ความสัมพันธ์ระทว่างภาระในการดูแลกับวิธีการเพชิญปัญหา ของพู้ดูแลพู้ป่วยโรคจิตเกท

บทความวิจัย

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The relationship between burden of care and coping Volu Volu Strategies among caregivers of patients with schizophrenia

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บทคัดย่อ

การวิจัยเชิงพรรณนานี้ มีวัตถุประสงค์เพื่อศึกษาความสัมพันธ์ของภาระในการดูแลและวิธีการเผชิญ ปัญหาของผู้ดูแลผู้ป่วยโรคจิตเภท กลุ่มตัวอย่าง เป็นผู้ดูแลผู้ป่วยจิตเภท 98 คน ในเขตเมืองเปกาโลงัน ประเทศ สาธารณรัฐอินโดนีเซีย เก็บข้อมูลระหว่างเดือนกุมภาพันธ์ ถึงเดือนเมษายน พ.ศ. 2558 ใช้แบบประเมินภาระใน การดูแลและแบบประเมินการเผชิญปัญหาของผู้ดูแล วิเคราะห์ข้อมูล โดยใช้สถิติเชิงพรรณนา และสัมประสิทธิ์ สหสัมพันธ์ของเพียร์สัน ผลการวิจัย พบว่า ผู้ดูแล ส่วนใหญ่เป็นเพศหญิง (ร้อยละ 74.1) และเป็นพ่อแม่ผู้ป่วย (ร้อยละ 48) อายุ 50 ปีขึ้นไป (ร้อยละ 48) ให้การดูแลผู้ป่วยที่ส่วนใหญ่เป็นเพศซาย (ร้อยละ 59) และให้การ ดูแลมานานกว่า 5 ปี และพบว่า ภาระในการดูแลมีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติกับวิธีการเผชิญปัญหา ทั้งแบบการจัดการที่ปัญหา และแบบการจัดการที่อารมณ์ อย่างมีนัยสำคัญทางสถิติ (r = −0.389, p ≤ 0.001 และ r = 0.321, p ≤ 0.001 ตามลำดับ) ผู้ดูแลใช้กลวิธีทั้งแบบการจัดการที่ปัญหาและวิธีการจัดการที่อารมณ์ ผู้ดูแลที่

คำสำคัญ: ผู้ป่วยจิตเภท ผู้ดูแล ภาระในการดูแล วิธีการเผชิญปัญหา

Abstract

This descriptive study aimed to examine the relationship between burden and coping strategies among 98 caregivers of patients with schizophrenia in Pekalongan, Indonesia. Data were collected during February to April, 2015 using the Burden Assessment Schedule (BAS) and the Brief Cope instrument (BCI). Data analyzes used were descriptive statistics and Pearson's product moment correlation coefficient. Results showed that most of caregivers: were female (71.4%); were parents of patients (48%), and aged more than 50 years (48%). They provided care for patients which were mostly men (59%) and were taken care of them for more than 5 years. Caregivers used both problems focused and emotion focused coping strategies. It was found that burden was negatively significant correlated with coping strategies, both problem focused coping (r = -0.389, p ≤ 0.000) and with emotion focused coping (r = 0.321, p ≤ 0.001) respectively. Caregivers used both strategies: problem-focused and emotional focused. Caregivers who had high burden tended to use emotional focused coping more than problem-focused coping.

keywords: schizophrenic patients, caregivers, burden of care, coping strategy

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Introduction

Number of schizophrenic patients was high. In Indonesia approximately 20.7 million Indonesian people suffered from schizophrenia, with about 700,000-1.4 million were active schizophrenia.¹ Most of people with schizophrenia are taken care by their family caregivers in community. The countries with low- and middle-income tended to have problems concerning mental health. In Indonesia, around 76-85 % of people with schizophrenia received no treatment for their mental health problems.²

In recent years, the medical and social care of mental illness has improved significantly by community health and rehabilitation services. Most of schizophrenic or other mental problems were discharged from hospital and sent back to community that requiring family care support. The duration in taking care of patients resulting in increasing demands for caregivers, thus, increasing responsibilities as well as stress for caregiver.³

