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ORIGINAL ARTICLE

Multimorbidities and quality of life in adult cerebral palsy over 40 years

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Abstract

Aim This study aimed to describe the most common combinations of comorbidities and their relationship to quality of life in a sample of adults over 40 years of age with cerebral palsy.

Methods Patients who are 40 years or older and admitted to the hospital in the last 5 years and were diagnosed with cerebral palsy were included. Demographic data and comorbidities were both questioned through the Patient Information Management System and confirmed by asking the individual about their diseases. The patients' quality of life was evaluated with the EQ-5D-3L Telephone interview version. Principal component analysis was used to determine comorbidity combinations for multiple morbidity.

Results Comorbidity was found in 72.1% of the participants and multimorbidity was found in 47.5%. The 5 most common comorbidities were musculoskeletal diseases (34.4%), psychiatric diseases (21.3%), essential hypertension (21.3%), osteoporosis (18%) and hyperlipidemia (18%). As a result of principal component analysis, a total of five components are formed and this most common comorbidity combinations in the sample explained 66.78% of the total variance.

Conclusions New combinations of comorbidities have been demonstrated that may perhaps serve as a starting point for identifying new association of pathways. Future efforts are needed to identify modifiable factors for early intervention and prevention of chronic health problems in this population.

Keywords Adult · Cerebral palsy · Comorbidity · Multimorbidity · Quality of life

Introduction

Although CP is considered a "non-progressive" neurological condition, it is a lifelong condition with many of the individuals reaching normal life spans [1].

Aging with cerebral palsy is accompanied by a diminished state of health and function in all systems in the body. Adults with CP are at risk of early development of various medical conditions that give rise to excess health care resource utilization and healthcare costs compared to adults without CP and indicate a considerable patient and caregiver burden [2]. There is a need to understand the frequency and associations of comorbidities for adults with cerebral palsy to inform guidelines for clinical assessment and interventions to improve healthy aging [3].

There are a limited number of studies in the literature investigating comorbid conditions individually. Peterson et al. demonstrated that adults with CP have high rates of cardiometabolic diseases; and disease-free survival shortens significantly with higher ages [4]. Whitney et al. found the

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prevalence of kidney disease in adults with CP to be 7.3% and showed that kidney disease was associated with mortality in adult CP [5]. It has been reported that Alzheimer's disease and related dementia are seen 2.4 times higher in adults with CP (> 45 years old) [6]. Won et al. reported decreased bone mineral density in 25.3% of adult CP individuals [7].

With the LIFEspan Model of Transitional Care initiated in Canada, individuals with CP were followed up from childhood to adulthood, and it was observed that continuity of care and healthcare utilization increased [8].

In their study, Heijningen et al. [9] investigated the concept of optimal citizenship in adult CP and the factors affecting it. It is reported that adults with CP see citizenship as the ability to participate in and belonging to the community. One of the barriers mentioned in this study is aging and related multimorbidities. Determining the frequency of these morbidities in this population gains importance in this context.

Many comorbidities seen in individuals with cerebral palsy can be delayed, prevented or better managed. However, there are no evidence-based guidelines for monitoring morbidity in adults with cerebral palsy.

To begin to define multiple morbidity in adult individuals with CP, this study aimed to describe the most common combinations of comorbidities and their relationship to quality of life in a sample of adults over 40 years of age with cerebral palsy.

Methods

Sample selection

This study utilized a descriptive, cross-sectional design. Patients who are 40 years or older and admitted to the hospital in the last 5 years and were diagnosed with cerebral palsy were scanned through the Hospital Information Management System. Inclusion criteria included a diagnosis of cerebral palsy using ICD 9 code 343.x or ICD 10 codes G80, age 40 and older, and having an encounter with the medical system (inpatient or outpatient) during a 5 year period of 01/09/2016 to 01/09/2021. Patients were excluded if they did not have a definitive diagnosis of cerebral palsy.

The phone numbers of the patients registered in the system were accessed and the patients were reached by phone. The records of 81 patients were accessed in the Hospital Information Management System. Twenty of the patients could not be reached by phone (the phone number was not registered or the person did not pick up the phone), the study was carried out with a total of 61 patients.

