

## FUNCTIONAL STATUS AND QUALITY OF LIFE IN YOUNG ADULTS WITH CEREBRAL PALSY

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**Abstract.** *Objective:* To identify the sociodemographic characteristics, pain level, quality of life, functional state, mobility, and depression level in adults with cerebral palsy (CP). *Material and methods.* Our study included 78 adults with CP (mean age 24.75±7.66 years, 40.5% males) and 79 control subjects (mean age 26.74±6.72 years, 38.5% males). The quality of life, depression, and mobility of all participants were evaluated. In addition, functional status, functional independence and activity level were evaluated in the adult CP group. The depression level was determined by the Beck Depression Inventory (BDI), the mobility level was identified via Rivermead Mobility Index (RMI), and the quality of life was evaluated by the Short Form-36 (SF-36). The functional level of adults with CP was assessed with Gross Motor Function Classification System. Functional independence and activity level were evaluated using the Functional Independence Measure scale (FIM). Pain level was assessed with Visual Analogue Scale (VAS). *Results.* The patient and control groups were statistically different in terms of their educational status, marital status, duration of marriage, employment status, and monthly income ( $p<0.05$ ). SF-36 summary scale scores and subgroup scores, as well as RMI and FIM scores of CP patients, were lower than in the control group. In addition, we revealed a statistically significant positive correlation of FIM scores with SF-36 physical and mental components, along with a statistically significant negative correlation of VAS with FIM, and of FIM with GMFCS:  $p<0.001$ ,  $r=0.450$ ;  $p=0.013$ ,  $r=0.279$ ;  $p=0.022$ ,  $r=-0.257$ ;  $p<0.001$ ,  $r=-0.741$ , respectively. *Conclusion.* We established that the quality of life, along with the mobility and functional levels, were lower in young adults with CP than in the control group, while the depression and pain levels were higher vs. control group. Hence, pain, depression, mobility, functional level, and quality of life should be assessed during the follow-up of adult patients with CP.

**Keywords:** young adults with cerebral palsy, functional status, pain, depression, quality of life

**Introduction.** Cerebral palsy (CP) is a non-progressive disease that occurs in the brain of fetuses or infants, causing limitation of their activity, as well as affecting sensation, perception, communication and behavior [1]. Despite changes in antenatal and perinatal care over the past 40 years, its overall prevalence persisted at 2–3 cases per 1,000 live births [2]. CP is the most common cause of motor impairment in children, often causing their lifelong disability [3]. The number of children with CP reaching adulthood ranges 65–90% [4]. Currently, we observe a steady growth in the number of adults with CP, which is due to an increase in survival rates of neonates born with a low birth weight and a longer life span of the adult population [4].

In addition to the problems experienced in childhood, adults with cerebral palsy may face a variety of problems, such as limitations in daily activities and mobility; social problems; difficulties in learning, work and social

communication; pain in the musculoskeletal system; fatigue; deformities of the musculoskeletal system, sexual problems and limitations in involvement in social activities [5]. Although the disorder is not progressive, people with CP were reported to experience a severe decline in the motor function with age, resulting in a loss or reduction of their independence 5–15 years after adolescence or pre-adulthood. Some published reports demonstrated significant decreases in mobility of adults with CP [6].

According to the definition of the World Health Organization, quality of life is how people perceive their position within their own culture and value judgments in relation to their goals, expectations, standards and interests. In other words, the quality of life determines the subjective perception of one's own health in the sociocultural environment. The main goal of determining the quality of life is to find out to what extent individuals are satisfied with their physical, psychological and social functions and to what extent they are concerned about the presence or absence of features associated with these aspects of their lives [7]. The health-related quality of life in children

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and adolescents is becoming an increasingly relevant research topic [8]. The objective of this study was to determine the sociodemographic characteristics of adults with CP and their clinical characteristics, including pain, quality of life, functional status, mobility and depression.

