Parkinson's Disease Follow Up Self-Assessment Scale

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Abstract

Parkinson's disease is a neurodegenerative progressive disorder end with independency for many years at late life, leading to great burden on patient and family life. The available treatment is symptomatic focused on improving life quality of the patient and it's in need for good communication with the physician.

So far there is no easy and practical way for follow up, thus we've designed the Parkinson's disease follow up self-assessment scale aiming to detect ON and OFF time, it's include PD manifestations, medications and medications adverse effects filled out by the patient family at home in order to mailing it to the physician, and intend to testing it by comparing the performance of patient family with expert staff in using the scale at hospital for 24 hours. Then enquiring about difficulty of using the same scale at home.

A 44 PD patient were completed the study. All items accuracy filling out was 93.4% in compare to expert staff. Its mean degree of difficulty was 4/10 and among patients families only 29.54% consider it difficult to use. The ON and OFF time was detected precisely in 92.2% by follow up physician. The proposed scale is precise in detection ON an OFF time and not difficult to use.

Keywords: *health; patient; self-assessment scale; disease*

Introduction

Per neurodegenerative disorder Parkinson's disease (PD) prevalence ranked next to Alzheimer's disease[1]. Worldwide about 10 million people are living with PD[2]. Although it's progressive, the parkinsonians life is slightly shorter than general population[3] and survive approximately 10.3 years from onset[4] but more than half of patients will lose the ability to live independently and become in need for secondary care after 5 years of onset[5].

Moreover after several years of L-dopa treatment the patients eventually present with more complications mainly motor fluctuations[6] and dyskinesia particularly young patients[8] leading to deterioration of patient life and rising caregiver burden[7] necessitating frequent medication adjustment. To delay motor fluctuations progression [9] each patient needs best regimen therapy, and in order to improve regimen efficacy an early detection of motor fluctuations is essential [10].

Consequently management of Parkinson's disease is complex with early involvement of neurological or elderly services. PD Patients significantly had more emergency unit visits and physician consultation mainly attributed to medications response[11].

Till now the main parameter to evaluate therapeutic efficacy is ON and OFF time[10]. Thus, obtaining precise timing of ON and OFF is necessary for providing optimal therapeutic regimen for each patient individually [12]. Currently, to assemble such data the available methods consists of either self-reporting diaries[13] or Inertial Sensor[14]. Both are either not always available or difficult to perform. While Unified Parkinson's disease Rating Scale [15] is suitable for staging and needs expert supervision.

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Most of guideline encourage the participation of PD patient in judgements about their own care and nessisate the alerting of patient and family members about PD disorder and medications problems [9]. The Shared decision making practice is offering an opportunity of treatment preferences to the patient including therapeutic regimen[16]. PD had its impact on patient daily life activities (drinking, swallowing, dressing, walking etc.)[15]. And practically the patient and his family are more familiar with the patient daily difficulties, so they can provide precise information about the patient condition. Hence engagement of patient can be expanded to include gathering information about his condition which may make a change in regimen selection.

At early stage of PD it's important to decide when to initiate and electing suitable medication and follow up is vital for validation of effectives of regimen. While in later stages a best regimen selection is individual and may requiring a secondary care and specialist services. So follow up of PD patients is in need for effective way of communication with the clinicians. Hence we aimed to design and testing a simple scale filled out at home by the PD patient himself or one of his family member to be useful for follow up even without patient attendance.

Method

The proposed scale designed to follow PD manifestations and adverse effects of medications each hour in relation to time of medication intake, meal and sleep time. The evaluation of each item relying on patient difficulty in performing usual life activities. Basically the system of scaling estimate the level of difficulty in performing each activity considering a value of (+ = ON) when patient finish the task normally or Have difficulty but still helpful for others, (0) score when patient not in need for assistance or help to complete the task but he is not helpful, whereas (- = OFF) scoring when he is in need for assistance or help or completely dependent. (Table 1)

In consistent with the United Kingdom PD Society Brain Bank diagnostic criteria[17], a 48 PD patients were admitted for one day to Al- Diwaniyah teaching hospital neurology center with one of the patient family member. Both learned to fill out a proposed scale (Table 2). For each patient; two copy of same scale were filled one by patient or family member and the second by expert staff at same time.

