Reprint of this article is prohibited without consent from the publisher.

ABSTRACT
Shifting from hospital-based care to community-based care involves the family as advanced caregivers to the patients with Schizophrenia at their home. Yet, they have need of knowledge and skill in caring the patients as well as support from health care providers and society. Family caregivers should be well-prepared to take care the patients with Schizophrenia at home since it gets some negative consequences on their physical, psychological, social, and financial. Nurse needs to assess the factors that might influence the family caregivers to felling burden, and include the family caregivers into nursing care in which would not only to improve the patients’ mental health but the family caregivers as well.

Keywords: Schizophrenia, family caregivers, factors of burden

INTRODUCTION
Schizophrenia is a complex disorder with an extremely varied presentation of symptoms. The World Health Organization (WHO) estimated 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. Data from the Health Ministry Indonesia stated there were 18,800 schizophrenic patients in Indonesia that were confined in 2011.

The essential in caring the patient is maintaining the wellness while encouraging the self-care ability on the patient and the family caregiver. Patients with Schizophrenia have long duration of illness, and extent disabilities both of daily functions and social interactions, therefore their family have to look after them to prevent the relapse episode. In Indonesia, most of the caregivers of patients with Schizophrenia are their own family. In order to help the family caregivers in caring for the patients at home, nurse need to understand the burden they may feel during caring the patients. This paper aims to provide the insight of knowledge about...
the burden of family caregiver, its related factor, and the assessment of the burden.

**DEFINITION OF FAMILY CAREGIVER BURDEN**

*Definition of family caregiver.* Caregivers or carers are people who provide care to family members, life partners or friends whose sick, elderly or disabled, without paid.\(^4\) Family caregiver is someone who is responsible for the physical, emotional, and financial supports of the family member who unable to care for him/herself due to illness, injury or disability.\(^5\)

*Definition of burden.* From literature review, burden has been defined since 1966. Grad and Sainsbury stated that burden is any negative impact to the family caused by caring for ill member.\(^6\) Hoenig and Hamilton was divide burden into objective and subjective.\(^7\) Objective burden as an event or activity associated with negative caregiving experiences, whereas subjective burden referred to feeling that appeared in the caregiver caused by the fulfillment caregiving of the caregiving function. From Chan, objective burden relates to the patient's symptoms, behavior, and sociodemographic characteristics; and subjective burden is the mental health and subjective distress among family members.\(^8\) Conceptual clarity is elusive here, however. Rose stated the conceptual of burden is difficult to find, and what has been described as a "burden" is more accurately described as a "stressor".\(^9\)

*Definition of family caregiver burden.* is the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their ill relative. They viewed burden as a product subjective perception of caregiver when caring for impaired person.\(^10\) The term caregiver burden used to express any negative consequences of caring for patients with mental disorders by family caregivers.\(^11\) Recently, the area of caregiving burden has been widened to involve the physical, psychological, social, and financial aspects experienced by family caregivers. From World Federation of Mental Health,\(^4\) burden experienced by family refers to affect for those who close to the person with mental health problems.

*Development Knowledge of Family Caregiver Burden.* In the past, patients with schizophrenia have been cared focus only in hospital; in these days, caring for the patients would be performed by their families at home.\(^12\) Shifting from hospital-based care to community-based care has identified the family as the caregiver. In Western countries, the studies showed about 25%-50% of discharged patients with schizophrenia live and need advanced caring from their families.\(^8\) Likewise, in Indonesia, almost all discharged patients with schizophrenia will return to their own homes in the communities.

The shift from hospital-based care to community-based care requires the gather role of health care providers, family of patient, the public at large, and policy marker function as well. The essential in caring the patients is maintain the wellness while encourage the self-care abilities on patients, family, and community. Some caregivers report the duties of family caregiver are hardly responsibilites that affect on their daily lives and include lack of household financial, disrupt of either work or leisure activites, and also their both of physical and mental health status. For another, they enjoy the time they spend with their spouse, the chance to grow closer to the care receiver, the intimacy of personal care, and the sense of being needed and appreciated.\(^13\) It represents that some family caregivers cope the burden better than others.

