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NAME: Miss Karina Megasari Winahyu

THIS THESIS HAS BEEN ACCEPTED BY

THESIS ADVISOR

(Miss Monthana Hemchayat, R.N., Ph.D.)

THESIS CO-ADVISOR

(Miss Sukjai Charoensuk, R.N., Ph.D.)

GRADUATE COMMITTEE CHAIRMAN

(Miss Monthana Hemchayat, R.N., Ph.D.)

APPROVED BY THE GRADUATE SCHOOL ON _____

DEAN

(Associate Professor Gunjana Theeragool, D.Agr.)

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THESIS

FACTORS INFLUENCING QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN INDONESIA

KARINA MEGASARI WINAHYU

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Providing prolonged care for patients with schizophrenia could be burdensome for the family caregivers, in turn affected their quality of life. The purpose of the study was to determine factors influencing quality of life (QoL) among family caregivers of patients with schizophrenia in Indonesia. The study was focused on quality of life consisted seven dimensions of the QoL. The model of three sets factors affected the QoL of caregivers of family members with mental illness was used to guide the study. The study was cross-sectional research design involving 137 family caregivers of patients with schizophrenia by using a purposive sampling technique to recruit the participants in the outpatient department of mental hospital, Jakarta, Indonesia. A standard multiple regression analysis was employed to estimate the effects of explanatory variables on the QoL.

The main results showed that the model explained 54.4 % of the variance in the QoL. The strongest factor influencing the QoL was perceived social support, followed by caregiver burden, and employment status. The results of this study suggest that maintaining low caregiver burden, encouraging the caregivers to obtain high social support, and prioritizing the employed caregivers need to be considered for improving the QoL of family caregivers.

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Student's signature Thesis Advisor's signature

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Karina Megasari Winahyu

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LIST OF ABBREVIATIONS

BAS	=	Burden Assessment Schedule
MSPSS	=	Multidimensional Scale of Peceived Social Support
S-CGQoL	=	Schizophrenia Caregiver Quality of Life
QoL	=	Quality of Life
WHO	=	World Health Organization

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FACTORS INFLUENCING QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN INDONESIA

INTRODUCTION

Mental illness is increasingly becoming an issue which has been damaged caused by the impact of the illness in many countries around the world. The World Mental Health Survey (2005) stated that mental illness was listed as one of the most burdensome diseases and the prevalence will rise over the next decade worldwide. According to Global Burden of Disease Study 2010, showed that mental disorder was a common cause of disability; moreover, schizophrenia was included as one of the leading causes of disability in the world (Murray *et al.*, 2012). Furthermore, the prevalence of mental illness such as Schizophrenia reached 26.3 million people in the world and 6.2 million in South-East Asia (WHO, 2008). Accordingly, 26 people over a million of people in the world have been suffering from schizophrenia and going through the difficulties caused by the illness.

In addition to the prevalence on a global level, the report of the Basic Health Survey (2013) showed that the prevalence of severe mental illness in Indonesia was 0.17% (Ministry of Health Republic of Indonesia, 2013). The prevalence showed that one to two people over thousands of people have been suffering from severe mental illness in Indonesia. Correlating with that, one of severe mental illness, for example, schizophrenia in Jakarta was 0.11%. Although the prevalence is lower than the prevalence in 2008 (2.03 %) (Department of Health Republic of Indonesia, 2008), the prevalence in Jakarta is still higher than the majority of provinces in Indonesia (Ministry of Health Republic of Indonesia, 2013). The significance of the mental illness has been given attention showed by an amount of previous studies about the impact of mental illness to the patients (Greenberg, 2006; Hwang *et al.*, 2009; Hayhurst *et al.*, 2012; Sigaudo *et al.*, 2014). Nevertheless, the impact to the quality of

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life of family caregivers while caring for their patients had not been given much attention and this should receive more consideration.

Mental illness encompasses a wide range of difficulties which included various signs and symptoms along with time-consuming treatments. In addition, the symptoms of mental illness are regarded as a mixture of irregular beliefs, feelings, behaviors and interactions with others (World Health Organization [WHO], 2013). According to Sadock and Sadock (2007), the severity of mental illness consisted from mild to moderate that needed fundamental support and social intervention, while for severe mental illness such as major depressive and psychotic disorder there was a need for mental health services in a hospital or community services. Schizophrenia is one of the most severe forms of mental illness. The prevalence of people with schizophrenia is higher than the incidence (WHO, 2013). Accordingly, a patient with schizophrenia needs long term care due to the chronicity of the disease.

Furthermore, schizophrenia as a severe mental illness has caused disability situations and has disturbed the capabilities of people with mental illness and in turn could have an effect on their families. Patients with schizophrenia are characterized by emotional and cognitive dysfunctions that could be a huge impact on their lives. According to WHO (2008) stated that mental illness was a frequent disorder that caused disability because mental illness could affect the capabilities of people who were in charge of the family or community activities. Since the onset of the illness is in the age of early adult, people who suffered with schizophrenia would have faced the difficulties to finish their education and to get a job. Consequently, the living skills of patients with schizophrenia will be dependent on their families. Moreover, schizophrenia is considered just as chronically severe as mental illness in that both needs long term care, which could be perceived as another financial burden related to the cost of treatment of their loved ones. As a result, mental illness can affect the lives of individuals and their families.

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The impact of schizophrenia is overwhelming caused by its cognitive and social dysfunction (Hooley, 2010; Sigaudo *et al.*, 2014); therefore, reducing the impact of schizophrenia is noteworthy. The shifting of health care from hospital-based care to community-based care forced families to take an important role in the caregiving task of the patients with schizophrenia. Moreover, the family could be contributing to the cost effectiveness of hospital-based care services. The previous studies showed that the cost of schizophrenia in hospitalization was higher for the unstable patients (Zeidler *et al.*, 2012) while the cost was also higher than community based-care services (Chisholm *et al.*, 2008).

Furthermore, along with the existence of the shifting in care, patients with schizophrenia, as part of a family unit, might need other people who could help them consider their current condition to adapt to live in the family within the community. In general, caregiver is a voluntary individual (spouse, colleagues, family members, friends, or neighbors) concerned with supporting others with activities of daily living and/or medical tasks (Family Caregiver Alliance, 2012). Therefore, the family assumed the role as the caregiver could be considered as one resource to promote the health of the patients in the family within the community. The previous study found that patients with schizophrenia living and having a close relationship with their families had achieved the highest score in terms of their quality of life (Greenberg *et al.*, 2006). On the other hand, caregiving activities for the patients with schizophrenia were experienced by family caregivers as stressful events that affected the quality of their lives (Foldemo *et al.*, 2005; Chou *et al.*, 2009). Therefore, the impact of caregiving to the family caregiver's QoL was important to further explored to promote both the family caregivers and the patients.

The caregiving process affected caregiver' lives, this could later be found to have a profound effect on their loved ones. For example, the study of Caseiro *et al.* (2012) suggested that the caregiving activities might affect to the continuity of care of patients with. However, the caregiving situation, as a stressful activity, pushed the caregivers to go through economic problems, enjoyed less time for socialization and

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caused distressed feelings (Leimkuhler & Wiesheu, 2011). Moreover, caregivers of patients with schizophrenia had declining health conditions (Urizar *et al*., 2009) and one-third of the caregivers showed signs of psychological morbidity caused by caregiving (Moller *et al.*, 2009; Kate *et al.*, 2013). Consequently, the family caregivers reported the low score in their QoL (Weimand *et al.,* 2010; Boyer *et al.,* Wong *et al.,* 2012). Moreover, a previous study found that the QoL of Caucasian family caregivers was higher than African-American family caregivers (Zauszniewski *et al.,* 2009). However, Boyer *et al.* (2012) suggested that the physical quality of life dimension of the caregivers from developing country showed significantly lower score than the caregivers from developed country. The differences between physical QoL dimensions in both countries could be associated with the provision of health and economic resources for the caregivers (Boyer *et al.,* 2012). Hence, studying the quality of life of the caregivers were essential to prevent the possible adverse effects from the caregiving.

Furthermore, family caregivers of patients with schizophrenia perceived their quality of life to be poorer than the general population (Foldemo *et al.*, 2005; Angermeyer *et al.,* 2006; Margetic *et al.*, 2011; Wong et al., 2012). In contrast, a previous study found that family caregivers of patients with schizophrenia had a significantly higher score in regards to their quality of life than the general population (Awadalla *et al.,* 2005). Interestingly, most of the studies regarding the quality of life of family caregivers of patients with schizophrenia were measured by using a generic instrument of quality of life (Foldemo *et al*., 2005; Li *et al*., 2007; Weimand *et al*., 2010; Boyer *et al*., 2012; Kate *et al*., 2013). Hence, this study attempted to assess the quality of life of family caregiver by using a disease-specific instrument, for example Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL) (Richieri *et al.,* 2011).

The quality of life of the family caregivers could be determined by a multitude of factors since the quality of life is a multi-dimensional concept. The quality of life is defined as an ‘‘individual's perception of their position in life in the context of the

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culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997). As a multi-dimensional concept, the quality of life consists of physical, social, psychological, and environmental domains. In addition, previous studies found that significant factors associated with the quality of life of family caregivers of patients with schizophrenia comprised demographic characteristics of patients and caregivers, symptoms of the patients, psychological morbidity of caregiver, satisfaction of health services, and sense of coherence (Chen *et al*., 2004; Weimand *et al.,* 2010; Urizar *et al.*, 2011; Mizuno *et al.,* 2012; Wong *et al.,* 2012; De-Regil *et al.,* 2013) .

Furthermore, a conceptual model with three sets of factors affecting the QoL of caregivers of family members with mental illness (Wong *et al.,* 2012*)* was adapted for the selection of the appropriate variables of the study. Since the quality of life is a multi-dimensional concept, previous studies found that significant factors associated with the quality of life of family caregivers of patients with schizophrenia consisted of three factors, including caregiving situation, caregiver factors, and environmental factors (Wong *et al.*, 2012). Previous studies found that the factors affecting QoL of the caregivers consisted of characteristics of caregivers, caregiver burden, perceived control of symptoms, and perceived social support (Awadalla *et al.,* 2005; Li *et al.,* 2007; Chou *et al.,* 2009; Weimand *et al.,* 2010; Zamzam *et al*., 2011; Purkayastha *et al*., Boyer *et al***.,** Wong *et al*., 2012; De-Regil *et al.,* 2013) would be proposed as factors influencing quality of life of caregivers of patients with schizophrenia.

The findings from previous studies related to the factors associated with the quality of life of family caregivers of patients with schizophrenia were inconsistent. Firstly, the characteristics of family caregivers were found to be a significant factor that contributed to the quality of life. For instance, some studies found that many of the caregivers' characteristics, such as age, gender, health status, level of education, employment status, family relationship, financial problems of the family, and a high number of care hour periods of being a caregiver were associated with their quality of life (Hsiao, 2010; Zamzam *et al.,* 2011; Boyer *et al.*, Wong *et al.,* 2012; Quah, 2013).

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On the other hand, inconsistent findings of previous studies showed that the characteristics of caregivers, including gender, level of education, and employment status showed no significantly different with general population and had no association with the quality of life of family caregivers of patients with schizophrenia (Foldemo *et al.,* Awadalla *et al.,* Maldonado *et al.,* 2005*;* Kate *et al.,* 2013).

Secondly, caregiver burden as a perception of the caregivers in relation to the impact of their activities was found to be associated with the quality of life of family caregivers. According to Hoenig and Hamilton (1966), burden was defined as care in usage and consisted of objective and subjective burden. Moreover, caregiver burden was found to be negatively correlated with the quality of life of caregivers (Foldemo *et al.*, 2005; Li *et al.*, 2007; Fan and Chen, 2009). In addition, family caregivers of patients with schizophrenia in Indonesia showed that 67.8 % of caregivers experienced the caregiver burden (Darwin *et al.*, 2013). The caregiver burden caused by caregiving situation could be related to the quality of life of caregivers. Some previous studies found that caregiver burden influenced the quality of life of family caregivers (Chou *et al.*, Fan and Chen, 2009). In addition to the effects to caregivers, quality of life of caregivers related to the caregiving activities might affect the continuity of care of patients with schizophrenia (Caseiro *et al.*, 2012). In contrast, the study of Kate *et al.* (2013) found that perceived caregiver burden was not associated with the quality of life of the family caregivers. Thus, the correlation between caregiver burden and quality of life of family caregiver need further explored since its significance for the caregivers and their loved one.

Thirdly, the perceived social support as a perception of individuals about the availability of the support was used to manage the caregiving situation and could have been the factor associated mostly with the quality of life of family caregivers of patients with schizophrenia. Even though social support was considered as a protective factor that could help to stay psychologically healthy in stressful life events, few studies explored the impacts of perceived social support to the health of family caregivers (Lee *et al.,* 2006) and the quality of life of family caregivers of

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schizophrenia (Chou *et al.*, 2009; Ochieng, 2011; Kate *et al.*, 2013). Previous studies suggested that perceived social support was associated with the quality of life of family caregivers of mental illness (Chou *et al.*, Urizar *et al.*, 2009; Ochieng, 2011). Conversely, the study of Kate *et al.* (2013) found that perceived social support was not correlated with the quality of life of family caregivers of patients with schizophrenia. Hence, the association between perceived social support and the quality of life remained unclear and need further exploration.

In conclusion, the caregiving process might bring huge impacts to the quality of life of the family caregivers. Due to various kinds of the findings of study, it might be caused by cultural differences in the setting of the study which mostly conducted in Western and Europe countries. Therefore, the results of previous studies might not be able to apply to all countries. Moreover, different constructs of the instruments that were used in the previous studies were not speficically measured for the quality of life of caregivers of patients with schizophrenia (Boyer *et al*., 2012; Kate *et al*., 2013). Thus, it seemed to be important to examine factors influencing the QoL by using instrument developed based on point of view of the caregivers and using a conceptual model purposed to assess the factors affecting QoL. The present study used a cross-sectional approach and was conducted in the outpatient department of Mental Hospital Dr. Soeharto Heerdjan, Jakarta. The findings of this study are expected to be used as the sources for intervention development for family caregivers of patients with schizophrenia in regard to the factors affecting to increase the quality of life of caregivers by organizing the significant factors of caregiver burden and perceived social support according to the particular characteristics of caregivers in Indonesia.

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OBJECTIVES

1. Overall Objective

The purpose of the study was to determine factors influencing quality of life among family caregivers of patients with schizophrenia in Indonesia.

2. Specific objectives

2.1 To examine the levels of caregiver burden, perceived social support, and quality of life among family caregivers of patients with schizophrenia in Indonesia

2.2 To estimate the effects of the characteristics of caregivers, including gender, level of education, period of being a caregiver, health status, and employment status, perceived control of symptoms, caregiver burden, and perceived social support on the quality of life among family caregivers of patients with schizophrenia in Indonesia

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LITERATURE REVIEW

The purpose of this literature review was to explain the information related to the study, which was consisted of five parts. The first part was focused on schizophrenia. The second part explained the quality of life of family caregivers. The third part explained factors influencing the quality of life. The fourth part explained the conceptual model that was adapted for the study and the conceptual framework of this study. Finally, the fifth part explained the definition of terms of the variables of the study.

1. Schizophrenia

Schizophrenia is one kind of severe mental illness that is characterized by thought and emotional disturbance. The prevalence of schizophrenia worldwide reached 26.3 million (WHO, 2008). The prevalence was pointed out that 26 people over a million of people in the world have been suffering from schizophrenia. For Indonesia, the prevalence of schizophrenia in 2013 was 17 per 10,000 (Ministry of Health Republic of Indonesia, 2013). The number of the population of Indonesia reported in 2010 was 237,641,326 (Statistics Indonesia, 2010). The statistics pointed out that there was approximately 400 thousand of people have been suffering from schizophrenia.

According to March and Schub (2012), schizophrenia is an impaired brain disorder characterized by a range of emotional and cognitive dysfunctions that affect thought, feelings, idea, concern, behavior monitoring, affect, speech, drive, and decision making capacity. People with schizophrenia are diagnosed by the symptoms that consist of positive, negative, and cognitive symptoms (March and Schub, 2012). First, positive symptoms showed a deviation of normal thought, idea, and function. Second, negative symptoms showed a decline of normal function which included an affective flattening (March and Schub, 2012). Finally, cognitive symptoms showed a decline of concern, memory, and management functions (March and Schub, 2012).

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Moreover, the diagnosis of schizophrenia relied on the examinations of mental status that was measured by clinical interviews and observations of behaviors of patients (WHO, 1998). The approach of diagnosis for schizophrenia was suggested to use the International Classification of Disease-10 (ICD-10) because it represented a compromise between research findings and various diagnostic practices in different countries and was most likely to have been utilized worldwide (WHO, 1998). In addition to the diagnostic approach, schizophrenia was divided into subtypes based on the degree of psychosis, including paranoid, disorganized, catatonic, undifferentiated, and residual (March and Schub, 2013). Previous studies found that the majority of the case were paranoid schizophrenia (Urizar *et al.,* 2011; Kate *et al.,* 2013; Sigaudo *et al.,* 2014). Similarly, a previous study in Indonesia showed that paranoid subtype was the most common subtype of schizophrenia (Erlina *et al.,* 2010).

Furthermore, the appearance of the signs and symptoms of patients were varied over time; however, the effect of the illness was constantly severe and frequently lasted a long time (Sadock and Sadock, 2007). The consequences of schizophrenia contributed to the impairment of the cognitive and social functions of people who suffered with the illness. The cognitive dysfunction, for example the impaired verbal memory caused by schizophrenia found to contribute to the quality of life of the patients (Sigaudo *et al.,* 2014). Moreover, the social dysfunction contributes to the performance disturbing in the life skill of the people with schizophrenia condition (Hooley, 2010). Consequently, patients with schizophrenia needed to be assisted in the daily life activities. In addition to the manifestation of the illness, the shifting of health care services for hospital-based care to community-based care caused family members to take the role as family caregiver and providing care for their loved ones. As a result, the impact of the illness, including social isolation and poor care were suffered by patients and their families (Sadock and Sadock, 2007).

Families living with patients with schizophrenia condition could experience the disturbing role and function of the family and the relationship between the

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caregivers and their loved one. For instance, the change of the role and function in the family made family members assumed the role to be caregivers for their loved one. A previous study found that the family member who assumed the role to be a caregiver experienced a role distress and role overload caused by the caregiving (Quah, 2013). Moreover, role distress arises caused by the difficulties of the caregiver performed their role in providing unconditional love and care and giving medication for the loved one (Quah, 2013). Correlating with that, previous studies also suggested that the caregiving activities affected to the psychological morbidity of the caregiver (Moller *et al.*, 2009; Kate *et al.*, 2013). In addition, Quah (2013) suggested that the role overload emerged since the caregivers provided care in a long hour. Moreover, a qualitative study exploring the consequences of caregiving that was seen as a process of gain or loss depended on how the caregivers perceived the caregiving situation (Zegwaard *et al.*, 2013). As a result, the change of the role and function in the family caused by the impact of the illness to the family might influence the provision of care.

In addition, patients with schizophrenia were more likely to influence the burden perceived by the caregivers and lowered the score of quality of life than other types of mental illness, such as major depressive or obsessive compulsive disorder. Moreover, families living with mentally ill patients had experiences of living with their loved ones of uncertainty, sources of frustration, limited financial resources, and social support (Moss *et al*., 2005). Since the chronicity of schizophrenia, a long term care was needed and in turn this could affect to the cost of the treatment of the illness that borne by the family. The previous studies showed that the health care cost for unstable schizophrenia and substance abused patients who were hospitalized was higher than the stable patients (Zeidler *et al.*, 2012) and community-based care found to be more cost-effective than hospital-based care (Chisholm *et al.*, 2008). However, even families taking care stable patients with schizophrenia were still found to experience a considerable burden (Vasudeva *et al.*, 2013). A previous study found that family caregivers of patients with schizophrenia showed the lowest score of quality of life compared to family caregivers of patients with major affective disorder, neurosis, and the general population (Awadalla *et al.*, 2005). However, this previous

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study attempted to control the effect of severity of the illness on the caregiver's QoL by recruiting caregivers who taking care stable patients without the need for hospitalization or an increase in medication. Briefly, schizophrenia, as a severe mental illness, could be correlated to their family's assumed role as caregiver to the perceived burden and quality of life.

