Relationships between Demographic Characteristics, Knowledge, Expression of Emotion, and Burden of Family Caregivers of Patients with Schizophrenia

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Abstract—The purpose of this study is to explore the relationships between demographic characteristics, knowledge, expression of emotion, and burden of family caregiver of patients with schizophrenia. This study is a cross-sectional descriptive study. A total of 120 family caregivers were recruited from Mental Health Hospital, Bali Province, Indonesia. The Demographic Data Questionnaire (DDQ), Burden Assessment Schedule (BAS), Knowledge Scale (KS), and Family Questionnaire (FQ) were provided based upon validity and reliability tests. Statistical analysis was conducted by employing Pearson’s correlation with 120 respondents. The majority of caregivers have a moderate to high level with regard to the knowledge of schizophrenia (39.2%) and (35%). A large number of caregivers have high expression of emotion (87.5%) and almost (95%) of respondents carry a positive burden. Knowledge and emotional expression have a positive correlation with caregivers’ burden. This does not prove that knowledge causes burden, but anxiety and negative belief factors may mediate the relationship between knowledge and burden.

Keywords—Schizophrenia; knowledge; expression of emotion; burden; caregivers.

I. INTRODUCTION

Schizophrenia is a major contributor to the global disease burden [1]. A number of people with schizophrenia in the world, especially in developing countries have increased. The World Health Organization [2] estimates that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness [2]. In Indonesia, the prevalence of schizophrenia is 0.3 to 1%, and it usually occurs at the age of approximately 18 to 45 years old. If the population of Indonesia is about 200 million people, it is estimated that about 2 million people are suffer from schizophrenia [3].

There are several gaps in the previous studies with regard to caregivers’ knowledge of schizophrenia. Lim and Ahn [4] claim that knowledge is negatively correlated with perceived burden, where as Seifasi, et al. [5] suggest that knowledge is positively correlated with the perceived burden of caregivers. It means many factors can impact on the burden of family caregivers. Therefore, this study will examine the relationships between knowledge, expression of emotion and burden of family caregivers of patients with schizophrenia.

II. METHOD

A. Design

A cross-sectional study design was performed.

B. Sample

The population in the study was family caregivers with Schizophrenia patients who were admitted in Bali Province Mental Health Hospital. To estimate the sample size was calculated by using A-priori sample size calculator for multiple regressions, with $a = .05$, power = .80, and effect size (medium size) = .15 [6]. The 120 family caregivers were involved for this study by purposive sampling with inclusion criteria: family caregivers who lived with schizophrenia patients, primary caregivers for at least 6 months, whose age was at least 18 years old, were able to speak, read, and write in Indonesian language, and had no history of mental illness.

C. Data Collection

Data collection was begun by self-introduction and the provision of the information about the purpose of the study via participant information sheet until the family caregivers understood about the study, then they caregivers who met the inclusion criteria and were willing to be the participants were asked to sign the consent form. Data was collected for two months (May to June 2013) at the Mental Health Hospital Bali Province.

D. Questionnaire

1) The Demographic Data Questionnaire:

Demographic Data Questionnaire was based on the literature review. The questionnaire was then translated into Indonesia version by a professional translator.

2) The Burden Assessment Schedule (BAS): is a questionnaire to measure the burden of family caregivers, which is designed by Thara et al., 1998, and translated by Djatmiko, [7] in Bahasa Indonesia version. The Cronbach’s alpha score was 0.73.
3) Knowledge scale: Knowledge scale is a self-report questionnaire about schizophrenia. It is a simple multiple choice questions consisting of seven questions based on NAMI Quiz test about schizophrenia [8]. The score of Kuder-Richardson (KR20) was 0.82.

4) Family Questionnaire (FQ): Family Questionnaire (FQ) is a self-report scale to measure expression of emotion developed by Wiedemann et al. (2001) which consists of 130 questions and were then simplified into 20 questions in 2002. The Indonesian version was translated by Nurtantri [9]. FQ includes two domains of expression emotion from family caregivers of patients with schizophrenia, including critical comments (CC) and emotional over involvement (EOI). In this study, the reliability test was 0.91 score of Cronbach’s alpha.

E. Ethical Approval

This study was approved by Ethics Review Board Committee for Research Involving Human Research Subjects, Borommarajonani College of Nursing Nopparat Vajira (ERB of BCNNV). Participant information sheet (PIS) has been provided, and consent form was required from all participants in this study. This study considers the anonymity and confidentiality. All information was de-identified by assigning a unique code number for this study. The data security was maintained by using computer password protection. Besides, research files were kept in a locked file cabinet in a restricted area accessible only by authorized personnel. The researchers gave freedom to the potential respondents to participate. Participants who met the inclusion criteria and were willing to take part in the study were asked to sign the consent form. The participants could withdraw from the study at any time without any consequences.

