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A Study on Awareness on Speech and Language Disorders in Cerebral Palsy
Serebral Palside Dil ve Konuşma Bozukluklarına Yönelik Farkındalık Çalışması

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ABSTRACT

Aim: The aim of the study was to examine the social awareness of cerebral palsy (CP) and speech and language disorders in individuals with CP. It was also aimed to investigate the change in social awareness among participants whether they have a relative with CP. **Subjects and Method:** 95 participants, 57 women and 38 men, participated in the study. A Google survey form developed based on literature review was used. In the form consisting of a total of 18 questions; demographic information of the participants, general information about CP, awareness of speech, language, feeding, and swallowing disorders in CP are questioned. **Results:** 80% (n = 76) of the participants did not have a relative with CP. Among those who had no relatives with CP, 59.2% stated that they had no opinion about the questions "CP is not a progressive disease" and 56.6% stated that "siblings of children with CP are not expected to have CP". Among the individuals with relatives with CP, 36.3% had no idea whether CP was a progressive disease or not. It was determined that 51.6% of all individuals had no opinion about dysphagia in individuals with CP, followed by 50.5% about feeding difficulties. More than half of those who had no relatives with CP stated that they had no opinion on 6 out of 8 questions related to speech and language. **Conclusions**: It was observed that the general knowledge level and general awareness of individuals with relatives with CP were higher. Swallowing and feeding difficulties in CP were the least understood by all. Being more aware of speech, language, feeding, and swallowing difficulties in CP can help people participate in activities, communication, and living and improve their quality of life. Trainings, seminars, and TV and social media campaigns can raise public awareness in this area.

Keywords: Awareness, cerebral palsy, deglutition, feeding, speech and language

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ÖZ

Amaç: Çalışmanın amacı serebral palsi (SP) ve SP'li bireylerin dil ve konuşma bozukluklarına yönelik toplumsal farkındalığın incelenmesidir. Ayrıca toplumsal farkındalığın SP'li yakını olan ve olmayan katılımcılarda değişiminin araştırılması amaçlanmıştır. **Örneklem ve Yöntem**: Araştırmaya 57 kadın ve 38 erkek olmak üzere 95 kişi katılmıştır. Literatürdeki yayınlar incelenerek geliştirilen Google anket formu kullanılmıştır. Toplam 18 sorudan oluşan formda; katılımcıların demografik bilgileri, SP hakkındaki genel bilgileri, SP'de konuşma, dil, beslenme ve yutma bozuklukları hakkındaki farkındalıkları sorgulanmaktadır. **Bulgular:** Katılımcıların %80'inin (n=76) SP'li bir yakını yoktu. SP'li yakını olmayanların %59.2'si ''SP ilerleyici bir hastalık değildir'' ve %56.6'sı ''SP'li çocuğun kardeşlerinin de SP'li olması beklenmez'' sorularında fikri olmadığını belirtti. SP'li yakını olan bireylerin %36.3'ünün SP'nin ilerleyici bir hastalık olup olmadığı konusunda fikri yoktu. Tüm bireylerin %51.6'sının SP'li bireylerde disfaji, %50.5'inin ise beslenme güçlüğü hakkında fikri olmadığı tespit edildi. SP'li yakını olmayan bireylerin yarısından fazlası dil ve konuşma ile ilgili 8 sorudan 6'sı hakkında fikri olmadığını belirtti. **Sonuç:** SP'li yakını olan bireylerin genel bilgi düzeyi ve genel farkındalığının daha yüksek olduğu görülmüştür. Tüm bireyler için en az farkındalığın SP'de yutma ve beslenme bozuklukları konusunda olduğu belirlenmiştir. Toplumun SP ve SP'li bireylerin dil, konuşma, beslenme ve yutma bozukluğuna yönelik farkındalığın artması ve daha bilinçli hale gelmesi; bireylerin aktivitelere, iletişime ve hayata katılımları ve yaşam kalitelerinin artmasını destekleyebilir. Bu alanda toplumun farkındalığını ve bilgi düzeyini artırmak amacıyla eğitimler, seminerler düzenlenebilir; televizyon ve sosyal medya kullanılarak toplumsal farkındalık çalışmaları yürütülebilir.