2. Quality of Life

Quality of life (QoL) is a broad concept and multi-dimensional based on individual perception. Even though the definition of quality of life had been defined by many theorists, there was no universally accepted definition of the quality of life (King and Hinds, 2012). According to King and Hinds (2012), the quality of life was defined as a personal and multi-dimensional experience that comprised an appraisal of positive and negative aspect of the life of people. Other theorists of Quality of Life defined the QoL as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/ her" (Ferrans and Powers, 1992, cited in King and Hind, 2012).

Moreover, quality of life was a subjective, multi-dimensional experience, an evaluation about both positive and negative characteristics of the individual's psychological, physical, social, and spiritual well-being in the time when health, illness, and treatment conditions were appropriate (Padilla *et al.*, 1996). On the other hand, Haas (1999) defined the quality of life as the multidimensional evaluation of an individual life event based on their culture, could be subjective or proxy evaluated by other people related to their physical, psychological, social, and spiritual. The definition of quality of life differs among quality of life theorists, yet the agreement about the concept of QoL is that the quality of life is a multi-dimensional concept.

Since the quality of life is a multi-dimensional concept, the majority of theorists of quality of life agree that the dimensions of quality of life would consist of four to five dimensions, including physical, psychological, social, somatic/ disease

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and treatment-related symptoms, and spiritual (King and Hinds, 2012). According to the World Health Organization (WHO, 1997), the quality of life was defined as an ‘‘individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1997). The WHO (1997) also pointed out that the QOL consisted of four domains, including physical, social, psychological, and environmental domains. For the physical domain, it can be measured by the perception of individual related physical health that comprised energy and fatigue, pain and discomfort, and sleep and rest. Secondly, the domain of psychological assessed individuals related to body image and appearance, negative feelings, positive feelings, thought, learning, memory, and attention. Thirdly, the domain of social relationship assessed an individual’s relationship, social support, and sexual activity. The last, the domain of environment assessed financial resources, freedom and physical environment safety, health and social care. In summary, the quality of life is a subjective evaluation of positive and negative aspects of life and multi-dimension of individuals that linked to their backgrounds.

2.1 Quality of Life among Family Caregivers

The family caregiver was a voluntary individual (spouse, colleagues, family members, friends, or neighbors) concerned with supporting others with activities of daily living and/or medical tasks (Family Caregiver Alliance, 2012). According to Mitnick *et al.* (2010) the family caregiver was an unpaid relative or friend of a disabled individual. The family caregivers were expected to help and assist a family member with schizophrenia activities of daily living. Furthermore, family caregivers also had roles to help the loved ones for financial support and medication monitoring at home.

According to the role of caregivers, caregiving situations could influence the activities of caregivers. For instance, caregivers go through economic problems, have limited time for socialization, and have distressed feelings (Leimkuhler and

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Wiesheu, 2011). Therefore, caregivers of mental illness had poor quality of life (Urizar *et al.,* 2009). Family caregivers that have taken care patients with paranoid schizophrenia received the poorest score of quality of life when measured by the Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL) (Richieri *et al.,* 2010). Similar findings were found in the study of Weimand *et al*. (2010) that stated the relatives of patients with severe mental illness had poor quality of life. On the other hand, according to Awadalla *et al*. (2005), caregivers of patient with schizophrenia had similar scores of quality of life with that of the general population group. In addition, the duration of the illness in the caregiving situation found to be not significantly associated with the quality of life of the caregivers (Angermeyer *et al.,* 2006). Therefore, a caregiving situation could affect on the performance of the caregivers and in turn influenced to their quality of life.

Interestingly, the majority of the results of a study about the quality of life of family caregivers of patients with schizophrenia were assessed by using generic measurements of quality of life rather than measurements that were constructed based on the point of views of the caregivers. Previous studies found inconsistent findings of factors associated with the quality of life of caregivers with schizophrenia by using general instruments, such as World Health Organization Quality Of Life- BREF, Short Form-36, Short Form-12, and the Quality of Life Index (QLI) (Foldemo *et al*., 2005; Li *et al*., 2007; Weimand *et al*., 2010; Boyer *et al*., 2012; Kate *et al*., 2013). On the other hand, there have been few studies that assessed the quality of life of family caregivers by using instruments that were developed based on the point of views of the caregivers. According to the expert reviews, the measurement or questionnaire about quality of life of caregivers of patients with schizophrenia were WHOQOL-100/ WHOQOL-BREF and S-CGQoL instruments (Testart *et al.,* 2013). However, according to the viewpoint of the questionnaire, the instrument that was developed based on family caregivers' viewpoints was S-CGQoL (Testart *et al.,* 2013). The S-CGQoL was developed by Richieri and colleagues (Richieri *et al.,* 2011) to measure quality of life of the caregiver as the impact of providing are for the patients with schizophrenia. The questionnaire consisted of 7

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dimensions, such as Psychological and Physical Well-Being, Psychological Burden and Daily Life, Relationship with Spouse, Relationship with Psychiatric Team, Material Burden, Relationship with Family and Relationship with Friends (Richieri *et al.*, 2011). Therefore, the utilization of specific instrument developed based-on point of view of the caregivers is important to measure factors influencing quality of life among family caregivers of patients with schizophrenia.

3. Factors Influencing Quality of Life of the Family Caregivers

According to a previous study, factors influencing the quality of life of family caregivers were divided into three groups, including caregiver factors, caregiving situation, and environmental factor (Wong *et al.*, 2012).

3.1 Caregiver Factors

3.1.1 Characteristics of caregivers

Particular characteristics which related to quality of life caused by caregiving activities for patients with schizophrenia have been observed in numerous studies (Zamzam *et al.*, 2011; Boyer *et al.*, Wong *et al.*, 2012; Quah, 2013). Since the characteristics of family caregivers differ across race and setting of previous studies, the conclusion of the contribution of demographic characteristics of family caregivers to quality of life is difficult to draw. The demographic characteristics are explained as follows:

3.1.1.1 Gender

Gender of the family caregivers could be one of the factors influencing the quality of life as the impact of caregiving patients with schizophrenia. Previous studies suggested that females were the greater proportion in providing care for a family member with mental illness (Djatmiko; Magliano *et al.*, 2005; Hastrup *et*

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al., 2011; Zendjidjian *et al.*, 2012). In addition, a statistical significant association was found between sexual category with social support and the burden of caregivers (Hsiao, 2010). Female family members in some cultures usually assumed the role as caregivers for their family members that suffered from illness. Previous studies in Indonesia showed that the majority of the caregivers were parents, particularly mothers (Adianta *et al.*, 2013; Darwin *et al.*, 2013) with a range of the age of caregivers 18-80 years old (Adianta *et al*., 2013). Correlating with the gender of the caregivers, the female caregivers were found to have a decreased level in their quality of life compared to the male caregivers (Richieri *et al.*, 2011; Purkayastha *et al.*, 2012). However, another previous study found that the domain of psychological and environmental of quality of life of female caregivers was higher than the males (Mizuno *et al.*, 2012). Moreover, the measurement of the quality of life of family caregivers that used the Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL) suggested that female caregivers had lower QOL than male caregivers in the dimensions of psychological well-being, physical well-being, and their relationships with their spouses (Richieri *et al.*, 2011).

According to Chou *et al*. (2009), female ageing caregivers of adults with mental illness had a higher level of subjective quality of life than caregivers of intellectual disability. Awadalla *et al*. (2005); Lua and Bakar (2011) found that male caregivers had a significantly higher quality of life domain score than female caregivers. Similar findings that were also found in a study conducted by Zamzam *et al*. (2011) suggested that female caregivers had an association with caregiver's QOL. On the other hand, inconsistent findings found in study of Kate *et al*. (2013) suggested that no significant relationship between gender and any domain of quality of life of caregivers. In addition, previous studies suggested that gender was not predicting factor of the QoL (Angermeyer *et al.*, 2006; Fan and Chen, 2009). Thus, further exploration of the contribution of gender to the QoL could benefit for health care providers to maintaining the QoL.

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3.1.1.2 Period of being a caregiver

A Period of being caregivers had a different level of burden. Some studies used inclusion criteria to find the associated factors of caregiver' burden and quality of life, such as: family caregivers who were responsible to care for at least a period of one year (Awadalla *et al.*, 2005; Chou *et al.*, 2009; Weimand *et al.*, 2010; Wong *et al.*, 2012). Family caregivers of patients with mental illness condition found to have 17.7 years as an average period for being a caregiver (Chou *et al.*, 2009). Moreover, caregivers who provided the highest number of care hours for a schizophrenia patient were found to be at a high risk for low quality of life (Quah, 2013). Furthermore, Chang *et al.* (2009) found that hours per day of caregiving predicted the mental health of caregivers. Conversely, another previous study found that duration of exposure of the caregiver to to patient's illness was not a significant predictor of the quality of life (Angermeyer *et al.*, 2006). Thus, the variable of the period of being a caregiver is still inconclusive and need to further assessed concerning its contribution to the quality of life of family caregivers.

3.1.1.3 Health status of caregiver

The perception of family caregiver related their current health status is an important issue to be assessed since its contribution to the quality of life. Previous studies found that mental health had a stronger effect on the physical health of caregivers (Chang *et al.*, 2009). Studies of Foldemo (2005); Urizar *et al.* (2009); Zauszniewski *et al.* (2009) suggested that higher obvious burden correlated to QOL of caregivers and suggested physical and emotional difficulties influenced the quality of life of caregivers. According to Li *et al.* (2007), the study showed that the physical health of family caregivers had a positive association in relation to their QOL. Moreover, caregivers who had chronic illness would have a poorer quality of life (Wong *et al.*, 2012). The findings were similar to a study conducted by Zamzam *et al.* (2011) which suggested that caregivers who did not have medical problems significantly had higher QOL scores in the domains of physical, psychosocial, and

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environmental. Furthermore, Awadalla *et al.* (2005) found that the perceived state of health by caregivers predicted the quality of life of caregivers. Hence, the perception of the caregiver about their health status related to the caregiving task they experienced could influence the quality of life and need to further explore.

3.1.1.4 Level of education

The level of education is needed to take into consideration to assess the quality of life since it may help the caregivers to have a better understanding of the caregiving task. Some studies found that the degree of education was associated with the quality of life of caregivers (Chou, 2009; Zauszniewski, 2009; Hsiao, 2010; Zamzam *et al.*, 2011; Wong *et al*., 2012). According to Wong *et al.* (2012), education level of the caregivers influenced positively to the score of quality of life of caregivers of patients with schizophrenia. A caregiver with higher education tend to have better employment and in turn could have higher income and more resources to improve the quality of life (Wong *et al*., 2012). Moreover, higher level of education could provide a caregiver better knowledge to cope with the caregiving situation (Zamzam *et al.,* 2011). Furthermore, higher level of education, for example, secondary and above level of education found to have a higher score of quality of life in the domain of physical, psychological, social, and environmental (Zamzam *et al.,* 2011). Similar findings from the study of Lua and Bakar (2011) suggested that a better educated caregiver significantly associated with the domain of physical function and mental health. In contrast, a study conducted by Maldonado *et al*. (2005) and Kate *et al.* (2013) found that the level of education had no significant association with the caregivers' quality of life. Therefore, the level of education of the caregiver is one of the potential factors that could influence the way the caregivers perceived the quality of life.

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3.1.1.5 Employment status

The employment status could be one factor that contributed to one's quality of life. Previous studies pointed out that family caregivers who were employed and had a regular income were significantly associated with their quality of life (Lua and Bakar, 2011). Since employment and income are closely related, family caregivers who are employed and received income could spend time to do other activities beside the caregiving task and might be more satisfied to evaluate some aspect in their quality of life. According to Lua and Bakar (2011), the employed family caregivers had significantly different scores of two domains of the QoL, including physical and mental domains compared to the unemployed (Lua and Bakar, 2011). A previous study also found that employed outside the home showed to have a significantly positive effect on the quality of life of the caregivers (Maldonado *et al.,* 2005). Moreover, the employment status of the caregivers was associated with two domains of the quality of life, including the physical and psychological domains (Zamzam *et al.,* 2011). On the other hand, a study conducted by Awadalla *et al.* (2005) found that the employment status of the caregivers had no significantly correlated to the quality of life and did not predict the quality of life of the caregiver of patients with schizophrenia (Zamzam *et al.,* 2011). Thus, the employment status is needed to further assess correlating to the quality of life of the caregivers.

3.2 Caregiving situation

Caregiving situation as the perception related to the role of being a caregiver could be a factor mainly influence on the quality of life. According to previous studies, caregiving situation was consisted of caregiver burden and perceived control of symptoms (Wong *et al.,* 2012; De-Regil *et al.,* 2013).

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3.2.1 Caregiver burden

Caregiver burden had started to get attention to be studied as the impact caused by taking care of family members with diseases. While the patients with schizophrenia are in need caregiving activities from their family, it could have given a negative impact to the caregivers that was perceived as caregiver burden. The term of "burden of family" was first defined by Treudley (1946) as the consequences caused by contact with severe mental illness patients (as cited in Thara *et al.,* 1998). Furthermore, burden was defined as "care in usage" and divided caregiver burden into objective and subjective burden (Hoenig and Hamilton, 1966). The objective caregiver burden was the amount of negative impact on the household, such as financial difficulties, health problems, distractions in the lives of family members, and abnormal behavior of patients that might have disturbed other family members. On the other hand, the subjective caregiver burden was the perception of caregivers that related to the burden they felt and to what extent they measured that they had endured the burden (Hoenig and Hamilton, 1966).

Caregiving situation was also found to have brought burden to the family member who assumed the role as family caregiver. Family caregivers of patients with severe mental illness experienced burden caused by the caregiving situation (Moller *et al.,* Leimkuhler and Wiesheu, 2011; Darwin, 2013). Interestingly, caregivers of patients with mental illness had a significantly higher caregiver burden than caregivers of patients with somatic illness (Magliano *et al.,* 2005; Hastrup, *et al.,* 2011). Therefore, it was clear that caregiving situation could brought impacts for the caregivers.

According to a longitudinal study of Hoenig and Hamilton (1966) showed that patients with schizophrenia who had suffered from the illness less than two years were evenly corresponded to the group of 'burden' and 'no burden'. Moreover, the duration of illness more than two years showed increased caregiver burden (Hoenig and Hamilton, 1966). In addition, previous studies aimed to

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investigate the relationship between perceived caregiver burden and health, such as findings of the study showed that subjective burden served as a mediator of the correlation between objective burden and the mental health of the caregiver (Suro and De Mamani, 2013); Family caregivers with greater perceived caregiver burden had poorer health (Weimand, 2010); Higher perceived caregiver burden had a significant relationship with depressive cogntion, personal resourcefulness, and caregiver' mental health (Zauszniewski *et al.*, 2009).

Furthermore, the perception of family caregivers about the impact of caregiving situation could have affected how family caregivers perceived their quality of life. For example, caregivers's perceived stigma as subjective burden were found to have a stronger effect on the quality of life of caregivers of patients with mental illness (Chou *et al.*, 2009). In addition to subjective burden, Foldemo *et al.* (2005) suggested that there was an association between the poor quality of life and higher objective burden of parents of patients with mental illness. According to a study by Fan and Chen (2011) found that caregiver burden influenced the physical, psychological, social, and environmental domains of the quality of life of family caregivers of patients with mental illness conditions. In contrast, a study conducted by Kate *et al.* (2013) found that caregiver burden had no significant correlation with the quality of life of caregivers. Therefore, the correlation between caregiver burden and quality of life of the family caregiver is still remain unclear and need to further explored to improve the quality of life of family caregivers of patients wih schizophrenia.

Generally, caregiver burden is measured interchangeably with the stress perceived by the caregivers. Previous studies used instruments measured burden of the caregivers of patients with mental illness, such as Caregiver Burden Scale, Overall Caregiver Burden Scale, Perceived Stress Scale, Perceived Chronic Strain Scale, Burden Assessment Scale, and Burden Assessment Schedule (Djatmiko, 2005; Li *et al.*, 2007; Suresky *et al.*, 2008; Chou *et al.*, Zauszniewski *et al.*, 2009; Hsiao., Weimand *et al.*, 2010; Wong *et al.*, 2012; Darwin *et al.*, 2013). However, the

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questionnaires that measured both objective and subjective burden, developed, and initially tested for the caregivers of patients with schizophrenia were Burden Assessment Scale (Reinhard *et al.,* 1994) and Burden Assessment Schedule (Sell *et al.,* 1998). Regarding to the items resources of the questionnaires, the Burden Assessment Schedule was developed based on the experiences of the caregivers and expert knowledge (Sell *et al.,* Thara *et al.,* 1998). Therefore, caregiver burden in this present study was measured by the instrument developed based on caregiver's point of view, which was Burden Assessment Schedule (Sell *et al.,* 1998).

3.2.2 Perceived control of symptoms

The perception of the caregivers to control the symptoms of the patients could be a factor influencing the QoL of the caregivers. According to previous studies, symptoms of the patients showed a consistent association with the quality of life of the caregivers. For instance, positive and negative symptoms of patients with schizophrenia were found to be correlated to the caregiver burden (Kate *et al.,* 2013) and later on influencing how the caregivers perceived the quality of life (Chen *et al.,* 2004; Urizar *et al.,* Zamzam *et al.,* 2011). In addition, the perception of the caregiver related to their ability to handle the symptoms of their loved one could be one factor that influenced how the caregivers perceived their quality of life.

A previous study found that the caregivers who faced difficulty handling the negative symptoms, the peculiar and disturbing behavior of the patients would significantly correlate with the quality of life of the caregivers (Wong *et al.,* 2012). Another study suggested that the perception of the illness by the caregivers would contribute to the caregiving outcome, for example, the psychological morbidity of the caregivers (Fortune *et al.,* 2005). Similar findings of the study stated that the caregivers who were more pessimistic about ability to control the illness of the patients would experience greater distress (Kuipers *et al.,* 2007). Also, a previous study found that the perception of the caregivers related the illness of the patients as being under the control of treatment would influenced better quality of

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life than the perception that the illness was being under control of the caregivers (De-Regil *et al.,* 2013). Therefore, the perceived control of symptoms could be one of the significant factors influencing quality of life of the family caregivers.

In general, perceived control of symptoms was measured by the Illness Perception Questionnaire – Schizophrenia Carers Version (IPQ-SCV) (Barrowclough *et al.,* 2001 as cited in Kuipers *et al.,* 2007; De-Regil *et al.,* 2013) and The Family Questionnaire, which measured the threat appraisal and control appraisal (Barrowclough and Parle, 1997 as cited in Fortune *et al.,* 2005). However, the scale used in the present study was the perceived control of symptoms scale ranged from 0 to 10, which measured the caregiver's perception regarding the ability to control symptoms of the patients while was benefit for time conserving in the data collection process.

3.3 Environmental factor

Environmental factors from the surrounding of the family caregivers could be the dominant factors influencing the quality of life. Previous studies assessed the environmental factor as the social support of the family caregivers (Urizar *et al.,* 2009; Wang and Zhao *et al.,* 2012; Kate *et al*., 2013).

3.3.1 Social support

Social support was defined as an evidence that a person was cared for, respected and valued, and felt that the person was part of a member of a network of people who had a mutual commitment to each other (Cobb, 1976). Two dimensions within the construct of social support are the received social support and perceived social support (Lakey and Cohen, 1983). Received social support means the assistance matched the demands of the stressors, and in turn will effectively promote the coping and reduce the effects of a stressor (Lakey and Cohen, 1983). Moreover, Cohen and Hoberman (1983) stated that the belief that support was

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available (perceived social support) decreased the effects of stress. As a result, social support might have protected the individuals against the adverse effects of the stressor by guiding them to interpret situations less negatively (Cohen and Hoberman, 1983).

Furthermore, social support was viewed as the mechanism explained the interpersonal relationship that apparently buffered people against their stressful surroundings (Cohen and McKay, 1984). In addition, social support consisted of two forms, such as psychological support that related to the provision of information and nonpsychological or tangible support that referred to the provision of material assists (Cobb, 1976). Moreover, psychological support consisted of appraisal support that reflected the cognitive and emotional support that reflected fulfillment of social-emotional needs (Cobb, 1976). Thus, social support could be an important factor to determine the contribution to the quality of life of the family caregivers while providing the care for the patients.

