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Agreement between physiotherapists and mothers in the rehabilitation of children with down syndrome

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Abstract
Aim: The aim of this study was to examine the agreement between physiotherapists and mothers about the treatment of children with Down syndrome who received treatment in special education and rehabilitation centers.
Material and Methods: Mothers of 117 children with Down syndrome whose mean age was 26.24±12.94 months, and physiotherapists were included in this study. All participants were treated at special education centers in the province of Aydın. A questionnaire consisting of 6 open-ended questions was used to describe the expectations and views of the physiotherapists and mothers about the physiotherapy and rehabilitation programs for the children.
Results: The mean age of the mothers with a child with Down syndrome was 36.74±4.15 years, and the mean age of the physiotherapists was 34.03±9.32 years and their mean number of working years was 9.91±8.76. Statistically, a moderate agreement was found between the physiotherapists and the mothers in terms of additional treatment (K=0.225 and p=0.000) and the effectiveness of the physiotherapy program applied to DS children (K=0.204 and p=0.000). When the agreement between the physiotherapists and the mothers about the appropriateness of the treatment applied to DS children was examined, a statistically good agreement was found (K=1.000 and p=0.000).
Discussion: We believe that the views and expectations of the mothers should be taken into account by the physiotherapists when preparing a treatment program for children with Down syndrome.

Keywords
Down Syndrome, Physiotherapist, Mother, Physiotherapy, Kappa

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Introduction

Down syndrome (DS) (or trisomy 21) is the most common genetic cause of intellectual disability, occurring in about 1 in 800 births worldwide [1].

DS has whole-of-genome and epigenetic effects, affecting the structure and function of the nervous, cardiovascular, musculoskeletal and endocrine systems. The primary clinical feature of DS is intellectual disability, which is usually moderate but can range from mild to severe. Central nervous system structural differences include a smaller cerebrum, cerebellum and brain stem [2] Common structural differences in the cardiovascular system are congenital heart defects, affecting 40 to 55% of infants with DS [3]. These problems also negatively affect developmental deficiency

Rehabilitation of DS children should be carried out as a team effort involving the family. In order to encourage the family in this regard, physiotherapy and rehabilitation program can be prepared, taking into account their opinions and wishes. For this reason, physiotherapists should talk to the mother to create the most appropriate program for the child before devising a treatment plan [4].

Families whose expectations are at the maximum level in the treatment of children often ignore the condition of their child, except for the treatments deemed appropriate by the physiotherapist, in order to achieve the best result, and want all treatment methods learned from both local and various publications to be applied to their child, which may or may not be appropriate for that child's condition. However, physiotherapists, who have assumed the full responsibility for the treatment, support this program with the most appropriate additional treatment recommendations or applications for the child's condition [5].

In this sense, this study was planned with the aim of investigating the compatibility of expectations of the physiotherapist and mothers from rehabilitation in relation to the treatment of children with DS who are treated in special education and rehabilitation centers.

Material and Methods

The study included mothers and physiotherapists of children with DS between the ages of 0-6 who were treated at various special education and rehabilitation centers . The study was approved by Pamukkale University Faculty of Medicine Ethics Committee (PAÜ.0.20.05.09/46).

Informed consent forms were obtained from mothers and physiotherapists. The study was completed in accordance with the ethical principles in the Declaration of Helsinki after obtaining written permission for the study from the directors of the rehabilitation center.

The inclusion criteria in the study were as follows:

- All participants agreed to participate in the study,
- Having a child aged 0-6 years with a diagnosis of DS,
- A mother who takes full care of the child

Assessment methods:

Socio-demographic information was recorded with the participants by face-to-face interview method.

Gross motor function classification system:

The Gross Motor Classification System for cerebral palsy is based on self-initiated and performed movements, focusing on sitting, transfers, and mobility. Differences between levels are based on functional limitations, the need for hand-held walking aids (such as walkers, crutches, or canes) or wheeled mobility devices and, to a lesser extent, quality of movement. The Turkish validity and reliability study of this classification system was carried out in 2007 [6]

Level 1: Walking without limitations.

Level 2: Walking with some limitations.

Level 3: Walking using hand-held ambulation tools.

Level 4: Self-actualization is limited. Can use motorized mobility vehicles.

Level 5: Mobility is severely limited, although assistive technologies are used.

