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ORIGINAL ARTICLE

Caregivers' Burden of Patients with Severe Mental Illnesses: A Cross-sectional Study

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ABSTRAK

Kajian ini bertujuan untuk mengenalpasti prevalens dan faktor yang menyebabkan beban dalam kalangan penjaga pesakit mental yang serius di Kuala Lumpur, Malaysia. Kajian keratan rentas ini telah dijalankan dalam kalangan 149 penjaga pesakit mental yang serius di Kuala Lumpur, Malaysia. Ciri-ciri penjaga, ciri-ciri pesakit dan beban penjaga telah direkod menggunakan soal selidik yang diisi oleh penyelidik. Perkaitan antara pelbagai faktor penyebab dan beban penjaga telah dianalisis menggunakan ujian khi kuasa dua dan regresi logistik berganda. Didapati 34.6% daripada penjaga mengalami beban semasa menjaga pesakit mental yang serius. Juga didapati bahawa jantina lelaki, tahap pendidikan yang rendah, pasangan kepada pesakit, menjaga pesakit skizofrenia, masalah kemurungan, masalah kebimbangan dan tekanan mempunyai hubungan yang signifikan dengan beban penjaga. Ujian logistik berganda menunjukkan bahawa penjaga lelaki, menjaga pesakit skizofrenia dan masalah kemurungan meningkatkan ods beban penjaga masing-masing 4.21 (1.37-12.88), 3.09 (0.98-9.59) dan 29.18 (7.33-116.09). Walau bagaimanapun, pasangan kepada pesakit mengurangkan ods beban penjaga sebanyak 84%. Sebahagian besar penjaga pesakit mental yang serius mengalami beban penjaga. Penjaga lelaki, mereka yang menjaga pesakit skizofrenia dan masalah kemurungan lebih mudah mengalami beban penjaga. Walau bagaimanapun, pasangan kepada pesakit mengurangkan beban penjaga.

Kata kunci: *Beban penjaga; kesihatan mental; penyakit mental serius*

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ABSTRACT

This study was aimed to determine the prevalence and predictors of burden among caregivers of patients with severe mental illnesses in Kuala Lumpur, Malaysia. A cross-sectional study was conducted among 149 caregivers of patients with severe mental illnesses in Kuala Lumpur, Malaysia. Caregivers' characteristics, patients' characteristics and caregivers' burden were captured using investigator-administered questionnaires. The association between various predictors and caregivers' burden was analysed using Chi-square tests and multiple logistic regression. A total of 34.6% of caregivers experienced caregiver's burden. Being a man, low education level, being a spouse to the patient, caring for schizophrenic patients, depression, anxiety and stress were significantly associated with caregivers' burden. A multiple logistic regression showed that being a man caregiver, caring for schizophrenic patient, and caregivers suffering from depression increased the odds of caregivers' burden by 4.21 (1.37-12.88), 3.09 (0.98-9.59) and 29.18 (7.33-116.09), respectively. However, being a spouse to the patient reduced the odds of caregivers' burden by 84%. A substantial number of the caregivers of patients with severe mental illnesses experienced caregivers' burden. Men caregivers, those providing care to schizophrenic patients, and caregivers suffering depression were more susceptible to caregivers' burden. However, being a spouse of the patients experienced a reduced level of caregivers' burden.

Keywords: Caregiver burden; mental health; severe mental disorder

INTRODUCTION

Providing care for patients with severe mental illness, such as schizophrenia, delusional disorder and bipolar disorder poses significant challenges (Walke et al. 2018). In numerous developing nations, including Malaysia, the responsibility of caring for non-institutionalised patients largely falls on family members due to a lack of adequate community-based support (Cham et al. 2022). The move towards deinstitutionalising patients began in the 1970s, although Malaysia's mental health system was not well-structured at that time (Ivan Vun et al. 2019). According to the World Health Organisation (WHO) Mental Health Atlas 2017, the Malaysia's Ministry of Health allocated only 1.3% of the total health budget for mental health, which was below the median budget of other upper-middle-income countries (World Health Organisation 2018). Limited financial assistance and an unstable economic climate hinder initiative for community-based training and the development of infrastructure for deinstitutionalised patients with severe mental illness.

