

# How to promote the stockpiling of medication for disaster preparedness among Parkinson's disease patients receiving home care services

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## Abstract

The purpose of this study was to identify factors, using the Health Belief Model (HBM) associated with Parkinson's disease (PD) medication stockpiling for disaster preparedness among PD patients receiving home care services. The survey was conducted through an anonymous, self-administered postal questionnaire between March and September 2013, targeting all 1,398 members of Japan Parkinson's Disease Association in nine prefectures in East Japan including the Hokuriku region. The analysis included 571 valid responses (40.8%). The results of a binary logistic regression analysis indicated that three of the modifying factors in the HBM, "possession of a disability certificate," "bringing a medicine notebook or information sheet when going out," and "awareness of the possibility of a future disaster" were significantly associated with stockpiling behavior. The "Cues to Action" factor ("encouragement from others or information promoting the stockpiling of medication") was

also significantly associated. However, the other constructs in the HBM, "Susceptibility," "Severity," "Perceived Threat," "Barriers," and "Benefits," did not show significant association. We concluded that encouragement of stockpiling behavior from healthcare professionals and the PD Association, making a habit of always bringing a medicine notebook when going out, and raising awareness of the possibility of a disaster are useful in promoting medication stockpiling among PD patients.

## Introduction

In March 2011, the Great East Japan Earthquake resulted in the death of 15,812 people. Among the 15,681 victims whose age could be determined, 10,360 were over 60 years of age, accounting for 66.1% [1]. The number of disaster-related deaths accumulated by the end of March 2013 and reached 2688, and those were people aged 66 and above, accounting for 89.1%. The disaster caused great damage to vulnerable people; in particular, many elderly people and

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people with diseases lost their lives.

For people with diseases receiving medical care at home, a disaster is an emergency situation which directly causes a life crisis. Through the experiences of large earthquakes such as the Great Hanshin-Awaji Earthquake of 1995 and the Chūetsu (Niigata) Earthquake of 2004, it has been recognized that patients with intractable diseases who are highly dependent on medical care require attention specific to the characteristics of their disease when such disasters occur. A number of publications have been developed, such as the *Manual on supporting patients with intractable diseases at the time of disaster* [2], *Guidelines on establishment of a support plan for patients with intractable diseases in time of disaster (the Guidelines)* [3], and *Ministry of Health, Labour and Welfare Emergency Action Plan* [4], and patients with intractable diseases have been introduced to healthcare professionals as people requiring assistance during a disaster.

Parkinson's disease (PD) is a progressive intractable neurological disease with a prevalence rate of 100 to 150 per 100,000 people in Japan. Most cases begin between the ages of 50 and 65, but the incidence rate increases with age, so the number of patients has been increasing in recent years [5]. The main symptoms of PD are tremor, muscle rigidity, bradykinesia, and postural instability. Drug treatment is the main method to control the symptoms of PD.

The *Guidelines* [3] identify anti-Parkinson's disease medication (PD medication) as a "special therapeutic drug" in the section explaining the individual support systems required for specific intractable diseases when disasters occur. It states, "If a patient suddenly stops taking the dopamine replacement drugs used for treatment of Parkinson's disease symptoms, rarely it may worsen the symptoms and cause neuroleptic malignant syndrome, which is characterized by high fever, increased sweating, and muscle stiffness; therefore, caution is required. If a

patient is undergoing dopamine replacement therapy, the patient always needs to keep several weeks' worth of medication on hand and must not stop taking the medication even if when it is impossible to seek medical attention."

At the time of the Great East Japan Earthquake, patients with chronic diseases such as PD experienced an interruption of their treatment that resulted from losing the drugs, leaving them behind when evacuating, or lack of access to medical supplies caused by disruption of transportation systems. The interruption of treatment resulted in a worsening of their condition [6,7].

A survey of the effects of the disaster on patients with intractable diseases such as PD who suffered from the Great East Japan Earthquake, 212 out of 1,457 respondents (14.5%) indicated "lack of medication" as one of the problems they experienced during the disaster [8].

To what extent are PD patients actually stockpiling their medication in preparation for a disaster? According to Imafuku et al. (2007) [9], among PD patients living in Shizuoka City, where the Tonankai Earthquake is expected in the near future, 17.4% had "no stockpile of medication," and 71.8% had "over three days' worth of medication." A study of patients with intractable diseases, including PD, revealed that 21.9% had "no stockpile" [10] and 45.0% indicated "medication" as a thing they would worry about in case of a disaster [11]. However, nursing research on people requiring assistance during a disaster, including PD patients, has been limited to small scale general surveys [9,12,13] and has focused only on methods of post-disaster support for home care patients on mechanical ventilation [14,15]. For patients in need of medication, only a few studies on the situation and education of diabetes patients have been reported [16,17]. There have been no studies reporting on the use of a psychological and behavioral model for supporting and promoting disaster preparedness

behavior.

