

働く世代のPwPにおける ”辛さ”の主観評価と その変動要因について (PwP : パーキンソン病患者)

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1. PD就労促進プロジェクトについて

Parkinson's Job Promotion Project (以下PJPP)は、働く世代にパーキンソン病の症状を発症した松野(PJPP発起人)の辛かった経験から立ち上げられました。

立ち上げ時、PwP5名、PT1名。2022年5月に、松野が急逝。

2023年の今は、PwP2名、PT1名で運営しています。

- 1) Pj1.難病患者への社会的理解を促進するための劇場用映画(松野の原案)の制作を支援する。
- 2) Pj2. 難病患者への理解を促進するための企業向け社員研修プログラムの開発・導入
- 3) Pj3.働く世代へのPwPの調査・広報活動

おもな事業は以下の3つ

本稿では、調査プロジェクトNo.3の結果を報告する。

Subjective Evaluation of "Painfulness" and Its Variation Factors in Working Generation PwPs (Persons with Parkinson's)

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1. About PD's Job Promotion Project

PD's Job Promotion Project (PJPP) was launched based on the experience of Mr. Matsuno (founder of PJPP), who had "painfulness" at his workplace.

At the time of its launch, there were 5 PwPs and 1 PT.

In May 2022, Mr. Matsuno has passed away suddenly.

Now, in 2023, it is operated by 2 PwPs and 1 PT.

There are three main projects as follows,

- 1) Pj1. To support the production of a theatrical film (Matsuno's original idea) to promote understanding of people with intractable diseases in society.
- 2) Pj2. Development and introduction of employee training programs for companies to promote understanding of people with intractable diseases.
- 3) Pj3. Survey and publicize to the "Working Generation PwPs"

This paper reports on the results of the survey project No.3.

2. 「働く世代のPDはつらいよアンケート」の計画

- ◆調査目的
「働く世代のパーキンソン病患者の”辛さ”に対する変動要因を明らかにする」
- ◆目標1
働く世代のPDの「発症から現在まで」の各時期における”辛さ”のレベルを把握する
- ◆目標2
辛さレベルの高低に影響する要因を明らかにし、関係者/関係機関に問題提起する
- ◆調査対象
全国の働く世代(20~60代)のPwP(目標回答数100)
- ◆調査方法
Web回答(回答紙記入も可)
- ◆調査内容1
「発症から現在まで」の過程を14時期に設定し、各時期における辛さを7段階(-3=とても辛い~+3=とても良い)で構成
- ◆調査内容2
「辛かった理由」や「乗り越えるために大切なこと」など(自由記述)

3. 「働く世代のPDはつらいよアンケート」の結果

- ◆調査時期 2021年11月~2022年3月
- ◆有効回答数 n=82
- ◆回答者属性・性別
男性38,女性40(無回答4)
- ◆回答者属性・診断確定時の年齢
平均49.2歳

4. 調査結果. (図1参照)

- ◆目標1に対して、
「発症から現在まで」の過程において、最も辛かった時期は、14の時期の中で、以下の6つの時期であった。
()内の数字は、辛さポイントの平均
(-3=とても辛い~+3=とても良い)
- period #2 [-1.13],
period #3 [-1.24],
period #4 [-1.73],
period #6 [-0.86],
period #9 [-0.79],
period #11 [-0.72]

2. Plan of the

"Working Generation PwPs is Painful" Questionnaire

- ◆Purpose of the survey:
To clarify the variable factors of "painfulness" of PwPs in the working generation.
- ◆Objective1:
To understand the level of "painfulness" at each period of "from the onset to the present" of PwPs in the working generation.
- ◆Objective2:
To clarify the factors that influence the level of "painfulness", and to raise the issue with related persons/agencies.
- ◆Survey target:
PwPs of working age (20s-60s) nationwide.
(target response number of 100)
- ◆Survey method:
Web-based response (paper-based response also possible)
- ◆Survey Content 1:
The process from the onset of the disease to the present was divided into 14 periods, and the level of painfulness during each period was rated on a 7-point scale (-3=very painful to +3=very good).
- ◆Survey Content 2:
"Reasons for the painfulness" and "Important things to overcome the painful" (free description)

3. Results of the

"Working Generation PwPs are Painful" Questionnaire.

- ◆Survey period:
November 2021~March 2022
- ◆Number of valid responses:
n=82
- ◆Respondent Attributes
 - Gender:
Male: 38, Female: 40
(4 non-responses)
 - Age at diagnosis:
49.2 years on average.

