

# UPDRS & Acupuncture

## Introduction

The autumn of the year 2006 – approximately 1 year before my retirement - was the point in time when I first became aware of unusual tremors primarily in my left arm. At first I did not pay much attention, but as the tremors grew stronger I eventually in the summer of 2008 sought the advice of my local GP. He subsequently referred me to a neuro-specialist who without hesitation diagnosed me as having Parkinson's disease (PD), a diagnosis which has since been confirmed when I sought a second opinion.

I was born in 1942 and it is now 2021 from which the attentive reader will conclude that I am 79 years of age and have had to cope with PD for the past 15 years. I am not particularly interested in medical matters generally, but I am interested in how PD affects me, particularly how it may progress, how it may affect me in the future, and how I might adjust my style of living to make it easier to cope with PD. This current note addresses the therapy known as *acupuncture* which I feel is beneficial without being able to say exactly how.

Sometime in the summer of 2015 I learnt about the Unified Parkinson's Disease Rating Scale (UPDRS) and began to rate myself regularly and an idea gradually took shape in my mind, the idea that I could use the UPDRS as an instrument by which to measure the progression of the disease and possibly how symptoms might react to treatments one way or another. However, I needed some yardstick or benchmark against which to assess the progression with or without acupuncture.

Until March 2020 I have had regular acupuncture therapy which of course was brought to an end by the Covid-19 outbreak. I cannot be 100% sure, but after a couple of months I began to feel that tremors have got stronger than I would expect given the 'natural' progression, and I cannot think of any other reason for this than the absence of acupuncture. I would therefore think it beneficial if I had a kind of fool-proof, objective method of measuring the effect of acupuncture on the standard symptoms of PD, which could also help me assess whether the improvements, I have felt, were real or products of my imagination.

Individual 'readings' of UPDRS fluctuate too much for them to be a practicable, useful yardstick. I needed something else.

What is described in this essay is in part the outcome of a search for such a yardstick and in part an attempt at an objective assessment of the effect of acupuncture treatment. I have sought to summarise the outcome of these activities which as the reader will realise span a 6 year period. It does not constitute formal research, but are my own creation except for reference to scientific literature which has been downloaded or copied from the internet.

## The Three Elements

There are three – what I will describe as ‘elements’ in this investigation, the first of which is the disease itself known as **Parkinson's disease (PD)**, simply **Parkinson's**, sometimes also referred to as **Parkinsonism**. It is a long-term degenerative disorder of the central nervous system that mainly affects the motor system. The symptoms usually emerge slowly, and as the disease worsens, non-motor symptoms become more common. The most obvious early symptoms are tremor, rigidity, slowness of movement, and difficulty with walking. Cognitive and behavioural problems may also occur with depression, anxiety, and apathy occurring in many people with PD. Those with Parkinson's can also have problems with their sleep and sensory systems. The motor symptoms of the disease result from the death of cells in the substantia nigra, a region of the midbrain, leading to a dopamine deficit. The cause of this cell death is poorly understood, but involves the build-up of misfolded proteins into Lewy bodies in the neurons.

Source: [en.wikipedia.org/wiki/Parkinson%27s\\_disease](https://en.wikipedia.org/wiki/Parkinson%27s_disease)

So far my problems have been what is referred to as ‘early’ symptoms. I am not aware of any significant or behavioural problems.

The second element is the **unified Parkinson's disease rating scale (UPDRS)** used to follow the longitudinal course of Parkinson's disease. The UPDRS rating scale is the most commonly used scale in the clinical study of Parkinson's disease.

The UPDRS is made up of four sections which are evaluated by interview and clinical observation. Some sections require multiple grades.

Clinicians and researchers alike use the UPDRS and the motor section in particular to follow the progression of a person's Parkinson's disease. Scientific researchers use it to measure benefits from a given therapy in a more unified and accepted rating system. Neurologists also use it in clinical practice to follow the progression of their patients' symptoms in a more objective manner.

Following the UPDRS scores over time provides insight into the patient's disease progression. For instance Michael J. Fox's symptoms started with a slight tremor, so his motor score would have been less than 10 (and with full use of the scale it could theoretically reach 199!). For most patients, the "mentation, behaviour and mood" scores increase later in the disease.

Source: 1) [en.wikipedia.org/wiki/Unified\\_Parkinson%27s\\_disease\\_rating\\_scale](https://en.wikipedia.org/wiki/Unified_Parkinson%27s_disease_rating_scale). 2) <https://neurotoolkit.com/updrs/>

The four sections referred to above are:

1. Mentation, behaviour and mood.
2. Activities of daily living (for both “on” and “off”).
3. Motor examination.
4. Complications of therapy (in the past week).

Source: Ibid

However, for the purpose of this essay I have mainly used section 2, 3 and 4.

