Improvement Process of Unconvincing Outcomes in Patients with Parkinson’s Disease Following Deep Brain Stimulation: Analysis of Interview Results using a Modified Grounded Theory Approach (M-GTA)

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Abstract

Background & Aims: To obtain a better guide for the nursing care of patients with Parkinson’s disease undergoing long-term care by describing the improvement of unconvincing results after deep brain stimulation (DBS).

Methods: Using a modified grounded theory approach, semi-structured interviews were performed with 11 patients (aged 50-80 years) who had undergone 5-14 years of DBS before this study.

Results: The improvement process of unconvincing outcomes in patients with Parkinson’s disease following DBS starts with the patients’ attempts to share the unconvincing outcomes, followed by repeating the cycle of ambiguity in unconvincing outcomes and becoming saddled with them under maintainable support, and ends in achieving realization of the improvement plan.

Conclusions: Patients could hide their unconvincing outcomes from the other patients while struggling for a long time, and they stated that they tried to cope with unconvincing outcomes by reconsidering the meaning of DBS. Its course differs for each person. These findings may be helpful in improving long-term care, enhancing patient satisfaction and quality of life, and in educating patients considering post-DBS care.

Introduction

Parkinson’s disease (PD) is a progressive neurodegenerative disease with an unknown cause, and a cure has not yet been identified. Since aging is a risk factor for PD onset, the number of patients with PD is increasing with the advent of a super aging society. Worldwide, the number of patients with PD is estimated to reach 30 million by 2030, which can cause significant economic burden.1 In 1987, a surgical procedure known as deep brain stimulation (DBS) was developed to help control symptoms in patients with PD who had ceased responding to pharmacotherapy.2,3 DBS has been administered to more than 100,000 patients, worldwide.4 Towards the end of the 1990s, DBS was introduced in Japan and has been covered under national health insurance since 2000; the number of patients with PD who have undergone DBS is now drastically increasing. In Japan, DBS was being administered to 668 patients by 2002. However, it rapidly increased to more than 7,000 in 2014.5

Although medical care for patients with PD is nearly free in Japan, DBS is expensive (i.e., the device itself costs 2,897,600 yen and the surgery costs 713,500 yen);6 however, DBS is believed to be effective for 3-6 years.7,8 Although DBS can aid in ameliorating movement disorders, the quantitative survey, PDQ-39 showed that negative outcomes, such as speech impairments can occur, which can degrade patients’ quality of life.9 Moreover, some patients experience adverse psychiatric events post-DBS.9 Major et al. reported that 25% of patients with PD had experienced dissatisfaction with
their outcome following DBS during the 12 months post-surgery. However, no study has examined the dissatisfaction with regard to nursing care for patients with PD post-DBS.

Although DBS may have some advantages for patients with PD, it is difficult to definitively predict the effectiveness of DBS in advance before the operation because the pathological condition differs among individuals. Therefore, this has the potential to cause DBS-related disappointment or unconvincing outcomes for patients. Hence, a critical issue is to understand the improvement process of unconvincing outcomes in patients with Parkinson’s disease following deep brain stimulation in order to provide a convincing and satisfactory medical service for patients.

A few studies have focused on the errors in the decision-making process, pre-DBS and the short-term nursing care experiences of patients post-DBS. However, little attention has been given to long-term care. Additionally, while several studies have addressed successful cases of DBS accompanied by convincing outcomes and satisfaction, little attention has been given to cases of DBS where patients receiving long-term care are left with feelings of unconvincing outcomes and disappointment.

Patients in the advanced stages of PD often find it difficult to speak or describe their experiences post-DBS due to complications such as dysarthria, dysgraphia, and psychiatric symptoms. Hence, to provide quality nursing care for patients with PD, it is important to understand the variable subjective experiences from patients’ perspectives. An understanding of DBS-associated unconvincing outcomes is necessary and helpful to enhance the satisfaction and quality of life of patients with PD post-DBS receiving long-term care. Thus, we clarified the current improvement process of patients with PD who received long-term care post-DBS and who were dealing with DBS-related disappointment and unconvincing outcomes.

Theoretical background of being unconvinced

According to a concept analysis on being convinced, it is a state in which one can understand a certain event by recognizing one’s value in it and the benefits one should expect from it; one can also accept the event cognitively and emotionally. Convincing is a fluid process that is created subjectively in the relationship of trust with others. Furthermore, convincing entails multiple factors and is dynamic.

In the process of convincing, an association is observed among ‘satisfy’ and ‘consent to’ and ‘understand’. In English, ‘convince’ and ‘assure’ are similar terms and are used an equivalent number of times. In Japan, studies involving the terms ‘convince’, ‘assure’, and ‘satisfy’ are considered to have quite different meanings.