The concern of family caregiving brings two ways of safety issues in nurse
views. First, caregivers referred to as “secondary patients”. They need protection and guidance in terms of the high risk for injury and adverse events in caring for the patients at home. Second, family caregivers are “unpaid providers”. They need any information to learn how perform the caregiver role in order to properly caring for the patients. Mental health nurse have the ideal opportunity in assisting the families who living with schizophrenic patients to develop more effective coping behaviors, communication skills, and social support systems.

**FACTORS RELATED TO FAMILY CAREGIVER BURDEN**

Burden of family caregivers leads to negative consequences not only for themselves but also for patients, other family members, and health care system. Numerous studies conducted to examine the factors associated with family caregivers’ burden on vary dimensions. In this review, the factors related to family caregiver burden would be classified into internal factors and external factors.

**Internal Factors**

Internal factors are some aspects of the family caregivers’ characteristics which affect the burden.

1. Socio-demographic (gender, age, religion, cultural, marital status, education, occupation, income, relationship with the patient, number of family members)

   **Gender**

   Mostly family caregiver was being female. Female caregivers had significantly higher burden scores on the “emotional strain” and “financial/physical strain domains. The findings suggest that female caregivers rather than male caregivers had less positive coping with symptoms of their ill relatives.

   **Age**

   There was a significant difference between the caregivers’ age groups with those aged 40 or above scored significant higher levels of burden. On other study, the younger caregivers had significantly higher score on caregiver burden. However, age of caregiver has little influence on caregiving burden. No age-specific effect of either the patient's age or the caregiver's age on the amount of burden of caregiving.

   **Religion**

   The results of the Chien study indicated that the caregivers with traditional Chinese religions such as Confucianism and Buddhism reported higher levels of burden than those who were Christians or Catholics. The another study which data collected by in-depth interviews and observation involving 17 caregivers in Thailand, found evidence that the Thai health care system has made little provision for caregiver burden.

   **Cultural**

   The relationship between culture and burden affected by other intervening factors such as socioeconomic status or the sense of obligation and responsibility. The aim of study from Caqueo-Urízar and colleagues was to describe the levels of burden in Aymaras caregivers (aborigines who are located on the highlands of Northen Chile) from schizophrenic patients, and the finding was significant differences between Aymara and non-Aymara families in the total burden score and the incompetence subscale.

   **Marital status**

   Single (unmarried) caregivers experienced more tension. Higher caregiver burden by the single caregivers may be understood from the perspective that most of these would be either widowed parents or unmarried siblings and hence having lower social support and thereby perceive more burden.

   **Education**

   In the context of caring for an adult with schizophrenia, low level of education...
means that fewer resources are available to caregivers who are faced with challenging behaviours and other caregiver-related stressors. Lower educational attainment by the caregiver was predictive of higher burden scores in various domains.

**Occupation**

Employed caregivers had significantly higher burden scores on the “self-criticism” and “time/dependence” domains. On the other hand, unemployed caregivers reported higher levels of burden on the “financial/physical strain” domain.

**Income**

Studies found caregivers’ burden score was negatively correlated with their household income. The mean burden scores were significantly higher among caregivers who had lower monthly household income. Same result also on Kate and colleagues’ study, was significantly higher score in caregiver burden was associated with lower income. A high burden score was associated with rural setting and poorer economic circumstances of the family.

**Relationship with the patient**

Caregivers who were parents or spouses of the patients had significantly higher burden scores on the “uncertainty” domain. Parents had significantly lower scores on all the domains (except tension domain) of caregiver burden compared to spouses. Relationship between parent and patient had a direct impact on the burden, means that caregivers who were parents experienced higher perception of burden than as other relationships.