As the trend toward changing care dynamics persists, many primary caregivers in Malaysia, often family members who lack proper training, find themselves responsible for providing care within the home setting without formal compensation (Jawahir et al. 2021). In Southeast-Asian cultures, the concept of filial duty is prevalent, where family members are socially designated as informal caregivers. They shoulder a range of responsibilities, including daily care, medication supervision, accompanying the patient to hospital appointments, and occasionally dealing with the patients' aggressive or suicidal behaviours (Ivan Vun et al. 2019). Consequently, these caregivers are more susceptible to experiencing caregivers' burden, which is defined as a multifactorial situation in which the patients' illness imposes emotional, physical, and financial demands and responsibilities on their family, friends, and others outside the healthcare system (Walke et al. 2018).

A recent meta-analysis indicated that the global prevalence of caregivers' burden among those caring for patients with mental health illnesses was 31.7% (95% CI: 26.2-37.1) (Cham et al. 2022). However, many studies concentrate on specific diagnoses including schizophrenia, dementia or bipolar disorder only (García-Martín et al. 2023; Tanna 2021; Zhou et al. 2016), making it unclear how diverse psychiatric disorders contribute to caregivers' burden. Additionally, the factors significantly influencing this health condition remain uncertain. Despite local national statistics indicating a high prevalence of mental illnesses at 29.0% and a consequent high frequency of family involvement in caregiving, the burden on caregivers is often underestimated and overlooked (Institute of Public Health 2015). Given the lack of evidence on the predictors and local statistics of caregivers' burden, the present study aimed to firstly determine the prevalence of caregivers' burden in Malaysia, secondly to explore the psychological implications of this burden on caregivers, and finally to investigate the predictors of caregivers' burden among those caring for deinstitutionalised patients with severe mental illnesses in Malaysia.

MATERIALS AND METHODS

Study Design and Study Setting

A cross-sectional study was conducted from 1st April 2022 to 30th September 2022 at all three public hospitals in Kuala Lumpur, Malaysia, namely the General Hospital Kuala Lumpur (GHKL), Hospital Canselor Tuanku Muhriz (HCTM), and University of Malaya Medical Center (UMMC). These hospitals are tertiary hospitals with 1054 to 2300 beds. They consist of multiple subspecialty clinical departments and are major referral centres for mental health illnesses.

Study Population

Caregivers of patients with severe mental illnesses, who were currently receiving follow-up care in the outpatient psychiatric units of the three mentioned hospitals in Kuala Lumpur, Malaysia were recruited. The severity of the psychiatric condition was objectively assessed by the investigators using the Global Assessment of Functioning (GAF) in DSM-4 (American Psychiatric Association 2000). In the context of this study, the patient was considered to have a severe mental illness if their GAF score was 50 or below, and they had been experiencing the illness for a minimum of two years (Aas 2011).

Sampling Technique and Sample Size Estimation

In this study, a proportionate random sampling method was employed. Lists containing the names of patients with severe mental illnesses along with their primary caregivers were obtained from the three hospitals, serving as the sampling frame. Subsequently, caregivers of the patients with severe mental illness from these hospitals were randomly chosen as the sampling unit. Based on Cham et al.'s (2022) findings indicating a 31.7% prevalence of caregivers' burden among psychiatric patients, and considering a finite population of 224 caregivers of patients with severe mental illnesses in Kuala Lumpur, a sample size of 134 was calculated using Epi Info software (Centers for Disease Control and Prevention, Atlanta, Georgia, United States) with a 95.0% confidence interval and a 5.0% margin of error. To account for potential missing data, the sample size was increased by 20%, resulting in a final required sample size of 168.