This study aimed to identify the factors associated with PD medication stockpiling behavior using the Health Belief Model in order to develop methods for supporting and promoting disaster preparedness behavior among PD patients receiving home care services.

## Materials and Methods

### 1. Research Framework

The Health Belief Model (HBM) is used to promote preventive health behavior (Figure 1) [18,19,20]. This relatively accessible model is based on behavioral science theory and has been applied in research on cancer screening behavior [21]. The HBM was used in this study because the stockpiling of PD medication is a type of preventive health behavior and because it provides a useful set of factors that are likely to affect stockpiling behavior.

The framework used in this study examines the association of “Modifying Factors,” “Perceived Threat,” “Susceptibility,” “Severity” “Cues to Action,” “Benefits,” and “Barriers” with the likelihood of change in a PD patient’s behavior of stockpiling medication for disaster preparedness in the past year.

### 2. Participants

Questionnaires were sent to all 1,398 members of Japan Parkinson’s Disease Association who lived in nine prefectures in East Japan including the Hokuriku region (Hokkaido, Aomori, Akita, Yamagata, Ishikawa, Toyama, Yamanashi, Gunma, and Niigata prefectures). These prefectures were selected because they each had less than five deaths due to the Great East Japan Earthquake of 2011 [22] and because it was possible to administer the questionnaires through local branches of Japan Parkinson’s Disease Association. We took into consideration the possibility that members of the association who lived in prefectures with five or more deaths

caused by the Great East Japan Earthquake may have become more aware of the importance of disaster preparedness and thus be more likely to stockpile PD medication. Therefore, members in prefectures with less than five deaths from the Great East Japan Earthquake were selected as the research participants for this study.