According to the previous studies related to social support of the family caregivers, 64.8% of the family caregivers of patients with schizophrenia in Indonesia perceived their social support in moderate level and found that the higher used number of coping strategies related to lower social support perceived by family caregivers (Rafiyah *et al.*, 2011). Moreover, perceived social support had an association with burden and predicted the quality of life of caregivers in families with mental illness (Hsiao, 2010; Ochieng, 2011). Furthermore, the lack of social support had a relationship with the QOL of caregivers (Urizar *et al.*, 2009). On the other hand, previous studies found inconsistent findings that showed social support had no significant association with any domains of the quality of life (Kate *et al.*, 2013).

In addition to the relationship between perceived social support and the quality of life of caregivers, family caregivers of patients with mental illness reported that perceived social support from family members was stronger than with perceived social support from friends or significant others (Wang and Zhao, 2012). Previous study suggested that level of education and the family relationship of

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caregiver influenced the social support perceived by the family caregiver (Hussein and Khudiar, 2013). The overall social support from family, friends, and significant others also perceived at a moderate level by using the Multidimensional Scale of Perceived Social Support (MSPSS) by the family caregivers of patients with schizophrenia (Hussein and Khudiar, 2013). Moreover, caregivers reported that professional health care providers sometimes excluded the involvement of family caregivers (Urizar *et al.,* 2009).

In general, previous studies assessed perception related the availability of support suggested that perceived social support was measured by the Perceived Social Support Scale, Social Support Scale, and the Multidimensional Scale of Perceived Social Support (Chou *et al.,* 2009; Hsiao, 2010; Wang and Zhao, 2012; Hussein and Khudiar, 2013). However, the Multidimensional Scale of Perceived Social Support was used for this questionnaire specifically measured the subjective evaluation related to the availability of social support from three subgroups, which were significant other, family, and friends. Also, the questionnaire was self-explanatory, easy to use, and time conserving (Zimet *et al*., 1988), which made it fit for the study that measured some other questionnaires at the same time. Therefore, social support from the three resources of support, for instance, family, friends, and significant others could have been used to manage the caregiving situation that leads to contribute to the quality of life of family caregivers of patients with schizophrenia.

4. Conceptual Framework

A conceptual framework is important to guide a study and to promote the selection of variables of the study. The quality of life in this study is a multi-dimensional, including physical, psychological, social, and environmental factor which were evaluated subjectively according to individual's background, culture, and expectation, and goals in their life (WHO, 1997). The model with the three sets of factors affected the QoL of caregivers of family members with mental illness (Wong

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et al., 2012) was used as a model to guide the study to predict the quality of life of family caregivers of patients with schizophrenia. The model was adopted from a model of White *et al.* (2004) that was developed for predicting the quality of life of family caregivers of physical illness. Then, Wong and colleagues (Wong *et al.,* 2012) adopted the model to be fitted for the family caregivers of patients with mental illness (Figure 1). The model was fit to use in this study since the quality of life explained some aspects in the life based on their perception related to their background. This model has been used to measure the impact of caregiving to the quality of life by assessing three main aspects from the caregiver, such as caregiving situation, caregiver factors, and environmental factors. In addition to that, the model was fit to be adopted in this present study since it was already applied in the same characteristics of the samples, that were family caregivers of patients with mental illness (Wong *et al.,* 2012).

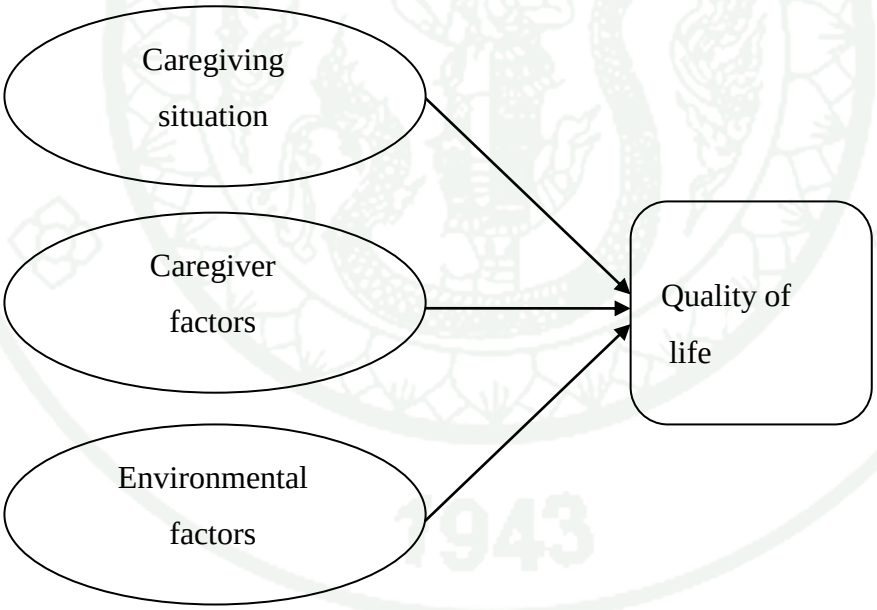

Figure 1 A model with three sets of factors affected the QoL of caregivers of family members with mental illness (Wong *et al*., 2012).

The model is focused on the three main factors that related to the quality of life of family caregivers of patients with mental illness, including, caregiving

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situation, caregiver factors, and environmental factors. Firstly, the caregiving situation was defined as variables associated with the characteristics of the patients with mental illness conditions. According to Wong *et al*. (2012), the variable may have included the functional status of the patients or the perception of the caregiver and the evaluation of the needs of the patients. Moreover, caregiving situation was also commonly defined as caregiver burden (Wong *et al*, 2012). In terms of caregiving situation, caregiver burden was defined as the evaluation of caregiver related to their caregiving role (Wong *et al.,* 2012). The caregiver burden was evaluated by using Perceived Chronic Strain Scale (Short Form) and showed that the difficulty handling the bizarre and disturbing behavior, and difficulty managing fluctuating emotions of the ill relatives as the most highly rate strains experienced by family caregivers of patients with mental illness condition (Wong *et al.,* 2012).

Even though the caregiver burden has not found to be the strongest correlation with the quality of life of caregivers, but the caregiver burden and satisfaction with mental health service within environmental factors were contributed 3 % of the variance of QoL of the caregivers (Wong *et al.,* 2012). Thus, the contribution of caregiver burden to the QoL could be one of the important factors in caregiving situation that need to investigate further. In addition, the ability to manage the caregiving situation also needed to be investigated. Since the family caregiver reported difficulties to control the symptoms of the patients and perceived the experience as caregiver burden (Wong *et al.,* 2012), then the perception of the family caregiver to control the symptoms of the patients is important to explore together with the caregiver burden to get a better understanding related to the factors in a caregiving situation, which might influence to the QoL.

Secondly, caregiver factors were defined as the characteristics of the caregivers, for instance the circumstance of life and demographic characteristics (White *et al.,* 2004). The demography of caregivers consisted of socioeconomic status, ethnicity, age, gender, and family stage and composition of the caregiver (Wong *et al*., 2012). Moreover, caregiver characteristics as caregiver factors in the

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model, including period of being a caregiver, caregiver's own chronic illness, family income, and the age of the caregivers were contributed 12 % of the variance in the QOL of caregivers of patients with mental illness conditions (Wong *et al.*, 2012). In addition, previous studies suggested that characteristics of the caregivers contributed to the quality of life of caregivers of patients with mental illness conditions (Awadalla *et al.*, 2005; Li *et al.*, 2007; Fan and Chen, 2009; Zamzam *et al.*, 2011). Furthermore, the caregiver factors in this study were characteristics of caregivers, including gender, a period of being a caregiver, health status, level of education, and employment status.

Thirdly, environmental factors comprised of support from the family and friends, the health care system, and the provision and the satisfaction with resources from the environment (White *et al.*, 2004). A study of Wong *et al.* (2012) measured the correlation between the environmental factors and quality of life found that the satisfaction of family caregivers with mental health services was correlated to the quality of life of family caregivers. Moreover, caregiver' satisfaction of mental health services explained 3 % of variance of quality of life of the family caregivers (Wong *et al.*, 2012). However, the environmental factor in this study was the perceived social support, that is the perception of availability support from significant other, family, and friends while taking care patient with schizophrenia. Briefly, all three of these factors were very important factors that were associated with the quality of life of family caregivers of patients with mental illness condition.

According to the explanation above, the conceptual framework of this study is shown in the figure 2. The dependent variable is quality of life. The independent variables are caregiver burden and perceived control of symptoms which is involved within the caregiving situation in the adapted model. Another independent variable is characteristics of caregivers which is involved in the caregiver factors in the adapted model. Moreover, perceived social support was the last independent variable which was involved in the environmental factors in the adapted model. Therefore, variables of caregiving situation, including caregiver burden and perceived control of

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symptoms, characteristics of caregivers, including gender, period of being a caregiver, health status, level of education and employment, and perceived social support as independent variables will be proposed as factors influencing quality of life among family caregivers of patients with schizophrenia.

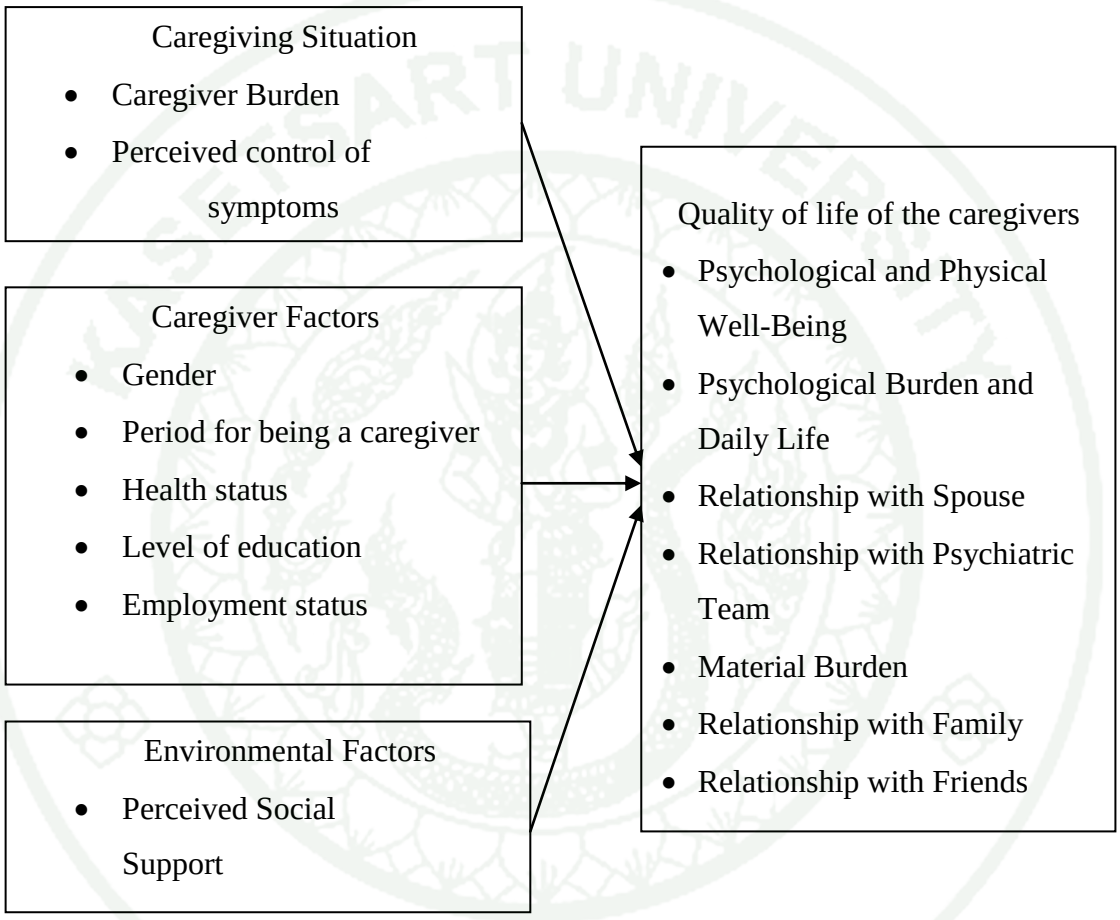

Figure 2 Conceptual Framework of Study

5. Definition of Terms

Operational definitions were explained as the description of each variable in the study. The operational definitions of this study were as follows:

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5.1 Quality of life in this study was the perception of family caregivers that related to some aspects in their life, such as, their general health status, feelings that related to caregiving task, and the relationship with friends and health care providers as the impact of caregiving activities for patients with schizophrenia. The study has assessed the quality of life of family caregiver by using the Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL) (Richieri *et al.*, 2011).

5.2 The caregiver in this study was a family member who took care of a patient with schizophrenia in daily life and was involved in the treatment and medication of the patient for at least a one year period of time as a caregiver.

5.3 Period of being a caregiver in this study was the time in years that family member used in taking care of the patient with schizophrenia at least for a one year time frame.

5.4 Health status was the perception of the caregiver related to their condition of health that ranged from 0-10. The caregiver needed to rate their perception about the health condition. For instance, a score of 0-5 represented a negative perception of health status, while a score of 6-10 represented a positive perception of health status of the caregivers.

5.5 Level of education was defined as the degree of formal education of family caregivers that can be categorized into lower levels of education, including elementary school and junior high school, and high level of education including senior high school, diploma, bachelor and above.

5.6 Employment status was a status or condition of a caregiver being employed that explained a caregiver worked and received regular income or being unemployed which did not work and did not receive a regular income by themselves.

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5.7 Perceived control of symptoms was the perception of the caregivers to handle or control the symptoms or behavior of the patients with schizophrenia. The caregivers needed to rate their perception to control the symptoms from 0-10, which 0 represented completely could not control and 10 represented completely were able to control.

5.8 Perceived social support was the perception related to helping, encouragement, feedback, or advice from others perceived by family caregivers, the availability of people who could be counted on by family caregivers, and the relationship with others. The perceived social support was measured by using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet *et al.*, 1988).

5.9 Caregiver burden was the difficulties experienced and felt by the caregivers caused by taking care of a family member with schizophrenia. For instance, financial problems, limitation of caregiver's activities, limitation of social interaction, feeling of anxiety, depression, loneliness, satisfaction with professionals' help. The perceived caregiver burden was measured by using the Indnesian version of Burden Assessment Schedule (BAS) (Djatmiko, 2005).

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MATERIALS AND METHODS

Materials

The data were collected by using five questionnaires, which three of them had been granted the permission from the authors and the others were developed by the researcher. Firstly, the characteristics of caregiver questionnaire assessing the characteristics of caregivers. Secodly, a questionnaire of the Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL) assessing the quality of life of caregivers. Thirdly, a questionnaire of Burden Assessment Schedule (BAS) assessing the perceived caregiver burden. For the fourth questionnaire, perceived control of symptoms scale assessing the perceived control of symptoms by the caregivers. The last, a questionnaire the Multidimensional Scale of Perceived Social Support (MSPSS) assessing perceived social support of the caregivers.

For these questionnaires, the BAS was available in Bahasa Indonesia version (Djatmiko, 2005), while S-CGQoL and MSPSS were not available in Bahasa Indonesia version. Therefore, the two questionnaires for this study, S-CGQoL and MSPSS were translated by adapting the back translation for cross-cultural research method (Brislin, 1970) by three sworn translators.

Concerning the translation process, three steps for the translation process of the questionnaires for cross-cultural research. For the first step, the original questionnaires in English language were translated into Bahasa Indonesia by the first sworn translator. Secondly, a different sworn translator did the back-translation from the questionnaire of the Bahasa Indonesia version of the English language version without had known the original English version of the questionnaires. Thirdly, another different sworn translator translated the translated English version into Bahasa Indonesia version. After the translation process, content validity of the instrument carried out by three experts who were experienced working with the family in mental health services in Indonesia. These three experts, including, mental

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health nurse, psychiatrist, and psychologist in the outpatient department in the setting of this study validated the Bahasa Indonesia version of questionnaires to ensure the content validity and language appropriateness.

1. Characteristics of Caregiver Questionnaire

The questionnaire of the characteristics of caregiver was developed by the researcher based on the literature review. The characteristics of caregiver consisted of gender, period of being a caregiver, level of education, employment status, and health status. The three experts who experienced working with family in mental health services examined the content validity of the instrument. The researcher revised and improved one item of the questionnaire based on their suggestions. The Content Validity Index for Scale (S-CVI) measured for content relevance that was 0.98 and for content clarity 0.95. The result met the criteria of Lynn's criteria for content validity ≥ 0.90 (Lynn, 1986 as cited in Polit and Beck, 2006).

2. The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL)

Quality of life of family caregivers of patients with schizophrenia was assessed by using the The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL). The questionnaire was constructed by Richieri and colleagues (Richieri *et al.*, 2011). The questionnaire consisted of 25 items developed based on the point of view of caregivers of patients with schizophrenia (Richieri *et al.*, 2011). The component of the questionnaire comprised of 7 dimensions, such as, Psychological and Physical Well-Being, Psychological Burden and Daily Life, Relationship with Spouse, Relationship with Psychiatric Team, Material Burden, Relationship with Family and Relationship with Friends. The questionnaire was rated on a 6-point Likert scale, defined as "1-Never/Not at all", "2-Rarely/ A little", "3-Sometimes/ Somewhat", "4-Often/ A lot", "5-Always/ Very much", and "6-Not applicable". All dimensions were linearly transformed to 0 - 100 scale, with 100 indicating the best possible level of QoL and 0 indicating the worst. The interpretation of the data on

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quality of life was reported separately from each dimension. A global QoL index, the S-CGQoL index was computed as the mean of the individual dimensions. The mean score was used as a cut point to categorize the family caregivers into a low level of the QoL and a high level of the QoL. The Content Validity Index for the scale was 0.96 for content relevance and 0.95 for content clarity. According to the suggestion from panel experts, six items were modified relating to the language appropriateness to fit with the situation in this study. The reliability test of internal consistency was carried out before collecting the data. The internal consistency of reliability was conducted with 30 family caregivers who had the same inclusion criteria with the sample of the study. The Cronbach's alpha coefficient was 0.85. The instrument has shown a highly desirable reliability. For the Cronbach's alpha coefficient of the current study, it was 0.86. The Cronbach's alpha coefficient for each domain of S-CGQoL were also measured in the present study. The Cronbach's alpha for domain of physical health and psychological well-being was 0.78; the domain psychological burden and daily life was 0.79; domain of relationship with spouse domain was 0.83; domain of relationship with psychiatric team domain was 0.89; domain of material burden was 0.74; domain of relationship with family was 0.91; and domain of relationship with friends was 0.95. The results pointed out a good internal consistency.

3. The Burden Assessment Schedule (BAS)

The perceived caregiver burden was assessed by using the Burden Assessment Schedule (BAS). The questionnaire was developed by Thara and colleagues (Thara *et al.*, 1998), which consisted of 40-items, including nine subscales assessing burden of the caregivers of patients with mental illness. Moreover, the questionnaire was developed based on the point of view of the caregivers of patients with schizophrenia (Thara *et al*., 1998). After the factors analysis, which resulted in a 20-items measured both objective and subjective burden, the final version of BAS was used in this present study since the questionnaire was addressed to mental health workers in South-East Asian countries (Sell *et al.*, 1998). The Bahasa Indonesia

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version of the 20-items of BAS had been studying for the validity and reliability (Djatmiko, 2005). The component of the questionnaire comprised of 5 factors, such as impact on well-being, impact on marital relationships, appreciation for caring, impact on relationship with others, perceived of the disease.

The questionnaire was rated on a 3-point scale, marked 1-3, with responses that ranged from "not at all, to some extent, or very much". Items which were not applicable to the subject, then a score of 9 was used. For example, items 3-6 were meant for subjects who were the spouse of the patient. The higher the score was indicated higher perceptions of caregiver burden. The computation involved the sum of the scores of all the items and the calculation of the mean for the individual. The mean score was used to group the family caregivers into low burden and high burden for further analysis. The validity and reliability test were conducted before collecting the data. The content validity index showed that 0.97 for both content relevant and content clarity. In this study, the reliability for internal consistency was tested by using Cronbach's alpha coefficient based-on the pilot study among 30 family caregivers who had same characteristics with the sample of this study. The Cronbach's alpha coefficient from the pilot study was 0.77, while the Cronbach's alpha coefficient for the current study was 0.78 which showed a desirable reliability.

