International Journal of Public Health Science (IJPHS)
Vol. 13, No. 4, December 2024, pp. 1634~1640
ISSN: 2252-8806, DOI: 10.11591/ijphs.v13i4.24381

Unraveling spinal cord injury caregiver burden in Indonesia

Vitriana Biben[1], Novitri Sumardi[1], Arya Wijaya[2], Septania Elvira Simatupang[3], Sitti Ayu Hemas Nurarifah[1]
[1]Physical Medicine and Rehabilitation Department, Faculty of Medicine, Padjadjaran University, Bandung, Indonesia
[2]Physical Medicine and Rehabilitation Department, Indramayu District General Hospital, Indramayu, Indonesia
[3]Physical Medicine and Rehabilitation Department, Kalideres District General Hospital, Jakarta, Indonesia

Article Info

Article history:

Received Dec 19, 2023
Revised Mar 15, 2024
Accepted Apr 24, 2024

Keywords:

Burden
Caregivers
Indonesia
Quality of life
Spinal cord injuries

ABSTRACT

Diverse cultural, social, and economic backgrounds significantly influence the caregiver burden of spinal cord injury (SCI) patients, affecting their quality of life (QoL) and the overall care experience. This study was done to identify spinal cord caregivers' QoL in Indonesia through their burden and the variables that influence it. A cross-sectional study was conducted at Dr. Hasan Sadikin Hospital, Bandung, Indonesia, involved 137 primary SCI caregivers. The burden of these caregivers was evaluated using the Indonesian version of the Zarit Burden Interview (ZBI) and the World Health Organization Quality of Life-BREF questionnaires. The data was analyzed with multiple linear regression and spearman analysis using SPSS version 24. The majority of SCI caregivers have a mild to moderate burden (54.7%). The burden score was significantly correlated, especially with occupational status and the length of interaction each day ($p<0.001$). It also found a significant with strong negative correlation (referring to the Guilford criteria) between caregiver burden and QoL (r-value −0.750; p-value <0.001). Indonesian caregivers' cultural and economic backgrounds may alleviate their burden in caregiving, but attention to patient occupational status and care duration is crucial to prevent worsening their quality of life, particularly for SCI survivors they care for.

Corresponding Author:

Vitriana Biben
Physical Medicine and Rehabilitation Department, Faculty of Medicine, Padjadjaran University
Bandung, Indonesia
Email: vitriana@unpad.ac.id

1. INTRODUCTION

Spinal cord injuries (SCI) cause loss of motor, sensory, and autonomic functions, resulting in disability and life-threatening consequences [1]. Epidemiological data on SCI in Indonesia and its disability are not yet available nationally; however, there are only two study about SCI epidemiology data. The recent study in 2021 showed there were 126 cases, of which 85 cases were traumatic SCI, and 41 were non-traumatic SCI in Dr. Soetomo General Hospital Surabaya [2]. The disability associated with SCI will cause dependence on others, so it will take at least one caregiver to accompany the patient and provide primary care [3]. Studies have shown that primary caregivers of individuals with SCI have some level of caregiver burden [4], [5]. The high burden of caring significantly affects the caregiver's physical and emotional well-being and is associated with a lower quality of life (QoL) [5]. There is an urgent need for focused interventions and support networks to counteract these negative impacts. Caregiver QoL is essential because it may impact the care they provide [6]. The burden on caregivers of individuals with SCI can be influenced by several factors, including the patient's and caregiver's characteristics, and it tends to be country-specific, determined by socio-economic, geographical, and cultural values [7], [8].

