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# Correlation of Quality of Life and Burden among Caregivers of Schizophrenic Patients: A Preliminary Study

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Abstract: Malaysia implemented a deinstitutionalization policy a few decades ago and since, then there had been evidence that two-thirds of schizophrenic patients returned to live at home with family members. Past studies considered caring the most challenging and burdensome task. Thus, the aim of the study was to determine the level of caretaking burden and to explore the correlation between caretaking burden and Quality of Life (QoL) of the caregivers. This was a cross-sectional study which involved 60 caregivers of schizophrenic patients at the Outpatient Clinic of Hospital Canselor Tuanku Muhriz (HCTM). The Short Form-12 (SF-12) and Zarit Burden Interview (ZBI) questionnaires were used to assess quality of life and caretaking burden through face to face interview. Results showed that approximately 13.3% of the caregivers reported experiencing moderate to severe burden 40% reported having mild to moderate burden and the remaining had little or no burden. In addition, caretaking burden was correlated to all other domains in the SF-12 which were Bodily Pain (BP), Mental Health (MH), Vitality (VT), Role-Physical (RP), Role-Emotional (RE), Physical Functioning (PF) and Social Functioning (SF) except General Health (GH). The findings help health service providers and government aid to decrease the burden on caregivers and increase their QoL through appropriate programmes and interventions for improving the efficacy of the caring process.

Key words: Schizophrenia, quality of life, caretaking burden, caregiver, zarit burden interview

## INTRODUCTION

The World Health Organization (WHO, 1993, 2014) reported that about 24 million people worldwide have been diagnosed with schizophrenia and affecting 7 per thousand adults population. According to National Institute of Mental Health (NIMH) schizophrenia is a severe, chronic brain disorder that involves a set of complex disturbances of thinking, perception, affect and social behaviour. It is considered one of the most chronic and restricting disorders among major illnesses because people with schizophrenia often have problems functioning at their work or school in their relationships andwith society. It also continues with a recurring course if symptoms remain and patient suffers an incomplete social recovery (Balasubramanian et al., 2013; WHO, 2011). In Malaysia, there has been an increase in the number of people diagnosed with schizophrenia and they are currently receiving psychiatric treatment (Ministry of Health Malaysia, 2007). According to the National Mental Health Registry (NMHR, 2003) in Malaysia, a total of 7351 schizophrenia cases were

registered from 2003-2005 in Malaysia. Malaysia has also followed other countries in moving towards deinstitutionalization. Deinstitutionalization has shifted the responsibility of caring for schizophrenic patients to their caregivers and this can be a challenging and burdensome task (Li *et al.*, 2007; Koujalgi and Patil, 2013).

Perlick et al. (2005) have established some criteria to define a family caregiver that is, as a family caregiver an individual must fulfill at least three of the following criteria: an individual is a parent, partner, child, sibling or other relative; maintains frequent contact with the patient; provides significant financial support to the patient; is often present during the patient's treatment or is aware of the severity of the patient's illness; the person the therapy team is asked to contact during emergencies (Martin et al., 2013). Unlike a formal caregiver, an informal caregiver was defined as "the person belonging to the patient's informal support system who takes the responsibility of caregiving without receiving any money in return" (Caqueo et al., 2009).

Schizophrenic patients often resist treatment (NIMH, 2014) therefore, it does not only affect their lives but also the lives of the people around them, especially that of their caregivers (Srinivasamurthy, 2011; Balasubramanian et al., 2013). In the last decades, it was found that main caregivers had committed most of their time to take care of schizophrenic patients which resulted an increased burden among them (Yarrow et al., 1955; Kuipers, 1993; Caqueo et al., 2009; Martinez et al., 2000). Platt (1985) and Martin et al. (2013) found that physical and mental stress as well as constant worry about their loved one's health status were reasons caregivers of patients with chronic diseases always felt burdened. The burden was found to be associated with their Quality of Life (QoL) and it negatively affected their health. Having a caregiving role also damaged social and family life and the lack of social support made them feel unsatisfied with the services of health professionals. Zam et al. (2011) concluded that caregivers in the past had potential to experience lower QoL and a higher level of caretaking burden.

Previous studies has focused only on schizophrenic patients, more recently the caregiver's burden and QoL have gained significant attention because studies have shown that indirectly the have impact on the health of schizophrenic patients. Studies on this topic in Malaysia is lacking but more cases has been reported each year and it is noted that in past findings deinstitutionalization indirectly leads to higher caretaking burden and lower QoL among caregivers. Thus, this study aimed to assess the level of burden of care and QoL and their correlation in the Malaysian context.