**Number of family member**

Caregivers of patients living in households with fewer numbers of people had higher burden scores on the “financial/physical strain” and “time/dependence” domains. The number of family members was significant in reducing the demands for care and involvement of caregiving and, thus, lower the caregiving burden.

**2. Duration of caring the patient**

The amount of daily contacts with the patients predicted the burden of family caregivers. The higher the number of hours spent with the patient, the greater the degree of perceived burden by the caregiver. Due to the sociocultural sense of obligation to care for sick family members oneself (rather than delegating care), caregivers who spend lesser time with the patient may be vulnerable to self-reproach.

**3. Perceived social support**

Social support is one of predictors in family caregivers’ burden. Poor social support was predictive of higher burden scores on the “financial/physical strain”, “emotional strain”, and “time/dependence” domains. Chien and colleagues explored the effect of the mutual support group intervention on family burden. The findings demonstrate that the efforts by mental health workers to establish and support mutual support groups for family caregivers of patients with schizophrenia is likely to lead to major benefits for family carers and indirect benefits for their relatives with schizophrenia associated with living in a more supportive and harmonious family environment.

**4. Coping strategies**

There are many significant findings between the burden and the coping strategies in caregivers when they cared for their relatives with schizophrenia. Caregivers’ poor management styles lead to frequent conflicts with their sick relatives, resulting in distress and suffering. Tension domain of caregiver burden had significant positive correlation with caregiver’s coping strategies of avoidance, collusion, coercion and total coping checklist score. The passive oriented or emotion-focused coping strategies (resignation, avoidance) have
less impact on burden than active oriented or problem-focused strategies.26
5. Quality of life
Evidence shows that caregivers experience negative changes in their quality of life. Decreased quality of life may be associated with caregivers' burden, lack of social support, course of the disease and family relationships problems. In addition, in developing countries, quality of life is affected by caregivers' economic burden.12 Tension domain of caregivers’ burden had significant negative correlation with all the domains of caregivers’ quality of life.18
6. Physical status
According to Bull (as cited in Chou10), caregivers in poor health were consistently found to have significantly higher burden levels than those in good health. Relationships between burden and health can change over time as the situation becomes more burdensome. The high levels of burden might relate to the poor health condition of older caregivers, which has been consistently found to result in high burden level and subsequently increases the physical and psychological demands of caregiving.11
7. Knowledge about Schizophrenia
If caregivers do not have adequate knowledge and support, they might not be able to take up the responsibilities of taking care of the ill persons.8 The relationship between the caregivers’ knowledge about schizophrenia and their burden was negatively correlated through the family coping with the patients’ symptoms. It means the lesser knowledge caregivers have about schizophrenia, the poorer coping they used, the higher burden they perceived.17

External Factors
External factors are stimuli of burden that originate in the outside of family caregivers’ areas.
1. Socio-demographic of patient (age, duration of illness)
Family burden was unaffected by patient’s previous admissions, age of illness onset and the duration of illness. All these variables are related to patient’s psychiatric history and may not have an accumulative effect on the caregiver’s well-being.23 In study from Othman and Salleh19 found that no age-specific effect of either the patient's age or the caregiver's age on the amount of burden of caregiving. However, on another study found that the correlates of family caregiver burden with patient’s age was significant negative as well as illness duration that 11 or more years since illness onset, it means young patient age was related to increased family caregiver burden.27 One of predictor factor that had higher caregiver burden scores is longer duration of illness of patient and correlated with higher scores on the “uncertainty” domain.16
2. Severity of patient illness
The symptoms of schizophrenia on patient would impact to the burden of family caregiver as well as the severity of patient illness. Higher Positive and Negative Syndrome Scale (PANSS) scores predicted higher caregiver burden scores in several domains.16 There is a positive correlation between the total amount of symptomatic behaviour and the different burden variables. The more symptomatic behaviour the family member reported, the more efforts family members had made, the more extra work they had had, the worse the mood had been at home, the more emotionally burdened they had felt, the more often other family members had left home or threatened to do so and the more inconvenience had been experienced.28 Patient’s global psychosocial functioning, incorporating severity of psychotic illness, was also found to be positively associated with perceived burden. Impaired psychosocial
functioning (low Global Assessment Scale score) of patient have a direct negative impact on both objective and subjective dimensions of family burden (high Family Burden Scale score). The strong correlation between social problem behaviour of patient score with total objective and subjective family caregiver burden also found on Othman and Salleh study. The correlation between symptom severity and caregiver burden underscores the need to ensure effective treatment for patients with schizophrenia as a vital step in addressing caregiver burden.