As the fourth most populated country in the world and the biggest archipelago, Indonesia is home to a diverse range of ethnicities and cultures, making it difficult for residents to receive equal healthcare [9]. This dilemma impacts many areas of healthcare, most notably on how SCI survivors are managed during their rehabilitation. Facilities with specialized rehabilitation units are still hard to come by in Indonesia. Only two hospitals provide SCI services, and they are located on Java Island in the provinces of Jakarta and Central Java. Although general rehabilitation services can be provided in many different hospitals, the difficulty for SCI rehabilitation is worsened by the lack of skilled personnel. Transportation-related obstacles further impair the situation by making it more difficult for patients to go from home to the hospital [10]. Because of this, a large number of SCI survivors are required to receive their care at home from their relatives. Primary carers, which are frequently family members, are unpaid informal carers who live with the patient and provide care [4]. However, Indonesia is among numerous Asian countries whose traditions values caring for family members as a sign of respect and honor [11]. Most carers are psychologically and emotionally inadequate to perform demanding and complex care obligations because they lack the proper knowledge and training, which might result in the increase of the carer’s load [4]. The shortage of thorough epidemiological data about the caregiver burden in Indonesia highlights a crucial knowledge gap regarding the complete range of difficulties informal caregiver face. This scarcity prevents the creation of the focused treatments and support networks required to successfully reduce the strain on carers. Given the significance of reliable epidemiological data in shaping healthcare policy and allocating resources, filling this knowledge vacuum is essential in improving the health of Indonesian carers and care users.

It is critical to identify factors influencing caregiver burden in Indonesia so that appropriate action can be taken to address them. This study intends to analyze caregiver burden and its correlation with the QoL of caregivers and determine the factors that influence them. The communal nature of Indonesian society holds family members to a high standard of care and commitment throughout life, which could overburden the family as caregivers [12]. We hypothesized that the occupational status of individuals with SCI, SCI level, SCI duration, health insurance ownership, the caregiver’s education level, the duration of care, and the length of interaction each day would be associated with caregiver burden in Indonesia.

The strong sense of community in Indonesian society, which holds family members to a high standard of care and commitment throughout life, could lead to an overburdening of the family as caregivers. We conduct this study because it is crucial to conduct research on caregivers in Indonesia, as understanding the factors that influence caregiver burden can help develop effective strategies to reduce the burden, thereby improving the quality of life of caregivers which has never conducted before [13]. The caregiver burden and QoL showed a statistically significant and substantial negative correlation. A high caregiver burden can have negative impacts on physical, emotional, mental health, and social life, which lowers the QoL of the caregiver [3], [5], [13], [14]. The condition of family caregiving is one example of how cultures are a sort of intergenerational inheritance that actively impacts people's lives [15]. Research on family carers particularly Indonesia, is essentially required because by recognizing the factors that can influence the caregiver burden, a proper approach to reduce the burden will improve caregiver QoL that also its impact to QoL of SCI patient.

2. METHOD

This study adopted a cross-sectional analytic design. The population of this study included the primary caregivers of SCI patients at the physical medicine and rehabilitation department, Dr. Hasan Sadikin Hospital, Bandung, Indonesia, from June to August 2021. A consecutive sampling procedure was used to select the study participants. A sample size of at least 137 participants was needed to achieve a significance level of 0.05, a power of 0.8, and a 95% confidence interval. The study was approved by the Research Ethics Committee of Dr. Hasan Sadikin Hospital (number: LB.02.01/X.6.5/137/2021) and received research permission from the hospital. All participants provided written informed consent prior to data collection.

The study’s inclusion criteria were as follows: primary caregivers of SCI individuals over the age of 18 years, caring for SCI individuals for at least four hours per day for at least three consecutive months, having a minimum primary school education, agreeing to participate in the study, and providing written informed consent. Participants who had a cognitive issue (Montreal cognitive assessment-indonesian version score <26) and were unable to communicate in Indonesian were excluded.

The sociodemographic data were divided into two categories: individuals with SCI and caregivers. Sex, age, education level, marital status, occupation, health insurance ownership, SCI level, American Spinal Injury Association (ASIA) impairment scale classification, the etiology of SCI, and the duration of SCI were among the sociodemographic and clinical factors examined in individuals with SCI. The caregivers’ sociodemographic factors included sex, age, education level, marital status, occupation, and relationship with the individuals with SCI, the duration of care, and interaction duration in a day.

