Predicting Factors of Burden among Family Caregivers of Patients with Schizophrenia in Surabaya, Indonesia

นิพนธ์ต้นฉบับ

Original Article

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วารสารไทยเภสัชศาสตร์และวิทยาการสุขภาพ 2558;10(3):87-97

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บทคัดย่อ

วัตถุประสงค์: เพื่อศึกษาภาระการดูแลผู้ป่วยจิตเภทของผู้ดูแลชาวอินโดนีเซีย และทดสอบตัวแปรพยากรณ์ของการรับรู้ภาระการดูแล ได้แก่ การรับรู้ความรุนแรงของโรค ความรู้และทัศนคติเกี่ยวกับโรคจิตเภท การประเมินค่าการดูแลและการสนับสนุนทางสังคม **วิธีการศึกษา:** กลุ่มตัวอย่างคือ ผู้ดูแลผู้ป่วยจิตเภทจำนวน 120 รายที่พาผู้ป่วยจิตเภทมาตรวจตามนัดที่แผนกผู้ป่วยนอก ณ โรงพยาบาลด้านสุขภาพจิตแมนัว เมืองสุราบายา ประเทศอินโดนีเซีย เก็บข้อมูลช่วงมกราคม ถึงกุมภาพันธ์ 2558 สุ่มตัวอย่างโดยการสุ่มอย่างง่าย เก็บข้อมูลโดยใช้แบบสอบถามเพื่อเก็บข้อมูลเกี่ยวกับ ข้อมูลทั่วไปทั้งของผู้ป่วยและผู้ดูแล การรับรู้ความรุนแรงของโรค ความรู้และทัศนคติเกี่ยวกับโรคจิตเภท การประเมินค่าการดูแล และการสนับสนุนทางสังคม และภาระการดูแล วิเคราะห์ข้อมูลโดยใช้สถิติเชิงบรรยาย และการวิเคราะห์ถดถอยพหุคูณ **ผลการศึกษา:** ผลการวิจัยพบว่าผู้ดูแลจำนวน 93 ราย (ร้อยละ 77.50) รับรู้ว่าการให้การดูแลผู้ป่วยจิตเภทที่บ้านถือเป็นภาระ จากผลการวิเคราะห์ถดถอยพหุคูณ พบว่าการรับรู้ความรุนแรงของโรค ความรู้และทัศนคติเกี่ยวกับโรคจิตเภท การประเมินค่าการดูแล และการสนับสนุนทางสังคม สามารถร่วมกันอธิบายความแปรปรวนของการรับรู้ภาระการดูได้ ร้อยละ 51 (R^2 = 0.51, F = 24.07, $P < 0.001$) จากตัวแปรเหล่านี้ พบว่าตัวแปรที่สามารถทำนายภาระการดูแลได้อย่างมีนัยสำคัญทางสถิติคือ การรับรู้ความรุนแรงของโรค (β = 0.41, $P < 0.001$) ทัศนคติเกี่ยวกับโรคจิตเภท (β= -0.38, $P < 0.001$) และการสนับสนุนทางสังคม (β = -0.27, $P < 0.01$) **สรุป:** ผลการวิจัยนี้ช่วยส่งเสริมความเข้าใจเกี่ยวกับการรับรู้ภาระการดูแลและปัจจัยทำนายภาระการดูแลในผู้ดูแลผู้ป่วยจิตเภทของประเทศอินโดนีเซีย สามารถใช้เป็นข้อมูลพื้นฐานเพื่อการพัฒนาการบำบัดการพยาบาลที่เหมาะสมและช่วยลดภาระการดูแลอันจะส่งผลต่อการมีคุณภาพชีวิตที่ดีขึ้น ทั้งผู้ดูแลและผู้ป่วยจิตเภท