The third element is **acupuncture**, a form of alternative medicine and a key component of traditional Chinese medicine (TCM) in which thin needles are inserted into the body. There is a range of acupuncture variants which can be divided into two main foundational philosophical applications and approaches, the first being the modern standardized form called eight principal TCM and the second an older system that is based on the ancient Taoist Wuxing. Acupuncture is most often used to attempt pain relief though acupuncturists say that it can also be used for a wide range of other conditions. Acupuncture is generally used only in combination with other forms of treatment.

The conclusions of trials and systematic reviews of acupuncture are inconsistent, which suggests that it is not effective. An overview of Cochrane reviews found that acupuncture is not effective for a wide range of conditions. A systematic review conducted by medical scientists at the universities of Exeter and Plymouth found little evidence of acupuncture's effectiveness in treating pain. Overall, the evidence suggests that short-term treatment with acupuncture does not produce long-term benefits. Some research results suggest that acupuncture can alleviate some forms of pain, though the majority of research suggests that acupuncture's apparent effects are not caused by the treatment itself. A systematic review concluded that the analgesic effect of acupuncture seemed to lack clinical relevance and could not be clearly distinguished from bias. One meta-analysis found that acupuncture for chronic low back pain was cost-effective as an adjunct to standard care while a separate systematic review found insufficient evidence for the cost-effectiveness of acupuncture in the treatment of chronic low back pain.

Acupuncture is generally safe when done by appropriately trained practitioners using clean needle technique and single-use needles. When properly delivered, it has a low rate of mostly minor adverse effects. Accidents and infections do occur, though, and are associated with neglect on the part of the practitioner.

Source: <https://en.wikipedia.org/wiki/Acupuncture>

The above extract shows clearly the dominant view of **acupuncture** that trials and reviews are inconsistent and acupuncture therefore probably not effective; more reviews found “little evidence” of effectiveness in treating pain; and a systematic review found that the analgesic effect of acupuncture “seemed to lack clinical relevance and could not be distinguished from bias”.

In fairness it would seem relevant to mention that most ‘honest’ reviewers of research into acupuncture recognize that much of this research appears to be underfunded and conducted with a number of participants too small to render any possible conclusions meaningful or trustworthy.

“In conclusion, the evidence for the effectiveness of acupuncture for treating PD is not convincing. The number and quality of trials as well as their total sample size are too low to draw any firm conclusion. Further rigorous trials are warranted.”

Source: Lee MS et al, *Effectiveness of acupuncture for Parkinson's disease: a systematic review*, Movement Disorder Society, University of Exeter, Aug. 2008

“The results were limited by the methodological flaws, unknowns in concealment of allocation, number of dropouts, and blinding methods in the studies. Large, well-designed, placebo-controlled RCTs with rigorous methods of randomization and

adequately concealed allocation, as well as intention-to-treat data analysis are needed.”

Source: Lam YC et al, *Efficacy and safety of acupuncture for idiopathic Parkinson's disease: a systematic review*, Complementary Medicine, Hong Kong Baptist University, July 2008.

There would seem to be a considerable measure of traditional Western European thinking involved when the efficacy or otherwise of acupuncture is assessed. One may respectfully add that the evident failure of much of this research is due to the lack of an agreed, scientifically and theoretically sound yardstick by which to assess this type of treatment.

My own experience of acupuncture is that it is a kind of life-saving, recovery therapy in which slumbering or dying nerve cells such as the dopamine producing cells are reawakened and brought back and stimulated into full activity at least for a period. However it is a very slow process and benefits are slow to emerge.

As acupuncture therapy is working so slowly it is difficult for an individual patient, such as myself, to know with certainty whether or not it is having any effect, but people around me commenting on my physical state of health tells me that this is better than they would have expected given the length of time since I was first diagnosed. For me therefore, the research by Bai-Yun Zeng et al seems especially relevant:

