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To cite this article: Ayşe Ünal, Filiz Altuğ, Gönül Kilavuz, Güzin Kara & Uğur Cavlak (2018): Expectations of patients with hemiparesis from physiotherapy programme: concordance among patients, patients' caregiver and physiotherapists, European Journal of Physiotherapy, DOI: [10.1080/21679169.2018.1447012](https://doi.org/10.1080/21679169.2018.1447012)

To link to this article: <https://doi.org/10.1080/21679169.2018.1447012>



Published online: 06 Mar 2018.



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Expectations of patients with hemiparesis from physiotherapy programme: concordance among patients, patients' caregiver and physiotherapists

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ABSTRACT

Purpose: The aim of this study was to examine the agreement between physiotherapists (PTS), patients and caregivers about the physiotherapy of patients with hemiparesis.

Materials and methods: Fifty-two patients with hemiparesis ($M = 24$, $F = 28$), caregivers ($N = 52$) and PTs ($N = 52$) who applied for the physiotherapy programme were interviewed. Demographic and clinical characteristics of the patients were recorded. A questionnaire composed of six questions was used to describe the expectations of the PTs, caregivers and patients about the physiotherapy programme.

Results: The Kappa calculator revealed a statistically moderate level of agreement between PTs and caregivers ($K = 0.532$, $p = .0001$), patients and caregivers ($K = 0.496$, $p = .0001$) and PTs and patients ($K = 0.401$, $p = .0001$) regarding the expectations of physiotherapy programme.

Conclusion: Expectations of the patients and caregivers must be considered for rehabilitation; hence, participation in the therapy and efficacy of the physiotherapy programme will increase. Consequently, we believe that the expectations of the patients and caregivers should be considered by the PTs when preparing a treatment programme for patients with hemiparesis.

ARTICLE HISTORY

Received 7 October 2017
Revised 19 February 2018
Accepted 25 February 2018
Published online 6 March 2018

KEYWORDS

Caregivers; concordance; expectation; hemiparesis; physiotherapist

Introduction

Following hemiparesis that develop due to cerebrovascular problems, various systemic complications may arise in addition to neurological complications [1]. These complications pose an obstacle for patients in performing their daily living activities [2]. In addition, factors such as shamefulness, lack of motivation, insufficiently informed and rejected by people around influence individuals to gain independence and to be protected negatively [3].

The physiotherapy programme of the patients with hemiparesis is a team effort [4]. Considering the needs and expectations of the patients from the treatment by determining their priorities using an organised treatment programme decreases long-term disability and impairment rates of patients with hemiparesis [5]. This, in turn, is important for successful rehabilitation. Thus, caregivers want to be informed about the physiotherapy programme employed and to learn about other additional treatments.

Physiotherapists (PTs) plan a patient-specific treatment by evaluating what the patient can do and cannot do objectively and apply. A directly proportional increase was found in the expectations of both the families and PTs after the completion of the treatment [6].

Patients and their caregivers may request from PTs to apply treatment methods other than the treatments favoured by the PT, which they learn from different publications while ignoring the current status to the patient, to obtain the best results. However, PTs support this programme by employing

the most appropriate treatment, with recommendations for or application of additional treatments when necessary.

Patient's participation and motivation to the treatment increase because how the programme was included in the physiotherapy programme was determined based on the common aims of the patients and their caregivers [7]. This, in turn, allows the PT to use the treatment period more effectively. Moreover, treatment expenditures decrease because the patient achieves the desired functional level within a shorter time period.

This study aimed to investigate the concordance among expectations of patient, caregiver and PT about the physiotherapy programme of patients with hemiparesis.