The Indonesian version of the Zarit Burden Interview (ZBI), which had been translated, validated, and shown to have good reliability for assessing caregiver burden, was used to assess the caregiver burden [14].

There are 22 questions with a total score of 88. Each item receives a score between 0 and 4, with the options being: never (0), infrequently (1), occasionally (2), rather frequently (3), and almost always (4). The overall scores of the individuals were divided into four groups, each representing a distinct level of burden severity. “little or no burden” was defined as a score between 0–20, “mild-to-moderate burden” was defined as a score between 21–40, “moderate-to-severe burden” defined as a score between the number 41-60, and “very severe burden” was defined as a score between 61–88 [16].

The caregivers’ QoL was assessed using the Indonesian version of the World Health Organization (WHO) QoL-BREF (WHOQoL-BREF) questionnaire, which had been determined to be a valid and reliable questionnaire [15], [16]. The WHOQoL-BREF questionnaire has 26 items to measure quality of life through four domains: physical, psychological, social, and environmental. A Likert scale of 1 to 5 is used to score each item, with 1 indicating "very dissatisfied" and 5 indicating "very satisfied". The scores are classified into: “very poor” (0-20), “poor” (21-40), “average” (41-60), “good” (61-80), and “very good” (81-100) [15], [16].

Numerical variables were reported using means and standard deviations, whereas frequencies and percentages were used to report descriptive statistics for categorical variables. Using multiple linear regression analysis, these characteristics were correlated with caregiver burden levels. The association between caregiver burden and caregiver QoL was analyzed using a rank correlation analysis (Spearman’s rho). The statistical significance level was set at $p<0.05$. SPSS ver. 24, was used for all data analyses.

3. RESULTS AND DISCUSSION

3.1. Results

The characteristics of the subject were showed as in Table 1 with most caregivers having mild-to-moderate burden. The caregiver burden score, assessed using the ZBI, showed a mean score of 35.98±13.26, with most of the caregivers having mild to moderate burdens as illustrated in Table 1 and having moderate QoL, which has an average of 50.45±8.62 as detailed in Table 2. Table 3 shows the patient's occupation, level of injury, duration of SCI, ownership of health insurance, caregiver education level, duration of care, and length of interaction per day as a whole had a statistically significant effect on caregiver burden scores.

To see the effect of each variable examined in this study on the caregiver burden score partially, the t-test was used with the results as shown in Table 4. Statistical analysis, as shown in Table 4, showed that the occupational status of individuals with SCI and the interaction length per day were found to have a significant effect on the caregiver burden ($p<0.05$). The findings indicate that the burden on caregivers and employment status increases as the duration of daily interaction increases. Additionally, the lack of occupation among individuals with SCI will further heighten the burden on caregivers. Other variables such as the severity of injury, duration of SCI, presence of health insurance, caregiver's level of education, and length of caregiving had no significant correlation with caregiver burden. Based on Spearman’s statistical analysis, it also found a significant, strong negative correlation (referring to the Guilford criteria) between caregiver burden and QoL (r-value −0.750; $p<0.001$) as illustrated in Table 5. It shows that a caregiver's quality of life would decline with increasing caregiving burden.

3.2. Discussion

This study showed that most SCI caregivers experience a mild to moderate burden. It may be influenced by Indonesian culture, which believes caring for the infirm members of the family is considered an obligation and is also consistent with religious values [17], [18]. Inherent family values, such as commitment, solidarity, protection, and concern for others, are cultural factors. However, in many cultures, especially in nations with patriarchal cultures like Indonesia, these social standards are detrimental to women. Caring duties have a profound impact on caregivers' quality of life. Caregivers, in particular, frequently encounter physical and health-related challenges, resulting in a reduction in their perceived quality of life [19], [20]. The workload and responsibilities of women in the home cause various issues, including familial conflict, financial stress, and a decline in the health of female caregivers. The stress that comes with caring for others also impacts women's mental health [21]. These characteristics may alter for family caregivers in developed countries, where education levels are higher, access to healthcare facilities is better, and a preference for professional caregivers exists. In Western countries, caring for a family is not a cultural norm [22].

