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ORIGINAL ARTICLE

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Survey of Caregivers' Care Burden Perception Relating to Excretion-Related Actions of Parkinson's Disease Patients

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ABSTRACT

Background: Parkinson's disease (PD) is a progressive disease, and competence in performing activities of daily living declines during its progression, increasing caregiver's care burden perception. Care in relation to excretion-related actions is frequently required against the background of motor and non-motor symptoms, and the contents of nursing care vary, including movement and dressing. Therefore, in this study, the care burden perception in relation to excretion-related actions was investigated and classified by severity and intra-day changes in symptoms.

Methods: The analysis included 25 caregivers of patients who had joined the Gunma Prefecture Branch of the Japan Parkinson's Disease Association. The questionnaire items addressed care burden perceptions relating to nine excretion-related actions. Responses were classified by whether the caregiver's movement was easy (ON) or difficult (OFF). The analysis involved placing the subjects in three groups (1/2, 3, and 4) based on the Hoehn and Yahr severity scale.

Results: An increase in care burden perception due to the progression of symptoms was confirmed. In addition, although the difference between ON and OFF was not significant, care burden perception tended to be higher with OFF.

Conclusions: Care burden perception increased with PD symptom progression, suggesting a tendency toward more significant effects of intra-day symptom variation. This may constitute helpful information when considering rehabilitation linked to reducing caregiver's care burden perception in connection with PD and/or reorganization/refitting of the domestic environment.

Registration No. Ethical Review Board, Takasaki University of Health and Welfare (approval no. 2952).

Keywords: Parkinson's disease; excretion-related actions; caregivers' burden perception; Hoehn and Yahr severity scale, intra-day variation.

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INTRODUCTION

Parkinson's disease (PD) is a progressive disorder in which many abilities needed for activities of daily life (ADL) deteriorate with time [1]. In addition, the care burden on family caregivers increases with disease progression, as the ability to adapt to the domestic environment decreases [2,3]. This increased care burden significantly impacts caregivers' mental health and quality of life [4,5]. Thus, reducing the care burden on family caregivers is an important issue.

Among the types of care for people with PD, frequent movement to the toilet is required [6]. In addition to gait disturbance, a motor symptom, this requirement involves frequent urination and urinary urgency, which are due to bladder dysfunction caused by non-motor symptoms. Bladder dysfunction is the most frequent non-motor symptom in PD, reported in 38–71% of patients [7,8]. Furthermore, bladder dysfunction has been linked to disease progression [9], but unlike motor disorders, it is characterized by the low therapeutic efficacy of levodopa [10]. Frequent urination, urinary urgency, and associated urinary incontinence are significant causes of the decrease in patients' quality of life [11]. An increased risk of falls has also been reported in patients with these symptoms [12].

The contents of nursing care are diverse because various actions such as moving to the toilet, turning around at the toilet, standing up, post-excretion procedures, and getting dressed are required for excretion. In addition, PD involves intra-day variation in symptoms as part of disease progression and/or adverse effects from drugs, resulting in inhibited physical activity [13,14]. Therefore, this study was performed as a survey. The care burden perception relating to various actions needed to perform excretion-related actions was classified by disease severity and intra-day symptom changes. By elucidating the actions for which there is often a care burden perception, the study was performed to provide information about actions to consider given the context of rehabilitation and the reorganization and refitting of the patient's home.

METHODS

1.1 Subjects

The target population for the survey was 160 patients who were members of the Gunma Prefecture Branch of the Japan Parkinson's Disease Association. The survey method was a self-completed questionnaire sent by mail. Responses were obtained from 38 caregivers (response rate: 23.7%). The exclusion criteria were that the carer failed to complete one or more items in the questionnaire; and/or that one or more of the following applied to the cared-for person: (i) he/she was using a portable toilet, (ii) he/she was wearing diapers, (iii) he/she had undergone urinary catheterization, (iv) he/she had a motor disorder other than PD, and (v) he/she moved to the toilet by mobility means other than walking (e.g., used a wheelchair). After applying these exclusion criteria, the analysis was performed with 25 persons (15.6%).

1.2 Survey items

1.2.1 Basic information

For all caregivers, sex, age, and relationship with the cared-for person were determined. In addition, for the cared-for person, sex, age, grade on the Hoehn and Yahr severity scale (H&Y), history of illness, and the number of daily bowel movements and urinations were determined.

