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Determinants of caregiver burden in community-dwelling caregivers of patients with severe and persistent mental illness

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ABSTRACT

Loss of independence due to cognitive and functional ability is the main challenge experienced by individuals with severe mental illness. This study aimed to investigate the associated factors of caregiver burden among caregivers of individuals with severe and persistent mental illness living in the community. We used a cross-sectional design with open-ended questions to determine the contributing factors to caregiver burden. A self-administered questionnaire was used to measure caregiver burden and resilience (n=201). Caregiver burden and resilience were operationalized using the caregiver burden inventory scale (CBI) and Connor-Davidson resilience scale (CD-RS), respectively. The findings showed that the caregivers were experiencing a moderate level of caregiver burden (M=30.7, SD=20.3). Caregiving-related stressors are the most important predictor of caregiver burden, explaining 28.3% of the variance in caregiver burden. Finally, the hierarchical analysis found that resilience, caregiver-related stressors, and socio-demographic factors contributed to 52.4% of the variance in caregiver burden. New factors that contributed to the burden, such as lack of support and knowledge deficit, emerged from the qualitative findings. The results highlighted the growing evidence of the role of caregivers' socio-demographic variables, caregiving-related stressors, and resilience to caregiver burden.

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1. INTRODUCTION

Globally, approximately 792 million individuals suffer from mental disorders [1]. From 1996 to 2015, Malaysia’s National Health and Morbidity Survey (NHMS) found that mental illness morbidity rose from 10.7% to 29.2%. The NHMS also reported that depression among individuals over 16 was 2.3% in 2019 compared to 1.8% in 2011 [2].

Severe and persistent mental illness (SPMI) can be defined as a prolonged and recurrent mental illness diagnosed for more than two years and impairs the cognitive and functional ability of the patients [3]–[5]. The most common causes of SPMI are bipolar mood disorders, schizophrenia, and major depression. Like many other developing countries, Malaysia is on its way to deinstitutionalizing patients with mental illness. However, since many people with serious mental illness require long-term care, informal caregivers (family members, kin, close friends) often assume the responsibility and accountability for patients' care. Yet, some of the caregivers are not prepared to accept this responsibility. Caregivers are essential in improving the prognosis and reducing hospitalization rates for patients with mental illnesses. However, caring for patients can be taxing on caregivers' physical and emotional health. A study in the USA reported a significant difference in cortisol profiles between parents of children with severe mental illness, highlighting the stress associated with caregiving [6]. Furthermore, qualitative study findings showed that caregivers experience exhaustion and grief as well as ongoing tension and irritation [7]. In addition, caregiver stress is exacerbated by the stigma associated with mental illness, which differs from other chronic diseases [8].

There is a consensus that the factors contributing to caregiver stress are diverse and multifaceted. Several studies have shown that older female carers with depression symptoms and those with a greater sense of self-stigma are more likely to feel a higher degree of caregiver burden than their younger counterparts [8]–[10]. In addition, further characteristics related to caregiver burden include the availability of social support, spending more time with patients, and the duration of caring. There are contradictions in some of these indicators when predicting caregiver burden. For example, external help received by caregivers was linked to caregiver burden in Malaysia [11]. However, there was no correlation between caregiver assistance and the same condition among Italian caregivers [10]. Cultural differences may affect how caregiving impacts carers from different ethnic groups and cultural backgrounds.

Despite the contradictions in the data on the factors contributing to caregiver burden, resilience may be a crucial determinant in understanding how carers "bounce back" and deal with the difficulties of caring for people with severe mental illness. Published concept analyses of resilience have addressed comparable characteristics of this concept, such as rebounding, favorable outcomes, personal mastery, and the existence of support [12], [13]. Previously, studies on caregivers for people with Alzheimer's disease, female caregivers of persons with major mental illness, and child caregivers indicated that more resilient caregivers reported lower levels of hardship [14], [15]. However, the data measured the factors that contributed to caregiver burden, and the roles of resilience are scarce in Malaysia. Thus, there is a need to investigate the influence of resilience on caregiver burden in caregivers of patients with severe mental illness in Malaysia. The primary aim of this study is to explore the relationship between resilience and caregiver burden amongst those who care for people with severe mental illness. We formulated the following research questions to guide this research: i) What are the levels of caregiver burden and resilience among caregivers of patients with severe and persistent mental illness?; ii) What are the predictors for caregiver burden in this population?; and iii) What is the experience of caring for patients with severe and persistent mental illness?