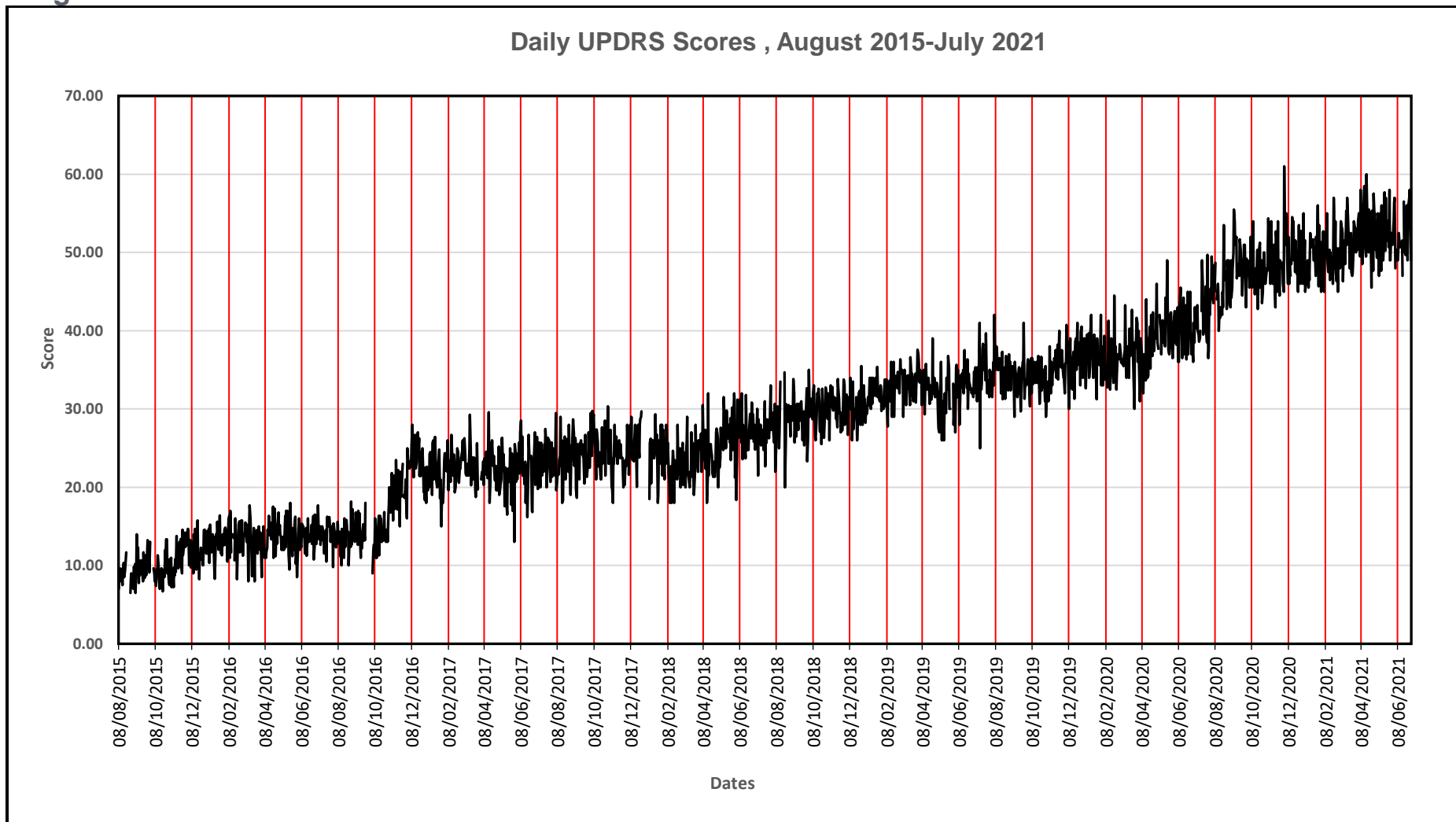
“... acupuncture treatment is in fact a neuroprotective therapy that increase the release of various neuroprotective agents such as brain-derived neurotrophic factor, glial cell line-derived neurotrophic factor, and cyclophilin A. In addition, acupuncture therapy slows cell death process and attenuates oxidative stress to dopaminergic neurons in the substantia nigra. .... These results suggest that early application of acupuncture therapy to Parkinson's patients may be helpful for the best efficacy of acupuncture treatment.”

Source: Bai-Yun Zeng et al, *Current development of acupuncture research in Parkinson's disease*, International Review of Cell and Molecular Biology.2013;111:141-58.doi: 10.1016/B978-0-12-411545-3.00007-9.

## Longitudinal observations

In diagram 1, overleaf, page 5 is set nearly all (except for holiday periods) the daily average UPDRS “observations” since August 2015 when this monitoring exercise first began, covering in total 2155 days. Each daily observation is the average of 1, 2 or more observations made that day, so the diagram is the visual expression of 7,360+ observations.

Diagram 1



It will come as no surprise to a person familiar with the progression of PD that the graph shows a positive slope from left to right starting with average observations of around 10 in August 2015 and ending with observation of an average score of 50-55 in June 2021.