1.2.2 Excretion-related activity

The survey covered the following nine stipulated actions requiring nursing care before excretion: (i) movement to the toilet, (ii) turning round in the toilet area, (iii) lowering the pants, (iv) sitting on the toilet, (v) maintaining a seated position, (vi) tearing the toilet paper to the appropriate length, (vii) post-excretion procedure (wiping the anal area), (viii) standing up from the toilet, and (ix) raising the pants and arranging clothes. For these items, the caregiver's care burden perception was defined as his/her subjective feeling of burden concerning care. It was classified according to the following five levels: (i) no care, (ii) unproblematic, (iii) mostly unproblematic, (iv) somewhat difficult, and (v) very difficult. In addition, care burden perception was assessed when the caregiver could move spontaneously (ON period: ON) and when such movement was difficult (OFF period: OFF). Regarding the care burden perception associated with all actions, the request was for a comprehensive assessment without classification as urination and defecation. In addition, even subjects who did not have ON/OFF were asked to respond for ON and OFF, and the same care burden perception was entered.

3. Analytical methods

The analysis involved allocating cared-for persons to three groups—Stage 1/2, Stage 3, and Stage 4—based on the H&Y grade. A one-way ANOVA or Kruskal-Wallis test was used for the basic information. For the care burden perception for each action, "no care" and "unproblematic" were taken as indicating the absence of a care burden perception, whereas "mostly unproblematic," "somewhat difficult," and "very difficult" indicated the presence of a care burden perception. Furthermore, the proportion of subjects responding that care burden was present was analyzed as per the classification as ON or OFF. In addition, the change in care burden perception with ON and OFF for each action was analyzed using the Wilcoxon signed-rank test. The level of significance was set at 5%.

4. Ethical considerations

After obtaining permission from the Gunma Prefecture Branch of the Japan Parkinson's Disease Association, this study was performed. Together with the questionnaire, prospective subjects were given written explanations about (i) the details of the study, (ii) the fact that the decision whether or not to participate could be made freely, and (iii) that prospective subjects would suffer no disadvantage as a result of deciding not to participate. Each subject's consent was obtained by the questionnaire being returned. This study was performed based on the Ethics Review Board of Takasaki University of Health and Welfare (approval no. 2952).

RESULTS

1.1 **Basic information**

Table 1 provides the basic information on the caregivers and cared-for persons. The number of cared-for persons at different H&Y stages was 5 at Stage 1/2, 11 at Stage 3, 9 at Stage 4, and 0 at Stage 5. Although no significant differences were found between the groups, the history of the illness tended to be longer with persons in Stage 4 than in Stage 1/2.

Table 1. Basic Information

									n = 25
		Cared-for person				**Caregiver**			
H & Y	**n**	**Sex**		**Age (yrs)**	**History of illness (yrs)**	**Relationship with cared-for person**	**Sex in relation to caregiver care**		**Age (yrs)**
		Male	**Female**				**Same sex**	**Opposite sex**	
1/2	5	4	1	72.8±3.7	5.6±4.1	Spouse: 3 Child: 2	1	4	Spouses: 70.6±4.5 Children: 45.5±2.1
3	11	2	9	73.8±4.9	10.0±4.8	Spouse: 7 Child: 4	2	9	Spouses: 71.3±5.6 Children: 42.2±3.2
4	9	4	5	69.8±5.5	16.1±9.4	Spouse: 7 Child: 2	1	8	Spouses: 68.4.5±7.6 Children: 46.5±4.9

Unit: mean ± SD

H&Y: Hoehn and Yahr severity scale

2. Number of persons with care burden perception in each group and for each action, and comparison between ON and OFF

2.1 Stage 1/2

Table 2 shows that in ON, there was no care burden perception for any action. There was care burden perception in OFF with one of five subjects (20%) for all actions. No significant differences between ON and OFF were found for any items.

2.2 Stage 3

In ON, there was a care burden perception with 1 of 11 persons (9%) for all actions. There was a care burden perception in OFF with two subjects (18%) for all actions. No significant differences between ON and OFF were found for any of the items.

