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Abstract

In device-aided therapy (DAT) for Parkinson's disease (PD), factors such as device-related adverse effects, psychological and lifestyle changes, and specific disease progression can affect the quality of life (QoL) of patients with advanced PD. However, there is no existing QoL scale that includes the effects of therapeutic devices. From a semi-structured interview with patients with PD undergoing deep brain stimulation (DBS), we extracted the content of utterances that were thought to affect the QoL and created a draft questionnaire consisting of 113 items. This questionnaire was administered to 54 other patients undergoing DBS, whose data were examined for reliability and validity by factor analysis, and finally, a 24-item PD QoL questionnaire for patients on DAT (PDQ-DAT) was developed. Presently, the PDQ-DAT is the only scale that can assess the QoL of patients on DAT, including the influence treatment devices have on them. In the future, it might be used to help in shared decision-making in medicine by incorporating the patient's sense of burden and values in the selection of treatment methods.

Keywords: quality of life (QoL), device-aided therapy (DAT), deep brain stimulation (DBS), Parkinson's disease (PD)

Introduction

Parkinson's disease (PD) is characterized by a variety of symptoms,[1] and it is difficult for physicians to fully assess patient's instrumental activities of daily living and quality of life (QoL).

In recent clinical practice, diurnal motor fluctuations due to levodopa therapy in patients with PD are treated with device-aided therapy (DAT), such as deep brain stimulation (DBS), levodopa-carbidopa continuous infusion gel (LCIG), and subcutaneous apomorphine infusion. Patients undergoing DAT for PD (DAT-PD) are likely to have specific QoL effects related to the device usage; for example, complaints in regard to the device, such as maintenance work necessary for the use of the device, psychological tendencies to be anxious or dependent on the device, and problems with the treatment.[2] Thus, although

PD treatment has changed significantly over the last 20 years, there is no comprehensive QoL measure that takes into account the negative aspects of device usage.

In this study, we developed a novel QoL assessment scale with incorporated items specific for DAT-PD to better evaluate the QoL of these patients, including the influence of the therapeutic devices.

Materials and Methods

Patients

Using the significant sampling method, 54 patients undergoing DBS who visited Fukuoka Mirai Hospital for routine visits between December 2018 and February 2019 were included in the study (Table 1).

The type of DAT was bilateral subthalamic nucleus (STN)-DBS in all cases. Patients underwent contemporaneous bilateral STN-DBS implantation using MRI-guided indirect targeting and the multitrack microrecording method.[3] The initial postoperative DBS programming in all patients was performed using unipolar stimulation of the contact located at the dorsal STN. The stimulation parameters were reevaluated and adjusted as required during hospital visits to achieve maximal therapeutic effect on PD symptoms.

Investigation

Based on an analysis of the data obtained during the semi-structured interview process in a previous study on the psychology of patients after bilateral STN-DBS surgery,[4] we developed a prototype QoL scale consisting of 113 questions (Table 2). The prototype QoL scale was administered to our patients, and their responses and opinions were collected.

Data collection methods

The outpatient nurses gave the prototype scale to the patients and asked them to answer the

questionnaire in a self-administered format, and then the scale was collected on the same day. Blank spaces were provided for the patients to write their opinions and impressions on the questionnaire, but considering a possible psychological burden, we opted not to ask them to write their personal information.

Work procedure from draft to completion of a tentative version

Creating an item pool

Based on the content of the patient's remarks obtained in a previous study,[4] we created a pool of items by extracting the factors that may affect the QoL to the largest extent possible. Thirteen patients (2 men and 11 women) undergoing STN-DBS in the referenced study, whose higher brain function was stable at 6 months or later after surgery, were included in this process.

On the basis of the items obtained from the patient's statements, two neurosurgeons, a statistician, and a graduate student in neurosurgery (hereinafter referred to as "relevant professionals") also listed and added items that could be considered from a professional point of view. These were based on the viewpoints of a neurologist, a nurse specializing in functional neurosurgery, and a certified psychologist.

Creating a questionnaire

The questions in the item pool were checked by the relevant professionals, and the details, including the wording of the items, were discussed thoroughly. The questionnaire format was designed to be applicable to all DATs, such as LCIG and continuous subcutaneous infusion of apomorphine, in view of a possible expanded application in the future.

