Characteristics of Behavioral and Psychological Symptoms of Dementia, Severity and Levels of Distress on Caregivers

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Objective: To describe the characteristics of the Behavioral and Psychological Symptoms of Dementia (BPSD) and its severity among patients with dementia and their caregivers' stress.

Material and Method: A cross-sectional descriptive study of 158 patients with Alzheimer's disease, mixed vascular dementia and Alzheimer's disease, and unspecified dementia and caregivers in Songkhla Rajanakarindra Psychiatric Hospital were selected by a consecutive sampling. The BPSD and severity of dementia was assessed with the Neuropsychiatric Inventory Questionnaire - Thai version (NPI-Q Thai), the Global Clinical Dementia Rating Scale (CDR), the Mini Mental Status Thai version 2002 (MMSE Thai 2002), and a clinical diagnosis. Consensus of a psychiatrist and a neurologist according to diagnostic criteria of DSM IV-TR was achieved for every patient.

Results: Overall, 90.5% had at least one BPSD symptom. Common symptoms were irritability (60.8%), sleep problems (57%), depression (54.5%), anxiety (52%), and agitation/aggression (44.9%). The least common symptom was eating problems (23.5%). The caregivers rated the patient's physical symptoms as more severe than psychological symptoms. The symptom that caused the highest burden to caregivers was agitation/aggression, followed by dis-inhibition, aberrant motor behaviors, and sleep problems. The less burdensome symptoms included irritability, depression, and anxiety.

Conclusion: BPSD were commonly found among patients with dementia. The top five symptoms were irritability, sleep problems, depression, anxiety, and agitation/aggression. Not only assessment of BPSD, but also feeling and suffering of the caregivers should be assessed by using the NPI-Q. This would help the clinician plan appropriate treatment. Physical symptoms were perceived by caregivers as causing the most anguish and distress, while psychological symptoms were perceived as less severe. Further studies should be done, such as the factors related to burden of caregivers of dementia with BPSD.

Keywords: BPSD, Dementia, Caregivers stress, NPI-Q Thai

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The change in the age structure of the global population has resulted in a higher proportion of the elderly. By 2050, it is expected that many Asian countries will face a situation where over 40% of the population cohort will be those over 60 years of age⁽¹⁾. Currently (2012), Asia has approximately 55% of the world's elderly people⁽²⁾. An aging population influences the composition of families, living arrangements, and the need for health-care services. The health of the elderly typically deteriorates with increasing age, inducing greater demand for long-term care as the number of older people increases.

It is estimated that nearly 35.6 million people worldwide are living with dementia, with the number

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Phone: 074-317-400 ext. 64557, Fax: 074-323-202 E-mail: unchulee44@gmail.com being projected to double by 2030 (65.7 million) and more than triple by 2050 (115.4 million). More than half (58%) of dementia patients live in low and middle-income countries, and the proportion is likely to rise to more than 70% by $2050^{(3)}$. The population of Thailand is also progressively aging. The proportion of the elderly in the Thai population will increase to 14.0% in 2015, 19.8% in 2025, and nearly 30% by $2050^{(4)}$. Consequently, the prevalence of illnesses and diseases among the elderly will increase, including the prevalence of dementia, which increases with age.

Dementia is devastating not only for the patients, but also for their caregivers and families. Aside from impairment of memory, thinking processes, and cognitive function, 78% of patients with dementia also have co-existing behavioral psychological symptoms (BPSD). This prevalence is especially high among those with Alzheimer's disease^(5,6). Many studies reported the prevalence of

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BPSD among dementia patients varied from 61 to $90\%^{(7-10)}$.

The dementia patients with BPSD cause stress, depression, and a feeling of burden to their caregivers. This negatively affects their quality of life and patients are subsequently admitted to institutions for treatment, further increasing the cost of care. Leinonen E et al⁽¹¹⁾ conducted a comparative study among care-giving spouses of depressive and dementia patients with and without BPSD and found that care-giving spouses of patients with BPSD were the most burdened.

