

## **Review: Burden on Family Caregivers Caring for Patients with Schizophrenia and Its Related Factors**

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**Background:** Family caregiver is the most important person who cares for patient with schizophrenia. However when care is provided for long time, he/she may experiences the burden.

**Purpose:** The purpose was to review concept and factors related to burden on family caregivers caring for patients with schizophrenia.

**Method:** A literatures were searched from databases: Pubmed, CINAHL, and Science Direct. Key words used to retrieve literature include caregiver burden and schizophrenia. Searching was limited in English language, full text, and the year of publication from 2000 to 2009 was used.

**Results:** Twenty two studies were reviewed in this paper. The result showed that the caregivers caring for patients with schizophrenia experience burden. Burden was defined as a negative impact of caring for the impaired person experienced by caregiver on their activity (objective burden) or feeling (subjective burden) that involves emotional, physical health, social life, and financial status. Factors related to burden on family caregiver were grouped into: 1) caregiver's factors included age, gender, educational level, income, health status, and spent time per day, knowledge of schizophrenia, culture, and coping; 2) patient's factors included age, clinical symptoms, and disability in daily life; 3) environmental factors included mental health service and social support.

**Conclusion:** Definition of burden have quite same meaning and mostly factors focus on the patient's symptoms, demographic factors of caregiver, and time spent per day. Most of studies cannot be generalized due to small sample used in the study and that too conducted in western countries. For further research, the correlation between burden and resources of family caregiver should be investigated particularly in eastern country.

**Key words:** burden on family caregiver, caring, schizophrenia.

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## **Background**

The number of people with schizophrenia in the world, particularly in developing countries, are increasing. Approximately 1 out of 100 people in the world suffer from schizophrenia (Mental Health Research Association, 2006). In Indonesia, the prevalence of schizophrenia was reported to be approximately 2 million from 200 million populations (Setiadi, 2006).

Schizophrenia is concerned as a chronic and severe mental illness. The patients with schizophrenia may experience impairment in thought process which influences their behavior. Generally, their behaviors are odd and sometimes harmful for themselves, such as committing suicide (Pompili et al., 2009) or violence to others (Vivera, Hubbard, Vesely, & Papezova, 2005). In addition, the disease may relapse during treatment and recovery (Bostrom & Boyd, 2005). Therefore, patients with schizophrenia are frequently hospitalized and usually need long term care and treatment in order to reduce negative impacts.

Family caregiver is the most important person who cares for the person with schizophrenia. Approximately 60 to 85% of the disabled or impaired people are cared by the family caregiver (Clement, Gerber, & McGuire, 1995). She/he usually help patient in performing their daily activities such as, bathing, eating, cooking, dressing; taking drug, and checking up. However when care is provided for longer time, particularly for patients with schizophrenia, family caregiver can experience burden that leads to negative consequences (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Grandon, Jenaro, & Lemos, 2008; Roick et al., 2007; Shu-Ying, Chiao-Li, Yi-Ching, For-Wey, & Chun-Jen, 2008).

Burden of family caregivers leads to negative consequences not only for themselves but also for patients, other family members, and health care system. For caregivers, burden negatively affects caregiver's physical, emotional, and economic status (Caqueo-Urizar, Gutierrez-Maldonado, & Miranda-Castilo, 2009). Furthermore, their negative quality of life have impacted on poor caring, mistreatment or behaving violently to the patients which can cause patients relapse (Bostrom & Boyd, 2005; Havens, 1999). Burden of family caregivers also causes family conflict and financial problem in individual, family, and health care system. However these impacts might be different among caregivers, as level of burden is related to various factors. Therefore, this review paper will include theoretical foundation of burden, in particular when caring for persons with schizophrenia, and its related factors.

## **Objectives**

The objectives of this study are to synthesize research findings about caregiver burden including concept of burden and factors related to burden on family caregiver caring for patients with schizophrenia.

## **Methods**

The relevant literatures were searched from databases. The databases used to carry out the literature were: Pubmed, CINAHL, and Science Direct. Key words used to retrieve sources were: caregiver burden, schizophrenia. Searching was limited to English language, full text, and the year of publication was from 2000 to 2009. Before the articles were retrieved, the title and abstract were read to determinant relevant literature. History search was also done for relevant citations. All the relevant citations were retrieved. After got relevant articles, all full text article identified were download and printed, then those are extracted for significant content. Twenty-two articles were retrieved. Each article was briefly read to identify main idea/content and usefulness relevant to this current topic. Furthermore, each article was organized and critiqued. Finally, all those bibliography were collected and written using APA format.

## **Results**

### *Burden on family caregivers caring for patients with schizophrenia*

Many studies were developed to measure burden on family caregivers caring for patients with schizophrenia. From those studies, result showed that caregiver caring for patients with schizophrenia experience burden (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Grandon, Jenaro, & Lemos, 2008; Roick, et al. 2007; Shu-Ying, For-Wey, Chiao-Li, & Chun-Jen, 2008).