Evaluation questionnaire:

A questionnaire consisting of six open-ended questions was used about the expectations and opinions of the mother and the physiotherapist regarding the rehabilitation programs. The questionnaire form was prepared by specialist physiotherapists working in the field of pediatric rehabilitation in university hospital and special education rehabilitation centers [5].

Statistical analysis:

For all statistical analyzes, SPSS 21.0 package program was entered into the Windows operating system, continuous variables were given as mean ± standard deviation, and categorical variables were given as numbers and percentages. As a result of the power analysis of this study, when 117 people were included in the study, it was calculated that 90% power would be obtained with 95% confidence. In all statistics, the level of significance was determined as $p \leq 0.05$ and interpreted. The kappa coefficient ranged between 0 and 1. The kappa coefficient for two values between 0.0 and 0.20 was considered to indicate statistically insignificant concordance, and one between 0.21 and 0.40 was considered to indicate statistically moderate concordance [7].

Results

The study involved 117 children with DS and their mothers and physiotherapists. The mean age of the children was 26.24 ± 12.94 months, and the mean age of the mothers was 36.74 ± 4.15 years. It was found that 64.1% of the mothers had 12 years of education or less, 20.5% were over 12 years and 15.4% were illiterate. While the mean age of the physiotherapists was 34.03± 9.32 years, the mean number of working years was 9.91 ± 8.76 years (Table 1).

It is seen that 33.3% (39) of children with DS belong to level 3 and 22.2% (26) to level 4. The distribution of children with DS according to GMFCS is given in Table 1.

According to the results of the survey questioning the views of physiotherapists and mothers about the treatment of children with DS, while 40.2% (47) of physiotherapists and 36.8% (43) of mothers defined the children's health as "good" in their definitions of the general health of children, agreement between them was found to be 9.4%. While 26.5% (31) of physiotherapists and 22.2% (26) of mothers defined their children's health as "very good", the agreement between them was determined as 8.5%. There is no statistically significant agreement between physiotherapists and mothers in terms

of the definition of children's general health (K=0.020 and p=0.673) (Table 2).

When the awareness of mothers and physiotherapists regarding the treatments received by DS children was examined, 100% (117) of the physiotherapists and 28.2% (33) of the mothers stated that the treatment their children received was the Bobath treatment, while the agreement between them was 28.2%; 62.4% (73) of the mothers stated that the treatment they received was special education. When the agreement between the awareness of mothers and physiotherapists about the treatments received by children was examined, there was no statistically significant agreement (K=0.000 and p=1.000) (Table 2).

Table 1. Demographic characteristics of DS children, their mothers and physiotherapists

Child with DS	X±SD	Min-Max
Age	26.24 ± 12.94	9 – 56
Physiotherapist		
Age	34.03± 9.32	23-60
Working Year	9.91 ± 8.76	1.35
Mother		
Age	36.74±4.15	28-45
Mother Education Level	**n**	**%**
12 years and under	75	64.1
12 years and above	24	20.5
illiterate	18	15.4
GMFCS	**n**	**%**
level 1	18	15.4
level 2	23	19.7
level 3	39	33.3
level 4	26	22.2
level 5	11	9.4

X: Mean, SD: Standard deviation, Min: Minimum, Max: Maximum, GMFCS: Gross motor function classification system, DS: Down syndrome

While 100% (110) of the physiotherapists and 82.1% (96) of the mothers stated that the treatments applied to DS children were appropriate, the agreement between them was 82.1%. When the agreement between the physiotherapists and the mothers about the appropriateness of the treatment applied to the children was examined, a statistically good agreement was found (P=0.000 and K=1.000) (Table 2).

Regarding the application of additional treatments to the DS child, 39.3% (46) of the physiotherapists and 32.5% (38) of the mothers think that they should receive "language and speech therapy" as an additional treatment. The agreement between the physiotherapists and the mothers regarding the application of language and speech therapy to the child was found to be 17.1%; 28.2% (33) of the physiotherapists and 17.1% (20) of the mothers requested "special education, group training, psychosocial support" as additional treatment, and the agreement between them was found to be 8.5%. Statistically significant agreement was found between mothers and physiotherapists in the application of additional treatments to children, around moderate level (K=0.225 and p=0.000) (Table 3).

In terms of the usefulness of the physiotherapy and rehabilitation program applied to children, 41.0% (48) of the physiotherapists and 41.9% (49) of the mothers defined the treatment as "very good" and the agreement between them was found to be 25.6%. When the agreement between physiotherapists and mothers in terms of the usefulness of the physiotherapy program applied to children was examined, a statistically significant agreement was found around the middle level (K=0.204 and p=0.000) (Table 3).