Conversely, unconvincing is the antonym of convincing. We can conclude from convincing that being unconvinced is state which one cannot understand a certain event by recognizing one’s value in it and benefits one expect from it and cannot also accept the event cognitive and emotionally. Being unconvincing is a fluid state that is not created subjectively in the relationship of trust with others. Furthermore, being unconvinced entails multiple processes and is dynamic. Being unconvinced is associated with ‘dissatisfaction’ and ‘disappointment’; ‘dissatisfaction’ is caused by an unsatisfactory result. Disappointment occurs when there is a difference in expectations. These terms differ from being unconvinced in which a concept described to an individual does not result in an outcome that the individual wants. Therefore, in this study, it was important to discriminate being unconvinced from dissatisfaction and disappointment. Additionally, being unconvinced is a concept that is being newly established in this study, which is used outside Japan for decision making. However, few studies have been conducted on unconvincing outcomes in healthcare.

This study aimed to elucidate the subjective experiences of patients with PD who received long-term care post-DBS and who were in a state in which they were unable to understand a certain event by recognizing its personal value or expected benefits, and were unable to accept the event cognitive and emotionally. Further the patients were in a fluid state that was not created subjectively in the relationship of trust with others.

Definition of terms

Being unconvinced

In this study, being unconvinced is state which one cannot understand a certain event by recognizing one’s value in it and benefits one expect from it and cannot also accept the event cognitive and emotionally. It is a fluid state that is not created subjectively in the relationship of trust with others.

Long-term care

In this study, long-term care is defined as care that occurs for more than 5 years following DBS.

Methods

Research design

Qualitative factor search type design

Period of data generation

June 2015 to March 2018

Participants

The survey was performed in the A and B prefectures in the Japan Parkinson’s Disease Association (JPDA), which assisted with mailing out a questionnaire to 170 of its members. The questionnaire determined members’ basic information regarding whether they had undergone DBS and whether they were willing to engage in a face-to-face interview. Participants were selected from among those who had expressed a willingness to be interviewed and who matched the following selection criteria: (a) at least 5 years post-DBS; (b) able to communicate either verbally or in writing; (c) either stage 4
or 5 on the Hoehn and Yahr scale; (d) no impairment in cognitive function; and (e) in a stable condition.

Data generation
The data generation was conducted using the method of qualitative research by Gregg et al. One semi-structured interview was conducted with each participant at his/her convenience. An interview guide determined basic patient attributes, changes in their lives and conditions post-DBS, and their difficulties following unconvincing DBS outcomes and how they coped and processed them. Variables, such as age at Parkinson's disease onset, background decision-making for DBS, and DBS outcomes, were recorded. In the interview, the researcher ensured that the participants recalled the events in chronological order. If the interview with the participants was recorded using an IC recorder, their responses were written verbatim.

In order to supplement the data generation, during these interviews, a researcher visited the participants’ home or rooms in their respective facilities and collected observational data. Some participants found it difficult to talk about their experiences because of their advanced PD. Therefore, non-linguistic data based on the observations during participation was used as a reference for the analysis. For participants who were unable to speak, the researcher conducted the interviews through writing. To ensure the trustworthiness of the interviews, participants were asked to confirm their comprehension of words or sentences by repeating those that were difficult to understand.

The researcher also consulted the participants about the collected data and the interpretations derived from the observations. The participants were informed that the researcher was a nurse before beginning the interview. During the observation, life support service and assistance was continued for participants that required them. As a rule, family caregivers were asked to be present for the interview. If the researcher found it difficult to understand the participant’s language or in case the participants’ memory failed, the data were confirmed with the family caregivers, thus maintaining data trustworthiness. If the participants or their caregivers presented a note of medical treatment, it was included in the analysis.

Data analysis
The researcher used the modified grounded theory approach (M-GTA), which originated from the grounded theory approach based on the theory of symbolic interactionism. The grounded theory provides sufficient information regarding the explanations and predictions of human beings within the scope of precisely set restrictions: this approach may possess superior interpretability when compared with the results obtained using other methods, including quantitative methods. Additionally, M-GTA values the practical utilization of research results as a role of research. In this study, the use of M-GTA was appropriate because (1) the theme in this study was a process, (2) we elucidated the current improvement process of patients with PD who received long-term care post-DBS and who were dealing with DBS-related disappointment and unconvincing outcomes. Analytical targets were set as patients with PD who had received DBS > 5 years prior to the study onset and who felt DBS-related outcomes were unconvincing.

M-GTA was considered a suitable method because it could assist with understanding the unspoken, deeper implications and experiences of this participant population. Data analyses proceeded as follows: (1) After reading the verbatim record, the analysis theme was set as “The improvement process for dealing with DBS-related unconvincing outcomes in patients receiving long-term care post-DBS.” (2) To enhance transferability, analytical targets were set as patients with PD who had received DBS > 5 years prior to the study onset and who felt DBS-related outcomes were unconvincing. (3) The participants were selected in the first analysis, as the narrative content of their data was rich. The analysis theme was then focused on to generate a concept. (4) While continuing to compare similar and contrary examples of concepts, new concepts were simultaneously generated. The following is an example of concept generation. (5) When there were no new concepts, similar examples, or contrary examples, a theme was considered theoretically saturated. (6) The relationship between created concepts was examined. (7) Categories were created using a set of concepts. (8) Relationships among the concepts and among the categories were diagrammed to produce a story line. To ensure the dependability and confirmability of the analysis, the researcher used the M-GTA analysis worksheet. Furthermore, to ensure the rigor and credibility of the analysis, this study was supervised by one researcher specialized in M-GTA and one researcher specialized in nursing. The following is an example of the concept generation process obtained from participant G. “(Post-DBS) Mr. XX did not require PD medicine. I thought this would be nice and I had requested that DBS be performed by the same doctor.” “The doctor told me that nobody for whom the doctor had ever performed surgery on had lost the ability to write. But that is what actually happened to me. (Before I underwent surgery) I had never imagined that I would lose the ability to write.” The generated concept was as follows: “(Before I underwent surgery) I had never imagined that I would lose the ability to write.” (G).

