## การเผชิญปัญหาและภาระของผู้ดูแลในครอบครัว ที่ให้การดูแลผู้เป็นจิตเภทอินโดนีเซีย

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Coping and Burden of Indonesian Family Caregivers Caring for Persons with Schizophrenia.

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## บทคัดย่อ:

**Original Article** 

**ิวัตถุประสงค์:** การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อศึกษาความสัมพันธ์ระหว่างการเผชิญปัญหาและภาระของผู้ดูแล ในครอบครัวที่ให้การดูแลผู้เป็นจิตเภทอินโดนีเซีย

**วัสดุและวิธีการ:** การศึกษาเป็นรูปแบบการวิจัย แบบหาความสัมพันธ์ กลุ่มตัวอย่างมีทั้งหมด 88 คน ได้จากแผนก ผู้ป่วยนอกของโรงพยาบาลจิตเวชในจังหวัด West Java ผู้วิจัยเก็บข้อมูลด้วยแบบสอบถาม ภาระของซาริท (Zarit Burden Interview: ZBI) และแบบวัดการเผชิญปัญหาของจาโลวิเอค (Jalowiec Coping Scale: JCS) วิเคราะห์หาความสัมพันธ์ระหว่างการเผชิญปัญหาและภาระด้วยค่าสหสัมประสิทธิ์สัมพันธ์ของเพียร์สัน (Pearson's product-moment correlation coefficient) ในขณะที่อีกสองมิติของภาระจะใช้การวิเคราะห์ด้วยค่าโรของ สเปียร์แมน (Spearman's rho)

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สรุป: การศึกษาครั้งนี้แสดงให้เห็นว่าผู้ดูแลผู้ที่เป็นจิตเภทควรได้รับการสอนเกี่ยวกับวิธีการเผชิญปัญหาเพื่อ จัดการกับปัญหาโดยตรง และควรได้รับการสอนให้มองตนเองอย่างเต็มความสามารถเมื่อต้องดูแลผู้ที่มีปัญหา เช่น ผู้เป็นจิตเภท นอกจากนี้ผู้ดูแลควรได้รับการสนับสนุนช่วยเหลือที่เหมาะสมเช่นกัน

**คำสำคัญ:** การเผชิญปัญหา, ผู้ดูแล, ผู้เป็นจิตเภท, ภาระ

### Abstract:

**Purpose:** This study aimed to examine the relationship between coping and burden of Indonesian family caregivers caring for persons with schizophrenia.

Materials and methods: The study was a correlational design. Eighty-eight subjects were selected from the outpatient department of the West Java Province Mental Hospital. Data were collected with self-report questionnaires using the Zarit Burden Interview (ZBI) and the Jalowiec Coping Scale (JCS). Pearson's product-moment correlation coefficient was used to examine the relationship between coping and burden. Two dimensions of burden were analyzed using Spearman's rho. **Results:** The findings showed that 43.2% of the subjects perceived burden as being at a moderate level. The coping method most often used was optimistic coping, followed by self-reliance coping, confrontative coping, and supportant coping. There was significant positive correlations between evasive coping, fatalistic coping, and emotive coping and perceived burden (r = 0.50, r = 0.57, r = 0.38; p < 0.01), while confrontative coping, optimistic coping, and supportant coping were significantly negatively correlated with perceived burden (r = -0.40, r = -0.31, r = -0.36; p < 0.01). There were no significant correlations between palliative coping or self-reliant coping, and burden. Conclusion: This study indicates that caregivers caring for persons with schizophrenia should be taught effective coping for dealing with the problems, such as problem-solving skills and how to maintain an optimistic attitude when dealing with difficult patients, and appropriate support for family caregivers should be available when required.

Key words: coping, burden, family caregivers, schizophrenia

#### Introduction

The prevalence of schizophrenia inIndonesia is approximately 2 million in a population of 200 million.<sup>1</sup> In the West Java Province Mental Hospital, there were approximately 1,855 schizophrenic patients in 2008, of whom approximately 173 had been rehospitalized following relapse.<sup>2</sup>

Family caregivers are the most important caregivers for persons with schizophrenia. Family caregivers usually help these patients perform activities for daily living and taking medication. However, when long-term care is required, these caregivers may begin to feel they are carrying a burden.<sup>3-6</sup> Therefore, burden is one interested concept frequently discussed in psychiatric nursing practice. Similarly, the eastern literature review, burden can be conceptualized as subjective and objective burden and the findings suggested that family caregivers suffer a high level of burden when caring for a family member with schizophrenia.<sup>7</sup> The studies also found that there are various factors associating with burden such as quality of life, and coping, etc.

Coping strategies have been found to be an important factor in how heavy the caregiver perceives their burden.<sup>8-10</sup> Persons' appraisal of the situation and the method used to cope with a stressful situation can have an impact on their physical and emotional well being.<sup>11</sup> Therefore, nurses need to understand coping and family caregiver's burden to provide appropriate nursing interventions.