Materials and methods

This study was performed at the Department of Neurological Rehabilitation of Pamukkale University between January 2014 and January 2015. Fifty-two patients with hemiparesis, their caregivers ($N = 52$) and PTs ($N = 52$) volunteered to participate in the study. The first-degree relative who took care of the patient was recognised as the caregiver. All the patients with hemiparesis and their caregivers were informed about the mechanism of cerebrovascular diseases, their effects on the human body and neurodevelopmental status and the contents of the physiotherapy programme. Thereafter, informed written consents were obtained. The experienced PT gave information about the disease and physiotherapy

programme to each participant before starting the programme. The questionnaire was administered face-to-face to patients, caregivers and PTs by the same PT with 5-year experience in neurological rehabilitation. The study was approved by the Ethics Board Committee of Pamukkale University Medical Faculty (Ref No:17, Date:17.12.2013), and ethical principles laid down in Declaration of Helsinki have been followed.

Stable patients with hemiparesis who were 20 years old or older and without cognitive (had 8 points and higher in the Hodkinson Mental Test) and communication problems, without accompanying neurological problems and received physiotherapy at least for 4 weeks were included in the study [8].

Evaluation methods

Clinical data of the patients that participated in the study and demographic data of patients' caregivers and PTs were recorded. The modified Rankin scale was used to evaluate the impairment status. This scale is graded between 0 and 6 points. As the point increases, the impairment rate also increases. Those who received 1 and 2 points live independently, and those who received 3 points and higher live dependently [9,10].

The level of independence of patients in daily living was evaluated using the functional independence measure (FIM). This scale includes 13 physical and 5 socio-cognitive statuses and evaluates within the range of 18–126 points. A higher score means higher independency level. The FIM is composed of a 7-stage scale that evaluates self-care, sphincter control, transfer, motion, communication, social relationship and cognitive status [11,12].

The assessment form consisted of six questions created by Kavlak et al., which asked about the expectations and opinions of the individual with hemiparesis, caregiver and PT with regard to the physiotherapy programme employed. Moreover, questions at the beginning of the questionnaire are concerned about the general information of the individual with hemiparesis, caregiver and PT followed by questions on the general health and treatment employed [13].

Statistical analysis

Power analysis was performed, which revealed 90% power obtained with 95% reliability when 52 patients, 52 caregivers and 52 PTs were included in the study. Data were analysed using the SPSS 18.0 software. Continuous variables were given as mean \pm standard deviation, and categorical variables were given as number (*n*) and percentage (%). The significance threshold was determined to be $p < .05$. Kappa coefficient (*K*) was used to investigate the concordance of the expectations of patients with hemiparesis, caregivers and PTs. The kappa coefficient ranged between 0 and 1. Cohen suggested that the kappa coefficient result will be interpreted as follows: ≤ 0 , agreement; 0.01–0.20, none to slight; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; and 0.81–1.00, almost perfect agreement [14,15].

Table 1. Demographics of individuals with hemiparesis.

Variables	Mean \pm SD	Min–Max
Age (year)	49.76 \pm 18.02	21–84
Therapy duration (week)	29.73 \pm 38.54	5–156
Educational status	<i>n</i> (%)	
Unliterated	1 (1.9)	
Literated	6 (11.5)	
Primary school	22 (42.3)	
Secondary school	3 (5.8)	
High school	14 (26.9)	
University	6 (11.5)	

SD: Standard deviation.

Table 2. Clinical characteristics of individuals with hemiparesis.

Variables	<i>n</i> (%)
Hemiparesis aetiology	
Ischemia	24 (46.2)
Tumour	13 (25)
Trauma	7 (13.5)
Haemorrhage	4 (7.7)
AVM	4 (7.7)
MRS	
1	5 (9.6)
2	11 (21.2)
3	18 (34.6)
4	14 (26.9)
5	4 (7.7)
Using assistive devices	
Walking stick	7 (13.5)
Shoulder strap	5 (9.6)
Walker	5 (9.6)
Tripod	4 (7.7)
AFO	4 (7.7)
Forearm supported walking cane (Canadian)	3 (5.8)
None	24 (46.2)
FIM	Mean \pm SD
Motor score	62.88 \pm 22.41
Cognitive score	32.48 \pm 3.68
Total score	95.36 \pm 24.44
	Min–Max
	14–91
	18–35
	41–126

MRS: Modified Rankin Scale; FIM: Functional Independence Measure; AFO: ankle-foot orthosis; AVM: arteriovenous malformation.