Inclusion and Exclusion Criteria

Caregivers were eligible for recruitment if they met the following criteria: (i) served as the primary caregiver; (ii) cohabitated with the patients with severe mental illness for at least one year; (iii) were at least 18 years old; and (iv) did not receive payment for their caregiving duties. However, caregivers were excluded if they: (i) had a history of mental illness (e.g., schizophrenia, bipolar disorder, acute psychotic disorder, etc.); (ii) had difficulty in understanding the questionnaire; or (iii) declined to participate in the study.

Data Collection

The investigators reached out to randomly selected caregivers through telephone calls. They explained the study's objectives and procedures in detail, ensuring the caregivers' privacy and anonymity. Those expressing interest underwent a check for inclusion and exclusion criteria. Eligible caregivers were then invited to their respective hospitals, where they were briefed on the study and asked to provide written informed consent in a private room before participation. Three investigators, one in each hospital, possessing medical qualifications, were trained to assist caregivers in administering the questionnaire (as described in "Study Tools" section below). Caregivers were encouraged to seek clarification on any inquiries and had the option to skip questions they preferred not to answer. The questionnaire only captured relevant information, and no personal identifiers were recorded during data collection to safeguard patient confidentiality and anonymity.

Study Tools

The investigator-administered questionnaire comprised of four sections. The initial section gathered information on caregivers' characteristics, encompassing details such as age, gender, ethnicity, religion, education level, marital status, employment status, household income, location of staying, relationship with the patients, underlying comorbidities and daily caregiving hours. The second section contained queries about the patients' characteristics, including their age, gender, primary diagnosis and duration of illness.

The third section utilised the Malay version of the 21-item Depression, Anxiety, and Stress Scale (DASS-21) questionnaires to assess the mental health status of the caregivers (Musa et al. 2007). This section consisted of 21 items measuring three domains - depression, anxiety and stress. Caregivers provided responses on the DASS-21 using a 4-point Likert scale, ranging from 0 ("never") to 3 ("almost always"). The total score ranged from 0 to 42. The Malay version of DASS-21 had been previously validated locally and demonstrated good reliability (Cronbach α = 0.74 - 0.84). Regarding validity, both exploratory factor analysis and confirmatory factor analysis indicated a 3-factor solution, consistent with the original DASS-21 (Musa et al. 2007).

The fourth section included the Malay version of the Zarit Burden Interview (ZBI) questionnaire (Shim & Ng 2017). This questionnaire, comprising 22 items, was designed to assess caregivers' experiences related to social networking, personal economic situation, stigma, health status and interaction with care recipients. Caregivers were instructed to respond to the ZBI using a 4-point Likert scale, ranging from 0 ("never") to 4 ("almost always"). The total score ranged from 0 to 88. Caregivers who scored below

21 points were categorised as having low burden, while those scoring 22-40, 41-60 and 61-88 points were classified as having mild-to-moderate, moderate-to-severe and severe burden, respectively. The Malay version of the ZBI questionnaire had been previously validated locally and exhibited good reliability with a Cronbach α of 0.89. Additionally, the criterion validity of the Malay version of the ZBI questionnaire was assessed by correlating it with the Malay version of Center for Epidemiologic Studies-Depression (MCES-D) and English version of Zarit Burden Interview (EZI) scales. The MZBI showed a moderate significant correlation with MCES-D ($r = 0.58$, $p < 0.010$) and a high significant correlation with EZBI ($r = 0.84$, $p < 0.010$) (Shim & Ng 2017).

Data Quality Control

The current study maintained data quality by establishing a uniform data collection protocol for all researchers, providing training to ensure consistency, and using a standardised study tool. Furthermore, the questionnaires utilised in the current study (i.e., Malay version of DASS-21 and Malay version of ZBI) were previously validated in local studies and approved for use (Musa et al. 2007; Shim & Ng 2017). Hence, validation of these questionnaires was not required in this study. Additionally, a pilot test was conducted at HCTM before data collection began. Following data collection, thorough data entry and cleaning processes were implemented to detect and correct errors, inconsistencies or missing information. Missing data was cross-checked with caregivers and electronic records to ensure accuracy.

