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CAREGIVER COMPLIANCE WITH PHYSICAL THERAPY HOME PROGRAM: A PILOT STUDY IN PEDIATRIC OUT-PATIENT CLINICS IN KUWAIT

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ABSTRACT

Background: Compliance depends on the caregiver and the health care professional committing to the same objectives. Compliance with the prescribed physical therapy (PT) home program is a significant contributor to treatment success.

Methods: One hundred caregivers were invited to fill in a questionnaire after the explanation of the procedure, and signing the consent form. The questionnaire explored factors affecting compliance including nature of the exercise, physical and emotional stresses on the caregiver, and the role of PT in teaching and counseling the caregiver.

Result: Ninety-one participants out of the 100 were committed to administering the exercises with their children. Despite this, there was a discrepancy in either the frequency of repeating the exercises per day or the content of the exercise program when compared with the exercise program prescribed by the therapist. Some of the primary reasons for these differences were the pain experienced by the child when exercising (71%), having other family commitments (57%), not having the time to administer the home program (37%), and lacking skills or equipment to administer the exercises (34%).

Conclusion: Adherence to treatment is a complex act that requires an understanding of treatment approach, having the confidence in one's skills to administer the unsupervised home program and the existence of a support system both in the hospital and at home that can provide aid when needed. It is the PT role to address all these issues when prescribing a home program to meet treatment objectives.

Keywords: Compliance, physical therapy, caregiver, Pediatrics, children with neurological conditions, exercise.

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INTRODUCTION

Compliance, or adherence, as it relates to health care is the extent to which a person's behavior coincides with a health care professional advice [1]. It is defined as performing the exercises as directed by the physical therapist (PT) in their mode, type, duration, and frequency [2]. The word compliance and adherence have been used interchangeably in this text to reflect the degree to which the caregiver can follow instructions given by the healthcare professional.

The success of home treatment with children depends on the caregiver compliance with the prescribed home program. The objectives are met by the development of a therapeutic alliance between caregivers and providers and end with an independent functioning child [3]. The achievement of these objectives does not come without the support of the caregiver [4,5]. However, those outcomes might not be achievable, or sometimes their efficacy is misjudged if the caregivers are non-compliant or do not realize their role in achieving successful outcomes.

Poor adherence to treatment is commonplace and may adversely affect results, efficacy and healthcare cost [3,6]. Compliance rates were recorded to be lower in children compared to adults [7] and were found to decrease as time goes by [6]. Factors such as chronicity of the disability, the complexity of the home program, child's age and the family lifestyle were recognized in the literature as barriers to compliance [8,9]. All these shortfalls may have serious and detrimental effects from the perspective of long-term management of children with neurological conditions (CNC).

Home program Exercises are prescribed to improve mobility, flexibility, strength, to prevent contractures and muscle wasting and to improve the quality of motor control. These exercises are essential to complement therapy. Carrying out exercises in the clinic is not sufficient, and the patient needs to continue to perform them regularly between clinic sessions, which is why compliance becomes an issue. Depending on the child's diagnosis, these programs could continue over a long period, and their therapeutic efficiency is dependent on the manner and the accuracy in which the caregiver administers the exercise to the child [8].

In Kuwait, CNC are referred to PT outpatient departments in the major governmental hospitals for rehabilitation. Treatment sessions vary in number depending on the condition, but usually, do not exceed 12. Patients are then followed on a regular basis by the therapist while the caregiver is administering the whole treatment at home. This is when the role of the caregiver is highlighted as being the core pillar upon which the success of the treatment relies. This is the first study in Kuwait that addresses adherence to the home program from a PT perspective. The current pilot study aims to explore the level of compliance among caregivers of CNC and investigates the factors underlying their compliance or lack of compliance. Though the study is conducted on neurological patients in Kuwait, it is anticipated that some of the findings will be adaptable to the general health community.

METHODS

Procedure and Participants

Two of the major governmental hospitals (Al-Farwaniya Hospital, and Al-Adan Hospital) were chosen to conduct the study. It was a qualitative cross-sectional survey, the opinion of caregivers on their experience with their physically disabled children was investigated. Ethical approval was obtained from Ministry of Health ethical committee and approval of the concerned hospitals was granted from the directors of the hospitals and the involved PT heads of departments. All the caregivers of CNC attending the clinic were approached and invited to participate in the survey. Following their approval, the procedure and information about the study were explained to them, and they were asked to sign a consent form. Caregivers were instructed to read the questionnaire and complete it without assistance. Data was collected over a period of six months (September 2005- March 2006).