Anahtar Kelimeler: Farkındalık, serebral palsi, yutma, beslenme, dil ve konuşma

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Introduction

Cerebral palsy (CP) is a static, non-progressive disorder that occurs as a result of different causes affecting the developing central nervous system during the prenatal, perinatal, and postnatal periods. CP may affect all stages of development and is characterized by inadequate motor functions (Garne et al., 2008). CP is the most common type of motor disorder in children and affects approximately two children in every 1000 live births (Stanley & Watson, 1992; Himmelmann, Hagberg, & Uvebrant, 2010). In a study in Turkey, this rate was reported to be 4.4 per 1000 live births (Serdaroğlu et al., 2006). There are multiple etiologies for CP, including genetic causes affecting intrauterine fetal brain development, congenital malformations, and intrauterine infections such as rubella and cytomegalovirus. Other causes include birth asphyxia, low birth weight, twin pregnancy, neonatal stroke, and jaundice (Alruwaished et al., 2020).

Surveillance of Cerebral Palsy in Europe (SCPE) has reported an improved classification of CP. According to this classification, two terms, unilateral and bilateral, are defined according to the distribution of the motor impairment of CP in the body. Unilateral CP includes monoplegia and hemiplegia, while bilateral CP includes diplegia, triplegia, and quadriplegia. In the classification of CP according to motor type, spastic, dyskinetic (dystonic, choreatotic), ataxic, and mixed types are defined (Cans, 2000; Johnson, 2002). The diagnosis of CP is made clinically based on physical examination findings and a history of risk factors. However, magnetic resonance imaging (MRI) and other imaging studies can be used as an adjunct to confirm brain damage if there is no obvious etiology for the patient's symptoms (Wood, 2006; Gulati & Sondhi, 2018). The time and cause of a child's diagnosis of CP may vary, but the recommended age for determining the type of CP is 4-5 years. Along with motor impairment, which is the main sign of CP, people often have problems with their senses, thinking, communicating, and behavior, as well as epilepsy and other musculoskeletal problems (Rosenbaum et al., 2007; Patel et al., 2020; Sadowska et al., 2020).

Children with CP may have various communication disorders and may have difficulties with communication skills in areas such as expressive language, receptive language, gestures, and facial expressions (Pennington, Goldbart, & Marshall, 2005). It has been reported that children with these disorders show more limited participation in their daily lives compared to children with CP who do not have communication difficulties (Dickinson et al., 2007). When kids with CP do participate, they are more likely to do activities that are mostly at home, not very different from each other (Majnemer et al., 2008), passive, sedentary (Maher et al., 2007), not very formal (Imms et al., 2008), less often than kids without CP (Michelsen et al., 2009), and not very active. In addition, individuals with disabilities are generally exposed to stigmatization, discrimination, disrespect, and a lack of autonomy (WHO, 2015). Individuals with disabilities lose their self-esteem and avoid active participation in life due to the negative attitudes and behaviors that they are exposed to (Hayward et al., 2021). In this case, a study looked at how parents felt about the activities and participation of children with CP who had different communication skills (Mei et al., 2015). It was found that the main barriers were how parents interacted with their children (for example, not giving them choices), new people and places, and the negative attitudes of others. In order for individuals with disabilities to actively participate in life, negative attitudes should be prevented and social awareness should be increased (WHO, 2011).

Investigating the knowledge, attitudes, and social awareness of CP, which is common in our country, is important in terms of ensuring the active participation of these individuals and determining the barriers to their participation. In the literature, only one study (Kepenek-Varol & Menevşe, 2022) was found to investigate social awareness about CP in our country. However, it is seen that this study is limited to the Kayseri province sample and does not focus on the awareness of speech and language disorders in CP. Therefore, the first aim of this study is to examine the social awareness of CP and speech and language disorders in CP. The second aim is to investigate the change in social awareness among participants with and without relatives with CP.

Subjects and Method

Permission was obtained from the Üsküdar University Non-Interventional Research Ethics Committee for the research (04/07/2023, Decision No. 61351342). Research data were collected between September 5, 2023 and September 30, 2023. Our study is a research article and designed in a descriptive cross-sectional design.

Participants

The inclusion criteria were to be between the ages of 18 and 65, to be willing to participate in the study, to be a native Turkish speaker, to be literate, and to be able to use a smartphone, tablet, or computer at least at a basic level. After the inclusion criteria, a total of 95 participants, 57 (60%) women and 28 men (40%) with a mean age of 36.5±10.3 years, participated in the study (Table 1).