**Table 1**

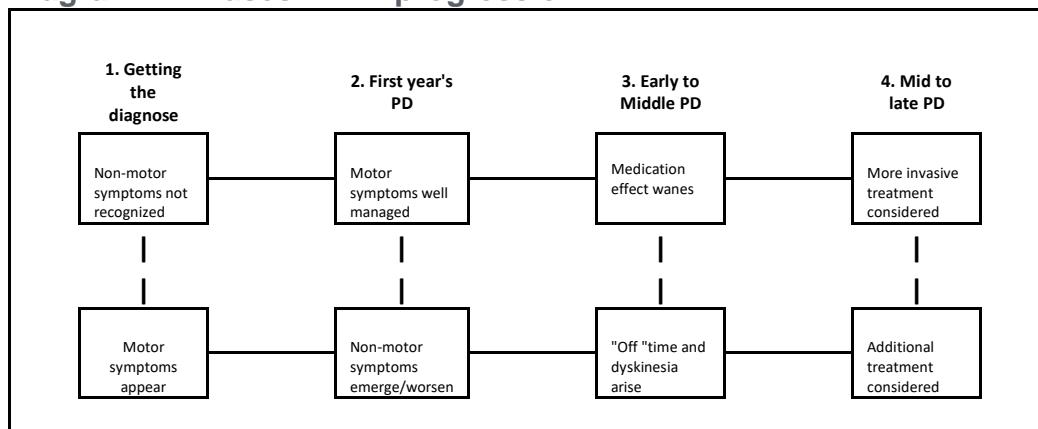
Year	No of Months	UHPDRS			Monthly Increase
		1	2	Difference	
2015	5*)	8.79	12.02	3.23	0.65
2016	12	13.00	23.37	10.37	0.86
2017	12	21.56	25.96	4.40	0.37
2018	12	24.46	30.40	5.94	0.50
2019	12	31.63	36.28	4.65	0.39
2020	12	36.89	50.25	13.36	1.11
2021	6**)	49.51	52.26	2.75	0.46
	71	8.79	52.26	43.47	0.61

\*) August to December. \*\*) January to June.

The average annual and monthly scores are set out in table 1 above, and it is noted that the annual rise in each year falls within the range referred to by Holden et al\*): “Several studies have examined – the ability of UPDRS to track symptom progression over time, reporting rather wide ranges for annual score increases (total score, 3.0-14.0 points per year; .....)”

\*) Holden, Samantha K, et al, *Progression of MDS-UPDRS Scores Over Five Years in De Novo Parkinson Disease from the Parkinson's Progression Markers Initiative Cohort*, Movement Disorders Clinical Practice, Jan.-Feb., 2018.

**Diagram 2: Phases in PD progression**



Source: Copied from memory; The Michael J. Fox Foundation's webinar "What Comes Next? Living with Parkinson's Years after Diagnosis", 17<sup>th</sup> of July 2021.

A recent webinar from the American “The Michael J Fox Foundation” had the life-long progression of PD partitioned into four phases as shown in diagram 2. I would estimate that I am somewhere between the 2<sup>nd</sup> and 3<sup>rd</sup> phase, but I do not know whether that is typical for a person at my age with a PD-history for 13 years.

If a typical PD patient would have reached a more advanced stage in the progression it may be argued that the therapy of acupuncture have succeeded in slowing down the development of the disease. On the other hand if a typical patient would have reached a less advanced stage it might be argued that the therapy of acupuncture have hastened the progression.

However, the progression is not uniformly straight and linear. There are periods when the PD apparently has progressed faster than at other times, the graph showing a steeper slope eg in November-December 2015, in December 2016, in April-May 2018 and July-August 2020. Likewise there are periods when progression is virtually stagnant like during most of the year 2015 before November, during most of the year 2016 before December of that year and again during most of the year 2017. The challenge now is how these observations can be related to ongoing sessions of acupuncture therapy.

## **Methodology and Analysis**

The sequence of therapy and UPDRS observations has been divided into a number of sub-periods according to when therapy was received or not received as follows:

Without acupuncture: 1) 18. Aug '16-10. Oct '16 (55 days); 2) 2. Aug '17- 12. Mar '18 (224 days); 3) 1. Apr '20- 15. Jun '20 (77days).

With Acupuncture: 1) 8. Aug '15 – 17. Aug '16 (377 days); 2) 11. Oct '16 – 1. Aug '17 (296 days); 3) 13. Mar '18 – 31. Mar '20 (751 days); 4) 16. Jun '20 – 30. Apr '21 (320 days).