Several studies have demonstrated that caregivers caring for persons with schizophrenia experience high stress and high levels of burden.⁴⁻⁸ Burden and psychological distress is related to several factors: expressed as emotions of caregivers, caregiver needs, coping strategies and social support. Coping is mediated with the relationship between a stressful situation, caring situation and the outcomes of care such as burden on care.⁹ Caregivers can develop coping strategies to overcome their burden by themselves in different ways. These could be positive or negative coping strategies. Expressing caregivers need to reduce burden related to how they cope with their situations depending on their cultures. According to the study, burden of caregiver depended on characteristics of patients and caregivers and their environment.³ Previous study showed that caregivers' coping strategies were related to depression, burden and quality of life.⁹ Studies stated that caregiver burden was associated with social supports and coping strategies that used by caregivers.^{5,8} Coping is a mediating role associated with burden feelings and negative consequences.⁴ The ability of coping mechanism depends on individual temperament, perception and cognition to stressors. Problem focused coping and emotion focused coping are typically coping strategies which resolve the problem to manage and relieve a stressful situation.⁴

Indonesia has an extensive health care infrastructure but mental and psychiatric health care still remains scare. Poor understanding and knowledge concerning schizophrenia as well as the stigma attached to mental health problems continues to exacerbate the mental health burden across Indonesia.¹⁰ Pekalongan was chosen as the study site as it is one of the biggest cities in Central Java with the official number of **615** schizophrenia patients.¹¹

This study examined: the relationship between caregiver burden and coping strategies when taking care of patients with schizophrenia, the characteristics of caregivers and schizophrenia patients, and to explore burden and coping strategies of caregivers of patients with schizophrenia.

Method

Design. A descriptive cross sectional study was conducted during February to April, 2015 in the community area of a primary health care unit, Pekalongan District, Central Java Province. The sample was 98 caregivers from Republic of Indone– sia. The number of participants in this study is determined by using Power analysis of Pearson's with (Power .80; $\alpha = .05$; r = .330). The sample was recruited using systematic random sampling. This study was approved by the Institutional Review Board (IRB) Khon Kaen University, Thailand: record No.4.3.03:02/2015 and Reference No. HE572305.

The researcher made an appointment to meet the chosen caregivers in a primary health care unit and amid community mental health nursing (CMHN) activities. The researcher introduced herself and asked permission to explain the purpose of the study, i.e. benefits of the study for quality of life among caregivers and their relatives in addition to explaining about the steps of the technical process for filling out the questionnaire. Caregivers who agreed to participate were asked to complete the questionnaire. The researcher gave the questionnaires to the participants who then answered them independently. Literate participants were allowed to fill out the questionnaires on their own in a room together and sit comfortably. The researcher asked illiterate if they needed assistance in completing the questionnaires hence the researcher accompanied as required. The time required for completing the questionnaires taken approximately 30 minutes.

Instruments. The questionnaires include 3 parts: 1) Demographic Data Form The demographic data form in this study was used to describe the caregivers' and patients' characteristics. Information on patients' characteristics included sex, age, and number of admittances. Caregiver's characteristics comprise of sex, age, religion, marital status, educational level, occupation, duration of care taking, and monthly income; 2) Burden Assessment Schedule of SCARF, This research used the Burden Assessment Schedule (BAS) developed by Thara, Padmavati & Kumar from the World Health Organization Regional Office for South-east Asia, New Delhi (1998). BAS is a 20-item and a 3-point scale. The scores ranged from 20 to 60, with higher scores indicating higher burden.¹²⁻¹³ BAS measures 5 domains: impact on well-being, impact on marital relationship, appreciation of care, impact on relations with others, and perceived severity of the disease; 3) Brief COPE, The Brief Cope was developed by Carver based on the concept of coping consisting of 28 items with a 4 point scale. Problem focused coping consisted of 8 subscales: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support and use of instrumental support. Emotion focused coping consisted of 6 subscales: self-distraction, denial, venting, substance use, behavioral disengagement and self-blame.