4. Perceived Control of Symptoms Scale

The perception of the caregivers to handle or control the behavior or symptoms of the patient was measured by the Perceived Control of Symptoms Scale, developed by the researcher. The scale measured the perception of the caregiver to control the symptoms of patients by ranging from 0 to 10, which 0 represented completely cannot control the symptoms to 10 represented completely able to control the symptoms. The content validity of the questionnaire was examined by the three experts and the content validity index showed 0.91 for both content relevant and content clarity. The content validity index for the scale met Lynn's criteria for content validity ≥ 0.90 (Lynn, 1986 as cited in Polit and Beck, 2006).

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5. The Multidimensional Scale of Perceived Social Support (MSPSS)

Perceived social support of family caregivers was assessed by using The Multidimensional Scale of Perceived Social Support (MSPSS). The questionnaire was developed by Zimet and colleagues (Zimet *et al.*, 1988). This questionnaire consisted of 12 items, which were grouped into three subscale groupings measuring the perceived social support from family, friends, and significant others. The questionnaire was rated on a 7-point scale, marked 1-7, with responses that ranged from "1-very strongly disagree", "2-strongly disagree", "3-mildly disagree", "4-neutral", "5-mildly agree", "6-strongly agree", "7-very strongly agree". Before collecting the data, the reliability test for internal consistency was carried out with 30 family caregivers who had the same characteristics with the samples in the present study. The Cronbach's alpha coefficient was 0.79. In the present study, the Cronbach's alpha coefficients of significant other, family, and friends subscales were 0.76, 0.79, 0.85, respectively. The Cronbach's alpha coefficient for the whole scale for the present study was 0.85. The analysis involved the mean score of each subscale and the mean of total score. The respondents were divided into 3 groups on the basis of their scores (trichotomies) with 2 cut points, which were the 33.3 and 66.6 percentiles and considered the lowest group as low level of perceived social support, the middle group as a moderate level of perceived social support, and the high group as high level of perceived social support.

Methods

This part presented the research methodology which consisted of hypothesis, study design, population and sample, data collection, data analyses, and ethical consideration.

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1. Hypothesis

The hypothesis was set according to the conceptual framework of the study. The hypothesis was as follows:

Characteristics of caregivers, including gender, level of education, period of being a caregiver, employment status, and health status, caregiver burden, perceived control of symptoms, and perceived social support were significant factors influencing the quality of life among family caregivers of patients with schizophrenia.

2. Study Design

A cross-sectional approach was used in this study, to measure the phenomena at one point of time (Bordens & Abbott, 2011). The method was appropriate for this study because this study aimed to determine factors influencing quality of life among family caregivers of patients with schizophrenia in Indonesia during a specific time period.

3. Population, Sample, and Sampling

3.1 Population

The target population of this study was family caregivers of patients with schizophrenia in Indonesia.

3.2 Sample

The sample of the study was taken from family caregivers that accompanied a family member with schizophrenia to the outpatient department of Mental Hospital Soeharto Heerdjan, Jakarta where is one of the top referral of the mental hospital in Jakarta. Estimation of the sample size required for multiple

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regression based on Tabachnick and Fidell (2007), N > 50 +8m (where the m = number of independent variable). For eight independent variables, the study needed 114 participants. The formula was used for the multivariate analysis, with the medium effect size which was 0.05 (Tabchnick and Fidel, 2007). For encountering the probability of missing data, the total sample was 138 family caregivers were used as participants of the study. However, after managing the outliers and the missing data, the total sample used for multivariate analysis was 114 samples.

3.3 Sampling

The study was used purposive sampling based on the inclusion and exclusion criteria since the sample in this study were family caregivers taking care of patients with schizophrenia, who might have limited number of population compare to other diseases. The inclusion criteria of the study comprised of caregivers who: (1) 18-65 years old; (2) had taken care a patient with schizophrenia according to International Classification of Disease-10 (ICD-10); (3) had taken care a patient who was functioning stably in the community that was indicated by no need for hospitalization in the last 3 months to ensure the similarity of current condition of the illness; (4) accompanied a patient with schizophrenia to the outpatient department; (5) had been a family caregiver for at least one year. For the exclusion criteria of the study, they were family caregivers who: (1) were not willing to participate; (2) had taken care of more than one family member with mental illness; (3) were caregivers of patients with comorbid schizophrenia and substance abuse. People who met the inclusion of the criteria after interviewed by the researcher were recruited to be the participants.

4. Data Collection

Data were collected during July-August, 2014. The data collection process was conducted as follows:

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4.1 An approval from the Ethical Review Board for Research Involving Human Research Subjects, Boromarajonani of College Nopparat Vajira committee was granted in this study (ERB No. 42/ 2014).

4.2 An official document related to the plan of study was issued to get permission from the head of Mental Hospital Dr. Soeharto Heerdjan Jakarta to collect data in the outpatient department of Mental Hospital Dr. Soeharto Heerdjan Jakarta.

4.3 The proposal of the study was submitted to the head of Mental Hospital Dr. Soeharto Heerdjan and presented briefly to the head of the Nursing Department.

4.4 The head of the nursing department accompanied the researcher in the beginning step of the data collection for selecting the family caregivers, according to the inclusion criteria of patient' diagnosis in the medical record to serve as the potential participants in this study.

4.5 Before gathering data, one research assistant (RA), who is the fifth year of nursing student was trained by the researcher to help the data collection process. Firstly, the researcher trained the research assistant about the objective of the study, the ethical consideration, and questionnaires; thus, the research assistant understood the same data collection procedure as the researcher. The research assistant was involved in the reliability test and observed the data collection process that employed by the researcher. The inter-rater reliability between two raters employed by interviewing a case that had the same characteristics with the sample of the study. The Cronbach's alpha coefficient determined the inter-rater reliability was 0.96. In addition, the researcher accompanied the RA for interviewing five cases until the RA could assess the sample of study by herself. The family caregivers were interviewed according to the inclusion and exclusion criteria of the study.

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4.6 The permission to look at some data in the medical record of the patient to make sure about the patient's diagnosis had been granted by the head of the nursing department, then the family caregivers who met the inclusion criteria were offered to be the participants of the study. The participation was voluntary and prior to the participants filled out the questionnaires, information related to the study and participants' right to withdraw from the study were given.

4.7 The family caregivers were given time to decide to be a participant of this study for a day that the family caregivers had been in the OPD.

4.8 All questionnaires were estimated to be completed around 60 minutes.

4.9 For the caregivers who were willing to participate but could not fill the questionnaire because of the participants could not read or write by themselves, the researcher helped the participants to fulfill the questionnaires. The researcher helped by reading each question in the questionnaire and filling the questionnaire according to the participants' answers.

4.10 The data of the study were assessed until completed 138 family caregivers in July-August, 2014 in the outpatient department of Mental Hospital Dr. Soeharto Heerdjan Jakarta.

5. Data Analyses

The accuracy of the data were checked by confirming to the participants related to their understanding of the items in the questionnaires and confirmed the filled-out questionnaire to ensure and to prevent missing data. The data analysis was performed by using a computer software program. The data analyses were begun by descriptive analysis of the levels of caregiver burden, perceived social support, and quality of life. Descriptive analysis was performed to compute mean and standard deviation for continuous variables, and frequency and percentage for categorical

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variables. Preliminary analyses were employed and showed that the quality of life in this study was normally distributed. Outliers were showed in the boxplot of data. After deleting the outliers, the total samples were 137 family caregivers, which were used for the descriptive analysis. However, after managing the missing values, the final samples were 114 that met the criteria for the further analyses. Bivariate analyses using Pearson Product Moment Correlation coefficient to assess the correlations between QOL and continuous independent variables, including the period of being a caregiver, health status, perceived control of symptoms, caregiver burden, and perceived social support were performed. In addition, the Spearman Rank Order Correlation was used to examine the correlation between QOL and discontinuous independent variables, including gender, employment status, and level of education. Finally, the linear multiple regression was performed to determine factors influencing quality of life of family caregivers of patients with schizophrenia.

6. Ethical Consideration

The proposal of the study was submitted to the committee of Boromarajonani College of Nursing Nopparat Vajira to get an ethical consideration approval from the Ethics Review Board Committee for Research Involving Human Research Subjects. The researcher provided information related to the objectives and benefits of the study in a participant information sheet (see Appendix F). The informed consent was offered for participants by the researcher. In addition to the information about the study, the participants were strictly voluntary to participate in the study and also were given the rights to withdraw at any time without any consequence, for example the participants and their patients still receive the same usual services in the hospital. Furthermore, this study also addressed the concerns about anonymity and confidentiality. Therefore, the data of study from the participants used a different code number for each participant. In addition, the participants were provided a private room in OPD to fulfill the questionnaire for reducing the adverse effect from data collection using some sensitive questions.

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Regarding to reveale the findings of this study, the researcher asked for the participants' permission to inform the findings of the study to the Mental Hospital Soeharto Heerdjan Jakarta. Moreover, the researcher kept the questionnaire of each participant in locked cabinets and kept the information provided by the participants by using computer password protection. The file data have only been accessible by the researcher and the advisors and will be destroyed after 2 years of the time frame of the study.

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RESULTS AND DISCUSSION

Results

The present study was conducted to determine factors influencing quality of life among family caregivers of patients with schizophrenia in Indonesia. The results of the study were presented in two parts. For the first part, description of factors influencing quality of life, including the characteristics of caregivers; caregiving situation which was composed of caregiver burden and perceived control of symptoms; and environmental factors which was perceived social support were presented. Secondly, the results from linear multiple regression analysis were presented to demonstrate the effects of explanatory variables on the quality of life.

1. Description of Factors Influencing Quality of Life

The preliminary analyses were employed to ensure no violation to the assumption of normal distribution by checking the Kolmogorov-Smirnov and Saphiro Wilk values and the histogram. The results revealed that the quality of life among family caregivers of patients with schizophrenia was normally distributed.

1.1 Caregiver factors

1.1.1 Characteristics of caregivers

The characteristics of caregivers, including gender, level of education, employment status, health status, and period of being a caregiver were analyzed from 137 family caregivers who completed the questionnaires. Regarding the health status, the family caregivers were asked to rate their current health status in the 0-10 scale with 10 indicating the excellent health status and 0 indicating the poorest health status. Then, the results were transformed into a dichotomous with the

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rating from 0 to 5 indicating a poor health status and the rating from 6 to 10 indicating a good health status.

Table 1 Frequency and percentage of characteristics of caregivers among family caregivers of patients with schizophrenia (N=137).

Characteristics of Caregivers	n	%
Gender		
• Female	102	74.45
• Male	35	25.55
The highest level of education		
• Elementary	51	37.22
• Junior High	25	18.25
• Senior High	47	34.31
• Higher education	14	10.22
Period for being a caregiver (years)		
• 1–5	77	56.20
• 6–10	36	26.28
• > 10	24	17.52
M = 6.51, SD = 4.89, Range = 1-18 years		
Health status		
• Poor health status	42	30.66
• Good health status	95	69.34
M = 6.59, SD = 2.15, Range = 1-10		
Employment status		
• Employed	58	42.34
• Unemployed	79	57.66

The majority of the samples were females (74.45%). Out of 137 of the family caregivers achieved their highest level of education in elementary school (37.22%) and being unemployed (57.66%). The results showed that only 34.30 % of the

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caregivers completed senior high school. The majority of family caregivers have been being a caregiver for less than 5 years with the maximum period of 18 years (M = 6.51, SD = 4.89). The result also showed that the caregivers rated their current health status in the range 1-10 (M = 6. 59, SD =2. 15). Out of 137 family caregivers, 69.34 % of the caregiver perceived a good health status (M = 6.59, SD = 2.15).

1.2 Caregiving situation

1.2.1 Caregiver burden

Caregiver burden was measured based-on the difficulties experienced of the caregivers caused by taking care patient with schizophrenia. The results were presented in Table 2.

1.2.2 Perceived control of symptoms

The perceived control of symptoms was measured by assessing the perception of the family caregivers related to their capability to control symptoms of the patients with schizophrenia. The family caregivers were asked to rate their perception of being able to control the symptoms in 0 to 10 scale, with 0 indicating the perception of being incapable to control completely the symptoms and 10 indicating the perception of being capable to control completely the symptoms.

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Table 2 Mean, standard deviation, and range of caregiver burden and perceived control of symptoms among family caregivers of patients with schizophrenia (N = 137).

Variables	M	SD	Range[a]	Range[b]
Caregiver Burden	29.88	5.21	19-41	20-60
Perceived control of symptoms	6.65	2.16	1-10	0-10

Range[a] = Range of scores based on sample's responses
Range[b] = Range of score based on the questionnaires

The results in Table 2 showed that based-on the possible maximum score of 60, the maximum reported scores of caregiver burden was 41 with the mean score was 29.88 (SD = 5.21). For the perceived control of symptoms, the mean score was 6.65 (SD = 2.16).

1.3 Environmental factors

1.3.1 Perceived social support

Perceived social support was measured by assessing the perception related to the availability of support from significant other, family, and friends.

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Table 3 Mean, standard deviation and range of perceived social support and its domains among family caregivers of patients with schizophrenia (N = 137).

Variable	M	SD	Range[a]	Range[b]
Perceived social support	4.63	0.96	2.17 – 6.58	1 – 7
• Significant other	4.77	1.18	1.00 – 6.75	1 – 7
• Family	5.18	1.11	2.25 – 7.00	1 – 7
• Friends	3.93	1.41	1.00 – 7.00	1 – 7

Range[a] = Range of scores based on sample's responses
Range[b] = Range of score based on the questionnaires

The results in Table 3 revealed that based-on the possible maximum score of 7, the maximum reported score of perceived social support was 6.58 with the mean score was 4.63 (SD = 0.96). The highest mean score amongst domains of perceived social support was family (M = 5.18, SD = 1.11), followed by significant other (M = 4.77, SD = 1.11), and friends (M = 3.93, SD = 1.41).

1.4 The levels of caregiver burden, perceived social support, and quality of life among family caregivers of patients with schizophrenia in Indonesia

Caregiver burden was measured by assessing the difficulties experienced by the caregivers caused by taking care patient with schizophrenia. The mean score was used to categorize the caregiver burden into the low and high level. The family caregivers were also asked about their perception related to the availability of support from three sources, including significant others, family, and friends. The scores of respondents were divided into three groups, including the low, moderate and high perceived social support groups. The quality of life was measured by assessing the perception of the caregivers related to some aspects in their life, including psychological and physical well-being, psychological burden and daily life, relationship with spouse, relationship with psychiatric team, relationship with family,

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relationship with friends, and material burden as the impact of caregiving the patients with schizophrenia. The mean score was used as a cut point to categorize the low and high level of quality of life.

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Table 4 Frequency, percentage, and levels of caregiver burden, perceived social support, quality of life and its domains among family caregivers of patients with schizophrenia (N = 137).

Variables	Levels	n	%
Caregiver Burden	Low	70	51.10
	High	67	48.90
Perceived Social Support	Low	43	31.39
	Moderate	50	36.50
	High	44	32.11
Quality of Life (N = 114)	Low	63	55.26
M = 60.98, SD = 14.66,	High	51	44.74
Range[a] (25.15 – 97.24), Range[b] (25 – 125)			
• Psychological and Physical Well-Being	Low	73	53.28
	High	64	46.72
• Psychological Burden and Daily Life	Low	77	56.20
	High	60	43.80
• Relationship with Spouse	Low	61	53.51
	High	53	46.49
• Relationship with Psychiatric Team	Low	54	39.42
	High	83	60.58
• Material Burden	Low	69	50.36
	High	68	49.64
• Relationship with Family	Low	68	49.64
	High	69	50.36
• Relationship with Friends	Low	48	35.04
	High	89	64.96

Range[a] = Range of scores based on sample's responses

Range[b] = Range of score based on the questionnaires

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Among 137 family caregivers, 51.10 % of them reported the low score of caregiver burden, while 48.90 % reported the high score of caregiver burden. Approximately 36.50 % of family caregivers perceived social support on the moderate level. The total mean score of quality of life in this study was 60.98 (SD = 14.66) out of 125 as the possible total score of the quality of life. More than half of the family caregivers (55.26 %) perceived low quality of life. For the domains of quality of life, four out of seven domains showed low levels of quality of life, such as physical and pschological well being, psychological burden and daily life, relationship with spouse, and material burden. The frequency and percentage of responses for all items of variables, including caregiver burden, perceived social support, and quality of life were presented (see Appendix Table J).

2. Multiple Linear Regression of Explanatory Variables on the Quality of Life

2.1 Bivariate correlations

Preliminary analyses were employed to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. After testing the correlation by using bivariate correlation to ensure no violation in the assumption of multicollinearity (Table 5), which the bivariate correlation between each independent variables need to be less than 0.7 to be retained in the same analysis (Pallant, 2010). The study also ensured no violation of the assumption of homoscedasticity, which showed that the residuals were constant and around the predicted value.

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Table 5 Bivariate correlation between gender, level of education, period of being a caregiver, employment status, health status, caregiver burden, perceived control of symptoms, perceived social support and quality of life among family caregivers of patients with schizophrenia (N = 114).

Variables	1	2	3	4	5	6	7	8	9
1. Gender[a]	-	.21*	-.10	-.05	.17*	.16	- .04	.24**	.19*
2. Level of education[a]		-	-.06	.04	.24**	.23**	.23**	.20*	.32***
3. Employment status[a]			-	.08	- .04	- .09	- .02	.11	.19*
4. Period of being a caregiver[b]				-	- .09	- .11	.11	.01	- .09
5. Health status[b]					-	.37***	.24***	.25**	.33***
6. Perceived control of symptoms[b]						-	- .27**	.37***	.36***
7. Caregiver burden[b]							-	- .26**	- .56***
8. Perceived social support[b]								-	.58***
9. Quality of life									-

(a) = Spearman Rank Order correlation coefficient; ([b]) = Pearson Product-Moment correlation coefficient

*p < .05; **p < .01; ***p < .001; Sig (2-tailed)

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Table 5 showed the correlations among explanatory variables and the quality of life. The relationships between gender, level of education, employment status and quality of life were investigated using Spearman Rank Order correlation coefficient, while period of being a caregiver, health status, perceived control of symptoms, caregiver burden, perceived social support were investigated using Pearson Product-Moment correlation coefficient. Regarding the results of Spearman Rank Order correlation, for the first variable, gender was consistently associated with level of education, health status, perceived social support, and quality of life (*rho* = .26, $p <$ .05; *rho* =.17, $p < .05$; *rho* = .24, $p < .01$; *rho* = .19, $p <$.05, respectively). Secondly, level of education was correlated with health status (*rho* = .24, $p < .01$), perceived control of symptoms (*rho* = .23, $p < .01$), caregiver burden (*rho* = - .23, $p < .01$), perceived social support (*rho* = .20, $p < .05$), and quality of life (*rho* = .32, $p < .001$). Regarding the employment status, the employment status was weak positively correlated with the quality of life (*rho* = .19, $p < .05$).

Concerning the results of Pearson Product Moment correlation coefficient, period of being a caregiver was not significant correlated with all variables, including gender, level of education, employment status, period of being a caregiver, health status, perceived control of symptoms, caregiver burden, perceived social support, and quality of life. Regarding health status, the results showed that health status was associated with perceived control of symptoms, caregiver burden, and perceived social support ($r = .37$, $p < .001$; $r = -.24$, $p < .001$; $r = .25$, $p < .01$; $r = .33$, $p < .001$, respectively). For the perceived control of symptoms, the results revealed that perceived control of symptoms was correlated with caregiver burden, perceived social support, and quality of life ($r = -.27$, $p < .01$; $r = .37$, $p < .001$; $r = .36$, $p < .001$, respectively). Concerning the caregiver burden, results of Table 5 showed that caregiver burden was negatively associated with perceived social support ($r = -.25$, $p < .01$) and quality of life ($r = -.56$, $p < .001$). The last, perceived social support was strong positively correlated with quality of life ($r = .58$, $p < .001$).

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2.2 Multiple linear regression

To answer the hypothesis: characteristics of caregivers, including gender, period of being a caregiver, health status, level of education, and employment status, caregiver burden, perceived control of symptoms, and perceived social support are significant factors influencing the quality of life among family caregivers of patients with schizophrenia, a standard multiple regression was used to test whether the independent variables could predict the quality of life of the caregivers. After that, the predicting factors, including gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, caregiver burden, and perceived social support were entered into the regression analysis.