There are few studies on the prevalence and characteristics of BPSD in Thailand. Those had been conducted in memory clinics of general hospitals^(12,13). From Songklanagarindra Psychiatric Hospital's Annual Report 2012⁽¹⁴⁾, it was shown that BPSD was the leading cause of admission among patients with dementia. Not only mental health personnel but also the other medical personnel should be alert of BPSD. This will lead to proper investigation and treatment for the patients and caregivers. Therefore, the present study aims to determine the characteristics of BPSD, as well as the severity and levels of stress among the caregivers in a psychiatric setting.

Material and Method

This cross-sectional descriptive study was approved by the Human Research Ethical Review Board and written informed consents were obtained from all caregivers and patients.

Study participants

The study population and samples included dementia patients with Alzheimer's disease, mixed vascular and degenerative dementia, and unspecified dementia whom had been jointly diagnosed by psychiatrists and neurologists and primary caregivers.

One hundred fifty eight patients and primary caregivers were collected by consecutive sampling from all of the patients with dementia who were treated at Songklanagarindra Psychiatric Hospital between January 2011 and April 2012. The patients who had the scores below cut off points of MMSE Thai 2002 were confirmed by jointly diagnosed by a psychiatrist and a neurologist according to DSM IV-TR. In the first visit, the patients were assessed with the Clinical Dementia Rating (CDR) Scale by a neurologist; the primary caregivers were interviewed about BPSD by the Neuropsychiatric Inventory Questionnaire - Thai version (NPI-Q Thai).

Inclusion and exclusion criteria

The patients were included only if they were 60 years old and above and had not been taking psychotropic drugs within one month prior to the assessment. Primary caregivers and patients who had co-morbidity with a major psychiatric illness or lifethreatening conditions were excluded. The primary caregivers were 20 years and above and must have been caring for the patient for more than six months, more than three days per week.

Study tools and statistical analysis

The study tools^(15,16) consisted of the Mini Mental Status Thai version 2002 (MMSE Thai 2002) was conducted by a well-trained psychiatric nurse by using the cut off points at 22 and below, 17 and below, and 14 and below for secondary school education or higher, primary school education, and illiterate. A psychiatrist interviewed the feeling of primary caregivers about BPSD severity and were graded in three levels (mild = 1, moderate = 2, severe = 3). They also reported for six levels of suffering and manageability of BPSD (none = 0, a little suffering and no problem = 1, a little suffering and easy to manage = 2, moderate suffering and a little difficult to manage = 3, most suffering and difficult to manage = 4, severe suffering and cannot manage = 5) by using the Neuropsychiatric Inventory Questionnaire - Thai version (NPI-Q Thai). The Clinical Dementia Rating (CDR) Scale was conducted by a neurologist. Differentiation of mild, moderate, and severe dementia was done using CDR 0.5 - 1, 2, and 3. Data entry was done by using Epi Data software version 3.1. The R 3.0.2 software was used for statistical analysis. The data were analyzed with descriptive statistics.

Results

One hundred eighty patients with dementia and primary caregivers were invited, with a response rate of 87.7%. It fulfilled the trial requirements. The Demographic characteristics of the patients and caregivers are presented in Table 1 and 2. The present study found that 90.5% of patients had at least one symptom of BPSD.

Common symptoms were irritability (60.8%), sleep problems (57%), depression (54.5%), anxiety (52%) and agitation/aggression (44.9%). The least common symptom was eating problems (23.5%) (Table 3).

The caregivers rated the patient's physical symptoms as more severe than psychological

Table 1. Demographic characteristics of the patients

Items	Number	Percent (%)
Gender		
Male	66	41.77
Female	92	58.23
Age (years)		
Between 60-69 years	38	24.05
Between 70-79 years	75	47.46
Between 80-89 years	44	27.85
90 years and over	1	0.63
Education		
No education	29	18.35
Primary school	106	67.08
Secondary school or higher	23	14.55
MMSE Thai 2002 among those with no education (cut-off point at 14 or less)	29	18.35
MMSE Thai 2002 among those with primary school education (cut-off point at 17 or less)	106	67.08
MMSE Thai 2002 among those with secondary school education or higher (cut-off point at 22 or less)	23	14.56
1 Global CDR (mild)	129	81.64
2 Global CDR (moderate)	18	11.39
3 Global CDR (severe)	11	6.96
Length of illness		
6 months to <2 years	47	29.75
2 years to <6 years	61	38.60
6 years to <10 years	29	18.35
10 years or longer	21	13.29

MMSE = mini mental state examination; CDR = clinical dementia rating

symptoms. The symptom that caused the highest burden to caregivers was agitation/aggression, followed by disinhibition, aberrant motor behavior, and sleep problems. Less burdensome symptoms included irritability, depression and anxiety (Table 3, 4).