4. Results for Goals. (See fig.1)

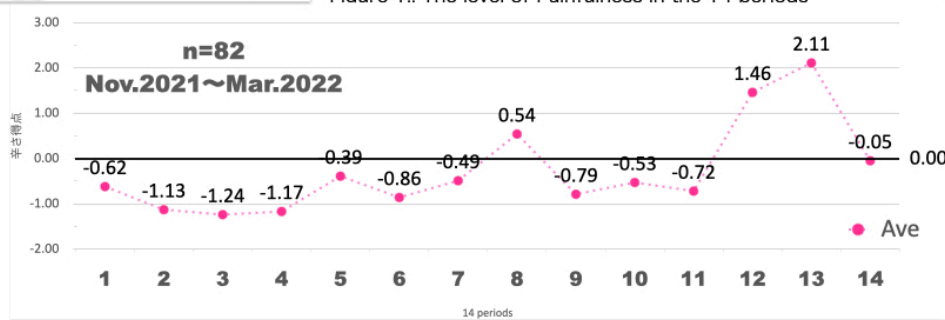
- ◆Against the Goal 1
In the process of "from onset to present", the most painful periods were the following 6 periods out of 14 periods.
Numbers in parentheses indicate the level of "painfulness" (-3=very painful to +3=very good)
 - period #2 [-1.13],
 - period #3 [-1.24],
 - period #4 [-1.73],
 - period #6 [-0.86],
 - period #9 [-0.79],
 - period #11 [-0.72]



Results of the Questionnaire

Working Generations PwPs are Painful

Figure 1.: The level of Painfulness in the 14 periods



(multiple answers)

14の時期	時期毎の平均値	辛かったコメントの件数
1 [PDの症状が出てきた頃は、どんな状況でしたか]	-0.62	
2 [発症後・PDと診断されるまでの期間の状況はいかがでしたか]	-1.13	12
3 [PDと知らされた時の状況はいかがでしたか]	-1.24	11
4 [診断結果を聞いた後の状況はいかがでしたか]	-1.17	
5 [診断結果を仕事関係者に告げる時の状況はいかがでしたか]	-0.39	
6 [診断結果を家族に告げる時の状況はいかがでしたか]	-0.86	3
7 [診断結果を知人(ご近所, 友人, 学校, PTA, 趣味サークルなど)に告げる時の状況はいかがでしたか]	-0.49	2
8 [病状が安定していると感じていた時期の状況はいかがでしたか]	0.54	
9 [病状が進んだと感じた時期の"仕事"の状況はいかがでしたか]	-0.79	21
10 [病状が進んだと感じた時期の"家庭"や"知人"との関係はいかがでしたか]	-0.53	10
11 [仕事を続けられるかどうかを考えていた時期の状況はいかがでしたか]	-0.72	7
12 [デバイス治療(DBS, FUS, Duo-Dopaなど)を検討している時期の状況はいかがでしたか]	1.46	
13 [デバイス治療を受けた後の状況はいかがでしたか]	2.11	
14 [最近の状況はいかがですか]	-0.05	

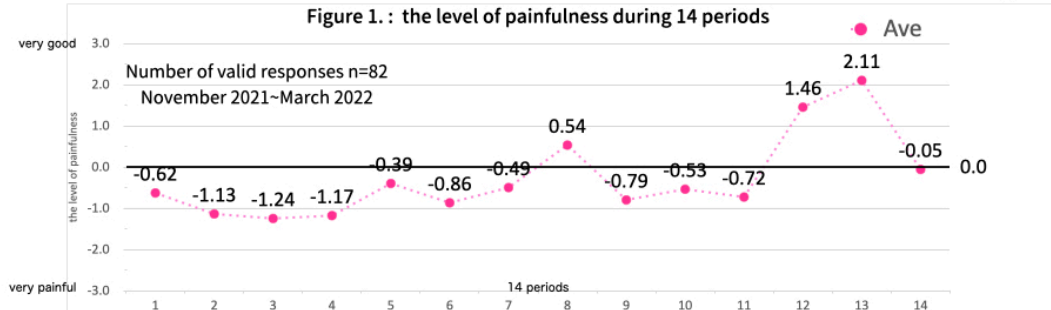
Factors of pain	
a 物事の見方(楽観主義/悲観主義)	15
b 医師の患者心理への理解不足	25
c 医師の専門性の不足	15
d Co-medicalsによる患者心理の理解不足	5
e Co-medicalsの専門性の不足	8
f 運動症状	53
g 非運動症状	26
h 家族のPDIについての理解不足	19
i 会社/職場の合理的配慮の不足	10
j 顧客のPDIについての理解不足	5

Period #	Question	Ave	Comments
2	How was the situation after the onset and before the diagnosis of PD?	-1.13	12
3	How was your situation when you were informed that you had PD?	-1.24	11
4	How did things go after you heard the diagnosis?	-1.17	-
6	How was the situation when you told your family about your diagnosis?	-0.86	3
10	How were your relationships with "family" and "acquaintances" during the period when you felt your disease was progressing?	-0.57	10
9	How was your "work" situation during the period when you felt your disease was progressing?	-0.79	21
11	How was the situation during the period when you were considering whether or not you could continue working?	-0.72	7