Table 6 Standard multiple regression of explanatory variables on quality of life among caregivers of patients with schizophrenia (N=114).

Model	*β*	SE	Beta	*t*	*p*-value
• **Gender**	.33	2.26	.01	.14	.88
• **Level of education**	3.66	2.01	.12	1.82	.07
• **Period of being a caregiver**	- .17	.19	-.05	- .90	.36
• **Employment status**	4.42	1.93	.15	2.28	.02
• **Health status**	.61	.48	.08	1.25	.21
• **Perceived control of symptoms**	.36	.50	.05	.72	.47
• **Caregiver burden**	-1.09	.19	-.39	-5.67	< .001
• **Perceived social support**	6.05	1.10	.40	5.47	< .001

Constant = 52.57
R^2 = .576, Adjusted R^2 = .544, F (8, 105) = 17.86, p < .001

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Gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, caregiver burden, and perceived social support were used in the standard multiple regression analysis to predict the quality of life. The correlations of the variables showed that all correlations, except for the period of being a caregiver, were statistically significant.

The prediction model was statistically significant, F (8, 105) = 17.86, p < .001, and accounted for approximately 54.4% of the variance of quality of life (R^2 = .576, Adjusted R^2 = .544).

Equation 1 The regression equation of the model of the quality of life

Predicted Quality of Life = 52.57 + .33(gender) + 3.66(educ) - .17(period) + 4.42(employ) + .60(health) + .36(symptoms) – 1.09(burden) + 6.05(support)

Regarding the results of the multiple analysis coefficients, equation of the predicted quality of life was presented in Equation 1. Concerning the regression equation, the score quality of life will increase for each increment of each independent variables. Regarding gender, level of education, period of being a caregiver, and health status, all these variables were not significantly contributed to the QoL. The level of education showed a borderline significantly influenced to the QoL (Coefficient b = 3.66, p-value = .07). Furthermore, the results showed that quality of life will increase 4.42 units for each increment of the value of employment status. In addition, the QoL will increase 1.09 unit for each increment of caregiver burden (Coefficient b = -1.09). The result also found that for each increment of perceived social support, the score of QoL will increase 6.05 units (Coefficient b = 6.05).

For the standardized regression coefficient Beta, the results in Table 6 showed that perceived social support was the strongest predictor in the regression model (Beta = .40, t = 5.47, p < .001), followed by caregiver burden (Beta = -.39, t = -5.67,

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$p < .001$), and employment status (Beta = .15, $t = 2.28$, $p < .05$) after controlling other variables in the regression model.

Discussion

The purpose of the study was to determine factors influencing quality of life among family caregivers of patients with schizophrenia in Indonesia. The discussion part consisted of three parts related to specific objectives of the study and the limitations. For the first part, the discussion of levels of caregiver burden, perceived social support, and the quality of life were presented. Secondly, factors influencing the quality of life, which estimated the effects of the characteristics of caregivers, including gender, level of education, period of being a caregiver, health status, and employment status, caregiver burden, and perceived social support were discussed. The last, the limitations were also addressed in this study.

1. The Levels of Caregiver Burden, Perceived Social Support, and Quality of Life

According to the results, nearly half of the family caregivers perceived high caregiver burden. The possible reason to explain this situation is that providing long care for the patients with schizophrenia might be perceived as astressful event showed by the majority of the family caregivers in this study reported anxious, depressed, and frustrated feeling. The family caregivers also might experience difficulties in their daily life performance, which is showed by nearly half of the family caregivers reported that the patient to some extent prevent the caregivers from looking for a job (see Appendix Table J2). As a result, the family caregivers perceived high caregiver burden. The finding was consistent with previous studies, which found that taking care the family member with schizophrenia was burdensome, which presented that more than half of the family caregivers reported high level of caregiver burden (Darwin; Kate *et al*., 2013).

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Concerning perceived social support, the perception of the majority of family caregivers in this study regarding the availability of support from their significant other, family, and friends were on the moderate level. The possible reason to explain this situation is that the belief that the family caregivers were supported by others in difficult situation would help the caregivers in managing the caregiving activities. Hovewer, in the culture of Indonesia, it is common that the family caregivers may feel embarrassed or uncomfortable to share the problems of the caregiving, especially related to the stigma in taking care patients with schizophrenia. Thus, despite the existing resource of support from significant other, family, and friends, the family caregivers in this study perceived social support at moderate level. The finding of this study was consistent with previous studies revealed that the greater number of the family caregivers perceived moderate level of social support (Rafiyah *et al.*, 2011; Hussein and Khudiar, 2013).

With regard to quality of life, the greater number of the family caregivers in this study perceived low quality of life. The finding confirms a previous study, which pointed out that the family caregivers in Chile, which is developing country, reported low quality of life (Boyer *et al.*, 2012). The possible reason to explain this consistency is that being the primary person providing long treatment for the patients with schizophrenia may bring impact to some aspects of of life of the caregivers showed by family caregivers in this present study reported low score in four out of seven domains of the QoL, which were physical and psychological well-being, psychological burden and daily life, relationships with spouse, and material burden.

In conclusion, the family caregivers in this study experienced difficulties perceived as a burden. In addition, since Indonesian culture might make the caregivers uncomfortable to share their problems; thus, the greater number of family caregivers perceived social support on the moderate level despite their sources of support. Furthermore, taking care patients with schizophrenia is perceived as a burdensome activities and this situation might affect to the family caregivers in this study perceived low level of quality life.

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2. Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

Based on the result of standard multiple regression, three factors influencing the quality of life, including employment status, caregiver burden, and perceived social support were found statistically significantly influenced to quality of life among family caregivers of patients with schizophrenia. Perceived social support showed the strongest unique contribution to explaining the quality of life, followed by caregiver burden and the employment status which made a less unique contribution to explaining the quality of life. The findings indicated that the quality of life of the caregivers was strongly influenced by their perception related to the availability of social support from significant other, family, and friends, the caregiver burden, and their employment status.

Regarding the characteristics of the caregivers, the results of the study showed that gender was not a factor influencing the quality of life. It means that whether female or male family caregivers did not influence how the family caregivers perceived the quality of life. The finding of the study was supported by a previous study (Angermeyer *et al.*, 2006; Fan and Chen, 2009). The possible reason to explain the result was that the gender had collinearity with perceived social support. In the context of Indonesian, the general population of the caregivers was the female family member. However, while experienced difficulties in caregiving task, the female family caregiver in this study would perceive high QoL when they perceived high social support. According to Tabachnik and Fidel (2007), the multicollinearity between each independent variable affect their own contribution to the multiple regression model. Thus, It seemed that the QoL in this study cannot be explained by the gender itself since the family caregivers had another factor that they perceived more affect to the evaluation of their QoL.

With regard to the level of education, the results showed that the level of education was not a factor influencing the QoL. The finding of the study was in line

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with a previous study (Fan and Chen, 2009). The possible reason to explain this result was that the level of education was correlated with the caregiver burden, which suggested that the family caregivers who had higher levels of education could have a better knowledge for taking care the patient and managing the caregiver burden. Thus the collinearity between level of education and caregiver burden could affect to the quality of life in regression model in this study. Thus, the QoL in this study cannot be explained by the level of education.

Concerning the employment status, the result showed that employment status positively influenced the quality of life. The finding indicated that being unemployed will increase the quality of life perceived by the family caregivers. The study showed that the majority of family caregivers were unemployed, which means that they did not have regular income by themselves. The possible reason to explain this finding is in the culture of Indonesia, it was common that other family members will support each other, including the financial support; thus, it might affect to how the family caregivers evaluate some aspects of their life. The finding was consistent with a study reported by Zamzam *et al.* (2011) who suggested that family caregivers who were unemployed were more likely to report higher in physical and psychological domain of the quality of life. The consistency could be explained that the family caregivers who were unemployed were more likely to have more time to manage the difficulties in caregiving task and have less adjustment between the working life and the caregiving activities, which could influence to the better perception regarding the quality of life. The explanation could be supported by the results from bivariate analysis (See Table 5) that showed a positive correlation between employment status and caregiver burden, which indicated that the caregivers who were employed were more likely to perceive higher caregiver burden, yet this correlation did not reach statistically significant. However, the finding of this study was in contrast with a previous study suggested that the unemployed family caregivers had the low score of QoL (Maldonado *et al.*, 2005). This inconsistency could be caused by the differences of culture of previous study conducted in Europe county, could relate to how the family caregivers evaluate their QoL. Therefore, the result of this study suggests that

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the unemployed caregivers are more likely to have better quality of life compared to employed family caregivers.

Regarding the period of being a caregiver, the result indicated that the longer period of being a caregiver will decrease the score of the QoL reported by the family caregivers. However, the results did not reach statistically significant in the model of multivariate regression analysis. The possible reason to explain this finding was that the majority of the family caregivers in this study has been being a caregiver for less than five years out of 18 years as the maximum period of time reported by the caregivers; thus, it may affect to how the family caregivers perceived the burden and evaluated their QoL as the impact of caregiving. In addition, the period of being a caregiver was not a significant factor related to the QoL in this study (see Table 5). The finding of this study was consistent with a previous study (Angermeyer *et al.,* 2006; Fan and Chen, 2009). Therefore, it is possible to conclude that the QoL cannot be explained by the period of being a caregiver.

For health status, the result of the study presented that health status was not a factor influencing the QoL. The possible reason to explain this finding is that the relationship between health status and the caregiver burden. The difficulties faced by the caregivers could bring to the life of the caregivers, for instance less time to take care themselves and stress feeling, which could make them perceived more burden. It also was supported by other previous studies suggested psychological morbidity experienced by the caregivers caused by caregiving (Moller *et al.,* 2009; Kate *et al.,* 2013). Thus, it seems that the health status might not directly influence the quality of life since the collinearity with the caregiver burden could diminish the contribution of health status to the quality of life.

Concerning the perceived control of symptoms, the result of the study pointed out that the family caregivers who perceived themselves for being capable to control symptoms of the patients will increase their score of quality of life. However, this result did not reach statistically significant influence to the QoL. The possible reason

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to explain this result was that the perception of the family caregivers about the ability to manage the symptoms caused by the illness of the patient could relate to how the caregivers perceived the caregiver burden while providing care for the patients in the daily life. Also, the belief that social support from significant other, family, and friends might help the family caregivers since they had other people to rely on for controlling the symptoms appeared in the patients and later on could affect to their QoL. Thus, the perceived control of symptoms in this study did not directly influenced to the QoL. Conversely, the finding of this study was inconsistent with a previous study (De-Regil *et al.,* 2013). The possible reason to explain this inconsistency was that the family caregivers in the previous study had taken care patients who had the illness less than 10 years and controlled for the patient's clinical and functional status in the regression model that lead to the contribution to the QoL. Hence, perceived control of symptoms in the present study was not a factor influencing the QoL.

For the caregiver burden, it made a moderate unique contribution to explaining the quality of life compare to the perceived social support and employment status. The finding pointed out that higher score of caregiver burden will influence to lower quality of life. This could possibly happen since providing long term care for the patients is perceived as a stressful event might lead to the family caregivers evaluate themselves as poor quality of life. This finding was supported by previous studies found that the caregiver burden had a stronger effect on the quality of life and predicted the physical, psychological, social, and environmental domains of the quality of life (Chou *et al.,* Fan and Chen, 2009). The caregiving situation, as demanding activities for the caregivers resulted to the caregivers go through economic problems, enjoyed less time for socialization and caused distressed feelings (Leimkuhler and Wiesheu, 2012). Therefore, the finding of the current study confirmed that taking care of a patient with schizophrenia was perceived as a burden by the family caregivers and in turn, the difficulties experienced by the family caregivers affect to how they perceived the quality of life.

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Concerning the perceived social support, the current study found that perceived social support made the strongest unique contribution to explaining the quality of life, when the variance explained by gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, and caregiver burden was controlled. The finding revealed that perceived social support positively influenced the quality of life. It means that the higher perceived social support will influence to higher quality of life. The possible reason to explain this finding is that the perception of availability of support from three resources of support, including significant other, family, and friends might have been used as the emotional support, which helped the family caregivers relieving the distress feeling caused by the caregiving activities. Thus, the family caregivers may feel more satisfied in evaluating the aspects of life as the impact of taking care the patients since the family caregivers perceived that they had other people to rely on in the stressful events. As a result, it could contribute to the high score of the QoL.

The finding of the study was in line with a previous study that suggested that social support of the caregiver influenced the quality of life among family caregivers with mental illness (Chou *et al.*, 2009). Moreover, Cohen and Hoberman (1983) stated that the belief that the support was available decreased the effects of stress. Thus, social support perceived by the family caregivers in this present study could be a factor helped to reduce the negative impact of caregiving. However, another previous study revealed that the caregivers reported that professional health care providers sometimes exclude the involvement of family caregivers (Urizar *et al.*, 2011). The finding from the previous study indicated that social support from the surroundings of the caregivers were a significant factor to influence the QoL of the caregiver. However, the involvement of the caregivers did not really recognize by the health care provider, which could limit their chance to get help or advice from the professionals about what kind of support that the family caregivers need in their own situation. Therefore, the perceived social support is an important factor could be used to prevent the negative impact, which is the poor quality of life while providing care for the patients.

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Regarding the result of the model of standard multiple regression in this study, the regression model of this study accounted for 54.4 % of the variance in the quality of life. The finding of this study pointed out that 54.4 % of the variation in quality of life of family caregivers of patients with schizophrenia in Indonesia can be explained by differences in gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, caregiver burden, and perceived social support. On the contrary, gender, level of education, period of being a caregiver, health status, and perceived control of symptoms were not found to be making a statistically significantly unique contribution to the prediction of the quality of life of the family caregivers. These not significant predictors are consistent with findings of some previous studies (Angermeyer *et al.*, 2006; Fan and Chen, 2009). These results indicated that whether female or male, low or high level of education, the amount of years of being a caregiver, perceived poor or good health status, and perceived controlled or uncontrolled the symptoms of patients could not predict the quality of life of the family caregivers. The possible reason to explain this was that the correlation of the variables with the QoL may not be strong enough to influence the quality of life perceived by the family caregivers.

In conclusion, this study found that the significant factors influencing quality of life in this study consisted of employment status, caregiver burden, and perceived social support, while the perceived social support was the strongest factor influencing the quality of life. The model of the regression showed in this study explained 54.4 per cent of the variance in the quality of life among family caregivers of patients with schizophrenia. So, this means there are other factors, which could explain the other 45.6 % of the variability that the findings of this study could not explain.

3. Limitations of the Study

Even though this study has provided information regarding significant factors influencing the quality of life, limitation of the study is need to address. For instance, the number of samples in this study was only using the minimum amount of samples

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required for multiple regression analysis that could influence to the significant factors founded in the study. Moreover, the samples were selected by purposive sampling, which was drawn from the family caregivers in only one geographical in Jakarta, Indonesia. Thus, it is limited to generalize the results of the study. This study also did not consider the family caregivers by the severity of the patients regarding the schizophrenia subtype to prevent underreport of the case. Furthermore, this study was conducted in health care setting that could make the respondents tend to give the favorable answer regarding the satisfaction of the relationship with the psychiatric team as a part of the quality of life.

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CONCLUSION AND RECOMMENDATION

Conclusion

The study was focused on the factors influencing quality of life among family caregivers of patients with schizophrenia. The findings revealed that the significant factors influencing the QoL were perceived social support, caregiver burden, and employment status. In addition, it was also found that the perceived social support showed the strongest contribution to the quality of life, followed by caregiver burden, and employment status when the variance explained by other factors were controlled. The study also reported that the model of the standard multiple regression accounted for 54.4 per cent of the variance in the quality of life among family caregivers of patients with schizophrenia in Indonesia.

Recommendation

Based on the results and limitations of this study, the recommendations consisted of three areas are made:

1. Research

Some recommendations are made to be employed in the further research. Firstly, the larger sample size is needed to employ multiple linear regression to determine factors influencing the QoL. Secondly, the generalization of the study findings could be employed by simple random sampling, which also gathered from more than one representative area of Indonesia. Thirdly, further examination of other possible factors influencing the QoL should be conducted, in relation to coping strategies, sense of coherence, and satisfaction with the health care system, which are found from literature to be factors relating to the QoL. Thus, it may help to be better understanding regarding factors influencing the QoL. The last, the possibility to conduct the further study in the community setting may reduce the favorable answer

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from the family caregivers related to the self-administered questionnaire about the quality of life.

2. Practice

Based on the main results, the following recommendations are made. First, the health care provider could promote the health of both the family caregivers and the patients by maintaining factors influencing quality of life of the caregivers. The findings could be a basis resource to develop an intervention to help improve the family caregiver's quality of life by considering their employment status; the health care provider should help to maintain the low caregiver burden and to assist the caregiver in obtaining and maintaining their social support from significant other, family, and friends. Regarding subscale of perceived social support, perceived social support from family was the most satisfied subscale of perceived social support. Therefore, it is also important to encourage the family caregivers to seek help from their friends, which showed the less satisfied social support. Additionally, encouragement for the family caregivers to share the caregiving problem with others and to involve other family member in making decision regarding the patient's condition, which showed the most satisfied items of perceived social support reported by the caregivers were also essential for maintaining the family caregiver's QoL.

3. Education

According to the findings of the study, it can be stated that new knowledge regarding factors influencing quality of life of the family caregivers in Indonesia has been found. The nurse educators may utilize the findings for the teaching materials in the course of community mental health nursing. The teaching materials could emphasize the influencing factors to approach family caregivers to improve the quality of life of them, who are considered as a population at risk by exploring and maintaining the caregiver burden and their social support, especially fo the employed family caregivers.

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APPENDICES

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Appendix A
The Questionnaires

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Characteristics of Caregivers Form

Code number :

Date :

Instruction:

Please answer all the following questions and tick [√] in the most appropriate box " ☑ ".

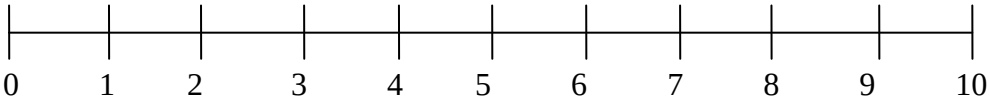
1. Gender ☐ 1. Female ☐ 2. Male

2. The highest of level of education
   - ☐ 1. Elementary school
   - ☐ 2. Junior high school
   - ☐ 3. Senior high school
   - ☐ 4. Higher education

3. Period for being a caregiver: _____ years

4. Employment status
   - ☐ 1. Employed
   - ☐ 2. Unemployed

5. Please rate your current health status on a scale from 1 to 10, with 1= poor and 10=excellent. Circle the number that best describe your health.



poor health excellent health

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The Schizophrenia Caregiver Quality of Life Questionnaire
(S-CGQoL)

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The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL)

The information contained in this questionnaire is strictly confidential.

We are asking you to answer these questions because it will help us in assessing the quality of your daily life as well as the general state of your health. We would like to better understand the impact of caregiving on your quality of life.

Please answer each question by ticking the box that describes as closely as possible how you have felt for the last 12 months. Some questions concern your private life. They are necessary to evaluate all aspects of your state of health. However, if you feel that a question does not concern you or if you do not wish to answer it, skip it and go on to the next question.