The researcher made analysis worksheets after reading the verbatim records and wrote in variation category based on the underlined text. The researcher construed the point as “patients losing of hope due to DBS-related disappointment” as [Loss of hope due to disappointment], which represents the definition of the thought most clearly. The researcher wrote the definition in the analysis worksheet, and searched for a similar variation. One analysis worksheet was completed for each category. A written analysis worksheet was used to generate an association between processes and relationships; i.e. it can be presumed that an effect on the relationship.
between Ms. G and her doctor would occur as a consequence of **[Loss of hope due to disappointment]**. Therefore, the relative concept needed to be determined. The same method was used for other concepts; 15 categories were finally generated.

**Ethical considerations**

This study was approved the ethics review boards of epidemiological studies and medical and health research involving human subjects in the university. First, the research review boards approved the investigation in A prefecture (approval number 27-13). However, the survey did not lead to theoretical saturation. Therefore, an additional study in B prefecture was planned and approved by the review boards (approval number 2017-117).

**Results**

1. **Summary of participant characteristics**

   Table 1 summarizes participant characteristics. Eighty-two individuals responded to the questionnaire survey (response rate, 48.2%) of which, 19 participants indicated an intention to cooperate in the investigation.

<table>
<thead>
<tr>
<th>Case</th>
<th>Age</th>
<th>Sex</th>
<th>Duration of PD (y)</th>
<th>Time between DBS and this study (y)</th>
<th>Family caregiver participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>60s</td>
<td>Female</td>
<td>14</td>
<td>9</td>
<td>+</td>
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<tr>
<td>B</td>
<td>70s</td>
<td>Female</td>
<td>25</td>
<td>10</td>
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<td>C</td>
<td>80s</td>
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<td>15</td>
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<td>D</td>
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<td>Female</td>
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<td>E</td>
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<td>60s</td>
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<td>60s</td>
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<td>J</td>
<td>50s</td>
<td>Female</td>
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<td>12</td>
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<tr>
<td>K</td>
<td>60s</td>
<td>Male</td>
<td>21</td>
<td>12</td>
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</table>

Table 2 Categories and concepts of improvement process of unconvincing in patients with Parkinson’s disease post-DBS undergoing long-term care

<table>
<thead>
<tr>
<th>Category</th>
<th>Concept</th>
<th>Definision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempt sharing the unconvincing outcomes</td>
<td>Loss of hope due to disappointment</td>
<td>Loss of hope following complaints of DBS-related disappointment.</td>
</tr>
<tr>
<td></td>
<td>Having distrust of her (his) doctor</td>
<td>Become suspicious of their doctors.</td>
</tr>
<tr>
<td></td>
<td>Complaining of dissatisfaction</td>
<td>Complaining of a negative outcome post-DBS.</td>
</tr>
<tr>
<td></td>
<td>Seeking help from peers with unconvincing outcomes</td>
<td>Looking for someone with the same unconvincing experience.</td>
</tr>
<tr>
<td>Becoming saddled with unconvincing outcomes</td>
<td>Feeling of mum’s the word</td>
<td>Experiencing difficulty in telling the doctors and people around them about their disappointment with DBS.</td>
</tr>
<tr>
<td></td>
<td>Lose peers</td>
<td>Feeling that the DBS results did not meet their expectations, and thus they had to bear the agony of unconvincing not being able to understand that reality.</td>
</tr>
<tr>
<td>Submission to authority</td>
<td></td>
<td>Oblied to obey authority to maintain relationships with her (his) doctor.</td>
</tr>
<tr>
<td>Ambiguity in unconvincing outcomes</td>
<td>Deverting to endure</td>
<td>Searching for new activities to divert the patient’s attention.</td>
</tr>
<tr>
<td></td>
<td>Effort of maintain relationships with her (his ) doctor</td>
<td>Made an effort to continue maintain relationships with her (his) doctor.</td>
</tr>
<tr>
<td>Maintainable support</td>
<td>Maintainable relationships to patients association</td>
<td>Maintaining the connection with patients association.</td>
</tr>
<tr>
<td></td>
<td>Maintainable support by keyperson</td>
<td>Support provided by key person.</td>
</tr>
<tr>
<td></td>
<td>Keeping communication and scope</td>
<td>Holding on to their ability to communicate and to think.</td>
</tr>
<tr>
<td></td>
<td>Use of wisdom</td>
<td>Acquire knowledge to improve their DBS-related unconvincing outcome.</td>
</tr>
<tr>
<td>Reconsidering the meaning of DBS</td>
<td></td>
<td>Rethink their personal meaning of DBS.</td>
</tr>
<tr>
<td>Realization of an improvement plan</td>
<td>Negotiations for improvement</td>
<td>Try to lessen and improve their sense of DBS-related disappointment.</td>
</tr>
</tbody>
</table>
Of these individuals, 11 met the selection criteria and agreed to participate in this study. The interval between the onset of PD and the time of completing the survey ranged from 12 to 31 years, while the interval between DBS and the time of completing the survey ranged from 5 to 14 years (mean = 9.09 years). Patients’ ages ranged from the 50s to the 80s, and most participants had severe dysarthria. Family caregivers of six participants attended the interview according to participants’ wishes. One family caregiver wished to confirm the data separately. The interview duration ranged from 49 to 116 minutes (mean = 82 min).