Data Analysis

The data analysis was conducted using IBM SPSS Statistics 26 (Armonk, USA). Descriptive statistics, including frequencies and percentages were used to describe categorical variables. Chi-square tests were performed to identify the associations between independent variables (i.e., caregivers' characteristics, patients' characteristics and mental health status of caregivers) and the dependent variable (i.e., caregivers' burden). Variables with $p < 0.250$ in the chi-square tests were included into the multiple logistic regression model. The backward elimination technique was used to construct the final model, removing one variable at a time, starting with the variable having the highest p-value. Subsequently, variables in the multiple logistic regression with a p-value < 0.050 were deemed as significant predictors of caregivers' burden.

Ethical Consideration

The Research Ethics Committee of the Universiti Kebangsaan Malaysia (UKM) approved the current study (JEP-2022-223). Written approval was obtained from the original authors of the questionnaires before the survey was conducted. Participants were informed about any potential issues or risks associated with the study that could impact their psychological or emotional well-being. They were assured of their right to withdraw from the study at any point. Participation in this study by caregivers is entirely voluntary, and all participants have provided signed informed consent prior to their participations.

RESULTS

A total of 149 caregivers responded to the invitation, resulted in a response rate of 88.7%. The mean age of the caregivers was 45.9 ± 3.6 years old. A majority of the caregivers were aged 30-39 years old (24.8%), men (57.1%), Malay (47.0%), Muslim (59.7%), received tertiary education (52.9%), unmarried (61.4%) and non-governmental employees (46.4%). Most caregivers had low household income (78.0%) and were staying with the patient (80.1%). In terms of relations, these caregivers were either the sibling (33.6%), parent (24.3%), spouse (22.9%), children (12.1%) or relative (7.1%) of the patients. Most of the caregivers did not have underlying comorbidity (70.1%). More than half of the caregivers provided caregiving of more than half a day (53.1%). Table 1 summarised the results.

Most of the patients were aged 30-39 years old (24.2%), men (50.2%) and with illness duration of less than five years (56.3%). The most common mental illness was schizophrenia (48.5%), followed by delusional disorders (22.1%), bipolar disorder (13.6%), depression (11.6%) and obsessive-compulsive disorder (OCD) (4.2%). Table 2 summarised the results.

The most common psychological implications experienced by the caregivers was anxiety (29.5%), out of which a majority reported moderate severity (19.4%). It was followed by depression (22.2%) and stress (10.7%). Figure 1 illustrated the results.

The mean ZBI score among caregivers was 31.7 ± 18.5 points. In terms of prevalence, 34.6% of the caregivers experienced burden. Specifically, 16.8%, 13.8% and 4.0% of the caregivers had mild-to-moderate, moderate-to-severe and severe burden, respectively.

The association between the independent variables (i.e., caregivers' characteristics, patients' characteristics and mental health status of caregivers) and the dependent variable (i.e., caregivers' burden) was demonstrated using Chi-square tests (Table 3). It was found that being a man ($\chi^2 = 6.67$, $p = 0.010$), lower education level ($\chi^2 = 4.39$, $p = 0.040$), being a spouse to the patient ($\chi^2 = 20.37$, $p = 0.001$), caring for schizophrenic patients ($\chi^2 = 7.11$, $p = 0.008$), suffering from depression ($\chi^2 = 51.15$, $p = 0.001$), suffering from anxiety ($\chi^2 = 45.95$,

TABLE 1: Sociodemographic characteristics of caregivers

Variables	Categories	Frequencies (n = 149)	Percentages (%)
Age (year)	< 20	3	2.0
	20-29	26	17.4
	30-39	37	24.8
	40-49	26	17.4
	50-59	17	11.4
	60-69	35	23.5
	≥ 70	5	3.4
Gender	Men	85	57.1
	Women	64	42.9
Ethnicity	Malay	70	47.0
	Chinese	24	16.1
	Indian	32	21.5
	Others	23	15.4
Religion	Muslim	89	59.7
	Christian	17	11.4
	Hindu	19	12.8
	Buddhist	22	14.8
	Others	2	1.3