2. METHOD

2.1. Design

We measured the caregiver burden and resilience levels and their associated factors using a cross-sectional design with closed and open-ended questions. We also adapted both closed-ended (quantitative data) and open-ended (qualitative data). Quantitative data from the questionnaire measured the factors contributing to caregiver burdens, such as resilience and caregiver stressors. In contrast, open-ended questions allow for exploring other factors affecting caregivers' lives. Asking additional open-ended questions at the end of the questionnaire allows the participants to elaborate more on the answers given in the closed-ended [16].

2.2. Setting and sample

The sample size was determined using a list of caregivers of people with serious mental illness who visit a psychiatric facility in Selangor, West Malaysia. Non-probability, purposive sampling was used to recruit 201 caregivers of patients with severe mental illnesses. The patients they cared for must have been diagnosed with several mental illnesses, including schizophrenia, bipolar disorder, or major depressive disorder with psychotic characteristics, for at least two years. The inclusion criteria were caregivers who were: i) at least 18 years old, ii) residing in the same house as the patients for whom they were providing care, iii) able to communicate in Malay or English, and iv) identified as the primary caregivers. The researchers approached caregivers who accompanied patients to their outpatient appointments. Caregivers who consented to participate were then asked to sign a permission form and complete the questionnaire.

2.3. Instruments

The caregiver burden inventory (CBI) [17] was used to evaluate caregiver burden. The CBI had already been translated into Malay [18] using an internationally accepted standard for translating and adapting self-report measures [19]. A four-point Likert scale answer set of 0 (not at all descriptive) to 4 (very descriptive) is used for this scale of 24 items. There are five factors or subscales of the CBI, namely the burden of time dependence (an objective burden), developmental burden (a sense of being “left out”), physical burden (exhaustion and chronic illness), social burden (a lack of positive relationships at home and work), and emotional burden (negative feeling toward the patient). All items on the scale are scored from 0 to 96 points, with a greater number denoting more burden [20]. There is a range of 0 to 20 for each of the four subscales: time-dependence, developmental, social, and emotional. The physical burden subscale scores were multiplied by a correction factor of 1.25 to get an equal score out of 20 [17]. Cronbach's alpha was 0.95 for the overall scale, indicating high internal consistency.

The Conor Davidson Resilience Scale (CD-RISC) was used to assess resilience [21]. The 25 items include responses on a Likert scale of 0 to 5, with 0 meaning "not true at all" to 5 indicating "true nearly all of the time". The overall score goes from 0 to 100, with higher scores suggesting better resiliency. The Cronbach's alpha for the CD-RISC used in this study was 0.92. Socio-demographic data and caregiving-related stressors were also collected using researcher-developed questions. The authors also included the open-ended question, "Do you have any further comments on how caring for patients with severe mental illness affected your life?". All questions were validated during the pilot study.

2.4. Ethical considerations

The UiTM Research Ethics Committee granted ethical approval for this study REC/03/2021(UG/MR/121). This study was carried out following the ethical principles outlined in the Helsinki Declaration and the Malaysian Good Clinical Practice (GCP) guideline to ensure that the data and reported results are credible and accurate and that respondents' rights, integrity, and confidentiality are respected and protected. The ethical principles of beneficence, respect for human dignity, and justice were considered when this research was conducted. The researcher explained to the caregivers that their participation was voluntary and they could withdraw from the study at any time. They were assured of the confidentiality and anonymous presentation of the findings.

2.5. Data collection procedure

Data collection was facilitated by distributing an informational booklet and extending an invitation to participate in the study to family members accompanying the patients to mental health clinic appointments. Clear explanations were provided, emphasizing the optional nature of participation and the assurance of anonymous presentation of findings. Participants were then requested to sign a consent form and complete a questionnaire as part of their involvement in the study.