Instrument

Questions were developed based on the literature reviewed and previous experience in the area. The questionnaire was piloted on four university staff and four caregivers. Content validity and the questionnaire reliability was tested at the pilot stage and modifications were made based on the findings. The replies of the pilot participants, and all of their comments were utilized to overcome problems in terminology or sequencing of questions. Neither the people who participated in the pilot nor their data were included in the main data results.

The questionnaire was divided into four sections: demographic information about participants and their children, factors that may affect compliance including nature of the exercise, physical and emotional stresses on the caregiver, and the role of PT in teaching and counseling the caregiver and how would that affect compliance.

Responses were obtained using Likert scale (strongly agree, agree, do not agree, strongly disagree, don't know).

Data analysis

Each participant was given an identification number, and no names were included in the analysis. The data was categorical measurement. All data was entered into a spreadsheet, and the results were analyzed using SPSS 23.

Descriptive analysis was used to report frequencies, and findings were displayed in tabular and graphic formats.

For the purpose of analysis, the authors have developed criteria for classifying compliance. The compliance score was divided into two categorical outcomes (compliance / non-compliance) as detailed in Table (1).

Table 1: Description of the level of compliance

Type of compliance	Meaning
Compliant	Caregiver administers exercise as regularly and as frequently as prescribed by the therapist.
Non-compliant	Caregivers were described as non-compliant if they: 1-Fail to administer the home program in the same manner taught to them (increase or decrease in number). 2- Do not administer the exercise

RESULTS

Description of study sample

Information was gathered from two of the major general hospitals in Kuwait. The caregivers of 100 children (44 boys and 56 girls) with a mean age of 2.3± 1.1 years participated in the study. Responders were asked to complete the questionnaire while in the department and return it before leaving the clinic. This data collection method resulted in 100% response rate. The age of the caregivers ranged between 17 - 59 years with most of the caregivers being between 30-39 years (40%). Ninety-six of the caregivers were females, 88% of the sample were married, 5% were single, and 7% were divorced. Thirty-two of the caregivers (32%) were unemployed; they were either retired or did not work at all. The educational level of the caregivers and other demographic data are further detailed in Table 2.

Table 2: Socio-demographic profile of the study participants

Item	Total n=100
Gender	
Caregiver	
Male	4
Female	96
Patients (children)	
Male	44
Female	56
Age	
Caregiver age	
17- 24 years	21
25-29 years	31
30-39 years	40
40-49 years	3
50-59 years	1
Not reported	4
Child's age	
<1 year	22
1-2 years	35
3-4 years	20
>4 years (up to 12 years)	20
Not reported	3
Marital status	
Single	5
Married	88
divorce	7
Educational level	
Illiterate	2
Elementary	9
Intermediate	16
High school	37
Diploma	23
University	9
Not reported	4

Factors contributing to compliance

Exercise

The exercise was either performed by the mother (57%), both the mother and the nanny (20%) or shared between the father and the nanny (18%). However, even if the father or the nanny are administering exercise, the mother was the main person providing the supervision as reported by 85% of cases.

Factors affecting compliance were explored regarding the number of exercises that should be administered by the caregiver in comparison to the actual number of exercise the caregiver was, in fact, administering and also regarding the frequency of repeating the home program per day.

Table 3: Description of caregivers compliance to number of exercise in home program

Home program (i.e. No. of exercise prescribed by the therapist)	% of caregivers who should administer this number of exercises	Actual % of caregivers administering this number of exercises
1 exercise	4%	6%
2 exercise	12%	20%
3 exercise	22%	29%
4 exercise	9%	15%
5 and more exercises	36%	21%
The caregiver did not know the number of exercises they need to do	17%	-

The total number of caregivers who were administering exercise to their children was 91% (adding up the percentages in the last column). To have 100% compliance, column 3 in Table 3 must be identical to column 2. However, as could be seen in the last column of the table, there was differences between what the caregivers were asked to administer in comparison to the actual number of exercise they are administering. For example, 22% of the sample were asked to administer 3 exercise to their children. However, 29% reported that they were administering 3 exercise with an increase of 7%. Additionally, 9% of the sample were requested to administer 4 exercise to their children. However, findings reveal that 15% of the sample were administering four exercises with an increase of 6%. According to the findings, the discrepancy increased as the number of exercises escalated.

Additionally, an alarming 17% of caregivers did not know how many exercises they need to administer to their children and end up administering no exercise at all or administering any set number of the exercise of their choice.

