is given depending on the selected duration. After item 6, caregivers are asked whether their children are mobilized independently, and if the response is “no”, the questionnaire is terminated where the entire instrument is answered if the answer is “yes”. Therefore, while the minimum score that an individual without independent mobility can get is 6, the minimum score that an individual with independent mobility can get is 10. The highest possible score is 50. A higher total score means that the endurance required to be physically active is higher, while higher scores in items 4 and 9 indicate more fatigue (10,19).

Assessment of Quality of Life of Children

The functional health condition and health-related quality of life of children with CP were assessed with the child form of the Pediatric Outcomes Data Collection Instrument (PODCI) (20,21), which has been demonstrated to be a valid and reliable tool for use with Turkish children with CP aged 2 to 10 years. The instrument includes 86 questions under the subscales as global function, upper extremity function, transfers and basic mobility, sports and physical function, pain and comfort and happiness sub-parameters. According to each subscale score and the global score, which is calculated by summing each subscales' scores, 0 point indicates worser health condition while 100 points indicate maximum level of health quality (20).

Assessment of Psychosocial Characteristics of the Caregivers

The impact of child's disease on caregivers was assessed by the Impact on Family Scale (IFS) which was adapted to Turkish and tested for reliability and validity by Beydemir et al. in 2009 (22,23). The IFS includes four basic categories including financial burden, familial and social affection, personal difficulty and coping with 27 items in total. Three items of the IFS are not included in the scoring system. Each remaining item is scored between 1 to 4, and a minimum score of 24 and maximum score of 96 can be obtained from the questionnaire. The higher the overall score the more the parents are affected by the disease of their child (22,23).

Caregivers' depression levels were assessed by the Beck Depression Inventory (BDI). The BDI is a scale developed by Beck et al. to assess the severity of depression, which contains the symptoms frequently shown by depressed individuals, and it was found to be valid and reliable in Turkish. It includes 21 items in total, and each item is scored between 0 to 3. BDI takes approximately 5 to 10 minutes to complete. The score between 10 and 16 points indicates mild depression symptoms, 17 to 29 points indicates moderate depression symptoms, and 30 to 63 points indicates serious depression symptoms (24,25).

The Turkish version of the State-Trait Anxiety Inventory (STAI) was used to assess the anxiety levels of the caregivers. It is a two-part scale with 20 items in each part. State anxiety is an indicator of the emotions and individual feels due to stressful situations. Trait anxiety indicates anxiety that is persistent and does not occur according to a specific situation or time. The total score ranges between 20 to 80, and a higher score indicates higher levels of anxiety (26,27).

Statistical Analysis

Statistical software package SPPS 25 (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.) was used to assess the data. Descriptive statistics (mean-X, standard deviation-SD, minimum value-min, maximum value-max, number-n and percentile-%) were given for categorical and continuous variables in the study. The homogeneity of the variances, one of the preconditions of parametric tests, was checked by the "Levene" test. The assumption of normality was checked by the "Shapiro-Wilk" test. Since it was found that the data did not conform to the normal distribution, it was decided that non-parametric conditions were fulfilled. The relationships between continuous variables were analyzed by the Spearman Correlation Coefficient (r). A relationship strength of r>0.90 was defined as very strong, 0.70 to 0.90 as strong, 0.40 to 0.70 as moderate, 0.20 to 0.40 as weak, and <0.20 as very weak or insignificant correlation (28). Statistical significance level (p) was accepted as 0.05.

RESULTS

A total of 55 preschool children with CP and their caregivers were included in the study. The descriptive and physical information related to the children and their caregivers was shown in Table 1. The CP types of the children were as follows: 22% (n=12) hemiparetic CP, 31% (n=17) diparetic CP, 31% (n=17) quadriparetic CP, 11% (n=6) hypotonic CP, and 5% (n=3) ataxic CP. It was found that 23 (58%) of the individuals with CP used different orthoses such as ankle foot orthoses or knee-ankle foot orthoses while 22 individuals (42%) did not use any orthoses.

According to the GMFCS levels, 11% of children (n=6) were in level I, 38% (n=21) were in level II, 20% (n=11) were in level III, 15% (n=8) were in level IV, and 16% (n=9) were in level V. Table 2 shows the

Table 1. Descriptive Characteristics of Children with CP and Their Caregivers (n=55).

Children with Cerebral Palsy	**Minimum**	**Maximum**	**X ± SD**
Age (months)	24	60	46.96±14.66
Height (cm)	75	120	93.87±12.21
Weight (kg)	8	25	14.57±4.3
Body Mass Index (kg/m2)	10.7	29.6	16.46±3.42
		n	**%**
Gender	Female	28	51
	Male	27	49
Caregivers of Children with Cerebral Palsy	**Minimum**	**Maximum**	**X ± SD**
Age (years)	22	56	33.81±7.65
		n	**%**
Gender	Female	45	82
	Male	10	18

X: Mean, SD: Standard Deviation.

results of T-EASE and PODCI scores of the children and the IFS, BDI, and STAI results of the caregivers.