3. Mental health service and its utilization

Roick et al. (as cited on Rafiyah) conducted a study on 333 Germany caregivers and 170 Britain caregivers with schizophrenia to compare burden experienced by caregivers caring for schizophrenia person in those countries. Results showed that Britain caregiver reported more burden than Germany caregiver. The major cause of difference of burden was differences in the provision of mental health service. Germany has on average 7.5 psychiatric beds per 10,000 populations, whereas Britain has only 5.8. Therefore, the unmet needs for care (covering the dimension basic living condition, health care, functioning and service) seem to be higher among the people with schizophrenia in Britain.

ASSESSMENT OF BURDEN

Family caregiver burden were viewed widely on the physical, psychological, or emotional, social and financial problem experienced by family caregiver. Therefore, some scales are required to measure different aspect or single issues in terms to answer the research questions on study. Numerous questionnaires have been developed to quantify the largely subjective domain of caregiver burden, but the Zarit Burden Interview is the most widely referenced scale in studies of caregiver burden. However, many researchers use another instruments to assess the family caregiver burden. Some of instruments include Family Burden Interview Schedule, Family Burden Scale, Burden Scale, Burden Assessment Scale, and Caregiver Burden Scale.

The Zarit Burden Interview explores the caregiver burden on the negative physical, mental, social, and economic impacts of caregiving on the life of the caregiver. This instruments was constructed by Zarit et al to assess caregiver burden in dementia, but it has also shown satisfactory psychometric properties in assessing caregiver burden in schizophrenia. The Family Burden Interview Schedule is a 25-item semi-structured interview schedule designed by Pai and Kapur, consists of objective and subjective dimensions of burden measurement and also includes six domains of perceived burden, including effects on family finance, routine, leisure, interaction, physical health, and mental health. The Burden Assessment Scale designed by Reinhard and colleagues, measured burden objectively and subjectively. The objective burden items were the visual behavioural effects of care giving in several areas, including financial problems, limitations on personal activity, household disruption and social interactions; and subjective burden items referred to the feelings, attitudes and emotions expressed by the caregivers and included area of shame, stigma, guilt, resentment, grief and worry.

CONCLUSION

Many studies conducted to explore the burden of family caregivers of patient with schizophrenia and its relationship with other variables. The studies found that their characteristic of family caregivers, include their perceived social
support, coping strategies, and knowledge about the disease, as their internal factors affect their burden of caring the Schizophrenic patient as well as with their external factors such as characteristic of patient include severity of illness and mental health service and its utilization. However, the knowledge of family caregiver about caring the Schizophrenia patient is not identify yet. On the future study may examine this factor related to family caregiver burden.

There are three parties to the issue of burden of care: the patient, in terms of the impact of the schizophrenia disorder itself, its symptom profile and long-term course; the caregivers and their ability to cope with the challenges and frustrations; and equally significant, the community and the context caregiving takes place. However, the concern of family caregiving on patients with schizophrenia should not be seen on negative consequences only. Nurse needs to help the family caregivers in preparing themselves to perform the role while preventing them in perceive burden. This underlying could expand the effectiveness of nursing interventions through family role as caregiver of patient, thus decrease the number of relapse period of patient with Schizophrenia.

REFERENCES

of Life Outcomes, 7(84). 1-5. doi:10.1186/1477-7525-7-84


Cite this article as: Annisa F. Burden of Family Caregiver. Belitung Nursing Journal 2016;2(1):10-18.