Data Collection Tools

In this study, the researchers used a Google survey they created after reviewing the literature (Garne et al., 2008; Himpens et al., 2008; Patel et al., 2020; Sadowska et al., 2020; Kepenek Varol & Menevşe, 2022) to ascertain the participants' awareness of speech and language disorders in CP. The questionnaire was finalized after the review of three speech and language therapy experts. The first five questions of the forminvestigate demographic information such as age, gender, and educational status of the participants, while five questions measure general knowledge about CP, and eight questions measure the participants' awareness of speech and language disorders in CP. The items consist of "yes, no, no idea" answer options. Data collection in this cross-sectional study was conducted according to Goodman's (1961) Snowball Sampling technique. The survey was delivered to the participants from online platforms.

Data Statistical Analysis

Since the data obtained were categorical variables, they were evaluated as numbers and percentages. All questions were analyzed in three groups: having a relative with CP, not having a relative with CP, and all individuals.

Ethical Approval

Permission was obtained from the Üsküdar University Non-Interventional Research Ethics Committee for the research (04/07/2023, Decision No. 61351342).

Results

Of the participants, 51.6% were university graduates, and 29.5% were high school graduates. 80% did not have a relative with CP, and of the 19 people who had a relative with CP, 51.6% had a child with CP (Table 1).

When asked for general knowledge about CP, 64.2% of all participants believed that a brain issue was the cause of CP. However, 39.5% of those who did not have a relative with CP stated that they had no opinion on this issue. While those with relatives with CP have generally correct answers to the general knowledge questions, 59.2%, 56.6%, and 55.3% of those without relatives with CP stated that they had no opinion on the questions of whether CP is a progressive disease, whether siblings of a child with CP are not expected to have CP, and the occurrence of CP, respectively. Among those with relatives with CP, 36.3% had no opinion on whether CP was a progressive disease (Table 2).

Table 1. Sociodemographic Information of the Participants and Their Closeness to a Person with CP

Sociodemographic Information		**n (%)**
Age (year) Overall ($\bar{X}$±SD) 36.5 ± 10.3		
Gender n (%)	Female	57 (60.0)
	Male	38 (40.0)
Education n (%)	Primary Education	7 (7.4)
	Middle School	4 (4.2)
	High School	28 (29.5)
	University	49 (51.6)
	Master's Degree	6 (6.3)
	Doctorate	1 (1.1)

CP: Cerebral Palsy

Table 2. Participants' General Awareness about CP

General Awareness About CP		**All individuals n (%)**	**Who has a relative with CP n (%)**	**No relative with CP n (%)**
Cerebral palsy is caused by a problem in the brain	Yes	61 (64.2)	17 (89.5)	44 (57.9)
	Not	2 (2.1)	0	2 (2.6)
	No Idea	32 (33.7)	2 (10.5)	30 (39.5)
Cerebral palsy is not a contagious disease	Yes	55 (57.9)	16 (84.2)	39 (51.3)
	Not	8 (8.4)	3 (15.8)	5 (6.6)
	No Idea	32 (33.7)	0	32 (42.1)
Cerebral palsy is not a progressive disease	Yes	25 (26.3)	10 (52.6)	15 (19.7)
	Not	20 (21.1)	4 (21.1)	16 (21.1)
	No Idea	50 (52.6)	5 (36.3)	45 (59.2)
The sibling of a child with cerebral palsy is not necessarily expected to also have cerebral palsy	Yes	48 (50.5)	17 (89.5)	31 (40.8)
	Not	2 (2.1)	0	2 (2.6)
	No Idea	45 (47.4)	2 (10.5)	43 (56.6)
Cerebral palsy can occur in the womb, during birth or soon after birth	Yes	48 (50.5)	17 (89.5)	31 (40.8)
	Not	3 (3.2)	0	3 (3.9)
	No Idea	44 (46.3)	2 (10.5)	42 (55.3)
Total		95 (100.0)	19 (100.0)	76 (100.0)

CP: Cerebral Palsy

It was determined that 51.6% of all individuals had no opinion about the fact that individuals with CP have swallowing difficulties and then feeding difficulties. Two questions, "Some children with CP have speech and language disorders while others do not" and "Speech and language disorders of children with CP do not continue in adulthood." were answered correctly with 50.5% (Table 3).

More than half of those without relatives with CP stated that they had no opinion on 6 out of 8 questions related to speech and language. It was observed that both general knowledge about CP and general awareness about speech and language were higher among those with relatives with CP compared to those without. The details of the answers given by those with and without relatives with CP are shown in Table 3.