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Education level	No formal education	3	2.1
	Primary	18	12.1
	Secondary	49	32.9
	Tertiary	79	52.9
Marital status	Married	51	34.3
	Unmarried	91	61.4
	Others	7	4.3
Employment status	Government	31	20.7
	Non-government	69	46.4
	Pensioner	4	2.9
	Unemployed	30	20.0
	Other	15	10.0
Household income	Low	116	78.0
	Medium	30	20.0
	High	3	2.0
	With patient	119	80.1
Location of staying	Not with patient	30	19.9
	Parents	36	24.3
Relationship with patient	Children	18	12.1
	Siblings	50	33.6
	Spouse	34	22.9
	Relatives	11	7.1
	Yes	43	29.9
Underlying comorbidities	No	106	70.1
Daily caregiving hours	< 12 hours	70	46.9
	≥ 12 hours	79	53.1

TABLE 2: Sociodemographic characteristics of patients

Variables	**Categories**	**Frequencies** (n = 149)	Percentages (%)
Age (year)	< 20	5	3.4
	20-29	34	22.8
	30-39	36	24.2
	40-49	28	18.8
	50-59	21	14.1
	60-69	21	14.1
	≥ 70	4	2.7
Gender	Men	75	50.2
	Women	74	49.8
Psychiatric diagnosis	Schizophrenia	72	48.5
	Delusional disorders	33	22.1
	Bipolar disorder	20	13.6
	Depression	18	11.6
	Obsessive-compulsive disorder	6	4.2
Duration of illness	< 5 years	84	56.3
	≥ 5 years	65	43.7

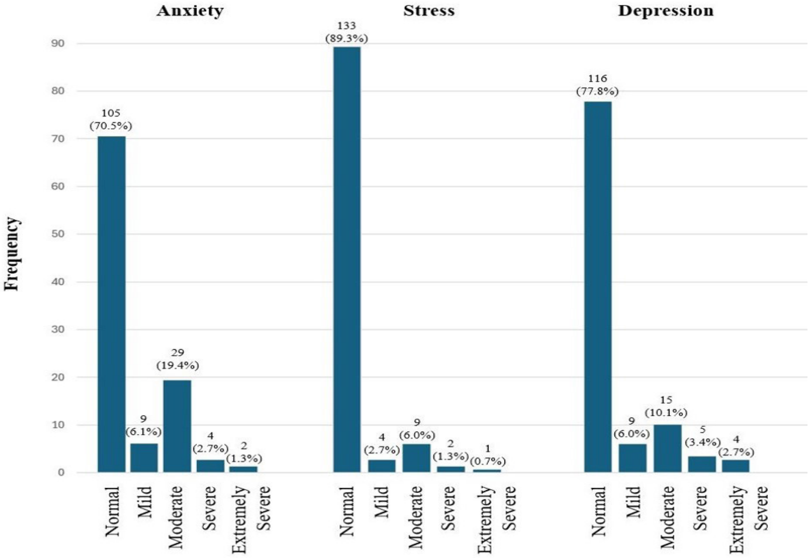

FIGURE 1: Mental health status of caregivers

TABLE 3: Association between caregivers' characteristics, patients' characteristics, and mental health status of caregivers with caregivers' burden using chi-square tests

Variables	Categories	Not burden n (%)	Burden n (%)	Total (n = 149)	χ^2 value	p-value
Caregivers' Characteristics						
Age (year)†	< 50	62 (67.4)	30 (32.6)	92	4.460	0.893
	≥ 50	37 (64.9)	20 (35.1)	57		
Gender	Men	49 (57.6)	36 (42.4)	85	6.673	0.010*
	Women	50 (78.1)	14 (21.9)	64		
Ethnicity	Malay	48 (68.2)	22 (31.8)	70	0.172	0.678
	Non-Malay	51 (64.6)	28 (35.4)	79		
Religion	Muslim	58 (65.2)	31 (34.8)	89	0.085	0.770
	Non-Muslim	41 (68.3)	19 (31.7)	60		
Education Level	Low education	40 (57.1)	30 (42.9)	70	4.388	0.036*
	High education	59 (74.7)	20 (25.3)	79		
Marital status	Married	33 (64.7)	18 (35.3)	51	0.113	0.945
	Unmarried	66 (67.3)	32 (32.7)	98		
Employment status	Employed	66 (66.0)	34 (34.0)	100	0.032	0.984
	Unemployed	33 (67.3)	16 (32.7)	49		
Household income	Low	84 (72.4)	32 (27.6)	116	0.016	0.900
	medium-to-high	15 (45.5)	18 (54.5)	33		
Location of staying	With patient	74 (62.2)	45 (37.8)	119	1.057	0.057
	Not with patient	25 (83.3)	5 (16.7)	30		
Relationship with patient	Non-spouse	68 (59.1)	47 (40.9)	115	20.374	0.001*
	Spouse	31 (91.2)	3 (8.8)	34		