2.6. Data analysis

SPSS version 26 was used to analyze the data. Hierarchical multiple regression was used to test if resilience predicted caregiver burden levels. Graphical and numerical approaches were used to verify the assumptions of normality, linearity, homoscedasticity, and residual independence. Outliers were also examined, both for their presence and their possible impact. While collinearity statistics like VIF and Tolerance were within acceptable bounds in this study, correlations among the independent variables showed that all correlations varied from weak to moderate, between r=-0.01 and r=0.50. Thus, multicollinearity was fine in our research. After completing the bivariate analysis, we selected variables with a p-value of less than 0.25 for inclusion in the multivariate analysis.

It is important to note that open-ended questions can be analyzed using quantitative or qualitative methods. Qualitatively, thematic analysis is a common method to analyze this type of question. In this study, the responses to the open-ended question were analyzed using quantifiable data based on the answers provided by participants. A subset of responses was read, and a coding frame was devised. Codes were then assigned to responses. Two coders (ZAM and NM) independently tested the reliability of codes. Codes were then imported into SPSS Statistics version 26 and used as variables. Table and hierarchical coding frames are used to present the findings.

3. RESULTS AND DISCUSSION

3.1. Socio-demographic characteristics of caregivers

Most carers were Malay women in their mid-to-late 40s and 50s who were married, had a high school qualification, and were employed full-time. Most carers lived in the same house as the patient and other family members. Approximately one-third of carers reported having at least one medical condition, while nearly half of those surveyed perceived they were in excellent health Table 1.

The CBI averaged 30.7 (SD=20.3), indicating moderate caregiver burden. Results revealed that the most difficult aspect of caregiving was time dependency (M=9.61, SD=4.93, n=201). On top of that, there was stress on the individual's growth and development (M=7.07, SD=5.62, n=197), as well as physical and emotional stress (M=6.46, SD =5.72, n=201), and social stress (M=3.75, SD=4.37, n=200). Meanwhile, the mean score for the CD-RISC was 70.19 (SD=15.82).

Table 1. Socio-demographic characteristics of caregivers and caregiving-related stressors.

Characteristics	Frequency	Percentage
Socio-demographic characteristics of caregivers		
Age (*Mean, SD*)	45.0	14.1
Gender		
Male	70	34.8
Female	131	65.2
Ethnicity		
Malay	132	65.7
Chinese	27	13.4
Indian	42	20.9
Marital status		
Married	143	71.1
Single	42	20.9
Widowed, separated or divorced	16	8
Educational level		
No formal education/Primary school	36	18.0
Secondary school	101	50.5
College/University	63	31.5
Employment status		
Working	113	56.2
Retiree	24	11.9
Unemployed	36	17.9
Housewife	28	13.9
Relationship with patient		
Spouse	42	20.9
Parent	57	28.4
Son/daughter	56	27.9
Other	46	22.9
Living arrangement		
Live with patient only	33	16.4
Live with patient and other people/family members	166	82.6
Having medical condition?		
Yes	75	37.5
No	125	62.5
Perceived health status		
Very Good	51	25.5
Good	91	45.5
Moderate	58	29.0
Caregiving-related stressors		
Duration of caregiving (*Median, IQR*)	5.0	8.0
Time spent for caregiving per day		
Less than 4 hours	48	24.4
4 to 8 hours	60	30.5
9 to 12 hours	37	18.8
More than 12 hours	52	26.4
Availability of support or assistance		
Assistance with caregiving tasks	108	55.4
Informational support	115	58.4
Financial support	85	42.7
Emotional support	95	48.5
Patients' behavioural disturbances in previous month		
Disturbed	119	59.5
Bizarre	94	47.5
Aggressive	58	29.1
Embarrassing	33	16.6
Violent	24	12.1

3.2. Factors associated with caregiver burden

Results from the Pearson correlation coefficient (r=0.19) indicated that older caregivers were more likely to feel burdened, with a small, positive correlation between age and caregiver burden. Male caregivers (M=26.17, SD=18.71) and female carers (M=33.09, SD=20.79; t (199)=-2.33, p=0.02) were found to have significantly lower ratings than female caregivers (M=26.17, SD=18.71).