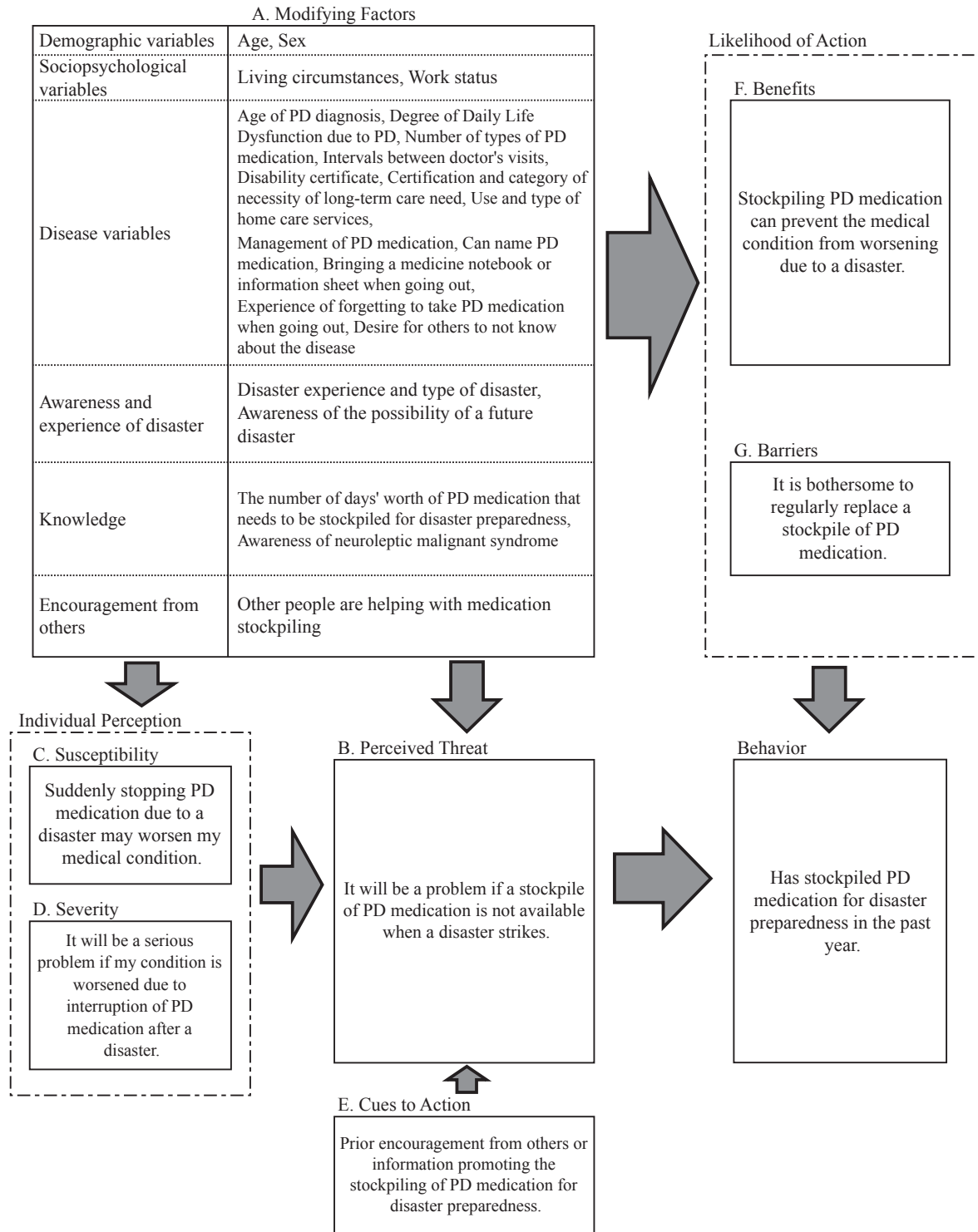
### 3. Data Collection

#### 1) Preliminary study and questionnaire development

In order to develop the questionnaire to be used in this study, semi-structured interviews were conducted using an interview guide with four members of the Niigata Prefecture branch of the Japan Parkinson’s Disease Association who had experienced the Chūetsu (Niigata) Earthquake of 2004. The interview guide was developed based on previous studies [9,23] and was designed to investigate the following three points: (1) details of the disaster experience and challenges in receiving medical treatment after the disaster, (2) the status and awareness of disaster preparedness at the time of the interview, and (3) encouragement from others regarding disaster preparedness.

The interviews were conducted between May 2011 and October 2012 and took an average of 107 minutes. The four interview participants were all women; two of them were in their 60s and two were in their 70s, with an average age of 71.0 at the time of the interview. All of them lived with their family, were at the second stage of Daily Life Dysfunction, required some assistance with activities of daily living and doctor’s visits (corresponding to Stage III and IV of Hoehn and Yahr scale which is commonly used a system for describing how the symptoms of Parkinson’s disease progress.), and maintained a stockpile of more than three days’ worth of PD medication. The duration of PD was over ten years for three participants and two years for one participant at the time of the disaster in 2004.

Figure 1. Research framework based on the Health Belief Model



<sup>1)</sup> This framework was developed by the researcher, based on the Health Belief Model.

<sup>2)</sup> The statements in the boxes are the questionnaire items.

A verbatim transcription of the audio recorded interview data was created and analyzed to identify items relating to the status and awareness of disaster preparedness. To ensure validity, three researchers discussed the interpretation of the content until consensus was reached.

Questionnaire items relevant to each construct of the HBM framework (Figure 1) were developed based on the results of the preliminary study. For "Perceived Threat," "Susceptibility," "Severity," "Benefits," and "Barriers," respondents indicated their level of agreement on a four-point scale with the following options: "strongly agree," "agree," "somewhat disagree," and "disagree." Separate four-point scales were used for "Cues to Action" (options: "many," "some," "very few," and "none") as well as "Behavior" (options: "never" "sometimes" "most of the time" and "always").

## 2) Survey Method

A postal survey was used to collect data. An anonymous self-administered questionnaire was sent with a Parkinson's Disease Association newsletter and returned by mail. Patients were asked to complete the questionnaire by themselves, or with someone's assistance if needed. The survey was conducted from March to September 2013.

## 4. Data Analysis

To determine the association between the relevant factors and whether or not participants had stockpiled PD medication for disaster preparedness in the past year (April 2012 to March 2013), a chi-squared test was used to compare the difference in the proportions between those who had stockpiled and those who had not, for each factor. Respondents who answered that they "sometimes," "most of the time," or "always" had a stockpile of medication for disaster preparedness in the past year were included in the stockpiling group, and those who

answered "never" were treated as the non-stockpiling group.

A binary logistic regression analysis (BLRA) (forward selection method, variable selection criteria  $p = 0.05$ ) was performed with medication stockpiling as the dependent variable (stockpiling = 0, non-stockpiling = 1) and the 27 items covering the various factors in the HBM framework (Table 2) as the independent variables. IBM SPSS Statistics version 22.0 for Windows was used for the statistical analysis. The four-point scale was consolidated into a binary rating scale: "strongly agree" and "agree" versus "somewhat disagree" and "strongly disagree"; "know very well" and "know" versus "know little" and "don't know at all."

## 5. Definitions

In this study, ten natural disasters were defined based on the Disaster Countermeasures Basic Act [24]. In keeping with a previous study [25], a "natural disaster experience" was defined as a situation where "property such as housing or cars as well as physical safety were threatened or injured, or serious problems were caused in daily life." A home care PD patient was defined as a person who was either currently receiving home care treatment, or they were currently hospitalized or in a nursing facility but were planning to return home and receive home care treatment. Stockpiling PD medication for disaster preparedness was defined as having over three days' worth of medication prescribed for PD treatment, excluding medicines for constipation, digestive health, blood pressure, etc.