Preparing a draft questionnaire

We prepared a draft QoL questionnaire with a response format based on the five-point rating method, which is often used to measure the QoL because it is easy to score and analyze quantitatively.

Creating a tentative version

The number of factors was determined by factor analysis and the items were selected by using all items that were implemented in the prototype QoL scale. The items that were confirmed to be statistically supported in the final factor analysis were used in consultation with the relevant professionals, and the instructional text and score columns were arranged at the beginning and formatted as a questionnaire (Fig. 1).

Table 1 Patient profiles

Gender	Age (years)				
	30–39	40–49	50–59	60–69	70–79
Men	0	1	7	15	4
Women	1	1	2	19	4
Total	1	2	9	34	8

On/off	Modified Hoehn and Yahr scale				
	1	2	3	4	5
On	0	9	39	5	1
Off	0	7	37	9	1

Table 2 Tentative QOL-related questions for PD

1	Does your body move on its own accord?	58	Do you feel that your memory is impaired?
*2	Do you experience any difficulty walking inside your home?	59	Do you feel that you can't think straight and forget what you want to say?
*3	Do you experience any difficulty walking outside?	60	Do you ever fall asleep suddenly?
*4	Do you experience any difficulty in rolling over in bed?	*61	Do you daydream?
5	Does it hinder your ability to make the same movements as others?	62	Are you easily angered?
6	Is it a problem for you to move around?	63	Do you feel passive?
*7	Do you experience any difficulty performing tasks which requires the use of hands, e.g., folding laundry?	64	Do you feel weak in the knees?
8	Are you slow at completing activities relating to your hands?	*65	Are you short tempered?
*9	Do you have any chores you no longer perform?	66	Do you feel short-tempered?
*10	Do you experience any difficulty with changing your clothes?	67	Do you have trouble sleeping?
11	Has the body move on its own accord and dropped something?	68	Do you ever worry that you might have a mental illness?
12	Does it interfere with your ability to walk to the bathroom?	69	Does the thought of not being able to move your body make you anxious?
13	Are there times when the medication does not have any effect?	70	Are you depressed?
14	Does the medication wear off quickly?	71	Do you talk in your sleep?
15	You don't have much of a good time.	72	Do you get annoyed?
16	Is it difficult to use medication to control when you are in a good?	73	Do you hallucinate?
17	Do you look forward to the time you take your medicine all day long?	74	Do you have back pain?
18	Do you move around too much and get tired when the medicine works?	75	Is it hard to open your eyes?
19	Is it more difficult to walk when the medicine is working?	76	Is it impossible to open your eyes?
20	Does any part of your body shaking affect your movements?	77	Do you sweat a lot?
21	Is it difficult to walk?	78	Do you not sweat enough?
22	Do you find it difficult to walk because of your sluggishness?	79	Have you gained weight?
23	Is it easy to lose your balance and fall?	80	Do you swell?
24	Does your neck tend to bend down?	81	Is it hard to move your mouth when you speak?
25	Does your upper back tend to bend over?	82	Is it hard to make your voice when you speak?
26	Does your lower back tend to bend over?	83	Do you feel pain anywhere in your body?
27	Does your body lean naturally?	84	Do your fingers bend on their own?
28	Do you try to refrain from bathing on your own?	85	Do you ever felt sick?
29	Do you ever fail to make it to the bathroom on time?	86	Do you yawn a lot?
30	Do you find it difficult to speak and convey what you want to say?	87	Do you have a crazy obsession with anything?
31	Does saliva pool up in your mouth?	*88	Is it difficult to share your hardship with others?

