



ISSN: 2230-9926

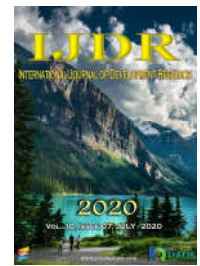
Available online at <http://www.journalijdr.com>

# IJDR

International Journal of Development Research

Vol. 10, Issue, 07, pp. 37847-37852, July, 2020

<https://doi.org/10.37118/ijdr.19287.07.2020>



RESEARCH ARTICLE

OPEN ACCESS

## THE QUALITY OF CHILDREN'S LIFE WITH MOTOR DISABILITIES IN GREECE

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### ARTICLE INFO

#### Article History:

Received 03<sup>rd</sup> April, 2020  
Received in revised form  
17<sup>th</sup> May, 2020  
Accepted 06<sup>th</sup> June, 2020  
Published online 25<sup>th</sup> July, 2020

#### Key Words:

Quality of life, Motor Difficulties,  
Parents, Physiotherapy,

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### ABSTRACT

**Introduction:** Families with children with motor disabilities are called upon to face a variety of problems from day to day child care, treatment, child education, social inclusion and, most importantly, their independence. Tackling the problems children with motor disabilities face is the ultimate goal of improving their quality of life. Improving the quality of life requires the protection of public health, as there is no social and economic progress without the involvement of the 'health' factor. Health researchers argue that there is a correlation between living standards and health. **Purpose:** The aim of this study is to evaluate the quality of life of children with motor disabilities in Greece up to the age of adulthood, through the parents' opinion. Parents' reactions to their child's initial diagnosis were also studied and recorded. **Method:** The study involved 37 parents of children with motor disabilities. The research was conducted in Thessaloniki at the Neuro Physio Kids Physiotherapy Center Konstantinou Karamanlis 60 Thessaloniki. **Results:** The living standard of children with motor disabilities in Greece is characterized by 57% of parents as 'bad', 30% 'average', 10% 'good' and only 1 person responds 'excellent'. The results show that parents have been affected by their child's disability in various aspects of their daily lives, such as social and family relationships, financial status and individual well-being. **Conclusion:** In our sample, parents / guardians of children with motor disorders in the majority respond that the standard of living for children with motor disabilities in Greece is low. Further research on a larger number of parents / guardians of children with motor disorders is recommended.

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Citation: Amanda Schultz Macedo, Gislene de Jesus Cruz Sanches, Kay Amparo Santos, Mona Freitas Santos and Marcio Pereira Lobo. "The quality of children's life with motor disabilities in Greece", *International Journal of Development Research*, 10, (07), 37847-37852.

### INTRODUCTION

Quality of life is a need but also a right of every human being, especially those with disabilities, where their quality of life is not largely ensured by themselves. People with physical disabilities now make up a large percentage of the world's population. Their mobility problems can come from a variety of causes such as accidents, some kind of illness or even from birth (Allen 1991). The children included in this study have been diagnosed mainly with cerebral palsy in the largest percentage and in smaller percentages with other diseases that are chronic and require physiotherapy and other treatments for many years. Physiotherapists work with parents to improve children's functionality and quality of life. Parents must complete the work of the physiotherapist and take care of the

performance of a comprehensive care for the child (Hristara et al. 2014, Cummins 1997). Although mobility difficulties first appeared in ancient times, in recent decades only more emphasis has been placed on the etiology and treatment (Access - Supportive Technology in the Education of Persons with Severe Kinetic Problems) as well as the active involvement of the family in treatments these children receive. In recent decades, the concept of quality of life has come to the forefront of both teaching and research staff (Nakou 2001). Quality of life leads man to a level characterized by satisfaction, success, health, well-being and life which refers to all aspects of human existence. Quality of life is man's innate tendency to acquire something better that will bring them more comfort. However, what is good has a subjective character depending on the point of view that each person approaches