Discussion

Most of the dementia patients were female (58.23%) and age between 70 and 79 years old (47.46%). Most had at least a primary level education (67.08%). Most dementia patients had mild level of CDR (81.64%). The most common length of illness was two to six years (38.60%), followed by six months to less than two years (29.75%).

Most caregivers were female (73.42%) and were age between 20 and 76 years old, had bachelor's degree or higher (39.24%), and were married. These caregivers were working/middle aged (68.98%) and had work and family obligations. Thus, it is necessary to consider that, in addition to caring for the patient, work and family obligations may have contributed towards stress, feelings of anguish, and perceived severity of BPSD of the patients. The present study found that 90.5% had at least one BPSD symptom. This is in accordance with both clinical-based and epidemiology studies⁽¹⁷⁾, which found that up to 90% of dementia patients will experience at least one symptom of any severity over the course of their diseases.

Among the 158 samples in the present study, 90.5% had at least one BPSD symptom. The most common BPSD symptom was irritability (60.76%), followed by sleep problems (56.96%) and depression (54.43%) while the least common symptom was eating problems (23.42%). The prevalence of BPSD in the present study was similar to the study by Charernboon, which found a prevalence of 100%⁽¹²⁾, while Phanasathit et al found a prevalence of 95%⁽¹³⁾, although the characteristics of BPSD were different. Charernboon found the most prevalent symptom to be apathy at 71%, followed by aberrant motor behavior at 61.3%, sleep problems at 56.5%, eating problems at 51.6%, and agitation/aggression at 45.2%. The least common problem was euphoria at 6.5%⁽¹²⁾. On the other hand, Phanasathit and colleagues found that eating problems were twice as much as the present study

Table 2.	Demographic	characteristics	of the	caregivers
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Item	Number	Percent (%)
Gender		
Male	42	26.58
Female	116	73.42
Age (years)		
Between 20-39 years	30	18.99
Between 40-59 years	109	68.98
60 years and over	19	12.02
Education		
No education	6	3.79
Primary school	30	18.98
Secondary/vocational school	60	37.97
Bachelor's degree or higher	62	39.24
Marital status		
Single	41	25.95
Married	101	63.92
Widowed/divorced/separated	16	10.12
Occupation		
Agriculture	41	25.94
Household work	36	22.78
Civil service/state enterprise	37	23.41
Vendor/business owner	29	18.35
Student	3	1.89
General employee	12	7.59
Time caring for the patient		
Less than 1 year	30	18.90
1-5 years	70	44.30
5 years or longer	58	36.70

and was the most common symptom of BPSD (57.5%), followed by apathy and aberrant motor activity (52.5% each) and followed by eating problems at $45\%^{(13)}$.

Comparison of the present study with the previous studies shows the prevalence of BPSD to be similar, but with quite different characteristics. The present study was conducted in the setting of a psychiatric hospital where most patients who sought treatment would have problems with irritability, depression, and sleep problems. Studies by Charernboon and Phanasathit were conducted at a university hospital, which is similar to a general hospital in nature, and where the patients might not present psychiatric symptoms.