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Relationship with patient	Non-spouse	68 (59.1)	47 (40.9)	115	20.374	0.001*
	Spouse	31 (91.2)	3 (8.8)	34		
Underlying comorbidities	Yes	12 (27.9)	31 (72.1)	43	0.172	0.458
	No	64 (60.4)	42 (39.6)	106		
Daily caring hours	< 12 hours	26 (37.1)	44 (62.9)	70	0.588	0.710
	≥ 12 hours	25 (31.6)	54 (68.4)	79		
Patients' Characteristics						
Age	< 50	18 (36.0)	32 (64.0)	50	3.311	0.478
	≥ 50	42 (42.4)	57 (57.6)	99		
Gender	Men	34 (45.3)	41 (54.7)	75	5.012	0.744
	Women	36 (48.6)	38 (51.4)	74		
Diagnosis	Schizophrenia	30 (41.7)	42 (58.3)	72	7.112[a]	0.008*
	Non-schizophrenia	53 (68.8)	24 (31.2)	77		
Mental Health Status of Caregivers[§]						
Depression	Normal	86 (81.9)	19 (18.1)	105	51.151	0.001*
	Abnormal	6 (13.6)	38 (86.4)	44		
Anxiety	Normal	111 (83.5)	22 (16.5)	133	45.945	0.001*
	Abnormal	4 (25.0)	12 (75.0)	16		
Stress	Normal	84 (72.4)	32 (27.6)	116	45.945[a]	0.001*
	Abnormal	4 (12.1)	29 (87.9)	33		

*Significant p-value < 0.05

[§] Determined from DASS-21 score

[†] 50 years old was used as the cut-off point for the age of caregivers as caregivers above this age was found to experience higher burden, based on a recent literature (Ansari et al. 2024).

p = 0.001) and suffer from stress ($\chi^2 = 45.95$, p = 0.001) were significantly associated with caregivers' burden.

Variables with a significant level of $p<0.25$ in the Chi-square test, namely caregiver's gender, education level, relationship with patient, caring for schizophrenic patient, depression, anxiety and stress were modelled into the multiple logistic regression. The multiple logistic regression showed that being a man, caring for schizophrenic patient, and suffering from depression increased the odds of caregivers' burden by 4.21 [adjusted odds ratio (AOR): 4.21, 95% confidence interval (CI): 1.374-12.877], 3.09 (AOR: 3.09, 95% CI: 0.982-9.589), and 29.81 (AOR: 29.81, 95% CI: 7.332-116.090), respectively. Interestingly, being a spouse to the patient reduced the odds of caregivers' burden by 84% (AOR: 0.16, 95% CI: 0.032-0.824). Table 4 summarised the results.