## 6. Ethical considerations

This study was approved by the ethics committee of Niigata University of Health and Welfare (17231-110307). The preliminary study was conducted after explaining the purpose, confidentiality measures, the planned publication of results, the voluntary nature of the requested

cooperation, the fact that non-participation would not result in any disadvantage, and the opportunity to withdraw consent orally or in writing, and after obtaining a signed informed consent document.

A self-administered questionnaire was mailed to the participants in the main study with a request form describing the study objectives, the voluntary nature of the requested cooperation, assurance of anonymity, and the planned publication of results. The postal questionnaire was anonymous and return of the questionnaire was taken as consent to participate.

## Results

### 1. Characteristics of participants

The questionnaire was mailed to 1,398 members, and 685 were returned (collection rate of 49.0%). Among the 685 respondents, 67 who were hospitalized or in a nursing home and eight respondents who were not taking PD medication were excluded from the data analysis. Also, 29 respondents who did not answer the basic characteristic questions regarding the respondent, age group, gender, and whether they had stockpiled PD medication in the past year were excluded. An additional ten respondents who had five or more missing data cells other than the previously mentioned items were also excluded. Data from the remaining 571 respondents were analyzed, and items with missing values other than multiple choice were handled using the mode imputation method. The basic characteristics of the subjects are shown in Table 1.

### 2. Participants' knowledge and behavior relating to PD medication (Table 2)

Two hundred ninety-seven respondents (52.0%) reported that they had a stockpile of PD medication, while 274 (48.0%) did not. Three hundred thirty-four respondents (58.5%) reported seeing a doctor more than once a month. Four hundred twenty (73.6%) respondents said they

self-manage their PD medication. Three hundred eighty-nine (68.1%) stated that they can name their PD medications. Two hundred seventy-six (48.3%) reported that they bring their medicine notebook with them when going out (in the past year). Ninety-eight (17.2%) reported that they have had trouble remembering to take their medication when going out or staying overnight away from their home in the past. Five hundred twenty-four (91.8%) indicated awareness that a stockpile of three days' to two weeks' worth of PD medication is necessary for disaster preparedness. One hundred seventeen (20.5%) indicated awareness of neuroleptic malignant syndrome.

### 3. Differences between participants with and without a PD medication stockpile in the past year (Tables 2 and 3)

The percentage of respondents with a stockpile of PD medication was significantly higher for those diagnosed with PD by age 59 than for those diagnosed at age 60 or above ( $p = 0.004$ ), for those taking at least five types of PD medication than for those taking up to four types ( $p = 0.033$ ), for those with a disability certificate ( $p = 0.002$ ), for those receiving home care services ( $p = 0.010$ ), for those that say they can name their PD medications ( $p = 0.023$ ), for those who bring a medicine notebook or information sheet when going out ( $p < 0.001$ ), for those with disaster experience ( $p = 0.010$ ), for those who are aware of the possibility of a future disaster ( $p = 0.005$ ), and for those aware of the necessity of stockpiling over three days' to two weeks' worth of PD medication for disaster preparedness ( $p = 0.049$ ).

A significantly higher percentage of stockpiling was also found among respondents who agreed or strongly agreed that suddenly stopping PD medication due to a disaster may worsen their medical condition ("Susceptibility" factor) ( $p = 0.038$ ), and those who reported receiving encouragement from others or information

Table 1. Participant characteristics n = 571

	n	%
<b>Respondent</b>		
Patient	517	90.5
Family member	53	9.3
Other	1	0.2
<b>Living circumstances</b>		
Living alone	45	7.9
Living with family	526	92.1
<b>Age</b>		
30s	1	0.2
40s	3	0.5
50s	28	4.9
60s	189	33.1
70s	280	49.0
Over 80	70	12.3
<b>Sex</b>		
Male	257	45.0
Female	314	55.0
<b>Work status</b>		
Employed	18	3.2
Housework or working at home	182	31.9
None	340	59.5
Others	31	5.4
<b>Age of Parkinson’s disease diagnosis</b>		
Under 30	10	1.8
30s	10	1.8
40s	57	10.0
50s	163	28.5
60s	217	38.0
70s	107	18.7
Over 80	7	1.2
<b>Degree of Daily Life Dysfunction</b>		
Does not need assistance with activities of daily living and doctor’s visits	173	30.3
Needs some assistance with activities of daily living and doctor’s visits	330	57.8
Needs full assistance with activities of daily living	68	11.9
<b>Natural disaster experience</b>		
No	442	77.4
Yes	129	22.6
Among respondents answering “Yes,” 128 indicated the type of disaster <sup>1)</sup>	78	60.9
Earthquake	33	25.8
Heavy snow	32	25.0
Storm/Typhoon	25	19.5
Flooding	14	10.9
Heavy rain	18	14.1
Others		