**Material and methods.** Our study included 78 adult patients with CP and 79 control subjects who were treated or followed up at the Outpatient Clinic for Physical Therapy and Rehabilitation of Konya Training and Research Hospital. The control group comprised healthy companions who accompanied their relatives to the hospital. This study was performed in compliance with the principles of the Declaration of Helsinki. An approval was granted by the Ethics Committee of Necmettin Erbakan University (07.06.2013/435). Prospective participants were informed about the study, and their consent was obtained. Patients with mental and communication issues, systemic diseases, major psychiatric disorders, endocrine diseases, antidepressant use; history of lumbar or cervical radiculopathy, orthopedic surgery and cervical myelopathy were not included in the study. Detailed anamneses and examinations of adults with CP were recorded. If needed, family support was obtained for anamnesis. Information was collected regarding the age, height, weight, employment status, academic status, social status, income level, living environment and marital status of the study participants. In the adult CP group, information about the type and etiology of the disease, complications, treatment, use of mobility aids (wheelchair, walker, walking stick, tripod), comorbidity, urinary incontinence, fecal incontinence, and speech disorders was obtained.

Questionnaires in Turkish and scales with proven validity and reliability were applied to all participants. Depression level of all participants was determined by the Beck Depression Inventory (BDI), their mobility level was assessed by Rivermead Mobility Index (RMI), and quality of life level was evaluated by the Short Form-36 (SF-36). Functional level of adults with CP was evaluated with Gross Motor Function Classification System (GMFCS). Functional independence and activity level were assessed using Functional Independence Measure scale (FIM). Pain level was evaluated via Visual Analogue Scale (VAS).

Beck depression inventory (BDI) was developed by Beck et al. [9]. It is a 21-question multiple-choice self-report inventory with scores ranging from 0 to 3, including symptoms typical for the depression. The highest score is 63. A high total score indicates the severity of the depression. The validity and reliability study of the Turkish adaptation was conducted by Hisli and the threshold in our research was set at 17 [10].

Gross Motor Function Classification System (GMFCS), a special classification system developed for children with CP. The GMFCS is divided into 5 groups based on gross motor functions. Level 1: Walks independently but there are limitations in advanced motor skills. Level 2: Walks without a mobility aid but there are limitations to walking in the community. Level 3: Walks with a mobility aid and there are limitations to walking in the community. Level 4: Walking ability is severely restricted even with mobility aids, wheelchair is employed most of the time, can independently propel electric wheelchair. Level 5: Cannot sit or stand independently even with adaptive equipment [11]; cannot walk independently, but can use motorized mobility aid. It was determined that the GMFCS can be used to classify gross motor function in the adult CP [12].

Short Form 36 (SF-36) is a valid and frequently used tool for assessing the quality of life. It is not specific for any age, disease or treatment group and considers general health concepts. It comprises 36 questions representing

eight subscales: physical function, physical role limitation, emotional role limitation, bodily pain, social function, mental health, vitality and general health perception. All questions refer to the last four weeks. For each dimension, component scores are used and converted into a weighted scale from 0 (worst health) to 100 (best health). There are two summary scales for the physical and mental components [13]. Validity and reliability study of the Turkish version of SF-36 was previously conducted [14].

Functional Independence Measure scale (FIM) includes sections on self-care, sphincter control, mobility, locomotion, communication and social communication. The maximum score is 126. The FIM motor component score and the total FIM score were employed in this study. FIM cognitive component score is part of the total FIM score. It includes sections on comprehension, expression, social communication, problem solving and memory assessment. Scoring is between 1–7. The score of 7 is given in case of complete independence, while the score of 1 is given in case of complete dependence. The maximum score is 35 [15]. The validity and reliability assessment of the FIM Turkish version was performed by A.A. Küçükdeveci et al. [16].

Rivermead Mobility Index (RMI) is a unidimensional index that focuses on measuring mobility and considers basic mobility activities [17]. It includes a series of step-by-step activities, from rolling in bed to running, consisting of 14 questions and one observation that matches the Guttman Scale. The RMI was developed primarily to evaluate the outcome of physical therapy interventions after traumatic brain injury or stroke, and is reported to be used in hospitals, outpatient clinics, or at home without the need some specific expertise. A patient's statement is essential to answering questions. The interviewer observes and rates item 5 only. One point is given for each 'yes' response, with a score ranging from 0 to 15. A score of 15 indicates that mobility is not a problem, whereas score of 14 or less indicates that mobility constitutes a problem. Since RMI creates a hierarchical structure from simple to complex, this means that the problem increases as the score decreases [17]. A study was conducted on the validity and reliability of the Turkish version of the RMI [18].