At home, each PD patient or family member asked to use the same scale for a random days / month for 3 months and mailing a copy to the neurology center.

In addition, the PD patient and family member asked to evaluate the proposed scale by a questionnaire enquiring about the difficulty of using the scale ranging from 1 to 10 and whether its adding more information to the family about PD manifestations, medications and medications adverse effects as YES or NO for each.

Via another questioner the PD patients following physicians evaluating the precision of ON and OFF timing for each patient by YES or NO.

Table 1: The basic system of scale.

Level of performance		**Manifestations**						**Adverse effects**	
		Tremor	**Dressing**	**Walking**	**Bed turning**	**swallowing**	**Swallowing**	**Dyskinesia**	**Hallucination**
ON	Normal Or Have difficulty but still helpful	+2		+2					
		+1	+1	+1	+1	+1	+1	+1	+1
	Not needs for help or assistance	0	0	0	0	0	0	0	0
OFF	In need for assistance or help	-1	-1	-1	-1	-1	-1	-1	-1
	Completely dependent	-2	-2	-2	-2	-2	-2	-2	

Name: Date:

Table 2: Parkinson's disease follow up self-assessment scale.

Write the score for each item below corresponding to time										**Mark by X the items corresponding to time**					
Time		Tremor	Dressing	Walking	Bed turning	swallowing	Speech	Dyskinesia	Hallucination	Meals	Sleep	Drugs			
												1	2	3	4
Am	8														
	9														
	10														
	11														
	12														
Pm	1														
	2														
	3														
	4														
	5														
	6														
	7														
	8														
	9														
	10														
	11														
	12														
Am	1														
	2														
	3														
	4														
	5														
	6														
	7														

	Drug	**Dose**
1		
2		
3		
4		

Note: If asymmetric take the score of worst side

Tremor +2 = Absent.
+1 = Slight at rest
0 = drink by a cup without spilling water
-1 = drink by a cup with spilling water
-2 = cannot use cup for drink

Dressing +1 = Normal.
0 = Slow not need assistance.
-1 = cannot fastening button
-2 = cannot put arm in sleeve

Walking +2 = Normal
+1 = Can shopping tend to drag leg.
0 = can go to toilet without assistance.
-1 = requiring assistance.
-2 = can't walk

Bed Turning +1 = Normal.
0 = have minimum difficulty
-1 = cannot turn alone.
-2 = cannot adjusting blanket

Swallowing +1 =. Normal
0 = Occasional choking.
-1 = requires soft food.
-2 = tube or gastrostomy feeding

Speech +1 = Normal.
0 = understandable.
-1 = difficult to understand.
-2 = Unintelligible.

Dyskinesia +1 = non
0 = not annoying
-1 = annoying not affect activities
-2 = Disturbing walking and talking

Hallucination +1 = non
0 = Not disturbing life
-1 = Disturbing life

Gambling, Binge eating, hyper sexuality, Obsessive shopping	yes	
	No	

Results

A 44 (91.7%) PD patient were complete the study, 4 (8.3%) patients are not compliance, 25 (56.8%) were male whereas 19 (43.2%) were female, age range was (46 - 87) years average 71 years.