individually and the social, political and economic factors that prevail (Theofilou 2010). Quality of life is associated with self-determination, through which a person can organize and manage his life as he wishes, without coercion, coercion and oppression, escaping from what others want and doing what he wants (Ioannidis *et al.* 1999, Yfantopoulos 2007, Cramer 2004). The concept of quality of life is very broad and complex. Parents have a crucial role to play in shaping their child's quality of life, as they guide and support him throughout his life (Jokinen 2011, Leung 2003). Children are better served and nurtured within their families, and professionals who work with families are better able to meet the needs of a child with a disability (Poston *et al.* 2001, Turnbull *et al.* 2005), in improving functional their problem, posture and walking (Civita 2005, Fayers 2008). Families with children with mobility problems face significant challenges in their daily lives, which of course affect their quality of life. However, parents try to do as much as possible to ensure a better future and to be able to help the child to develop to the best of his ability. The family has a very important role to play in the development of the child's personality and skills with mobility difficulties. However, due to the problems that arise, many times her attitude is negative, aggravating the existing problem (Appleton 1991, Collins 1990). Emotions in the family environment fluctuate, depending on the problems that arise. Having a child with mobility difficulties is one of the problems that will shake the cohesion of the family and upset the balance of relationships. The family has to deal with internal and external pressures. Parents go through a series of emotional stages until they accept the diagnosis of their child's disability. Therapeutic intervention aims to maximize the child's potential to acquire daily functional skills that will allow him to participate effectively in society (Hristara *et al.* 2014). The role of the professional in dealing with children with motor impairments must, in addition to providing therapeutic services, be supportive. This will make it easier for the family to show all these positive elements in order to help the child's development. After all, it must be understood that the family itself is responsible for the child's development through the right and appropriate decisions that it will make and implement. The role of the professional is to make her able to understand and display this role. Regardless of the cause, an organized therapeutic group framework is required, where the effort to limit deficits (motor - functional - cognitive and communicative) will be made by specialized scientists (Collins *et al.* 1990). Lowering the motor deficit, it is necessary to educate and strengthen the skills that will help the child in his future independence. This is, after all, the purpose of the time-consuming, laborious, and costly treatment program whose ultimate goal is to improve quality of life (Ware *et al.* 1992).

**Purpose:** The main purpose of this study was to evaluate the quality of life of children with motor disabilities in Greece. up to the stage of adulthood through the opinion of parents. Also, study and record parents' reactions to their child's initial diagnosis. The importance of the study stems from the fact that in Greece such a test has not been widely applied.

## METHODS AND MATERIALS

The study involved 37 parents of children (7 of whom were their father and 30 of them mothers) with motor disabilities. The study was conducted in Thessaloniki at the Neuro Physio Kids Physiotherapy Center Konstantinou Karamanlis 60 Thessaloniki. Parent children had a range of 9 months to 18

years old boys and girls with motor disabilities. With diagnoses such as: cerebral palsy in the largest percentage (14.37%) and in smaller percentages, developmental deviation, Down syndrome, myopathy / myasthenia, individual cases involving diagnoses such as neurological etiology, generalized hypertension with psychomotor behavior, psychomotor retardation problems, leukocytosis which are chronic and require physiotherapy and other treatments for many years.

**Protocol:** A specific questionnaire was used as a measuring tool for parents of children and adolescents with motor disabilities, designed and developed by the first three authors of this thesis and includes 3 sections. A. 1st section: Demographic, information on each child's data, such as age and disability, as well as parents' data, such as occupation, educational level, home and family structure.

**Section 2:** General Quality of Life Questions from the Parent Questionnaire for Children with Disabilities (Fyka, 2006). This section includes general questions about parents' feelings during the diagnosis, the current family situation and the extent of the disability that has affected the parents' routine. Γ. Section 3: Specific Questions on Parents' Opinion on Physiotherapy and How It Helps Improve the Child. The questionnaires were collected through personal interviews during February - April 2019 and descriptive statistics and correlation analysis were performed.

**Statistical analysis:** The variables in our sample are qualitative and we use descriptive statistics. The variable emotion is described by a set of query questions that allowed us to create a new quantitative variable that emerged as the ratio of the sum of all the queries. This led us to apply additional methods of statistical analysis. The multiplicity of sample per case as well as the irregularity of our distributions led to non-parametric assumptions. Kruskal-Wallis test was used to test for mean differences in dichotomous variables. In all cases the level of statistical significance was  $p < 0.05$ .

## RESULTS

From the following results we can see that our sample is representative as all the main variables are distributed proportionally to the population as a whole. Ages are distributed around 20% in each category, gender 60% girls and 40% boys, 2/3 of the surveyed resides in the city and approximately 1/2 has an income between € 1,000 and € 2,000 (Table. 1).