Table 2 (Continued)

32	Is it hard to swallow?	89	Do you feel depressed for no reason?
33	Is it difficult to open your eyes?	90	Do you feel sad for no reason?
34	Do you find it difficult to sleep at night?	91	Do you get frustrated a lot?
35	Is it hard to eliminate feces?	92	Do you often get upset?
36	Does pain in part of your body interfere with your daily life?	93	Are you lonely?
37	Have you ever felt anxious imagining what you would do without the device?	94	Do you feel that people don't care about you?
*38	Have you ever regretted using your therapeutic device?	95	Is it hard to live?
*39	Have you ever wanted to remove the device?	96	Do you feel ashamed of people are looking at your symptoms (movements)?
*40	Have you ever felt that the device is meaningless?	97	Do you feel like your inconveniencing your family (caregivers)?
41	Have you ever feel like your device was shutting down?	98	Have you had people stop you from doing what you want to do?
42	Have you ever sometimes feel like you were being manipulated by the device?	*99	Do you experience any difficulty in having a hobby?
43	Are you bothered by the maintenance of the device?	100	Have you ever had trouble using of the advice of those around you?
44	Have you ever experience any discomfort with the device?	101	Have you ever been restricted from going out of the house because of your device?
45	Are you always worried about operating the treatment device?	102	Have you ever been restricted from traveling because of the device it contains?
*46	Do you constantly think about maintenance of the device?	*103	After installing the therapeutic device, have your social relationships decreased?
*47	Are you concerned about malfunction of the device?	*104	Do you act in a way that is criticized by others?
48	Are you worried about the faults the device?	*105	Are there things you cannot help but doing even if stopped?
*49	Do you feel manipulated by the device?	106	Do you find it difficult to maintain relationships with friends?
*50	Do you feel your fate is destined by the device?	107	Is it difficult to live alone?
51	Do you find it difficult to live your daily life without the therapy device?	108	Are you worried about your future?
52	Are you concerned about the appearance of the part of your body that has the treatment device in it?	109	Is it difficult to get a job?
53	Do you suffer from any memory loss?	*110	Do you experience any difficulty to be useful to society?
*54	Do you feel your thinking speed is slow?	111	Is it hard to do what you love?
*55	Do you have any difficulty to recollect names of objects?	112	Do you find it difficult to make time for your hobbies?
56	Do you have difficulty remembering people's names?	113	Do you have more illnesses to worry about besides Parkinson's disease?
*57	Do you have difficulty making decisions?		

*Adopted items in the PDQ-DAT.

In the tabulation method, the items were scored on a 0–4 scoring system, where "never" was scored as 0, "almost never" as 1, "sometimes" as 2, "almost regularly" as 3, and "regularly" as 4. The factor scores were scored from 0 to 100 and calculated as follows: (sum of scores by item in the domain/32) × 100.

Parkinson's Disease QOL for Device-Aided Therapy（PDQ-DAT）

This is a questionnaire in regards to daily life for those who continue to be treated for Parkinson's disease with therapeutic devices.
Please circle the option most closely related to your experiences within the past month.

【A】 Have you had any of the following problems relating your daily activities？

		Never 全くない	Almost never ほとんどない	Sometimes 多少ある	Almost regularly 時々ある	Regularly かなりある
A1	Do you experience any difficulty walking inside your home? 家の中で歩くことに支障がありますか	0	1	2	3	4
A2	Do you experience any difficulty with changing your clothes? 着替えに支障がありますか	0	1	2	3	4
A3	Do you experience any difficulty walking outside? 外出先で歩くことに支障がありますか	0	1	2	3	4
A4	Do you experience any difficulty performing tasks which requires the use of hands? e.g. folding laundry. 手作業（洗濯物をたたむなど）に支障がありますか	0	1	2	3	4
A5	Do you have any chores you no longer perform? しなくなった家事がありますか	0	1	2	3	4
A6	Do you experience any difficulty in rolling over in bed? 寝返りに支障がありますか	0	1	2	3	4
A7	Do you experience any difficulty to be useful to society? 社会の役に立つことが難しいですか	0	1	2	3	4
A8	Do you experience any difficulty in having a hobby? 趣味の活動に支障がありましたか	0	1	2	3	4

A1-A8 sum Total /32×100
【A】 /100

【D】 Have you had any of the following problems relating the therapy device?