		n	%
<b>Disability certificate</b>			
No		309	54.1
Yes		262	45.9
Among respondents answering “Yes,” 261 indicated the degree of disability.	Grade 1	20	3.5
	Grade 2	115	20.1
	Grade 3	83	14.5
	Grade 4 or above	43	7.5
<b>Certification of long-term care need</b>			
No		222	38.9
Yes		349	61.1
Among respondents answering “Yes,” 347 indicated the degree.	Support Required 1	39	6.8
	Support Required 2	64	11.2
	Long-term Care Required 1	33	5.8
	Long-term Care Required 2	100	17.5
	Long-term Care Required 3	59	10.3
	Long-term Care Required 4	32	5.6
	Long-term Care Required 5	20	3.5
<b>Use of home care services</b>			
No		310	54.3
Yes		261	45.7
Among respondents answering “Yes,” 259 indicated the type of home care services <sup>2)</sup>	Outpatient Day Long-Term Care	150	57.9
	Home-Visit Long-Term Care	92	35.5
	Home-Visit Rehabilitation	85	32.8
	Home-Visit Nursing	59	22.8
	Short-Term Admission for Daily Life Long-Term Care	51	19.7
	Others	28	10.8
<b>Prefecture of residence</b>			
Hokkaido		124	21.7
Aomori		63	11.0
Akita		51	8.9
Yamagata		42	7.4
Yamanashi		41	7.2
Toyama		58	10.2
Ishikawa		36	6.3
Niiigata		102	17.9
Gunma		54	9.5

<sup>1) 2)</sup> Answers total over 100% due to multiple responses.



Table 2. Differences between participants with and without a PD<sup>1)</sup> medication stockpile in the past year

n = 571

		Stockpile of PD medication in the past year				p value <sup>2)</sup>	
		Total	With stockpile n =297	%	Without stockpile n=274		%
<b>A. Modifying factors</b>							
Demographic variables							
Age	Less than 70	221	126	57.0	95	43.0	0.057
	70 and over	350	171	48.9	179	51.1	
Sex	Male	257	132	51.4	125	48.6	0.778
	Female	314	165	52.5	149	47.5	
Sociopsychological variables							
Living circumstances	Live alone	45	21	46.7	24	53.3	0.469
	Live with family	526	275	52.3	251	47.7	
Work status	Yes	200	109	54.5	91	45.5	0.383
	No	371	188	50.7	183	49.3	
Disease variables							
Age of PD diagnosis	up to 59	240	142	59.2	98	40.8	<b>0.004</b>
	60 and over	331	155	46.8	176	53.2	
Degree of Daily Life Dysfunction	Does not need assistance with activities of daily living and doctor’s visits	173	87	50.3	86	49.7	0.586
	Needs partial or full assistance with activities of daily living	398	210	52.8	188	47.2	
Number of types of PD medication	1 to 4	362	176	48.6	186	51.4	<b>0.033</b>
	5 or more	209	121	57.9	88	42.1	
Intervals between doctor’s visits	More than once a month	334	172	51.5	162	48.5	0.769
	Less than once a month	237	125	52.7	112	47.3	
Disability certificate	Yes	262	155	59.2	107	40.8	<b>0.002</b>
	No	309	142	46.0	167	54.0	
Certification of long-term care need	Yes	349	189	54.2	160	45.8	0.199
	No	222	108	48.6	114	51.4	
Use of home care services	Yes	261	151	57.9	110	42.1	<b>0.010</b>
	No	310	146	47.1	164	52.9	
Management of PD medication	Patient	420	221	52.6	199	47.4	0.629
	Someone else	151	76	50.3	75	49.7	
Can name PD medication	Can, Mostly can	389	215	55.3	174	44.7	<b>0.023</b>
	Mostly cannot, Cannot	182	82	45.1	100	54.9	
Bringing a medicine notebook or information sheet when going out	Always, Most of the time	276	166	60.1	110	39.9	<b>p&lt;0.001</b>
	Sometimes, Never	295	131	44.4	164	55.6	
Experience of forgetting to take PD medication when going out	Often, Sometimes	98	52	53.1	46	46.9	0.820
	Seldom, Never	473	245	51.8	228	48.2	
Desire for others to not know about the disease	Yes	151	76	50.3	75	49.7	0.629
	No	420	221	52.6	199	47.4	