In research by Sinha *et al.* [7], the majority of participants indicated a moderate-to-severe load. This could be due to a higher interaction duration each day (>12 h) than reported in this study, and the value of taking care of the family is a natural condition in Indonesia. Close relationships among extended family members in Indonesia may reduce the stress on caretakers [23]. Other research has found that the main domain of caregiver burden in affluent countries is time-dependent [3], [24]. The duration of daily engagement between caregivers and people with SCI had a substantial impact on caregiver burden. The majority of caretagivers were in their productive years, with a mean age of 40.7±11.2 years. By providing long-term care, even lifelong assistance might interfere with the caregiver's daily activities and lifestyle, increasing multiple responsibilities conflict, limiting their social activities, and increasing their load [25], [26]. The caregiver's burden grows in proportion to the amount of time spent providing care [7].

Table 1. Characteristics of individuals with spinal cord injury and caregivers

Characteristics		SCI individuals (n=137)	Caregivers (n=137)
Gender, n (%)	Male	66 (48.2)	43 (31.4)
	Female	71 (51.8)	94 (68.6)
Age (years), mean (SD), range		43.7 (14.6), 19-69	40.7 (11.2), 21-67
Occupation, n (%)	Working	39 (28.5)	47 (34.3)
	Not working	98 (71.5)	90 (65.7)
Education, n (%)	Elementary school	16 (11.7)	7 (5.1)
	Junior high school	38 (27.7)	45 (32.8)
	Senior high school	81 (59.1)	84 (61.3)
	Bachelor/Diploma	2 (1.5)	1 (0.7)
Marital status, n (%)	Married	116 (84.7)	130 (94.9)
	Single	19 (13.9)	8 (5.1)
	Widow/widower	2 (1.5)	0 (0)
Health insurance, n (%)	Has health insurance	137 (100)	
	No health insurance	0 (0)	
Level of injury, n (%)	Paraplegic	121 (88.3)	
	Tetraplegic	16 (11.7)	
ASIA classification, n (%)	AIS A	35 (25.5)	
	AIS B	14 (10.2)	
	AIS C	34 (24.8)	
	AIS D	53 (38.7)	
	AIS ND (not determined)	1 (0.7)	
Etiology, n (%)	Traumatic	38 (27.7)	
	Nontraumatic	99 (72.3)	
Duration of SCI (months), mean (SD), range		13.4 (8.4), 3-60	
Relationship status, n (%)	Parent		20 (14.6)
	Child		28 (20.4)
	Sibling		2 (1.5)
	Spouse		86 (62.8)
	Other		1 (0.7)
Caregiving duration (months), mean (SD), range			13.4 (8.3), 3-60
Interaction duration in a day (h), mean (SD), range			7.7 (2.8), 4-20
Caregiver burden score	Median		34
	Range		17-62
Caregiver burden classification, n (%)	Little or no burden		(6.6)
	Mild to moderate		75 (54.7)
	Moderate to severe		49 (35.8)
	Severe		4 (2.9)

American spinal injury association (ASIA); American spinal injury association impairment scale classification (AIS); spinal cord injury (SCI); Zarit Burden Interview (ZBI).

Table 2. Quality of life score in caregivers

Variable	Mean (SD)	Median	Range
Caregiver quality of life score (WHOQoL-BREF)	50.45 (8.62)	49	35-71

WHOQoL-BREF, World Health Organization Quality of Life-BRIEF

Table 3. The effect of independent variables to caregiver burden

	Sum of squares	df	Mean square	F	Sig.
Regression residual total	12035.90	7.00	1719.41	18.66	<0.001
	11889.03	129.00	92.16		
	23924.93	136.00			

Note: df, degree of freedom; F, F ratio: Sig, significance.