According to the classification developed by the authors (Table 1), and by calculating the discrepancy between expected (as prescribed by PT) and actual execution of exercise by a caregiver, the non-compliance was 38% hence the compliance rate was 62%.

Compliance was also explored regarding the frequency of repeating the home program during the day (Table 4). Caregivers were asked to administer the home program and repeat it several times a day ranging between 1 time to more than five times a day.

Table 4: Description of caregivers compliance to the frequency of administering home program per day

Home Program: Number of times the exercise program should be repeated per day	% of caregivers who should administer this number of sessions per day	% of caregivers who administered this number of sessions per day
1 time	4%	10%
2 time	19%	31%
3 time	26%	19%
4 time	6%	9%
5 and more times	23%	12%
Did not know how many times the exercise should be repeated	22%	-

Inconsistency was also apparent in the frequency of repeating the prescribed home program per day. For example, only 19% were expected to repeat the home program twice a day, however, 31% were repeating home program twice a day with a discrepancy of 12%. Additionally, 26% of caregivers were instructed to repeat the home program three times a day. However, 19% were repeating the home program three times daily with a discrepancy of 7%.

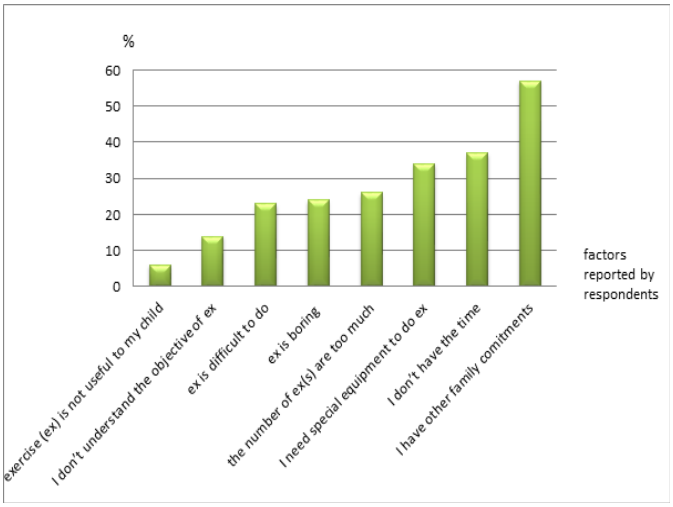
The issue of not knowing the number of the required repetitions was also clear in this section. Twenty-two percent (22%) of caregivers did not know how many times they have to administer the home program to their children.

According to the classification developed by the authors (Table 1) and by calculating the discrepancies between column 2 and 3, the non-compliance was 39% hence the compliance rate was 61%.

Factors related to the caregiver

Caregivers were allowed to choose as many applicable factors that may limit the caregivers' commitment to administering exercise. Results are reported in Figure (1).

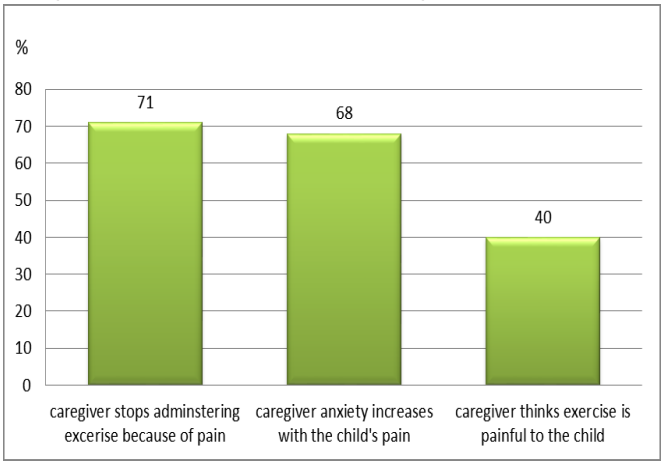
Figure 1: Factors limiting caregivers commitments to administering home exercise



Pain

The pain as a factor in determining compliance was investigated, and the results are displayed in Figure (2).

Figure 2: Pain as a factor in caregivers compliance



Home program education as a factor in compliance

The PT role was investigated through questions that aimed at exposing the quality of education provided to the caregiver. Ninety-three percent (93%) of therapists demonstrated the exercise in front of the caregivers to make it less problematic for them to administer it at home. Eighty-nine percent (89%) of the caregivers were satisfied with the way the therapists explained the exercise to them. Eighty-five (85%) of the caregivers reported that PT had follow-up sessions, and had discussed difficulties encountered when administering the home program. Sixty-nine percent (69%) of caregiver expressed their satisfaction with the follow-up they were receiving from the therapists.