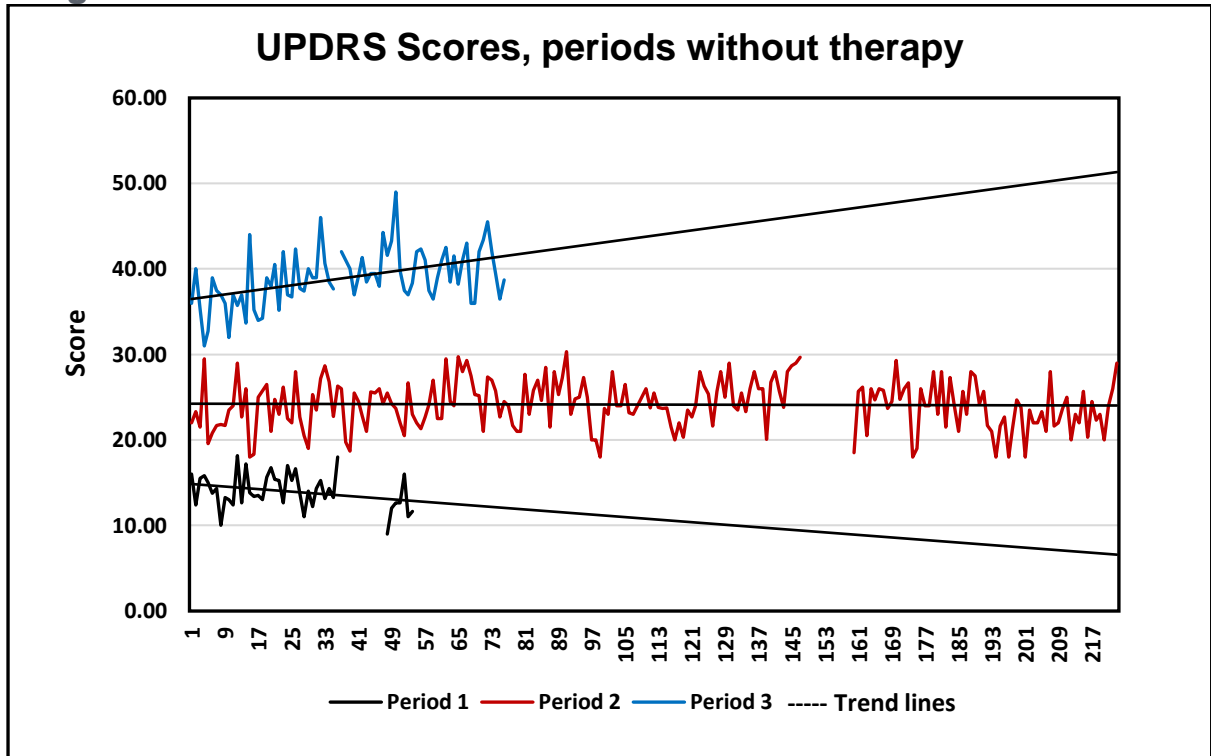
It is noted that there were three relatively short periods during which acupuncture therapy was not received. By contrast there were four relatively longer periods when such therapy was received.

### **Graphic representations - without therapy**

The results of monitoring the symptoms during the three periods, when the patient (myself!) has not undergone acupuncture therapy, are plotted in diagram 3 below.

The condition is progressive and therefore the first period is shown as the graph nearest the horizontal axis while the two subsequent periods are shown above that.