Thank you

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For the last 12 months, have you…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
1 felt sad, depressed ?	☐	☐	☐	☐	☐
2 felt overworked, burnt-out ?	☐	☐	☐	☐	☐
3 lacked energy ?	☐	☐	☐	☐	☐
4 been tired, worn-out?	☐	☐	☐	☐	☐
5 felt anxious, worried ?	☐	☐	☐	☐	☐
6 had to give up doing things that you were very keen to do?	☐	☐	☐	☐	☐
7 had to reduce the amount of time devoted to your leisure activities (outings, gardening, shopping, odd jobs…)?	☐	☐	☐	☐	☐
8 been embarrassed to leave your child to attend your day or professional life?	☐	☐	☐	☐	☐
9 had the feeling that you didn't devote enough time to the rest of your family ?	☐	☐	☐	☐	☐
10 had the feeling that you weren't free?	☐	☐	☐	☐	☐

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For the last 12 months, have you…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
11 had the feeling that you led a day-to-day existence?	☐	☐	☐	☐	☐
12 had difficulty in making professional or personal plans?	☐	☐	☐	☐	☐
13 been helped, supported by your spouse?	☐	☐	☐	☐	☐
14 been listened to, understood by your spouse?	☐	☐	☐	☐	☐
15 had a satisfying emotional and sexual life?	☐	☐	☐	☐	☐
16 been listened to, understood by doctors and nurses?	☐	☐	☐	☐	☐
17 been helped, supported by doctors and nurses?	☐	☐	☐	☐	☐
18 been satisfied with information given by doctors and nurses?	☐	☐	☐	☐	☐
19 been helped, supported by your family?	☐	☐	☐	☐	☐

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For the last 12 months, have you…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
20 been listened to, understood by your family?	☐	☐	☐	☐	☐
21 been helped, supported by your friends?	☐	☐	☐	☐	☐
22 been listened to, understood by your friends?	☐	☐	☐	☐	☐
23 encountered difficulties because of your child's illness when applying to administration departments?	☐	☐	☐	☐	☐
24 had financial troubles in facing your child's illness?	☐	☐	☐	☐	☐
25 had material difficulties (housing, transport…)?	☐	☐	☐	☐	☐

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Algorithme SPSS of the S-CGQoL Questionnaire

```
IF (NVALID(cq1, cq2, cq3, cq4, cq5) >= 2) csqol1  = 100 * ((5 * MEAN(cq1, cq2, cq3, cq4, cq5)- 5) / 20) .
VARIABLE LABEL csqol1  "Psychological and physical well_being".
EXECUTE .

IF (NVALID(cq6, cq7, cq8, cq9, cq10, cq11, cq12) >= 3) csqol2  = 100 * ((7 * MEAN(cq6, cq7, cq8, cq9, cq10, cq11, cq12)- 7) / 28) .
VARIABLE LABEL csqol2  "Psychological burden and loss".
EXECUTE .

IF (NVALID(cq13, cq14, cq15) >= 1) csqol3  = 100 * ((3 * MEAN(cq13, cq14, cq15)- 3) / 12) .
VARIABLE LABEL csqol3  "Relationships with spouse".
EXECUTE .

IF (NVALID(cq16, cq17, cq18) >= 1) csqol4  = 100 * ((3 * MEAN(cq16, cq17, cq18)- 3) / 12) .
VARIABLE LABEL csqol4  "Relationships with psychiatric team".
EXECUTE .

IF (NVALID(cq23, cq24, cq25) >= 1) csqol5  = 100 * ((3 * MEAN(cq23, cq24, cq25)- 3) / 12) .
VARIABLE LABEL csqol5  "Material burden".
EXECUTE .

IF (NVALID(cq19, cq20) >= 1) csqol6  = 100 * ((2 * MEAN(cq19, cq20)- 2) / 8) .
VARIABLE LABEL csqol6  "Relationships with family".
EXECUTE .
```

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```
IF (NVALID(cq21, cq22) >= 1) csqol7  = 100 * ((2 * MEAN(cq21, cq22) - 2) / 8) .
VARIABLE LABEL csqol7  "Relationships with friends".
EXECUTE .