Table 2 shows the categories and concepts. Following data analysis, 15 concepts were generated and 5 categories included semantic homophily of the content. The researcher identified saturation wherein a new concept was not generated when data was analyzed for all 11 participants. There was no concept that had its own power category. The categories are presented in <angular brackets>, and the concepts are written in [square brackets], with participant quotations either enclosed within “quotation marks” and/or in italics. Supplementary information for these quotations and codicil is written within parentheses. Due to space limitations, only representative data are presented.

2. Data analysis results

The following 5 categories and 15 concepts related to the improvement process for DBS-related feelings about unconvincing outcomes in patients with PD under long-term medical care were assessed.

Story line

Patients with PD under long-term medical care who had feelings about DBS-related unconvincing outcomes went through the following four stages:

In the first stage, patients did <Attempt to share the unconvincing outcomes>. Following <Attempt to share the unconvincing outcomes>, [Loss of hope due to disappointment] began, as patients expected good outcomes later. Thereafter, patients began having suspicions about their doctors ([Having distrust of her (his) doctor]) and [Complaining of dissatisfaction]. However, patients thereafter began [Seeking help from peers with unconvincing outcomes].

With regard to <Becoming saddled with unconvincing outcomes>, [Feelings of mum’s the word] influenced the loss of patients sharing their experiences about unconvincing outcomes ([Lose peers]) and caused them to obey authority to maintain relationships with their doctor ([Submission to authority]).

Fig. 1  The improvement process of unconvincing outcomes in patients with Parkinson’s disease post-DBS undergoing long-term care
Additionally, in the category <Ambiguity in unconvincing>, patients held [Diverting to endure] and maintained their relationships with their doctor [Maintaining relationships with her (his) doctor]. <Maintainable support> to achieve <Realization of the improvement plan> in <Maintainable support>, [Maintainable relationships to patients association], and [Maintainable support by keyperson] are cyclical processes.

In the final stage, patients had [Use of wisdom] and carried out [Negotiations for improvement] and [Reconsidering the meaning of DBS] by [keeping communication and scope] to achieve <Realization of the improvement plan> (Fig. 1).

Categories and Concepts
Category 1: <Attempt to share unconvincing outcomes>
This category was generated to include concepts wherein patients tried sharing their loss of hope because of DBS-related disappointment.

[Loss of hope due to disappointment]
This concept is defined as, “patients loss of hope following complaints of DBS-related disappointment.”

Participant E had expected that undergoing the surgery would reduce the use of PD medicine. However, she did not feel any changes in her condition after undergoing DBS. The patient was not able to reduce the use of PD treatment drugs.

“(Six months passed after DBS) I needed PD medicine.” (E)

Participant G had enjoyed composing haiku as a hobby before DBS; however, dysgraphia was reported at 1 week post-DBS and she was unable to compose haiku.

“(Before I underwent surgery) I had never imagined that I would lose the ability to write.” (G)

[Having distrust of her (his) doctor]
This concept is defined as, “patients become suspicious of their doctors.”

Participant A had distracting thoughts about her doctor because women introduced by her doctor were expected to have DBS.

“(There was a break down) the trust in a relationship between my doctor and I remember it (register my disappointment at the doctor), it was all the more important for me.” (A)

Participant C decided to go through with the operation after a neighbor experienced improvement after undergoing DBS. Although their dyskinesia improved, the ability to walk did not improve as much as Participant C had hoped. (With regard to the changes pre- and post-operation) “There wasn’t much change. The first operation cost about five million yen. I did not receive an explanation (in detail from the doctor before the operation), so I began to distrust the doctor, but I had no choice but to obey the doctor. I was very scared and couldn’t speak.” The DBS operation is backed by the national subsidy for high medical expenses and the participant began to suspect that the primary doctor and hospital recommended the operation purely for the financial gain of the hospital, but C felt fearful and could not say anything. (C)

[Complaining of dissatisfaction]
This concept is defined as, “complaining of a negative outcome post-DBS.”

Participants experienced DBS-related distress and disappointment and reported these feelings to her (his) doctor.