Parent occupational status is also distributed across categories according to the population as a whole and is considered as the dominant representative of the employment relationship and the self-employed of both parents. As far as the educational level of the parents is concerned, they are mainly of higher education. University education is dominated by 30% in mothers and 35% in fathers (Table 2). The most common problems in children are cerebral palsy and developmental abnormality. Most children attend regular school and only 8 attend special school. All families worked with pediatric psychiatrists, pediatric psychologists and pediatric neurologists. At least 2 to 3 times a week, 70% of children receive physiotherapy, and 95% start physiotherapy immediately (Table. 3,4,5). The very strong negative feelings they felt when they were diagnosed were 'Stress' at 68%, 'Fear'

at 68%, 'Shock' at 51%, and 'Sorry' at 54%. The rest of the emotions were not as vigorous as their responses (Table. 6). Parents' time for the various activities has clearly been reduced because of their children's other 'not enough' as shown by the results. The degree of influence of their children's particularity on the different facets of their lives is generally 'sufficient' or 'moderate' according to the percentages that appear in the results (Table. 7). However, they are very comfortable in their social outings and their child has friends. Very often, 73% of families have social expenses (Table. 8).

**Table 1. Frequencies and rates, age, residence, income**

Child Sex		Individuals	(Percentage)
Boy		15	(40.5%)
Girl		22	(59.5%)
Total		37	(100.0%)
Ηλικία παιδιού			
Από 9 μηνών έως 2 ετών		7	(18,9 %)
2 - 5 ετών		9	(24,3 %)
6 - 10 ετών		9	(24,3 %)
11 - 15 ετών		6	(16,2 %)
16 - 18 ετών		6	(16,2%)
Total		37	(100.0%)
Area of residence			
Province		10	(27%)
City		27	(73%)
Total		37	(100.0%)
Monthly net family income			
up to € 500		2	(5.4%)
500 € - 1,000 €		7	(18.9%)
1,000 € - 2,000 €		18	(48.6%)
€ 2,000 and up		10	(27%)
Total		37	(100%)

**Table 2. Parental educational level**

Maternal Education	People (Percentage)
Ph.D.	1 (2,7%)
Postgraduate	7 (18,9%)
University education	11 (29,7%)
IEK - Higher School	9 (24,3%)
High School	8 (21,6%)
High school	1 (2,7%)
Total	37 (100%)
Father's educational level	
Postgraduate	4 (10,8%)
University education	13 (35,1%)
IEK - Higher School	10 (27%)
High School	9 (24,3%)
Δημοτικό	1 (2,7%)
Total	37 (100%)

Support for a child with a motor disability involves several costs that are usually covered by families. ½ of families receive social benefits but only 1/3 declare that they are adequate (Table. 9).

**Table 3. Main Diagnosis**

What is the diagnosis of your child	People (Percentage)
Cerebral Palsy	14 (37,8%)
Cerebral Palsy and Developmental Dysfunction	5 (13,5%)
Growth gap	8 (21,6%)
Syndrome	3 (8,1%)
Myopathy / Myasthenia	2 (5,4%)
Neurological justification for pleuroplasty	1 (2,7%)
Generalized hypertension with psychomotor delay	1 (2,7%)
Leukoencephalopathy	1 (2,7%)
Hyperactivity, behavior problems	1 (2,7%)
No more diagnosed	1 (2,7%)
Total	37 (100.0%)

**Table 4. School attendance**

What is the child's functional limitation?	What school is he attending		
	Normal School	Special School	Remains at home
Kinetic	5 (29.4%)	1 (5.9%)	11 (64.7%)
Mental	1 (50.0%)	1 (50.0%)	0 (0.0%)
Speech / Speech	1 (100.0%)	0 (0.0%)	0 (0.0%)
Multiple	8 (47.1%)	6 (35.3%)	3 (17.6%)
Total	15 (40.5%)	8 (21.6%)	14 (37.8%)

**Table 5. Frequency of Physiotherapy**

Frequency of Physiotherapy	People (percentage)
Every day	1 (2,7%)
Two times a week	25 (67,6%)
Once a week	10 (27%)
Rarely	1 (2,7%)
Total	37 (100%)

**Table 6. Diagnosis feelings**

	Very	Moderate	Not at all
Anger	12 (32 %)	5 (14 %)	20 (54 %)
Regret	20 (54 %)	10 (27 %)	7 (19 %)
Anxiety	25 (68 %)	8 (22 %)	4 (11 %)
Fear	25 (68 %)	6 (16 %)	6 (16 %)
Disappointment	10 (27 %)	14 (38 %)	13 (35 %)
Desperation	9 (24 %)	13 (35 %)	15 (41 %)
Loneliness	7 (19 %)	11 (30 %)	19 (51 %)
Shock	19 (51 %)	9 (24 %)	9 (24 %)