คำสำคัญ: ภาระ, โรคจิตเภท, ผู้ดูแล, อินโดนีเซีย

Abstract

Objective: To describe burden among Indonesian family caregivers, and examine its predictors including family caregivers' perceived severity of patients' illness, knowledge and attitude towards schizophrenia, caregiving appraisal, and perceived social support. **Method:** A sample of 120 family caregivers of schizophrenia patients visiting outpatient department of Menur Mental Hospital, Surabaya, Indonesia participated in this study. Data collection was performed during January to February 2015 with simple random sampling to recruit the sample. Structured questionnaires for data collection included general information of both family caregivers and the patients, perceived severity of patients' illness, knowledge and attitude towards schizophrenia, caregiving appraisal, perceived social support, and burden. Descriptive statistics and standard multiple regression were employed for data analysis. **Results:** Ninety-three caregivers (77.50%) reported burden during their patient care. Perceived severity of patients' illness, knowledge about schizophrenia, attitude towards schizophrenia, caregiving appraisal, and perceived social support significantly explained 51% of the variance in family caregivers' burden (R^2 = 0.51, F = 24.07, $P <$ 0.001). Significant predictors were perceived severity of patients' illness (β = 0.41, $P < 0.001$), attitude towards schizophrenia (β= -0.38, $P < 0.001$), and perceived social support (β = -0.27, $P < 0.01$). **Conclusion:** The findings provided better understanding regarding burden and its predictors among Indonesian family caregivers of schizophrenia patients. These results can be used for developing proper nursing intervention aiming at alleviating burden which will in turn help enhance the quality of life among these caregivers and their patients.

Keywords: burden, schizophrenia, caregivers, Indonesia

Introduction

Schizophrenia, meaning *split minds*, is one of the most severe mental illnesses and it presents in all cultures, races, and socioeconomic groups.[1] The World Health Organization estimated that schizophrenia affects more than 21 million people worldwide, and typically begins in late adolescence or early adulthood.[2] According to data from the Ministry of Health of the Republic of Indonesia, the prevalence of severe mental disorder (schizophrenia) in Indonesia was 1.7 per 1000 people, or, in other words, it affected around 3,400 people from the total of 2,000,000 people.[3] Schizophrenia was the most common mental disorder in Menur Mental Hospital Surabaya, Indonesia.[4] In the outpatient department of this hospital, from a total of 28,466 registered patients in 2013, there were 24,589 patients diagnosed with schizophrenia.

Patients with schizophrenia have a long duration of illness and a limited ability to perform daily activities and interact with other people. When patients with schizophrenia are discharged from hospitals, the obvious effect is the impact to those who care for them in the community. The shifting from hospital-based care to community-based care that began more than forty years ago resulted in most psychiatric patients now being cared for by their families.[5-7] In Indonesia, almost all discharged patients with schizophrenia will return to their own home in the community. However, the families may not be aware of what they will face as well as what they should do in caring for their patients[8-9], even though they naturally feel responsible to do it. Family caregivers for persons with schizophrenia may find their tasks more challenging than family caregivers for other patients of disabilities. This is because the caregiving demands for patients with schizophrenia are influenced by the severity of psychotic symptoms and functional limitation of the patients.[10] In addition, the caregiving demands involve the available resources of family caregivers, including their physical and mental health status, their financial resources, and sufficient information and skills regarding the patients' illnesses and care, which requires adequate social support.[11-13] Therefore, family caregivers in almost every country are more likely to perceive their burden as one of negative consequences in caring for patients with schizophrenia.[5,14,15] Awad and Voruganti[16] defined the burden of care as "its impact and consequences," where it refers to the physical, psychological, social, and financial statuses. When family caregivers perceive providing care as a burden, the results will not only affect themselves, but also the patients, other family members, and the health care system.[17]

The assumption underlying the caregiver's burden is that caring for a family member with schizophrenia imposes a caregiving burden of which the degree of the burden will vary according to other factors.[6] Patients with schizophrenia usually have relapse episodes which occur sometime after recovery, thus the patients' progress should be reevaluated regularly and adjusted for treatment when needed. Assessing the family caregivers' perceptions about the severity of the patients' illness will provide information about what families face when coping with the behaviors and psychotic symptoms of patients, which may relate to how they perceive burden. It has been found in numerous studies that the higher disturbance behaviors and severe psychotic symptoms of patients with schizophrenia were associated with higher levels of burden among family caregivers.[18-23] Various characteristics of family caregivers influence their perceived burden[5]. One of characteristics that has a significant correlation with the burden is the knowledge about schizophrenia. Some studies have shown the effectiveness of psycho-educational intervention in order to reduce family caregivers' burden by providing information about schizophrenia.[24,25] However, it is unclear whether an increase in knowledge about schizophrenia among family caregivers will affect their attitude toward the patients and the illness itself, thereby affecting their burden. The relationship between burden and attitude was found in the study conducted in Chile by Caqueo-Urizar and colleagues.[26] Its results affirmed that the worse the caregivers' attitude, the higher level of burden perceived by the caregivers. When family caregivers have a positive attitude, they will respond to the patients in positive way regarding their cognitive, emotional, and behavioral status, and this will also influence their appraisal of the caregiving experience to be more positive. This will have an impact on caregivers' level of burden.[27,28] Moreover, receiving necessary social support would help family caregivers feel less burden. Social support was found to be one of the major significant predictors of caregiver burden in various studies; the more social support the family caregivers obtained, the less burden they perceived.[10,18,29-32]

Nevertheless, most of those studies have been conducted outside Indonesia. There was still a gap of knowledge towards family caregivers' burden and its predictors during caring for the patients at home. Therefore, the aims of this study were to describe the burden of family caregivers and examine its influencing factors including family caregivers' perceived severity of patients' illness, their knowledge about schizophrenia, attitude towards schizophrenia, caregiving appraisal, and perceived social support in Surabaya, Indonesia.