		Never 全くない	Almost never ほとんどない	Sometimes 多少ある	Almost regularly 時々ある	Regularly かなりある
D1	Do you constantly think about maintenance of the device? 治療機器のメンテナンスのことばかり考えていますか	0	1	2	3	4
D2	Do you feel your fate is destined by the device? 治療機器に運命を握られていると感じますか	0	1	2	3	4
D3	Do you feel manipulated by the device? 治療機器に操られている感じがしますか	0	1	2	3	4
D4	Are you concerned about malfunction of the device? 治療機器の故障が不安ですか	0	1	2	3	4
D5	Have you ever wanted to remove the device? 治療機器を外したいと思うことがありましたか	0	1	2	3	4
D6	Have you ever felt that the device is meaningless? 治療機器が無意味だと感じることがありましたか	0	1	2	3	4
D7	After installing the therapeutic device, have your social relationships decreased? 治療機器を入れたことで対人関係が疎遠になることがありましたか	0	1	2	3	4
D8	Have you ever regretted using your therapeutic device? 治療機器を使用していることを後悔することがありましたか	0	1	2	3	4

D1-D8 sum Total /32×100
【D】 /100

【P】 Have you had any of the following psychological problems？

		Never 全くない	Almost never ほとんどない	Sometimes 多少ある	Almost regularly 時々ある	Regularly かなりある
P1	Do you feel your thinking speed is slow? 考える速さが遅いですか	0	1	2	3	4
P2	Do you have any difficulty to recollect names of objects? 物の名前を思い出すことが難しいですか	0	1	2	3	4
P3	Do you act in a way that is criticized by others? 周囲から非難される行動をすることがありますか	0	1	2	3	4
P4	Do you have difficulty making decisions? 判断力に支障があると思いますか	0	1	2	3	4
P5	Do you daydream? ぼーっとすることがありますか	0	1	2	3	4
P6	Are there things you can not help but doing even if stopped? 止められてもやめられないものがありますか	0	1	2	3	4
P7	Are you short tempered？ 怒りっぽいですか	0	1	2	3	4
P8	Is it difficult to share your hardship with others? 自分の苦しみは周りに伝わりにくいですか	0	1	2	3	4

P1-P8 sum Total/32×100
【P】 /100

* To be filled by hospital staff

Facility name: _____   Patient age: _____   Gender: Men/Women

H&Y stage: when ON _____ , when OFF _____   DATE of start: _____ months ago

Summary Index _____ /100

Fig. 1 Parkinson's disease quality of life questionnaire for patients on device-aided therapy (PDQ-DAT). The questions from the original Japanese version used in the statistics are also included.

The summary index was calculated by dividing the sum of the three scores by 3, with lower scores indicating a better QoL and higher scores indicating a worse QoL.

Ethical considerations

This study was approved by the Ethics Committee of Fukuoka Mirai Hospital (approval number: 202001-1, date of approval: February 12, 2020). In accordance with the Declaration of Helsinki, the study was conducted after obtaining informed consent from all participants. Patients who underwent DBS in our hospital were asked to confirm their willingness to agree or disagree with the "Consent to use clinical data for research" section of the surgical consent form. In addition, verbal informed consent was obtained before the questionnaire was administered. To ensure patient anonymity, personal information was managed separately with encryption and linkage tables.

Results

Factor analysis was performed on the results of the prototype scale using the statistical software JMP Pro, version 15.1.0 (SAS Institute Inc., Cary, NC, USA). A total of 113 items were analyzed, and the main factor was used to extract various components. The promax oblique rotation method was used under the assumption that there was a correlation between the subscales.

The number of factors was examined in the initial analysis, and as a result, three highly interpretive factors were adopted. Items were selected through a second and subsequent factor analysis. The criterion for deletion of items was set to be less than 0.4 factor loadings after rotation, and the analysis was repeated while confirming that three was the appropriate number of factors based on the difference in eigenvalues between the factors and the magnitude of the slope of the scree plots. The items that met the deletion criterion were eliminated through a fifth repeated factor analysis, leaving 77 items that met the statistical criteria.

The 77 items were reviewed by the relevant professionals with the following deletion criteria; intersection of multiple factors, factor loadings of 0.5 or less after rotation, suspected semantic overlap within a factor, lack of clarity in item representation, and semantic deviations within a factor. A final analysis was performed on 24 items selected under these specific conditions. As a result, the 24 items were classified into three factors, each consisting of eight items. The factor names were discussed based on similar concepts between each item.

Based on the results of the final factor analysis, Cronbach's alpha coefficients were obtained and verified to be internally consistent (Table 3), and the absence of interfactor correlation confirmed that the three factors were independent of each other (Table 4).