2.3 Stage 4

In ON, for item (ix) only, "raising pants and arranging clothes," there was a care burden perception with one of nine subjects (11%). In OFF, there was a care burden perception with four subjects (44%), especially for the following items: (i) movement to the toilet, (ii)turning round in the toilet area, (iii) lowering the pants, and (ix) raising the pants and arranging clothes. A comparison of ON and OFF showed no significant differences between ON and OFF for any items, but the care burden perception tended to increase in OFF compared with ON.

Table 2. Number (proportion) of people with care burden perception for each action, and comparison between ON and OFF, in each group

																			n = 25
H & Y	N	Movement to toilet		(ii)Turning around at toilet		(iii)Lowering pants		(iv) Sitting on toilet		(v)Maintaining sitting position		(vi) Tearing toilet paper to appropriate length		(vii) Post-excretion (wiping anal area)		(viii) Standing up from toilet		(ix)Raising pants, arranging clothes	
		ON	OFF	ON	OFF	ON	OFF	ON	OFF	ON	OFF	ON	OFF	ON	OFF	ON	OFF	ON	OFF
1/2	5	0	1(20)	0	1(20)	0	1(20)	0	1(20)	0	1(20)	0	1(20)	0	1(20)	0	1(20)	0	1(20)
3	11	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)	1(9)	2(18)
4	9	0	4(44)	0	4(44)	0	4(44)	0	3(33)	0	3(33)	0	2(22)	0	1(11)	0	3(33)	1(11)	4(44)

Proportion (%) of people with care burden perception:

Number of subjects with care burden perception in each group / Total number of subjects in each group

H&Y: Hoehn and Yahr severity scale

ON: ON period

OFF: OFF period

DISCUSSION

This study showed that in ON, even at H&Y Stage 4, that is, with relatively advanced disease, the care burden perception relating to excretion-related actions was low. In OFF, in the case of H&Y Stages 1–3, the care burden perception was low despite the increase, whereas no significant differences were observed at H&Y Stage 4 compared to ON. However, the care burden perception increased with many actions and tended to be elevated for movement, turning round, and dressing actions. Reportedly, care burden perception increases as PD progresses [3]. The present study demonstrated a similar tendency in a survey restricted to excretion-related actions. In a previously reported survey by the current authors of the actions with which PD patients themselves felt difficulties in relation to excretion-related actions, the most sense of difficulty in both ON and OFF was found for taking off and putting on undergarments [15]. On this basis, improvement in dressing and undressing ability at the time of excretion has had beneficial effects for both the caregiver and cared-for person. Therefore, it is considered an important factor when assessing the domestic environment's rehabilitation and reorganization/refitting.

Nishii et al. [16] investigated the care burden perception of caregivers providing care at home for elderly persons certified as requiring care, comparing the care contents between caregivers with low and high care burden perceptions. The results showed that for excretion-related actions, the level of care involved in the items "care with dressing and undressing," "care with post-excretion procedures," "care with diapers," and "care with excretion at night" increased significantly among caregivers' increasing care burden perception. On the other hand, no significant differences were found for "care in movement" or "care with movement to the toilet." Therefore, it is considered that "care with dressing and undressing" is an action that readily gives rise to care burden perception with both PD patients and elderly people living at home. In contrast, care burden perception relates to "movement" and "turning around," which is found in PD patients, has little importance for elderly people at home. This suggests that care burden perception regarding these actions may be characteristic of caring for PD patients. This result shows the necessity of including in the area of concern the potential for care burden perception with specific ADL when support is provided for PD patients' caregivers and providing help to the caregivers based on that.

One limitation of this study is that family functionality was not investigated [17]. Nakai et al. reported that the family environment surrounding caregivers, including family members' emotional connections with each other (family closeness), and the ability to flexibly change the authority structure, role relationships, rules, and so on within families (family adaptability), are essential for the care burden perception of the caregivers of PD patients. In this regard, considering the results of the present study is not sufficient because this aspect was not sufficiently investigated here. In the future, the living and social environments of the caregiver and cared-for person will be investigated. In addition, the present study included an analysis in which the subjects were allocated to three groups according to the severity of the caregivers' situation. Therefore, the number of subjects in each group was small and differed between groups. This may have resulted in bias in the results. Therefore, we wish to perform a survey continuing from the present one that provides more information on these aspects.