The relationships between the T-EASE and PODCI scores of children with CP and the psychosocial status of their caregivers were given in Table 3. Significant weak-to-strong correlations were found between the T-EASE scores and the PODCI-upper extremity (r=0.639, p=0.001), PODCI-transfer and basic mobility (r=0.827, p=0.001), PODCI-sport and physical function (r=0.809, p=0.001), PODCI-happiness (r=0.320, p=0.017), PODCI-global (r=0.787, p=0.001) scores of children. Statistically significant correlations were detected between PODCI-happiness and IFS (r=-0.293, p=0.042) and PODCI-transfer/mobility and BDI (r=-0.273, p=0.044). However, there were no significant correlations between the T-EASE scores and the caregivers' IFS (r=0.152, p=0.268), BDI (r=-0.182, p=0.184) and state anxiety (r=0.091, p=0.511), trait anxiety (r=-0.114, p=0.407) scores.

DISCUSSION

In this study which was performed to determine the relationship between the ability to sustain physical activity in preschool children with CP and their

Table 2. The Results of the Outcome Measures (n=55)

Outcomes Measures (Minimum-Maximum)	**Subscales of the Scale (Minimum-Maximum)**	**X±SD**	**Minimum-Maximum**
Children with Cerebral Palsy			
Early Activity Scale for Endurance (6-50)		26.58±13.65	6-49
Pediatric Outcomes Data Collection Instrument	Upper Extremity (0-100)	29.89±14.03	0-53
	Transfers and Basic Mobility (0-100)	31.07±22.89	0-91
	Sports and Physical Function (0-100)	25.87±12.11	1-49
	Pain and Comfort (0-100)	38.38±17.93	1-55
	Happiness (0-100)	32.22±18.67	0-57
	Global (0-100)	30.49±16.52	0-59
Caregivers			
Impact on Family Scale (24-96)		52.02±12.25	34-88
Beck Depression Inventory (0-63)		12.44±9.34	0-36
State-Trait Anxiety Inventory	State Anxiety (20-80)	35.78±14.59	20-73
	Trait Anxiety (20-80)	42.69±9.11	29-63

X: Mean, SD: Standard Deviation.

Tablo 3. The Associations Between the Outcome Measures (n=55).

Outcomes Measures		**Early Activity Scale for Endurance (EASE)**	**Pediatric Outcomes Data Collection Instrument**					
			Upper Extremity Function	**Transfers and Basic Mobility**	**Sports and Physical Function**	**Happiness**	**Pain and Comfort**	**Global**
Early Activity for Endurance Scale	r	-	0.639	0.827	0.809	0.320	0.180	0.787
	p	-	**0.001***	**0.001***	**0.001***	**0.017***	0.189	**0.001***
Impact on Family Scale	r	0.152	0.045	0.105	0.009	-0.293	0.254	0.136
	p	0.268	0.744	0.447	0.950	**0.042***	0.062	0.323
Beck Depression Inventory	r	-0.182	-0.256	-0.273	-0.200	-0.012	-0.094	-0.245
	p	0.184	0.059	**0.044***	0.143	0.933	0.495	0.071
State Anxiety	r	0.091	-0.163	-0.057	0.016	0.035	-0.039	-0.086
	p	0.511	0.234	0.678	0.906	0.800	0.775	0.533
Trait Anxiety	r	-0.114	-0.110	-0.199	-0.197	-0.030	-0.243	-0.214
	p	0.407	0.422	0.145	0.149	0.828	0.074	0.117

*: $p<0.05$, r: Spearman Correlation Coefficient

quality of life, and psychosocial state of the caregivers, it was found that the endurance levels required to sustain physical activity of children with CP is closely related to their quality of life. Even though no direct relationship was found between the ability to maintain physical activity in preschool children with CP and the psychosocial status of their caregivers, the “happiness” of children was determined to be associated to the impact of child’s disease on caregivers. In addition, the depression level of caregivers was related to the transfer and mobility skills of their children.