From literature review, burden has been defined since 1966. Grad and Sainsbury (1966) stated that burden is any negative impact to the family caused by caring for ill member. Furthermore, burden was dichotomized into objective burden and subjective burden (Hoenig & Hamilton, 1966). Hoenig and Hamilton defined 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.

Zarit, Reever, & Bach-Peterson (as cited in Chou, 2000) defined caregiver burden as 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.

Platt (1985) stated that burden consists of objective and subjective burden. Objective burden involves disruption to family/household life that is potentially verifiable and observable. However subjective burden is feeling that the caregiver share to others regarding the caregiving for impaired person. Montgomery, Gonyea, and Hooyman (1985) also defined burden as an objective burden and subjective burden. They stated that subjective burden is caused by emotional reaction impacted by caregiving experience, while objective burden is the disruption or change in many aspect of caregiver's household/life. On the contrary, Braitwaite (1992) argued that the distinction between experience and the distress is not clear. Braitwaite defined burden as a caregiver's distress arising from dealing with care receivers' physical dependence, and mental incapacity.

Burden is not viewed as multidimensional construct even though in the past burden was viewed as a subjective or objective dichotomy. The term caregiver burden is now more widely used to the physical, psychological, or emotional, social and financial problem that are experienced by family members caring for a chronically ill, or impaired family member (Chow, 2000).

In conclusion, mostly caregiver who takes care for member with schizophrenia feels burden. Burden can be defined as negative impact experienced by caregiver while caring for the impaired person. Impact can be on household (objective burden) or on feeling (subjective burden).

#### *Factors related to burden of family caregiver*

Based on literature review, caregiver burden are influenced by several factors. Those factors are grouped into three categories: 1) caregiver factors; 2) patient factors; and 3) environment factors.

##### *1. Caregiver's factors*

*Age.* Study by Juvang, Lambert, and Lambert (2007) investigated relationship between demographic characteristic of caregiver's burden when providing care for a member with schizophrenia in China. Purposive sampling technique was used to recruit 96 subjects from 3 hospitals. Finding showed that the age of caregiver was positive correlated to burden

of caregiver. When caregiver becomes older, they are worried about who will take care of their ill family member in the future. Older caregiver also cannot provide care well to the ill member. In addition, younger age of caregiver which has to provide caring for ill member, result in increasing sense of life is worth living (Fujino & Okamura, 2009).

*Gender.* Men and women may experience burden differently. Schneider, Steele, Cadell, and Hemsworth (2010) conducted study in Canada to determine gender difference in 273 parents caring for children with life-timing illness. Results showed that there was a significant difference in gender in term of their burden. Women had higher score in caregiving, depression and burden compared with men. It can be explained by social gender role and hormonal factors. Related to social role, women were predominant in caregiving, in other word women spent more time in caregiving than men. In terms of hormonal, oxytocin hormone also contributed in distress and women's need to nurture. When caring for patient with schizophrenia, women experienced distress, her oxytocin level and nurture need will increase, but in the same time she had to pay more attention to the patient. Therefore women felt more burden than men.

*Educational level.* Juvang, Lambert, and Lambert (2007) investigated relationship between demographic characteristic of caregiver and family caregiver's burden when providing care for a member with schizophrenia in China. They also predicted the best predictor of caregiver's burden. Findings showed that the education level has negative correlation with caregiver's burden. It was assumed that higher the level of education, higher the salary will be. High salary would decrease financial problem related to providing care for ill family member. Level education of the caregiver also tends to have more knowledge to deal with the stressful event. Therefore caregiver's education level influences burden of the caregiver .

*Income status.* Income may have influence on the burden of the caregiver. Andren and Elmstahl (2006) conducted a study in Sweden to examine relationship between income, subjective health and caregiver's burden in people with dementia. Finding showed that low income was associated with a higher degree of burden on the caregivers. Lower income was a stressor that influence stress feeling during providing care for ill family member. Beside caregivers providing care for ill member, they also had to solve financial problem and find out source of money.

*Health status.* The best predictor of caregiver's burden is the health status (Mengdan, Lambert, & Lambert, 2007) and self perception toward health condition (Shu-Ying, Chiao-Li,

Yi-Ching, For-Wey, & Chun-Jen, 2008). Caregiver with good health status experienced the lower levels of subjective stress burden. In term of psychological health status, Fujino and Okamura (2009) conducted cross sectional study in Japan to identify factors affecting the sense of burden felt by 30 family members caring for mental illness. Result showed that “sense of life is worth living” was associated with burden felt by caregiver. “Sense of life is worth living” was associated with psychological impact from caring mental illness member.