Translation and reliability. The BAS and Brief Cope instruments were translated using back-translation technique by a bilingual person from a health research center, University of Muhammadiyah Yogyakarta. The reliability testing was calculated based on 20 caregivers with similar eligibility criteria as the sample. Cronbach's alpha of BAS and Brief Cope were 0.917 and 0.827, respectively.

Statistical analysis. This study was analyzed using the Statistical Package for Social Sciences (SPSS). Descriptive statistics was used to analyze demographic data, burden and coping strategies among caregivers, including frequency, percentage, mean value and standard deviation. Pearson's Product Moment Correlation Coefficients were used to analyze the relationships between burden and coping strategies among caregivers of patients with schizophrenia.

Results

Demographic characteristics. Most of caregivers were female (71.4%), aged 19–65 years with a mean ages of (45.82 ± 11.39). Most of the caregivers: aged more than 50 years (48%), were married (95.9%), finished elementary school (40%), and had no education (24.5%). Most of the caregivers were parents (48%), with occupation as labors (52%) and had income less than IDR 1.000.000 per month. The duration of taken care of patients was more than 5 years (35.7%). Meanwhile,

the ages of patients with schizophrenia ranged from 18-80 years. Most of the patients aged 30-39 years (34.7%) with a mean of (30.47 ± 13.33). Most of them were males (59.2%) and had been admitted to the hospital for less than 3 times. Interestingly, all participants in this study were Muslim.

Relationship between burden and coping strategies. The relationships between burden and coping strategies showed that burden was negatively and significantly correlated with problem focused coping strategies (r = -.389, p< .05), whereas, burden was positively and significantly correlated with emotion coping strategies (r = .321, p< .05) as shown in table 1. Caregivers with high burden, exhibited less problem focused coping, in other words, they used more emotion focused coping.

 Table 1
 Relationship between burden and coping strategies (n=98)

		Bur	Burden 33.76 ± 12.01			
Coping strategies	Mean ± SD	33.76 =				
		r	р			
Problem focused coping	48.33 ± 11.52	-0.389	0.000			
Emotion focused coping	27.78 ± 8.42	0.321	0.001			

*Significant level 0.05 (*p*< 0.05)

Burden of care. Among 5 dimensions of burden, impact on well being domain showed that caregivers with burden on impact on well being displaying burden lower than the mean, used emotional focused coping strategies. Meanwhile, the majority of caregivers with burden on appreciation of care, impact on relationship with others, perceived severity of disease and impact on marital relationship domains exhibiting burden higher than mean, used problem focused coping strategies to cope with their situations.

There were five top characteristics of burden among caregivers: family did not appreciate the caregiver taking care of the patient; the inability to care for other family members; no appreciation from friends about care provided for patients; patients did not understand and did not appreciate the caregivers; and caregivers feel depressed and anxious regarding patient's illness. Coping strategies commonly used by caregivers were: praying or mediatting, selfdistraction, seeking comfort in their religion or spiritual beliefs, acceptance and learning to live with their situations, and seeking advice or help from others. Table 2 shows the numbers of caregivers with lower and higher mean scores on burden dimensions and coping strategies.

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	Mean score ± SD		Number of caregivers			
Burden			Problem focused coping 49.33 ± 11.512		Emotion focused coping 27.79 ± 8.406	
				Higher than	Lower than	Higher than
			49.33	49.33	27.79	27.79
Impact on well	7.54 ± 2.554	Lower than 7.54	25	26	32	19
being		Higher than 7.54	30	17	18	29
Appreciation of	$\boldsymbol{6.29 \pm 2.337}$	Lower than 6.29	24	30	26	28
care		Higher than 6.29	31	13	24	20
Impact on	5.86 ± 2.485	Lower than 5.86	19	27	25	21
relationship with others		Higher than 5.86	36	16	25	27
Perceived severity	$\boldsymbol{6.70} \pm \boldsymbol{2.112}$	Lower than 6.70	17	20	25	12
of disease		Higher than 6.70	38	23	25	36
Impact on marital	7.42 ± 2.662	Lower than 7.42	1	3	3	1
relationship		Higher than 7.42	5	3	3	4