COMPUTE csqol = (csqol1 + csqol2 + csqol3 + csqol4 + csqol5 + csqol6 + csqol7) /
7 .
VARIABLE LABEL csqol "Index" .
EXECUTE .
```

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Burden Assessment Schedule (BAS)

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Burden Assessment Schedule

1. Do you think that your family appreciates the way you care for the patient?

   Not at all 3
   To some extent 2
   Very much 1

2. Does the patient's illness prevent you from having a satisfying relationship with the rest of your family?

   Not at all 1
   To some extent 2
   Very much 3

3*. Does your spouse help with family responsibilities?

   Not at all 3
   To some extent 2
   Very much 1

4*. Is your spouse still affectionate towards you?

   Not at all 3
   To some extent 2
   Very much 1

5*. Is your spouse able to satisfy your needs for intimacy?

   Not at all 3
   To some extent 2
   Very much 1

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6*. Has the quality of your marital relationship declined since your spuse' illness?

Not at all	1
To some extent	2
Very much	3

7. Does caring for the patient make you feel tired and exhausted?

Not at all	1
To some extent	2
Very much	3

8. Do you think that your health has been affected because of the patient's illness?

Not at all	1
To some extent	2
Very much	3

9. Do you sometimes feel depressed and anxious because of the patient?

Not at all	1
To some extent	2
Very much	3

10. Do you sometimes feel that there is no solution to your problems?

Not at all	1
To some extent	2
Very much	3

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11. Has you family stability been disrupted by the patient's illness (frequent quarrels, break-up)?

Not at all	1
To some extent	2
Very much	3

12. Does the patiens cause disturbances in the home?

Not at all	1
To some extent	2
Very much	3

13. Are you able to care enough for others in your family?

Not at all	3
To some extent	2
Very much	1

14. Have you started to feel lonely and isolated since the patient's illness?

Not at all	1
To some extent	2
Very much	3

15. Does the patient's unpredictable behaviour disturb you?

Not at all	1
To some extent	2
Very much	3

16. Do you feel that your friends appreciate the way you care for the patient?

Not at all	3
To some extent	2
Very much	1

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17. Does patient's illness prevent you from having satisfying relationship with your friends?

Not at all	1
To some extent	2
Very much	3

18. Do you often feel frustated that the improvement of the patient is slow/ there is no improvement at all?

Not at all	1
To some extent	2
Very much	3

19. Do you have the feeling that the paient understands and apprecates your effort to help him/ her?

Not at all	3
To some extent	2
Very much	1

20. Is the patient's illness preventing you from looking for a job?

Not at all	1
To some extent	2
Very much	3

*These items apply only if the patient is a spuse to the caregiver

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Perceived Control of Symptoms

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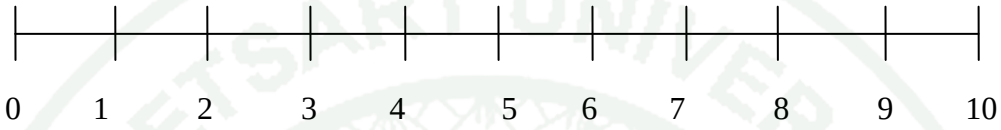
Instruction:

Please rate your ability to control the symptoms of the patient on a scale from 0 to 10, with 0= completely cannot control the symptoms and 10=completely control the symptoms. Circle the number that best describe your perception.



Completely cannot control the symptoms

Completely control the symptoms

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The Multidimensional Scale of Perceived Social Support (MSPSS)

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Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3.My family really tries to help me.	1	2	3	4	5	6	7
4.I get the emotional help & support I need from my family.	1	2	3	4	5	6	7

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	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
5.I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.My friends really try to help me.	1	2	3	4	5	6	7
7.I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.I can talk about my problems with my family.	1	2	3	4	5	6	7
9.I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.My family is willing to help me make decisions	1	2	3	4	5	6	7
12.I can talk about my problems with my friends	1	2	3	4	5	6	7

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Appendix B
Permission to Use the Picture and the Questionnaires

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From: karina Megasari Winahyu [karinawinahyu@yahoo.com]
Sent: Sunday, February 16, 2014 5:25 PM
To: dfk.wong@cityu.edu.hk
Subject: Asking for the permit to use a model

Dear Professor Daniel Fu Keung Wong,

I am Karina Megasari Winahyu, a student of Master of Science in Nursing writing my Thesis: Predictors of Quaity of Life of Family Caregivers of Patients with Schizophrenia. In my study I use a model with three sets of factors affecting the QoL of the caregivers of family members with menta illness as a conceptual framework to identify the predictors of quality of life of family caregives of patients with schizophrenia. Concerning with that, I would like to ask for the permission to use a picture of the model published in Journal of Health and Quality of Life Outcomes (2012), 10:15 in my thesis. Thank you for your attention and kindness.

Best Regards,
Karina Megasari W

Prof. WONG Fu Keung Daniel
To Me
Feb 17

Sure

Disc;aimer: This email (including any attachments) is for the use of the intended recipient only and may contain confidential information and/or copyright material. If you are not the intended recipient, please notify the sender immediately and delete this email and all copies from your system. Any unauthorized use, disclosure, reproduction, copying, distribution, or other form of unauthorized dissemination of the contents is expressly prohibited.

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Objet : Re: RE : RE : Asking for The Permit to Use The Schizophrenia Caregiver Quality of Life Questionnaire and The Manu

Dear Dr. Laurent Boyer,

Regarding the permission that I already got from you for using the S-CGQoL in my study: Predictors of Quality of Life of Family Caregivers of Patients with Schizophrenia in Indonesia, I would like to ask for the permission to translate the questionnaire into Indonesian Language. I hope that you will give the permission for translating the questionnaire. Thank you for your attention and kindness.

Best Regards,
Karina Megasari Winahyu

BOYER Laurent

To Me
Apr 11
Of course, no problem. It will be good also to validate it.

Laurent Boyer, M.D., Ph.D.
Epidémiologie, économie de la santé et prévention
Unité d'Information Médicale et de Recherche en Psychiatrie
Assistance Publique - Hôpitaux de Marseille (Tel.:+33-686936276)
EA 3279 Qualité de Vie Concepts, Usages et Limites, Déterminants, Aix-Marseille Université, 13284, Marseille,

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Dear dr. Prianto Djatmiko, Sp.KJ

I am Karina Megasari, a Master of Nursing Science student writing my thesis: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia. One of my independent variable is caregiver burden. In order to get the result of the study, I would like to ask for the permission to use the Indonesian version of Burden Assessment Schedule (BAS), which I found that You had studied about the BAS and had a good validity and reliability. Also, I would like to ask for the Indonesian version of the BAS and the permission to use the questionnaire from you. Thank you very much for your attention and kindness.

Best Regards,
Karina Megasari Winahyu

Prianto Djatmiko
To Me
Dear Karina,

Thank you for contacted me for the permission, and I'm happy to let you use the Indonesian version of BAS. Hope you will be sucsess in your study. Good Luck! Cheers!

Prianto Djatmiko
Psychiatrist
Mobile Phone: +6281218808806
Mental Health Check-Up Unit
Dr. Soeharto Heerdjan Mental Hospital
(http://www.rsjsh.com/index.php/read/pages/medical-health-check-up)
Jl. Prof. DR. Latumeten No. 1 Grogol Petamburan, Jakarta Barat 11460, Indonesia.

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From: karina Megasari Winahyu [karinawinahyu@yahoo.com]

Sent: Friday, April 11, 2014 5:06 AM

To: Zimet, Gregory D

Subject: Re: Asking for The Permit to Use The Multidimensional Scale of Perceived Social Support and The Manual

Dear Professor Gregory Zimet,

According to the permission for using the MSPSS in my study: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia, which I already got from you, I would like to ask for the permission for translating the questionnaire into Indonesian Language. Since my study will be conducted in Indonesia, I hope that you will give the permission for translating the questionnaire.

Thank you for your attention and kindness.

Best Regards,

Karina

Zimet, Gregory D

To Me

Apr 11

Dear Karina,

You have my permission to translate the MSPSS into Indonesian Language. When you complete the translation, please send me a copy, as I like to keep track of the different languages that the MSPSS has been translated into.

Best regards,

Greg Zimet

Gregory D. Zimet, PhD
Professor of Pediatrics & Clinical Psychology
Section of Adolescent Medicine, Indiana University School of Medicine. USA.

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Appendix C
The Letter of Translation Validation

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LBI
Lembaga Bahasa Internasional FIB UI

To Whom It May Concern:
No. 177/FIBUI/LBI/PPP/IV/2014

This is to certify that the Translation Program of LBI-FIBUI (the International Language Institute of the Faculty of Humanities, University of Indonesia) has translated "Burden Assesment Schedule of SCARF & The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL)" from *English* to *Indonesian*. The translated title is entitled "Jadwal Penilaian Beban SCARF & Kuesioner Kualitas Hidup Pemberi Perawatan untuk Kasus Skizofrenia".

This statement has been issued for use as stated and intended.

Jakarta, April 10, 2014

Dr. Grace Tiwon Wiradisastra
Manager, Translation and Interpretation Program

PROGRAM BAHASA INDONESIA UNTUK PENUTUR ASING • PROGRAM PELAYANAN BAHASA • PROGRAM PENGEMBANGAN PENERJEMAHAN
GEDUNG V, LT.1, KAMPUS FIB UI, DEPOK 16424, TELP: (021) 7864075, 78849082, FAKSIMILI: (021) 78849085

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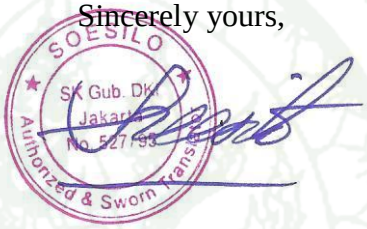
To: Ms Karina Megasari Winahyu

Re: **Statement of Translation**

I Soesilo, Sworn Translator in Jakarta Decree of Governor of DKI Jakarta No. 527/1995. In regard to the translation of ***The Schizophrenia Caregiver Quality of Life questionnaire*** *(S-CGQoL) and* ***Multidimensional Scale of Perceived Social Support,*** I certify that I have translated the foregoing from English to Indonesian that is true and complete and that I am competent in both languages.

Sincerely yours,



SOESILO

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Appendix D
The Bahasa Indonesia Version of the Questionnaire

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Karakteristik Pemberi Perawatan

Kode :

Tanggal:

Instruksi:

Isilah pertanyaan berikut dan berikan tanda centang [√] pada pilihan jawaban yang sesuai ☐ √

1. Jenis Kelamin

   ☐ 1. Perempuan ☐ 2. Laki-laki

2. Tingkat pendidikan tertinggi yang telah Anda capai:

   ☐ 1. Sekolah Dasar (SD)

   ☐ 2.Sekolah Menengah Pertama (SMP)

   ☐ 3. Sekolah Menengah Atas (SMA)

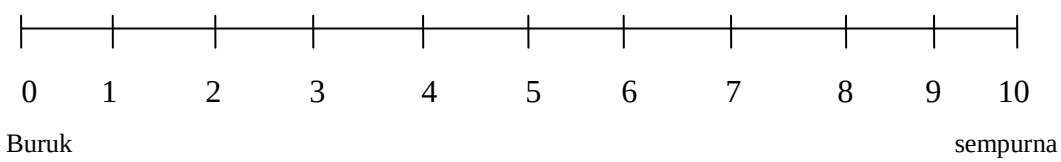
   ☐ 4. Perguruan Tinggi

3. Berapa tahun Anda telah menjadi seorang pemberi perawatan untuk keluarga Anda dengan skizofrenia? .....tahun

4. Status pekerjaan Anda saat ini

   ☐ 1. Bekerja ☐ 2. Tidak bekerja

5. Ukurlah status kesehatan fisik, mental dan psikologis Anda saat ini dalam skala dari 0 sampai 10, dengan 0= buruk dan 10=sempurna. Lingkarkanlah nomor yang paling sesuai menggambarkan kesehatan Anda.



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Kuesioner Kualitas Pemberi Perawatan Untuk Kasus Skizofrenia

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Kuesioner kualitas Hidup Pemberi Perawatan untuk kasus Skizofrenia (S-CGQoL)

Informasi yang terdapat dalam kuesioner ini bersifat sangat rahasia.

Kami meminta Anda menjawab pertanyaan-pertanyaan ini karena hal tersebut akan membantu kami menilai kualitas kehidupan sehari-hari Anda serta keadaan kesehatan Anda secara umum. Kami ingin memahami lebih baik dampak melakukan perawatan pada kualitas hidup Anda.

Mohon menjawab setiap pertanyaan dengan memberi Anda centang pada kotak tersedia yang menggambarkan sedekat mungkin apa yang Anda rasakan selama 12 bulan terakhir. Beberapa pertanyaan menyangkut kehidupan pribadi Anda. Pertanyaan tersebut perlu untuk mengevaluasi semua aspek keadaan kesehatan Anda. Namun, apabila Anda merasa bahwa sebuah pertanyaan tidak menyangkut Anda atau apabila Anda tidak ingin menjawabnya, lewati pertanyaan itu dan berlanjut ke pertanyaan berikutnya.

Terima kasih

PENERJEMAH BERSUMPAH
GRACE WIRADISASTRA
S.K. GUB. KDKI Jakarta
SWORN TRANSLATOR

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Untuk setiap pertanyaan, beri tanda centang pada kotak tersedia yang sesuai dengan apa yang Anda rasakan selama 12 bulan terakhir.

Selama 12 bulan terakhir, apakah Anda...	Tidak Pernah	Jarang	Kadang-kadang	Sering	Selalu
1. merasa sedih, depresi?					
2. merasa bekerja terlalu keras, kehabisan tenaga?					
3. kekurangan energi?					
4. merasa capek, letih?					
5. merasa gelisah, khawatir?					
6. harus berhenti melakukan hal-hal yang dulunya Anda senang lakukan?					
7. harus mengurangi jumlah waktu yang digunakan untuk kegiatan santai Anda (pergi keluar, bertaman, belanja, melakukan pekerjaan kecil-kecil...)?					
8. merasa malu meninggalkan anak Anda untuk menghadiri kegiatan harian Anda atau kehidupan profesional Anda?					
9. mempunyai perasaan bahwa Anda tidak mendedikasikan cukup waktu Anda untuk seluruh keluarga Anda?					
10. mempunyai perasaan bahwa Anda tidaklah bebas?					
11. mempunyai perasaan bahwa kehidupan Anda hanya dari hari ke hari tanpa dapat merencanakan masa depan?					
12. mempunyai kesulitan dalam membuat rencana-rencana profesional atau pribadi?					
13. dibantu, didukung oleh pasangan Anda?					
14. didengarkan, dimengerti oleh pasangan Anda?					
15. mempunyai kehidupan emosional dan seksual yang memuaskan?					

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S.K. GUB. KDKI Jakarta
no. 527/1995
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16. didengarkan, dimengerti oleh dokter dan suster?					
17. dibantu, didukung oleh dokter dan suster?					
18. merasa puas dengan informasi yang diberikan dokter dan suster?					
19. dibantu, didukung oleh keluarga Anda?					
20. didengarkan, dimengerti oleh keluarga Anda?					
21. dibantu, didukung oleh teman-teman Anda?					
22. didengarkan, dimengerti oleh teman-teman Anda?					
23. menemukan kesulitan karena sakitnya anak Anda ketika melamar ke departemen administrasi?					
24. mengalami kesulitan keuangan dalam menghadapi sakitnya anak Anda?					
25. mempunyai kesulitan secara materi (perumahan, kendaraan...)?					

Terima kasih atas partisipasi Anda

PENERJEMAH BERSUMPAH
GRACE WIRADISASTRA
S.K. GUB. KDKI Jakarta
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Instrumen Penilaian Beban Perawatan

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Instruksi:
Pertanyaan-pertanyaan berikut akan menanyakan pengalaman Anda selama merawat anggota keluarga dengan skizofrenia di rumah. Untuk setiap pertanyaan, jawablah yang paling menggambarkan perasaan Anda. Meskipun beberapa pertanyaan ini bersifat pribadi, cobalah untuk menjawab sejujur mungkin. Jawaban Anda akan dijaga kerahasiaannya. Mohon jawaban dengan memberi tanda √ pada kolom yang tersedia.

Pertanyaan	Tidak sama sekali	Ya, sampai taraf tertentu	Sangat	Skor
1. Apakah keluarga Anda menghargai cara Anda merawat anggota keluarga dengan skizofrenia?				
2. Apakah penyakit pasien menghambat Anda dalam menjalin hubungan yang baik dengan anggota keluarga Anda yang lainnya?				
3. Apakah pasangan Anda ikut membantu dalam kegiatan rumah tangga?				
4. Apakah pasangan Anda masih menunjukkan perhatian pada Anda?				
5. Apakah pasangan Anda mampu memuaskan kebutuhan Anda dalam kemesraan?				
6. Apakah kualitas hubungan Anda menurun sejak pasangan Anda sakit?				
7. Apakah dalam merawat pasien membuat Anda merasa lelah dan kehabisan tenaga?				

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Pertanyaan	Tidak sama sekali	Ya, sampai taraf tertentu	Sangat	Skor
8. Apakah Anda merasa bahwa kesehatan Anda terganggu karena sakitnya pasien?				
9. Apakah Anda kadang-kadang merasa tertekan dan cemas karena pasien?				
10. Apakah Anda kadang-kadang merasa bahwa persoalan yang Anda hadapi tidak ada jalan keluarnya?				
11. Apakah keharmonisan keluarga Anda terganggu oleh penyakit pasien (sering bertengkar, terancam berpisah)?				
12. Apakah pasien menimbulkan kekacauan di rumah				
13. Apakah Anda cukup mampu merawat anggota keluarga yang lain?				
14. Apakah Anda mulai merasa kesepian dan terkucil sejak pasien sakit?				
15. Apakah perilaku pasien yang tak terduga mengganggu Anda?				
16. Apakah Anda merasa bahwa teman-teman Anda menghargai cara Anda merawat pasien?				

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Pertanyaan	Tidak sama sekali	Ya, sampai taraf tertentu	Sangat	Skor
17. Apakah penyakit pasien menghambat Anda dalam menjalin hubungan yang baik dengan teman-teman Anda?				
18. Apakah Anda sering merasa frustasi karena lambatnya/ tidak adanya perbaikan pada pasien sama sekali?				
19. Apakah Anda merasa bahwa pasien dapat mengerti dan menghargai usaha Anda dalam menolongnya?				
20. Apakah penyakit pasien menghambat Anda dalam mencari pekerjaan?				

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Kemampuan Mengontrol Gejala yang Dirasakan

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Terjemahan dari bahasa Inggris

Persepsi mengenai Pengendalian Gejala Penyakit

Petunjuk:

1. Berilah nilai pada kemampuan Anda mengendalikan gejala penyakit pasien pada skala 0 sampai 10, dimana 0 = sama sekali tidak dapat mengendalikan gejala penyakit dan 10 = dapat mengendalikan gejala penyakit secara tuntas. Lingkari nomor yang mewakili penilaian Anda.

0 1 2 3 4 5 6 7 8 9 10

Sama sekali tidak dapat mengendalikan gejala penyakit

Dapat mengendalikan gejala penyakit secara tuntas

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Skala Multidimensional Dukungan Sosial yang Dirasakan

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Terjemahan dari bahasa Inggris

Multidimensional Scale of Perceived Social Support

Skala Multidimensional Dukungan Sosial Yang Dirasakan

Petunjuk: Kami ingin mengetahui bagaimana perasaan Anda tentang pernyataan-pernyataan berikut. Baca setiap pernyataan dengan teliti. Tunjukkan bagaimana perasaan Anda tentang setiap pernyataan dengan cara berikut:

Lingkari "1" bila Anda **Sangat Tidak Setuju**
Lingkari "2" bila Anda **Tidak Setuju**
Lingkari "3" bila Anda **Agak Tidak Setuju**
Lingkari "4" bila Anda are **Netral**
Lingkari "5" bila Anda **Agak Setuju**
Lingkari "6" bila Anda **Setuju**
Lingkari "7" bila Anda **Sangat Setuju**

	Sangat Tidak Setuju	Tidak Setuju	Agak Tidak Setuju	Netral	Agak Setuju	Setuju	Sangat Setuju
1. Ada orang khusus yang selalu ada ketika saya memerlukan bantuan	1	2	3	4	5	6	7
2. Ada orang khusus dengan siapa saya dapat berbagi suka dan duka.	1	2	3	4	5	6	7
3. Keluarga saya sungguh-sungguh mencoba membantu saya.	1	2	3	4	5	6	7
4. Saya mendapatkan bantuan emosional & dukungan yang saya butuhkan dari keluarga saya.	1	2	3	4	5	6	7
5. Saya mempunyai seseorang khusus yang merupakan sumber kenyamanan bagi saya.	1	2	3	4	5	6	7
6. Teman-teman saya benar-benar mencoba membantu saya.	1	2	3	4	5	6	7

PENERJEMAH BERSUMPAH
GRACE WIRADISASTRA
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Terjemahan dari bahasa Inggris

	Sangat Tidak Setuju	Tidak Setuju	Agak Tidak Setuju	Netral	Agak Setuju	Setuju	Sangat Setuju
8. Saya dapat membicarakan masalah saya dengan keluarga.	1	2	3	4	5	6	7
9. Saya mempunyai teman-teman dengan siapa saya dapat berbagi suka dan duka saya.	1	2	3	4	5	6	7
10. Ada orang khusus dalam hidup saya yang peduli tentang perasaan saya.	1	2	3	4	5	6	7
11. Keluarga saya bersedia membantu saya mengambil keputusan.	1	2	3	4	5	6	7
12. Saya dapat berbicara tentang masalah saya dengan teman-teman saya.	1	2	3	4	5	6	7

Referensi Skala:

Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Percieved Social Support. *Journal of Personality Assessment* 1988;52:30-41.

Informasi mengenai pemberian nilai:

Untuk menghitung nilai rata-rata:

Sub-skala Orang Lain yang Penting: Jumlahkan nilai butir 1, 2, 5, & 10, kemudian dibagi 4.
Sub-skala Keluarga: Jumlahkan nilai butir 3, 4, 8, & 11, kemudian dibagi 4.
Sub-skala Teman : Jumlahkan nilai butir 6, 7, 9, & 12, , kemudian dibagi 4.

Jumlah Total Skala: Jumlahkan nilai semua butir, kemudian dibagi 12.

PENERJEMAH BERSUMPAH
DRS. WIRADISASTRA
S.K. GUB. KDKI Jakarta
SWORN TRANSLATOR

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Appendix E
The Ethical Review Board

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Boromarajonani College of Nursing Nopparat Vajira

ERB No. 42 / 2014

ETHICAL REVIEW BOARD

Baromarjonnani College of Nursing Nopparat Vajira

681 Ramintra Road, Khannayao, Bangkok 10230, Thailand, Tel. 02-540-6500 ext 222

Certificate of Approval The Institutional Review Board of the Baromarjonnani College of Nursing Nopparat Vajira 681 Ramintra Road, Khannayao, Bangkok Thailand, has approved the following study which is to be carried out in compliance with the International guidelines for human Research protection as Declaration of Helsinki, The Belmont Report.

Study Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

Study Center: Indonesia

Principal Investigator: Ms. Karina Megasari Winahyu

Document Reviewed:

1. Principal Investigator (PI)
2. Proposal Version1
3. Patient Information Sheet Version2

Signature..... Signature.....

(BENJAMAS SIRIKAMONSATHIAN) (SUSHEEWA WICHAIKULL)

Chairperson of Ethical Review Board Secretary of Ethical Review Board

Date of Approval: 4 July 2014

Approval Expire Date: 3 July 2015

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Appendix F
Information Sheet and Inform Consent Form

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	Boromarajonani College of Nursing Nopparat Vajira	**Form of Patient/ Participant Information Sheet**

Title of research project: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

Principle researcher:

Name: Karina Megasari Winahyu Student ID: 5561250099

Position : Student in Master of Nursing Science Program, Boromarajonnani College of Nursing Nopparat Vajira, affiliated institution of Kasetsart University, Bangkok, Thailand.

Office address: Universitas Muhammadiyah Tangerang, Jln. Perintis Kemerdekaan 1/ 33, Cikokol, Tangerang, Banten, Indonesia

Home address : Perumahan Alam Indah, blok D 1/ 14, Cipondoh, Tangerang, Banten, Indonesia

Phone Number: +622155793802 (Office)
+6285771199955 (Indonesia)
+66846633910 (Thailand)

E-mail address: karinawinahyu@yahoo.com

You are being invited to take part in a research project. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and do not hesitate to ask if any information unclear or you would like more information about this study.

The worldwide prevalence of mental illness, including schizophrenia as a severe mental illness are increasing. In addition, Ministry of Health Republic of

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Indonesia (2013) stated that schizophrenia is included as one of an important diseases, among other physical chronic illness, such as cancer or heart disease. People with schizophrenia need a long term of treatment, including the treatment in a mental hospital and home care in the family. Therefore, a family member could be a person who will take care the patient at home. However, taking care the patient with schizophrenia could bring impacts for the caregivers. Consequently, the situation later on could affect the life of the caregiver, for example, disturbing the personal life activities or feeling of stress.

This research project involves family caregivers who taking care patients with schizophrenia. The purpose of this study is to identify factors influencing quality of life among family caregivers of patients with schizophrenia. The study will ask to family caregiver who accompanied the patient with schizophrenia to outpatient department about caregiver burden, perceived social support, and the quality of life of the caregiver

The characteristics of the participants in this study are caregivers who are 18-65 years old, take care a patient with schizophrenia who functioning stably in the community that is indicated by, no need for hospitalization or had not been increasing in medication for at least 3 month; accompany a patient with schizophrenia to the outpatient department, and had been a family caregiver for at least one year. In addition, the exclusion criteria of the study are family caregivers who are not willing to participate, took care of more than one family member with mental illness, caregivers of patients with schizophrenia and substance abuse. People who met the inclusion of the criteria after interviewed by the researcher will be a potential participant in the study. Number of participants needed are 136 participants. To approach the participants, the researcher got permission from the Head of Mental Hospital Dr. Soeharto Heerdjan to approach the caregivers to be interviewed to meet the potential participants. The caregivers are invited because the process of taking care of patients with schizophrenia was found to have impacts for the quality of life

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among family caregivers of patients with schizophrenia; therefore the caregivers are the source of good information for this study.

The researcher will approach and interview according to the inclusion and exclusion criteria. Participants who meet the inclusion criteria will be given information related the purpose, benefits, and procedure of the study. After that, the participants will be asked to sign the informed consent form. Also, the researcher may need to look at some of the patient' data in medical record in the outpatient department to make sure about your loved one diagnosis if needed with the permission of the nurse. Also, a trained research assistant who understood the same data collection procedure as the researcher will help the researcher in collecting data of the study.

The participants will fill out the questionnaires by themselves, yet if the participants illiterate/ cannot write or read, then the researcher will help to fill out the questionnaires by reading the questionnaire for the participants and let the participants choose the answer by themselves. The questionnaires are estimated to be complete around 60 minutes for each participant. The process of data collection will be conducted within 5 working days of outpatient department Mental Hospital Dr. Soeharto Heerdjan Jakarta in June-July, 2014. After the end of the study, all information about the participants will be kept confidential and the data of participants will be destroyed after 2 years of the study.

If you do not meet the criteria, then the researcher will explain about the inclusion criteria of the study related to the participant characteristics. Also, if you would like to know more information about the study so the researcher will give the information that related to the study.

There will be no harm/ risk in physical or mental of the participants in the study. However, you might feel some uncomfortable during the process of filling the questionnaire that could involve some sensitive questions related to the experience of

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taking care the patient with schizophrenia. Therefore, the researcher will provide a private room in the outpatient department for reducing the negative effect from some sensitive questions that could make the caregivers uncomfortable while answering the questionnaires. The participant is allowed to skip the question if you feel discomfort to answer and you can stop anytime to discuss any problem that you have found in the questionnaire.

There is no direct benefit to the participants in this study, but your contribution will be helpful to identify factors influencing quality of life among family caregivers of patients with schizophrenia, and also will be helpful to identify the potential intervention for the caregivers to improve the quality of life.