Results

The mean age of the patients with hemiparesis ($F = 28$, $M = 24$) was 49.76 ± 18.02 years, and the mean duration of physiotherapy was 29.73 ± 38.54 weeks (Table 1). The mean age of the caregivers was 45.03 ± 10.51 years. The mean age of the PTs was 27.25 ± 2.77 years, and their mean professional time was 4.84 ± 3.10 years. Clinical data of the patients are given in Table 2.

Investigation of the causes of hemiparesis revealed cerebral ischaemia in 46.2% ($n = 24$) of the patients, tumour in 25% ($n = 13$), trauma in 13.5% ($n = 7$), cerebral haemorrhage in 7.7% ($n = 4$) and arteriovenous malformation in 7.7% ($n = 4$) (Table 2).

Results of the questionnaire analysis on investigating the expectations of patients, caregivers and PTs about treatments of the patients are as follows: in the descriptions of the patients and caregivers about the general health of the individuals for whom treatment was applied, 28.8% ($n = 15$) of the patients, 36.5% ($n = 19$) of the caregivers and 44.2% ($n = 23$) of the PTs defined health of the patients as 'good', and concordance between the patient and their caregivers was 21.2% and that between the patient and PT was 9.6%. A statistically moderate concordance of 21.2% was found between caregivers and PTs ($K = 0.373$, $p = .0001$) (Table 3).

Table 3. Distribution of ideas belonging to the patients, caregivers, and physiotherapists.

Variables	Patient (n = 52) n (%)	Caregiver (n = 52) n (%)	PT (n = 52) n (%)	Patient-caregiver concordance n (%)	Patient-PT concordance n (%)	Caregiver-PT concordance n (%)
Definition of health						
Excellent	2 (3.8)	–	–	–	–	–
Very good	8 (15.4)	12 (23.1)	6 (11.5)	6 (11.5)	3 (5.8)	4 (7.7)
Good	15 (28.8)	19 (36.5)	23 (44.2)	11 (21.2)	5 (9.6)	11 (21.2)
Moderate	17 (32.7)	18 (34.6)	18 (34.6)	9 (17.3)	6 (11.5)	12 (23.1)
Bad	10 (19.2)	3 (5.8)	5 (9.6)	2 (3.8)	2 (3.8)	2 (3.8)
Awareness about treatments						
PTR	13 (25)	13 (25)	7 (13.5)	9 (17.3)	7 (13.5)	7 (13.5)
Medical	1 (1.9)	1 (1.9)	–	0 (0)	–	–
Medical + PTR	26 (50)	37 (71.2)	45 (86.5)	21 (40.4)	26 (50)	37 (71.2)
No idea	12 (23.1)	1 (1.9)	–	0 (0)	–	–
Thoughts on treatment compliance						
Yes	33 (63.5)	44 (84.6)	52 (100)	30 (57.7)	33 (63.5)	44 (84.6)
No	2 (3.8)	–	–	–	–	–
No idea	17 (32.7)	8 (15.4)	–	3 (5.8)	–	–

PT: Physiotherapist; PTR: physical therapy and rehabilitation.

When the treatments received by the patients were investigated, 50% ($n = 26$) of the patients, 71.2% ($n = 37$) of the caregivers and 86.5% ($n = 45$) of the PTs responded 'medical treatment and physiotherapy'. A concordance of 50% and 71.2% was found between the patient and the PT, and between the caregivers and the PT, respectively. A statistically weak concordance of 40.4% was found between the patient and their caregivers ($K = 0.267$ and $p = .003$) (Table 3).

Furthermore, 63.5% ($n = 33$) of the patients, 84.6% ($n = 44$) of the caregivers and 100% ($n = 7$) of the PTs believed that the physiotherapy programme was appropriate. A concordance of 84.6%, 63.5% and 57.7% was found between the caregivers and the PT, between the patient and the PT, and between the patients and their caregivers, respectively (Table 3).