Verbal consent was obtained from the individual himself/herself or the caregivers of those who could not respond, and the questionnaire was filled in.

Demographic data

Demographic data (age, gender), employment and accommodation status, monthly income, number of hospital visits per year were questioned.

Employment status was divided into five groups according to the answers given: (1) unemployed, (2) housewife, (3) retired, (4) elementary job, (5) professional job in accordance to SOC 2000 (Standard Occupational Classification).

The type of accommodation was divided into three groups: (1) alone, (2) with family, (3) with caregiver.

Cerebral palsy specific data

The protocol recommended by the SCPE group was used for SP classification. SCPE grouped children with CP into four categories: spastic (bilateral, unilateral), dyskinetic (dystonic, chorea-athetoid), ataxic, and unclassifiable [10].

Gross motor function levels of people with CP were determined using GMFCS. GMFCS is based on self-initiated movements with an emphasis on sitting, relocation and mobility. The main criterion in the five-level classification system is that the differences between the levels are meaningful in daily life [11].

Comorbidities

Comorbidities refer to the presence of one or more health conditions a person is having with a primary illness. Comorbidities of the participants were both questioned through the Patient Information Management System and confirmed by asking the individual about their diseases.

Comorbidities were classified into 15 categories according to patients' responses: (1) diabetes mellitus, (2) essential hypertension, (3) coronary artery disease or other heart diseases, (4) renal diseases, (5) pulmonary diseases, (6) thyroid diseases, (7) gastrointestinal diseases, (8) chronic anemia, (9) hyperlipidemia, (10) ophthalmologic diseases, (11) osteoporosis, (12) musculoskeletal diseases, (13) rheumatic diseases, (14) neurological diseases (stroke or neurodegenerative diseases), (15) psychiatric diseases.

Osteoarthritis, regional pains (such as low back and neck pain), spinal diseases (such as degenerative disc diseases, disc herniations, spinal stenosis), tendinitis, nerve entrapment neuropathies were grouped under the title of musculoskeletal diseases.

Mood disorders, anxiety disorders and behavioral disorders were grouped under the title of psychiatric disorders. Cognitive disorders were not evaluated in this context.

Diseases associated with cerebral palsy were excluded from the definition of comorbidity (such as epilepsy and intellectual disability).

Body mass index (BMI) was calculated with the height and weight information given by the individual, as weight divided by height in meters squared (kg/m^2). BMI measurements were organized into four categories: underweight (BMI < 18.5), normal (BMI 18.5–24.9), overweight (BMI 25.0–29.9), and obese (BMI ≥ 30.0).

Multimorbidity is defined as having ≥ 2 morbidities.

Quality of life

The patients' quality of life was evaluated with the EQ-5D-3L Telephone interview version. The EQ-5D-3L descriptive system comprises the following five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems, some problems, and extreme problems. The patient is asked to indicate his/her health state by ticking the box next to the most appropriate statement in each of the five dimensions. Based on a value set, EQ-5D states can be converted to a single summary index, namely health utility, which can be used to calculate the Quality-adjusted life years (QALYs). In the evaluation of the EQ-5D-3L index score, UK reference values, which is the most commonly used version, were used because there were no reference values for the Turkish population.

The EQ VAS records the patient's self-rated health on a vertical visual analogue scale where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state'.

The questionnaire is currently translated into Turkish, and is widely applied with good reliability and validity in specific diseases (diabetes mellitus, hypertension, coronary heart disease, chronic obstructive pneumonia disease, etc.) and general population [12].

Statistical analysis

The descriptive statistics of the categorical variables in the study are given as numbers and percentages, and the descriptive statistics of the numerical variables are given as mean, median, standard deviation, minimum and maximum. The conformity of the variables to the normal distribution was examined using the Shapiro Wilk test. Mann Whitney *U* test was used for the median comparisons of the groups consisting of two categories. Principal component analysis was used to determine comorbidity combinations for multiple morbidity. The varimax rotation method was used while calculating the factor loads. Factor loads were obtained from the correlation matrix, and comorbidities with factor loads greater than 0.40 were included. In principal component analysis, components with eigenvalues greater than 1 were analyzed. Statistical significance level was taken as 0.05 and SPSS 22.0 package program was used in the analysis.