Discussion

In this study, we aimed to develop a QoL assessment scale for patients on DAT-PD that would better evaluate their QoL by including the influence of the therapeutic devices. For this purpose, we analyzed data from interviews with 13 patients with PD undergoing DBS and extracted the items thought to affect their QoL, creating a draft questionnaire consisting of 113 items. This questionnaire was administered to 54 other patients undergoing DBS, whose data were examined for reliability and validity by factor analysis. Finally, a 24-item scale was developed, which we named the "Parkinson's Disease Quality of Life Questionnaire for Patients on Device-aided Therapy" (PDQ-DAT).

Although DAT may improve levodopa-responsive symptoms and reduce diurnal fluctuations, levodopa-refractory symptoms often become more apparent as PD progresses.[5] In some cases, axial symptoms, such as dysarthria[6] and falling, remain or worsen on behalf of improvement in motor function,[7] specific side effects such as apraxia of eyelid opening may occur,[6,8] and diurnal fluctuations may recur while DAT is used,[9] leading to a somewhat different clinical course compared with that when drug therapy alone is used.[10] DBS requires regular battery replacement and charging, restrictions on daily life to avoid electromagnetic interference, and risks of electrode and battery problems.[11–13] Similarly, LCIG has drawbacks such as morning and evening drug cassette pump operation, carrying a pump weighing about 500 g, gastrostomy and catheter problems, such as occlusion and removal, resulting in approximately one in four people eventually stop using LCIG.[14,15] Thus, the negative impact on the QoL cannot be ignored.

The current assessment of PD symptoms in clinical studies is based on the Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS), which is a modification of the UPDRS,[16] and the Nonmotor Symptom Questionnaire (NMSQuest)[17,18] for non-motor symptoms. Compared with the conventional UPDRS, the MDS-UPDRS has an additional item on non-motor symptoms. Parts I and IV are essentially a patient's self-assessment, but a caregivers' assessment is also acceptable. Part III is a physician-centered assessment; thus, it does not depart

Table 3 Factor loadings using promax rotation

Factor	Items	Factor loadings			Final communality estimates	Cronbach's α
		1	2	3		
Daily activities	Do you experience any difficulty walking inside your home?	**0.823**	−0.107	−0.240	**0.664**	**0.861**
	Do you experience any difficulty with changing your clothes?	**0.801**	−0.021	0.058	**0.66**	
	Do you experience any difficulty walking outside?	**0.767**	−0.126	−0.135	**0.573**	
	Do you experience any difficulty performing tasks which requires the use of hands, e.g. folding laundry?	**0.702**	−0.119	0.068	**0.512**	
	Do you have any chores you no longer perform?	**0.674**	0.066	0.101	**0.504**	
	Do you experience any difficulty in rolling over in bed?	**0.632**	0.071	0.169	**0.486**	
	Do you experience any difficulty to be useful to society?	**0.574**	0.343	0.038	**0.496**	
	Do you experience any difficulty in having a hobby?	**0.547**	0.053	0.273	**0.443**	
The therapy device	Do you constantly think about maintenance of the device?	0.042	**0.857**	−0.200	**0.721**	**0.836**
	Do you feel your fate is destined by the device?	−0.062	**0.806**	0.033	**0.654**	
	Do you feel manipulated by the device?	−0.163	**0.789**	−0.056	**0.619**	
	Are you concerned about malfunction of the device?	−0.148	**0.738**	0.074	**0.568**	
	Have you ever wanted to remove the device?	0.169	**0.647**	−0.040	**0.456**	
	Have you ever felt that the device is meaningless?	0.236	**0.536**	−0.013	**0.361**	
	After installing the therapeutic device, have your social relationships decreased?	−0.160	**0.531**	0.286	**0.409**	
	Have you ever regretted using your therapeutic device?	**0.433**	**0.516**	−0.040	**0.48**	
Psychological	Do you feel your thinking speed is slow?	0.032	−0.129	**0.755**	**0.563**	**0.836**
	Do you have any difficulty to recollect names of objects?	0.020	−0.088	**0.737**	**0.535**	
	Do you act in a way that is criticized by others?	0.017	−0.136	**0.726**	**0.516**	
	Do you have difficulty making decisions?	−0.045	−0.009	**0.697**	**0.474**	
	Do you daydream?	0.031	0.233	**0.690**	**0.597**	
	Are there things you cannot help but doing even if stopped?	0.027	0.038	**0.636**	**0.422**	
	Are you short tempered?	−0.055	0.038	**0.568**	**0.323**	
	Is it difficult to share your hardship with others?	0.202	0.066	**0.558**	**0.414**	
Variance explained		4.559	4.272	4.343		
Contribution		18.994	17.799	18.094		

The bold emphasis indicates the "main items (primary loadings)" related to each factor.