Visual Analog Scale (VAS) was used in this study to assess pain and fatigue levels. A 10 cm long line was drawn, and this line was divided into ten 10 mm wide intervals. Each patient was offered to score the most appropriate value corresponding to their pain on the following scale: 0 was indicative of no pain/fatigue, while 10 implied the most severe pain/fatigue. The distance between the starting point and the point marked by the patient specified the patient's pain [19].

**Statistical data processing.** Statistical analyses were performed using the Windows version of SPSS 25. Our quantitative findings were expressed as mean  $\pm$  standard deviation. We compared the parametric data via the Student's t-test. For nonparametric data, the chi-squared test was used. Nonparametric data were analyzed using the Mann-Whitney U test. Correlations were detected using Pearson's correlation coefficient for parametric variables and Spearman's correlation coefficient (Rho) for nonparametric ones. Statistical significance was assumed at  $p < 0.05$ .

The correlation coefficients were interpreted as follows based on their magnitude: no correlation (0–0.25), weak to moderate correlation (0.25–0.50), strong correlation (0.50–0.75) and very strong correlation (0.75–1.00).

**Results.** While the patient and control groups were statistically similar ( $p > 0.05$ ) in terms of age, BMI, gender, and family structure, the two groups were statistically different in terms of education, marital status, marriage

duration, employment, and monthly income ( $p<0.05$ ). The education level, monthly income, and duration of marriage in CP patients were lower than in the control group.

The sociodemographic characteristics of CP and control groups are presented in Table 1.

While the mobility levels were determined by RMI, functional levels assessed by FIM were lower in CP group than in the control group. In patients with CP, their depression levels determined via BDI, pain scores measured by the VAS, and depression percentages were higher than in the control group ( $p<0.05$ ) (Table 2).

Table 1

Sociodemographic characteristics of the adult cerebral palsy (CP) group and control group

Characteristics	CP, n=78	Control, n=79	p-value
Age	24.75±7.66	26.74±6.72	0.085
BMI	22.94±4.87	23.18±5.55	0.773
Gender			
Female	47 (59.5%)	48 (61.5%)	0.793
Male	32 (40.5%)	30 (38.5%)	—
Marital status			
Married	5 (6.3%)	33 (42.3%)	0.000
Single	73 (92.4%)	44 (56.4%)	—
Divorced	1 (1.3%)	1 (1.3%)	—
Duration of marriage, yrs.	0.59±2.63	3.32±5.57	0.000
Number of children	0.23±0.92	0.76±1.27	0.003
Living with:			
Alone	1 (1.2%)	10 (12.8%)	0.000
Parents	74 (93.7%)	36 (46.2%)	—
Spouse and/or children	4 (5.1%)	32 (41.0%)	—
Employment status			
Student	16 (20.3%)	23 (29.5%)	0.000
Civil servant	4 (5.1%)	30 (38.5%)	—
Small business	2 (2.5%)	7 (9.0%)	—
Receives disability pension	11 (13.9%)	0 (0.0%)	—
Unemployed	46 (58.2%)	10 (12.8%)	—
Housewife	0 (0.0%)	8 (10.3%)	—
Education level			
Illiterate	31 (39.2%)	1 (1.3%)	0.000
Elementary school	44 (55.7%)	39 (50.0%)	—
High school	4 (5.1%)	27 (34.6%)	—
University	0 (0.0%)	11 (14.1%)	—
Monthly income (TL)	1568.96±2384.72	2866.67±1639.90	0.000
Economic status			
My income is less than my expenses	42 (53.2%)	20 (25.6%)	0.001
My income is equal to my expenses	25 (31.6%)	45 (57.7%)	—
My income exceeds my expenses	12 (15.2%)	13 (16.7%)	—

Note: The data reported as mean ± standard deviation or number (%). Statistical significance is assumed at  $p<0.05$ . BMI — Body Mass Index TL — Turkish lira.