Results

In the Table 1, descriptive statistics for categorical variables are given as numbers and percentages, and descriptive statistics for numerical variables are given.

Comorbid diseases and multimorbidity status are demonstrated in Table 2.

No significant difference was observed between comorbidity status in terms of age, BMI, occupational status, accommodation status, sp subtype, GMFCS, monthly

Table 1 Demographic characteristics of the participants

	Min–Max	Mean ± SD
Age (years)	40–74	50.06 ± 8.17
BMI	11.69–41.62	25.19 ± 4.65
Monthly income (TL)	0–32,000	2609.83 ± 4207.83
Number of hospital visits per year	0–10	2.78 ± 2.69
EQ-5D-3L index score	.08–1.0	.428 ± .240
EQ-5D-3L VAS score	0–100	50.81 ± 25.18
	n	%
Gender		
Female	23	37.7
Male	38	62.3
Occupational status		
Unemployed	39	63.9
Retired	10	16.4
Elementary job	9	14.8
Professional job	3	4.9
Accommodation status		
Alone	3	4.9
Family	30	49.2
Paid caregiver	28	45.9
CP subtype		
Spastic bilateral	36	59.0
Spastic unilateral	25	41.0
GMFCS		
1	9	14.8
2	28	45.9
3	7	11.5
4	4	6.6
5	13	21.3
BMI categories		
Underweight	4	6.6
Normal	28	45.9
Overweight	21	34.4
Obese	8	13.1

Table 2 Comorbid diseases and multimorbidity status

	n	%
Comorbidity status		
Yes	44	72.1
No	17	27.9
Multimorbidity status		
Yes	29	47.5
No	32	52.5
Comorbidity		
Diabetes mellitus	6	9.8
Essential hypertension	13	21.3
Coronary artery disease	5	8.2
Renal disease	6	9.8
Pulmonary disease	10	16.4
Thyroid disease	8	13.1
Gastrointestinal disease	6	9.8
Chronic anemia	9	14.8
Hyperlipidemia	11	18.0
Ophtalmologic disease	4	6.6
Osteoporosis	11	18.0
Musculoskeletal disease	21	34.4
Rheumatologic disease	3	4.9
Neurologic disease	7	11.5
Psychiatric disease	13	21.3

income, number of hospital visits per year, EQ-5D-3L index score and EQ-5D-3L VAS scores ($p=0.834$; $p=0.936$; $p=0.137$; $p=0.723$; $p=0.257$; $p=0.727$; $p=0.837$; $p=0.268$; $p=0.334$; $p=0.307$, respectively). The mean age of those with comorbidity was significantly higher than those without ($p=0.01$).

No significant difference was observed between multimorbidity status in terms of age, BMI, occupational status, accommodation status, sp subtype, GMFCS, monthly income, number of hospital visits per year, EQ-5D-3L index score and EQ-5D-3L VAS scores ($p=0.778$; $p=0.756$; $p=0.263$; $p=0.922$; 0.953; $p=0.836$; $p=0.482$; $p=0.316$; $p=0.470$; $p=0.407$, respectively). The mean age of those with multimorbidity was significantly higher than those without ($p=0.000$).

Principal component analysis results

Principal component analysis (PCA) is one of the multivariate analysis techniques. The purpose of the method is to reduce the size of a large number of variables in a single group and to express them with fewer variables that can be explained more easily and meaningfully. The purpose of principal component analysis is to create variables that do not have a correlation structure between them. It is a method used to obtain new data structures that are independent of each other and less in number from data sets containing more than three variables related to each other. The general purpose of principal component analysis is data reduction and interpretation.