Table 4 The correlation matrix for each factor

Factor	1	2	3
1	1.000		
2	0.086	1.000	
3	0.190	0.172	1.000

from the objective assessment method. Such objective assessments are an important study measure for systematic medical evaluations that provide varying outcomes. However, the subjective view of patient-reported outcomes (PROs) is becoming increasingly important due to the changes in the medical care system, such as the prolongation of treatment time and the shift to patient-centered medicine resulting from recent medical advances. The representative PROs make up the QoL assessments.

Disease-specific QoL scales for PD include the 39-item Parkinson's Disease Questionnaire (PDQ-39)[19] and the Parkinson's Disease Quality of Life Questionnaire (PDQL),[20] which have been used to evaluate the QoL after DAT.[21] However, these existing QoL assessment scales created in the mid-1990s do not include items related to therapeutic devices. Hence, the impact of DAT on the QoL is not fully understood in current clinical practice. Considering the above, we recognized the necessity of assessing the QoL of patients on DAT and developed a patient-oriented assessment scale.

The areas of health-related QoL that are common between the PDQ-39 and the PDQL, the representative disease-specific QoL scales for PD, are physical function, mental health, social function, health-related distress, cognitive function, communication, and energy/fatigue. Sleep and rest, eating, and role function can be evaluated only by the PDQ-39, while self-image and sexual function can be evaluated only with the PDQL.[22] Comparing our QoL scale with these conventional scales, the PDQ-DAT consists of three factors: "activity-related," "treatment device-related," and "cognitive-psychological." An original factor related to treatment devices enables us to understand the QoL of patients on DAT-PD, which was not covered by the conventional scales. Furthermore, if we follow the conventional procedure for the quantitative psychological creation of QoL assessment scales, the work begins with the creation of an item pool by enumerating as many items as the expert can objectively conceive of in the process of extracting the basic elements. The PDQ-DAT is unique in that it was created by introducing the perspective of PROs from the point of origin and extracting elements mainly from the patient's own speech.

There are two limitations in this study. First, all included patients were undergoing STN-DBS. Thus, the PDQ-DAT needs to be validated in patients undergoing LCIG to confirm its general applicability to DAT. To this end, we have already started the validation of the PDQ-DAT in a multicenter study that includes LCIG data. As a result, if necessary changes are needed to correct the questionnaire items of PDQ-DAT, we will revise it in the second edition. Second, the English version of the PDQ-DAT was created through a process of translation, back translation, and cross-checking by native US English speakers. However, the validity of the translated version still needs to be verified.

In the future, we plan to administer the PDQ-DAT to patients with PD undergoing other DATs, such as LCIG, to clarify the scope of its expanded application by verifying its versatility. Through the accumulation of clinical data from more patients on DAT, we will examine the optimal timing and the need for readjustment of the assessment items, the relationships with drug adjustment, age dependence, and objective motor and non-motor symptoms, and comparisons among DATs. In addition, development of other language versions of this scale is being considered.

In conclusion, the PDQ-DAT is presently the only scale that can assess the QoL of patients on DAT-PD, including the influence of treatment devices. In the future, the PDQ-DAT might be used not only to understand the effect of treatment and for screening of pathological conditions, but also to help in shared decision-making in medicine by incorporating the patient's sense of burden and values in the selection of treatment methods. It might also be a tool for predicting future outcomes by using the accumulated results. We propose the wide use of the PDQ-DAT in future clinical practice for patients on DAT-PD.

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Conflicts of Interest Disclosure

The authors declare that they have no conflicts of interest. All authors who are members of the Japan

Neurosurgical Society (JNS) have registered online self-reported COI Disclosure Statement Forms through the website for JNS members.

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