Results of the Questionnaire

Working Generation PwPs are Painful



14 periods	Ave.	Number of Comments
1	-0.62	
2	-1.13	12
3	-1.24	11
4	-1.17	
5	-0.39	
6	-0.86	3
7	-0.49	2
8	0.34	
9	-0.79	21
10	-0.53	10
11	-0.72	7
12	1.46	
13	2.11	
14	-0.05	

Reason of painfulness (Multiple answers)	
<input checked="" type="checkbox"/>	View of things (optimism/pessimism) 15
<input checked="" type="checkbox"/>	Lack of understanding of patient psychology by doctors 25
<input checked="" type="checkbox"/>	Lack of doctors expertise 15
<input checked="" type="checkbox"/>	Lack of understanding of patient psychology by comedicals 5
<input checked="" type="checkbox"/>	Lack of comedicals expertise 8
<input checked="" type="checkbox"/>	Movement symptoms 53
<input checked="" type="checkbox"/>	Non Movement symptoms 26
<input checked="" type="checkbox"/>	Lack of understanding by family members 19
<input checked="" type="checkbox"/>	Lack of reasonable accommodations by the company/workplace 10
<input checked="" type="checkbox"/>	Lack of understanding PD by customers 5

Period #	Question	AVE	Comments
2	How was the situation after the onset and before the diagnosis of PD?	-1.13	12
3	How was your situation when you were informed that you had PD?	-1.24	11
4	How did things go after you heard the diagnosis?	-1.17	-
6	How was the situation when you told your family about your diagnosis?	-0.86	3
10	How were your relationships with "family" and "acquaintances" during the period when you felt your disease was progressing?	-0.57	10
9	How was your "work" situation during the period when you felt your disease was progressing?	-0.79	21
11	How was the situation during the period when you were considering whether or not you could continue working?	-0.72	7

◆目標2に対して.

辛さの要因は、以下のような順で件数が多くなっている。

運動症状/運動症状以外 (53件/25件)
 医師の患者心理への理解不足 (25件)
 家族の理解不足 (19件)
 医師の専門性不足 (15件)
 ものの見方(楽観性など) (15件)
 会社/職場の合理的配慮の不足 (10件)

Factors of pain		
a	View of things(optimism/pessimism)	15
b	Lack of understanding of patient psychology by Doctors	25
c	Lack of Doctors Expertise	15
d	Lack of understanding of patient psychology by Co-medicals	5
e	Lack of Co-medicals Expertise	8
f	Movement Symptoms	53
g	Non Movement Symptoms	26
h	Lack of understanding PD by Family Members	19
i	Lack of reasonable accommodation by the Company/Workplace	10
j	Lack of understanding PD by Customers of their company	5

5. 問題提起

- PD確定診断時の医師からの声の掛け方が患者を傷つけているケースが多い
- 運動症状に対して整形外科などの病院に行くケースにおいて、神経内科を紹介してもらおうことなく、長期に苦しんでいる患者が多い。
- 医療、行政、患者コミュニティなどによる家族へのアプローチが弱い
- 企業(特に上司、職場の同僚)の配慮不足もしくは排除志向
- 社会全体の難病への理解不足(弱者やマイノリティに対する理解不足)

◆Against goal 2.

The factors contributing to the “painfulness” in the above 6 periods were, in order of number of responses, as follows.

- Movement symptoms/non-movement manifestations (53cases/25 cases)
- Lack of understanding of patient psychology by doctors (25 cases)
- Lack of understanding by family (19 cases)
- Insufficient expertise of doctors (15 cases)
- View of things (e.g. optimism) (15 cases)
- Lack of reasonable accommodations in company/workplace (10 cases)

Factors of pain		
a	View of things(optimism/pessimism)	15
b	Lack of understanding of patient psychology by Doctors	25
c	Lack of Doctors Expertise	15
d	Lack of understanding of patient psychology by Co-medicals	5
e	Lack of Co-medicals Expertise	8
f	Movement Symptoms	53
g	Non Movement Symptoms	26
h	Lack of understanding PD by Family Members	19
i	Lack of reasonable accommodation by the Company/Workplace	10
j	Lack of understanding PD by Customers of their company	5

5. Issues raised

- In many cases, the way physicians speak to patients at the time of PD definitive diagnosis is hurting them.
- In cases where patients go to orthopedics or other hospitals for motor symptoms, many patients suffer for a long time without being referred to neurology.
- Weak approach to families by medical care, government, patient community, etc.
- Lack of consideration or exclusion orientation by companies (especially superiors and colleagues at work)
- Lack of understanding of intractable diseases in society as a whole (lack of understanding of the vulnerable and minorities)