They generally believe that if they lived in another country they would have more financial assistance. In our sample, parents / guardians of children with motor disorders in the majority respond that, the living standard of children with motor disabilities in Greece is characterized by 57% of parents as 'bad', 30% 'moderate', 10% "good" and only 1 person responds that they are "excellent". Further research on a larger number of parents / guardians of children with motor disorders is recommended. Also, the expectations for the level of education of children are observed to be distributed at all levels. About 27% want higher education also 4% (11%) are postgraduate and doctoral students. 16% are satisfied at primary level, 19% at secondary level and only 11% respond to any level of education (Table. 10,11). Parents try to do as much as possible to ensure a better future and to be able to help the child develop to the best of his ability. So the majority of parents want their child to go to university to have a better quality of life.

## DISCUSSION

Improving the lives of people with disabilities is a top priority for any advanced society. Any proven successful action in this direction must be maintained, maintained and evolved in order to improve and bring even more positive results. Physiotherapy belongs to this set of options that can offer life improvement to people with mobility difficulties. Addressing the problems faced by children with mobility difficulties is the ultimate goal of improving their quality of life. Achieving this goal requires the cooperation of an interdisciplinary team with family members of the child. The people who have frequent contact and interact with the child every day are the parents and family members. Their role is important in the quality of life of the child, as they provide a variety of stimuli in his daily life and receive the feeling of love and affection that surrounds them. Parents believe that physiotherapy improves their child's

Table 7. Impact on different life expressions

How much has the particularity of the child affected the different expressions in their lives	Very	Enough	Moderate	Not at all
Psychology	16 (43 %)	9 (24 %)	10 (27 %)	2 (5 %)
Level of stress	8 (22 %)	16 (43 %)	8 (22 %)	5 (14 %)
Work	7 (19 %)	11 (30 %)	13 (35 %)	6 (16 %)
In life with your partner	7 (19 %)	16 (43 %)	8 (22 %)	6 (16 %)
Social relationships	4 (11 %)	14 (38 %)	14 (38 %)	5 (14 %)
Family relationships	3 (8 %)	11 (30 %)	15 (41 %)	8 (22 %)
Economic situation	11 (30 %)	15 (41 %)	10 (27 %)	1 (3 %)
Individual well-being	9 (24 %)	7 (19 %)	14 (38 %)	7 (19 %)

Table 8. Sex frequencies and rates

Child and Social Life	Positive Answers
You are comfortable at social outings with your child	22 (59.5%)
Your child has friends and social contacts	28 (75.7%)
It is believed that if you lived in another country you would have more financial assistance	35 (94.6%)

Table 9. Family income

	Positive Answers	Negatives Answers
You receive a social allowance for your child	18 (48.6%)	19 (51.4%)
Social allowance is sufficient or not	6 (33.3%)	12 (66.7%)
It is believed that if you lived in another country you would have more financial aid	35 (94.6%)	2 (5.4%)

Table 10. Quality of life of children

How would you describe the standard of living of children with motor disabilities in Greece	People (Percentage)
Excellent	1 (2.7)
Good	4 (10.8)
Moderate	11 (29.7)
Bad	21 (56.8)
Total	37 (100.0)

Table 11. Target of education level

What level of education are you aiming to finish your child with?	People (Percentage)
Primary education	6 (16.2)
Secondary education	7 (18.9)
Higher education	10 (27.0)
IEK Higher School	2 (5.4)
Postgraduate	4 (10.8)
Ph.D.	4 (10.8)
No level of education	4 (10.8)
Total	37 (100.0)

functioning and, consequently, their daily lives, and the majority of children, almost 70%, do physiotherapy two to three times a week. A significant percentage of children go to regular school, although the majority of children in this study have mobility problems. The child's development and concern for his future is a source of stress and anxiety for parents. They themselves try to do as much as possible to ensure a better future and to be able to help it develop to its full potential (Summers *et al.* 2005). Parents and families of children with mobility difficulties in general are overwhelmed by anxiety, sadness, and worry, and this begins at the first stage of diagnosis. This often results in the social isolation and low quality of life of these individuals (Brown *et al.* 1991). As shown in Leung 2003's research, family quality of life is affected by the care of children with disabilities and parental time. The same conclusion was reached by Ertekin *et al.* 2014 and Brown *et al.* 2006, that indeed primary caregivers of children with mobility difficulties have stress and limited personal time, which negatively affects their emotional state and mental health. That is why the announcement of the diagnosis by the experts should be clear, polite and methodical. Parents need the support of specialists, from the