CONCLUSIONS

The nursing care burden perception for excretion-related actions of PD patients was investigated. PD patients were classified according to disease severity and intra-day symptom changes. The results showed that care burden perception increased due to symptom progression and intra-day variation. In addition, it was shown that there was high care burden perception with movement and dressing and undressing actions in connection with symptom progression. This information may help reduce the care burden perception through rehabilitation and reorganization/refitting of the domestic environment.

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REFERENCES

[1] Sperens M, Georgiev D, Domellöf ME, Forsgren L, Hamberg K, Hariz GM. Actions of daily living in Parkinson's disease: Time/sex perspective. Acta Neurol Scand. 2020; 141(2):168-76.

[2] Slaug B, Iwarsson S, Ayala JA, Nilsson MH. Housing accessibility problems for people with Parkinson's disease. Acta Neurol Scand. 2017; 136(5):501-10.

[3] Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. Parkinsonism Relat Disord. 2006; 12:35-41.

[4] Martínez-Martín P, Forjaz MJ, Frades-Payo B, Rusiñol AB, Fernández-García JM, Benito-León J, et al . Caregiver burden in Parkinson's disease. Mov Disord. 2007; 22(7):924-31.

[5] Smith ER, Perrin PB, Tyler CM, Lageman SK, Villaseñor T. Parkinson's symptoms and caregiver burden and mental health: A cross-cultural mediational model. Behav Neurol. 2019; 1396572.

[6] Shin JY, Habermann B. Key actions of caregivers for individuals with Parkinson disease: A secondary analysis. J Neurosci Nurs. 2020; 52(6):284-88.

[7] Tibar H, Bayad KE, Bouhouche A, Bouhouche A, Haddou EAH, Benomar A, et al. Non-motor symptoms of Parkinson's disease and their impact on quality of life in a cohort of Moroccan patients. Front Neurol. 2018; 4(9):170.

[8] Sakakibara R, Uchiyama T, Yamanishi T, Kishi M. Genitourinary dysfunction in Parkinson's disease. Mov Disord. 2010; 25(1):2-12.

[9] Araki I, Kuno S. Assessment of voiding dysfunction in Parkinson's disease by the international prostate symptom score. J Neurol Neurosurg Psychiatry. 2000; 68(4):429-33.

[10] Sakakibara R, Kishi M, Ogawa E, Tateno F, Uchiyama T, Yamamoto T, et al. Bladder, bowel, and sexual dysfunction in Parkinson's Disease. Parkinson's Dis. 2011; 924605.

[11] Sakakibara R, Shinotoh H, Uchiyama T, Sakuma M, Kashiwada M, Yochiyama M, et al. Questionnaire-based assessment of pelvic organ dysfunction in Parkinson's disease. Auton Neurosci. 2001; 92(1-2):76-85.

[12] Sakushima K, Yamazaki S, Fukuma S, Hayashino Y, Yabe I, Fukuhara S, et al. Influence of urinary urgency and other urinary disturbances on falls in Parkinson's disease. J Neurol Sci. 2016; 360:153-57.

[13] Marras C, Lang A, Krahn M, Tomlinson G, Naglie G. Quality of life in early Parkinson's disease: Impact of dyskinesia and motor variation. Mov Disord. 2004; 19(1):22-8.

[14] Hechtner MC, Vogt T, Zöllner Y, Schröder S, Sauer JB, Binder H, et al. Quality of life in Parkinson's disease patients with motor variation and dyskinesia in five European countries. Parkinsonism Relat Disord. 2014; 20(9):969-74.

[15] Ohno Y. Survey on difficulty in excretion-related motions in Parkinson's disease patients. J Japan Acad Home Care. 2020; 24(1):102-06.

[16] Nishii M, Izuta M, Sukeno O, Yoshimi Y, Miki T. Factors affecting the sense of caregiver burden: From the perspective of ADL. J Welf Sci. 2011; 15:93-105.

[17] Nakai T, Sugiyama K, Sawada Y, Kirino M, Kashihara K, Takemoto Y. Relationship between long-term care burden and cognitive assessment of family function in the primary caregiver of Parkinson's disease patients. J Health Welf Stats. 2014; 61(7):19-28.