“(A half year after DBS) My doctor told me that you must take PD medicine. I asked my doctor why do I need PD medicine? I had the surgery. (so I saw no need to use PD medicine) Still, I was unconvinced about it in my mind.” (E)

Participant B, when deciding to undergo the operation, was influenced by another patient with PD who had shown symptom improvement as a result of DBS. She, however, showed absolutely no change. She angrily said, “I don’t know (for what purpose I had the surgery).” Participant G had a complicated speech disorder after DBS, so she could not communicate.

“I told my doctor that I can’t talk to anyone.” (G)

[Seeking help from peers with unconvincing outcomes]
This concept is defined as, “looking for someone with the same unconvincing experience.”

Participants who felt that DBS was ineffective, looked for and found comfort in the company of others who had gone through the same experience.

“(Post-operatively), I thought that other people were going to get well. Then, when I went to (the hospital), some people seemed to find (the effects to be) unsatisfactory.” (E)

Participant C had something on her mind about her peers, and she could not participate in a patients association because of progression of PD.

“I have something on my chest about how peers spend their days (I could not participate in patients association because of progression of PD).” (C)

Category 2: <Becoming saddled with unconvincing outcomes>
This category was generated to include concepts on patients feelings about their unconvincing outcomes.

[Feelings of mum’s the word]
This concept is defined as, “experiencing difficulty in telling the doctors and people around them about their disappointment with DBS.”

Participants experienced distress and disappointment from the early stages after DBS and attempted to explain these feelings to their doctor.

Participant A experienced no change in her condition, causing her to become distrustful of the doctor.
She also began feeling that the doctor was using her for his own agenda, which impaired communication between them and led to further anguish.

“(My doctor) did it for their own profit. What was hardest for me was communicating with the doctor. (After the operation), I was suffering so much (so I told the doctor) that I did not want to talk anymore. (The doctors) What the doctor said is not true; that is a lie, isn’t it? I was cheated the doctor.” *(A)*

Participant A’s depression, due to the lack of effect of DBS and her inability to express her feelings and thoughts to others, culminated in an attempt to slit her wrists.

“Eventually, (as I lost the ability to think and could no longer carry out a conversation) I felt it would be better to die. Time felt so long. So, I thought I might as well (die). (When I cut my wrist) I had a strange feeling of being taken away (to the world after death).” *(A)*

Participant E did not experience any changes after DBS and reportedly made the following statement:

“I did not feel much (different after DBS). However, the doctor said if I had gone the normal route (of continuing usual care) then by now I would have been bedridden, so I must be thankful for the operation.” *(E)*

In this way, the participants felt it difficult to tell the doctors and people around them the anguish of going through DBS to find it did not bring about the expected results. This affected their relationship with the doctor and their peers.

[Lose peers]

This concept is defined as, “feeling that the DBS results did not meet their expectations, and thus they had to bear the agony of being unconvincing, and not being able to understand that reality.”

When Participant E complained to another patient with the same disease that DBS did not provide the expected results, that patient told her not to complain.

“A hundred people (with PD), 100 people (with) different (conditions). I was told that “You have it easier than others” and that made me feel guilty. I was told that I should not complain because (the cost of going through the DBS operation) is worth two to five new cars.”

Participant E was told by her primary physician not to join a patients’ association and therefore did not. This experience illustrates the psychological burden of not being able to express the frustrations of DBS to other patients with PD.

Participant H decided to undergo surgery, she was recommended to have DBS by Z (Z is a peer supporter).

“Ms. Z recommended DBS to me. But Ms. Z didn’t want to undergo DBS” *(H)*

[Submission to authority]

This concept is defined as, “obliged to obey authority to maintain relationships with her (his) doctor”.

Participant F suffered from articulation difficulties for a long time and reported the following:

“All I could do was put up with it. I could hardly speak to my husband. When I think back on it now, (I think that I did not have to put up with the situation) for that long.” “For 14 years (post-operatively), (the doctor) wouldn’t change the voltage at all. It would have been better if they had done that (adjusting the voltage) earlier.

“I thought that I only have the means to follow of the (her) doctor. I have gotten scared gradually, I could not talk to the doctor.” *(C)*

[Category 3: <Ambiguity in unconvincing outcomes>]

This category is generated as include concepts about unclear feelings of unconvincing outcomes.

[Diverting to endure]

This concept is defined as, “searching for new activities to divert the patient’s attention.”

Participant A had attempted suicide because of a painful relationship with the doctor and no improvement after DBS. After that Participant A tried some activities.

Participant C also said that she would take up Tanka (poetry) as a hobby.

“I had been a member of the Tanka (i.e., short poems) Society, and had submitted my short poems monthly. But I felt I could no longer do that. I will compose a Tanka by myself.” *(C)*

[Effort in maintainable relationship with her (his) doctor]

This concept is defined as, “making effort to maintain relationships with her (his) doctor.”

Participants felt resigned to conquer their unconvincing outcomes, but still made an effort to continue their long-term care.

Participant C originally utilized the home help services, but as the disease progressed, she ultimately entered a care facility when it became too difficult to live at home. Participant C had read books on palliative care and felt there was no choice but to prepare for the end of life.

