

Views on Co-occupation between Elderly Persons with Dementia and Family

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Abstract

Background: Long-term support is essential for individuals with dementia in order to improve their and their caregivers' quality of life. We need to investigate the unmet co-occupation needs of elderly persons with dementia and their family caregivers. This study aims to clarify the characteristics of co-occupations between family caregivers and elderly persons with dementia.

Methods: We administered a questionnaire survey to 39 caregivers regarding co-occupations between persons with dementia and caregivers, the co-occupations they perceived as troublesome, and the co-occupations they preferred.

Findings: Thirty-two caregivers (82.1%) perceived 74 co-occupations focused on the self-care of persons with dementia to be troublesome, while twenty-one (53.8%) indicated 30 co-occupations as their preferred ones. Those caregivers with preferred co-occupations placed significantly higher importance on troublesome co-occupations than the caregivers without preferred co-occupations. The number of troublesome co-occupations showed a weak positive correlation with dementia symptoms. The performance of troublesome co-occupations showed a weak negative correlation with the caregiving period, weekly amount of caregiving time. The satisfaction with troublesome co-occupations showed a weak negative correlation with the caregiving period. No other significant correlations were found.

Conclusion: More than 80% of the family caregivers perceived the troublesome co-occupations. We need to assist caregivers with co-occupations that they perceive as troublesome. Furthermore, providing support based on co-occupation might improve family caregivers' well-being and enable long-term home care.

Keywords: Co-occupation, Family caregivers, Persons with dementia, Questionnaire survey

Abbreviations:

PWD: Persons with Dementia; QOL: Quality of Life; BPSD: Behavioral and Psychological Symptoms of Dementia; ADL: Activities of Daily Living; NPI-Q: Neuropsychiatric Inventory- Questionnaire; N-ADL: Nishimura's Activities of Daily Living

Introduction

As the age of the world population has increased, there has been a corresponding increase in numbers of persons with dementia (PWD). There are currently 35,600,000 PWD in the world today. However, it is predicted that the PWD population will be three times or greater than that number in 2050 [1]. Long-term support for PWD is essential to improve their and their caregivers' quality of life (QOL). Occupational therapy proves effective for decreasing behavioral disorders, improving well-being, and promoting social participation for PWD [2,3]. Furthermore, occupational therapy practitioners better understand PWD needs and can improve, evidence-based ways to enable occupation, while considering the desires and preferences of PWD and their caregivers [4]. QOL maintenance is among the

primary needs of PWD. Unmet needs of PWD include the need to be accepted and respected as they are. Furthermore, for PWD, a primary goal of care is QOL maximization [5].

On the other hand, family caregivers of PWD often struggle with implementing co-occupations. Co-occupations are defined as occupations that involve more than one person [6]. They involve aspects of shared physicality, emotionality, and intentionality, embedded in shared meaning, and encompass purposeful daily activities [7]. Some reasons for this difficulty are the behavioral and psychological symptoms of dementia (BPSD) of PWD. BPSDs are greatly influenced by environmental characteristics including the quality and quantity of care and the physical environment [8]. Therefore, family caregivers of PWD need to assist with activities of daily living (ADLs), manage the PWD's safety and behavioral symptoms, coordinate supportive services, and make financial and healthcare decisions in proxy [9].

Unmet dementia-related needs for care, services, and support are known to increase the risk of undesirable health outcomes for caregivers [10]. However, in spite of the needs related to family caregivers' care of PWD, previous reports have not focused on the needs of family caregivers in co-occupations with PWD. In a recent study by Graff et al., it was found that occupational therapy

interventions focused on leisure or work were effective for family caregivers and PWD [11]. Therefore, it is necessary to investigate what kind of co-occupations family caregivers and PWD conduct to understand their unmet needs.

This study clarifies the characteristics of co-occupations between the family caregivers and elderly PWD with BPSD. We performed a questionnaire survey focusing on co-occupations they perceived as troublesome, and the co-occupations they preferred. The co-occupations were defined in this study as follows: activities of elderly PWD conducted with their family caregivers jointly in personal care, daily activities, job, pleasure, and rest. In this study, we hope to understand the needs of family caregivers in co-occupations.

Methods

Subjects

Subjects who satisfied the following conditions were selected.