Discussion

Results from this study showed, burden was negatively and significantly correlated with problem focused coping (r = -0.389 and p-value = 0.000). However, burden was positively and significantly correlated with emotion focused coping (r = 0.321and p-value = 0.001). Caregivers with high burden exhibited less problem focused coping strategies, but used more emotional focused coping strategies.

study was congruent with previous study in that burden and coping were significantly correlated.⁸ Burden among caregivers of schizophrenic patients was significantly associated with coping strategies.¹⁴ Maladaptive coping exhibited higher correlation with caregiver burden rather than adaptive coping (r = .42, compared to r = -14, respectively).⁵ Some studies reported that caregiver burden is positively correlated with avoidance type coping or use of denial.¹⁴ Others reported that problem focus coping increased it.⁵

This was not congruent with a study which showed that burden among 100 caregivers of

schizophrenic patients were not-significantly correlated with coping strategies.¹⁵ Another study also supported this study, i.e. no significant correlation between level of burden and coping (r = 0.258).¹⁶ It was also congruent with previous study that reported no correlation between the type of coping strategies and burden.¹² Burden of care are multidimensional factors. Internal factors had impact on burden, such as characteristics of patients and caregiver characteristics were associated with burden, for example, personal characteristics, socioeconomic condition and cultural characteristics. External factors that related to burden are factors such as social support, coping strategies, quality and degree of social labeling, accessibility of health care services.¹⁷

Understanding burden of care helped to understand coping which led to strengthen the adaptation on caregiver responsibilities.⁹ Coping strategies can mediate the relationship between stressful event and the outcome, and or mediate caring situation with care burden/distress on caregiver leading to better health.¹⁷ High level of caregiver burden was associated with self-blame and less use positive coping. Hence, maladaptive coping strategies was predicts distress and burden of care. Maladaptive coping mechanisms by caregivers indicated of express emotion.⁵ It was also concluded that adaptive coping strategies or problem focused coping are well used by caregivers.^{14,16}

The characteristics of patients and caregivers have an impact in stressful situations. A study explained that there was a relationship between demographic characteristics and caregiver burden.¹⁸ This study was supported by other researches in Asian countries that revealed more than 70% of caregivers

taking care of patients with schizophrenia were females.¹⁹⁻²³ In Indonesia, based on a study concerning caregivers of patients with schizophrenia, most were mother/father, sibling or spouse.²⁴⁻²⁵ This result was in line with several studies in Asian countries, which showed that most caregivers of patients with schizophrenia were their parents.²⁰⁻²³ Parents are persons who were in high contact with patients in daily life.²⁶ In Asian cultures, parents are the heads of the household with a major responsibility to take care of family members and they are responsible for their health conditions.²¹ The other relationship between caregivers and patients was spouse of the patients. Spouses who provide care were almost six times more likely to have depression and anxiety.²⁷ Various researches state caregivers of patient with schizophrenia experienced burden.^{8,14,28} Physical and psychological health is an important factor in determining burden among caregiver.²⁹ The present study showed that caregivers felt depressed and anxious in regards to the patient's illness. This result supported previous study, burden was reported in term of physical health in caregivers when taking care family of members with schizophrenia.³⁰ Other studies recorded that caregivers of patients with schizophrenia were busy in taking care and spending more time and physical effort.^{8,15,31}

Patients with schizophrenia only received care and were unable to provide care to others.³² Most of the caregivers in this study thought that the family did not appreciate their care efforts. Caregivers suffer from a lack of time for themselves and other responsibilities regarding family support.³³ Numbers of family members and the duty of caregivers to support day-to-day patient needs were reasons caregivers felt unable to take care of other family members. The best predictor of burden in an Asian based study was low social support from other family members.²⁰

Results from this study show that patient's illness prevent caregivers from having satisfying relationships with the rest of their family. Taking care of a patient with schizophrenia impacted on relations with others. Caregivers and their relatives sometimes had negative interactions. Relatives displayed conflicts with other family members and their own lifestyles.^{8,20,34} A study showed that the effect of caring for a schizophrenic patient has strong influences including emotional and psychological disturbances of specific roles and proper relationships among family members.²⁰