Table 3 Principal components subtypes

PC1	Diabetes mellitus
	Thyroid disease
	Chronic anemia
	Hyperlipidemia
	Psychiatric disease
PC2	Essential hypertension
	Coronary artery disease or other heart diseases
	Pulmonary disease
	Neurologic disease
PC3	Renal disease
	Rheumatologic disease
PC4	Osteoporosis
	Musculoskeletal disease
PC5	Gastrointestinal disease
	Ophthalmologic disease

Although there are p required components to generate all of the total variability in the system, as much of this variability as possible can be explained by k principal components, $k<p$. In this case, k principal components contain almost as much information as the original p variables. The k principal components are initially replaced by p variables and are reduced to a data set that consists of n observations of p variables. PCA, a data reduction technique, is an excellent analytical approach to identify combinations of comorbidities, as it explains the variance in a data set based on the interrelationships between variables. PCA for multiple morbidity creates the most common combinations in comorbidity and provides clinical interpretation. Loading factors are derived from the correlation matrix and provides a numerical interpretation of the PCs. Comorbidities with a loading factor of ≥ 0.40 were included for interpretation, which has been suggested previously. PCs with eigenvalues of ≥ 1.00 were retained and analyzed, as this is common practice for PCA.

As a result of principal component analysis, a total of five components are formed (Table 3). The percentage of variance explained for component 1 was 15,543%; for component 2 was 14,726%, for component 3 was 13,164%; for component 4 was 11,755%; for component 5 was 11,593%. Cumulative disclosure percentages are shown in the Table 4.

Discussion

Cerebral palsy (CP) occurs early in life and is defined as a nonprogressive pediatric condition that affects movement, muscle tone or posture [13]. Today, the majority of

Table 4 Principal component analysis results

Component	Initial eigenvalues			Rotation sums of squared loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3927	26,183	26,183	2332	15,543	15,543
2	1865	12,433	38,617	2209	14,726	30,269
3	1744	11,624	50,241	1975	13,164	43,433
4	1408	9390	59,631	1763	11,755	55,188
5	1073	7151	66,781	1739	11,593	66,781
6	942	6278	73,059			
7	810	5398	78,457			
8	695	4631	83,088			
9	641	4274	87,363			
10	487	3247	90,610			
11	418	2788	93,397			
12	336	2241	95,639			
13	303	2022	97,661			
14	202	1349	99,010			
15	149	990	100,000			

individuals with CP reach adult age [14]. Therefore, it is necessary to understand that CP is also an adult condition. With advancing age, they are faced with other medical problems that complicate their medical care and the care and interventions applied when they were children are no longer sufficient. However, in health care systems, CP is often limited to pediatric clinics and rehabilitation units, while adults with CP struggle to receive appropriate care for even the most common problems such as musculoskeletal disorders [14]. Therefore, in this study, the most common comorbidities and multimorbidity groups in individuals with CP over 40 years of age and the relationship of these health problems with socio-economic characteristics and quality of life were investigated.

When the demographic distribution of the sample was evaluated, the mean age of the participants was 50, approximately 60% were male, 65% were unemployed, half lived with their family and half with a caregiver, 60% were bilateral spastic subtype, and half were independently mobile.

According to the statements of the people, the average of their monthly income is below the hunger limit. It is not known whether this situation is only characteristic of the sample taken or how much it reflects the real situation because data is taken according to the statements of the individuals.

The number of annual admissions to the hospital is low compared to the literature [15, 16]. The reason for this situation is a new research topic (transportation problems, access restrictions, not knowing where to go, etc.)

There is no HRQoL scale developed for adult individuals with cerebral palsy. All developed scales are scales with validity and reliability in children. For this reason, EQ-5D, a general HRQoL scale, was used in the study. It is founded that the mean quality of life index (EQ-5D-3L) of the study sample was lower than the Swedish study (0.42 vs 0.77) [17]. There are not many studies examining the quality of life in adult cerebral palsy in the literature. Although a single study is not sufficient to make a comparison between countries, the quality of life of adult CP individuals living in Turkey seems to be worse than in northern countries. In this study, no relationship was found between comorbidity status and HRQoL. However, since there is no information about how well the comorbid conditions are under control, it is difficult to reach this decision based on the comorbidity status alone. In addition, the correct management of cerebral palsy can also affect comorbid conditions. Evaluation of the quality of the medical and rehabilitative treatments received is important in this respect.