Table 2

Clinical and functional levels in the adult cerebral palsy (CP) group and control group

Scores on various scales, pts.	CP, n=79 (%)	Control, n=78 (%)	p-value
BDI	16.17±14.11	8.03±7.45	0.000
Depression	32 (40.5%)	11 (14.1%)	0.000
VAS	3.52±3.22	1.52±2.07	—

Scores on various scales, pts.	CP, n=79 (%)	Control, n=78 (%)	p-value
FIM	89.67±34.29	—	—
RMI	9.37±5.32	15.00±0.00	0.000
RMI			
Limited mobility	65 (82.3%)	—	—
Unlimited mobility	14 (17.7%)		
GMFCS			
GMFCS-1	22 (27.8%)		
GMFCS-2	22 (27.8%)		
GMFCS-3	8 (10.1%)	—	—
GMFCS-4	9 (11.4%)		
GMFCS-5	18 (22.8%)		

Note: The data reported as mean ± standard deviation or number (%). Statistical significance is assumed at  $p < 0.05$ . VAS — Visual Analog Scale, BDI — Beck Depression Scale, RMI — Rivermead Mobility Index, FIM — Functional Independence Scale, GMFCS — Gross Motor Function Classification System.

Table 3

## SF 36 subgroup scores in the adult cerebral palsy (CP) group and control group

SF-36	CP, n=79 (%)	Control, n=78 (%)	p-value
SF-36 Physical Component	36.80±18.88	62.67±16.69	0.000
Physical Function	30.38±30.95	83.46±22.10	
Bodily Pain	61.27±30.04	74.94±24.94	0.002
Physical Role Limitation	13.29±18.28	37.66±17.27	
General Health Perception	42.28±19.51	54.62±12.56	0.000
SF-36 Mental Component	47.21±16.75	58.73±15.12	
Social Function	58.32±22.88	71.95±17.11	
Mental Health	54.83±20.61	62.00±19.66	0.027
Emotional Role Limitation	19.41±21.92	38.26±18.41	0.000
Vitality	56.27±23.39	62.69±19.17	0.062

Note: SF-36 — Short Form-36.

The scores of SF-36 summary components and subgroups in patients with CP were lower than in the control group ( $p < 0.05$ ) (Table 3).

Short Form 36 (SF-36) is a valid and frequently used tool for assessing the quality of life. It is not specific for any age, disease or treatment group and considers general health concepts. It comprises 36 questions representing eight subscales: physical activity, physical role limitation, emotional role limitation, bodily pain, social function, mental health, vitality and general health perception. All questions refer to the last four weeks. For each dimension, component scores are used and converted into a weighted scale from 0 (worst health) to 100 (best health). There are two summary scales for the physical and mental components [13]. Validity and reliability study of the Turkish version of SF-36 was previously conducted [14].

We established that the scores yielded by the SF-36 physical component, mental component, social function, perception of health, bodily pain, physical role limitation, and social function subscales, along with FIM scale, were lower in the adult CP group with limited mobility vs. adult CP patients with a normal mobility, while BDI scores exhibited a reverse trend ( $p < 0.05$ ) (Table 4).

There was a statistically significant positive correlation of FIM scores with SF-36 physical and mental components; along with a statistically significant negative correlation of VAS with FIM, and of FIM with GMFCS:  $p < 0.001$ ,  $r = 0.450$ ;  $p = 0.013$ ,  $r = 0.279$ ;  $p = 0.022$ ,  $r = -0.257$ ;  $p < 0.001$ ,  $r = -0.741$ , respectively.

Statistically significant positive correlations were revealed between RMI and FIM scores, and between SF-36 physical component and mental component:  $p < 0.001$ ,  $r = 0.740$ ;  $p < 0.001$ ,  $r = 0.489$ , respectively. At the same time, a statistically significant negative correlation was discovered for RMI with SF-36 mental component and BDI:  $p = 0.007$ ,  $r = -0.304$ ;  $p = 0.018$ ,  $r = -0.266$ , correspondingly.

A statistically significant negative correlation was found of SF-36 physical component with VAS and BDI:  $p = 0.003$ ,  $r = -0.336$ ;  $p < 0.001$ ,  $r = -0.481$ , respectively. In addition, a statistically significant negative correlation was found of the SF-36 mental component with VAS and BDI:  $p = 0.013$ ,  $r = -0.282$ ,  $p < 0.001$ ,  $r = -0.558$ , correspondingly (Table 5).