Quality of life is defined as physical and psychosocial well-being, and it is emphasized in previous studies that children with CP have a lower level of quality of life than their healthy peers (3, 26). In the literature, it was found that personal and environmental factors are related to the quality of life of children with CP (29). In terms of functionality, it was reported that GMFCS levels of preschool children with CP were related to their quality of life (30). Furthermore, ambulant children with CP demonstrated significantly enhanced parent-reported quality of life, functioning, participation, and physical health status in comparison to children without ambulation (29). In addition, it has been observed that the quality of life of children with CP varies according to the type of CP, with children with quadriparetic CP having a lower quality of life than children with other types of CP (2,29). The fact that 51% of the study population were between GMFCS Levels 3-5 without independent mobility and 62% consisted of diparetic and quadriparetic children in the current study, it was not surprising that the quality of life of overall study population remained below average. Among the other factors related to the quality of life of children with CP, previous literature also suggested that secondary problems such as musculoskeletal pain, the use of assistive devices, the lack of financial support and/or moral support from people around the children might also be associated with quality of life of children with CP (31). Physical activity is also known to be important in improving the quality of life of children with CP. Regular participation in physical activity is known to lead to improvements in musculoskeletal strength, cardiovascular fitness or endurance, quality of life, spasticity, and overall physical function including functional mobility and walking performance (29). Abanoz et al, in a study of individuals with CP, reported that determining the physical activity levels of ambulatory children with CP and directing them to individual programs of physical activity will enable them to participate more actively in life and pave the way for them to be active in older age (32). Besides these factors, this study revealed another factor, endurance to maintain physical activity, as a contributor to the quality of life of preschool children with CP. Therefore, considering the quality-of-life results of the current study, it reveals the importance of early detection of the ability to sustain physical activity in preschool children with CP to predict his/her quality of life, and suggests that timely intervention to increase the capacity for physical activity may lead to better health-related quality of life in many aspects in children with CP.

Caregivers of children with CP included in this study showed below-average family impact and anxiety levels with mild depression symptoms. Park et al. showed that the depression observed in caregivers negatively affected their caring skills and participation in social activity. It was stated that caregiving-related conditions such as depression, anxiety, and stress varied depending on the age of the disabled individual (33). Similarly, according to Beck et al., although depression was reported as a complex condition caused by the perception of a significant loss or the threat of such a loss (34), stressors played more important role in the course of depression than anxiety (35). Thus, it was stated that the depression and anxiety levels of the caregivers of disabled individuals might change depending on the age of the disabled person. It was also reported that mothers might experience higher levels of anxiety during the diagnosis where depressive symptoms might appear over time (35). The young adult caregivers in this study exhibited lower levels of anxiety with mild depressive symptoms, which aligns with the recent literature that suggests the age of the disabled individual is a contributing factor to depressive symptoms in caregivers.

The stress of caregivers who take care of an individual with a chronic condition is the primary risk factor for developing psychosocial problems in both the affected child and caregivers. These stressors may be caused by the severity of the disease and the functional limitations associated with the disease (36). According to a systematic review, the prevalence of depression and anxiety in the parents of children with CP is higher than the parents of typically developing children and with other diseases (37). In addition, a review of the relevant literature revealed that the mothers of CP children with lower motor functional level had higher levels of depression and anxiety (34). Ahmadizadeh et al. found that mothers of the children with CP have mild depression, and this maternal depression had a significant correlation with the daily activities of the individual with CP rather than the severity of CP (38). In this study, there was a relationship between the depression level of caregivers and the transfer/basic mobility sub-test of PODCI. According to this result of current study, it is thought that the decreased functionality of the children with CP due to the decreased mobility ability may affect the social participation of caregivers which, in turn, affect the depression level of the caregiver. On the other hand, according to some of the findings of the literature, depression or anxiety levels of mothers with CP were not related to the level of functionality or disability of children with CP (39,40). This is attributed to the failure of parents to meet their social needs due to the physical impact of an individual with CP. One of the main challenges observed in general with the parents of disabled individuals involves managing their children's chronic health problems effectively and fulfilling this role along with the requirements of daily life. Therefore, providing the necessary support for parents with disabilities may have an impact on their social and psychological well-being (36). The mental health of caregivers is of pivotal importance in this context. A greater caregiving burden is consistently associated with increased levels of depressive symptoms, a diminished quality of life for caregivers, and more pronounced physical disabilities in their children. Irrespective of the functional abilities of the child, caregivers frequently encounter a wide range of challenges, including restricted access to external assistance, financial limitations, and inadequate resources for both the caregiver and the child (39, 40). Prolonged social isolation and feelings of helplessness among caregivers can contribute to elevated stress levels, which in turn exacerbate the psychological burden (40). In the current study, the relationship between the family impact and the happiness sub-test of PODCI suggests that as the disease impact on caregivers increases, they may experience difficulty in providing the necessary psychosocial support to their children with CP, which can affect the emotional status of their children.

Limitations

The small sample size of the study, and therefore the inability to analyze subgroups by GMFCS level, is considered a limitation of the study.

CONCLUSION

This study indicated better quality of life of preschool children with CP if they performed better to sustain physical activity. The current study also indicated that the impact of the disease on caregivers' depression levels was related to the child's psychological well-being and mobility skills, respectively. The reduced ability to sustain physical activity in preschool children with CP, whose transfer and mobility skills decline with age, may lead to an increase in caregiver impact. Therefore, holistic approaches to improving the quality of life of children with CP should also aim to reduce the impact of the disease on caregivers by focusing on children's mobility skills and ability to sustain physical activity.

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