Seventeen percent (17.3%) did not see a clear role of the therapist with a home program.

A large proportion (46%) of the sample either did not receive an instruction sheet (leaflet) or any other visual aid supplement. Out of those who received a leaflet with the exercise, 54% reported that the exercise leaflet given to them contained sufficient details on the nature of the exercise and how it should be performed, which made it easy for the caregiver to understand the exercise.

DISCUSSION

The study used a self-administered questionnaire to examine the compliance of 100 caregivers to a home-based exercise program. The questionnaire explored the nature of the exercise, the role of both caregiver and PT as contributing factors to compliance.

Barriers to compliance

Exercise

Based on the classification developed by the authors, caregivers were considered non-compliant in three conditions:

- if they fail to do the home program
- if they administered fewer exercise than prescribed
- if they administered more exercise than prescribed.

In the current study, compliance was 61% when the frequency of repeating the home program per day was examined, and it was 62% when adhering to the prescribed set number of the exercise was investigated. The findings demonstrated comparable levels of compliance when compared to the literature; 47-76 % [6] and 76% [10].

Interestingly, increasing the number of exercise in the home program seems to result in less adherence. The smaller the number of the exercise, the higher was the adherence. The greater the number of exercises, the fewer caregivers, seem to do. When parents were asked to supervise only one exercise, compliance was almost 100%, but when the number of exercises was increased to five, 11% of caregivers did not perform all the exercise. This could be due to the difficulty in remembering the "how" of doing the exercise and the time it may consume from the caregiver on other family and life commitments. However, the findings of this study are observations based on caregiver reporting; it is worthy of exploring in more robust experimental approach.

Pain

The study highlighted the link detected between the amount of pain felt by the child and the increase in the caregiver's anxiety. Seventy-one percent of caregivers reported that they might stop administering the home program as pain augments. Moreover, 40% of the caregivers doubt the efficacy of the exercise when it causes pain to their children. These could be principal causes for decreased adherence by caregivers. Rone-Adams et al [11] reported a significant statistical relationship between the stress experienced by parents when supervising the home program and compliance and recommended more involvement of PT in addressing and preventing this unnecessary stress to improve the rate of compliance.

Caregiver

The size of the family and having other family responsibilities, lack of time, and lacking specialized tools to do the exercise were the highest reasons reported by the caregiver to limit full compliance. Findings were in accordance with other studies [8,11]. Despite all of that, caregivers in the current study have reported less stress and have attributed that to the presence of the nanny who can exchange roles and provide assistance to the parents when needed.

Caregivers' education and counseling

The amount of counseling and support provided by the therapist was reported by the caregiver to be the clear and facilitated performance of the home program without the need for direct supervision. Although over 80% of the sample were content that the therapist has demonstrated exercise in front of them and they were confident in their skills when executing the home program, around half the sample were not satisfied as they were not given brochures (exercise instructions) to help them remember the home program. To establish effectiveness and ensure adherence to the home program, efforts should be made to ensure that exercise instruction sheet is available in all hospitals and is being utilized by therapists.

The strategies to improve adherence to physical therapy treatment are likely to be broad in spectrum. Therefore it is important to understand the multidimensional nature of non-adherence. Reviews identified that psychological interventions, educational interventions, self-management strategies, spouse or family involvement and formal patient commitment using signed agreements were promising interventions worthy of further investigation [6].

Implication of the study

The current study has implications for PT practice that could be summarized in the following: practitioners need to take into consideration the number of exercises given to patients as findings showed that greater number of exercise could minimize compliance. Moreover, requesting caregivers to remember exercise and administer them without having a brochure or some sort of aid to help them recap could stress caregivers. Additionally, the pain seems to be a barrier to compliance as pain experienced by the child while exercising, is regarded one of the major concern to the caregiver.

Having a child with chronic illness in the family constitute a barrier to the family's normal life and poses an ongoing challenge to caregiver abilities. Findings of the current study demonstrated the need to address the coping strategies, the emotional and the physical stresses that the caregiver goes through, which could be underlying the limited compliance. Additionally, the current work has highlighted the need to incorporate another health professional in the treatment plan to deal with the emotional stresses, i.e., social worker or possibly a psychologist to refer to for consultation.