6. 今後、率先すること

医師がすべきこと

- 患者の心理を理解するためのスキルを身に付けるよう努めること
- 患者の心理学を理解した上で、診断結果を伝えるスキルを習得すること。

神経内科医の学会がすべきこと

- 整形外科医と協力して、パーキンソン病の疑いのある患者が神経内科を早期に受診する様に導くこと。

医師、患者自身(患者コミュニティ)、そして、行政がすべきこと

- 患者の家族へのアプローチを充実すること。
(家族を支援する、家族に理解を促す、家族のいない患者を支援するなど)

企業がすべきこと

- 難病を持つ人々や障害を持つ人々へ配慮することが、企業自身の強みとなることを理解して、雇用環境と職場環境の改善に努めること

私たち全員がしなければならないこと

- 難病理解を促進すること

7. 終わりに

- 今回ご協力頂いたPwPの方々は、辛かった「過去」を振り返るという質問に向き合って、多くのコメントを寄せていただきました。
- 一方、働く世代の難病患者の苦しみは、さまざまな場面で『今』の出来事です。

関係各位の、真剣な取り組みに期待します。

6. Initiatives

Doctors should

- strive to acquire skills to understand patient psychology.
- acquire the skills to convey diagnostic results after understanding patient psychology.

The Association of Neurologists should

- work with orthopedic surgeons to ensure that patients with suspected Parkinson's disease can be introduced to neurology.

Doctors, patients themselves (patient communities), and the administration should

- enrich their approach to patients' families. (Supporting families, encouraging families to understand, supporting patients without family members, etc.)

Companies should

- understand that consideration for people with incurable diseases and people with disabilities will be their strengths, and strive to improve the employment environment and working environment.

All of us must

- promote the understanding of intractable diseases.

7. In closing

- The PwPs who cooperated with us this time faced the question of looking back on their painful 'past' and provided us with many comments.
- On the other hand, the suffering of working-age patients with intractable diseases is a "now" event in many situations.

We have been looking forward to the serious efforts of all concerned.

Table 2-1 "Comments on what was painful" about period#2

Period	Comments
2	診断前 薬ももらえなかった頃
2	症状がいよいよ酷くなり、それでも原因不明が続いた約半年間がとても不安でした。
2	病名が分からないで、それでも、病院に通っていた時期。身体には、異変が起きているのに、病名がつかなかった時。 その前に、家族に身体の異変の事を気づかれない様にかくしていた時。(12さいから、21歳まで野隠していた時。
2	障害者枠での勤務でしたが、薬を飲めば動けるとは限らないので、そのところを理解してもらう事が難しく、給料泥棒みたいな目で見られている気がして休みがちになり、退職しました。
2	サードオピニオンで病名が分かりました。セカンドオピニオンで行った神経内科の先生からは、「肩凝りでしょう。整形外科に行って。」と、冷たくあしらわれたことが辛く、その後は病院に行くのが嫌になってしまいました。
2	(当初)医師からドーパミンブロッカーの薬を処方されたことが分かった。 しかも、病気を隠されたまま、症状があり、仕事を辞めることになったこと
2	何の病気か分からなかった時、何をしたら良いか分からなかったから。
2	どこの病院に行って 検査してもらっても異常無しといわれたこと
2	わかるまでの日々に 職場で理解されず作業が遅いと起こられ続いたこと
2	診断前。震えの理由が分からなかったから
2	一人では歩けず 夫に仕事を休んで病院に連れて行ってもらい 何軒いっても異常なしと言われどうしたらいいかわからず毎日 泣いていました
2	長い間、整形外科を巡り、パーキンソン病と診断されなかったこと。

Table 2-1 "Comments on what was painful"about period#2

Period	Comments
2	Before my diagnosis, when I didn't even get my meds.
2	I was very anxious for about six months when the symptoms finally got worse and still the cause remained unknown.
2	A time when I went to the hospital even though I didn't know the name of my disease. When there was something wrong with my body, but no name was given to it.
2	The neurologist I went to for a second opinion said, "It's probably stiff shoulders. Go to an orthopedist. It was painful, and I hated going to the hospital after that. I have found out the name of my disease through a third opinion.
2	(Initially) I found out that the doctor prescribed dopamine blocker medication. Moreover, that the disease was hidden from me, that I had symptoms, and that I had to quit my job.
2	When I didn't know what the disease was, I didn't know what to do.
2	I've been to every hospital where I've had tests done and been told there's nothing wrong with me.
2	In the days leading up to the diagnosed, I was constantly woken up at work for being slow because my colleague didn't understand me.
2	Before diagnosis. I didn't know why I was shaking.
2	I couldn't walk by myself, so my husband took off work to take me to the hospital, and no matter how many hospitals I went to, Doctors said there was nothing wrong, and I didn't know what to do. I had cried every day.
2	I had had to spend long time to go to orthopedic surgeons, but the doctors never diagnosed Parkinson's disease.