Majority of the patients had a comorbidity and nearly half had multimorbidity and comorbidity and multimorbidity increased with age. In accordance with our results in a small number of studies in the literature, it has been reported that many health problems are seen more frequently in adults with CP compared to the general population [18–21].

Adult cerebral palsy is a group that has emerged today as a result of the survival of infants with cerebral palsy with improved health care. Therefore, we will have to deal with the chronic health problems of these individuals more in the future. Since the mean age of the study sample is approximately 50 years, it can be expected that comorbidity rates will increase further in advanced ages. For this reason, changes in comorbidity and multimorbidity in all adult and senior age groups should be investigated longitudinally in future studies.

The relationship between socioeconomic parameters and comorbidity and multimorbidity could not be demonstrated.

There was no study in the literature investigating the relationship between multimorbidity and socioeconomic parameters. Conflicting results regarding BMI and comorbidity have been reported in the literature. While Peterson et al. [4] reported that there was no relation between BMI and cardiovascular comorbidity, Cremer et al. [19] reported the relation between BMI and multimorbidity. It can be thought that these results emerged both because the obese group was dominant in Peterson's study and because the sensitivity of BMI is low in individuals with functional mobility impairment [22].

In this study, the five most common comorbidities were musculoskeletal diseases (34.4%), psychiatric diseases (21.3%), essential hypertension (21.3%), osteoporosis (18%) and hyperlipidemia (18%). Whitney et al. reported the three most common comorbidities as uncomplicated hypertension (51.3%), depression (30.2%) and osteoarthritis and allied disorders (23.7%) in their study [3]. Peterson et al. [18], on the other hand, reported that the three most common comorbidities in adults aged 18 years and over with CP were joint pain (43.6%), arthritis (31.4%) and hypertension (30%). The results show that musculoskeletal diseases (joint pain, osteoarthritis), psychiatric problems and hypertension are the most common comorbidities reported in all studies. In this study, as in other reference studies, all musculoskeletal problems were discussed under one heading. In the literature, only one study specifically addressed musculoskeletal problems. Thorpe et al. categorized musculoskeletal system diseases in their study and reported the most common category as soft tissue disorders (86.6%). Considering its frequency, musculoskeletal problems should be addressed in detail in future studies.

The study specifically established the most common combinations of comorbidities and a general pattern of multimorbidity in adults with cerebral palsy. While some combinations are predictable (for example, pulmonary and coronary heart diseases or osteoporosis and musculoskeletal diseases), new combinations of comorbidities have been demonstrated that may perhaps serve as a starting point for identifying new association of pathways. The most common comorbidity combinations in the sample explained 66.78% of the total variance. This rate is higher than the rate reported by Whitney et al. (40%) [3].

Limitations

There are some limitations of the study. The fact that the sample was taken from a single center limits the generalizability of the results. The study was conducted with individuals who applied to the hospital for any reason. Since it did not include individuals with limited access to the hospital, the comorbidity rate may have been underestimated. In addition, the fact that their information was obtained by phone, some from their caregivers and some from themselves, may have caused some of the data to be inaccurate. Also the pathophysiological associations of the comorbidities reported in the study are the subject of new research and have not been discussed.

Another limitation is that since 1 out of 4 of the targeted sample could not be reached, the comorbidity information of this group could not be obtained. There was no other way to reach this group, as there was only phone number information in the hospital information management system. It is unknown whether the comorbidities of this group would affect the outcome of the study. This may affect the generalizability of the study.

The accumulation of comorbidities thought time should be investigated in future prospective studies.

Conclusions

New combinations of comorbidities have been demonstrated that may perhaps serve as a starting point for identifying new association of pathways.

Future efforts are needed to improve health care associated with these co-existing conditions and, more importantly, to identify modifiable factors for early intervention and prevention of chronic health problems in this population.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

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