ORIGINAL ARTICLE

Stress and Compliance with a Home Exercise Program among Caregivers of Children with Disabilities

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ABSTRACT

Objective: We sought to identify the relationship between caregiver stress and compliance with home programs in caregivers of children with disabilities.

Study Design: Cross-sectional survey.

Place and Duration of Study: The study was conducted from June 2023 – Dec 2023. The survey study was conducted in Karachi, Pakistan.

Material and Methods: In 2023, a population-based cross-sectional survey was conducted in Karachi, Pakistan. The study included 100 participants who were caregivers of children with disabilities aged between 20-50 and was selected according to a convenience sampling strategy. The outcome measure of this survey was stress associated with a prescribed home physical therapy program using a questionnaire on resources and stress (QRS) comprising 52 questions, and its compliance was identified utilizing 8 subjective questions.

Results: According to the results, it was reported that the caregivers showed noncompliance with the home programs being prescribed by the physical therapists. The data analysis through linear regression revealed a strong and significant relationship between the caregiver's non-compliance with the home program and the level of stress they stated. Correlation coefficients showed a strong and significant relationship between domestic problems and noncompliance with home programs. This reveals that the home program noncompliance increased due to the caregiver and family problems.

Conclusion: Caregivers of children with disabilities experience stress that should be addressed by the therapists to maximize compliance with home programs.

Key Words: *Stress, Compliance, Exercise, Disabled Children, Physical therapy*.

INTRODUCTION

A disability is defined as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease.[1]

Disability is conceptualized as a multidimensional

experience for the person involved. There may be effects on organs or body parts, and there may be effects on a person's participation in areas of life.[2] Correspondingly, three dimensions of disability are recognized in the International Classification of Functioning (ICF): body structure and function (and impairment thereof), activity (and activity restrictions), and participation (and participation restrictions). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. The World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) in 2001, which covers activity, participation, body structures, body functions, personal factors, health conditions, activity limitations, functional limitations, environmental factors, and participation restrictions.[3]

Disabilities can affect people in different ways. There are many types of disabilities, such as those that affect a person; some disabilities may be hidden, known as an invisible disability. Impairments can be termed as disability of the person to perform their day-to-day activity. "Disability" can be broken down into several broad sub-categories, which include: disability in mobility can be either inborn or acquired with age problems. It could also be the effect of a disease. People who have a broken bone also fall into this category of disability. Spinal cord injury (SCI) can sometimes lead to lifelong disabilities. This kind of injury mostly occurs due to severe accidents. The injury can be either complete or incomplete. In an incomplete injury, the messages conveyed by the spinal cord are not completely lost. Whereas a complete injury results in a total dysfunction of the sensory organs. In some cases, spinal cord disability can be a birth defect. A disability in the brain occurs due to a brain injury. The magnitude of the brain injury can range from mild to moderate and severe. There are two types of brain injuries: Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI). ABI is not a hereditary type defect, but is the degeneration that occurs after birth. The causes of such cases of injury are many and are mainly due to external forces applied to the body parts. TBI results in emotional dysfunction and behavioral disturbance.[4-6]

Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes and a lack of adequate policies and legislation, they are effectively barred from realizing their rights to healthcare, education, and even survival.[7] Estimates suggest that there are at least 93 million children with disabilities in the world, but the numbers could be much higher. They are often likely to be among the poorest members of the population. They are less likely to attend school, access medical services, or have their voices heard in society.[8] Their disabilities also place them at a higher risk of physical abuse and often exclude them from receiving proper nutrition or humanitarian assistance in emergencies. Physical therapists, families, patients, teachers, and physicians work together to jointly determine goals and provide the most appropriate therapy program for each patient. Each of these people is are essential member of the rehabilitation team; it is important to include them in the therapy program, as many therapy activities should be done at home as part of the patient's daily routine.[8,9]

Physical therapists help children and adults to strengthen their muscles and improve their movements. This work can include aiding individuals after injuries, as well as supporting those with lifelong motor-coordination difficulties related to conditions like cerebral palsy, Down syndrome, autism spectrum disorders, or gross motor dyspraxia. A person with a disability often has no choice but to rely on his/her family. Supporting a family member with a disability is one of the most challenging experiences. Many preceding studies have reported that family caregivers of a person with a disability experience deterioration in mental and physical health due to stress.[10,11]