Methods

Design and study settings

A predictive correlation design was employed in this study. This study was conducted at outpatient department of Menur Mental Hospital Surabaya, Indonesia. This hospital is a class A hospital (the highest rank of hospitals in Indonesia) which delivers health care service both mental health care and general health care which include emergency care, rehabilitation for drug/alcohol abuse, and outpatient department for many specialist areas. This study was conducted from January 19th to February 6th, 2015.

Sample

The sample consisted of 120 family caregivers of patients with schizophrenia who accompanied the patients for follow-up at the outpatient department. They were selected using simple random sampling technique. The inclusion criteria for these participants included: 1) being primary family caregiver for a patient with schizophrenia and taking most responsibility for caring the patient for at least 6 months, 2) age of 17 – 60 years old, 3) having no cognitive impairment, 4) living in the same household with the patient, and 5) being able to read and write Indonesian language. This sample size was calculated by using Tabachnick and Fidell's formula.[33]

Instruments

Data were collected by using 7 questionnaires.

Demographic Questionnaire

This questionnaire was developed by the researcher. It captured data regarding sociodemographic characteristics of both family caregivers, and patients.

Psychiatric Behavior and Symptom Perception Scale (PBSPS)

PBSPS was used to assess the perception of family caregivers regarding severity of patients' illness developed by Pipatananond.[34,35] Five aspects of illness severity on this instrument are depressive symptoms (item numbers 1, 3-5, 8, 13, 22), inappropriate performance (2, 6, 7, 9, 11, 21, 23-26), psychotic symptoms (10, 12, 14-16), attention and memory problems (17-20), and addictive behaviors (27-29). For example, an item of psychotic symptoms is "having hallucination." The Cronbach's alpha of 0.88 was obtained for the total 29-item scale. The PBSPS was a four-point Likert scale format ranging from 0 – 3 (never, rarely, often, always). The higher scores indicated more seriousness of the patients' illness as perceived by these family caregivers. In this study, the instrument yielded a high reliability with a Cronbach's alpha of 0.81.

Knowledge Scale (KS)

KS a simple 7-items version of NAMI (National Alliance on Mental Illness) Quiz test[36] was used to capture knowledge among the family caregivers. The KS was translated from the English version into Indonesian version[37] and used to assess the knowledge of family caregivers about schizophrenia including its definition, cause, symptoms, and treatment. An example of KS question is "what the cause of schizophrenia?" The incorrect answer would be scored as 0, and the correct answer as 1. The possible score is 0 - 7. The higher score indicates better knowledge the family caregivers have. For this study, the Kuder-Richardson coefficient of reliability equaled to 0.84.

Attitudes towards Schizophrenia Questionnaire (ATSQ)

ATSQ was used for assessing attitudes towards schizophrenia based on various responses that the family caregivers have regarding schizophrenia and the persons who are diagnosed with this mental disorder. This instrument was developed by Caqueo-Urizar and colleagues.[26] This 9-item questionnaire has a Likert scale ranging from strongly disagree (1) to strongly agree (5). It consisted of 3 components: cognitive (item numbers 4, 7, 9), behavioral (1, 2, 6), and affective (3, 5, 8). Example of an item in the affective component is "I prefer to hide the illness from the rest of my family and friends." Total score is the mean of all items; the higher score indicates a better attitude of the caregiver toward schizophrenia. For this study, the Cronbach's alpha was 0.73.

Scale for Positive Aspects of Caregiving Experience (SPACE)

SPACE was employed to assess the positive aspects of caregiving that family caregivers encountered while caring for the patient with schizophrenia. This instrument was developed by Kate, Grover, Kulhara, and Nehra[38] and was conducted with family caregivers of patients with schizophrenia. A 5-point Likert type scale (never, rarely, sometimes, often, and always) was adopted to measure their responses to each item. Forty-four items were retained in the 4-factor structure: caregiving personal gains (14 items), motivation for caregiving role (13 items), caregiver satisfaction (8 items), and self-esteem and social aspects of caring (9 items). An example of the item in caregiving satisfaction is "Caring for my ill relative has made me appreciate life more." For comparison of different subscales, the mean score of the subscale was divided with the number of items included in that subscale to derive the mean scores;

the higher means score indicates higher positive aspects of family caregiving experiences. This instrument yielded good psychometric properties with a Cronbach's alpha of 0.92.[38] In this study, the Cronbach's alpha was 0.96.