Table 2-2 "Comments on what was painful" about period#3

Period	Comments
3	まさかと思った診断で、今までのように活動出来ないことへの不安を感じた。
3	友人より左足のピッコを指摘され、整形外科や外科など診察を受け、検査技師よりパーキンソンかも…と言われた時
3	一生直らない病気にかかってしまったという精神ショック
3	これまで大きな病気にかかったことがなく、自分が健康であると過信していた上、パーキンソン病と言う難病を知っていたので、病気になったことにショックを受けました。
3	なんとなく予想はしていましたが、いざ診断されると今後の生活など、不安ばかりで辛かったです
3	宣告を受けたのが50歳、働き盛りの時期であり今後仕事を続けられるかどうか、確固たる将来設計が困難になったと感じられたことがとてもつらかった。
3	病気とわかった時
3	治らない病気であると告げられて、ネットで3年後には寝たきりになると書かれているのを読んだ時。
3	最初の診断時の主治医(大学病院)の、パーキンソン病に対する知識の乏しさに幻滅しました!
3	PDと診察された時全く眠れなくなり震えやすくみ足が酷くなったから。
3	診断が確定した数日後、今までみたいに走ったり、自由に散策できないと気づいたとき。

Table 2-2 "Comments on what was painful"about period#3

Period	Comments
3	The diagnosis, which I did not expect, made me feel anxious about not being able to work as I had done in the past.
3	A friend of mine pointed out that I had a disabilities left foot. So I went to an orthopedist and a surgeon. And I was told by the lab technician that I might have a Parkinson's....
3	Mental shock that you have a disease that will never be cured.
3	I had never had a major illness before and was overconfident that I was in good health, plus I knew about Parkinson's disease, an incurable disease, so I was shocked to learn that I was ill.
3	I had somewhat expected it, but when its to be diagnosed, I was so anxious about my future life, etc., it was hard.
3	I was 50 years old when I received the diagnosis, and I was in the prime of my career. It was very hard for me to realize that it had become difficult to have a firm future plan, whether I could continue to work or not.
3	When I found out I was Intractable disease.
3	When I was told that I had a disease that could not be cured and read on the internet that I would be bedridden in three years.
3	I was disillusioned by the lack of knowledge of Parkinson's disease by my doctor (university hospital) at the time of my initial diagnosis!
3	When I was diagnosed with PD, I couldn't sleep at all and my legs were shaking so much.
3	A few days after the diagnosis was confirmed, I realized I couldn't run and stroll freely like I used to.

Table 2-3 "Comments on what was painful"about period#6

Period	Comments
6	発症したとき婚約中でした。結婚はしましたが、相手の親に認めてもらえず結婚式をキャンセルしたこと
6	家族に知らせていない
6	家族に伝えづらかったこと

Table 2-4 "Comments on what was painful"about period#10

Period	Comments
10	家族にも友達にも苦しみを理解されなかった事
10	母に告げるとき
10	家族や友達、全てから理解を得られない事。
10	わかる様に伝えられず、実家の家族に理解をなかなかしてもらえなかった。
10	実の親が病気への理解がなく、責められた事。
10	子どもたちから、パパ電池切れたの?と言われた時
10	家族から誤解を受けている。ぐうたら、だらしない、甘えている、遅すぎる、散らかしてる
10	動けなくてイライラして主人と喧嘩して、でも動けなくて結局助けてもらわないといけなかった時
10	身近な人からの冷たい言葉。
10	主人や姑に仕事を辞めた理由が性格が悪いからと思われていた事

Table 2-3 "Comments on what was painful"about period#6

Period	Comments
6	I was engaged when I developed the disease. I got married, but my partner's parents did not approve and canceled the wedding.
6	Not informing family members.
6	Things that were hard to tell my family.

Table 2-4 "Comments on what was painful"about period#10

Period	Comments
10	That neither my family nor my friends understood my suffering.
10	When I Tell My Mother
10	The lack of understanding from family, friends and all.
10	I could not communicate in a way that they could understand, and my family at home had a hard time understanding me.
10	That my own parents had no understanding of my illness and blamed me.
10	When the kids say, "Daddy, are your batteries dead? When they say, "Daddy, did your battery run out?
10	Misunderstood by family members. Goofy, sloppy, spoiled, too slow, messy.
10	When I got frustrated because I couldn't move and fought with my husband, but I couldn't move and eventually had to get help.
10	Cold words from those close to you.
10	The fact that my husband and mother-in-law thought the reason I quit my job was because of my bad character.