F. Statistical Analyses

Analyses of data were completed by using computer software. The analytical procedures include the following purposes: to describe demographic characteristics, to identify the level of knowledge, expression of emotion, and burden of family caregivers of patients with schizophrenia by using descriptive statistics. The relationships were analyzed by using Pearson’s correlation.

III. RESULTS

A. Socio-demographic Characteristics

The data reveal that the caregivers’ age is ranged from 18 to 80 years old, with a mean age of 45.6 years old (SD= 14.285). Most of the respondents are adults 52 (43.3%). Moreover, 31 (25.8%) of them are male, whilst 89 (74.25%) are female. Regarding the level of education, 14 (11.7%) of them have no education level, 36 (30%) primary school, 20 (16.7%) elementary school, 39 (32.5%) high school, and 11 (9.2%) the university/college education level. The relationships between caregivers and schizophrenia patients show that 13 (10.8%) of them are husband/wife, 24 (20%) brother/sister, 12 (10%) son/daughter, 51 (42.5%) father/mother and 20 (16.7%) other relationships. The average of the monthly income is IDR 1.095.830 (One Million Ninety Five Thousand Eight Hundred and Thirty Rupiah). Duration of caregiver’s duty is from the minimum of 10 months up to the maximum of 220 months.

B. Level of Knowledge, Expression of Emotion, and the Burden of Family Caregivers of Patients with Schizophrenia.

The majority of caregivers have a moderate to high level with regard to the knowledge of schizophrenia 47 (39.2%) and 42 (35%). A large number of caregivers have high expression of emotion (87.5%) and almost 114 (95%) of respondents carry a positive burden.


Age, duration as caregivers, knowledge and emotional expression led to a positive correlation. Income and years of education had a negative correlation. Gender and the relationships of the respondents with schizophrenia patients had no significant correlation to the burden.

Table 1 Correlation between caregivers’ burden with demographic characteristics, knowledge, and expression emotion of caregivers (n=120).

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Caregivers’ Burden</th>
</tr>
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<tbody>
<tr>
<td>Age</td>
<td>.233</td>
</tr>
<tr>
<td>Gender</td>
<td>.003</td>
</tr>
<tr>
<td>Income</td>
<td>-.210</td>
</tr>
<tr>
<td>Education</td>
<td>-.217</td>
</tr>
<tr>
<td>Relationship</td>
<td>.082</td>
</tr>
<tr>
<td>Duration</td>
<td>.232</td>
</tr>
<tr>
<td>Knowledge</td>
<td>.479</td>
</tr>
<tr>
<td>Expression of emotion</td>
<td>.515</td>
</tr>
</tbody>
</table>

IV. DISCUSSION

A. Demographic Characteristics

In this study, the majority of the respondents are female. This is in accordance with the culture of Indonesian society. Generally, the Indonesian females are responsible for taking care of the household, including the ill family member. This study is also similar to studies in Asian that reveal 70% of family caregivers are females [10], [11]. Regarding the level of education, most of them finished high school. This is due to the compulsory education program of Indonesian Government providing education until 12 years.

With regard to the relationship between caregivers and patients, the majority of the caregivers are part of the same nuclear family of the patients. Caregivers from both nuclear and extended family are important as individuals who are able to support the recovery process of the patients [12]. They assist the patients to fulfill their daily activities. Family is also an integral part of the treatment system necessary for the healing process of chronic mental patients [12]. Studies in Asian countries show that most of the caregivers of schizophrenic
patients are their elderly parents [10], [11]. The average of monthly income is IDR 1,095,830, - (One Million Ninety Five Thousand Eight Hundred and Thirty Rupiah) equal 110 USD, which is still lower than the regional minimum wage rate in Bali province (IDR 1,400,000,-). The low income can lead to a financial problem regarding to provision of care for illness family members. The length of treatment, severity of disease, and the high cost of medicine could be the factors of financial burden of caregivers. According to the result, most of the respondent spend more than one year to look after the patients. This can eventually in the financial burden.

B. Level of Knowledge, Expression of Emotion, and the Burden of Family Caregiver of Patients Schizophrenia

According to the result, more than half of the respondents possess a moderate to high level of knowledge about schizophrenia. It is consistent with the level of education, because most of them finish high school. The duration of caregiver’s duties is more than 1 year. It means they look after the patients in the long term, and which means they already meet with health personnel and receive some information about the patient’s disease.

Most of the respondents have high expressions emotion, which are higher than the previous study conducted in Bali 12.9% [13], and more than the study in Jakarta 49.2% [14]. The roles of information technology have an impact on the increase of caregivers’ expression of emotion, since they really know about schizophrenia that makes them anxious.

Within this study, the level of caregivers’ burden is positive (95%). It can be seen that caregivers spend such a long period to look after the patients. In addition, the length of treatment, severity of disease and the high cost of medicine may be factors of caregivers’ burden [14]. Caregivers must spend more time to care for schizophrenia patients. The disease may also have brought about the burden because of unpredictable symptoms such as mania, depression and violence. This is associated with Sounders [15] claiming that family caregivers of persons with severe mental illness experience significant stresses and have a high level of burden.