Diagram 3



Graphic representations - with therapy

Diagram 4

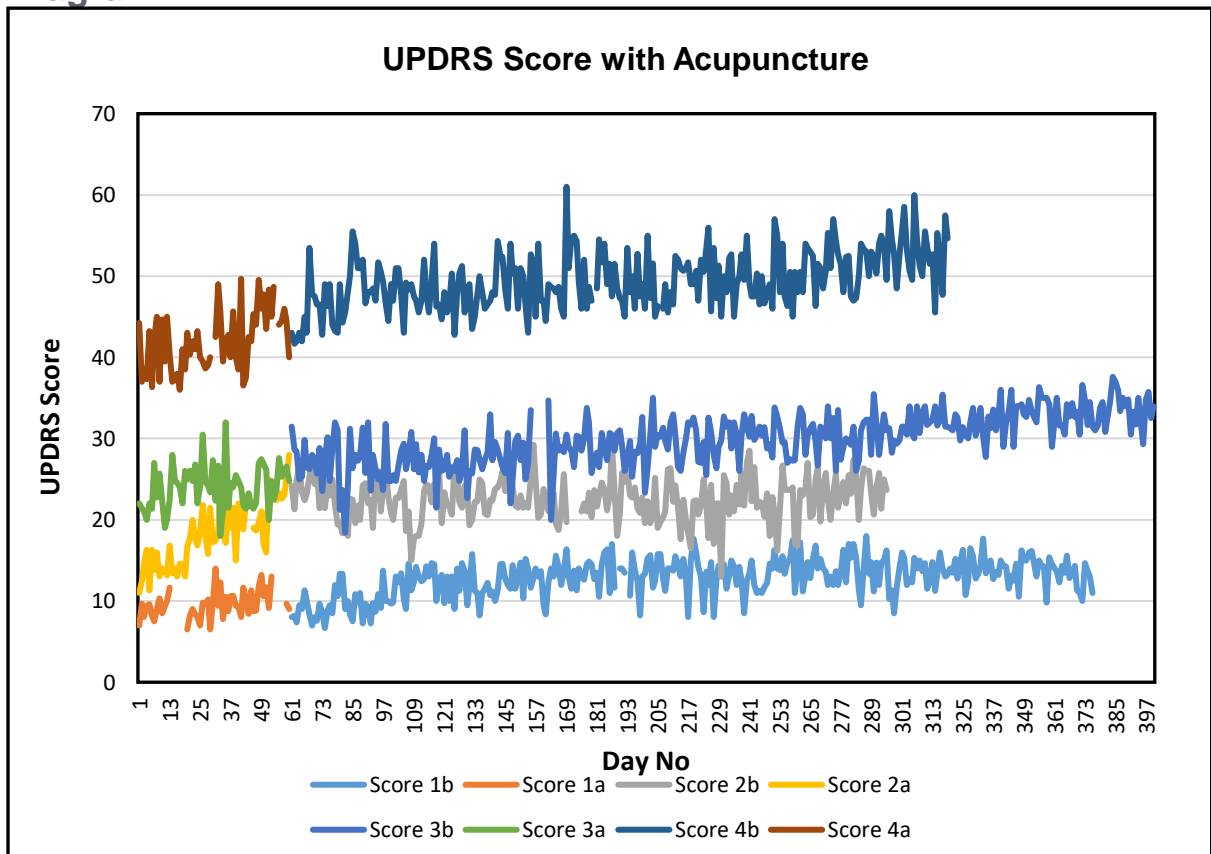




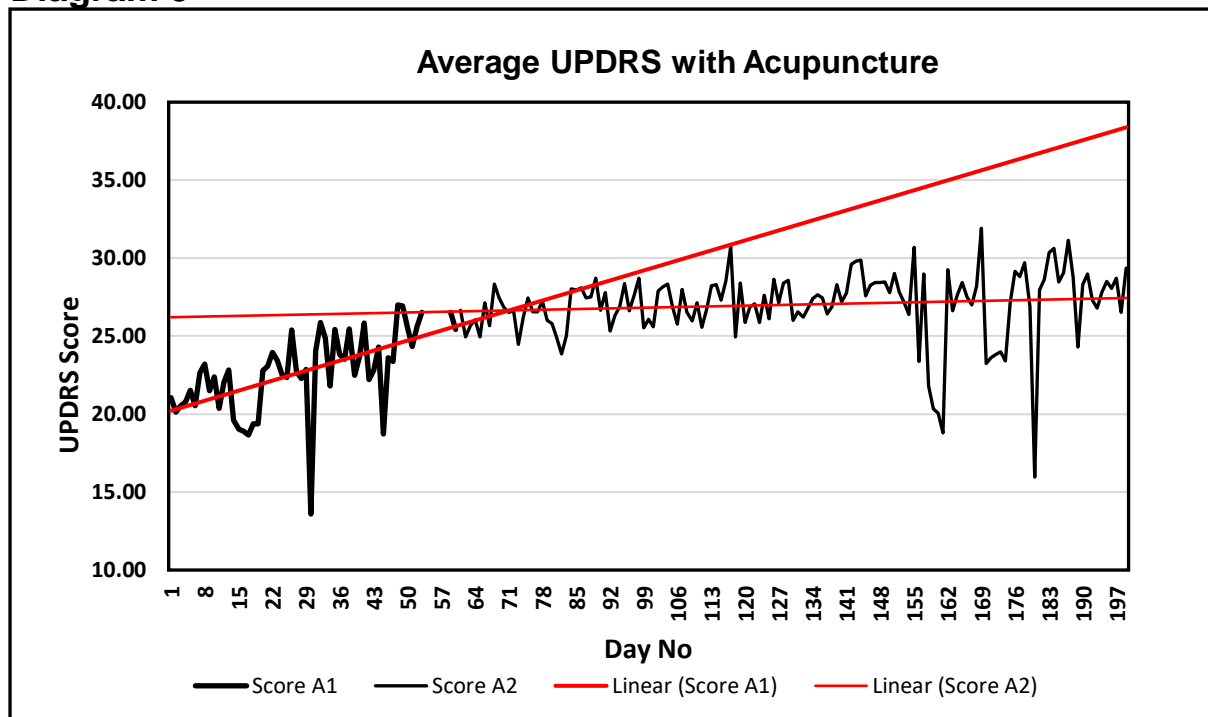
Diagram 4, page 8, above, concerns the four periods during which the therapy of acupuncture was received. There are four graphs, one for each period, and each graph showing the expected features that the earliest with the lowest UPDRS scores is closest to the horizontal axis and the latest graph with the highest scores is higher up in the frame.