The different clinical setting and assessment tools may contribute to the difference in prevalence of BPSD. The culture and background of each country may result in a varying interpretation of certain symptoms, e.g. apathy and agitation. Fuh conducted a systemic review on BPSD among Taiwanese Alzheimer's disease (AD) patients and found BPSD prevalence of 30 to 63%. The most common BPSD was anxiety (35%-76%), followed by depression (22%-50%), sleep problems (26%-61%). Fuh commented that neurobiological factors were likely the main cause for BPSD, as the prevalence and characteristics of BPSD among Taiwanese AD

Table 3. Characteristics of BPSD and levels of distress on caregivers	Table 3.	Characteristics	of BPSD	and levels	of distress	on caregivers
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Symptoms events of BPSD	No BPSD; number of patients	BPSD; number of patients	Caregiver's perceived severity of BPSD (percent)		
	(percent)	(percent)	Severe	Moderate	Mild
Delusion	83 (52.53)	75 (47.47)	42.66	36.00	21.33
Hallucination	98 (62.03)	60 (37.97)	30.00	46.66	23.33
Agitation/aggression	87 (55.06)	71 (44.94)	45.07	39.43	15.49
Depression	72 (45.57)	86 (54.43)	16.27	37.20	46.51
Anxiety	76 (48.10)	82 (51.90)	19.51	40.24	40.24
Euphoria	125 (79.11)	33 (20.89)	12.12	42.42	45.45
Apathy	106 (67.09)	52 (32.91)	21.15	40.38	38.46
Disinhibition	109 (68.99)	49 (31.01)	44.89	20.40	34.69
Irritability	62 (39.24)	96 (60.76)	14.58	45.83	39.58
Aberrant motor behavior	94 (59.49)	64 (40.51)	14.06	59.37	26.56
Sleep problem	68 (43.04)	90 (56.96)	50.00	25.55	24.44
Eating problem	121 (76.58)	37 (23.42)	16.21	37.83	45.94

BPSD = behavioral and psychological symptoms of dementia

(3) = Severe; (2) = Moderate; (1) = Mild

The caregivers rated the patient's physical symptoms as more severe than psychological symptoms

Symptoms events of BPSD	Level of suffering and manageability as perceived by the caregivers (5-0)					
	5	4	3	2	1	0
Delusion	14.66	33.33	17.33	16.00	18.66	0
Hallucination	10.00	15.00	20.00	45.00	10.00	0
Agitation/aggression	42.25	7.04	18.30	9.85	22.53	0
Depression	2.32	11.62	19.76	38.37	27.90	0
Anxiety	6.09	15.85	18.29	23.17	36.58	0
Euphoria	3.03	9.09	18.18	57.57	12.12	0
Apathy	3.84	7.69	17.30	53.84	17.30	0
Disinhibition	55.10	18.36	14.28	8.16	4.08	0
Irritability	3.12	21.87	11.45	27.08	36.45	0
Aberrant motor behavior	43.75	21.87	15.62	6.25	12.50	0
Sleep problem	33.33	31.11	20.00	8.88	6.66	0
Eating problem	10.81	5.40	18.91	54.05	18.91	0

Table 4. Level of distress and manageability of BPSD as perceived by the caregivers

(5) = In great difficulty and not capable of managing the problem; (4) = Greatly troubled and difficult to manage; (3) = Considerable trouble and no easily managed; (2) = Slight trouble and easily manageable; (1) = Very little/no problem; (0) = None

Physical symptoms were perceived by caregivers as more suffering and difficult for manageability than psychological symptoms

patients were similar to those reported in western countries⁽¹⁸⁾. Ballard CG and colleagues conducted a prospective cohort study on BPSD in 136 patients over a one-year period and found the initial prevalence of BPSD to be 76%. After one year, the prevalence increased to 82%, and the most common symptom was agitation⁽¹⁹⁾. However, the study was conducted on the elderly with dementia living as residents of a social care facility nursing home.

In the present study, the physical symptoms of BPSD that were commonly perceived as severe by the caregivers and relatives were agitation/ aggression (45.07%), disinhibition (44.89%), and delusions (42.66%). Symptoms at moderate level included aberrant motor behaviors (59.37%) and hallucinations (46.66%). In terms of the patient's emotions, the symptoms commonly perceived as mild by the caregivers included depression (46.51%) and eating problems (45.94%). Euphoria had similar ratings at moderate and mild levels (42.42% and 45.45%, respectively).