**Discussion.** In our study, we discovered that adults with cerebral palsy had more pain and depression than their healthy peers and a lower quality of life. Besides,

Table 4

## Clinical features and SF 36 subgroup scores in adult cerebral palsy (CP) patients with and without mobility limitation

Parameters and scores	Limited mobility CP, n=65	Normal mobility CP, n=14	p-value
Age	25.23±7.93	22.50±5.99	0.229
BMI	23.27±4.80	21.43±5.11	0.202
VAS	3.92±3.23	1.64±2.47	0.150
BDI Total Score	17.94±14.24	7.93±10.38	0.015
FIM Total Score	84.17±34.82	115.21±15.29	0.002
RMI Total Score	8.15±5.10	15.00±0.00	
SF-36 Physical Component	32.51±16.51	56.74±16.60	0.000
Physical Function	23.92±28.31	60.36±25.07	
Bodily Pain	56.92±29.55	81.43±24.19	0.005
Physical Role Limitation	10.96±17.05	24.11±20.49	0.014
General Health Perception	38.23±17.75	61.07±16.43	0.000
SF-36 Mental Component	45.21±16.21	56.49±17.13	0.021
Social Function	55.12±21.62	73.21±23.44	0.006
Mental Health	53.84±20.24	59.43±22.46	0.361
Emotional Role Limitation	17.95±21.91	26.19±21.40	0.204
Vitality	53.92±23.58	67.14±19.78	0.055

Table 5

## Correlations between the various scale scores (VAS, GMFCS, BDI, FIM, SF-36 physical component, SF-36 mental component and RMI)

Scores on various scales		VAS	GMFCS	BDI	FIM	SF-36 physical component	SF-36 mental component	RMI
VAS	r	1	0.000	0.265	-0.257	-0.336	-0.282	-0.058
	p	—	0.998	0.018	0.022	0.003	0.013	0.609
	n	79						
GMFCS	r	0.000	1	0.199	-0.741	-0.414	-0.325	-0.829
	p	0.998	—	0.079	0.000	0.000	0.004	0.000
	n	79						
BDI	r	0.265	0.199	1	-0.295	-0.481	-0.558	-0.266
	p	0.018	0.079	—	0.008	0.000	0.000	0.018
	n	79						
FIM	r	-0.257	-0.741	-0.295	1	0.450	0.279	0.740
	p	0.022	0.000	0.008	—	0.000	0.013	0.000
	n	79						
SF-36 physical component	r	-0.336	-0.414	-0.481	0.450	1	0.689	0.489
	p	0.003	0.000	0.000	0.000	—	0.000	0.000
	n	79						
SF-36 mental component	r	-0.282	-0.325	-0.558	0.279	0.689	1	0.304
	p	0.013	0.004	0.000	0.013	0.000	—	0.007
	n	79						
RMI	r	-0.058	-0.829	-0.266	0.740	0.489	-0.304	1
	p	0.609	0.000	0.018	0.000	0.000	0.007	—
	n	79						

Note: The correlation is significant at  $p < 0.05$ . VAS — Visual Analog Scale, BDI — Beck Depression Inventory scale, RMI — Rivermead Mobility Index, FIM — Functional Independence Measure scale, GMFCS — Gross Motor Function Classification System.

we determined that those with better mobility and functional status had less pain and depression and better quality of life.

Different results on sociodemographic characteristics, functional status, quality of life, level of mobility, gait disorder, musculoskeletal pain, and depression level of adults with CP were reported in various studies [5, 7, 20–23].

Among adult individuals with CP, 20% were able to walk independently, 40% were capable of walking with a mobility aid, and 40% were unable to walk at all. Consequently, the majority of adults with CP were dependent on others in their daily living routine and usually resided with their families [4, 5]. Since spasticity caused by the nature of CP limits the movements, it is not surprising that the activity level test scores are low. It was reported that most CP patients stop walking after the age of 25 years old, because as they move, difficulties arise, and pain due to physical loads generates a feeling of inadequacy [24]. Walking difficulties in conjunction with problems observed at later life stages, may cause activity limitation and loss of function [5]. In our study, in accordance with the published sources, the mobility levels of adults with CP determined by RIM scale were lower than in the control group: only 27.8% of adults with CP were GMFCS-1 (capable of walking independently). These results confirmed that one of the most important problems related to adult CP is the inability to walk independently.