Table 4. Linear regression analysis of factors influencing caregiver burden score

Variable	Caregiver burden score		
	Regression coefficients	SE	p-value
Occupational status of SCI individuals	-4.445	2.157	0.041*
Level of injury	2.919	2.660	0.275
Duration of SCI (months)	-0.878	0.901	0.332
Health insurance	2.915	1.952	0.138
Education of caregiver	0.464	1.423	0.745
Caregiving duration (months)	1.477	0.910	0.107
Interaction duration in a day (hours)	2.618	0.320	<0.01*

Note: *p-value <0.05: statistically significant standard error (SE).

Table 5. Correlation analysis between caregiver burden score and caregiver quality of life score

Variable	Correlation	r	p-value
Correlation between caregiver burden score and caregiver quality of life score	Spearman	-0.750	< 0.001*

Note: *p-value <0.05: statistically significant; r: correlation coefficient.

The financial burden is increasing, which may be caused by the Indonesian health system itself. The system now consists of public and private providers and financing [27], [28]. The only study about this system showed that the government share of total health expenditure also remains low, at only 39%, whereas private, primarily out-of-pocket expenditure, is 60%. The Indonesian government has implemented different health-care social insurance systems, although the emphasis is on curative care services and health infrastructure that supports medical care [29], [30]. This means that caring for SCI patients at home needs other economic support sources. Even if rehabilitation services are covered by social insurance, transportation to distant health facilities causes other financial burdens for the caregiver [31], [32], [33]. This study showed that health insurance had no statistically significant effect on caregiver burden scores. This might be because caregivers should still fund the additional costs associated with providing care, such as transportation, over-the-counter medications, and medical equipment that is not covered by health insurance [34]. To fulfill their numerous complex tasks, caregivers in Indonesia require support. These involve planning and providing hands-on care, keeping track of and managing symptoms, providing emotional support, taking care of and interacting with the larger family, accessing resources and managing finances, acting as the patient's advocate, navigating the healthcare system, as well as preparing for an uncertain future [35].

The limitations of this study were that it was conducted within a small group at one location; therefore, the study's results could not be applied to the overall population in Indonesia. Furthermore, we did not consider other factors predicted to affect the caregiver burden, such as medical rehabilitation programs; the caregiver's knowledge, skills, health problems, and coping mechanisms; social support; and kinship relationships with individuals with SCI. As a result, more research into the association between these variables and caregiver load is required.

4. CONCLUSION

The caregiver burden can be influenced by some factors. This study showed the occupational status of individuals with SCI and the duration of interaction per day had significant effects on caregiver burden. Interventions to manage these two aspects may help ease caregiver burden. There was also a substantial and significant correlation between the QoL of the caregivers of individuals with SCI and the burden of caregiving. Caregiver QoL may have an impact on the care they provide as well as the well-being of individuals with SCI. The results of this study can be used as the foundation for policies and strategies for improving the QoL of individuals with SCI.

REFERENCES

[1] A. Craig, Y. Tran, M. Arora, I. Pozzato, and J. W. Middleton, "Investigating dynamics of the spinal cord injury adjustment model: mediation model analysis," *Journal of Clinical Medicine*, vol. 11, no. 15, 2022, doi: 10.3390/jcm11154557.

[2] L. Widhiyanto, A. Japamadisaw, and K. D. Hernugrahanto, "A demographic profile of cervical injury: an Indonesian single tertiary hospital study with 6 months to 1-year follow-up," *Egyptian Journal of Neurology, Psychiatry and Neurosurgery*, vol. 57, no. 1, 2021, doi: 10.1186/s41983-021-00433-x.

[3] A. Conti *et al.*, "The relationship between psychological and physical secondary conditions and family caregiver burden in spinal cord injury: a correlational study," *Topics in Spinal Cord Injury Rehabilitation*, vol. 25, no. 4, pp. 271–280, Sep. 2019, doi: 10.1310/sci2504-271.