The caregivers reported that the physical symptoms caused more suffering and were more difficult to manage than emotional symptoms, including disinhibition (55.10%), aberrant motor behavior (43.75%), agitation/aggression (42.25%), and sleep problems (33.33%). The caregivers had little suffering and perceived no problem from

emotional symptoms of BPSD, including anxiety (36.58%), irritability (36.45%), and depression (27.90%).

Si-Sheng Huang had studied the burden of caregivers associated with BPSD in Taiwanese elderly and found a significant positive correlation between the total NPI caregiver distress scale (NPI-D) score and the total neuropsychiatric inventory (NPI) score (r = 0.898, p < 0.001). The high mean NPI-D scores were found in delusions, followed by the physical symptoms such as agitation/aggression, and emotional symptoms such as anxiety, irritability/ lability, and dysphoria/depression, with smaller mean NPI-D score⁽²⁰⁾. Onishi J had studied how the BPSD, the caregiver's background, and the care environment were related to the caregivers' stress using the Zarit burden interview (ZBI). They found that the caregiver's burden could be affected, not merely by the illness of the patients, but by the caregiver's background and the care environment. The level of stress experienced by caregivers and their ability to manage BPSD was, in large part, shaped by their background and environment⁽²¹⁾.

The present study found that the physical symptoms of BPSD were perceived by caregivers as a higher level of distress than psychological symptoms, the levels of distress on caregivers were implied from NPI-Q Thai.

Conclusion

BPSD were commonly found among dementia patients. Psysical symptoms were perceived by caregivers as the cause of the most distress, while psychological symptoms were perceived as less severe. NPI-Q Thai can be used by interviewing the caregivers to inform the symptoms of BPSD, not only assess of BPSD symptoms and its severity but also determine caregivers' distress.

The noteworthy limitation to the present study was that it was carried out in the setting of a psychiatric hospital. Further studies should explore BPSD in dementia patients in a general hospital and community dwellings. Factors that are related to caregivers burden and distress should also be explored so as to organize interventions that match the problems.

What is already known on this topic?

BPSD are common in patients with dementia, and cause distress for patients and caregivers. There are many studies on the prevalence, incidence, persistence, and resolution of BPSD. There is every reason to believe that BPSD is present across cultures in the developed as well as developing regions of the world. However, the prevailing level of public awareness about BPSD is low. It reduces the chances of correct identification and management of BPSD. Moreover, the caregivers frequently misinterpret these symptoms as deliberate misbehaviors. Others could even misinterpret BPSD as evidence of the poor quality of care provided by the family. Allegations of these kinds only add to the misery of the caregivers.

What this study adds?

BPSD was the leading cause of admission among patients with dementia in psychiatric setting. Mental health personnel should be able to recognize and assess BPSD. Physical aggression, screaming, cursing, agitation, restlessness, wandering, inappropriate sexual behavior, hoarding, anxiety, depression, hallucinations, and delusions in the elderly should be suspected dementia. Primary and secondary dementia with treatable cause will receive and appropriate investigation and treatment.

In caring for dementia patients, in addition to care for cognition, assessment and monitoring of BPSD is a necessary process, particularly for outpatients as the practitioners would see the patient only for a limited amount of time. Many symptoms of BPSD would present at night, and certain behaviors would be clearly exhibited at home but not at the hospital setting. Therefore, the caregivers play a key role in providing information through the NPI-Q Thai questionnaire to inform the practitioners of the patients' symptoms at home in addition to the symptoms presented at the hospital.

Studies on the prevalence and characteristics of BPSD could help to guide the procedures for care and service to the patients and their caregivers.

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Potential conflicts of interest

None.