Personal Resource Questionnaire (PRQ2000)

The PRQ2000 developed by Weinert[39] was used to assess perceived social support. The PRQ2000 was composed of 15 items on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). An example of statement is "There is someone I feel close to who makes me feel secure." The 15 items are summed to calculate the total score. Possible total scores range from 15 to 105, with higher scores indicating higher levels of perceived social support. This instrument was used in study with family caregivers of patients with schizophrenia.[40] Construct validity was acceptable by factor analysis and the internal consistency of this instrument for Cronbach's alpha was 0.93.[39] In this study, the Cronbach's alpha was 0.90.

Burden Assessment Schedule (BAS)

In this study, the BAS Indonesia version developed by Djatmiko[41] was used. He translated this English version BAS from Sell, Thara, Padmavati, Kumar, & WHO-SEARO (1998) into Indonesian version. It has 20 items which comprised five domains: impact on well being (question numbers 7 - 10), impact on marital relationships (3 - 6), appreciation of caring (1, 13, 16, 19), impact on relations with others (2, 11, 14, 17), and perceived impact of severity of the disease (12, 15, 18, 20). An example of the item regarding impact on well being is "Do you sometimes feel depressed and anxious because of the patient?" With each question rated on a 3-point scale, the responses would be "not at all," "to some extent," or "very much." Depending on how the questions are framed, the point for each of these responses would vary. The higher score means higher burden of care. The burden is perceived once the person has a score of ≥ 22. All items of the BAS Indonesian version had a good validity, a high sensitivity score of 85.1%, while a high specificity level of 89.4%, and a high accuracy level of 87.9%. Factor analysis showed that BAS Indonesian version had 5 underlying constructs of their 20 items in line with of the theoretical construct of the original version of the BAS instrument. The Cronbach's alpha coefficient was 0.87.[41] In this study, the Cronbach's alpha coefficient was 0.73.

Data collection procedure

Human subject's approval was obtained from the Ethical Approval Committee, Faculty of Nursing, Burapha University, Thailand, and from Menur Mental Hospital, Surabaya, Indonesia. After granting allowance from authorities of Menur Mental Hospital, the process of data collection began. Patients who met the study criteria and agreed to participate in the study signed a consent form. With their written consent, each participant was asked to complete the questionnaire at the outpatient department which data collection was took place. It took about 30 - 45 minutes to complete the questionnaire.

Data analyses

A computer statistical program was used to analyze data. The alpha level for significance was set at 0.05. The descriptive statistics was used to describe the sample characteristics and the studied variables. The standard multiple regression was performed to determine the predictors of burden which include family caregivers' perceived severity of patients' illness, knowledge about schizophrenia , attitude towards schizophrenia, caregiving appraisal, and perceived social support among the family caregivers of patients with schizophrenia.

Results

Description of patients and family caregivers' characteristics

A total of 120 family caregivers of patients with schizophrenia who accompanied the patients for follow-up and met the inclusion criteria were recruited at the outpatient department of Menur Mental Hospital, Surabaya, Indonesia. The demographic characteristics of the patients and family caregivers in the present study are presented in table 1 and table 2.

Table 1 shows that the patients had a mean age of 37.69 (±12.69) years and were more males (55.80%) than females (44.20%). The majority of them were single (66.70%) and unemployed (78.40%). The mean score of duration of illness, and number of inpatient admission were 9.52 (±7.81) years, and 2.37 (2.14±) times, respectively.

Table 1 Demographic characteristics of patients (n = 120)

Characteristics	n	%
Age		
≤ 20	5	4.20
21 – 30	35	29.20
31 – 40	41	34.20
41 – 50	18	15.00
51 – 60	13	10.80
> 60	8	6.60
Mean = 37.69; SD = 12.69; Range = 17 – 73		
Gender		
Male	67	55.80
Female	53	44.20
Marital status		
Single	80	66.70
Married	32	26.70
Divorced	8	6.60
Education		
Not finished primary school	2	1.70
Primary school	36	30.00
Secondary school	33	27.50
High school	46	38.30
Undergraduated/Graduated	3	2.50
Occupation		
Unemployed	94	78.40
Housewife	7	5.80
Retired	1	0.80
Government employee	1	0.80
Private company employee	7	5.80
Farmer	2	1.80
Others	8	6.60
Duration of illness (years)		
1 – 10	75	62.00
11 – 20	33	27.00
21 – 30	12	11.00
Mean = 9.52; SD = 7.81; Range = 1 – 30		
Number of inpatient admission		
< 5	105	87.00
≥ 5	15	13.00
Mean = 2.37; SD = 2.14; Range = 0 – 10		