Many studies in the Western literature have reported that effective coping strategies can reduce the burden felt by those caring for persons with schizophrenia.<sup>5-6,8,12-13</sup> The coping studies was also found in some eastern context and it showed the relationship between perceived burden and coping strategies.<sup>9,14</sup> It was also found that in Chinese family, parents perceived significant caregiver burden, while caring for their child with a mental illness, vet used limited coping patterns to maintain a functional family life. Also, a significant negative correlation was found between the parents' caregiver burden and the way of coping.<sup>15</sup> There is a gap in the knowledge in terms of whether the coping strategies used in western settings are relevant to Asian cultures such as in Indonesia. The researcher was unable to find any studies about coping strategies and perceived burdens in regard to persons with schizophrenia in Indonesia. Only the relationship between social support and coping was found in Indonesian family of schizophrenia persons.<sup>16</sup> Therefore, this study was conducted using the Lazarus and Folkmanstress and coping theory to examine the relationships between coping strategies and perceived burden on family caregivers caring for persons with schizophrenia in West Java Province, Indonesia.

#### Materials and methods

This was a correlational study. The study was conducted at the outpatient department, the West Java Province Mental Hospital because it was the top referral of mental hospital in West Java Province. Sample size was determined by using power analysis at the significance of 0.05, power of test of 0.80, and previous research study findings,<sup>9,14,17</sup> the researcher used an effect size of 0.30. Based on these calculations, 88 family caregivers were randomly recruited according to the selection criteria. Data were collected by three set questionnaires: **Demographic Data Form (DDF).** The DDF was developed by the researcher. It was grouped into demographic characteristics, patient's medical condition characteristics, and caregiving.

Revised Jalowiec Coping Scale (JCS). The revised Jalowiec Coping Scale (JCS) was developed by Jalowiec in 1987.<sup>18</sup> The revised JCS has 60 items classified into 8 coping methods: 1) confrontative coping: constructive problemsolving; 2) evasive coping: doing things to avoid confronting a problem; 3) optimistic coping: maintaining positive attitudes about a problem; 4) fatalistic coping: pessimistic or hopeless attitudes toward a problem; 5) emotive coping: rely on expressing or releasing emotions to try to relieve stress; 6) palliative coping: doing things to make oneself feel better, such as eating, drinking, or taking medication; 7) supportant coping: using a support system to cope, such as personal, professional, or spiritual; and 8) self-reliant coping: depending on oneself to deal with a problem. The JCS is rated on a 0-3 point Likert scale, with higher scores indicating more frequent use of the coping method.

**Zarit Burden Interview (ZBI).** The ZBI was developed by Zarit and coworkers in 1985.<sup>19</sup> The ZBI consists of 22 items classified into five dimensions: burden in relationship, emotional well being, social and family life, finances, and loss of control over one's life. The ZBI score is measured on a 0 to 4 point Likert scale. The greater the score, the greater the perceived burden.

Because these instruments used English language, the researcher did back translation by

three translators who were expert in both the English and Indonesian languages to ensure equivalence the instrument in Indonesian language.<sup>20</sup> The internal consistency reliability test using Cronba ch's alpha showed a value of 0.79 for the JCS and 0.91 for the ZBI. There were no any cultural issues during try out period.

Data collection was done after the study was approved by the Institutional Review Board, Faculty of Nursing, Prince of Songkla University, Thailand. Permission to undertake the study was obtained from the Director of the West Java Hospital, and informed consent was given by all subjects.

For data analysis, Pearson's product-moment correlation coefficient was used to examine the relationship between coping and burden, as the data were normally distributed. However, Spearman's rho statistic was applied in the relationship between financial and social/family life burdens dimensions and coping, as the data were non-normally distributed.

#### Results

#### **Demographic characteristics**

Majority of the subjects were 35–60 years old (72.7%), female (68.2%), married (83%), Sundanese (92.1%), Muslim (98.9%), educated to elementary school level (61.4%), and housewives (42.0%), and had income less than 500,000 rupiahs per month (50%). The majority of the persons with schizophrenia were 25–34 years old (46.6%), were male (70.5%), had a history of 1–2 times hospitalization (65.8%), visited the doctor every month (100%), patient's violent behavior was behavior making caregiver worry the most (61.6%), and subjects perceived the patient's disease at moderate level (45.5%). Based on caregiving, the majority of the subjects were the patient's mother (51.2%), had provided care for 1-5 years (53.4%), for the full day (90.9%), cared only for the mentally ill members (89.8%), and had other family members helping them (61.4%).

#### Coping

The coping methods mostly used was optimistic coping (M = 2.3, SD = 0.34), followed by self-reliant coping (M = 1.95; SD = 0.36), confrontative coping (M = 1.74; SD = 0.50), supportant coping (M = 1.74; SD = 0.45), fatalistic coping (M = 1.62; SD = 0.56), evasive coping (M = 1.58; SD = 0.41), palliative coping (M = 1.53; SD = 0.33), and emotive coping (M = 1.14; SD = 0.50).