C. Relationship between Demographic Characteristics, Knowledge, Expression of Emotion, and the Burden of Caregiver of Patients with Schizophrenia

Caregivers’ age has a positive correlation to the burden of caregivers at a moderate level. This is similar to studies in Asian, which suggest that caregivers’ burden score is positively correlated with their age [10], [11]. The older the age of caregivers, the heavier the perceived caregivers’ burden. Li, et al. [16] state that when caregivers became older, they are anxious about who will take care of their ill family member in the future. In addition, Fujino & Okamura [17] claim that younger caregivers can increase the sense of life is worth more. However, the results of these studies are different from the Mexican Americans’ study that caregivers with younger age experience higher level of family burdens [18]. The differences could be supported by different cultures between two studies. In a traditional Asian culture, the elderly in a family are the heads of household who have the main person to take care of all family members, and are also responsible for their health condition [11].

Regarding the relationship of caregivers with schizophrenia patients, there is no significant correlation with the burden in this study, which is because most of caregivers are members of the nuclear family (parents). This is similar to the studies in Asian that most family caregivers of adult clients with schizophrenia are their parents [10], [11]. In addition, gender of the caregiver has no significant correlation with the burden, and the majority of caregivers are females. In Indonesian culture, females have to take responsibilities to look after ill family members rather than male. This may link with the Asian culture that females are responsible for taking care of the household, including the ill family member [14], which means females spend more time in care giving than male do. Females also have experienced distress in caring for schizophrenia patients. Therefore, females have more burden than males do, which is consistent with the study by Schneider, et al. [19] that shows there is a significant difference in gender in terms of the burden. The female have higher scores in care giving, depression and burden compared to the male.

The income of the caregiver has a negative correlation to caregivers’ burden. The lower caregivers’ income, the higher burden they carry [11], [20]. The lower income is a stressor that influences stress felling during the care provision for an ill family member. In addition, caregivers provide care for ill family member, they also have to solve financial problem and find out source of income [21]. Years of education also have a negative correlation with caregivers’ burden. It can be assumed that the higher years of education, the higher salary will be. The high salary would decrease financial problem related to providing care for an ill family member, and decrease the burden of caregivers [16].

Duration of care giving has a positive correlation to the burden. The higher duration of care giving means the greater perceived burden of the caregivers. There are consistent findings by Li, et al. [16]. When caregivers spend more time with their ill family member, they could have less time for themselves.

Caregivers’ knowledge about schizophrenia has a positive correlation with the burden, which contrasts with a study by Lim & Ahn [4] who state that knowledge is negatively correlated with perceived burden, but there is also a consistent finding by Sefasi, et al. [5]. The greater level of knowledge, the greater the burden. Knowledge about schizophrenia may increase anxiety and then perceived burden. People know more about schizophrenia that it is a chronic illness and time-consuming for taking care of patients, which can lead to perceived burden. Also, if they know about the disease, they consider that it cannot be cure; and caregivers are responsible for care giving. Therefore, it might have an impact on the burden.

It is possible that higher levels of knowledge are associated with the higher level of stigma, and which has been reported
to contribute to the burden among caregivers of mentally ill patients in Africa. Besides, the belief that a mental disorder is a hereditary disease that must be accepted and the supernatural cannot be controlled [13].

Expression of emotion has a positive correlation with the burden. The higher score expression of emotion, the higher burden of caregivers. There is a similar study by Maldonado & Caquezo [22], suggesting that a reduction of family burden is found over time among relatives who adopt less emotion-focused coping strategy. Szczutka & Kulper (1996) point out that family with a high expression of emotion has a level of assessment for family burden higher than those with low expression of emotion [9]. High expression of emotion has a high problem, more complaints of subjective burden, and even fewer have the effective coping mechanism [22], [23].

Although this study brings about important information related to burden and its related factors, some limitations need to be addressed. Firstly, the sample was selected by purposive sampling, which was drawn from caregivers in only one geographical region in Bali Province, thus, it is limited to generalize the results of this study. Secondly, this study is a cross-sectional study that is unable to investigate causal relationships and change over time. Finally, a further methodological concern is that, because all of the measures are based on self-reports, there is a possibly common method variance that may inflate the obtained results.

V. CONCLUSION

Knowledge and expression of emotion have positive correlations with caregivers’ burden. This does not prove that knowledge causes burden, but anxiety and negative belief factors may mediate the relationship between knowledge and burden.

Finally, in planning for program development should aim at alleviating burden among these caregivers. All factors mentioned above should be taken into account. This study brings about the baseline data and enables healthcare professionals, nurses in particular, to have better understanding. These will lead to better address the needs, reduce the distress or negative consequences in caring for persons with schizophrenia, as well as promote quality of life for both the caregivers and the patients.

ACKNOWLEDGEMENTS

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