It was shown that Chinese carers felt a greater burden than Malay and Indian participants (F (2, 198)=3.65, p=0.03). A higher burden level was also linked with unemployment (F (3,197)=3.00, p=0.03). Carers with a medical condition were more likely to report high levels of caregiver burden than caregivers without a medical condition. Findings show substantial disparities in caregiver burden among three categories of health status. Caregivers who perceived themselves to be in better health reported lower burden levels than those who perceived themselves to be in worse health. Caregiving-related stress was associated with the amount of time spent caring for patients (F [3,193]=17.24, p=0.001), the lack of emotional and caregiving assistance (t=-2.29, p=0.02), and all patients' behavioral disturbances (p=0.01).

There was an inverse correlation between caregiver burden and resilience. This correlation was moderate (r (197)=-0.354, p<0001) but shows that increased resilience corresponded with a decreased burden.

3.3. Predictors of caregiver burden

Socio-demographic factors were entered in stage 1 of the regression analysis, followed by stressors related to caregiving in stage 2 and resilience in stage 3. In order to determine if resilience predicted caregiver burden after adjusting for socio-demographic characteristics and caregiving-related stressors, resilience was entered last in this regression analysis.

At the beginning of stage 1, the model was significant when demographic characteristics were entered F (14,168)=2.96, p=0.01, and explained 19.8% of the variation in caregiver burden scores. Adding in caregiving-related stressors at stage 2 increased the model's overall variance explanation to 48.1 percent (F [26,156]=5.56, p=0.01), while the inclusion of stressors explained an additional 28% variance in caregiver burden. We entered resilience to a regression model in stage 3 (F (27, 155)=6.31, p=0.01) after adjusting for socio-demographic and caregiving-related stressors; it explained an extra 4.2% of the variation in caregiver burden.

Hierarchical multiple regressions found that caregiver-related stressors were the most significant predictor of caregiver burden, accounting for 28.3% of the variance in caregiver burden. In total, 52.4% of the variance in caregiver burden was accounted for by socio-demographic characteristics, stressors linked to caregiving, and resilience. Table 2 shows the results of these analyses.

Table 2. Results of the hierarchical multiple regression analyses for factors predicting caregiver burden

Characteristics	Model 1		Model 2		Model 3	
Variables	B	95%CI	B	95%CI	B	95%CI
Constant	31.80	14.35,49.25	26.03	9.67,42.40	44.88	26.23,63.53
Caregivers' socio-demographic characteristics						
Age	0.10	-0.22,0.54	-0.03	-0.31,0.25	0.01	-0.26,0.28
Gender	-3.16	-9.81,3.49	-1.55	-7.30,4.19	-0.25	-5.80,5.32
Male†						
Ethnicity						
Chinese	13.16**	4.87,21.45	7.21*	0.02,14.41	5.57	-1.41,12.54
Indian	2.60	-4.40,9.60	1.89	-4.12,7.91	1.64	-4.14,7.43
Malay†						
Marital status **						
Single	-1.18	-9.68,7.33	-2.49	-9.94,4.97	-1.80	-8.97,5.38
Widowed/Divorced	13.40*	1.74,25.07	19.48**	9.28,29.67	17.63**	7.78,27.48
Married†						
Educational level						
Primary school	-1.55	-10.05,6.96	-0.70	-7.98,6.57	0.48	-5.27,6.22
College/University	-1.60	-8.24,5.04	-1.95	-7.78,3.88	-2.78	-7.28,6.71
Secondary school†						
Employment status						
Retiree	-2.30	-12.49,7.87	-0.99	-9.73,7.75	-2.13	-10.55,6.30
Unemployed	7.03	-1.22,15.29	2.52	-4.66,9.71	0.58	-6.41,7.56
Housewife	1.66	-7.68,11.00	-1.25	-9.74,7.24	-1.86	-10.02,6.31
Working†						
Medical condition	-3.81	-11.89,4.27	-6.89	-14.03,0.25	-6.25	-13.12,0.63
Health status *						
Good	-6.77	-14.87,1.33	-8.76*	-15.98,-1.55	-7.75*	-14.70,-0.79
Very good	-13.84**	-23.24,-4.44	-13.08**	-21.05,-5.10	-10.70*	-18.47,-2.93
Moderate†						
Caregiving-related stressors						
Time spent for caregiving **						
4 to 8 hours			4.92	-1.70,11.54	4.36	-2.01,10.73
9 to 12 hours			14.27**	6.24,22.31	14.73**	7.00,22.46
> 12 hours			13.70**	6.25,21.14	14.92**	7.73,22.10
< than 4 hours†						
Sharing caregiving			0.74	-5.50,6.99	1.00	-5.00,7.00
Support with caregiving task			-2.19	-8.66,4.30	-2.02	-8.26,4.21
Support with financial			-3.49	-9.07,2.10	-5.24	-10.70,0.21
Support with emotional			0.50	-5.53,6.52	1.14	-4.40,7.23
Disturbed behaviour *			6.81*	0.74,12.89	6.23*	0.38,12.08
Bizarre behaviour			6.13	-0.14,12.41	4.74	-1.34,10.81
Aggressive behaviour			4.16	-2.71,11.02	3.06	-3.56,9.68
Violent behaviour			-2.19	-11.07,6.70	-1.59	-10.14,6.96
Embarrassing behaviour			6.93	-0.55,14.40	7.00	-0.19,14.19
Resilience **					-0.30**	-0.46,-0.14
R^2	0.198		0.481		0.524	
R^2 change	0.198		0.283		0.042	
F for R^2 change	2.960		5.563		6.309	
p-value	<0.01		<0.01		<0.01	