Adults with CP with GMFCS levels 2–5 report more pain than control subjects, while those with GMFCS levels 3–5 report more fatigue. GMFCS level 1 patients have less pain, fatigue and depression than those with GMFCS levels 2–5. Pain and fatigue correlate with each other and are strongly associated with mental health in people with CP [24–27]. In our study, age, BMI, VAS and BDI scores were higher, while FIM, mental health, vitality, emotional role limitation and quality of life scores were lower, in the group with limited mobility vs. the group with a normal mobility, which confirmed previously published studies. In other words, adult CP individuals with a more limited mobility had lower quality of life, higher pain levels, higher depression rates, and worse functional status. Considering the importance of mobility for all of listed parameters, such results were expected.

Opheim et al. determined that the physical component of health-related quality of life is associated with the number of painful areas [21]. R. Jahnsen et al. reported that the quality of life evaluated via SF-36 was lower in adults with CP than in younger patients with CP [28]. We compared the quality of life of CP cases over 18 years of age with healthy controls of similar age groups and yielded the following results: the quality of life in the CP group was significantly lower than in the control group, except for the vitality subgroup score. We identified adverse effects in both physical health and psychosocial health domains. We believe that the quality of life in our patients is negatively affected by their physical disabilities during walking, running, doing daily routine work, and by high dependence on others: they cannot perform their activities due to environmental and architectural obstacles, they cannot integrate into society, and often face physical problems. In addition, we think that lack of communication with friends, physical appearance issues, unemployment, economic difficulties, and environmental conditions are the factors affecting their independence, thereby reducing their quality of life.

A systemic review established that most adults with CP (70%) experienced pain, localized primarily in their legs, but sometimes in the neck, back and arms. Mean

pain severity was reported at the level of 3.7/10 [29]. Looking at the subgroups, it was concluded that pain was higher in females and adults with GMFCS levels 2 and 4; leg pain was more severe in people with GMFCS level 3, while arm pain was stronger in people over 45 years of age. It was reported that the pain in the arms increased with age, which was caused by the use of walker and walking aids due to the decline in walking ability [29]. Another study reported that the incidence of pain was higher in adults with CP and GMFCS level 5, in females, and in the elderly. In addition, this study confirmed that pain was most commonly seen in the lower extremities, back and abdomen and was associated with reduced quality of life or health status [30]. In a study conducted on 97 young adults with CP (age: 18–30 years), the severity of pain preventing daily routine activities were measured with the Behavioral Risk Factor Surveillance System (BRFSS) and Brief Pain Inventory (BPI): a large share of young adults reported pain, fatigue and depression [31]. In our study, musculoskeletal pain levels determined by VAS in adults with CP were significantly higher than in the control group, and this pain was associated with female gender, depression level, decrease in physical functions, and reduction in quality of life, which supported other published results. Our research highlighted an importance of musculoskeletal pain factor in its association with the level of depression, deterioration of physical functions, and quality of life. Therefore, musculoskeletal pain should be assessed during the follow-up and treatment of adults with CP.

Physical or communication problems may have a negative effect on emotional wellbeing and mental health. There is evidence of an increased risk to develop depression and anxiety in this group [32]. In a study conducted on 97 young adults with CP (age ranging 18–30 years old), signs of depression were observed in 42% of them: mild in 25%, moderate in 13% and severe in 4% [31]. In our study, depression levels and depression rates were higher in adults with CP, compared with the control group. In addition, there was a relationship between musculoskeletal pain and depression levels in adult CP patients.

Our study has several limitations. Our CP patient and control groups included solely the patients at just one medical center. Multicenter studies on a larger scale are needed to obtain more powerful results. Also, the levels of depression and anxiety in the participants of the CP patient and control groups were assessed exclusively via different evaluation scales. Structured psychiatric interview should be employed in future studies as well.

**Conclusion.** Cases of cerebral palsy in adults should be assessed during follow-up in terms of pain, depression, quality of life, and mobility. Our results demonstrated that, in addition to trying to increase their independence, patients with CP also need psychological support in order to work on their vocational rehabilitation and social adaptation, and to overcome their problems in adulthood. Future studies with more participants and more parameters will shed light on the lives of adults with CP, elucidating the solutions to their everyday problems. Future research needs to explore the complex relationship between pain and depression in order to develop preventive measures and more effective interventions to treat disorders that affect the health and wellbeing of CP patients as they age.

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