The second expected feature is the sloping from left to right as is also shown diagram 1.

A third - unexpected – feature is that all four graphs seem to have two parts: one depicting the earliest part of the period with a relatively steep slope covering the first approximately 60 days of the period. After these 60 days the second part of the graphs seems to show a less steep, but steady progression.

Having noticed these features an average of all four graphs was calculated and set out as one graph in one diagram, diagram 5.

**Diagram 5**



Note: Score A1 ~ the average score of the first 61 days of each of the four periods with acupuncture.

Score A2 ~ the average score of the following 138 days of each of the four periods with acupuncture.

If there is a reality behind these features it may be that when a period of therapy commences after a long period without receiving any, the nervous system responds as if being shocked into action and later settles into slow and steady progress.

## Numerical representation

**Table 2**

	No days	End	Start	Change	
	(1)	(2)	(3)	Total (4)	Daily Mean (5)
<b>Without 1</b>	36	12.28	14.28	-2.00	-0.056
<b>Without 2</b>	194	22.67	23.18	-0.51	-0.003
<b>Without 3</b>	51	39.86	36.64	3.22	0.063
<b>With 1</b>	345	13.63	8.80	4.83	0.014
<b>With 2</b>	265	23.72	15.65	8.07	0.030
<b>With 3a</b>	348	33.21	23.85	9.36	0.027
<b>With 3b</b>	343	38.38	33.27	5.11	0.015
<b>With 4</b>	289	53.03	40.17	12.86	0.044

Notes:

- (1) ~ No of days between start and end of period with/without acupuncture
- (2) ~ Average UPDRS observations at the end of period
- (3) ~ Average UPDRS observations at the start of period
- (4) ~ Difference between (3) and (2)
- (5) ~ (4)/(1)

An alternative to analyse of graphical representation of the development or progression of PD would be an analysis of the numerical observations of the UPDRS.

In table 2 above is set out average observations at the start and end of the periods outlined on page 7, column (2) and (3), and the difference is calculated, column (4). Also included in the table is the number of days of each period, column (1), and this is related to column (4) to arrive at the daily mean set out in column (5).

The table is further split into two halves of which the upper half depicts the findings for the three periods 'without' acupuncture when therapy was not received. The lower half depicts the findings for the four periods (period three has been split into two numbered 3a and 3b) 'with' acupuncture when therapy was received.

The 'minus' sign in line 1 and line 2 of the first periods 'without' acupuncture would signify a negative progression in the symptoms or an actual improvement in the condition, which seems somehow improbable.

However, the outcome of a daily progression of 0.063 UPDRS units may be accepted as authoritative for the third period 'without' therapy. It is then worth noting that the daily progression for each of the four periods 'with' therapy is lower than the 0.063, which in turn would signify that the progression during each of these periods was slower than during the last periods 'without' therapy.

## **Discussion**

### **Acupuncture**

It seems that there is a growing consensus among scientist with neurological expertise that the insertion of needles into the nervous system under the skin as in acupuncture stimulate the system to release certain chemicals and possibly a nerve growth factor into the muscles, spinal cord and brain. This in turn may stimulate the body's natural healing abilities, promote physical and emotional well-being, and help the nerves to regenerate.

While it may promote physical and emotional well-being we still need to see this changed and hopefully improved well-being expressed in a way that can be reasonably accurately assessed against the UPDRS scale or similar, both at selected points in time and as changes over a period.

Johns Hopkins Medicine in their website note: "Some people report acupuncture makes them feel energized. Others say they feel relaxed." However, it should be possible to include both cases under a common label of 'improved well-being'.

Source: <https://www.hopkinsmedicine.org/health/wellness-and-prevention/acupuncture>

### **UPDRS**

The symptoms of PD are numerous and can be difficult to communicate and quantify. The variability in symptoms week-by-week, day-by-day and hour-by-hour can make this even more difficult. It poses a challenge when explaining how they have been to the PD specialist and their family. The purpose of the above investigation has been to find a reliable way of monitoring symptoms and especially tracking day-by-day variation and the long-term progression.

In order to do this I have used the UPDRS system, but in so doing there is a danger, as in all research and investigations, that the researcher, consciously, sub-consciously, deliberately or not will give the record of his/her observations a bias that may twist the final result and obscure a final conclusion.

Each of the four sections referred to above (page 2) is divided into a number of sub-sections, one for each sign or symptom. Each sub-section is rated on a 5-point scale (ranging from 0 to 4), with higher scores indicating more severe impairment with descriptions such as "Normal, Slight, Mild, Moderate or Marked" or similar. The task for the researcher is to classify each symptom within this framework. However, to classify the manifestation of each symptom as say "mild" or "moderate" in a consistent and reliable manner over time would seem difficult if not impossible even for a trained observer. And it will be even more so if we seek a consistent description of progression over time and have to decide when the manifestation of a symptom moves from "mild" to "moderate".