In addition, 48.1% ($n = 25$) of the patients, 42.3% ($n = 22$) of the caregivers and 25% ($n = 13$) of the PTs expressed their targets as 'assisted/unassisted walking'. Concordance between the patient and the caregiver was 32.7% and that between the patient and the PT was 19.2%. Within the scope of all expectations, statistically moderate concordances exist between the caregiver and PT ($K = 0.532$, $p = .0001$), between the patient and the caregiver ($K = 0.496$, $p = .0001$) and between the patient and the PTs ($K = 0.401$, $p = .0001$) (Table 4).

Regarding the application of additional treatments to the patient, 17.3% ($n = 9$) of the patients, 42.3% ($n = 22$) of the caregivers and 38.5% ($n = 20$) of the PTs declared that more intensive physiotherapy should have been applied. A concordance of 9.6% was found among the patient and the PTs, and a concordance of 28.8% was found between the caregivers and PTs. On the contrary, a concordance of 15.4% was found between the patient and the caregiver, and a statistically weak concordance was found between them regarding additional therapies ($K = 0.307$ and $p = .0001$) (Table 4).

Generally, 36.5% ($n = 19$) of the patients and 42.3% ($n = 22$) of the caregivers and PTs considered the applied physiotherapy programme as 'good' in terms of contents. Concordance was 23.1% between the patient and the caregiver and 17.3% between the patient and the PT. However, the concordance between the caregiver and the PT was

28.8%, and a statistically weak concordance was determined between them ($K = 0.373$, $p = .0001$) (Table 4).

Discussion

The results obtained from this study indicate differences in terms of expectations regarding the physiotherapy programme between patients, caregivers and PTs. Patients and caregivers reported more expectations than the PTs because the PTs could think more realistically than the patients and caregivers.

Only one study on the physiotherapy programme of children with cerebral palsy was conducted [13]. Hence, we performed the present study on patients with hemiparesis to fill this gap in neurorehabilitation. The biggest strength of our work is that this is the first study in this area.

Holliday et al. studied 202 stroke survivors to determine agreement between rehabilitation goals of patient and health professionals. This study found a 60% agreement [16]. In our study, this rate is lower than that of Holliday, and a moderate concordance was found among the patients, caregivers and PTs.

Many patients with a history of stroke and their caregivers do not have sufficient knowledge to maintain physiotherapy programme at home [17]. A competent and well-informed caregiver has an important role in the development of mental and physical health and socialisation of the individual with a history of stroke [18,19]. For training of the patients with hemiparesis and caregivers, different training methods such as individual education, meetings for caregivers to benefit from experiences of each other and educational leaflets can be used [20–22].

Many studies emphasise that a treatment plan should be prepared by evaluating the patient as a whole and including caregivers, even the post-discharge living environment and external support, so that the applied treatment programme can be successful [23–25]. Although we informed the patients and caregivers about the mechanism of cerebrovascular illness at the beginning of the physiotherapy programme, effects of the disease on the daily life, contents of the physiotherapy programme and concordance between

Table 4. Details regarding of the expectations of treatment, additional therapies, and content of physiotherapy programme.