Attending therapy sessions for a few hours per week is not enough to help a child meet developmental milestones. By continuing treatment at home, parents or caregivers will integrate daily functions taught in therapy with the child's daily life.[12]

The severity of the functional limitation of children with CP seems to enhance the adherence of caregivers to home exercise programs, while the exhaustion and burnout of caregivers have a negative impact. In Pakistan, there is limited research addressing the behavior and challenges

of primary caregivers of children with special needs. With scarce resources and minimal awareness regarding disability-related social issues such as stigma, poverty, and gender inequality, caregivers often face significant stress that affects their ability to comply with prescribed home exercise programs. Furthermore, understanding these challenges is crucial to identifying barriers to compliance and areas where educational interventions can provide support. This will benefit in designing targeted programs to equip caregivers with the knowledge and tools they need to manage their responsibilities effectively. Such efforts are vital for creating a more inclusive and supportive environment for families of children with special needs in Pakistan.

MATERIAL AND METHODS

This study was designed to measure the variables of caregiver stress and compliance with a home exercise program for a child with a disability. The research survey was conducted from June 2023 to December 2023 to gather the data for this study. The compiled data were then correlated to examine the relationship between stress and compliance. The sample size was 100, and a non-probability, convenience sampling method was used. The inclusion criteria of this study were participants aged between 20 and 50 years and older, caregivers of children with cerebral palsy, Down syndrome, and others. The exclusion criteria were individuals below 18 years of age and those dealing with muscular dystrophy. An institutional review approval was obtained with reference number (ASC-PT-043/06/2023).

The measurement tool used to measure stress was the Short-Form of the Questionnaire on Resources and Stress, which consists of 52 true/false questions. Four factors comprise the short form of the questionnaire on resource and stress (QRS). These factors are (Factor 1: parent and family problems, Factor 2: pessimism, Factor 3: child characteristics, Factor 4: physical incapacitation). This tool was chosen because research supports the utility of the QRS as a measure applicable to parents of children with disabilities. To measure the variable of compliance, the researchers designed a compliance survey. The form contained a series of six closed-ended questions. These questions aimed to determine eligibility to participate in the study and the level of compliance with the child's prescribed home exercise program. The level of compliance, termed the compliance score, was determined by comparing how often the caregiver was instructed to follow the home program with how often they reported following the home program.

For the analysis of the questionnaire data, descriptive measures like proportions, means, and histograms were used. Data were then further analyzed on the statistical program SPSS version 22. The questionnaire data were analyzed using descriptive measures. Informed consent was given to the participants before completing the questionnaire.

RESULTS

Within Karachi total of 100 individuals were enrolled in the study. Frequency distributions of responses were determined for each of the questions on the compliance survey. Statistical computations were performed to determine individual factor scores. (Data is presented in tables 2-7). Linear regression analysis was performed to determine the level of compliance (table 8). Correlation coefficients were calculated to address the autocorrelation problem among the variables. Alpha was set at 0.05 levels for all analyses (table 9).

In the light of Borg and Gall (1986), reliability is the near internal consistency or measuring the stability over time. To get consistent results, so measuring instrument must be perfect and reliable. In the research of the study reliability coefficient indicates to the researcher how much data is reliable. According to (Mugernda and Mugenda, 2003), the Coefficient is 0.70 or more than 0.70, which shows the high reliability of the data. In our research, we have checked the reliability of our questionnaire; the value of Cronbach's Alpha is 0.73 for the stress questionnaire and 0.72 for the compliance questionnaire, which indicates that the data is highly reliable (table 10).

In the table of diagnoses of the children, 42% responded that their children were diagnosed with cerebral palsy, 17% with Down syndrome, and

about 41% with other diseases categorized into neurological, genetic, neuromuscular, developmental, and sensory conditions (table 11).

Respondents reported how often they were instructed by a physical therapist to follow a home exercise program. 66% of respondents were instructed to perform the home exercise program 5 to 6 times per week, 16% of respondents were instructed to perform the home exercise program (HEP) 3 to 4 times per week, 11% of respondents were instructed to perform HEP at least 1-2 times per week, and only 7% respondent instructed to perform HEP more than 6 times in a week. Data is represented in table 12.