Discussion

In our study, there was an insignificant agreement between the views of physiotherapists and mothers about the definition of the general health status of children with DS and the treatment

Table 2. Physiotherapist and mother; Awareness of children with DS about their health, the treatments they receive, and the appropriateness of treatments

	Physiotherapist		Mother		Physiotherapist Mother Agreement		p	K
Definition of the DS Child's Health	n	%	n	%	n	%	0.673	0.020
Excellent	8	6.8	7	6	2	1.7		
Great	31	26.5	26	22.2	10	8.5		
Good	47	40.2	43	36.8	11	9.4		
Moderate	12	10.3	35	29.9	3	2.6		
Poor	19	16.2	6	5.1	5	4.3		
Awareness of Treatments	**n**	**%**	**n**	**%**	**n**	**%**	**p**	**K**
Bobath	117	100	33	28.2	33	28.2		
Special education	-	-	73	62.4	-	-	1.000	0.000
Vojta	-	-	-	-	-	-		
Reflexology	-	-	-	-	-	-		
I Have No Idea	-	-	11	9.Nis	-	-		
Opinion on Appropriateness of Treatments	**n**	**%**	**n**	**%**	**n**	**%**	**p**	**K**
Yes	110	100	96	82.1	96	82.1	0.000	1.000
No	-	-	1	0.9	-	-		
I Have No Idea	-	-	13	11.1	-	-		

DS: Down syndrome, K: Kappa, Significance level: p<0.05

Table 3. Expectations of physiotherapists and mothers of children with DS regarding the treatments their children receive, their opinions on additional therapy and its benefits.

	Physiotherapist		Mother		Physiotherapist Mother Agreement		p	K
Treatment Expectations	**n**	**%**	**n**	**%**	**n**	**%**		
Assisted / unassisted walking	42	35.9	68	58.1	30	25.6		
Standing with/without support	7	6.0	-	-	-	-		
Supported / unsupported sitting	22	18.8	3	2.6	1	0.9	0.000	0.168
Independence in activities of daily living	15	12.8	40	34.2	11	9.4		
Increased balance, strength and postural control	31	26.5	6	5.1	4	3.4		
Additional Therapy Applications	**n**	**%**	**n**	**%**	**n**	**%**	**p**	**K**
Not Necessary	12	10.3	46	39.3	10	8.5		
Language and Speech Therapy	46	39.3	38	32.5	20	17.1		
Water Exercise	15	12.8	3.4	3.4	2	1.7	0.000	0.225
Sense – Perception – Fine Motor Skill Training	11	9.4	9	7.7	5	4.3		
Special Education, Group Education, Psychosocial Support	33	28.2	20	17.1	10	8.5		
Usefulness of Physiotherapy and Rehabilitation Program	**n**	**%**	**n**	**%**	**n**	**%**	**p**	**K**
Excellent	18	15.4	18	15.4	8	6.8		
Great	48	41.0	49	41.9	30	25.6		
Good	47	40.2	9	7.7	8	6.8	0.000	0.204
Moderate	4	3.4	40	34.2	-	-		
Poor	-	-	1	0.9	-	-		

K: Kappa, Significance level: p<0.05

methods applied to children.

A significant agreement was found between the opinions of physiotherapists and mothers in terms of the additional treatments that should be applied to the DS child, the suitability and usefulness of the physiotherapy and rehabilitation program applied.

Families face many difficulties in the post-diagnosis process, especially ignorance of medical issues, they also state that they suffer from inadequacy in education and rehabilitation and that they suffer from loneliness in terms of social support [8]. These situations also cause conflicts and a lack of communication within the family. Aksoy and Demirli stated in their study as follows: "It is thought that mothers should be supported and informed by experts after the diagnosis process and they should find support against the difficulties they experience during the process." [8].

A high level of education is important for families to adequately care and treat a disabled child. In the study conducted by Kavlak et al, it was found that 83.1% of the mothers had an education level of 12 years or less. In our study, it was found that 64.1 of the mothers had an education level of 12 years or less [5].