		Stockpile of PD medication in the past year				p value <sup>2)</sup>	
		Total	With stockpile n =297	%	Without stockpile n=274		%
<b>Awareness and experience of a disaster</b>							
Experience of a disaster	Yes	129	80	62.0	49	38.0	<b>0.010</b>
	No	442	217	49.1	225	50.9	
Awareness of the possibility of a future disaster	Strongly agree, Agree	328	187	57.0	141	43.0	<b>0.005</b>
	Somewhat disagree, Disagree	243	110	45.3	133	54.7	
Knowledge		0					
The number of days' worth of PD medication that needs to be stockpiled for disaster preparedness	Over three days to two weeks	524	279	53.2	245	46.8	<b>0.049</b>
	Not necessary, Less than three days	47	18	38.3	29	61.7	
Awareness of neuroleptic malignant syndrome	Know very well, Know	117	54	46.2	63	53.8	0.155
	Know a little, Don't know at all	454	243	53.5	211	46.5	
<b>Encouragement from others</b>							
Other people are helping with medication stockpiling	Yes	382	197	51.6	185	48.4	0.763
	No	189	100	52.9	89	47.1	
<b>B. Perceived Threat</b>							
It will be a problem if PD medication is not stockpiled when a disaster strikes.	Strongly agree, Agree	542	284	52.4	258	47.6	0.427
	Somewhat disagree, Disagree	29	13	44.8	16	55.2	
<b>C. Susceptibility</b>							
Suddenly stopping PD medication due to a disaster may worsen my medical condition.	Strongly agree, Agree	521	278	53.4	243	46.6	<b>0.038</b>
	Somewhat disagree, Disagree	50	19	38.0	31	62.0	
<b>D. Severity</b>							
It will be a serious problem if my condition is worsened because of stopping PD medication due to a disaster.	Strongly agree, Agree	534	282	52.8	252	47.2	0.149
	Somewhat disagree, Disagree	37	15	40.5	22	59.5	
<b>E. Cues to Action</b>							
Received encouragement from others or information promoting the stockpiling of PD medication for disaster preparedness	Many, Some	138	116	84.1	22	15.9	<b>p&lt;0.001</b>
	Very few, None	433	181	41.8	252	58.2	
<b>F. Benefits</b>							
Stockpiling PD medication can prevent my medical condition from worsening due to a disaster.	Strongly agree, Agree	534	281	52.6	253	47.4	0.269
	Somewhat disagree, Disagree	37	16	43.2	21	56.8	
<b>G. Barriers</b>							
It is bothersome to regularly replace my stockpile of PD medication.	Strongly agree, Agree	227	117	51.5	110	48.5	0.854
	Somewhat disagree, Disagree	344	180	52.3	164	47.7	

<sup>1)</sup> Parkinson's disease

<sup>2)</sup> from chi-squared test

Table 3. Binary logistic regression analysis results, with PD<sup>1)</sup> medication stockpiling for disaster preparedness in the past year as the dependent variable n=571

Item	Category	Odds ratio <sup>3)</sup>	95% Confidence Interval	p value
<b>A. Modifying Factors</b>				
Disease variables				
Disability certificate <sup>3)</sup>	Yes	1.5	1.018-2.100	0.039
	No	1.0		
Bringing a medicine notebook or information sheet when going out	Always, Most of the time	1.8	1.236-2.541	0.002
	Sometimes, Never	1.0		
Awareness and experience of disaster				
The possibility of a future disaster	Strongly agree, Agree	1.5	1.037-2.144	0.031
	Somewhat disagree, Disagree	1.0		
<b>E. Cues to Action</b>				
Encouragement from others or information on promoting the stockpiling of PD medication for disaster preparedness	Many, Some	7.0	4.222-11.505	p<0.001
	Very few, None	1.0		

<sup>1)</sup> Parkinson’s disease

<sup>2)</sup> Analytical Method: Binary logistic regression analysis (forward selection method), variable selection criteria: p=0.05 with SPSS Statistics Ver. 22.0 for Windows

<sup>3)</sup> Odds ratios are relative to the reference category, which is the lower item.

<sup>4)</sup> Independent variables: 27 items in Table 2

<sup>5)</sup> Nagelkerke R<sup>2</sup>=0.218, Omnibus tests of model coefficients, Step 4, Model p<0.001

<sup>6)</sup> Collinearity was considered to be non-problematic with standard error <2.0

<sup>7)</sup> Odds ratios for “Perceived Threat,” “Susceptibility,” “Severity,” “Benefits,” and “Barriers” were not significant and thus not included in this table.

promoting the stockpiling of PD medication for disaster preparedness (“Cues to Action” factor) (p < 0.001).

The results of the BLRA indicated that among the items measuring “Modifying variables,” having a disability certificate (odds ratio [OR] = 1.5), bringing a medicine notebook or information sheet when going out (OR = 1.8), and being aware of the possibility of a future disaster (OR = 1.5) were significantly associated with the stockpiling of PD medication for disaster preparedness. Encouragement from others or information promoting the stockpiling of PD medication for disaster preparedness (“Cues to Action”) (OR = 7.0) had the most significant

effect on medication stockpiling for disaster preparedness (Table 3).

On the other hand, there was no association between “Perceived threat,” “Susceptibility,” “Severity,” “Benefits,” or “Barriers” and stockpiling behavior.