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้ลักษณะของปัญหาพฤติกรรม จิตใจ อารมณ์ของผู้ป่วยสมองเสื่อม ความรุนแรง และความรู้สึกทุกข์ใจของผู้ดูแล

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วัตถุประสงค์: เพื่อศึกษาถึงถักษณะของปัญหาพฤติกรรม จิตใจ อารมณ์ของในผู้ป่วยสมองเสื่อมในโรงพยาบาถ ความรุนแรง และ ความรู้สึกทุกข์ใจของผู้ดูแถ

วัสดุและวิธีการ: เป็นการศึกษาแบบตัดขวางเชิงพรรณนา กลุ่มตัวอย่างที่ศึกษา คือ ผู้ป่วยสมองเสื่อมชนิด Alzheimer's disease, mixed vascular dementia และ Alzheimer's disease unspecified dementia ที่ได้รับการวินิจฉัยร่วมกันโดยจิตแพทย์และ ประสาทแพทย์ตามเกณฑ์ DSM IV-TR และเข้ารับการรักษาตัวที่แผนกผู้ป่วยนอกและใน โรงพยาบาลจิตเวชสงขลาราชนครินทร์ เก็บกลุ่มตัวอย่างแบบเจาะจง จำนวน 158 ราย มีค่าคะแนน Clinical Dementia Rating Scale (CDR) ตั้งแต่ 1 ขึ้นไป ประเมิน ปัญหา BPSD โดยใช้แบบประเมิน Neuropsychiatric Inventory Questionnaire-Thai version (NPI-Q Thai)

ผลการสึกษา: กลุ่มตัวอย่างเป็นเพศชายร้อยละ 41.8 เพศหญิงร้อยละ 58.2 อายุเฉลี่ยเท่ากับ 71 ปี ส่วนใหญ่ร้อยละ 81.6 มีความ รุนแรงของโรคอยู่ในระดับน้อย (mild, global CDR = 1) พบความชุกของ BPSD มีตั้งแต่ 1 อาการขึ้นไป ร้อยละ 90.5 ไม่พบ BPSD ร้อยละ 9.49 อาการที่พบมากที่สุดได้แก่ irritability (ร้อยละ 60.8) ตามด้วย sleep problem (ร้อยละ 57) depression (ร้อยละ 54.5) anxiety (ร้อยละ 52) และ agitation/aggression (ร้อยละ 44.9) ส่วนอาการที่พบน้อยที่สุดได้แก่ eating problem พบร้อยละ 23.5 พบว่าระดับความทุกข์ใจของผู้ดูแลและผู้ดูแลบ่งชี้ระดับความรุนแรงของอาการ BPSD ในกลุ่ม physical symptoms สูงมากกว่าในกลุ่ม psychological symptoms และพบว่าญาติมีความทุกข์ใจมากและไม่สามารถจัดการ ปัญหาได้ใน 5 ถำดับแรก คือ dishibition, aberrant motor behavior, agitation/aggression และ sleep problem ญาติ มีความทุกข์ใจเล็กน้อยในกลุ่มอาการ irritability, depression, anxiety พบว่า aggression เป็นอาการที่ผู้ดูแลบ่งชี้ระดับความ รุนแรงมากที่สุด รองลงไป เป็น dishibition อาการที่ผู้ดูแลบ่งซี้ระดับความรุนแรงน้อย คือ depression, euphoria

สรุป: จากการศึกษานี้ BPSD เป็นอาการที่พบได้สูงมากในผู้ป่วยสมองเสื่อมชนิดต่าง ๆ BPSD เป็นอาการนำที่สำคัญที่ทำให้ผู้ดูแล นำผู้ป่วยมาพบแพทย์มากกว่าปัญหาเรื่องความจำ 5 อาการแรกที่พบบ่อยคือ อารมณ์หงุดหงิด ปัญหาการนอน อารมณ์เศร้า วิตกกังวล ก้าวร้าวกระวนกระวาย ในการศึกษานี้ การตระหนักถึงความสำคัญของการประเมินติดตามดู BPSD ควบคู่กับ cognition โดย สัมภาษณ์ผู้ดูแลมีประโยชน์มากในทางคลินิก อาการดังกล่าวอาจจะไม่พบขณะที่ผู้ป่วยมาโรงพยาบาล การประเมินถึงความรู้สึกของ ผู้ดูแลรวมทั้งความทุกข์ใจ โดยใช้แบบสอบถาม Neuropsychiatric Inventory Questionaire Thai version (NPI-Q Thai) ทำให้ผู้รักษาสามารถช่วยเหลือผู้ดูแลได้ตรงประเด็น และช่วยในการวางแผนการรักษาให้ดีมากยิ่งขึ้น