[4] M. S. Khan *et al.*, "Level of mental burden among caregivers of spinal cord injured patients," *Romanian Journal of Neurology/ Revista Romana de Neurologie*, vol. 20, no. 4, pp. 490–495, 2021, doi: 10.37897/RJN.2021.4.15.

[5] D. Jacob, J. K. Muliira, E. R. Lazarus, and H. Roslin, "Predictors of quality of life among Omani family caregivers of patients with traumatic brain injury," *Sultan Qaboos University Medical Journal*, vol. 23, no. 4, pp. 463–471, 2023, doi: 10.18295/squmj.5.2023.028.

[6] A. A. Hazzan, J. Dauenhauer, P. Follansbee, J. O. Hazzan, K. Allen, and I. Omobepade, "Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews," *BMC Geriatrics*, vol. 22, no. 1, p. 86, Dec. 2022, doi: 10.1186/s12877-022-02787-0.

[7] P. Sinha, R. S. Mehta, P. Parajuli, P. Chaudhary, and R. P. Kushwaha, "Burden of care among primary caregivers' of spinal cord injury patients attending a tertiary care center in Eastern Nepal," *Discover Social Science and Health*, vol. 2, no. 1, 2022, doi: 10.1007/s44155-022-00016-y.

[8] G. Steinsheim, W. Malmedal, T. Follestad, B. Olsen, and S. Saga, "Factors associated with subjective burden among informal caregivers of home-dwelling people with dementia: a cross-sectional study," *BMC Geriatrics*, vol. 23, no. 1, Oct. 2023, doi: 10.1186/s12877-023-04358-3.

[9] A. Rizkianti, I. Saptarini, and R. Rachmalina, "Perceived barriers in accessing health care and the risk of pregnancy complications in Indonesia," *International Journal of Women's Health*, vol. 13, pp. 761–772, 2021, doi: 10.2147/IJWH.S310850.

[10] F. Keihanian, L. Kouchakinejad-Eramsadati, S. Yousefzadeh-Chabok, and E. Homaie Rad, "Burden in caregivers of spinal cord injury patients: a systematic review and meta-analysis," *Acta Neurologica Belgica*, vol. 122, no. 3, pp. 587–596, 2022, doi: 10.1007/s13760-022-01888-2.

[11] M. S. Kristanti, Kusmaryanto, and C. Effendy, "Common ethical dilemmas of family caregivers of palliative patients in Indonesia," *Belitung Nursing Journal*, vol. 7, no. 3, pp. 246–250, 2021, doi: 10.33546/bnj.1457.

[12] C. I. H. Purba, B. Johnston, and G. Kotronoulas, "An exploration of family caregivers' health care needs when caring for patients with cancer in the resource-challenged context of West Java, Indonesia," *Seminars in Oncology Nursing*, vol. 39, no. 3, 2023, doi: 10.1016/j.soncn.2022.151369.

[13] A. Farajzadeh, M. Akbarfahimi, S. Maroufizadeh, and N. Miri Lavasani, "Factors associated with quality of life among caregivers of people with spinal cord injury," *Occupational Therapy International*, pp. 1–10, Oct. 2021, doi: 10.1155/2021/9921710.

[14] M. L. Bratu *et al.*, "Evaluating the aspects of quality of life in individuals with substance use disorder: a systematic review based on the WHOQOL questionnaire," *Journal of Multidisciplinary Healthcare*, vol. 16, pp. 4265–4278, 2023, doi: 10.2147/JMDH.S440764.

[15] A. C. M. Gratão *et al.*, "Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers," *Dementia e Neuropsychologia*, vol. 13, no. 1, pp. 122–129, 2019, doi: 10.1590/1980-57642018dn13-010015.

[16] Y. S. E. Putri, I. G. N. E. Putra, A. Falahaini, and I. Y. Wardani, "Factors associated with caregiver burden in caregivers of older patients with dementia in Indonesia," *International Journal of Environmental Research and Public Health*, vol. 19, no. 19, 2022, doi: 10.3390/ijerph191912437.