Table 2 shows that the family caregivers had a mean age of 48.81 (±10.78) years and there were more females (72.50%) than males (27.50%), and being housewives (52.50%). The majority of them were married (90.00%) and completed primary school (40.00%). About half of them are parents of the patients (50.80%). The mean score of household income, number of family member, duration of providing care, and average time of caring per day were 2,080.00 thousand IDR/month, 3.85 (±1.58) persons, 7.52 (±7.58) years, and 4.53 (±3.99) hours/day, respectively.

Table 2 Demographic characteristics of family caregivers (n = 120)

Characteristics	n	%
Age		
≤ 20	1	0.80
21 – 30	9	7.50
31 – 40	17	14.20
41 – 50	30	25.00
51 – 60	63	52.50
Mean = 48.81; SD = 10.78; Range = 19 – 60		
Gender		
Male	33	27.50
Female	87	72.50
Marital status		
Single	9	7.50
Married	108	90.00
Divorced	3	2.50
Education		
Not finished primary school	1	0.80
Primary school	48	40.00
Secondary school	11	9.20
High school	44	36.70
Undergraduated/Graduated	16	13.30
Occupation		
Unemployed	7	5.80
Housewife	63	52.50
Retired	6	5.00
Government employee	2	1.70
Private company employee	21	17.50
Farmer	5	4.10
Business	2	1.70
Others	14	11.70
Relationship with patient		
Spouse	15	12.50
Parent	61	50.80
Son/daughter	9	7.50
Sibling	31	25.80
Uncle/aunt	2	1.70
Other	2	1.70
Income on household (IDR/month)		
≤ 2,000,000	57	47.50
> 2,000,000	38	31.70
Not specified	25	20.80
Mean= 2,080,000.00 (approximately 175 USD); Median= 2,000,000.00; Range= 500,000 – 4,500,000		
Number of family member		
< 6	106	88.30
≥ 6	14	11.70
Mean= 3.85; SD= 1.58; Range= 2 – 13		
Duration of providing care (years)		
1 – 10	91	75.80
11 – 20	21	17.50
21 – 30	8	6.70
Mean= 7.52; SD= 7.58; Range= 1 – 30		
Average time of caring (hours/day)		
1 – 12	114	87.50
13 – 24	6	12.50
Mean= 4.53; SD= 3.99; Range= 1 – 20		

Description of the study variables

The mean score of perceived severity of patients' illness, knowledge about schizophrenia, attitude towards schizophrenia, caregiving appraisal, perceived social support, and family carregivers' burden were 12.23 (±8.16), 4.27 (±2.12), 31.21 (±4.49), 143.54 (±26.06), 75.88 (±11.02), and 24.76 (±4.09), respectively (Table 3). From 120 family caregivers, 93 (77.50%) of them perceived burden.

Table 3 Description of the study variables (n = 120)

Variables	Mean	SD	Actual score	Possible score
Perceived severity of patients' illness	12.23	8.16	0 – 30	0 – 87
Inappropriate performance	4.78	3.13	0 – 12	0 – 30
Depressive symptoms	3.92	3.20	0 – 14	0 – 21
Psychotic symptoms	2.47	2.16	0 – 11	0 – 15
Attention and memory problems	1.03	1.63	0 – 9	0 – 12
Addictive behaviors	0.03	0.22	0 – 2	0 – 9
Knowledge about schizophrenia	4.27	2.12	0 – 7	0 – 7
Attitude towards schizophrenia	31.21	4.49	19 – 40	9 – 45
Behavioral	10.87	1.69	5 – 15	3 – 15
Cognitive	10.45	2.04	4 – 15	3 – 15
Affective	9.88	2.25	3 – 14	3 – 15
Caregiving appraisal	143.54	26.06	82 – 216	44 – 220
Caregiving personal gains	43.94	8.81	24 – 67	14 – 70
Motivation for caregiving role	37.52	9.13	18 – 62	13 – 65
Self-esteem and social aspects of caring	35.13	5.69	18 – 45	9 – 45
Caregiver satisfaction	24.55	5.64	12 – 39	8 – 40
Perceived social support	75.88	11.02	51 – 95	15 – 105
Family caregivers' burden	24.76	4.09	16 – 36	16 – 60
Appreciation of caring	8.13	1.34	4 – 12	4 – 12
Impact on well-being	5.48	1.55	1 – 11	4 – 12
Perceived impact of severity of disease	5.19	1.43	4 – 10	4 – 12
Impact on relationship with others	4.96	1.28	3 – 9	4 – 12
Impact on marital relationship	1.01	2.77	0 – 10	4 – 12