1. Subjects were families who lived together with elderly PWD with BPSD.
2. Subjects were considered the primary caregiver.
3. Subjects were without cognitive dysfunction and judged to be able to reliably answer the questionnaire.
4. Subjects who had free time, and agreed to the purpose of this study.

This study was a cross-sectional study using a questionnaire survey. Between August and December 2013, the questionnaire survey was performed at six institutions (three outpatient rehabilitation centers, one home-visit nursing station, one home-visit rehabilitation center, and one home care support office) within Okayama Prefecture in Japan. The family caregivers received the questionnaire from the study coordinator at the institution, and were asked to reply by themselves. The completed questionnaires were collected by the study coordinator of the institution directly or via a self-addressed envelope posted to the researcher.

Variables and instruments

For the elderly PWD, information was collected about gender, age, primary nursing care requirement authorization, causative disease, degree of BPSD, and performance of daily activities. For the family caregivers, information was collected about gender, age, family relationship with the elderly persons living at home, the family structure, caregiving period (years), longest and shortest caregiving time (hours) within the last week, and their feeling of burden caused by BPSD. In addition, the following were included in the variables of the family caregivers: co-occupations which currently trouble a family caregiver while performing it with an elderly PWD (hereinafter referred to as troublesome co-occupation); co-occupations which a family caregiver prefers to perform with elderly PWD (hereinafter referred to as preferred co-occupation); presence or absence of each type of co-occupation; name of each co-occupation; importance of the occupation; performance of the occupation; and satisfaction with the occupation.

All variables were investigated through the questionnaire completed by the family caregivers. BPSDs of elderly PWDs were examined using the Neuropsychiatric Inventory- Questionnaire (NPI-Q). The NPI-Q is a questionnaire in which a caregiver reads the questions regarding

psychological symptoms of a PWD requiring nursing care, reports the presence or absence of the relevant psychological symptoms in dementia, and evaluates the severity using a rating scale from 1 to 3 [12]. The scale comprises 12 items and the total scores range from 0 to 36. The items on the burden of caregiving in the NPI-Q were used to evaluate the degree of burden felt by the caregiver as a result of coping with BPSD. This is a questionnaire designed to evaluate the degree of burden felt for each item of the NPI-Q with a rating scale from 0-5. Total scores ranged from 0 to 60. Higher scores mean greater severity. The Japanese edition of the NPI-Q was used for this study.

The performance of daily activities of the elderly PWD was examined using Nishimura's Activities of Daily Living (N-ADL). The N-ADL is a behavior observation grading system to evaluate five activities: "walking, transferring"; "going outside"; "dressing, bathing"; "feeding"; "toileting". Assuming a score of ten points for each item means complete independence, total scores were from 0-50. Higher scores mean higher independence [13].

We developed original questionnaires to survey troublesome co-occupations and preferred co-occupations separately. Troublesome co-occupations were defined as subjects perceiving co-occupations as currently difficult to perform. Preferred co-occupations were defined as co-occupations subjects are not able to perform currently but want to perform in the future.

On the questionnaire of troublesome co-occupations, the first response was presence or absence of troublesome co-occupations. If the reply was positive, the co-occupation names were shown, and the importance and performance of and the satisfaction with the occupation to caregivers were evaluated using a 10-point scale rating. The questionnaire forms were created based on the Canadian Occupational Performance Measure [14]. In addition, we asked whether subjects wanted to continue the troublesome co-occupations. When there were no co-occupations, the subjects described the reason.

On the questionnaire of preferred co-occupations, the procedure was the same as troublesome co-occupations. The performance of and the satisfaction with the occupation to caregivers were answered the value that is predicted.

The caregivers were also asked to reply to each question regarding troublesome or preferred co-occupations if they perceived two or more troublesome or preferred co-occupations. The original questionnaires were previously tested by family caregivers and experts to establish face and content validity.

Statistical analysis

Total and mean numbers of troublesome and preferred co-occupations per person were calculated to determine how many the family caregivers of the elderly PWD perceived.

The subjects were classified into groups with and without preferred co-occupations. The differences between the two groups were analyzed using the Mann-Whitney test. We examined the number, importance, and performance of and satisfaction with troublesome co-occupations, and the basic attributes of the elderly PWDs and their family caregivers. In addition, among the family caregivers who perceived two or more troublesome and preferred co-occupations, the mean values of the importance and performance of and satisfaction with the occupation were evaluated.