*Time spent per day.* Time spent for caregiving per day is related to burden. Chii, Hsing-Yi, Pin, and Hsiu (2009) studied relationship between received social support and caregiver burden in 315 caregivers in Taiwan. One of sub-variable which received social support was caregiving circumstances. Result showed that there was a significant positive correlation between hours of care per day and caregiver burden. Higher the number of hours spent on providing cares per day, greater is the caregiver’s burden. Other study conducted by Juvang, Lambert, and Lambert (2007) showed that there was a positive correlation between the amounts of time that caregiver spent with their family member and objective burden faced by them. More the time spent with ill family member, more will be the objective burden felt by the caregiver. When caregiver spent more time with their ill family member, they may have less time for themselves. Finally, it affects on the burden of caregiver in doing daily activity.

*Knowledge of schizophrenia.* According to study of Sefasi, Crumlish, Samalani, Kinsella, and O’Callaghan (2008) in Malawi, it was reported that knowledge influences burden. However, their finding was contradictory with their hypothesis. They found that more the knowledge possessed by the caregiver, more is the burden on caregiver. They explained that it may be related to the culture. In Malawian culture a person who had higher knowledge, they believe in curing of ill member medically than traditionally. When they believe to cure the illness medically, they thought the disease can be cured and caregivers were responsible in caregiving and thus it might have an impact on burden.

*Cultural.* Related to the racial, ethnic, and culture, Janevic and Connell (2001) had conducted research review on 21 studies and 18 samples which include: African Americans, Chinese, Chinese Americans, Koreans, Koreans Americans, Latinos, Whites, and residents of 14 European Union Countries. The study purposes of the study were to compare two or more racial, ethnic, national, or cultural groups on aspects of the dementia caregiving experience. The result showed that mostly white caregivers were spouses and they were more depressed and stressful than African American. Differences in the coping ability and social

support suggested having an influencing effect on their experience. In addition, minority groups might get little more support than Whites. Spurlock (2005) conducted a study about relationship between spiritual well being and caregiver burden in 148 alzheimer's caregivers (71 African American and 77 Caucasians). The result showed that there was significant difference in spiritual well being and burden between African American and Caucasian. Caucasian tends to be more stressful in caregiving than African American. African American used prayer as a coping strategies, but Caucasian more like seeks professional assistance. Their religious practice showed that how their approach is used to provide care that was influenced by ethnic background.

*Subjective perception.* In a similar situation burden can affects caregiver seriously but not others. Romeis (as cited in Chou, 2000) reported that the evaluation of burden was based on how the caregivers interpret the demand of ill person and how the caregivers can organize and use available resources. Therefore the concept of burden should involve the subjective perception of caregivers. In other word, burden was processed through caregiver's subjective perception.

*Coping.* Mengdan, Lambert, and Lambert (2007) conducted study in China to investigate relationship between parent's burden and coping on parents having a child with mental illness. Results showed that the parents who maintaining functional family life, are optimistic, preserving social support and self esteem, and understanding medical condition experienced fewer burdens. Other study found that a reduction of family burden was found over time among relatives who adopted less emotion-focused coping strategies (Magliano et al., 2000).

## *2. Patient factors*

*Age.* Study by Juvang, Lambert, and Lambert (2007) in China on 96 caregivers showed there was correlation between patient age and subjective stress burden and subjective demand burden. Younger patients with schizophrenia had not been able to take care of themselves, and they might be in early stage of disease. Therefore caregiver feel burden when they take care the younger patient in long time period. Other study in Africa also showed that caregivers who had patient with schizophrenia also displayed a very high degree of burden, especially while taking care of younger patients (Caquezo-Urizar & Gutierrez-Maldonado, 2006). The younger patients may require more caregiving that have consequences on more caregiver spent time.

*Clinical symptoms.* Clinical symptoms and have an influence on caregiver's burden. Several studies found that clinical symptoms were predictor of caregiver's burden (Perlick et al., 2006; Roick, Heider, Toumami, & Angermeyer, 2006). Positive symptoms can predict caregiver's burden more than the negative symptom (Grandon, Jenaro, & Lemos, 2008; Tang, Leung, & Lam, 2008). Factor affecting burden of caregiver is the severity of patient symptoms (Shu-Ying, Chiao-Li; Ying-Ching, For-Wey, & Chun-Jen, 2008). Symptoms caused by disease were associated with impaired health function which influence the patient's behavior and capability to carry out daily activity. These result in patient's dependence on caregiver. Moreover in case of severe disease, caregiver may feel burden in caregiving due to characteristic of illness of the patient and disease which need long term care.