Table 2-5 "Comments on what was painful" about period#9

Period	Comments
9	家族をやしなう
9	職場の同僚から後ろ指をさされているような感じを強く覚え、出勤不能となった。
9	人格を疑われたこと。仕事への信頼をなくした気分で一気に落ち込んだ。
9	職場の環境が悪くなり、人員も減り、全体的にも一人当たりの仕事量が増え、結果的に自分も以前より仕事量が増え、毎日8時間以上の勤務で、ヘトヘト。特に午後は身体も動きが悪くなりきつい。PDだからと、配慮はなく他の方と変わらない仕事量なので、こなすのが大変
9	パソコン作業や、書字が遅く、またすぐに身体が痛み出し仕事はかどらなかつた。
9	介護の必要な息子がいるのでこの子のことができなくなること、いつまでできるか不安
9	仕事をするにあたって、右手が動きにくく、薬が増えていき、結局は減薬のために入院して、薬調整した時のしんどさ
9	仕事をフルタイムでできないと宣告された時
9	何の説明もなく、バツサリ仕事を減らされたこと、差別を感じた
9	パーキンソン病だけが原因だったか解りませんが、仕事が思うようにできなくなり上司に相談。そのことで、逆に職場環境が悪くなり休職することに。復職を希望して、復職プログラムを受けたが、パワハラのような無視されてるような状況で、復職を諦め退職を選ばざるを得なかった。再就職を目指していたが、自信がなく再就職には至らず。また、気持ちの切り替えができていない。
9	最後の上司のパワハラで適応障害になり、必要とされてないと悟った時。思い出すたびに泣けます。
9	仕事量が増え、残業も増え、身体が悲鳴をあげた時、
9	作事中に症状が出て、迷惑をかけてしまったこと
9	好きだった看護師の仕事が続けられないことに対する絶望感。
9	料理ができない時
9	会社を経営していたので 対外的に自分がパーキンソン病だと言うことが出来なかつた
9	左手の動作緩慢(キーボードを叩きづらい。入力に時間が掛かる) 仕事の効率が悪いため。以前できていたことができない事の自己嫌悪。
9	会議で上手く発言できなくなった、頭の回転が悪くなり、疲れやすいため
9	眼鏡店勤務でして、手の震えを見られたお客様が「ほかの方に代わってくださいと、指摘された。仕事の内容は自信がったのツラかつた。
9	仕事をするいじょうは、PDは関係なく、他の人と同じようにしないといけない、さらには逆にできない人の分もしないといけない状況は辛い。病気のことの配慮はなかつた
9	子どもの1人がまだ小学生だったので、成長を見届けられないかもしれないと思うととても悲しかつた。

Table 2-5 "Comments on what was painful"about period#9

Period	Comments
9	I can't get my family up.
9	I strongly felt like I was being pointed at by a colleague at work, and I was unable to go to work.
9	Being suspected of personality. I was depressed all at once because I felt like I had lost my trust in my work.
9	The work environment has deteriorated, the number of employees has decreased, the workload per person has increased, and as a result, I have to work more than 8 hours every day. The workload is the same as other people's without any consideration for the fact that I am a PD, so it is very hard for me to handle it.
9	I have gotten slow typing the keyboard and writing. My body started to hurt again soon and I couldn't get to work.
9	I have a son who needs caregiving and I'm worried how long I will be able to do so.
9	When I was working, my right hand was difficult to move, and the medicine increased. Finally, I was hospitalized to reduce the medicine. It was hard when I adjusted my medication.
9	It was hard when I was told that I couldn't work full-time.
9	Without any explanation, the work was reduced. I felt discrimination.
9	I consulted with my boss because it started to interfere with my work. Because of that, the work environment deteriorated and I had to take a leave of absence. Even when I was back to work, I was harassed as if I was ignored by employees around me, so I had to retire. I was aiming to get a new job, but I lost my confidence and I can't get a new job. I haven't been able to change my mind yet.
9	I became an adjustment disorder due to my boss's power harassment, and I felt that I was not needed. I cry every time I remember it.
9	When the workload increases, overtime work increases, and my body screams a lot.
9	I felt hopelessness about not being able to continue the work of a nurse that I loved.
9	I get painfulness in my heart when I can't cook.
9	I ran my own company, so I couldn't outwardly tell people I had PD.
9	Sluggish left hand movement (difficulty tapping on the keyboard. It takes time to type) Poor work efficiency. That makes me self-hatred.
9	No longer able to speak well in meetings, due to slow thinking and fatigue.
9	I was working in an optician's store and a customer saw my hand trembling and pointed out that I should be replaced by someone else. I was confident in my work, but it was painful.
9	As long as I work, I have to do the same as other people, regardless of the PD. However, it's hard to be in a situation where I have to work for people who can't work well. There was no consideration for illness in the workplace.
9	One of my children was still in elementary school, so I was very sad to think that I might not be able to watch him grow up.