## MATERIALS AND METHODS

Study design and participants: This was a cross-sectional study using survey questionnaires among caregivers of individuals with schizophrenia. Participants of this study were the caregivers of outpatients with schizophrenia who obtained treatment or follow-up from the Psychiatry Clinic, Hospital Canselor Tuanku Muhriz (HCTM) in Kuala Lumpur. Purposive sampling was employed during the recruitment of participants. Participants were family members of patients diagnosed with schizophrenia and their eligibility for this study was based on the following criteria: that they were identified as the main caregiver were 18 year of age or older; caregivers met the patients >4 h a day had no psychiatric illness themselves and is a Malaysian by nationality. Caregivers who did not meet the criteria were excluded from the study. This study involved 63 caregivers of schizophrenic patients aged between 18 and 80 year. The 3 participants did not complete the questionnaires so their responses were omitted from the study.

**Data collection:** Approval was obtained from the HCTM Scientific Research and Ethical Committee before proceeding with data collection. The researcher identified the caregivers of schizophrenic patients at the psychiatry clinic at HCTM by firstly obtaining the patient's name, registration number, index number and brief diagnosis from the registration counter at the clinic. The researcher then called the names at the clinic's waiting area and approached the patients. The researcher then sought permission to conduct the survey and distributed a consent form to the caregivers who came along with the selected patients on that day. After obtaining the completed consent form, the researcher then passed a set of self-rated questionnaire to the caregivers and proceeded to the face-to-face interview. Participants were approached while waiting for patient's treatment session.

**Instruments:** The self-rated questionnaire comprised of 3 parts: demographic data, the Zarit Burden Interview (ZBI) and the 12-item Short Form (SF-12).

Sociodemographic data and history: The researcher obtained information onparticipants including their gender, age, ethnicity, level of income, marital status, level of education, working status, duration of being a caregiver, relationship with the patient; patient's working status, their age and frequency of their appointments with the doctor.

Zarit Burden Interview (ZBI): Next, the Zarit Burden Interview (ZBI) was used to measure the burden of care among caregivers of schizophrenic patients. ZBI is a well-known measure to assess the level of burden because of its reproducibility and validity (Razali *et al.*, 2011; Choo *et al.*, 2003) with internal consistency of Cronbach's alpha coefficient of 0.92 (Hebert *et al.*, 2000). The ZBI is a 22-item questionnaire on 5-point Likert scale stating 0 as Never, to 4 as Nearly always, the higher scores indicated a higher level of caretaking burden.

The 12-item Short Form (SF-12): The last part of the questionnaire was the SF-12, a questionnaire to assess various aspects of functioning and well-being and to determine the overall level of quality of life (Ware *et al.*, 1996). The SF-12 consisted of eight dimensions: General Health (GH); Physical Functioning (PF); Role-Physical (RP); Role-Emotional (RE); Bodily Pain (BP); Mental Health (MH); Vitality (VT) and Social Functioning (SF).

The functioning dimensions were divided into 2 major aspects: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). PCS and MCS among the population in the United States showed test-retest reliability of 0.89 and 0.76, respectively (Ware *et al.*, 1996). Higher scores generally indicated better quality of life. The exception was on the BP where higher scores indicated a lower quality of life.

**Data analysis:** Data was analysed using the Statistical Package for Social Sciences (SPSS) Version 22 Software. A descriptive analysis was carried out to explore and describe the demographic information of the participants. Only details of participants who fulfilled the inclusion criteria were taken into account for further analysis. Pearson's correlation analysis was used to examine the relationship between the quality of life and burden among caregivers.

#### RESULTS AND DISCUSSION

A total of 60 out of 63 respondents (95.2%) were used in the study. The mean age of the participants for this study subjects was 53.2 year (SD = 1.91). There were more females (60%) than males (40%) who participated in the study and there were mostly Malay (45%) and Chinese (43.3%) with fewer Indian (8.3%) and other races (3.3%). The participants were mostly those who had embraced Islam (45%) followed by those who were Buddhists (30%), Christians (13.3%), Hindus (8.3%) and other religions or no religion (3.3%). Most of them (83.3%) were married, only some were single (8.3%) widowed (6.7%) and divorced (1.7%). The majority of the participants were staying in the city (86.7%) were not working (55%) and had took care of the patients for >3 year since the onset of the disorder (78.3%). Participants were educated mostly up to SPM or equivalent level (30%) STPM or equivalent (21.7%) and undergraduate (21.7%). Most of the participants had a parent-child relationship (70%) with the patients, followed by spouse (15%) sibling (8.3%) relative (5%) and non-relative (1.7%) was the least (Table 1).