*Disability in daily life.* Fujino and Okamura (2009) conducted cross sectional study in Japan to identify factors that affects the sense of burden felt by family member while caring for mental illness. Data were gathered from 30 patients and 30 family caregivers from rural psychiatric hospital. Results showed that patient's disability in daily life or community function was associated with burden on caregiver. The patients' impairment of social function was associated to severity of illness, such as disturbance n patient's behavior and long time illness that result in dependency of patients on caregiver to carry out their daily activities. Thus, it results in limiting time, energy and attention of caregiver.

### 3. *Environment factors*

*Mental health service and its utilization.* Roick et al. (2007) 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. Study conducted by Roick, Heider, Toumi, and Angermeyer (2006) proved that the utilization of community health service decreases the caregiver's burden. Schizophrenia patients who visited community health service routinely showed significant increase in the health function. Patients with increasing health function would increase their capability in



carrying out their daily activities. Therefore, increasing health function is related to decreasing caregiver's burden.

*Social support.* Chii, Hsing-Yi, Pin, and Hsiu (2009) conducted a study on 301 caregivers in Taiwan to examine correlation between caregiver's burdens and perceived and received social support. The result showed that the perceived social support, and perceived family function had a negative correlation with burden of caregiver. Better family function had an impacted on better adaptation that is associated with effective coping. Utilization of formal support received had a positive correlation with burden. Caregiver's burden increased when informal support could not meet caregiver's need. Supporters could reduce the burden if they fulfill unmet need of caregiver. Magliano et al. (2000) also found that a reduction of family burden over a time was found among relatives who received more practical support from their social network.

In conclusion many factors related to burden on caregiver's caring for patient with schizophrenia person. These factors include caregiver factors, patient factors, and environment factors as summarized in table 1:

Table 1

*Factors Related to Burden on Family Caregivers Caring for Patients with Schizophrenia*

Classification	Factors
Caregiver factors	Age, gender, educational level, income status, health status, time spent per day, knowledge of schizophrenia, cultural, subjective perception, and coping.
Patient factors	Age, clinical symptom, and disability in daily life.
Environment factors	Mental health services and its utilization, and social support.

## **Discussion**

Result showed that mostly caregiver who takes care for patient with schizophrenia feels burden (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Grandon, Jenaro, & Lemos, 2008; Roick, et al. 2007; Shu-Ying, For-Wey, Chiao-Li, & Chun-Jen, 2008). Gallagher and Mechanic (1996) conducted a study to compares health outcomes of someone living with mentally ill (N=776) and someone not living with mentally ill (N=716). They examined the effect of living with mentally ill on three dimension of health and functioning, namely, self reported physical health, service utilization, and activity limitation. The result study found

that respondent living with mentally ill person reported poorer physical health, more physician visits, more some activities limitation than someone who did not live with mentally ill person.

The review also showed several definitions of burden. Burden can be defined as negative impact faced by caregiver while caring an impaired person. Impact can be on household (objective burden) or on feeling (subjective burden). However burden is known to be a physical, psychological, or emotional, social and financial problem that experienced by family members caring for a chronically ill, or impaired family member (Chou, 2000).

Based on literature, there are several factors related to burden. However, these factors focuses on patient's symptoms; demographic factors of caregiver, such as gender, economic status, employment; and time spent per day. It may be due to the fact that schizophrenia is concerned as a chronic and severe mental illness. The patients with schizophrenia may experience impairment in thinking process that influences their behavior. Generally, their behaviors are odd and sometimes harmful for themselves, such as committing suicide (Pompili et al., 2009) or violence to others (Vivera, Hubbard, Vesely, & Papezova, 2005). In addition, the disease may relapse during the treatment and recovery (Bostrom & Boyd, 2005). Therefore, patients with schizophrenia are frequently hospitalized and usually need long term care and treatment. Even though there are some factors related to burden in caring for person with schizophrenia, but the most important is how the caregiver is able to use coping technique and utilize the social support (Roick, Heider, Toumami, & Angermeyer, 2006). These two factors can act as a buffer for stressor (Kaptein & Weinman, 2004). Furthermore, coping strategies and received more practical support from their social network proved a reduction of family burden over time (Magliano et al., 2000).

The other finding showed that most of the studies were conducted in western countries. Furthermore, no study was conducted in Indonesia. It is perhap due to the lack of a researcher or lack of publication.

## **Conclusions**

In summary, most of the definitions of burden have same meaning, namely, difficulties faced by caregiver while caring for ill member involving physical, psychological, social and financial factors. Factors related to burden can be from caregiver's characteristics, patients, and environment. However these are more focused on patient's symptoms, demographic factors of caregiver, and time spent per day. Most of studies cannot be

generalized due to small sample and most of the studies have been conducted in western countries.

## **Recommendations**

The findings of this review have implication for nursing practice and research. In term nursing practice, it will provide basic information for nurses while rendering appropriate nursing care for caregiver to decrease burden. For further research, studies may investigate caregiver resources on decreasing burden, such as coping and social support especially in the eastern countries.

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