Your participation is strictly voluntary. You have your right to refuse or withdraw at any time without giving a reason or without negative consequences. You and the patient can still receive the same usual services in Mental Hospital Dr. Soeharto Heerdjan Jakarta. If you have any question or you would like to obtain more information related to the study, you can contact me according to the address I had written above. If the researcher has new information regarding benefits or risk/ harm, you will be informed as soon as possible.

Your answer will be anonymous and confidential. The data will use a different code number for each participant. The data of participants will be saved in a locked cabinet and the soft file of data will be saved in the password protected computer. The data in the questionnaires will be accessible only for the researcher and the advisor. Regarding the findings of the study, if the study finds any family caregiver has poor quality of life, then the researcher will inform the result to the health care provider in outpatient department mental hospital Dr. Soeeharto Heerdjan based on the agreement of the participants. In any case of publication, and/ or or result of the study will be reported as a total picture that the researcher will not provide any sort of information that could identify you.

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In this great opportunity I would like to convey my thankfulness to you by giving a small souvenir (a wallet) for taking part in the study. No incentive will be used to favor for participating the study. Your participation in this study will be highly valued and much appreciated. Thank you very much for being a participant in this study.

If the researcher does not perform upon the participants as indicated in the information, the participants can report the incident to the Ethic Review Committee for Research Involving Human Research Subjects, Boromarajonani College of Nursing Nopparat Vajira 681 Ramintra Road, Khannayao, Bangkok 10230, Thailand, Tel. 02-540-6500 ext 257, 246.

Yours faithfully,
(Karina Megasari Winahyu)

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	Boromarajonani College of Nursing Nopparat Vajira	**Form of Informed Consent Form**

Date……..…....

Code number of participant ……....

I who have signed here below agree to participate in this research project

Title "Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia"

Principle researcher:

Name : Ms. Karina Megasari Winahyu

Student ID : 5516250099, Master of Nursing Science Program, Kasetsart University, Thailand.

Phone number: +6285771199955 (Indonesia)
+66846633910 (Thailand)

E-mail address: karinawinahyu@yahoo.com

I have **read** about rationale and objective(s) of the project, what I will be engaged with in details, risk/ham and benefit of this project. The researcher has explained to me and I **clearly understand with satisfaction.**

I willingly **agree** to participate in this project and consent the researcher to answer to the questionnaires for around 60 minutes. The findings that showed any caregiver who has poor quality of life will be informed to the mental health hospital Dr. Soeharto Heerdjan Jakarta to be followed up data.

After the end of the project the questionnaire and data about participants will be kept as confidential and will be destroyed after 2 years of the project. In case of

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publication, the researcher will not provide any information that could identify the participant.

I have **the right** to withdraw from this research project at any time as I wish with no need to **give any reason**. This withdrawal **will not have any negative impact upon me, for example, still receive the usual services.**

Researcher has guaranteed that procedure(s) acted upon me would be exactly the same as indicated in the information. Any of my personal information will be **kept confidential.** The results of the study will be reported as total picture. Any personal information which could be able to identify me will not appear in the report.

If I am not treated as indicated in the information sheet, I can report to the Ethics Review Committee for Research Involving Human Research Subjects, Baromarjonnani College of Nursing Nopparat Vajira 681 Ramintra Road, Khannayao, Bangkok 10230, Thailand, Tel. 02-540-6500 ext 257, 246

I also have received a copy of the information sheet and informed consent form

Sign…..……... Sign……..…….……..

(……...……...……) (……...……)

Researcher Participant

Sign……

(…….....……)

Witness

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Appendix G
Letter of the Research Permit

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KEMENTERIAN KESEHATAN RI

DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT JIWA Dr. SOEHARTO HEERDJAN
Jl. Prof. DR. Latumeten No. 1, Jakarta Barat 11460 Telp. 021-5682841 - 43, Fax : 021-5682843

Number : DM 03.01/II.2/1110/2014
Subject : Approval for data collection of Ms. Karina M.W

June 30, 2014

Director of Boromarajonani College of Nursing Nopparat Vajira
Affiliated Institution of Kasetsart University
681 Ramintra Road, Kannayao, Bangkok 10230
Thailand

Referring to your letter No.0203.0932/542 dated May 12, 2014 and with the recommendation from Head of Research and Development Department No. DL 05.02/II.3/2389/2014, regarding the approval for data collection conducted by Ms. Karina Megasari Winahyu, we hereby approve this project to be taken place at Dr. Soeharto Heerdjan Mental Hospital starting from the beginning of July in order to support the completion of her thesis, entitled "Factors Influencing Quality of Life among family Caregivers of Patients with Schizophrenia in Indonesia".

We have appointed one of our staffs namely Ns. Carolina, MKep to help as well as support the assignment done by Ms. Karina Megasari Winahyu at our hospital.

In addition, we inform you that this activity will be charged as much as Rp 750,000 and payment for this fee can either be made by :
1. Paid to the cashier of the Hospital
2. Transfer to a/c no: 041801000021300 BRI Jelambar Branch in Jakarta, Indonesia, in the name of RS Jiwa Dr. Soeharto Heerdjan.

Should you have any further enquiries, do not hesitate to contact our hospital, phone no. (+62) 215682841.

Sincerely yours,
President Director

dr. Bella Patriajaya, SpKJ, MARS
NIP. 19610226 198902 1001

Cc. : 1. Head of Research and Development
2. Ns. Carolina, MKep

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Appendix H
The Letters and Names of Experts for the Content Validity

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Statement Letter of Content Validity of Research Instrument

I, Sri Supami, S.Kp., M.Kes. hereby declare that the research instrument of thesis of Ms. Karina Megasari Winahyu, entitled "Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia" has been reviewed for the content validity. Therefore, the instrument can be used in the aforementioned research instrument.

Yours Faithfully,

Sri Supami, S.Kp., M.Kes.
email: sri.supami@yahoo.com
Nurse instructor
Mental Hospital Dr. Soeharto Heerdjan

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Statement Letter of Content Validity of Research Instrument

I, dr. Galianti Prihandayani, Sp.KJ., hereby declare that the research instrument of thesis of Ms. Karina Megasari Winahyu, entitled "Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia" has been reviewed for the content validity. Therefore, the instrument can be used in the aforementioned research instrument.

Yours Faithfully,

dr. Galianti Prihandayani, Sp.KJ.
email: pgalianti@yahoo.co.id
Psychiatrist
Mental Hospital Dr. Soeharto Heerdjan

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Statement Letter of Content Validity of Research Instrument

I, Wilianti, S. Psi., M. Psi., Psikolog hereby declare that the research instrument of thesis of Ms. Karina Megasari Winahyu who are student from Boromarajonani College of Nursing Nopparat Vajira, affiliated institution Kasetsart University and who will undertaken quantitative research entitled "Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia" has been reviewed for the content validity in Bahasa Indonesia version "Faktor-Faktor yang Mempengaruhi Kualitas Hidup Para Pemberi Perawatan Keluarga Pasien dengan Skizofrenia di Indonesia. Therefore, the instrument can be used in the aforementioned research instrument.

Jakarta, July 7th, 2014

Yours Faithfully,

Wilianti, S. Psi., M. Psi., Psikolog
Phone: +62817776572
Psychologist
Mental Hospital Dr. Soeharto Heerdjan

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Appendix I
The Content Validity Index of the Quetionnaires

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Appendix Table I1

FORM OF CONTENT VALIDITY

(CHARACTERISTICS OF CAREGIVER FORM)

Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

1. Please rate each of the following items using the following rating. **Content relevance** of each item separately using a 4-point rating scale as follows: 1 = not relevant; 2 = item is in need revision; 3 = relevant but needs minor alteration; 4 = very relevant. **Content clarity** of each item separately using a 4-point rating scale as follows: 1 = not clear; 2 = item is in need revision; 3 = clear but needs minor alteration; 4 = very clear. **Categorized** =1-2 = content is invalid, 3-4 = content is valid. The content validity of instrument performed by three experts.

Part	**Statement**	**Content Relevance**				**Content Clarity**				**Comment**
		A	**B**	**C**		**A**	**B**	**C**		
Part I	1. Gender	4	4	4	1	4	4	4	1	
	2. The highest of level of education	4	4	4	1	3	4	4	0.9	
	3. Period for being a caregiver:..... years	4	4	4	1	4	4	4	1	

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Part	Statement	Content Relevance				Content Clarity				Comment
		A	**B**	**C**		**A**	**B**	**C**		
	4. Employment status	4	4	4	1	4	4	4	1	
	5. Please rate your current health status on a scale from 1 to 10, with 1= poor and 10=excellent. Circle the number that best describe your health.	4	3	4	0.9	4	3	3	0.83	Add explanation that current health status related to physically and psychologically.
	Content Validity Index for Scale (S-CVI)	1	0.95	1	**0.98**	0.95	0.95	0.95	**0.95**	

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Appendix Table I2

FORM OF CONTENT VALIDITY

SCHIZOPHRENIA-CAREGIVER QUALITY OF LIFE QUESTIONNAIRE (S-CGQoL)

Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

1. Please rate each of the following items using the following rating. **Content relevance** of each item separately using a 4-point rating scale as follows: 1 = not relevant; 2 = item is in need revision; 3 = relevant but needs minor alteration; 4 = very relevant. **Content clarity** of each item separately using a 4-point rating scale as follows: 1 = not clear; 2 = item is in need revision; 3 = clear but needs minor alteration; 4 = very clear. **Categorized** =1-2 = content is invalid, 3-4 = content is valid. The content validity of instrument performed by three experts.

Part	**Statement**	**Content Relevace**				**Content Clarity**				**Comment**
		A	**B**	**C**		A	B	C		
Part II	***For the last 12 months, have you…...***									
	1. Felt sad, depressed ?	4	4	4	1	4	3	4	0.9	
	2. Felt overworked, burnt-out ?	4	4	4	1	3	3	4	0.83	The question might need to use a complete sentence

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Part	Statement	Content Relevace				Content Clarity				Comment
		A	**B**	**C**		A	B	C		
	3. Lacked energy ?	4	4	4	1	4	4	4	1	
	4. Been tired, worn-out?	4	4	4	1	4	3	4	0.9	Tired or worn-out has sama meaning, choose and use either one.
	5. Felt anxious, worried	4	4	4	1	4	3	4	0.9	
	6. Had to give up doing things that you were very keen to do?	4	4	4	1	3	4	4	0.9	"Had to give up doing things" might need to change to "can not doing things"
	7. had to reduce the amount of time devoted to your leisure activities (outings, gardening, shopping, odd jobs…)?	4	4	4	1	4	4	4	1	
	8. been embarrassed to leave your child to attend your day or professional life?	4	3	4	0.9	3	3	4	0.83	"been embarassed" might need to change to "been uncomfortable"
	9. had the feeling that you didn't devote enough time to the rest of your family ?	4	4	4	1	3	3	4	0.83	"devote enough time" might need to change to "spend enough time"

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Part	Statement	Content Relevace				Content Clarity				Comment
		A	**B**	**C**		A	B	C		
	10. had the feeling that you weren‟t free?	4	4	4	1	4	4	4	1	
	11. Had the feeling that you led a day-to-day existence?	4	4	4	1	4	4	4	1	
	12. Had difficulty in making professional or personal plans?	4	4	4	1	4	4	4	1	
	13. Been helped, supported by your spouse?	4	4	4	1	4	4	4	1	
	14. Been listened to, understood by your spouse?	4	4	4	1	4	4	4	1	
	15. had a satisfying emotional and sexual life?	4	4	4	1	4	4	3	0.9	“emotional and sexual life” might need to change to “emotional and sexual relationship”
	16. Been listened to, understood by doctors and nurses?	4	4	4	1	4	4	4	1	
	17. Been helped, supported by doctors and nurses?	4	4	4	1	4	4	4	1	
	18. Been satisfied with information given by doctors and nurses?	4	4	4	1	4	4	4	1	

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Part	Statement	Content Relevace				Content Clarity				Comment
		A	**B**	**C**		A	B	C		
	19. Been helped, supported by your family?	4	4	4	1	4	4	4	1	
	20. Been listened to, understood by your family?	4	4	4	1	4	4	4	1	
	21. Been helped, supported by your friends?	4	4	4	1	4	4	4	1	
	22. Been listened to, understood by your friends?	4	4	4	1	4	4	4	1	
	23. Encountered difficulties because of your child's illness when applying to administration departments?	4	4	4	1	4	4	4	1	
	24. Had financial troubles in facing your child's illness?	4	4	4	1	4	4	4	1	
	25. Had material difficulties (housing, transport…)?	4	4	4	1	4	4	4	1	
	Content Validity Index for Scale (S-CVI)				0.96				0.95	

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Appendix Table I3

FORM OF CONTENT VALIDITY

BURDEN ASSESSMENT SCHEDULE (BAS)

Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

1. Please rate each of the following items using the following rating. **Content relevance** of each item separately using a 4-point rating scale as follows: 1 = not relevant; 2 = item is in need revision; 3 = relevant but needs minor alteration; 4 = very relevant. **Content clarity** of each item separately using a 4-point rating scale as follows: 1 = not clear; 2 = item is in need revision; 3 = clear but needs minor alteration; 4 = very clear. **Categorized** =1-2 = content is invalid, 3-4 = content is valid. The content validity of instrument performed by three experts.

Part	Statement	Content Relevace				Content Clarity				Comment
		A	B	C		A	B	C		
III	1. Do you think that your family appreciates the way you care for the patient?	4	4	4	1	4	4	4	1	
	2. Does the patient's illness prevent you from having a satisfying relationship with the rest of your family?	4	4	4	1	4	3	4	0.9	Use a consistent word for 'patient' or 'child' that refer to the people with schizophrenia.

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Part	Statement	Content Relevace				Content Clarity				Comment
		A	B	C		A	B	C		
	3. Does your spouse help with family responsibilities?	4	4	4	1	4	4	4	1	
	8. Is your spouse still affectionate towards you?	4	4	4	1	4	4	4	1	
	5. Is your spouse able to satisfy your needs for intimacy?	4	4	4	1	4	4	3	0.9	
	6. Has the quality of your marital relationship declined since your spouse's illness?	4	4	4	1	4	4	3	0.9	
	7. Does caring for the patient make you feel tired and exhausted?	4	4	4	1	4	4	4	1	
	9. Do you think that your health has been affected because of the patient's illness?	4	4	4	1	4	3	4	0.9	
	10. Do you sometimes feel depressed and anxious because of the patient?	4	4	4	1	4	3	4	0.9	
	11. Do you sometimes feel that there is no solution to your problems?	4	4	4	1	4	4	4	1	
	12. Has you family stability been disrupted by the patient's illness (frequent quarrels, break-up)?	4	4	4	1	4	4	4	1	
	13. Does the patiens cause disturbances in the home?	4	4	4	1	4	4	4	1	

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Part	Statement	Content Relevace				Content Clarity				Comment
		A	B	C		A	B	C		
	14. Are you able to care enough for others in your family?	4	4	4	1	4	4	4	1	
	15. Have you started to feel lonely and Isolated since the patient's illness?	4	4	4	1	4	4	4	1	
	16. Does the patient's unpredictable behaviour disturb you?	4	4	4	1	4	4	3	0.9	Give an example for unpredictable behaviour, such as violence.
	17. Do you feel that your friends appreciate the way you care for the patient?	4	4	4	1	4	4	4	1	
	18. Does patient"s illness prevent you from having satisfying relationship with your friends?	4	4	4	1	4	4	4	1	
	19. Do you often feel frustated that the improvement of the patient is slow/ there is no improvement at all?	4	4	4	1	4	4	4	1	
	19. Do you have the feeling that the patient understands and apprecates your effort to help him/ her?	4	4	4	1	4	4	4	1	
	20. Is the patient's illness preventing you from looking for a job?	4	4	4	1	4	4	4	1	
	Content Validity Index for Scale (S-CVI)				**1**				**0.97**	

***These items apply only if the patient is a spouse to the caregive**

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Appendix Table I4

FORM OF CONTENT VALIDITY

PERCEIVED CONTROL OF SYMPTOMS

Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

1. Please rate each of the following items using the following rating. **Content relevance** of each item separately using a 4-point rating scale as follows: 1 = not relevant; 2 = item is in need revision; 3 = relevant but needs minor alteration; 4 = very relevant. **Content clarity** of each item separately using a 4-point rating scale as follows: 1 = not clear; 2 = item is in need revision; 3 = clear but needs minor alteration; 4 = very clear. **Categorized** =1-2 = content is invalid, 3-4 = content is valid. It performed by three experts.

Part IV	**Statement**	**Content Relevace**				**Content Clarity**				**Comment**
		A	**B**	**C**		**A**	**B**	**C**		
	1. Please rate your ability to control the symptoms of the patient on a scale from 0 to 10, with 0= completely cannot control the symptoms and 10=completely control the symptoms. Circle the number that best describe your perception.	4	3	4	0.9	4	3	4	0.9	Give explanation to the caregivers what kind of symptoms that need to be cotrolled by them

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Appendix Table I5

FORM OF CONTENT VALIDITY

MULTIDEMSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Title: Factors Influencing Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

1. Please rate each of the following items using the following rating. **Content relevance** of each item separately using a 4-point rating scale as follows: 1 = not relevant; 2 = item is in need revision; 3 = relevant but needs minor alteration; 4 = very relevant. **Content clarity** of each item separately using a 4-point rating scale as follows: 1 = not clear; 2 = item is in need revision; 3 = clear but needs minor alteration; 4 = very clear. **Categorized** =1-2 = content is invalid, 3-4 = content is valid. The content validity of instrument performed by three experts.

Part V	**Statement**	**Content Relevace**				**Content Clarity**				**Comment**
		A	**B**	**C**		**A**	**B**	**C**		
	1. There is a special person who is around when I am in need.	4	4	4	1	4	4	4	1	
	2. There is a special person with whom I can share joys and sorrows.	4	4	4	1	4	4	4	1	
	3. My family really tries to help me.	4	4	4	1	4	4	4	1	

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Part V	Statement	Content Relevace				Content Clarity				Comment
		A	B	C		A	B	C		
	4. I get the emotional help & support I need from my family.	4	4	4	1	4	4	4	1	
	5. I have a special person who is a real source of comfort to me.	4	4	4	1	4	4	4	1	
	6. My friends really try to help me.	4	4	4	1	4	4	4	1	
	7. I can count on my friends when things go wrong.	4	4	4	1	4	4	4	1	
	8. I can talk about my problems with my family.	4	4	4	1	4	4	4	1	
	9. I have friends with whom I can share my joys and sorrows.	4	4	4	1	4	4	4	1	
	10. There is a special person in my life who cares about my feelings.	4	4	4	1	4	4	4	1	
	11. My family is willing to help me make decisions.	4	4	4	1	4	4	4	1	
	12. I can talk about my problems with my friends.	4	4	4	1	4		4	1	
	Content Validity Index for Scale (S-CVI)				1				1	

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Appendix J
Item Analysis of the Questionnaires

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Appendix Table J1 Frequency and percentage of items responses in the Schizophrenia Caregiver Quality of Life (S-CGQoL) questionnaire.

Items	Always n (%)	Often n (%)	Sometimes n (%)	Rarely n (%)	Never n (%)
1. Felt sad, depressed?	6 (4.4)	26 (19.0)	64 (46.7)	21 (15.3)	20 (14.6)
2. Felt overworked, burn-out?	3 (2.2)	25 (18.2)	43 (31.4)	32 (23.4)	34 (24.8)
3. Lacked energy?	5 (3.6)	23 (16.8)	61 (44.5)	21 (15.3)	27 (19.7)
4. Been tired, worn-out?	3 (2.2)	33 (24.1)	66 (48.2)	22 (16.1)	13 (9.5)
5. Felt anxious, worried?	7 (5.1)	33 (24.1)	61 (44.5)	29 (21.2.)	7 (5.1)
6. Had to give up doing things that you were very keen to do?	3 (2.2)	10 (7.3)	44 (32.1)	42 (30.7)	38 (27.7)
7. Had to reduce the amount of time devoted to your leisure activities (outings, gardenings, shopping, odd jobs...?	5 (3.6)	35 (25.5)	45 (32.8)	32 (23.4)	20 (14.6)
8. Been embarassed to leave your child to attend your day or personal life?	23 (16.8)	20 (14.6)	50 (36.5)	20 (14.6)	24 (17.5)
9. Had the feeling that you did't devote enough time to the rest of your family?	5 (3.6)	21 (15.3)	56 (40.9)	20 (14.6)	35 (25.5)
10. Had the feeling that you weren't free?	7 (5.1)	27 (19.7)	47 (34.3)	17 (12.4)	39 (28.5)
11. Had the feeling that you led day-to-day existence?	10 (7.3)	25 (18.2)	46 (33.6)	26 (19.0)	30 (21.9)

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Appendix Table J1 (Continued)

Items	Always n (%)	Often n (%)	Sometimes n (%)	Rarely n (%)	Never n (%)
12. Had difficulty in making professional or personal plans?	6 (4.4)	21 (15.3)	49 (35.8)	35 (25.5)	26 (19.0)
13. Been helped, supported by your spouse?	31 (27.2)	20 (17.5)	32 (28.1)	13 (11.4)	18 (15.8)
14. Been listened to, understood by your spouse?	29 (25.4)	25 (21.9)	22 (19.3)	19 (13.9)	19 (16.7)
15. had a satisfying emotional and sexual life?	7 (5.1)	10 (8.8)	44 (38.6)	26 (22.8)	27 (23.7)
16. Been listened to, understood by doctors and nurses?	34 (24.8)	54 (39.4)	36 (26.3)	7 (5.1)	6 (4.4)
17. Been helped, supported by doctors and nurses?	39 (28.5)	51 (37.2)	36 (26.3)	5 (3.6)	6 (4.4)
18. Been satisfied with information given by doctors and nurses?	43 (31.4)	48 (35.0)	40 (29.2)	3 (2.2)	3 (2.2)
19. Been helped, supported by your family?	44 (32.1)	27 (19.7)	43 (31.4)	18 (13.1)	5 (3.6)
20. Been listened to, understood by your family?	47 (34.3)	21 (15.3)	48 (35.0)	17 (12.4)	4 (2.9)
21. Been helped, supported by your friends?	25 (18.2)	13 (9.5)	54 (39.4)	25 (18.2)	20 (14.6)
22. Been listened to, understood by your friends?	25 (18.2)	11 (8.0)	58 (42.3)	20 (14.6)	23 (16.8)

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Appendix Table J1 (Continued)

Items	Always n (%)	Often n (%)	Sometimes n (%)	Rarely n (%)	Never n (%)
23. Encountered difficulties because of your child's illness when applying	4 (2.9)	3 (2.2)	19 (13.9)	37 (27.0)	74 (54.0)
24. Had financial troubles in facing your child's illness?	13 (9.5)	19 (13.9)	46 (33.6)	29 (21.2)	30 (21.9)
25. Had material difficulties (housing, transport…)?	11 (8.0)	18 (13.1)	41 (29.9)	34 (24.8)	33 (24.1)

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Appendix Table J2 Frequency and percentage of items response in the Burden Assessment Schedule (BAS).

Items	Very much n (%)	To some extent n (%)	Not at all n (%)
1. Do you think that your family appreciates the way you care for the patient?	42 (30.7)	90 (65.7)	4 ((3.6)
2. Does the patient's illness prevent you from having a satisfying relationship with the rest of your family?	10 (7.3)	63 (46.0)	64 (46.7)
3*. Does your spouse help with family responsibilities?	13 (24.5)	28 (52.8)	12 (22.6)
4*. Is your spouse still affectionate towards you?	23 (43.4)	24(45.3)	6 (11.3)
5*. Is your spouse able to satisfy your needs for intimacy?	16 (30.2)	24(45.3)	13 (24.5)
6*. Has the quality of your marital relationship declined since your spouse's illness?	1 (1.9)	18(34.0)	34 (64.2)
7. Does caring for the patient make you feel tired and exhausted?	7 (5.1)	87 (63.5)	43 (31.4)
8. Do you think that your health has been affected because of the patient's illness?	12 (8.8)	76 (55.5)	49 (35.8)
9. Do you sometimes feel depressed and anxious because of the patient?	15 (10.9)	100 (73.0)	22 (16.1)
10. Do you sometimes feel that there is no solution to your problems?	12 (8.8)	78 (56.9)	47 (34.3)
11. Has you family stability been disrupted by the patient's illness (frequent quarrels, break-up)?	2 (1.5)	63 (46.0)	72 (52.6)
12. Does the patiens cause disturbances in the home?	12 (8.8)	69 (50.4)	56 (40.9)

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Appendix Table J2 (Continued)

Items	Very much n (%)	To some extent n (%)	Not at all n (%)
13. Are you able to care enough for others in your family?	21 (15.3)	107 (78.1)	9 (6.6)
14. Have you started to feel lonely and isolated since the patient's illness?	7 (5.1)	40 (29.2)	90 (65.7)
15. Does the patient's unpredictable behaviour disturb you?	23 (16.8)	67 (48.9)	47 (34.3)
16. Do you feel that your friends appreciate the way you care for the patient?	37 (27.0)	92 (67.2)	8 (5.8)
17. Does patient's illness prevent you from having satisfying relationship with your friends?	2 (1.5)	59 (43.1)	76 (55.5)
18. Do you often feel frustated that the improvement of the patient is slow/ there is no improvement at all?	14 (10.2)	78 (56.9)	45 (32.8)
19. Do you have the feeling that the paient understands and appreciates your effort to help him/ her?	29 (21.2)	97 (70.8)	11 (8.0)
20. Is the patient's illness preventing you from looking for a job?	5 (3.6)	58 (42.3)	74 (54.0)

*These items apply only if the patient is a spouse to the caregiver

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Appendix Table J3 Frequency and percentage of items response in the Multidimensional Scale of Perceived Social Support (MSPSS).

Items	Very Strongly Disagree n (%)	Strongly Disagree n (%)	Mildly Disagree n (%)	Neutral n (%)	Mildly Agree n (%)	Strongly Agree n (%)	Very Strongly Agree n (%)
1. There is a special person who is around when I am in need.	1 (0.7)	27 (19.7)	20 (14.6)	15 (10.9)	16 (11.7)	52 (38.0)	6 (4.4)
2. There is a special person with whom I can share joys and sorrows.	2 (1.5)	8 (5.8)	15 (10.9)	7 (5.1)	34 (24.8)	58 (42.3)	13 (9.5)
3. My family really tries to help me.	1 (0.7)	7 (5.1)	17 (12.4)	13 (9.5)	23 (16.8)	55 (40.1)	21 (15.3)
4. I get the emotional help & support I need from my family.	2 (1.5)	5 (3.6)	19 (13.9)	9 (6.6)	27 (19.7)	58 (42.3)	17 (12.4)
5. I have a special person who is a real source of comfort to me.	1 (0.7)	6 (4.4)	27 (19.7)	15 (10.9)	30 (21.9)	48 (35.0)	10 (7.3)
6. My friends really try to help me.	3 (2.2)	28 (20.4)	30 (21.9)	17 (12.4)	17 (12.4)	33 (24.1)	9 (6.6)
7. I can count on my friends when things go wrong.	11 (8.0)	57 (41.6)	16 (11.7)	13 (9.5)	14 (10.2)	19 (13.9)	7 (5.1)
8. I can talk about my problems with my family.	0 (0)	5 (3.6)	20 (14.6)	7 (5.1)	18 (13.1)	77 (56.2)	10 (7.3)
9. I have friends with whom I can share my joys and sorrows.	1 (0.7)	24 (17.5)	32 (23.4)	13 (9.5)	23 (16.8)	33 (24.1)	11 (8.0)

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Appendix Table J3 (Continued)

Items	Very Strongly Disagree n (%)	Strongly Disagree n (%)	Mildly Disagree n (%)	Neutral n (%)	Mildly Agree n (%)	Strongly Agree n (%)	Very Strongly Agree n (%)
10. There is a special person in my life who cares about my feelings.	4 (2.9)	16 (11.7)	18 (13.1)	11 (8.0)	23 (16.8)	57 (41.6)	8 (5.8)
11. My family is willing to help me make decisions.	3 (2.2)	6 (4.4)	17 (12.4)	10 (7.3)	18 (13.1)	74 (54.0)	9 (6.6)
12. I can talk about my problems with my friends.	4 (2.9)	26 (19.0)	32 (23.4)	15 (10.9)	24 (17.5)	33 (24.1)	3 (2.2)

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CURRICULUM VITAE

NAME : Miss Karina Megasari Winahyu

BIRTH DATE : November 24th, 1987

BIRTH PLACE : Tangerang, Banten, Indonesia

EDUCATION

: **YEAR**	**INSTITUTE**	**DEGREE**
2010	University of Indonesia	Bachelor of Nursing Science (BNS)
2011	University of Indonesia	Nurse (Ns.)

POSITION **:** Student in Master of Nursing Science Program, Boromarajonani College of Nursing NopparaVajira, affiliated institution of Kasetsart University, Bangkok, Thailand

SCHOLARSHIP : Directorate General of Higher Education (DGHE) Ministry of Education and Culture Republic of Indonesia (2012-2014)

HOME ADDRESS : Jl. KH. Hasyim Ashari, Perumahan Alam Indah Blok D1/14, Cipondoh, Tangerang, 15141, Banten, Indonesia

OFFICE ADDRESS : University of Muhammadiyah Tangerang, Jl.Perintis Kemerdekaan 1/33, Cikokol, Tangerang, Banten, Indonesia

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