DISCUSSION

This study underscores a notable level of burden experienced by caregivers of patients with severe mental illnesses. The average ZBI score was 31.7 ± 18.5 points, indicating a mild-to-moderate level of caregivers' burden. This score aligns with a previous local study, which reported a mean ZBI score of 35.4 ± 15.1 points among caregivers of dementia patients (Choo et al. 2003). In terms of prevalence, it was observed that 36.4% of the caregivers in this study were grappling with caregiver burden. This finding is also consistent with

Table 4: Association between caregivers' characteristics, patients' characteristics and caregivers' mental health status with caregivers' burden using multiple logistic regression

Variables		Adjusted Odds Ratio	95% Confidence Interval	P-value
Gender of caregiver	Women	Reference		
	Men	4.21	1.37-12.88	0.012*
Disease category	Non-Schizophrenia	Reference		
	Schizophrenia	3.09	0.98- 9.59	0.045*
Caregiver suffering depression	No	1.00		
	Yes	29.18	7.33-116.09	<0.001*
Relationship with patient	Non-Spouse	Reference		
	Spouse	0.16	0.03-0.82	0.028*

*Significant p-value < 0.050

a meta-analysis conducted by Cham et al. (2022) which reported a global prevalence of caregivers' burden at 31.7%. These results highlight that the burden on caregivers remains high, emphasising the need for regular mental health screenings for caregivers of patients with severe mental illnesses. Additionally, it is crucial to provide training to healthcare professionals to recognise early signs of depression, anxiety and stress among caregivers (Ivan Vun et al. 2019).

In this study, four factors contributing to caregivers' burden were identified. Surprisingly, men were found to experience more burden compared to their women counterparts. Traditionally, women have faced gender discrimination in various aspects of life, including the responsibilities of caring for sick family members, and have been deemed more susceptible to developing depressive symptoms, poorer mental health, and a lower quality of life than men (Sharma et al. 2016). However, contrary to this trend, the current study revealed that men caregivers were more burdened than women. This outcome can be explained by an increasing involvement of men in caregiving roles (Sharma et al. 2016). Balancing caregiving responsibilities with work commitments can be challenging for anyone, but men might face additional pressures related to the expectation of being the primary breadwinner (Lopez-Anuarbe & Kohli 2019). Juggling work and caregiving roles can lead to an increased sense of burden. Moreover, men caregivers are frequently reported to be less equipped to handle the adverse conditions of the illness (Lopez-Anuarbe & Kohli 2019). This is because caregiving tasks, typically considered feminine, such as bathing and feeding, are traditionally performed by housewives (Sharma et al. 2016). Consequently, men caregivers, who are naturally less experienced in these tasks than women, are more likely to experience burden while carrying out these unfamiliar responsibilities (Lopez-Anuarbe & Kohli 2019).

Furthermore, the present study revealed that caregivers of schizophrenic patients tend to experience a more substantial burden compared to those caring for individuals with non-schizophrenic psychiatric conditions. This heightened burden can be attributed to the fact that patients with schizophrenia are more susceptible to relapses and exhibit severe cognitive and social impairments, along with enduring persistent symptoms, thereby increasing their dependence on caregivers (Shamsaei et al. 2015). This is evident in this study, where more than half of the individuals with schizophrenia scored extremely low (i.e., less than 30 points) on the GAF scale compared to individuals with other psychiatric disorders, such as dementia and bipolar disorders. Additionally, caregivers of schizophrenic patients often lack the necessary skills and negatively cope with the diverse responsibilities associated with caregiving (Tamizi et al. 2020). Moreover, caregivers of schizophrenic patients encounter daily stressors, including the potential for aggression and self-harm, which are more prevalent than in other psychiatric disorders (Neha et al. 2021). Not to mention, they also face external stressors like stigma, isolation, frustration and family conflict (Shamsaei et al. 2015).

In general, caregivers tend to experience a poorer mental health status compared to the general population (Chakraborty et al. 2023). However, in the current study, only depression showed a significant association with caregiver burden. This can be attributed to the fact that depression often presents overt symptoms such as a depressed mood, loss of interest or pleasure, decreased energy, and fatigue (Chand & Arif 2023). These symptoms significantly impede the physical, cognitive and emotional functioning of caregivers (Schulz & Sherwood 2008). Furthermore, caregivers who are fatigue and exhausted may struggle to maintain the necessary level of care for the well-being of the person under their supervision (Jensen & Given 1993). As a result, depression can adversely affect the quality of care, decrease the overall time spent providing care, and contribute more significantly to caregivers' burden compared to anxiety and stress.