Table 2 shows that majority of the respondents have little or no burden (46.7%) and mild to moderate burden (40%). Only 3.3% had severe burden and the rest was having moderate to severe burden (10%). Table 3 summarises the means and standard deviation of the 8 domains of QoL and level of burden. The RE score was the highest (M = 89.17, SD = 19.18) and the lowest score was BP (M = 41.00, SD = 17.82). The results showed mean score of 25.42 (SD = 15.40) for level of care taking burden.

In Table 4, the Pearson's correlation test showed that there were significant positive relationship between caretaking burden and bodily pain (r = 0.389, p<0.01).

Table 1: Socio-demographic profiles of caregivers of schizophrenic patient			
Variables	Frequency	Percentage	
Gender			
Male	24	40.0	
Female	36	60.0	
Race			
Malay	27	45.0	
Chinese	26	43.3	
Indian	5	8.30	
Other races	2	3.30	
Religion			
Islam	27	45.0	
Buddhism	18	30.0	
Hinduism	5	8.30	
Christianity	8	13.3	
Other religions	2	3.30	
Marital status			
Single	5	8.30	
Married	50	83.3	
Divorced	1	1.70	
Widow/Widower	4	6.70	
Living in			
City area	52	86.7	
Suburban area	8	13.3	
Highest education			
Not schooling	4	6.70	
UPSR or equivalent	5	8.30	
PMR or equivalent	5	8.30	
SPM or equivalent	18	30.0	
STPM/Matriculation,	13	21.7	
A-level/Diploma			
Undergraduate	13	21.7	
Postgraduate (Master or PhD)	2	3.30	
Occupation			
Working	27	45.0	
Not working	33	55.0	
Duration of care (year)			
1-3	13	21.7	
>3	47	78.3	
Relationship with patient			
Spouse	9	15.0	
Parent/child	42	70.0	
Sibling	5	08.3	
Relative	3	5.00	
Non-relative	1	1.70	

Table 2: Level of caretaking burden among caregivers of schizophrenic patients

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Level of burden	Frequency	Percentage
Little or no burden	28	46.7
Mild to moderate burden	24	40.0
Moderate to severe burden	6	10.0
Severe burden	2	03.3

Table 3: Mean and SD of study variables

Components	Mean	SD
SF-12		
General Health (GH)	56.67	17.72
Physical Functioning (PF)	80.83	19.61
Role-Physical (RP)	85.42	18.58
Role-Emotional (RE)	89.17	19.18
Bodily Pain (BP)	41.00	17.82
Mental Health (MH)	75.83	17.94
Vitality (VT) 65.00	24.68	
Social Functioning (SF)	85.56	20.00
ZBI		
Caretaking burden	25.42	15.40

Table 4: Correlation of caretaking burden and QoL domains

Variables	Burden of care (r)
General health	-0.114
Physical functioning	-0.297*
Role-physical	-0.403**
Role-emotional	-0.366**
Bodily pain	0.389**
Mental health	-0.526**
Vitality	-0.385**
Social functioning	-0.376**

<sup>\*,\*\*</sup>p<0.05; 0.01

This showed that the higher the level of caretaking burden experienced by the caregivers, the higher their level of bodily pain. On the other hand, findings showed negative significant relationship between caretaking burden and PF (r = -0.297, p <0.05), RP (r = -0.403, p<0.01), RE (r = -0.366, p<0.01), MH (r = -0.526, p<0.01), VT (r = -0.385, p<0.01) and SF (r = -0.376, p<0.01). This suggested that higher caretaking burden among caregivers lowered their level of physical functioning, role-physical, role-emotional, mental health, vitality andsocial functioning. However, no significant relationship was found between care taking burden and general health.

This study examined the association between QoL and the burden of caregivers of schizophrenic patients. It was found that less than a quarter of the caregivers experienced a high level of burden. This was inconsistent with Talwar and Matheiken (2010) many caregivers in Malaysia reported having high perceived burden. Also burden was found to be high among caregivers of schizophrenic patients, according to Narasipuram and Kasimahanti (2012). Besides, Kaur (2014) had also found that about 50% of caregivers of schizophrenic patients reported experiencing moderate or severe level of burden. Zam *et al.* (2011) suggested that the source of the higher burden could be from the longer period of contact with the patients (Roick *et al.*, 2007; Fan and Chen *et al.*, 2003).