The factors associated with each characteristic of the troublesome and preferred co-occupations were analyzed using Spearman's rank

correlation coefficients. We investigated the number, importance, and performance of and satisfaction with the occupation, and the basic attributes of the elderly PWDs and their family caregivers.

Group	Variable	n	M	SD
Elderly	Age	39	85.1	6.0
	Male	15		
	Female	24		
	Caregiving needs (0 - 8)		5.6	1.5
	NPI-Q score		10.9	7.5
	N-ADL score		27.5	10.2
Family caregiver	Age	39	62.9	10.4
	Male	5		
	Female	34		
	Non-spouse	30		
	Spouse	9		
	Caregiving period (no. of years)		4.3	2.8
	Longest caregiving time ^a		11.3	8.2
	Shortest caregiving time ^a		5.4	5.7
	NPI-Q care burden		12	10.5
^a Time (in hours) within the last week				

Table 1: Basic Attributes of Subjects.

Group	Variable	Total Median (Interquartile Range) n=39	With preferred co-occupations n=21	Without preferred co-occupations n=18	p
Elderly	Age	87 (80-89)	86 (81-90)	87 (81-88)	0.79
	Caregiving needs (0-8)	6 (5-6)	6 (5-6)	6 (5-6)	0.83
	NPI-Q score	8 (5-17)	6 (5-17)	9 (6-20)	0.66
	N-ADL score	29 (23-35)	29 (23-35)	31 (24-37)	0.53
Family caregiver	Age	63 (57-68)	64 (58-72)	63 (55-66)	0.42
	Caregiving period (no. of years)	4 (2-5)	4 (3-6)	4 (2-5)	0.26
	Longest caregiving time (hr)	12 (4-20)	10 (4-14)	14 (5-24)	0.25
	Shortest caregiving time (hr)	4 (1-7)	3 (1-5)	4 (3-12)	0.66
	NPI-Q care burden	8 (3-19)	8 (3-19)	10 (5-18)	0.94
Troublesome co-occupation	Importance	9 (6.2-10)	9 (8-10)	7.3 (1-9.6)	0.04

We calculated a sample size based on Cohen's effect size [15]. The Mann-Whitney test and Spearman's rank correlation coefficients use large effect sizes ($r=0.80, 0.50$), power=0.80. Statistical significance was considered if the p value from a two-tailed test was less than 0.05. Statistical analysis software SPSS ver. 21.0J for Windows was used for data analysis.

Ethical considerations

This study was conducted with the approval of the ethical committee of Kawasaki University of Medical Welfare on 13 August 2013 (Acceptance number 399). Family caregivers gave informed consent to use data for this study when first asked.

Results

Of the 41 responses to the questionnaires collected, 39 were considered valid and were included in this study; two were incomplete and thus excluded. Demographic characteristics of the subjects (PWDs and caregivers) are found in Table 1.

Of 39 family caregivers, 32 (82.1%) reported troublesome co-occupations. A total of 74 co-occupations were reported, and the mean number of co-occupations was 1.9 per family caregiver. Similar co-occupations between caregivers included "feeding", "dressing", and "diaper changing". "Moves, transfers" and "hospital visits" were also included. In addition, caregivers stated "they want to continue" 66 of 74 troublesome co-occupations (89.1%). Twenty-one family caregivers (53.8%) said there were preferred co-occupations. A total of 30 co-occupations were extracted, and the mean number of the preferred occupations was 0.8 per family caregiver. The co-occupations that overlapped included "travel", "walking", and "shopping", "Exercise" and "meal preparation" were also included.

Table 2 shows the differences between the groups with and without preferred co-occupations. The importance of troublesome co-occupations was significantly higher in the group with preferred co-occupations as compared with the group without preferred occupations ($p=0.046$). No other significant correlation was found.

	Performance	3.7 (2.5-6)	4 (3-6)	3.5 (1.8-6)	0.42
	Satisfaction	4 (1.8-5)	4.5 (3-5)	3 (1.2-5)	0.07
	Number of troublesome co-occupations	2 (1-3)	2 (1-3)	2 (1-3)	0.37
Preferred co-occupation	Importance	2 (0-8)	8 (5-9)		
	Performance	2 (0-4)	3.5 (2-7)		
	Satisfaction	2 (0-5)	5 (4-8)		
	Number of preferred co-occupations	1 (0-1)	1 (1-1)		

Table 2: Differences between Groups with and without preferred co-occupations.