“My physical function began to deteriorate, so I gave up and entered (the facility). I recently read a book called “How You Die is How You Live.” I felt that I should prepare (for the end of my life).”

Although Participant C’s communication with her doctor had broken down after the DBS failed to produce the desired result (i.e., helping her walk again), she eventually felt able to talk to the doctor. This occurred about five years after the DBS operation: “Recently, after
the operation to exchange the batteries, I gradually found it possible to talk to my doctor.”

Participant F continued visiting the hospital regularly with a speech disability for more than 10 years.

“I go to the hospital once every 3 months. My doctor adjusts the DBS, but the doctor doesn’t see me every time.” (F)

Category 4: <Maintainable support>
This category is generated to include concepts of maintaining support to overcome experiences due to DBS-related unconvincing outcomes.

[Maintainable relationships with patients association]
This concept is defined as “maintaining the connection with patients association.”

Participant F still has anguish about dysarthria which is due to a cyclical process <Becoming saddled with unconvincing outcomes> and <Ambiguity in unconvincing> followed by <Realization of the improvement plan>. It influenced [Maintainable relationships to patients association].

“(Until improvement is obtained DBS-related dysarthria) It is 14 years. (She spent 14 years without saying a word). (The researcher asked her about how she overcame the difficulty to communicate).”

“I called a peer. The peer said that I could not hear about it, so she put the phone down. She said that we could not communicate. (I could not communicate) I could only explain half of what I was thinking. It was very hard for me.” (F)

“I cannot go alone (to patients association). (An omission) I need backup of social welfare council. When I go to (patients association), ride (members of patients association) every time. (driving by her husband).” (H)

[Maintainable support by keyperson]
This concept is defined as, “maintaining support by her (his) key person.”

Participant B who lived alone with her husband had become bedridden and had indeed looked as though she was at the end-stage of PD. In regard to the support she had been receiving in her long-term medical care, she answered as follows:

“It is my husband. He is my support.”

Participant B had difficulty even in moving her body to roll over in bed. Her husband was her primary support, as her main caretaker.

When Participant D was asked how she overcame the agony of dysphonia after DBS, she answered,

“I was able to overcome it because my husband has been kind to me.”

Participant D who was being cared for at home felt her family gave her the strength and support in her life.

Category 5: <Realization of the improvement plan>
This category was generated to include concepts such as “trying to improve their unconvincing outcomes.”

[Keeping communication and scope]
This concept is defined as, “holding on to their ability to communicate and to think.”

“As soon as I underwent surgery, I lost the ability to write. Therefore, I practiced using a computer and used the computer to write as I couldn’t write manually.” (G)

“I didn't think that I could talk. So I am in pain.” (D)

Participant D had a disorder of oral speech in the year after DBS. Participant D continued to try to communicate with her caregiver in handwriting.

[Use of wisdom]
This concept is defined as “acquire knowledge to improve their DBS-related unconvincing outcomes.”

“The newsletter of JPDA is very substantial and useful.” (G)

“When I listened to the lecture (on PD in patients from the association), I understood that I would be able to speak with a lower voltage of DBS. (omission) There’s a peer who struggles to be thick in utterance (after DBS). So, I thought it none of my business. I told that person that they should adjust their DBS to a lower stimulation level with the doctor.” (F)

This shows that information and lectures on PD by the association were of benefit. Participants received the knowledge about DBS from their peers that it is possible to adjust the stimulation level after DBS.

[Reconsidering the meaning of DBS]
This concept is defined as, “rethink their personal meaning of DBS.”

Participants coped with their perceived disappointment by considering the meaning of DBS-related decision-making. Participant C experienced conflicts with her doctor; however, she said DBS was helpful to her.

“Well, I challenged PD”. (C)

Participant A said “I have lived long enough thanks to DBS.”

“(I expected that DBS might keep me going for a long time) I think that it is good that DBS is effective for a limited time only of 2-3 years.” (I)

[Negotiations for improvement]
This concept is defined as, “try to lessen and improve their sense of DBS-related disappointment.”

Participant G suffered from chronic articulation difficulties. However, the doctor did not alter the DBS voltage when she described these limitations.

“When I said that I was doing well at the current voltage, (my attending physician) changed (the voltage) so that it was a little lower. As a result, I was
able to sing again.” (G)

Participant I had difficulty speaking after DBS.

“Because the DBS voltage was strong, I had to adjust my DBS to a little lower stimulation with the doctor.” (I)

Discussion

This study is the first to describe an improvement in the unconvincing outcomes in patients with PD following DBS. The improvement process starts with the patients’ Attempts to share the unconvincing outcomes and goes through repeating the cycle of Ambiguity in unconvincing and Becoming saddled with unconvincing outcomes under Maintainable support and ends in achieving Realization of the improvement plan. The study further clarified Ambiguity in unconvincing and Becoming saddled with unconvincing outcomes. In comparison with a previous concept analysis about being convinced,13 this study demonstrated close theoretical consistency. Therefore, it is assumed that the improvement process of unconvincing outcomes described in this study helped change outcomes in patients with PD from unconvincing to convincing. Attributes of the concept of being convinced include a deepening understanding, acceptance, involvement, one’s sense of value, relative benefit, positive proof, and relationship of trust.13 It is evident from these findings that the categories of Ambiguity in unconvincing and Becoming saddled with unconvincing outcomes as opposed to positive proof.