#### 4. Motivations for starting or not starting a stockpile of PD medication for disaster preparedness (Tables 4 and 5)

For the 279 respondents who reported that they maintain a stockpile of PD medication, many of them started stockpiling due to media information (36.6%), healthcare professionals (26.5%), and PD Association newsletters (25.4%), whereas

Table 4. Reasons for starting a stockpile of PD medication in the past year n=279<sup>1)</sup>

Reason	n	%
Media information	102	36.6
Health professional	74	26.5
Parkinson's Disease Association newsletter	71	25.4
Encouragement from family and friends	57	20.4
Social worker	31	11.1
Experience of a disaster	24	8.6
Others	56	20.1

<sup>1)</sup> Respondents with a stockpile of PD medication in the past year

<sup>2)</sup> Answers total over 100% due to multiple responses.

Table 5. Reasons for not stockpiling PD medication in the past year n=263<sup>1)</sup>

Reasons	n	%
Lack of knowledge of the medication's shelf life	76	28.9
Never thought about it	58	22.1
Reluctant to ask a doctor	52	19.8
Refused by a medical facility	24	9.1
Can't imagine being in a disaster situation	14	5.3
Plan to get medication from a patient with the same disease	4	1.5
Others	59	20.6

<sup>1)</sup> Among 274 respondents without a stockpile of PD medication in the past year, 263 gave their reasons.

<sup>2)</sup> Answers total over 100% due to multiple responses.

disaster experience played less of a role in their motivation.

The 263 respondents who said they do not stockpile PD medication gave reasons such as, "did not know the shelf life of the medication" (28.9%), "never thought about it" (22.1%), "was reluctant to ask a doctor" (19.8%), and/or "was refused by a healthcare facility" (9.1%).

## Discussion

This is the first study to use the Health Belief Model to identify factors relating to stockpiling behavior with a focus on the stockpiling of PD medication for disaster preparedness. The results show that "Cues to Action," one of the HBM

constructs, was significantly associated with PD patients' medication stockpiling behavior. However, "Perceived threat," "Susceptibility," "Severity," "Benefits," and "Barriers" did not show any association. Instead, "Modifying factors" such as bringing a medicine notebook or information sheet when going out, having a disability certificate, and awareness of the possibility of a future disaster were shown to be important factors.

### 1. Characteristics of the target population

According to the study by Taniguchi et al. on the status of PD patients [26], the average age of PD patients is 71.3 years, with the mean age of

onset being 62.7 years, and the male to female ratio is 1:1.47. The average age and age of onset of the participants in the current study were not considerably different. Therefore, while the possibility of selection bias in this study cannot be denied, but there seems to be no substantial difference between the two studies.

## 2. Status of PD medication stockpiling

Unlike medication for lifestyle-related diseases, only a limited number of people take PD medication; therefore, PD medication is not included in the list of essential medication to be provided at first-aid stations at disaster evacuation shelters. It is very difficult to receive a prescription for PD medication at a first-aid station [27,28]. Moreover, suddenly stopping use of the medicine can cause neuroleptic malignant syndrome and thus is a life-threatening emergency. Therefore, whether patients stockpile their own PD medication or not affects their health condition during the acute and sub-acute phases of the disaster cycle.

In this study, 52.0% of respondents reported that they stockpile over three days' worth of PD medication. This is lower than the percentage reported in a study by Imafuku et al. (2007) [9], in which a total of 71.8% stockpiled the medication. However, in that study, 12.2% of respondents stockpiled enough medication for "not more than three days," 33.5% for "about one week," and 26.1% for "more than one week." In our study, only a stockpile of over three days' worth of medication was counted as effective, whereas Imafuku et al. also included stockpiles of less than three days' worth of medication in the count. Therefore, the results of these two studies are difficult to compare, but still our result was 19.8 percentage points lower. This gap might be attributable to the region where the participants in Imafuku et al.'s study reside. That locale had already developed strong measures for disaster scenarios, because it had been specified as an area

for intensified measures against earthquakes under Article 3 of the Act on Special Measures for Large-Scale Earthquakes in 1978 due to its high earthquake occurrence risk. Also, there were only 230 respondents in that study, and 21% of them were hospitalized or in a nursing facility and therefore did not need to self-manage their own medication stockpiles. Based on the results of our study, the stockpiling of medication should be further encouraged.

## 3. Factors associated with medication stockpiling behavior, as identified by BLRA

"Cues to Action" was the factor most strongly associated with the stockpiling of PD medication. The main motivations to start stockpiling were media information, healthcare professionals, PD Association newsletters, and encouragement from family and friends. Other than media information, direct encouragement or promotion by a person with an interest in PD, particularly by a person familiar to the patient, seems to lead to the stockpiling of PD medication.