Limitation

The study used one method of exploring compliance and did not employ any form of monitoring actual performance at home. Adding more than one method (diary or interview) could have shed more light on the caregiver commitment with a home program.

CONCLUSION

Adherence to treatment is a complex act that requires an understanding of treatment approach, having the confidence in one's skills to administer the unsupervised home program and the existence of a support system both in the hospital and at home that can provide aid when needed. It is the PT role to address all these issues when prescribing a home program to meet treatment objectives. The current work has contributed to understanding the nature of the interaction between therapists and caregivers and identified some of the challenges facing caregivers and suggested areas of improvement that can be implemented to facilitate successful rehabilitation program.

Given all of these findings, it would be interesting to compare the results of the current study in similar setting after addressing the issue of caregiver stresses resulting from child's pain during exercise and deficiency of brochures.

The future longitudinal study is needed to monitor the long term changes in compliance levels.

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Conflict of interest

The authors declare no funding or conflict of interest related to this study; the authors alone are responsible for the content and writing of the article.

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Appendix

The study aims to measure the caregiver compliance to physical therapy home based program for children with special needs i.e neurological manifestations. The authors are seeking to explore the reasons for non-adherence, and explore the role of both the caregiver and the health provider in home program commitment.

Please answer the following questionnaire by placing a tick (√) in the box provided. Filling the questionnaire will not take more than 10 minutes from your time.

Your honesty and openness are really appreciated. We would also like to emphasize that all information collected will be treated with the strictest confidence and no individual name or personal information will be identified in the final report.

Thank You

Answer all questions by placing a tick (√) in the appropriate space

1. Child's age

Less than one year	1-2 years	3-4 years	More than 4 years

2.a Child's gender

Male	Female

2.b. What is the order of child between siblings?.....

3. Age of caregiver supervising home program

Less than 25 years	25-29 years	30-39 years	40-49 years	50-59 years	60-69 years	70 and more years

4. Gender of caregiver

Male	Female

5. Educational level of caregiver

Illiterate	Elementary	Intermediate	High school	Diploma	University degree	Higher degree (master, PhD)

6. Social status

Single	Married	Widow	Divorced

7. Salary

Less than 500 KD	500-1000 KD	1000-1500 KD	1500-2000 KD	More than 2000 KD

8. Name of Hospital:

Farwaniah	Adan

9. Do you do the prescribed exercise program for your child at home?

Yes	No

If you answer yes:

Answer the following questions:

9.a Who is doing the home program?

Mother	Father	Maid	Mother &Maid	Mother & Father	Maid & Father	Others

9.b If there is more than one person administering the exercises to the child, please answer this section

Who is the main person administering exercises to the child?

Mother	Father	Maid	Others

10. Please complete this table about the number of the exercise:

Item	1	2	3	4	5 and more	Don't know
How many exercises you are supposed to do at home?						
How many exercises you are actually doing at home?						
How many times you are supposed to repeat the exercise in a day?						
How many times you are supposed to repeat the exercise in a week?						
How many times you are actually repeating the exercise in a day?						
How many times you are actually repeating the exercise in a week?						

11. Please read the following items and indicate the degree of agreement by placing (√) in the space provided:

a- Exercise

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
Prescribed exercises are long and boring					
Home program exercises are usually difficult to do					
Number of exercises is too much					
Exercises need equipment and I cannot provide them at home.					
I don't have time to do exercises					
Goals of exercises are not clear					

b- Pain

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
Exercises may cause pain to my child					
I stop the exercises when my child feels pain					
I feel anxious and stressed when my child feels pain					
I believe that pain is one of the reasons that prevent me from doing home program					

c- Parents and caregivers

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
Sometime I forget to do exercises because of family commitments					
I can't do exercises the same as the physical therapist					
I need supervision when doing home program					
I'm not convinced that exercises could help my child to improve					
I'm afraid that exercises will increase my child's symptoms and/or disease					
I'm not satisfied with physical therapy program					
I ask the nanny to do home program a lot					
Exercises need a lot of effort that I can't tolerate					
My job takes a lot of effort					
My spouse doesn't understand my child's special needs					
I can't provide enough time to do exercises					
I can't take special leave to supervise home program					

d. Parents and caregiver's education

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
My physical therapist explained how to do home program					
My physical therapist demonstrated exercises in front of me					
My physical therapist gave me brochures on home program					
Brochures were not clear					
There was regular follow up sessions with my physical therapist to revise the way I do the exercises at home					
My physical therapist simplified exercises if they were difficult					