Considering that all rehabilitation processes of the child should be in the natural environment in which they live, it becomes a necessity for the child's family to participate in the rehabilitation process. The support given to the family on the care and rehabilitation process is as effective as directly focus on the child [9]. In order to increase the participation of the mother in the treatment, to apply the treatments consciously at home, and to better perceive the health status of the children, education should be provided and their communication with physiotherapists should be increased [5].

According to our study, we believe that it is necessary to ensure that the mother is more active during the rehabilitation process, to perceive the appropriateness of the treatments according to the developmental level and health status of the children, and to increase their communication with physiotherapists.

In the study conducted by Kavlak et al., families state that among the treatments applied to their children, the Bobath and special education treatment are the most appropriate and most beneficial treatments [5]. As a result of our study, in parallel with the information above, families state that the most appropriate and most beneficial treatments among the treatments applied to their children is the Bobath treatment.

Likewise, a low level of agreement was found between the views of physiotherapists and mothers about the treatments applied to children and the degree of benefit from the treatments [5]. In our study, there was a significant agreement between the views of physiotherapists and mothers about the treatments applied to children and the degree of benefit from the treatments.

The first expectation of mothers of children with CP is that their children can walk or improve the walking quality. It is observed that the severity of CP does not change the expectation of the mothers. Informing families of children with CP more about CP and rehabilitation goals can increase the efficiency of the rehabilitation program [10].

There are majority of mothers who think that their disabled children cannot manage their lives on their own. The expectations of mothers with low educational level about their disabled children are more similar to their own future. This similarity concerns who will take care of their children after death and whether the disabled child will be self-sufficient. In addition, among the expectations of mothers from educators in rehabilitation centers is to focus on self-care skills in the education of children [4].

In the study by Kavlak et al., 38.5% of mothers want their children

to be able to walk with or without assistance, and 35.4% want them to be independent in their daily living activities. There is a high degree of agreement between physiotherapists and mothers regarding treatment expectations [5].

In our study, 58.1% of the mothers wanted their children to be able to walk with or without assistance, and 34.2% wanted them to be independent in their daily living activities. In our study also, a high agreement was found between physiotherapists and mothers regarding expectations from treatment.

As a result of our study, in parallel with the above information, the first expectation of mothers is that their children can walk with or without assistance, and the other expectation is that they can make their daily living activities independent.

In the study conducted by Kavlak et al., 67.72% of mothers and 81.5% of physiotherapists think that alternative treatment methods are necessary [5]. In our study, 60.7% of mothers and 89.7% of physiotherapists think that alternative treatment methods are necessary.

In the study conducted by Kavlak et al., it is seen that there is an insignificant agreement between physiotherapists and mothers regarding the expectations from the treatments received by children with CP [5]. In our study, a statistically significant agreement was found between mothers and physiotherapists within the framework of all expectations. Taaniala et al., emphasize that it is important for the family to have sufficient information about the situation of their disabled children, for the family to adapt to the disabled child, for the care, education and rehabilitation of the child [11].

In addition, one of the most important factors that positively affect families' ability to cope with difficulties is education [12]. Singer et al., in their study with the families of disabled children, stated that families with higher education levels are more interested in their children, that is, they have higher awareness of the disease [13]. In the study conducted by Kavlak et al., the agreement between mothers and physiotherapists on the appropriateness of the treatment applied to children is 82.3%, and the agreement between them about treatment awareness (Bobath) is 36.2% [5]. In our study, the agreement between mothers and physiotherapists about the appropriateness of the treatment applied to children was 82.1%, and the agreement between them about treatment awareness (Bobath) was 28.2%. These compliances reveal the importance of informing and educating the family about the treatment given to us.

Our study was carried out in a single province as a region. Therefore, the cases were selected from a narrow population. If a wider region could be reached, the number of data could be increased by accessing cases with different socio-cultural structures. Thus, more precise, reliable and universal results could have been obtained.

Conclusion

As a result, the participation of the family in the treatment program applied to the child with DS and their awareness about the treatment applied are important. Evaluating the results obtained after our research, we think that the mothers' views on the treatment should be taken into account in determining the most appropriate and most beneficial treatment of the healthcare personnel dealing with the treatment of disabled children. In addition, adequate information is of great importance for mothers in this process.

We think that mothers should cooperate with physiotherapists during rehabilitation and receive informative training about their children's conditions in order to be aware of the disease of the family with a disabled child, to find the most appropriate treatment option, to apply home treatment effectively and appropriately, and to get more successful results from the applied treatment program.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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Conflict of interest

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