Table 3. Participants' Awareness of Language, Speech, Swallowing, and Feeding in CP

Language, Speech, Swallowing and Feeding Awareness About CP		All individuals n (%)	Who has a relative with CP n (%)	No relative with CP n (%)
Some children with cerebral palsy have speech and language disorders, while others do not	Yes	48 (50.5)	15 (78.9)	33 (43.4)
	No	5 (5.3)	1 (5.3)	4 (5.3)
	No Idea	42 (44.2)	3 (15.8)	39 (51.3)
Children with cerebral palsy can understand everything that is said but have difficulty expressing themselves	Yes	40 (42.1)	13 (68.4)	27 (35.5)
	No	10 (10.5)	3 (15.8)	7 (9.2)
	No Idea	45 (47.4)	3 (15.8)	42 (55.3)
Some children with cerebral palsy can not acquire the ability to speak	Yes	46 (48.4)	15 (78.9)	31 (40.8)
	No	7 (7.4)	2 (10.5)	5 (6.6)
	No Idea	42 (44.2)	2 (10.5)	40 (52.6)
Some children with cerebral palsy cannot continue their education and training due to speech and language disorders	Yes	38 (40.0)	13 (68.4)	25 (32.9)
	No	19 (20.0)	3 (15.8)	16 (21.1)
	No Idea	38 (40.0)	3 (15.8)	35 (46.0)
Speech and language disorders in children with cerebral palsy do not persist into adulthood	Yes	3 (3.2)	1 (5.3)	2 (2.6)
	No	48 (50.5)	10 (52.6)	38 (50.0)
	No Idea	44 (46.3)	8 (42.1)	36 (47.4)
Not all children with cerebral palsy have swallowing disorders	Yes	29 (30.5)	10 (52.6)	19 (25.0)
	No	15 (15.8)	4 (21.1)	11 (14.5)
	No Idea	51 (51.6)	5 (26.3)	46 (60.5)
All children with cerebral palsy have feeding difficulties	Yes	21 (22.1)	7 (36.8)	14 (18.4)
	No	26 (27.4)	8 (42.1)	18 (23.7)
	No Idea	48 (50.5)	4 (21.1)	44 (57.9)
Since children with cerebral palsy have oral motor (lip, tongue, cheek, etc.) muscle weakness, saliva control problems are observed and it flows out of the mouth uncontrollably	Yes	42 (44.2)	11 (57.9)	31 (40.8)
	No	7 (7.4)	6 (31.6)	1 (1.3)
	No Idea	46 (48.4)	2 (10.5)	44 (57.9)
Total		95 (100.0)	19 (100.0)	76 (100.0)

CP: Cerebral Palsy

Discussion

Investigating social awareness about CP, which is a common disorder of childhood seen in our country, is important in terms of ensuring the participation of these individuals in life and determining the barriers to their participation. Within the scope of the study, social awareness about CP and speech, language, feeding, and swallowing disorders in CP was examined, and the change in social awareness was investigated in participants with and without relatives with CP.

According to the study's findings, more than half of all participants correctly identified CP as a brain disorder. These findings are comparable to those of the Kepenek Varol & Menevşe (2022)'s study. It is evident that most of our participants know that CP is caused by a problem in the brain. The reason for this result may be the access to information about CP on television, social media, newspapers, and magazines. However, 39.5% of those who do not have a relative with CP state that they have no opinion on this issue (Table 2). Those with relatives with CP gave generally correct answers to general knowledge questions. In our study, in parallel with the literature, it was found that individuals who did not know anyone with CP were more likely to give incorrect or no-idea answers to the questions than the others. In their study, Gilmore and Wotherspoon reported that participants who had contact with an individual with CP, the elderly, and those with higher education levels were more likely to give correct answers (Gilmore & Wotherspoon, 2023). This may be due to the fact that those who have relatives with CP frequently meet with healthcare professionals during the treatment process and receive information about the relevant conditions from these individuals. Another reason for this situation may be that those who have relatives with CP do research with the desire to access more information about CP.

More than half of the respondents who did not have a relative with CP stated that they had no idea about "CP is not a progressive disease; siblings of a child with CP are not expected to have CP" and the questions about the occurrence of CP. Some of those who have relatives with CP stated that they had no opinion on the question of whether CP is a progressive disease or not (Table 2). These results showed that individuals in the community, especially those without relatives with CP, had limited knowledge on general knowledge questions about CP. In our study, the question of whether CP is progressive or not was mostly answered as “no" or "no idea". Kepenek Varol and Menevşe (2022) also reported in their study that according to the results of the SP awareness survey, many participants answered 'no idea'. (Kepenek Varol and Menevşe, 2022). Gilmore and Wotherspoon also reported that the most common misconception was that CP is degenerative (Gilmore & Wotherspoon, 2023). The reason for this result may be confusion due to the knowledge that the symptoms of the disease can change with age (Sadowska et al., 2020). Although the knowledge level of caregivers in our study was higher than that of those without relatives with CP, some studies have reported that caregivers have insufficient knowledge about the etiology and prognosis of CP (Arora et al., 2014; Alruwaished et al., 2020). In some studies reviewed in the literature on this subject, it was reported that educational programs for CP may be beneficial (Martin et al., 2005; Arora et al., 2014; Dambi et al., 2016). In light of this, it is thought that social awareness activities such as enriching television and social media with informative content on the subject and adding subjects related to disorders and individuals with CP to school curricula should be carried out in order to increase the awareness and knowledge levels of society about CP.