Table 2-6 "Comments on what was painful"about period#11

Period	Comments
11	仕事をまだ続けられるか悩んだ末に、接客であることから辞めざるを得なくなったこと。
11	子供たちがまだ小学生で、子育てや親としてやりたいこと、すべきことがたくさんあったため、難病を抱えての将来が不安になった。
11	仕事にやりがいを感じて来てた時の退職、部署異動等他の選択が無かった
11	同僚や生徒達に病名を告げることが出来ず、仕事を辞めることになったこと
11	当時の上司と信頼関係が持てず、PDであることを相談できないまま仕事をやめることに決めたこと
11	仕事が続けられないと感じた時
11	仕事をやめたこと

Table 2-7 "Comments on what was painful"about other period

Period	Comments
7	自分の辛い状況がうまく言語化できず、周りにわかりやすく伝えられなかったこと
7	あまり辛かったことはないが、周囲に言っていなかったので、歩き方がおかしいことと声が小さいことを指摘されて、言えないのが辛かった。
	身体をスムーズに動かせなかった。 仕事が出来なかった
	疲れる
	足が前に出なくてつまづいた
	患者と研究者の役割を切り離さなければならないこと、違う属性の中、一人で状況に直面すること
	日常の動作が鈍くなること。素早く(今まで通りに)動けない
	運動することが好きだった私が足を引きずりだしてから、マラソンに参加したりジョギングが出来なくなったこと。
	全般的に、患者の話に耳を傾けない。
	去年出来たことが、今できないことを実感するとき
	衝動制御不能に陥ったとき
	家族が日常生活から私の病状の進行を感じたときに、状況を指摘してもらっているが、現実をそのまま受け止めるには時間を要した。病状の進行は多くの情報より確認できるが、分かっているつもりでも現実を受け入れるのに少々時間を要した。

Table 2-6 "Comments on what was painful"about period#11

Period	Comments
11	After wondering so long time if I could still keep my job, I had to quit because I was in a hospitality business.
11	Since my children were still in elementary school and I had so many things I wanted to do and should be doing as a parent and raising them, I became concerned about my future with an incurable disease.
11	I was coming to feel fulfilled with my work, I had no other choice but to resign from my job or to transfer to another department.
11	It was really hard to quit my job without being able to tell my colleagues and students the name of my illness.
11	Deciding to quit my job without being able to discuss my PD with my boss at the time because I didn't trust him.
11	When I felt I can't keep my job.
11	Stopping work.

Table 2-7 "Comments on what was painful"about other period

Period	Comments
7	Inability to verbalize my difficult situation and communicate it clearly to others
7	It was not very painful, but since I had not told people around me, they pointed out that I walked funny and had a low voice, and it was hard for me not to tell them.
	I couldn't move my body smoothly I couldn't do my job.
	get tired
	My feet wouldn't move forward and I tripped.
	Having to separate the roles of patient and researcher, facing the situation alone, with different attributes
	Slowness in daily activities. Inability to move quickly (as before).
	I used to love to exercise, but since I started limping, I have not been able to participate in marathons or jog.
	In general, they do not listen to their patients.
	When you realize that what you were able to do last year, you cannot do now.
	When impulse control is out of control
	When my family sensed the progression of my disease from my daily life, they pointed out the situation to me, but it took time for me to accept the reality as it was. The progression of my disease was confirmed by a lot of information, but it took me some time to accept the reality even though I thought I knew what was going on.

Table 2-7 "Comments on what was painful" about other period

Period	Comments
	オンの時は普通に動けるのに、いつくるかわからないオフに怯える日々
	今まで出来た作業ができなくなってきたてイライラが募ってきた事。
	遺伝性かもしれないこと
	動きたいときに動けないこと
	子供の学費等、経済的な不安、地域社会との距離感
	私が若年性パーキンソン病であることは家族にとって当たり前のことである為、OFF時でも誰もなんとも思わない。
	動作が緩慢、便秘、頻尿がでた。
	振戦が出てきて動作緩慢になった
	どんどん進んでいく時
	わすれました
	今。診断確定から10年。
	腰痛は以前からあったが、急に腰が曲がり歩行困難になったこと
	電車を降りて動けなくなる。
	現在進行形です。1年以上就活に苦労し、何とか障がい枠で決まりましたが、若年性PDも発症からの経過年数が長いと50歳以下でも認知症になりうるという話を聞いてショックでした。現在はDBS手前で悩んでおります。仮にDBSでオフが緩和されても、病の進行が進み認知症になってしまった時のことを考えると複雑です。
	仕事
	多すぎてわからない。薬を飲めば元に戻った感じになって病気のことを忘れるが、薬が切れると自分がパーキンソン病だった再確認する辛さが毎日続くこと
	薬飲んでいるので、献血ができなくなった。
	まだ初期なのですが、自分の頭で考える動きと実際の動きにずれがあり、思うように動けていないこと
	歩きづらくなった時
	人前での手足の震え(病気を知らない人に対して)。緊張しているとかどう思われるか不安なため
	歩けなくなった。
	先の見えない絶望
	突然、階段を上るときに足が上がらなくなった最初の瞬間。兆候は以前からあったものの、急激に症状が悪化しました。