#### Burden

Overall burden was perceived as being a moderate level (M = 2.43, SD = 0.81). Financial was perceived as being a severe level (M = 3.03, SD = 1.16) and social and family life burden at a mild level (M = 1.58, SD = 0.91). Burdens dimensions at moderate level were burden in relationships (M = 2.89, SD = 0.77), emotional well-being (M = 2.58, SD = 0.91), and loss of control over one's life (M = 2.01, SD = 0.84). Overall, 43.2% perceived their burden to be at a moderate level, 36.4% at a mild level, and 13.6% at a low level and 6.8% at a severe level.

# The relationship between coping strategy and burden level

The relationships between coping strategies and perceived burden are presented in Table 1.

Variable	Burden					
	1	2	3	4	5	6
Coping						
Confrontative	-0.29**	-0.50**	-0.22*	-0.44**	-0.32**	-0.40**
Evasive	0.36**	0.48**	0.34**	0.50**	0.43**	0.50**
Optimistic	-0.36**	-0.36**	-0.21*	-0.17	-0.17	-0.31**
Fatalistic	0.42**	0.56**	0.35**	0.45**	0.53	0.57**
Emotive	0.18	0.40**	0.37**	0.23*	0.31**	0.38**
Palliative	0.08	0.11	0.10	0.27**	0.15	0.14
Supportant	-0.26*	-0.40**	-0.29**	-0.32**	-0.25*	-0.36**
Self reliant	0.14	0.08	0.25	0.12	0.17	0.18

 Table 1
 Correlation between coping and burden using Pearson's product-moment correlation (r) and Spearman's rho (rsp) (N=88)

Note 1 = burden in relationships, 2 = emotional well being, 3 = social and family life, 4 = financial, 5 = loss control over one's life, 6 = overall burden, a = spearman rho, \* p < 0.05, \*\* p < 0.01

#### Discussions

A positive association was found between evasive coping, fatalistic coping, and emotive coping and the level of perceived burden, a relationship that could be explained that all of these coping methods are more emotion-focused. Evasive, fatalistic, and emotive ways of coping with a problem can at best only reduce negative emotional feelings for a while, as these coping methods, which are not really coping with a problem at all, do not overcome a problem but simply hide it temporarily. This study is quite similar with one study which has found that over time, caregivers who relied less on emotional coping methods perceived fewer burdens over a longer period of time.<sup>8</sup>

A negative association was found between confrontative coping, optimistic coping and perceived burden. These findings are consistent with other studies, one of which also found that optimistic coping was negatively correlated with burden<sup>9</sup>, and another which found that problemsolving coping strategies, such as seeking information and crisis planning, were associated with lower perceived burdens.<sup>21</sup>

Confrontative coping and optimistic coping are coping methods that focus on the problem both directly and also on the self (emotional reaction) through problem solving and positive thinking. These coping methods can reduce negative emotions by positive thinking toward the problem and also by dealing with the problem in a positive fashion by seeking help from those more skilled in dealing with such problems. It is in line with the other study finding that a low level of threat appraisal was associated with high active coping which reported high levels of daily functioning.<sup>22</sup>

Interestingly, there was no significant association found between palliative coping or selfreliant coping and burden. According to Jalowiec<sup>18</sup> palliative coping indicates the attempt to reduce stress by doing things to make one feel better and self-reliant coping means trusting and relying on oneself to deal with the situation. These strategies could be correlated with the social life and culture of the caregivers in this study. Such things as smoking, drinking, or taking medication to reduce a perceived burden, activities which are commonly associated with stress in western cultures, are not common in Sundanese social life, particularly among women. However, activities such as meditation (dzikir) or doing something such as household work are normal parts of their life. In addition, people raised in the Sundanese culture feel shame or are hesitant to share their problems with others, even though social support is available for them.

Since all subject visit the doctor ever month, it can influence the result of burden and coping score therefore it may not be able generalized to other caregivers with different history of followup. Since many confounding factors of burden and coping, such as age, time of caring, duration of providing care and caregiver's attitude and culture<sup>5-8, 10,</sup> were not controlled as well as the, therefore the repetition of the study is recommended.

#### Conclusion

In conclusion, the study indicates that al though many caregivers have used optimistic coping when dealing with schizophrenic persons, there is still a considerable burden felt by many of them. It is thus recommended that nurses initiate a program directed towards caregivers with the necessary skills and other support to maintain their own quality of life. Encouraging and initiating appropriated program directed for the caregivers to maintain support and successful coping styles, decrease burden, increase quality of life will be needed. Furthermore, the two instrments using Indonesian language (JCS and ZBI) should be applied in other chronic illnesses.

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