Although most of the individuals who participated in our study were university graduates, their awareness of some items was low. In a study with similar findings, university medical students' attitudes and knowledge about CP were evaluated before and after watching a video about CP (Martin et al., 2005). As a result of the study, it was reported that medical students generally had limited knowledge about CP, had some misconceptions, and had negative attitudes towards individuals with CP before watching the video (Martin et al., 2005).

In other findings of our study, more than half of the participants who had relatives with CP had a high level of awareness of the question "Some children with CP have speech and language disorders while others do not". However, some of those who had no relatives with CP reported that they had no opinion on this question (Table 3). Our findings support the findings of the study in the literature (Kepenek Varol & Menevşe, 2022). It is interesting that some of the individuals with relatives with CP thought that some of the children with CP would never acquire the ability to speak. This may have been due to the fact that the participants' language and speech were affected depending on the type of CP in their relatives and that they generally saw that the person with CP could not speak. However, this finding contradicts their answers to the question that speech and language disorders do not persist in adulthood. This may suggest that individuals do not have accurate information on the subject.

More than half of all participants stated that they had no idea about the occurrence of dysphagia and subsequent feeding difficulties in individuals with CP (Table 3). These results showed that the questions related to swallowing and feeding difficulties had the lowest awareness. Besides, more than half of those who had no relatives with CP reported that they had no idea about the questions "CP is not a progressive disease; siblings of a child with CP are not expected to have CP" and the occurrence of CP (Table 2). In addition, it was determined that these individuals had no idea about the occurrence of dysphagia and subsequent feeding difficulties (Table 3). The reasons for these situations may be that those who do not have relatives with CP cannot access information on the subject in any environment or do not have the opportunity to observe the individual with CP.

Our study differs from other studies conducted in Turkey in terms of the items included, including questions about language, speech, swallowing, and feeding disorders in individuals with CP. The inclusion of questions about these disorders in the questionnaire may be instructive in raising awareness of these disorders and exploring treatment options. As a result of our study, it is thought that awareness about CP and individuals with CP should be increased. Making society more aware can support individuals' participation in activities, communication, and life and increase their quality of life. Trainings and seminars can be organized in this field. For this, various techniques and approaches can be used to reduce barriers, increase participation, and promote positive attitudes (Martin et al., 2005; Kepenek Varol & Menevşe, 2022). In addition to people who do not know or have remote contact with individuals with CP, caregivers of individuals with CP should also be informed and supported for family-centered care pathways (Elangkovan & Shorey, 2020).

Our study has some limitations. Since no scale with reliability and validity was found in the literature, a questionnaire was developed after literature review. The limited number of participants in the study sample is also among the limitations. Another limitation is that the responses of the respondents were limited to three options.

Conclusion and Recommendations

As a result, it was observed that the general level of knowledge about CP and general awareness about speech, language, feeding, and swallowing were higher in those with relatives with CP compared to those without relatives with CP. For all individuals, it was determined that the least awareness was about swallowing and feeding disorders in CP. Increasing public awareness and becoming more conscious of the general characteristics of CP and speech, language, feeding, and swallowing disorders in individuals with CP can support individuals' participation in activities, communication, and life and improve their quality of life. For this reason, social awareness activities can be carried out using television and social media in order to increase the awareness and knowledge level of society about children with CP, especially swallowing and feeding difficulties related to CP. Trainings and seminars can be organized to raise public awareness and knowledge in this area.

Ethical Approval

Permission was obtained from the Üsküdar University Non-Interventional Research Ethics Committee for the research (04/07/2023, Decision No. 61351342).

Conflict of Interest

The authors declare that they have no conflict of interest.

Author Contributions

M.M.P. was responsible for research design, data entry, data analysis, and writing. C.Y. was responsible for research design, data entry, and writing. M.S.A. was responsible for research design, data collection, and writing.

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