The unpredictable behaviors of patients with schizophrenia produce a high risk of suicide and caregivers experience disruption to routine family activities. A study reported that caregivers worry about their patient's future and about their own future.³² Another study informed that caregivers can balance employment and caregiving responsibilities,³ but some caregivers experienced conflicts of roles, work fewer than normal hours, and/or take unpaid leave of absence, as well as, conflicts in their job.³⁴

Spouse of schizophrenic patients could be shock with the patient's illness. Patients with schizophrenia were not able to satifying their spouse for intimacy. Symptoms of schizophrenia can be change the behavior and personality of patients and the intimacy among each other disappear.

Caregivers used both problem focused and emotional focused coping strategies. Interestingly, most of the caregivers who had burden use problem focused coping strategies to adapt to conditions. Regarding problem focused coping strategies, mostly implemented were praying and mediating to adapt to their situation. Caregivers did activities to release their problems and seek advice from others about what they should do to solve their problems.

This result is congruent with a study which investigated 42 caregivers of patient with schizophrenia showing that coping strategies took place through seeking emotional support, spirituality/ religion, active coping, acceptance, and positive reframing.³⁵ This was in line with a qualitative study comprising of 10 caregivers which revealed the common coping mechanisms among caregivers living with schizophrenic patients were behavioral and emotional support, religious, social, and professional support.³⁶

Strength of religious beliefs plays an important role in helping caregivers cope with stress full situations.³⁷ All caregivers in this study were Muslim. The Muslim culture in Indonesia displays precise religious principles in one's life. In reference to Islamic culture, as the Prophet said and Holy Qur'an says; for any sickness or the sick people, they must be treated patiently. The Islamic constitution encourages health and the performance concept in order to achieve the happiness of individuals & society.

Negative outcome of taking care of schizophrenic patients has been found and this can have negative effects on the emotions.⁸ A study explained that solving difficult situations and finding information about illness is the way to take care of patients.¹ Information can used by caregivers to find how best to care for the patient. Caregivers attempted to understand the condition of patients and accept the illness.³⁶ Positive thinking about their situation is the effect of undestanding the conditions with caregivers trying to find the relevant information.

A notable finding of this study showed that nursing services in this area were good. Psychiatric and mental health services provide services every week, one week in the primary care unit (PCU) and one week for community mental health nursing (CMHN). Patient with schizophrenia have good continuity in getting treatment both at the PCU and CMHN. Support from caregivers was high and it can be seen that caregivers always accompanied patients to treatment. A good environment and high social support, especially from health services had an impact on burden of care and coping strategies of caregivers. Better environments made caregivers enjoy their responsibility and be more able to cope with their situation with the result that caregivers experienced low burden.²⁶ Therefore, burden of care in this study did not score highly with good coping strategies shown to cope with situation when caring for patients with schizophrenia

Poor social support predicted high burden on caregivers. Less of burden on caregivers was affected by a long duration of remission and reduction of positive symptoms among patients. Caregivers had more understanding of problems and used specific coping.¹² Coping strategies can mediate the relationship between stressful events and the outcomes, and or mediate caring situations with burden/distress on caregivers leading to better health.³⁸ Coping is a set of strategies to reduce the effect of stress. Coping strategies of caregiver related to the stages, phases and situation of stress, and were influenced by

relatives perceptions of their situations.^{4,15} Good coping mechanisms exhibited by caregivers produced better environments. Caregivers who enjoyed their activities or their responsibilities were able to cope with their situation and thus reported low burden.²⁶

Limitations and recommendations

The results of this study provide basic information for future study on caregivers of patients with schizophrenia in Indonesia. There are some limitations: 1) this study was conducted on only a small participant group who attend a PHC every two weeks, thus, more participants should be explored; 2) this study is focused only on burden and coping, various influencing caregiver burden should be studied. A qualitative design study may be able to assist researchers in obtaining information from direct burden experience for the better understanding of caregivers who take care of patient with schizophrenia.

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