Predicting factors of family caregivers' burden

Table 4 presents the correlations among the study variables. Table 5 shows a result from standard multiple regression analysis which indicated that perceived severity of patients' illness, knowledge about schizophrenia, attitude towards schizophrenia, caregiving appraisal, and perceived social support could explained 51% of the variance in family caregivers' burden (R^2 = 0.51, *F* = 24.07, *P*-value < 0.001). Particularly, perceived severity of patients' illness explained the most variance in family caregivers' burden (β= 0.41, *P*-value < 0.001), followed by attitude toward schizophrenia (β = -0.38, *P*-value < 0.001), and perceived social support (β = -0.27, *P*-value < 0.01).

Table 4 Correlations among the study variables (n = 120)

Variables	1	2	3	4	5	6
1. Family caregivers' burden	1					
2. Perceived severity of patients' illness	0.38†	1				
3. Knowledge about schizophrenia	-0.15*	0.16*	1			
4. Attitude towards schizophrenia	-0.53†	-0.01	0.14	1		
5. Caregiving appraisal	-0.33†	-0.04	0.13	0.33†	1	
6. Perceived social support	-0.45†	0.06	0.19*	0.42†	0.45†	1

* *P*-value < 0.05 † *P*-value < 0.001

Table 5 Predicting factors of family caregivers' burden (n = 120)

Variables	b	SE	β	t
Perceived severity of patients' illness	0.20	0.03	0.41†	6.14
Attitude towards schizophrenia	-0.35	0.07	-0.38†	-5.19
Perceived social support	-0.10	0.03	-0.27$^{\$}$	-3.47
Knowledge about schizophrenia	-0.20	0.13	-0.10	-1.56
Caregiving appraisal	-0.01	0.01	-0.05	-0.68
Constant = 42.76†; R^2 = 0.51; *F* (5, 114) = 24.07†				

* *P*-value < 0.05 $^{\$}$ *P*-value < 0.01 † *P*-value < 0.001

Discussion and Conclusion

The first aim of this study was to describe the burden of family caregivers of patients with schizophrenia in Surabaya, Indonesia. Among 120 family caregivers, 93 (77.50%) of them perceived burden. According to previous studies conducted in Indonesia, most of 120 caregivers (95%) in Bali Province[37], 89 from 100 caregivers (89%) in Semarang[42], and 87 from 118 caregivers (74%) in North Sumatra Province[43] felt burden by the condition of patients with schizophrenia. It is similar with another countries that family caregivers perceived burden which reflected the negative consequences in caring for patients with schizophrenia.[5,6,14,15] The patients have been suffering with this illness for a long time, hence the family caregivers would face various problems and difficulties toward caring for them, and these would impact their well being. These negative consequences include financial difficulties, missed work, disturbance of domestic routines, constraints on their social and leisure activities, and reduced attention paid to other family members. As a consequence, psychological distress may occur as well such as guilt, loss, helplessness, fear, vulnerability, and cumulative feelings of defeat, anxiety, resentment, and anger. The distress mentioned above was also commonly reported in other studies.[6,44]

The second aim of this study was to examine the predicting factors of Indonesian family caregivers' burden. Standard multiple regression analysis showed that perceived severity of patients' illness, knowledge about schizophrenia, attitude towards schizophrenia, caregiving appraisal, and perceived social support significantly explained 51% of the variance in family caregivers' burden ($R^2 = 0.51$, $F = 24.07$, P–value < 0.001). The most significant predictors of family caregivers' burden was perceived severity of patients' illness ($\beta = 0.41$, P–value < 0.001), followed by attitude toward schizophrenia ($\beta = -0.38$, P–value < 0.001), and perceived social support ($\beta = -0.27$, P–value < 0.01). These findings were similar with various studies which reported significant correlation between selected variables and caregiver burden. Nevertheless, these associations failed to reach significant levels when the stronger method of regression analysis was used.[5]