Respondents also reported how often they were able to follow a home exercise program. 57% of respondents were able to perform the home exercise program more than 6 times per week, 7% of respondents were able to perform the home exercise program 5 to 6 times per week, 10% of respondents were able to perform HEP at least 3-times per week, 19% respondent able to perform HEP at least 1-2 times per week, and only 7% respondent not able to perform home exercise program. It shows that the majority of respondents can perform home exercise programs. Data is represented in table 13.

The results of regression analysis revealed a significant relationship (F 3.809, p 0.054, R2 0.037). This suggests that a caregiver's level of compliance can be predicted by the level of stress that he or she is experiencing. The level of compliance could also be predicted based on the level of stress and prescribed frequency of the home program. In the last, the value of Durbin Watson is 1.72, which means in this research, there is no autocorrelation problem and the variables are highly correlated with each other. (table 8).

The analysis of correlation was used to analyze the involvement as well as the strength of the relationship among the variables. A statistically significant relationship was found between the factor of parent and family problems and compliance score (p 0.027). This indicates that as parent and family problems increased, compliance with home exercise programs decreased. There were no significant correlations found between the other factors and the compliance score. Data is presented in table 9.

TABLE 1: Age distribution

		Frequency	Percent	Valid percent	Cumulative percent
Valid	20-29	09	9.0	9.0	9.0
	30-39	41	41.0	41.0	50.0
	40-49	41	41.0	41.0	91.0
	50 or older	9	9.0	9.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 2: Gender distribution

		Frequency	Percent	Valid percent	Cumulative percent
Valid	Male	38	38.0	38.0	38.0
	Female	62	62.0	62.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 3: Marital status

		Frequency	Percent	Valid percent	Cumulative percent
Valid	Single	12	12.0	12.0	12.0
	Married	88	88.0	88.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 4: Child age distribution

		Frequency	Percent	Valid percent	Cumulative percent
Valid	1-6 Years	22	22.0	22.0	22.0
	7-12 Years	25	25.0	25.0	47.0
	13-18 Years	19	19.0	19.0	66.0
	19-24 Years	17	17.0	17.0	83.0
	25 or older	17	17.0	17.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 5: Socioeconomic condition

		Frequency	Percent	Valid percent	Cumulative percent
Valid	Lower	61	61.0	61.0	61.0
	Middle	29	29.0	29.0	90.0
	Upper	10	10.0	10.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 6: Educational background

		Frequency	Percent	Valid percent	Cumulative percent
Valid	Middle or Low	23	23.0	23.0	23.0
	High	24	24.0	24.0	47.0
	Bachelors	37	37.0	37.0	84.0
	Masters	16	16.0	16.0	100.0
	Total	**100**	**100.0**	**100.0**	

TABLE 7: Educational background

Model Summary

R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
				R Square Change	F Change	df1	df2	Sig. F Change	
.193[a]	.037	.028	.49801	.037	3.809	1	98	.054	1.727

a. Predictors: (Constant), Stress b Dependent Variable: Compliance

TABLE 8: Regression analysis

Reliability statistics Stress	
Cronbach's alpha	**No of items**
0.737	52

TABLE 9: reliability analysis

Reliability statistics compliance	
Cronbach's alpha	**No of items**
0.720	8

TABLE 10: Correlation

Correlations

		Compliance	Stress
Pearson Correlation	Compliance	1.000	-0.193
	Stress	-0.193	1.000
Sig. (1-tailed)	Compliance	.	.027
	Stress	.027	.
N	Compliance	100	100
	Stress	100	100

TABLE 11: Frequency distribution of children's diagnoses

Diagnose	Frequency of Diagnoses (%)
Cerebral palsy	42.0
Down syndrome	17.0
Other	41.0
Total	**100.0**

TABLE 12: Frequency of subjects instructed to carry out a home exercise program

Times per week	Percentage
1-2 times per week	11.0
3-4 times per week	16.0
5-6 times per week	66.0
Greater than 6 times per week	7.0
Total	**100.0**

TABLE 13: Frequency of subjects to perform a Home exercise program

Times Per Week	Percentage
1-2 times per week	19.0
3-4 times per week	10.0
5-6 times per week	7.0
Greater than 6 times per week	57.0
Never	7.0
Total	**100.0**

DISCUSSION

The purpose of this study was to determine whether there was a relationship between stress and compliance in caregivers of children with disabilities. The results reveal that there is a significant statistical relationship between stress and compliance, suggesting that, in this study, a caregiver's level of compliance can be predicted by the level of stress that he or she is experiencing. These results are consistent with those of other studies examining stress experienced by parents of children with differing disabilities.[13,14] The factors studied have included age, gender, child age, marital status, socioeconomic status, and educational background. However, the degree to which these factors contribute to compliance is inconclusive. This study found that stress is another factor that decreases compliance.