[17] R. D. Tumanggor, E. Elfira, and E. Aizar, "Female caregiver devotion as a stress factor in caring for hospitalized elderly in Indonesia," *International Journal of Nursing Education*, Feb. 2020, doi: 10.37506/ijone.v12i2.4273.

[18] M. Hatefi, A. Vaisi-Raygani, M. Borji, and A. Tarjoman, "Investigating the relationship between religious beliefs with care burden, stress, anxiety, and depression in caregivers of patients with spinal cord injuries," *Journal of Religion and Health*, vol. 59, no. 4, pp. 1754–1765, Jun. 2019, doi: 10.1007/s10943-019-00853-3.

[19] F.-H. Wen *et al.*, "Family caregivers' subjective caregiving burden, quality of life, and depressive symptoms are associated with terminally Ill cancer patients' distinct patterns of conjoint symptom distress and functional impairment in their last six months of life," *Journal of Pain and Symptom Management*, vol. 57, no. 1, pp. 64–72, Jan. 2019, doi: 10.1016/j.jpainsymman.2018.09.009.

[20] G. Sittironnarit, W. Emprasertsuk, and K. Wannasewok, "Quality of life and subjective burden of primary dementia caregivers in Bangkok, Thailand," *Asian Journal of Psychiatry*, vol. 48, p. 101913, Feb. 2020, doi: 10.1016/j.ajp.2019.101913.

[21] I. Hanssen, F. M. Mkhonto, H. Øieren, M. L. Sengane, A. L. Sørensen, and P. T. M. Tran, "Pre-decision regret before transition of dependents with severe dementia to long-term care," *Nursing Ethics*, vol. 29, no. 2, pp. 344–355, Mar. 2022, doi: 10.1177/09697330211015339.

[22] I. W. W. Sari and N. Nirmalasari, "Preparedness among family caregivers of patients with noncommunicable diseases in Indonesia," *Nurse Media Journal of Nursing*, vol. 10, no. 3, pp. 339–349, 2020, doi: 10.14710/NMJN.V10I3.31954.

[23] S. P. Adhikari, G. Gurung, B. Khadka, and C. Rana, "Factors influencing depression in individuals with traumatic spinal cord injury and caregivers' perceived burden in a low-income country: a cross-sectional study," *Spinal Cord*, vol. 58, no. 10, pp. 1112–1118, 2020, doi: 10.1038/s41393-020-0451-5.

[24] H. Shahid, "Psychosocial burden of spinal cord injury survivors on their family caregivers," *Journal of the Dow University of Health Sciences*, vol. 14, no. 1, Apr. 2020, doi: 10.36570/jduhs.2020.1.900.

[25] C. Isac, P. Lee, and J. Arulappan, "Older adults with chronic illness – Caregiver burden in the Asian context: A systematic review," *Patient Education and Counseling*, vol. 104, no. 12, pp. 2912–2921, Dec. 2021, doi: 10.1016/j.pec.2021.04.021.

[26] Z. Liu, C. Heffernan, and J. Tan, "Caregiver burden: A concept analysis," *International Journal of Nursing Sciences*, vol. 7, no. 4, pp. 438–445, Oct. 2020, doi: 10.1016/j.ijnss.2020.07.012.

[27] A. Ferdiana, M. W. M. Post, U. Bültmann, and J. J. L. van der Klink, "Barriers and facilitators for work and social participation among individuals with spinal cord injury in Indonesia," *Spinal Cord*, vol. 59, no. 10, pp. 1079–1087, 2021, doi: 10.1038/s41393-021-00624-6.

[28] N. Sari, M. Omar, S. A. Pasinringi, A. Zulkifli, and A. I. Sidin, "Developing hospital resilience domains in facing disruption era in Indonesia: a qualitative study," *BMC Health Services Research*, vol. 23, no. 1, 2023, doi: 10.1186/s12913-023-10416-8.