The researcher discovered details about how patients aptly hid their unconvincing outcomes from the other patients while struggling for a long time. Patients expressed an attitude of trying to cope with the unconvincing outcomes and to create meaning about the decision making regarding DBS. Its course varies among individuals. In this section, the researcher mainly considers the five categories and their implications for nursing care.

Attempts to share the unconvincing outcomes

In this study, participants had decided to undergo DBS after being influenced by those who reported satisfactory outcomes following DBS. However, some participants did not report good outcomes following DBS, resulting in a loss of hope and disappointment. According to the survey, patient-doctor and nurse interaction influence patient dissatisfaction and disappointment.21 In this study, the participants showed less confidence in their doctors, which was the major factor resulting in them being unconvincing.

Docto 80 perform DBS primarily to improve movement disorders. However, patients with PD have high hopes that DBS would improve speech disorders and quality of life, in addition to movement disorders. This leads to a possible contradiction between doctors and patients, resulting in Loss of hope due to disappointment. The anticipated efficacy of DBS and satisfaction varied among individuals. In addition, the effects of DBS varied among patients. Nevertheless, with respect to patients Seeking help from peers with unconvincing outcomes, it appeared that patients with PD did not generally share their distress with peers. Therefore, it is important that nurses should show understanding toward patients with Loss of hope due to disappointment, Having distrust of her (his) doctor, and Complaining of dissatisfaction and toward patients expectations in regard to post-DBS decision making. Furthermore, it is important that nurses coordinate to provide convincing outcomes both for patients and doctors and to discuss the treatment priorities.

Becoming saddled with unconvincing outcomes

The participants in this study experienced DBS-related unconvincing results and disappointment during the early stages post-surgery. The patients opted to hide their unconvincing results from the other patients, while they struggled for a long time, and expressed an attitude that they try to cope with unconvincing results despite staying in the Becoming saddled with unconvincing outcomes category. There is free medical care for patients with PD and other incurable diseases in Japan. The purpose of this free medical care is to promote treatment and research. To maintain their relationships with doctors who provide leading edge treatment, patients undertook the Diverting to endure concept. DBS is quite expensive, and so the patients with PD who receive DBS surgery are in a minority with respect to all of the patients with PD in Japan. These factors probably discouraged them from disclosing their feelings about unconvincing outcomes following DBS. Attempts to hide feelings about unconvincing outcomes was implied by this type of conversation between peers: “I was told that I should not complain because (the cost of going through the DBS operation) was worth two to five new cars.” If the patients could not express their unconvincing outcomes because of feelings of being indebted to the expensive official financial support for DBS, they would not be contributing to the original purpose to promote medical research for incurable diseases. Communication among patients is being established as a framework based on available peer support, providing a way for them to share experiences.23 Patients expected their peers to understand suffering due to unconvincing outcomes. However, patients who could not share an experience could lose peers. Because of the Feelings of mum’s the word concept, patients could not express any changes in their conditions after undergoing DBS. It is, therefore, important to establish support groups for patients with unconvincing outcomes of DBS. It is equally important for nurses to create an environment for communication among patients with respect to freedom in expression of their emotions and for supporting communication and group dynamics.

Ambiguity in being unconvinced

Patients with PD who received long-term care post-DBS adopted the Diverting to endure concept to cope
with feelings about DBS-related unconvincing outcomes. The behaviors associated with this concept may be the ways and means for them to maintainable relationships with their doctors. There is a shortage of specialist physicians of neurology in the countryside compared to urban areas in Japan.

Specialist PD physicians are in a minority within the group of physicians of neurology. It is important for patients with PD to maintain relationships with their doctors. However, there were some patients who had maintained their relationships with their doctors while coping with being in the unconvinced state for about ten years by [Diverting to endure]. Compared with people in normal health, patients with PD are inclined to be modest and to restrain their emotions and to be negative in their relationships with other people. In nursing care, considering this characteristic of patients with PD, it is necessary to help support the relationship between patients and doctors.

Maintainable support

For patients who lose peers due to the difficulty of not understanding unconvincing outcomes, [Maintainable relationships to patient association] become important to relieve patient suffering, in which they experience <Becoming saddled with unconvincing outcomes> and <Ambiguity in unconvincing>. Additionally, patients who have a communication disorder due to dystarhria continue to [Maintain relationships to patient association], which is linked to <Realization of the improvement plan>. As suggested by the aforementioned observations, patients could not participate in patient associations because of isolation owing to PD progression. A previous study concluded that a consequence of convincing is mutual understanding. Therefore, it is important that nurses prevent loss of peers, which facilitate improvement of unconvincing outcomes. On the other hand, patients [Maintain relationships to patients association] through transportation by family caregivers. By doing so, there is an improvement in the process. Therefore, it is important that nurses continue to support [Maintainable relationships to patients association].