Table 3 describes the associations between the characteristics of troublesome co-occupations and the basic attributes. The number of troublesome co-occupations showed a weak positive correlation with the NPI-Q (p=0.028) administered to the elderly PWDs. The performance of troublesome co-occupations showed a weak negative

correlation with the caregiving period (p=0.024), the longest caregiving time (p=0.043), and the shortest caregiving time (p=0.023). The satisfaction with troublesome co-occupations showed a weak negative correlation with the caregiving period (p=0.022). No other significant correlations were found.

Variables	Troublesome co-occupations				Preferred Co-occupations			
	Number	Importance	Performance	Satisfaction	Number	Importance	Performance	Satisfaction
Elderly caregiving needs	-.107	.135	-.212	-.107	.097	.120	-.031	.010
NPIQ of elderly	.351*	.205	-.064	-.023	-.028	-.156	-.046	.009
NADL of elderly	-.265	-.128	.330*	.077	-.090	-.095	-.005	-.111
NPIQ of caregiver	.263	.217	-.075	-.036	-.009	-.132	-.023	.064
Caregiving period	.040	.183	-.361*	-.367*	.259	.215	.163	.050
Longest caregiving time	.081	.036	-.326*	-.308	-.101	-.184	-.104	-.124
Shortest caregiving time	.170	.111	-.364*	-.299	-.016	-.102	-.007	-.053
Family structure	.173	.135	.018	-.074	-.060	.092	.051	.077
Presence or absence of job	-.135	-.267	.108	.101	-.090	-.030	-.054	-.020
Age of elderly	.273	.011	.011	.102	.072	-.027	.102	.089
Age of caregiver	.083	.063	.049	.175	.146	.122	-.036	-.105

*p<.05

Table 3: Correlation Factors (rs) Associated with the Characteristics of Troublesome Co-occupations and Preferred Co-occupations

Discussion

In this study, the characteristics of troublesome and preferred co-occupations were investigated in the family caregivers of elderly PWD.

The subjects of this study were mostly women. This result was consistent with the characteristics of family caregivers reported by World Health Organization [1]. The caregiving period averaged 4.3 years (SD=2.8). This period corresponds to the middle stages of dementia. Later stages used resources such as residential or nursing homes [16]. Therefore, the subjects of this study were representative of family caregivers with elderly PWD at home.

Although some family caregivers perceived troublesome co-occupations, they wanted to continue those co-occupations. There was an association between the number of troublesome co-occupations and BPSDs of the elderly persons. Family caregivers who perceived preferred co-occupations perceived the troublesome co-occupations as more important than those without preferred co-occupations. Kielhofner [17] emphasized the significance of occupations as a determinant factor of connection with the occupation. In other words, for caregivers without preferred co-occupations, co-occupations may not be regarded as important. Alternatively, worsened cognitive function and changes in the environmental factors at home in elderly

PWDs may bring occupational loss to family caregivers [18] and may have a negative influence on their occupational performance.

Characteristics of troublesome occupations

When elderly PWDs experienced trouble performing the activities of daily life, the person most often providing support is a family member. These family caregivers often feel that they have poor caregiving skills and that they lack knowledge about how to communicate with a PWD [19]. Therefore, some caregivers recognize there are required troublesome co-occupations and want to continue performing them. If the family caregiver is a spouse, they may be attached to the elderly PWD, and the more severe the symptoms, the more anxiety the caregiver will feel [20]. In addition, family caregivers may be unwilling to ask others to assist with care and may refuse to be separated from the person requiring care [21]. Therefore, it is possible that family caregivers are in situations where they cannot avoid troublesome co-occupations.