[29] E. Owusu, F. Oluwasina, N. Nkire, M. A. Lawal, and V. I. Agyapong, "Readmission of patients to acute psychiatric hospitals: influential factors and interventions to reduce psychiatric readmission rates," in *Healthcare*, vol. 10, no. 9, 2022.

[30] A. Conti, F. Ricceri, G. Scivoletto, M. Clari, and S. Campagna, "Is caregiver quality of life predicted by their perceived burden? A cross-sectional study of family caregivers of people with spinal cord injuries," *Spinal Cord*, vol. 59, no. 2, pp. 185–192, 2021, doi: 10.1038/s41393-020-0528-1.

[31] C. Fekete *et al.*, "Cohort profile of the international spinal cord injury community survey implemented in 22 countries," *Archives of Physical Medicine and Rehabilitation*, vol. 101, no. 12, pp. 2103–2111, Dec. 2020, doi: 10.1016/j.apmr.2020.01.022.

[32] F. Keihanian, L. Kouchakinejad-Eramsadati, S. Yousefzadeh-Chabok, and E. Homaie Rad, "Burden in caregivers of spinal cord injury patients: a systematic review and meta-analysis," *Acta Neurologica Belgica*, vol. 122, no. 3, pp. 587–596, 2022, doi: 10.1007/s13760-022-01888-2.

[33] B. Theng et al., "Understanding caregiver challenges: a comprehensive exploration of available resources to alleviate caregiving burdens," *Curēus*, Aug. 2023, doi: 10.7759/cureus.43052.

[34] Z. S. Ahmad Zubaidi, F. Ariffin, C. T. C. Oun, and D. Katiman, "Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross-sectional study," *BMC Palliative Care*, vol. 19, no. 1, 2020, doi: 10.1186/s12904-020-00691-1.

[35] Y. Zhong, J. Wang, and S. Nicholas, "Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden," *BMC Geriatrics*, vol. 20, no. 1, 2020, doi: 10.1186/s12877-019-1403-9.

BIOGRAPHIES OF AUTHORS

Vitriana Biben is an Associate Professor in the Physical Medicine and Rehabilitation (PMR) Department at Universitas Padjadjaran, Bandung, West Java, Indonesia. She holds a Doctoral Degree in "The Association of Vitamin D Serum Status and Vitamin D Receptor Genes Polymorphism with sarcopenia in Indonesia Community-Dwelling Elderly." She is also the Head of the PMR Department at Dr. Hasan Sadikin Hospital Bandung and has been a consultant for Neuromuscular Rehabilitation. Her research interests include dysphagia rehabilitation, stroke rehabilitation, and quality of life. She is a PMR Indonesia Collegium committee member, secretary of the Faculty Senate, author of several international peer-reviewed publications and editor of NeuroRehabilitation Journal. She can be contacted at email: vitriana@unpad.ac.id.

Novitri Sumardi is a physiatrist who graduated in 2008 from the University of Indonesia. Currently working as medical staff at the main teaching hospital in West Java province as one of the main referral hospitals. Her main interest is neurorehabilitation with technology development including gait analysis and robotic rehabilitation. She can be contacted at email: novitri@unpad.ac.id.

Arya Wijaya is a physiatrist at the Indramayu district general hospital. He is a graduate of the Physical Medicine and Rehabilitation (PMR) medical education program at Padjadjaran University, Bandung, Indonesia. He is an administrator of the Indonesian Association of PMR in West Java. He can be contacted at email: aryaray5000@gmail.com.

Septania Elfira Simatupang is a physiatrist at the Kalideres district general hospital in Jakarta. She is a graduate of the Physical Medicine and Rehabilitation (PMR) medical education program at Padjadjaran University, Bandung, Indonesia. She can be contacted at email: septania18001@mail.unpad.ac.id.

Sitti Ayu Hemas Nurarifah is a general practitioner at Physical Medicine and Rehabilitation (PMR) Padjadjaran University, Bandung, Indonesia. Her main interest is neurorehabilitation and pain management. She can be contacted at email: ayuhemas@gmail.com.