Agrawal et al. (2013) had similar results to this study, where caregivers of mentally-ill patients reported a lower level of burden than expected as a result of the interventions introduced in community programmes. Panayiotopoulos et al. (2013) also reported a low level of burden among cypriot caregivers. It could also be that their burden was affected by the symptoms of the patients. Patient's less need for supervision with less symptom attack could lead to less burden and tension. In the recent years, HCTM had provided focus group interventions in the psychiatric department andthat might contribute to a lower score of burden among the caregivers. In addition, this study was done among caregivers of outpatients where some were fully functional and mostly having consistent treatment.

Past studies in several countries showed reduced QoL when caregivers experienced a high level burden. Boyer et al. (2012) also reported low QoL among the Chileans and French context after becoming caregivers. Although this study did not compare the QoL level of the caregivers with the non-caregivers, the findings of this study showed that the caregiver's level of burden seemed to associate significantly negatively with physical functioning, role-physical, role-emotional, mental health, vitality and social functioning and positively correlated with bodily pain. Study also indicated that the burden significantly correlated with most functioning including physical, emotional, social, mental and body health consistent with past researches (Caqueo et al., 2009). Similar to Grover and Dutt (2011), they found that higher burden was also predictive of poorer overall QoL. Fan and Chen (2009) also found that lower QoL was correlated with higher burden of care based on physical health, psychological status, social relationships and relationship with the environment among the Taiwanese context. Also, past findings reported that higher burden and mental health problems of the caregivers led to a lower QoL (Chen and Greenberg, 2004; Maruish, 2004; Zam et al., 2011).

This study showed that there was no significant correlation between caretaking and general health indicating that most caregivers might have generally moderate health andthat their overall perceived health may not be important factors that are associated with caretaking burden. On the other hand, lower QoL was found significant positively correlated with higher bodily pain which related to Rafiyah (2011) that stated that lower subjective burden was found among caregivers with good health status and less physical pain which may be leading to better QoL. Further more, caregivers with high level of burden scored lower in the physical health component as they were not able to get around (Narasipuram and Kasimahanti, 2012). Gupta et al. (2015) found that caregivers of schizophrenia generally had more health issues compared to the non-caregivers and caregivers of other disorders. This may be that caregivers experienced other conditions other than burden such as anxiety, sleep difficulties andinsomnia which were found contributing to poorer physical health condition while taking care of the patients.

In addition, Huang *et al.* (2012) suggested that high family burden, high psychological distress and various socio-demographic factors predicted low physical scores in QoL. Physical and mental stress and constant worries about their loved one's health status contributed to more burden that negatively affects their overall health (Platt, 1985; Martin *et al.*, 2013). Mengdan *et al.* (2007)

stated that health status is the best predictor of caregiver's burden. It was found that a caregiver with better health status reported lower levels of subjective stress burden, consistent with the findings of this study.

This study also found that caregiver's burden was significantly negative correlated with the mental components which were role-emotional, mental health, vitality and social functioning. Past research also showed that higher level of burden related to reduced social relationships and psychological health (Narasipuram and Kasimahanti, 2012). Caregivers also reported having unsatisfactory personal relationships and less support of friends influenced their QoL due to burden (Platt, 1985; Martin et al., 2013). Some studies showed that burden impacted the mental health of caregivers more than the physical health due to the emotional burden that resulted from the long duration of caring. Low scores of mental components in QoL could also be predicted by high family burden and other factors similar to the physical components (Huang et al., 2012).

#### CONCLUSION

Thus, this study found that caregivers displayed little burden while taking on the additional responsibility of caring for schizophrenic patients which also contributed to moderately higher OoL. This could be due to the characteristics of the socio-demographic profile of caregivers or their overall health status. The results also showed that caregivers had a low level of burden, thus contributing to better scores in most domains of QoL. The findings also indicated that burden correlated to most of the domains of QoL. Higher burden seemed to manifest in lowering physical, emotional, psychological and social functioning but related to higher bodily pain. Caregivers also play an important part in the process of treating patients, therefore their psychological state should be evaluated and taken into account when studying schizophrenic patients, treating both as a whole unit.

In conclusion, the findings from this study could help health service providers and government aid in decreasing the burden of caregivers and increasing their QoL through appropriate programmes and interventions for improving the efficacy of the caring process. Future research should focus on the cultural contexts, social support, size of the family or coping methods andvarious socio-demographic factors which might affect the level of burden and the QoL of caregivers.

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