The significantly higher stockpiling behavior of respondents who carry a medicine notebook or information sheet when they leave home (one of the "Modifying Factors") suggests that an important factor is understanding the importance of the medication and being prepared and able to explain the medication to others in case of an unexpected situation while they are out. PD patients may be at home or they may be away from home when a natural disaster strikes. By encouraging them to always bring a medicine notebook when they go out, stockpiling PD medication can be promoted.

Respondents who are aware of the possibility of a future disaster also displayed a significantly higher likelihood of stockpiling. This indicates that respondents' behavior is based on their understanding of the possibility of a disaster. The types of likely natural disasters and degree of risk thereof vary by locale. Municipalities publish

hazard maps and inform their residents of the risk of various disasters, and it can be assumed that these respondents have absorbed such information and been able to act on it.

The significant association between stockpiling behavior and possession of a disability certificate may be due to the fact that municipalities have identified these people as being in need of assistance during a disaster and have therefore encouraged them to prepare for a disaster. Specifically, municipal officers can recommend that patients with disability certificates be registered as persons requiring assistance during a disaster, and they can also recommend PD medication stockpiling. Therefore, PD patients with disability certificates are more likely to receive encouragement to stockpile PD medication.

On the other hand, “Perceived Threat,” “Susceptibility,” “Severity,” and “Benefits” did not show significant association with stockpiling behavior. This may be explained by the possibility that many respondents were already aware of the importance of PD medication, so they agreed with the statements measuring these constructs because PD medication is indispensable for their activities of daily living.

“Barriers” was another factor that was not significantly associated with stockpiling behavior. The questionnaire item for this factor was developed based on keywords extracted from the results of the preliminary study, and the resulting item was, “it is bothersome to replace my stockpile of medication regularly or when the type of medication changes.” However, respondents in the main study who did not stockpile PD medication gave reasons such as, “did not know the medications’ shelf life,” “never thought about it,” “was reluctant to ask for a doctor,” and/or “was refused by a medical facility.” Therefore, it is possibility that the respondents who do not stockpile their medication do not particularly think replacing

their stockpile would be a burden. It may also be the case that having only one questionnaire item to measure this construct resulted in the lack of association between “Barriers” and stockpiling behavior.

#### 4. Suggestions for nursing care

This study revealed that over 90% of PD patients know that they need to stockpile over three days’ worth of medication for disaster preparedness. Therefore, encouragement from healthcare professionals and improvement of the stockpiling environment are needed, and measures that focus on these approaches may be effective.

To promote the stockpiling of PD medication, the following three approaches are recommended. Hirose et al. [29] noted that people tend to put off things they do not want to do, and disaster preparedness is one of them. First, therefore, healthcare professionals should provide motivation to stockpile medication by encouraging PD patients to “start now and not later” as well as to take a medicine notebook or information sheet whenever going out. Second, not knowing the shelf life of their medication was cited as a reason for not stockpiling, providing patients with this information may help promote PD medication stockpiling. For example, healthcare professionals might ask pharmacists to tell patients about the shelf life of the medication when they prescribe medication. Third, to prevent PD patients from feeling reluctant to ask a doctor about stockpiling or having their request refused by a healthcare facility, medical institutions and pharmacies must work to create an environment where PD patients can feel free to ask about medication stockpiling. Such an environment can be promoted and improved by informing medical institutions and pharmacies about the *Guidelines* [3]. Also, PD Association newsletters are published four times a year, and these publications usually contain information about

the medication. Using these newsletters may be another effective method of promoting stockpiling.

#### 5. Limitations and future research

The present study has a few limitations. First, the participant pool was limited to members of the PD Association rather than all PD patients, so the results may not be representative of the PD patient population as a whole. It seems likely that the stockpiling behavior of association members would be better than that of the entire PD patient population, because membership implies a strong desire to learn about their disease and medication. Second, the design of this study was cross-sectional, with the data being collected at one point in time; therefore, the results cannot speak to a causal relationship between the hypothesized factors and stockpiling behavior. Finally, since this was the first study on disaster preparedness behavior based on the HBM and no previous studies have been conducted, there were some difficulties in the development of appropriate questionnaire items for each construct of the HBM. Moreover, all four of the women interviewed in the preliminary study had had disaster experience and had stockpiled their medication after the disaster; therefore, their situation and experiences may not have applied directly to the circumstances of the main study participants, particularly those who reported that they do not stockpile at all. Future research in this area should focus on creating a research framework which more fully considers and deals with these limitations.

#### Conclusions

In this study, four factors based on the Health Belief Model were identified as being associated with PD patients' stockpiling of medication for disaster preparedness. In addition to the "Cues to Action" factor (receiving encouragement or information), three of the "Modifying Factors

showed significant associations: possession of a disability certificate, bringing a medicine notebook or information sheet when going out, and awareness of the possibility of a disaster. These results suggest that making a habit of taking a medicine notebook whenever going out, encouragement from others including healthcare professionals, and being aware of the possibility of a disaster are useful in promoting medication stockpiling among PD patients.

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