3.4. Other challenges and outcomes associated with caregiving

The open-ended question was answered by 28.4% (57/201) of participants. Most respondents, or 66.7% (n=38), were female, whilst 33.3% (n=19) were male. We identified 59 codes from caregivers' responses to open-ended questions. From these codes, 27.1% (n=)16 related to the emotional impact of caring for individuals with severe mental illness, while 35.6% (n=21) related to lack of support and coping. Caregivers also identified that managing patients' destructive behaviors was the most challenging part of caregiving 37.3% (n=22).

Table 3 shows that most caregivers who answered the open-ended question found that the main challenges associated with caring for individuals with severe mental illness were confronting patients' disruptive behavior.

> *"Patients find it challenging to accept instructions and quickly get angry and become aggressive."* (Caregiver 23)
>
> *"My son threatens to do something to himself or his family when he is depressed."* (Caregiver 7)
>
> A lack of support was another challenge voiced while caring for patients with severe mental illness.
>
> *"I did not get support and encouragement from close family members in caring for patients"* (Caregiver 26).
>
> *"Some family members do not understand the patient, and the hospital does not consider the condition of the caregiver and the patient's environment"* (Caregiver 30).

Despite the negative experiences, almost a third of caregivers reported the positive emotional impact of caregiving. They believed that caring for family members with severe mental illness taught them to become more patient and eventually accept their condition.

> *"The challenge is there but can be overcome with patience and proper patient care techniques."* (Caregiver 51)
>
> *"The patient is my father, and he does not have any problems. I pray that he will be healthy."* (Caregiver 20)

Table 3. Qualitative findings on other challenges and outcomes of caregiving

Codes for challenges and outcomes	Frequency	Percent (%)
Destructive behaviors	22	37.3
Emotional impact and coping		
Patience	9	15.2
Acceptance	7	11.9
Lack of support		
Knowledge deficit	7	11.9
Lack of formal and informal support	14	23.7
Total	59	100

4. DISCUSSION

As Malaysia moves toward deinstitutionalization, recognizing the burden faced by informal carers can substantially impact patients with severe mental illness. Caring for people with mental illness at home may be ineffective if carers are overburdened. Therefore, this study assessed the factors contributing to caregivers' burden in Malaysia. Caregiver burden was shown to be inversely related to caregiver resilience, suggesting that caregiver burden is lower when the resilience is high. Several studies have found unfavorable correlations between caregiver burden and carers' physical and mental health. A study among caregivers of patients with dementia found that caregivers are at higher risk for physical and mental health problems such as sleep disturbance, anxiety and depression [22].

On the other hand, a few recent studies reveal that, despite the difficulties of caring, most carers experience personal growth and resilience as a consequence of their effort [14]. Findings from Alzheimer's disease caregivers and female carers of adults with major mental illness were consistent with this conclusion [15]. Caregivers with higher levels of resilience and perceived high levels of support are more likely to report improved mental health. Positive mental health has been linked to a decreased caregiver burden in those who care for others. Additionally, more resilient caregivers may report reduced burden levels while caring for someone with a mental illness, especially a family member, which has caused some caregivers to experience a more profound sense of self-awareness and inner strength. Moreover, more resilient caregivers may be more likely to develop healthy coping skills methods and, thus, less likely to feel burdened when caring for someone with a severe mental illness.