Surprisingly, the current study revealed that being a spouse to a psychiatric patient was associated with a decreased likelihood of caregiver burden. This finding aligns with a previous study focusing on caregivers of cancer patients, which indicated that the role of a spouse in caregiving is less burdensome compared to the caregiving role of children (Fenton et al. 2022). One plausible explanation is that spouses may perceive caregiving as a normal aspect of their marital responsibilities and commitment (Li et al. 2020). Additionally, spouses often share a deep emotional connection, and this emotional bond can form a strong foundation for caregiving (Stedje et al. 2023). The pre-existing relationship may cultivate empathy, understanding and a sense of shared responsibility. Furthermore, spouses typically possess a profound understanding of the individual's preferences, habits and history. This familiarity can contribute to more personalised and effective care, as spouses are attuned to the unique needs and nuances of their partner (Sanbonmatsu et al. 2011). Consequently, spouses may experience less conflict between their caregiving obligations and caregiver burden.

Strengths and Limitations of the Study

One major strength of the current study lies in the use of an investigator-administered questionnaire technique (i.e., the investigators asked questions to the participants and fill in the questionnaire accordingly). The investigators were trained to ask questions in a two-direction approach. Specifically, the caregivers were given ample opportunity to ask questions and to seek immediate clarifications when they had doubts about the questions. This approach ensured that the caregivers fully understood every question and this helped to prevent respondent bias and missing data. Additionally, caregivers of patients with severe mental illnesses were invited to participate in face-to-face questionnaire sessions in a quiet room at the hospitals, as opposed to providing response via online questionnaires. This approach was intended to enhance participant engagement and increase the response rate.

Having said the above, the study has its limitations. First of all, the impact of stigma towards caregivers of patients with serious mental illnesses was not investigated, although this has been proven as one of the predictors of caregivers' burden (Mohammed et al. 2019). This is due to the unavailability of a validated questionnaire in the Malay language designed for measuring stigma. Secondly, potential sources of bias, such as interviewer bias and social desirability bias, may also be present, as caregivers might be inclined to provide inaccurate responses to please the investigators, who are also clinicians. Nonetheless, efforts have been made to ensure the confidentiality and anonymity of the participants and, hence, they were able to provide honest responses via the questionnaires.

Implications of Study and Recommendation

This study enhances the understanding of caregiver burden and provides important insights into the factors that significantly affect it. It assists policymakers in recognising the needs and challenges faced by caregivers, which can inform the development of more effective support policies as described below. Additionally, the findings emphasised the need for future intervention programs designed to alleviate caregiver burden and improve the quality of care they provide to patients.

It is proposed that caregivers at higher risk (such as men caregivers, those caring for schizophrenic patients, caregivers experiencing depression and non-spouse caregivers) with severe mental illnesses should be offered supports, regular mental health assessments, and routine burden screenings to prevent the deterioration of their mental health. Caregivers should be equipped with essential insights into managing their burdens through various support avenues, including forums, seminars, support groups and practical training. In Malaysia, the National Dementia Caregivers Support Network serves as an example of a registered group with the aim of facilitating knowledge exchange and fostering interaction among caregivers. However, its activities are currently limited to a specific region (National Dementia Caregivers Support Network 2024). Additionally, it is advisable for the government to increase support for subsidised home care or respite centres. Future considerations should involve expanding the scope of reimbursements, particularly concerning caregiving expenses for individuals with mental illnesses.

CONCLUSION

It was shown that a substantial number of the caregivers of patients with severe mental illnesses in Kuala Lumpur, Malaysia experienced caregivers' burden, with a majority of them having mild-to-moderate level of burden. Men caregivers, those providing care to schizophrenic patients, and caregivers suffering depression were more susceptible to caregivers' burden. Notably, being a spouse to patients with severe mental illnesses is associated with a reduction in caregivers' burden. It is crucial to establish a comprehensive support framework to aid these high-risk caregivers in managing their burdens. Additionally, the government should take an active role by expanding resources, such as creating more respite centres or providing subsidised personal home care assistance for patients with severe mental illnesses.

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