It is important to incorporate home programs into the regular daily routines and activities followed by the family, such as bath time, playtime, and dressing. Additionally, emphasizing simplicity and minimizing the number of activities may also reduce stress and lead to better compliance.[15]

Stress is reported as an influential factor in adherence. The relationship between stress and adherence cannot be ignored. Increased stress is prevalent among families caring for a disabled child. Even though breeding and rearing a nondisabled child may be stressful for the mothers, it is inevitable for the mothers of children with disabilities to experience greater stress and emotional demands. Studies revealed that parents of disabled children had significantly higher levels of psychiatric symptoms and were more likely to indicate higher levels of depression and anxiety symptoms.[13,14,16]

The clinical implications of this study are important. If stress can be minimized, compliance with home exercise programs may increase in this population. Physical therapists working with families with a handicapped child can help prevent unnecessary stressful situations during and throughout physical therapy services.[17,18] Stress increases when there is a loss of a major functional skill such as walking, when modifications are needed to accommodate adaptive equipment for mobility, during transition to the educational environment, and during the terminal stages of the disease these are times that physical therapists should pay special attention and make great efforts to aid families in managing stress levels.[20]

The results of this study are based on the assumption that the caregivers answered the questions about compliance honestly. Research suggests that patient self-reports probably reflect an overestimation of compliance behavior. Therefore, it is possible that the caregivers reported greater compliance with the home exercise program than was actually carried out. Further research is needed to develop standardized ways to measure compliance with treatment regimens.

It is important to consider these results when developing home programs for parents with children with disabilities. Compliance with a home exercise program is critical to children with cerebral palsy and other debilitating diseases.

Unfortunately, compliance with home exercise programs is a problem for many caregivers

because of the demands that exist in their lives already. However, because caregiver involvement is critical to the success of therapy, physical therapists must identify caregivers with increased stress levels and recommend ways to reduce those stress levels.[21]

When establishing a home exercise program, physical therapists may need to consider the caregiver's needs as well as his or her day-to-day stresses to achieve the best possible outcomes. Considerations include the following: availability of personal time for the caregiver, inclusion of child or children in leisure activities, personal lifestyle, time management abilities of the caregiver, personal preferences for activities, geographic locations, means of transportation, and finances. Additionally, the caregiver's flexibility and receptiveness to identifying, acknowledging, and participating in stress reduction an important consideration.[22,23]

Suggestions for stress management reduction for caretakers appropriate to physical therapy include recommendations for regular exercise, autogenic training, imagery/visualization, breathing techniques, progressive relaxation exercises, and participation in any activity that the caregiver finds relaxing. Interventions may help to achieve better lifestyles both for themselves and their child. Education about the prognosis, aging with a disability, and expectations of an exercise program is important to prevent frustration and to keep their expectations reasonable. Coaching of the caregivers and consideration of the psychological status and expectations related to their children's future are important to achieve the best results in rehabilitation programs.[25]

However, caregivers of disabled children usually fail to cope with stress, and eventually, most of them get burned out. Lack of motivation, tiredness, and disappointment are inevitable during treatment. These adverse conditions may lead to exhaustion and burnout. The need for adherence to prolonged interventions, financial problems, special housing modifications, equipment needs, social isolation, and grieving reactions can contribute to stress and may increase exhaustion.[25,26] These results revealed that the caregivers do not give up home programs even if they are depressed or have anxiety. However, when they have difficulty overcoming stress and experience exhaustion, they fail to show treatment adherence.

CONCLUSION

The results of this study suggest that when instructing a home exercise program, physical therapists and rehabilitation professionals should consider the caregiver's emotional needs and mental health to enable adherence. Additionally, supporting the caregivers in coping with stress is an important consideration. If physical therapists only instruct caregivers on how to follow a home exercise program and do not address the stress levels of the caregiver, compliance may suffer. It is important that physical therapists not only treat the child but also educate and recommend ways for the caregiver to manage stress to maximize desired outcomes. Incorporating the home program into the daily routine might lead to better compliance, less exhaustion, and thus better adherence.

Conflict of interest: None

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