Clinical characteristic of patients that was rated by family caregivers had a significant impact on family caregivers' burden ($\beta = 0.41$, P–value < 0.001). The results showed consistent results with other studies as well.[18-23] A study in Chile found that positive symptoms of the patients with schizophrenia ($\beta = 0.19$, P–value < 0.01) and independence-performance of the patients ($\beta = -0.62$, P–value < 0.001) significantly influenced the caregivers' burden.[18] These findings demonstrated what have been faced by the family caregivers during their care for patients with schizophrenia at homes. The acute episodes of schizophrenia could appear again after receiving inpatient service from hospital. In addition, the more severe the illness, the more limitation regarding patients' abilities to perform their daily activities on their own as well as their interaction with others. Therefore, the more severity of patients' illness perceived by the family caregivers, the higher level of burden they felt. The assessment of functional ability and symptoms of the patients not only reflect the condition of patients, but also serve as useful information for the health care providers to predict the family caregivers' burden. Moreover, the effective treatment for the patients to improve their functioning abilities and reduce psychotic symptoms would result in the decrease of burden among the family caregivers.

From this study, the family caregivers' attitude toward schizophrenia significantly influenced the burden of family caregivers ($\beta = -0.38$, P–value < 0.001). According to attitude scale examined in this study, the higher score indicate a positive or better attitude of the family caregiver toward schizophrenia. The finding was consistent with the study conducted by Caqueo-Urizar and colleagues[26] which showed that the perceived burden of family caregivers is significantly correlated with their attitude toward schizophrenia; the worse attitude the caregivers had, the higher level of burden they would perceive ($R^2 = 0.104$, $F = 4.55$; P–value < 0.05). The sociocultural and ethnic characteristics of the family caregivers across countries have influence their attitude toward the patients with schizophrenia which in turn impact their burden of caregiving. The family in Asia is more likely to rely on each other family members for their living, and also more likely to be interdependent rather than independent. Therefore, the one whose interdependence level is high would perceive less burden.[52] These findings might exhibit the attitude towards schizophrenia as a noticeable predictor factor of burden, and as an explanation of the differences of burden between family caregivers of patients with schizophrenia in Eastern and Western countries through sociocultural and ethnic characteristics.

Consistent with various studies which found that the social support was the best predictor of caregiver burden[10,18,29-32], this study also showed similar results ($\beta = -0.27$, P–value < 0.01). The study conducted with Chinese families showed social support significantly explained the variance in family caregivers' burden ($\beta = -0.39$, P–value < 0.05).[30] These results confirm that the family caregivers need help and support to deal with any negative consequences in caring for the patients with schizophrenia. For example when the patients are in acute episode, they need other family members or neighbour or friends to keep the patients stable. Another situation is if the family caregivers need to go to work, thus they need secondary caregiver or someone who could take their roles for a while. These social supports provide opportunities for the family to maintain both their needs as well as their roles as caregivers.

Understanding the nature of patients' disease regarding the cause, symptoms, and treatment would influence the burden that the family caregivers would perceive. Even though family caregivers' knowledge about schizophrenia had negative correlation with burden ($r = -0.15$, P–value < 0.05), this variable failed to reach the significant level in regression model ($\beta = -0.10$, P–value > 0.05). The possible reason is that the scale used in this study was emphasized on assessing caregivers' knowledge regarding the disease and its treatment, it did not capture the knowledge of family caregivers regarding the management of care for the patients' behaviors and symptoms or the needed skin order to care for the patients at home. As the result of study that tested psychoeducational intervention among family caregivers of patients with schizophrenia, there were improvement in the patients' clinical status and decreases in family burden due to the caregivers' understanding of strategies in dealing with patients' daily problematic situations.[24] Simply stated, the higher level of knowledge about schizophrenia that the family caregivers have, the lower level of burden they would perceive. However, some studies showed opposite results in which the greater level of knowledge about schizophrenia, the greater burden they would perceive.[37,45] The authors stated that if the caregivers know about the disease, the caregivers would consider that it cannot be cured and they are responsible to continue caring for the patients for a long period of time, thus it leads to increase of their burden. For the study of Lim and Ahn[8], the path analysis revealed that family caregivers' knowledge had no direct effect on the burden of family caregivers, but it had an indirect impact (β = -0.31) on subjective burden through negative coping (β = 0.34) style of family caregivers (total effect = -0.11). They stated that the coping style was served as a mediator for the relationship between family caregivers' knowledge regarding schizophrenia and the perceived burden that the family caregivers had. These findings affirmed that family caregivers are still looking forward to receive necessary information about schizophrenia in order to adjust their care given to the patients as well as learn how to cope and manage with patients' behaviors and symptoms. Hence, obtaining better knowledge and understanding toward schizophrenia and care management should be prioritized in order to alleviate the family caregivers' burden.