Using the UPDRS in constructing the diagrams and tables that are shown above I have used the whole of the Rating Scale and every-one of the said sections in

arriving at every 'observation'. This may not be the correct way of using the scale. Some symptoms vary more than others and the timing and frequency of use should probably be adjusted to take account of that fact.

Having used the Rating Scale extensively for a number of years one also feels that in its present form it has some strikingly obvious omissions. It might for example be useful to record when the assessment was done vis a vis the consumption of medication, receipt of therapy such as acupuncture i.e. was the assessment done before or after the intake of medication and if so how long before or after. Timing in terms of the point in time of assessment during the course of a normal day i.e. immediately after rise in the morning, before or after any meals or before going to bed may also be a useful pointer.

Similarly, there is only one question relating to the presence or otherwise of **dystonia** with the answer being 'Yes' or 'No'. It has been my experience that a rating on a scale as described above would be very useful.

Section 2, *Activities of Daily Living*, seems to have more to do with not being as young as one used to be rather than PD as such.

More directly one may ask why some symptoms or tell-tell signs of PD are not included in the Rating Scale like for example constipation, changes to the patient's eye-sight, loss of smell and taste, dryness of the patient's scalp and may be more.

## **Research Design**

The above investigation suffers from the fact that it is just a one man project in which the results of measurements or observations as well as reporting and analysis has all been done by one and the same person. Some may therefore question whether the investigation has been appropriately un-biased and objective.

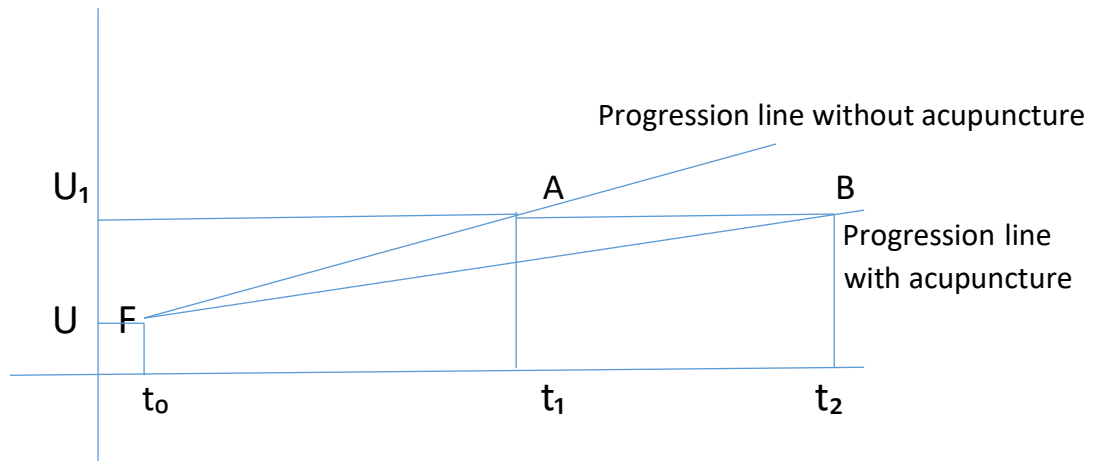
As described on page 3 above much research into the efficacy or otherwise of acupuncture therapy generally suffers from a lack of involvement of human resources which may lead to doubting the significance of the research.

It would be desirable if the design of a research project could include the specification of a number of PwP, some to undergo acupuncture therapy, and a control group, who should not receive therapy. Both groups should be monitored simultaneously over a specified time period of significant length, probably a few - say five! - years.

If the UPDRS is the measuring system of choice it will have to be decided whether symptoms should be assessed with reference to either one of the four sections separately or with reference to all four sections.

It may be that in this task recently developed sensors worn by the patient as wrist bands will facilitate remote monitoring of a patient's symptoms. In any case it would probably remove any doubt that may exist in respect of the quality of the data and objectivity of the observations.

## Postscript: Applying the theory



After a period  $t_0$  the Patient's progression line has reached a point  $F$  with a UPDRS measure of  $U$ .

If he/she continue life without receiving acupuncture therapy for a further period  $t_1$  the trend line will reach point  $A$  and the UPDRS measure will now have increased to  $U_1$ .

However if he/she engage with acupuncture therapy the progression line will be less steep and the UPDRS measure will increase at a slower pace and not have reached the value  $U_1$  until point  $B$  after a further period of time  $t_2$ .

It can therefore be argued that by engaging in acupuncture a critical issue **A** will have been subdued so that symptoms would be manageable and less critical until some time in the future when symptoms might be dealt with more effectively.