first stage of diagnosis, to be able to understand the condition, solve their questions and learn how to actively participate in treatment programs. The birth of a child with a dysfunction creates excessive stress in most families and the likelihood of emotional problems is increased. Parental education at the stage of daily care and treatment of the child is necessary to be able to cope with daily needs such as getting out of bed, dressing, walking and more (Collins B., & Collins 1990). Both parents and professionals (physiotherapists, occupational therapists, doctors and others) need to develop and maintain a beneficial and balanced relationship in order to create a safe environment around their therapeutic and supportive role for the child with motor impairment. The therapist should understand their feelings, deal with their reactions and be able to restore balance and answer any questions they may have in order to be actively involved with the parent in the treatment program. good psychology. without stress and anxiety. The transition periods of the life cycle bring different tasks to be fulfilled and create several requirements for a family. As a child grows up, parents need to be prepared for their independence and overcome many problems, while at the same time they need to learn to control the events that affect them,

to be aware of treatment options and to participate in decision-making. This will improve their compliance with the treatment, thereby improving the child's functionality, preventing musculoskeletal complications and generally good psychology. The degree of influence of their children's uniqueness beyond psychological (Parkes *et al.* 2011) is in other areas as well, such as the financial situation and the individual well-being that have been significantly affected, the life with the partner and the social relationships that Finally, work and family relationships were also less affected. According to the results of the present study, the highest percentage of parents 57% characterize the standard of living of children with motor disabilities as "bad". al. 2009). However, (60%) have frequent social outings and their child has friends and social contacts. This shows that parents try to have social relationships and continue their lives normally as if there are no difficulties and to integrate their child into society. As their answers show, they have not limited their outings with the child, but instead try to help him socialize and integrate into society. In addition, according to Tafa 1997, parents of children with special needs should make greater efforts to enable the child to learn to live and trade with other people. The family teaches the child to follow rules and to respect others so that he can later find his place in society (Tafa 1997).

At the same time, social outings and the development of social relations and therefore good social life are important factors that affect the quality of life. This is a finding that is confirmed by other research linking social isolation to quality of life (Ferrans & Powers, 2007; Nikas, 2009). The social allowance is insufficient, reports (70%) and this creates difficulties for them. Several studies have highlighted income as an important factor in predicting family satisfaction with their quality of life (Wang *et al.* 2004; Davis *et al.* 2009; Fujiura & Yamaki 2000; Turnbull & Turnbull 2002). In fact, many writers treat it as a dogma: as income declines, so does family quality of life (Zuna *et al.* 2009). Therefore, government spending on improving the quality of life of children with mobility difficulties should be a priority. Certainly, in terms of benefits for families with children with mobility problems, there is room for significant improvement, which is confirmed by the fact that the majority of participants state that if they lived in another country they would probably have more help from their side. state. This finding is to some extent related to parents' concerns about their child's future, which leads them to try to meet all their needs, so that they have the resources they can for the course of their lives (Summers *et al.* 2007, Wang 2004). This is confirmed by the parents' expectations for the level of education of the children, which are distributed at all levels, and 27% want higher education and obtain a master's and doctoral degree.

### Suggestions

**Based on the results of the present study, it is proposed to:**

- Establishment of specialized schools in all municipalities and counties of the country.
- Implementation of daily physical therapy to improve the quality of life of children with mobility difficulties.
- Training parents in physiotherapy techniques.
- Opportunity for teaching, creative work and physical therapy at home, to children who are unable to move.

- Creation of the necessary provisions and appropriate structures for working conditions and employment of people with disabilities.
- Learning some "easy" technical work in special schools, where these crafts are sold in charity bazaars for this purpose.
- A sufficient number of people with disabilities are recruited and professionally employed, by setting objective placement criteria and based on their disability rate in a job that they are able to handle.
- Ensuring a good level of health and social protection for children with motor disabilities by offering free medical care, treatments, mechanical support equipment.
- Establishment and operation of social support and information institutions for parents of children with disabilities. Also, attend special seminars and provide them with psychological support, counseling, and medical follow-up, especially at the first stage of diagnosis, which becomes a particularly critical time for awareness and management of their emotions.
- Conducting workshops, television programs, events as well as conferences. In order to inform parents about physiotherapy and their participation in physiotherapy programs.
- Optimizing the accessibility and mobility of people with disabilities in their natural and social environment.

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