Another variable on this study which failed to reach significant level in regression model was caregiving appraisal (r= -0.33, P–value < 0.001, β = -0.05, P–value > 0.05). The study from Kate, Grover, Kulhara, and Nehra[50] found that only caregiver's gain in positive experience on SPACE (Scale for Positive Aspects of Caregiving Experience) positively influences subjective burden. On the other hand, the study of Hsiao and Van Riper[49], Taiwanese family caregivers who had more positive interpretation of caregiving reported lower levels of their burden during their care for the patients with severe and persistent mental illness (β = -1.05, P–value < 0.001). The findings revealed that when the family caregivers experienced some positive aspects of caregiving such as learning new skill of caregiving, enhance sense of meaning, increase self-esteem, feeling needed and appreciated; those feelings somehow influence their perception of any adverse effects of caring for the patients with schizophrenia . For example, the feeling needed and appreciated by the patients might press the family caregivers at the time they realized that schizophrenia is chronic illness. However, it is suggested that over time, the family caregivers can learn more and adapt to attain the positive experience of caregiving rather than involve on the negative consequences of caregiving for the patients with schizophrenia.[51] Moreover, the sociocultural and ethnic characteristics of the family caregivers could influence the way they appraise the positive aspects of caregiving. Indonesian family caregivers have various ethnics and beliefs toward care given to the patients with schizophrenia.

Nevertheless, from this result, it confirms that successful family caregivers in fulfillment of the demands of caregiving for patients with schizophrenia requires the adjustments on their capabilities in providing care including how severe they perceive toward the severity of patients' illness, how their concerns about the patients and the disease, and how wide the social support they needs; thereby assist them to deal with the negative consequences of caring. The family caregivers would feel overwhelmed in caring because of the patients have more severe illness or unable in doing daily activities, and they may have no idea of the patients' symptoms and what should they do to face it. However, when they endorse good attitude regarding their beliefs, they would view the situation in different way which involve positive aspects of caregiving experience. Contrary if they have bad feelings toward the patients and the disease, the more burden they would perceive.

The burden would be also influenced by the support from other family members, friends, society, and health care professions that they have. Therefore, these findings would help the family caregivers to be able to cope the negative consequences during caring for the patients with schizophrenia as more acceptable and worthy without neglect their own needs and health.

Implications of the study

The results of this study provided better understanding towards the conditions of Indonesian family caregivers of patients with schizophrenia during their care for the patients at homes. The study results shed addition light towards how Indonesian family caregivers perceived about the negative consequences in providing care for the patients with schizophrenia, how they perceived the severity of patients' illness, their knowledge and attitude, their positive experience of caregiving, and how they perceived the help or support from other people. This information would help nurses to conduct in-depth assessment and develop proper interventions for the patients and family caregivers in order to improve the functional abilities of the family caregivers as well as the patients by enhancing family caregivers' skills to be more effective in caring for the patients and also for themselves. This study results could reinforce health personals to delivery suitable and adequate mental health services for family caregivers in community settings in Indonesia. The findings also contribute to nursing research by serving as an evidence-based findings regarding the predicting factors of Indonesian family caregivers' burden, and as a reference and baseline data for further research pertinent to family caregivers of patients with schizophrenia.

Limitation

One of limitations of this study is related to cross-sectional design since the burden of family caregivers are changed over time, therefore the data that collected on multiple times or longitudinal would be more fully depict the nature of variables. Another limitation is the setting of data collection. This study obtained data from only one hospital. Although the hospital is the largest mental hospital located in Surabaya, Indonesia, it may limit generalization of the study findings.

Recommendations for future study

Future research should be in longitudinal design in order to explore the relationships among variables, and/or experimental design to examine the effectiveness of intervention aimed at reducing the family caregivers' burden as the consequences of caring for patients with schizophrenia. More than one setting of data collection is also recommended in order to have better generalization of the findings. In addition, in consideration of assessing family caregivers' burden, this study relied on subjective report by the family caregivers themselves, using other sources of investigation to explore burden is also recommended.

Conclusion

Family caregivers of patients with schizophrenia in Surabaya, Indonesia perceived burden in caring the schizophrenics at home (77.50%). Their burden were predicted by their perceived severity of patients' illness, attitude towards schizophrenia, and perceived social support with explanation 51% of the variance ($R^2 = .51$, $F = 24.07$, $p < .001$). Understanding the characteristics of and the way of care provided by the family caregivers of patients with schizophrenia should not be viewed as an attempt to reflect negative views among family caregivers, but rather provide objective information that is helpful in determining how to alleviate distress among the family caregivers as well as how to improve both the patients' functional abilities and the family caregivers' resources, particularly among those family caregivers who have greater need of support or have limited access to health care services.

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