Variables	Patient (n = 52) n (%)	Caregiver (n = 52) n (%)	PT (n = 52) n (%)	Patient-caregiver concordance n (%)	Patient-PT concordance n (%)	Caregiver-PT concordance n (%)
Expectations of treatment						
Assisted/unassisted walking	25 (48.1)	22 (42.3)	13 (25)	17 (32.7)	10 (19.2)	10 (19.2)
Supported/unsupported standing	3 (5.8)	3 (5.8)	5 (9.6)	1 (1.9)	3 (5.8)	2 (3.8)
Supported/unsupported sitting	1 (1.9)	6 (11.5)	8 (15.4)	1 (1.9)	1 (1.9)	6 (11.5)
Independence in daily living activities	16 (30.8)	15 (28.8)	10 (19.2)	10 (19.2)	8 (15.4)	9 (17.3)
Increased balance and postural control	7 (13.5)	6 (11.5)	16 (30.8)	5 (9.6)	6 (11.5)	6 (11.5)
Additional therapies						
Not necessary	24 (46.2)	10 (19.2)	6 (11.5)	8 (15.4)	6 (11.5)	4 (7.7)
PTR	9 (17.3)	22 (42.3)	20 (38.5)	8 (15.4)	5 (9.6)	15 (28.8)
Speech therapy	2 (3.8)	1 (1.9)	2 (3.8)	1 (1.9)	1 (1.9)	1 (1.9)
Psychosocial support	3 (5.8)	11 (21.2)	15 (28.8)	1 (1.9)	2 (3.8)	10 (19.2)
Surgical treatment	5 (9.6)	4 (7.7)	2 (3.8)	4 (7.7)	2 (3.8)	2 (3.8)
Occupational therapy	–	–	3 (5.8)	–	–	–
Use of assistive devices	9 (17.3)	4 (7.7)	4 (7.7)	1 (1.9)	1 (1.9)	2 (3.8)
Content of physiotherapy program						
Excellent	7 (13.5)	7 (13.5)	4 (7.7)	5 (9.6)	3 (5.8)	3 (5.8)
Very good	17 (32.7)	21 (40.4)	21 (40.4)	12 (23.1)	8 (15.4)	12 (23.1)
Good	19 (36.5)	22 (42.3)	22 (42.3)	11 (21.2)	9 (17.3)	15 (28.8)
Moderate	8 (15.4)	2 (3.8)	5 (9.6)	0 (0)	2 (3.8)	1 (1.9)
Bad	1 (1.9)	–	–	–	–	–

PT: Physiotherapist; PTR: physiotherapy and rehabilitation.

patients, caregivers and PTs was moderate in terms of their priorities for treatment.

The level of interest of individuals with a history of stroke with regard to the contents, methods and effectiveness of the physiotherapy programme, education level, which is an important influencing factor and comprehensible and sufficient information that PT will make about the rehabilitation are also essential for patients' participation and the effectiveness of the physiotherapy programme [26,27].

Green et al. indicated that the caregivers should be encouraged to question their priorities and to set realistic goals, as well as informing the patient about the disease and treatment to achieve success in the physiotherapy programme [28]. Similarly, Watkins et al. emphasised that the caregiver's level of education and high awareness were important factors in physiotherapy programme after discharge [29]. Both the studies stated that as much as the patient, the motivation of the caregiver should be high to attain a successful physiotherapy programme. In our study, we found weak concordance between the caregiver and the PT, when they were asked about the effectiveness of physiotherapy programme.

Therefore, to eliminate this deficiency and encourage caregiver participation in the treatment during the rehabilitation process, our study found that education should be continued after discharge and caregivers should increase their contact with the PTs to apply treatments applicable to the patient at home consciously.

A limitation of our study was that only the participants who were admitted to the physiotherapy programme in the hospital were included in the study. We believed that further research involving more participants treated not only in hospital but also at home is needed.

Participation and awareness of patients with hemiparesis and their family to the treatment potentiate the effectiveness of the physiotherapy programme [30]. Information about the content and effectiveness of the treatment which both the

patients and caregivers receive from PTs following the stroke enables them to attain easily the goal of the physiotherapy which they decided together with their PTs. Otherwise, privileged goals could create an interactional dilemma for clinicians when they were incompatible with the objectives, attitudes and perceived capacity of patients and their caregivers [5]. In conclusion, physiotherapy goals decided together with the patient significantly contribute to motivation and rate of recovery, and it should be considered during the treatment process.

Patients' needs were determined in our study with questions such as requests for additional treatment of PTs and caregivers, expectations from the treatment and effectiveness of the treatment. We believed that caregivers should cooperate with PTs during the rehabilitation process and should receive informative education about the patient status to make their caregivers aware of the disease, to find the most appropriate treatment option, to apply the treatment at home effectively and properly and to obtain better results from the treatment programme.

The physiotherapy programme of patients with hemiparesis should be performed with teamwork. The patients are at the heart of this team. Considering the needs and expectations of the patient from the treatment by determining their priorities using an organised treatment programme decreases long-term disability and impairment rates of patients with hemiparesis.

Acknowledgements

The authors sincerely thank all the patients, caregivers and PTs who participated in this study.

Disclosure statement

The authors report no conflict of interest.

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