There was a weak positive correlation between the number of troublesome co-occupations and the degree of BPSDs. According to the Canadian Model of Occupational Performance and Engagement, the surrounding environment is assumed to have a major influence on occupational performance [18]. Factors that influence the BPSDs in PWD have certain environmental characteristics [22]. In other words, when the PWD is in a different environment, occupational adaptation may be more difficult. In addition, the performance of the troublesome co-occupations showed a weak negative correlation with the caregiving period, the longest caregiving time, and the shortest caregiving time, while satisfaction with the troublesome co-occupations showed a weak negative correlation with the caregiving period. The association between the performance of troublesome co-occupations and the caregiving period suggests that BPSDs of elderly PWDs appear regardless of time period, and family caregivers have to be involved in caregiving each time. Kielhofner [17] asserted that the failure of family caregivers to meet the performance standards they set for themselves and obtain satisfaction with occupations led to a reduction of occupational competence. Recently, in Japan, caregiving has become more difficult labor as the severity of dependent elderly living at home has increased [23]. In addition to the environmental problems mentioned above, very prolonged and difficult caregiving may reduce the perceived competence of caregivers, which makes occupational adaptation more difficult.

Characteristics of preferable occupations

Half of the subjects in this study stated there were co-occupations they preferred. The characteristics of the preferred co-occupations included mainly leisure activities or the activities that the elderly PWD conducted habitually prior to diagnosis.

There were fewer factors associated with preferred co-occupations than troublesome co-occupations. One of the reasons was measured variables of the family caregivers. According to Graff et al. [24], the occupational therapy intervention for the occupations, which both the elderly PWDs and the family caregivers considered important, improved the occupational performance of both and the self-efficacy of the family caregivers. The degree of cognitive impairment and caregiving burden, however, were not changed. Preferred co-occupations might have been influenced by factors other than the responsibilities examined in this study, or the caregiving burden caused by BPSDs.

Support for co-occupations

This study identified the characteristics of troublesome and preferred co-occupations. It also revealed that it is necessary to provide support to improve occupational performance of co-occupations between elderly PWDs and their family caregivers. As a specific policy, in order to improve the occupational performance of troublesome co-occupations, simple and easy measures for reducing the time spent on occupational performance are necessary. In addition, it may be necessary to allow caregivers to engage in preferred co-occupations in order to improve their satisfaction from co-occupations.

Limitations of this study

The main limitation of this study is that the contents of the questionnaire were self-constructed by the authors. Additionally, the test-retest reliability was not examined. The surveys were evaluated for face and content validity but not for criterion-related validity. The reasons for this include the inability to generate external criteria for the concept of co-occupation. We also might insufficiently represent the definition of troublesome and preferred co-occupations. In the future, it will be necessary to examine the troublesome co-occupations that family caregivers perceived. Second, the responding caregivers lacked similarity in terms of ages and relationships to the PWDs. Therefore, contradiction might occur with respect to the caregiver's interests. In particular, this factor is likely to have an effect on the characteristic of the preferred co-occupations. Future studies should be conducted in a larger sample of caregivers with similar characteristics, after revising the questionnaire.

Conclusion

This study showed the characteristics of co-occupations in family caregivers of elderly persons with BPSD. More than 80% of the family caregivers perceived the troublesome co-occupations and nearly 90% wanted to continue the troublesome co-occupations. In addition, the performance of and the satisfaction with troublesome co-occupations was reduced by prolonged care. This study suggests that addressing the needs of family caregivers may improve the quality of troublesome co-occupations. Family caregivers with preferred co-occupations perceived the troublesome co-occupations to be more important. This finding suggests the existence of unmet needs in caregivers who want to perform the co-occupations and maintain positive feelings. Some troublesome co-occupations reported by the family caregivers were activities of PWD self-care. This result was similar to "the contents of activities provided by caregivers" by the American Alzheimer's Association [25]. However, in our results, the importance of and satisfaction with occupation varied by family caregivers in the same co-occupation. Perhaps each caregiver has given their own meaning for co-occupation. In other words, to support co-occupations, it is necessary to understand the meaning of each co-occupation rather than summarizing all co-occupations as "care". In addition, disruption in the co-occupational experiences that provide fulfilling social participation may underpin the increased social isolation of adults with physical or mental illnesses, subsequently leading to an exacerbation of their symptoms [26]. Therefore, it is necessary to develop a questionnaire regarding co-occupation in order to evaluate each family caregiver's individual occupational competence. Furthermore, support based on co-occupation might contribute to improvement of family caregivers' well-being and enable long-term home care.

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