Table 2-7 "Comments on what was painful"about other period

Period	Comments
	I can move normally when I'm on, but I dread the day when I'm off, when I don't know when I'll be off.
	The fact that I am no longer able to do the tasks I used to be able to do, and I am getting frustrated.
	That it may be hereditary.
	Being stuck when you want to move.
	Financial concerns such as school fees for children, distance from local community
	No one thinks anything of it when I am OFF because it is a normal thing for my family to know that I have juvenile Parkinson's disease.
	Sluggish movements, constipation, and frequent urination.
	Tremor and slow movement.
	When you go on and on and on
	I forgot
	Now. 10 years since the diagnosis was confirmed.
	Having had lower back pain for some time, but suddenly having difficulty walking due to a bent back.
	I get off the train and get stuck.
	It's ongoing, I struggled to find a job for over a year and managed to get one with a disability slot, but I was shocked to hear that juvenile PD can also lead to dementia even under the age of 50 if the years since onset are long enough. Currently, I am struggling before DBS. Even if DBS alleviates my off-going symptoms, it is complicated to think about what will happen if the disease progresses and I end up with dementia.
	work
	I don't know, it's just that every day when I take my meds, I feel like I'm back to normal and forget about the disease, but when the meds wear off, it's a daily reminder that I had Parkinson's.
	I can no longer donate blood because I am taking medication.
	It is still early days, but there is a discrepancy between the movements I think of in my head and the actual movements, and I am not able to move as much as I would like.
	Trembling of limbs in public (to people who do not know the disease). Nervousness or anxiety about how they will be perceived.
	I couldn't walk.
	Hopelessness with no foreseeable future
	Suddenly, the first moment I couldn't lift my leg up the stairs. The signs had been there for some time, but the symptoms suddenly worsened.
	Suddenly, the first moment I couldn't lift my leg up the stairs. The signs had been there for some time, but the symptoms suddenly worsened.

Table 2-7 "Comments on what was painful" about other period

Period	Comments
	突然、階段を上るときに足が上がりなくなった最初の瞬間。兆候は以前からあったものの、急激に症状が悪化しました。
	OFFで動けない
	地元にしかりした決めた心の通う信頼しあえる主治医がないこと
	字が書きづらくなり、仕事がかどらないし、速記ができない、人前で箸が持ちづらい
	背中が強ばりが取れないので辛い。(鍼灸院に週に2~3回通っているが、...)
	根治療法が無く進行性の病気である事
	からだの自由が若干悪くなり始めて、難病が克服できないと感じていた
	2018年腰椎の病気から2か月半のベッド上安静となり、PDが一気に悪化して、生活のあらゆる自由がうばわれ、孤独と絶望につぶれました。
	薬のオンオフ
	これからどうなっていくのか分からず、不安だった
	寝たきりになってしまう、どうしようと思った。治療法についての知識不足。
	薬が効かず歩けない
	治療方法がなく医師により方針が異なるそうであり先が見えないこと
	気力がわかなくなった 寝てばかりだった
	後ろ向きに倒れた
	信頼していた人がいなくなったこと
	リラックスするとむずむず症状が出て、とにかく不快
	医者にも見捨てられてる、医者にキツク言われた事
	進行性
	仕事をしていく上で、支障が出るかもしれないと思った時、会社仲間に告知する時に理解が得られなかった時(仕事上助けたくも無いし、協力したいとも思わないといわれた時)

Table 2-7 "Comments on what was painful" about other period

Period	Comments
	OFF and stuck.
	Lack of a local doctor with whom I have a firm decision and can trust my doctor with my heart.
	Difficulty in writing, difficulty in getting work done, shorthand, and holding chopsticks in front of others
	It is hard because I can't get rid of the stiffness in my back. (I go to an acupuncture clinic 2-3 times a week, but...)
	The disease is progressive with no curative treatment.
	My bodily freedom began to deteriorate slightly, and I felt that my incurable disease was insurmountable.
	In 2018 I was on bed rest for 2.5 months from a lumbar spine illness and my PD deteriorated quickly, all freedoms of life were taken away and I was crushed by loneliness and despair.
	Medication on/off
	I was worried, not knowing what was going to happen.
	I'm going to be bedridden, what am I going to do? Lack of knowledge about treatment methods.
	Medication doesn't work, can't walk.
	There is no treatment method and different doctors have different policies, so the future is uncertain.
	I lost my energy. All I did was sleep.
	He fell backwards.
	The loss of someone I trusted.
	When I relax, I get itchy symptoms and it's just uncomfortable.
	The doctors have abandoned me, the things the doctors have told me so harshly. progressive (worsening disease or condition)
	When you feel that you may be hindered in your work, or when you cannot get understanding when notifying your company colleagues (when they say they do not want to help you or cooperate with you in your work).