Each item of the proposed scale were filled accurately by the patient in compared to expert staff as following; time 44 (100 %), tremor 44 (100 %), dressing 42 (95.5%), walking (100%), bed turning 41 (93.2%), swallowing 44 (100%), speech 38 (86.4 %), dyskinesia 32 (72.7 %), hallucination 39 (88.6%), drugs 40 (90.9%) and impulsive disorders 44 (100%). All items accuracy filling out was 93.4%. (Table 3)

The difficulty in filling the scale 7-10, 4-6, 0-3 / 10 for the participants was 11 (25 %), 20 (45.4 %), 13 (29.54%) sequentially, mean degree was 4/10 (Table 4) (Figure 1). Families awareness about PD were become better by acquiring more knowledge were 34 (77.3%), 37 (84.1%), 41 (92.2%) family for PD manifestations, medications and medications adverse effects consecutively (Table 5).

The ON and OFF time sensitivity by the proposed scale was precise in 41 (92.2%) patients. (Figure 2)

Table 3: The accuracy of items filling of proposed scale.

Item	Patients	Expert	%
Time	44	44	100 %
Tremor	44	44	100%
Dressing	42	44	95.5%
Walking	44	44	100%
Bed turning	41	44	93.2%
Swallowing	44	44	100%
Speech	38	44	86.4 %
Dyskinesia	32	44	72.7 %
Hallucination	39	44	88.6%
Drugs	40	44	90.9%
Impulsive disorders	44	44	100%
Sum	452	484	93.4%

Table 4: The level of difficulty of scale to the patient or family member.

Difficulty / 10	**0-3**	**4-6**	**7-10**
Participant number	16	20	8
Percentage	36.4%	45.4 %	18.2 %

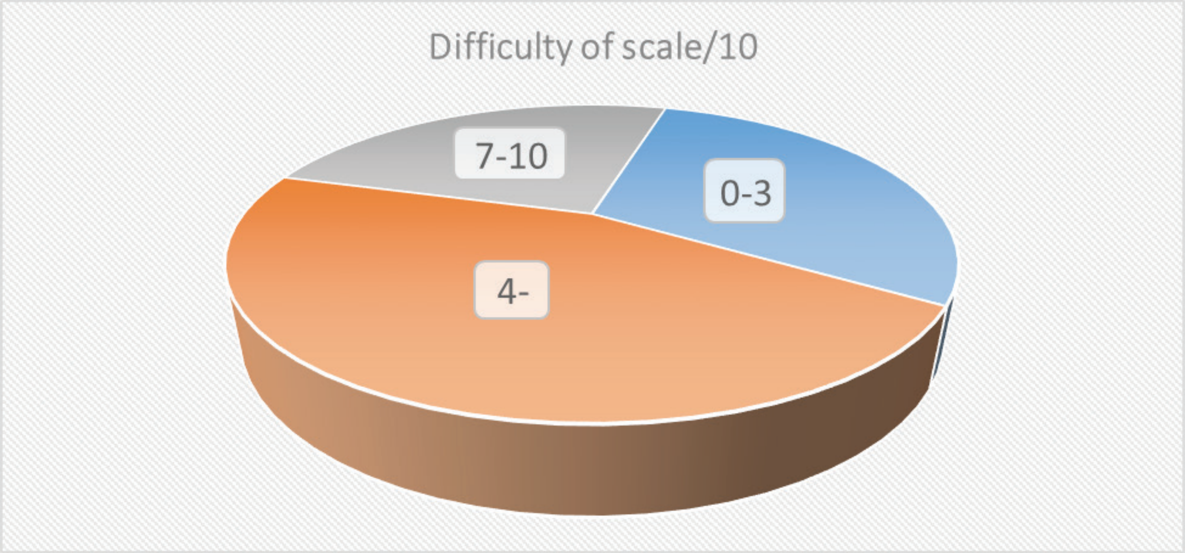

Figure 1: The level of difficulty of scale to the patient or family member.

Table 5: Families acquired more knowledge about PD.