Additionally, [Maintainable support by keyperson] helped patient improvement with respect to suffering because of unconvincing outcomes. In a previous study, however, it was noted that, when providing long-term care to patients post-DBS, family caregivers tend to experience an increasing burden as the patient’s disease worsens. With the amount of support they must provide, the spouses of patients with PD who undergo DBS experience major mood swings and changes in their quality of life. Therefore, it may be important to develop a system to support family caregivers, as such efforts may ultimately benefit patients receiving long-term care.

Realization of the improvement plan

[Use of wisdom] was a factor leading to improvement of DBS-related unconvincing outcomes. In particular, it is shown that information and lectures on PD was of benefit to patients. Patients who [Lost peers] felt that the DBS outcomes did not meet their expectations, and thus had to bear the agony of unconvincing outcomes and not being able to understand that reality. This showed an association between [Use of wisdom] and [Maintainable patient association], even if PD patients with post-DBS outcomes had misunderstood their experiences. Based on these results, it can be presumed that patients did [Negotiations for improvement]. Participants obtained knowledge from their peers about DBS that it is possible to adjust stimulation levels after DBS. In brief, it can be presumed that patients can be involved in <Realization of the improvement plan> in its early stages, if it can enrich the power of patients who attempt [Use of wisdom] and sharing among patients with unconvincing post-DBS outcomes.

Even if patients feel that the DBS outcomes do not meet their expectations, they accept living with PD by realizing the range of the efficacy of DBS and have second thoughts that challenge the effect of PD on the decision-making process of DBS. With respect to [Negotiations for improvement], patients negotiated with their doctors to reduce the DBS voltage. Patients for whom the DBS voltage was reduced by the doctors reported feeling better.

It was necessary for patients with PD undergoing long-term care after DBS [Keeping communication and scope] to show an improvement in their unconvincing DBS-related outcomes. However, it also came to light that with PD patients after an average of five years post-DBS, they developed severe speech disorders and that it impacts their social interactions and sharing of their day-to-day physical and emotional experiences with others. As the saying goes, man is a thinking reed. Language is a tool by which human beings can be human, and a patient’s autonomy will be blocked if they lose the ability to communicate. Therefore, it is important that nurses support patients by [Keeping communication and scope] to respect patient autonomy. Speech and language training by speech therapists is already being used to treat patients post-DBS. However, participants in this study had DBS-related speech and language disorders and dysgraphia. Patients with PD who develop DBS-related speech disabilities are likely to be isolated in society because of being confined to their houses owing to disease progression. Home speech therapy is badly off; therefore, it should be emphasized that home nurses can support patients [Keeping communication and scope]. Nurses must have the skill of carefully listening to non-verbal communication from patients. It is important that nurses help patients verbalize their unconvincing outcomes and the meaning of their illness in terms of long-term care.

A previous study concluded that consequence of convincing is satisfaction. However, it can be presumed that patients with PD post-DBS undergoing long-term care who have not yet had convincing outcomes and satisfaction, may experience the emergence of suffering due to the progressive course of the disease. Therefore, for patients with PD post-DBS who achieve

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Improved DBS-related unconvincing effects
the realization of improvement for unconvincing outcomes, the process should still be considered in a fluid state. Hence, palliative care is important for patients with PD.

**Implications for nursing**

In Europe and the United States, nurse practitioners usually consult with patients about side-effects and the adjustment of DBS stimulation levels. If we could provide a similar service for patients with PD in Japan, long-term care would be possible from an early stage. It is necessary to educate and train nurses who specialize in PD in Japan so that they can play important roles in pre- and post-operative DBS. Nursing of neurological diseases such as Parkinson’s disease involves neuroscience nursing. However, patients of PD are frequently at high risk for psychological symptoms. Therefore, the development of a new combined nursing program that includes psychiatric and neuroscience nursing should be considered.

**Limitations**

This study had two limitations. First, the researcher could not determine the details about the concept [Loss of hope due to disappointment]. Second, the researcher was not able to ensure the removal of patient disappointment in a clinical setting. As such, further studies are needed to prove transferability and to research the details of [Loss of hope due to disappointment].

**Conclusion**

To my knowledge, this study is the first to report an improvement in unconvincing outcomes in patients with PD following DBS. The findings of the study detail the improvement process of unconvincing outcomes in which patients with PD transition from being unconvincing to being convinced. Additionally, the results from this survey highlight important points associated with the nursing of PD patients. The findings further clarified the categories of <Ambiguity in unconvincing outcomes> and <Becoming saddled with unconvincing outcomes>. Furthermore, patients aptly hid their unconvincing outcomes from other patients while struggling for long periods of time; they expressed an attitude of trying to cope with unconvincing outcomes by creating meaning about the decision making process of DBS treatment. The course of DBS therapy differs among individuals. The findings of this study will be helpful in educating patients and their families who are considering DBS surgery, and in providing long-term care that enhances patient satisfaction and quality of life. Further discussion about the disappointment felt following DBS is required. As such, further studies are needed to prove the transferability of the results.

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The author has no conflict of interest to declare.

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