It is known that caregivers of persons with mental illness experience significant burdens. Previous research has also demonstrated that care recipients were more likely to have unmet needs if their primary caregiver was experiencing a high degree of burden [23], [24]. The findings of this study indicate that caregivers experienced a moderate burden. When this finding was compared with previous studies, the burden level was higher than caregivers of elderly patients with dementia in Italy [10] and patients suffering mild dementia in the USA [25]. However, the burden found in this study is lower than caregivers of older adults with dementia in Taiwan [20] and China [26].

Findings also revealed that caregivers of individuals with mental illness were less resilient than the general population [21]. Compared to previous research on caregiver resilience, the finding showed that caregivers reported lower levels of resilience than caregivers of individuals with Alzheimer's disease [27] and military veterans [28] but higher than homeless youth [29]. This indicates that the level of burden experienced by caregivers may vary depending on patients' illnesses. There were almost two-thirds of female carers in this study. We found that women who cared for patients with mental illness were more likely than males to feel the burden. These findings concur with previous research in this area. Female carers were more likely to report a greater burden level than male caregivers, which may be due to a higher level of perceived shame, guilt, and client dependence experienced by female caregivers [8]. This gender difference might be related to how men and women cope differently when dealing with stressful situations [30].

Ethnic background also impacted the caregiver burden. Malaysia has three major ethnic groups, a diverse and multiracial nation. Malay makes up 66.1% of Malaysia's population, followed by Chinese (25.3%) and Indian (7.4%). Our findings show that while Chinese caregivers tended to have the most significant burden levels, Malay caregivers were found to have the lowest levels. Ethnic differences in caregiver burden were shown to be similar to previous research in Malaysia and its neighboring nation, Singapore [31]. The impact of Confucian ideas on the Asian population, particularly the Chinese, may be a factor in this finding. The Confucian principles specify each family member's duties and emphasize the need to maintain a harmonious relationship between family members. Thus, any disruption in the equilibrium, such as mental illness in a family member's health, usually results in psychological and emotional disturbances for the whole family.

Caregivers in this study reported feeling more burdened when they said they did not have enough help with caring responsibilities and emotional support. Many negative implications of caring, such as a higher degree of caregiver burden, have been identified because carers received inadequate assistance. However, instrumental and emotional stress assistance do not sufficiently reduce carers' difficulties. Further research is needed to determine the level of help that carers need based on the discrepancies in findings. The findings from qualitative data in this study suggested that most of the caregivers had a knowledge deficit in caring for individuals with severe and persistent mental illness. As most caregivers need to prepare to accept the responsibilities, comprehensive nursing education should be implemented for the caregivers.

In order to deal with patients' unexpected behaviors, several caregivers said they were always in 'stand-by' mode when caring for persons with severe mental illness. The caregivers sometimes found it challenging to deal with irregular disruptive behaviors like disturbing or angry outbursts. Findings from this study show that carers of people who have severe mental illness are more burdened than those caring for people with no behavioral problems, such as violent or humiliating behavior. Responding to the open-ended question, the caregivers reported that patients' unexpected and disrupted behaviors contributed to the burden of caregiving. It is well known that caregivers require support when caring for people with physical illnesses and that such support can enhance the quality of life [32].

This study has limitations. Because the study was cross-sectional, any progression in caregiver burden levels over time is unlikely to be well represented. In addition, because so few Chinese caregivers took part in the study, the sample does not accurately reflect the current ethnic distribution of Malaysia; it is crucial to determine how the findings can be generalized.

5. CONCLUSION

Carers of people with mental illness face a unique set of challenges. The findings show that carers' socio-demographic characteristics, caring stressors, and resilience all play a role in predicting whether or not caregivers will experience burden. Health care practitioners, such as nurses, must be aware of the burden and suffering that caregivers experience when caring for these. It is suggested that caregiver burden should be included as part of an evaluation when caregivers accompany patients to their follow-up appointments or home visits. Furthermore, longitudinal research is warranted to assess caregiver burden over time.

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