Item	Number	%
Manifestations	34	77.3%
medications	37	84.1%
adverse effects	41	92.2%
Sum	112	84.8%

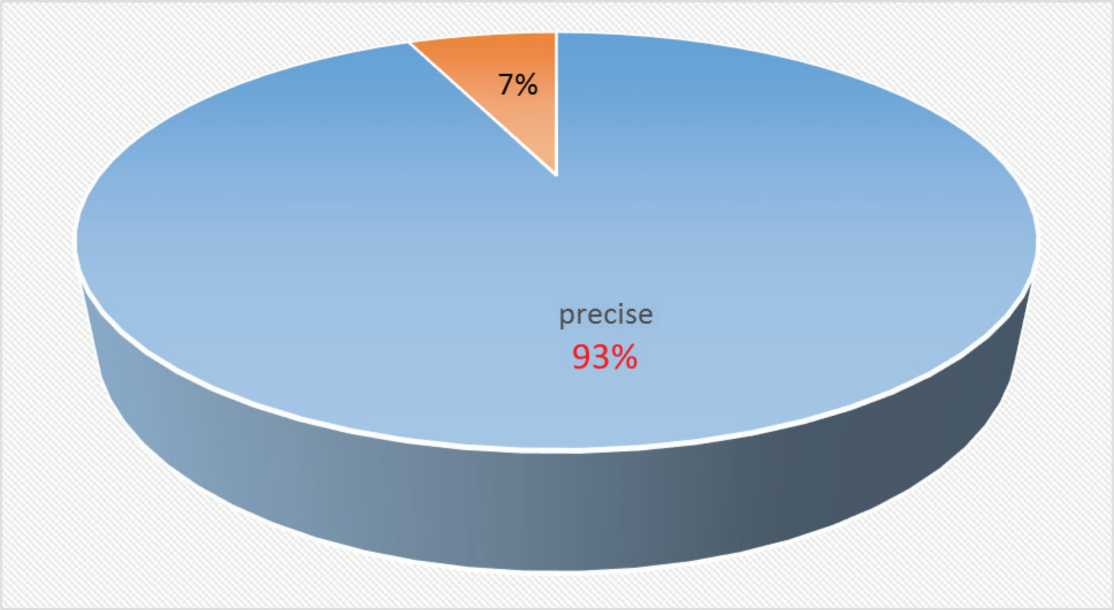

Figure 2: The ON and OFF time sensitivity of scale.

Discussion

For all items the scale were filled out accurately in 93.4% by the patient or his family member in comparison to professionals so generally it's sensitive and reliable for detecting patient condition.

Although 4 (8.3%) participants were not completed the study, but 91.7% completed it with mean degree of difficulty was 4/10. Concluding it's practical and not difficult.

The proposed scale add extra information about PD and its medications to the patient families and make them more familiar in 84.1%, so it's serving the aim of patient education.

The identification of ON and OFF time was precise in 41 (92.2%) patients indicating a high sensitivity which is the main aim of the scale. **The scale designed to demonstrate patient condition each one hour which can be manipulated to 2,3,4 hours according to patients condition , a result of + (green zone) equivalent to ON while - (red zone) resemble OFF (table 1).**

At early stage its helping to decide when to initiate treatment and election of suitable medication since it demonstrate the main disabling feature either in the pole of tremor or rigidity and hypokinesia. While in later stages it helping in validation of effectives of regimen and assisting in selection of the best regimen individually or the need for secondary care and specialist services. **The scale weighing the medications adverse effects with the** ON time for adjusting proper dose and timing medications intake with meals and sleep.

Conclusion

The proposed Parkinson's disease follow up self-assessment scale is useful for following PD patients since it's practical and sensitive as verified by all results. It can be used patient family, career, and nursing staff. It's not difficult, precise in detection ON an OFF time without patient attendance or hospitalization.

Recommendations

We recommend to test the same scale in other neurological centers with different communities and arranging for an internet page or application for easy communication between patients and physicians.

Ethical Clearance: The Research Ethical Committee at scientific research by ethical approval of both environmental and health and higher education and scientific research ministries in Iraq

Conflict Of Interest: The authors declare that they have no conflict of interest.

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