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Quality of Life in Patients with Central Post-Stroke Pain in Riau, Indonesia: A Cross-Sectional Study

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Abstract

Background: Central Post-Stroke Pain (CPSP) is a chronic neuropathic complication of stroke that substantially impairs long-term well-being. While its clinical characteristics are increasingly recognized, data regarding the multidimensional quality of life (QoL) impact of CPSP in regional Indonesian populations remain limited. This study aimed to describe the QoL profile of CPSP patients at Arifin Achmad General Hospital to provide a comprehensive understanding of the disease burden.
Methods: A descriptive cross-sectional study was conducted from August to October 2025 at the Neurology Outpatient Clinic of Arifin Achmad General Hospital, Riau. Forty-four patients diagnosed with CPSP were included. QoL was assessed using the validated Indonesian version of the Stroke-Specific Quality of Life (SS-QoL) scale. Descriptive univariate analysis was performed to determine median scores across domains.
Results: QoL scores demonstrated marked heterogeneity across domains. The Vision domain showed the highest median score (4.0), whereas Social Role recorded the lowest (2.7). Notable reductions were observed in Work, Upper Extremity Function, and Energy domains. In contrast, Language and Self-care domains were relatively preserved. These findings indicate that although basic functional abilities may remain intact, CPSP significantly compromises social participation, occupational capacity, and physical activity.
Conclusion: CPSP imposes a substantial multidimensional burden, particularly affecting social engagement, productivity, and physical endurance. Comprehensive management strategies extending beyond pharmacological pain control are essential to address the psychosocial and functional consequences of CPSP. Further longitudinal studies with larger sample sizes are needed to clarify determinants of QoL outcomes in this population.

Keywords: *Central Post-Stroke Pain, Neuropathic Pain, Quality of Life, Post-stroke Complications*

Introduction

Stroke remains a leading cause of long-term disability worldwide and significantly affects the quality of life (QoL) of survivors. Beyond motor and cognitive impairments, stroke also results in various secondary complications that increase patient morbidity.[1] Among these complications, Central Post-Stroke Pain (CPSP) represents a significant yet frequently underdiagnosed condition.[2] CPSP is defined as neuropathic pain caused by lesions within the central nervous system following a cerebrovascular event. It is characterized by a chronic and persistent course, with variable onset, and it substantially reduces patients' physical comfort and overall well-being.[3]

Quality of life serves as a critical outcome indicator in post-stroke management because it reflects multidimensional aspects of health, including physical, psychological, social, and functional domains.[4] Comprehensive evaluation of QoL is therefore essential in understanding the broader consequences of stroke-

related complications. Previous studies primarily focused on the clinical and neurological aspects of CPSP rather than its broader psychosocial consequences. Several investigations reported that patients with CPSP experienced significantly lower QoL compared to other stroke survivors. Individuals suffering from persistent neuropathic pain demonstrated poorer scores across multiple domains, particularly in energy levels and cognitive functioning. However, empirical evidence assessing QoL among CPSP patients in Indonesia, especially in Riau Province, remained limited.[5]

In regional settings outside major healthcare centers, multidimensional assessment of post-stroke complications such as CPSP becomes increasingly important. Arifin Achmad General Hospital functions as the main tertiary referral hospital in Riau Province. Evaluating the QoL of CPSP patients in this regional population provides essential baseline data for developing localized, multidisciplinary stroke rehabilitation strategies and for understanding the broader socio-economic burden of chronic neuropathic pain. Therefore, this study aimed to describe the quality of life profile of CPSP patients treated at this facility.

Methods

Study Design

This study employed a descriptive cross-sectional design to evaluate the quality of life (QoL) of patients with Central Post-Stroke Pain (CPSP) at a single point in time. The research was conducted at the Neurology Clinic of Arifin Achmad General Hospital, Riau Province, between August and October 2025.

Participants and Eligibility Criteria

The target population included stroke survivors who attended follow-up consultations during the study period. CPSP was diagnosed based on clinical assessment of neuropathic pain that arose as a direct consequence of a cerebrovascular lesion. The inclusion criteria consisted of patients with a confirmed diagnosis of ischemic or hemorrhagic stroke based on neuroimaging performed more than three months prior to recruitment, a clinical diagnosis of Central Post-Stroke Pain (CPSP), age of 18 years or older, and willingness to participate in the study. Patients with severe global aphasia, advanced dementia, or other chronic pain conditions that could confound pain assessment were excluded. A total of 44 patients met the eligibility criteria and were included in the final analysis.

Data Collection and Variables

Demographic and clinical characteristics, including age, sex, stroke type, lesion site, and lesion laterality, were retrieved from patients' medical records. Quality of life was assessed through guided interviews using the Indonesian version of the Stroke-Specific Quality of Life (SS-QOL) scale, which had previously been culturally adapted and validated. To ensure data validity and minimize misinterpretation, trained medical personnel conducted the interviews by reading each question aloud and providing standardized clarifications when necessary.

Data Analysis

Descriptive statistical analysis was performed using SPSS software. Univariate analysis was conducted to calculate frequencies, percentages, means, medians, standard deviations, and ranges.

Ethical Considerations

All collected data were anonymized to protect participant confidentiality. The study protocol was approved by the Ethics Committee of the Faculty of Medicine, Universitas Riau, and Arifin Achmad General Hospital (No. 072/UN19.5.1.1.8/UEPKK/2025). Written informed consent was obtained from all participants prior to data collection.

Results

A total of 44 patients with Central Post-Stroke Pain (CPSP) participated in this study. The demographic profile indicated a predominantly younger population, with 72.7% of participants aged under 60 years, and a male predominance (68.2%).

Regarding clinical characteristics, ischemic stroke accounted for 90.9% of cases. Extrathalamic lesions were more frequent (63.6%) than thalamic lesions (36.4%). The right hemisphere was identified as the most common lesion site (40.9%). Clinical Characteristics of Patients with Central Post-Stroke Pain (Tabel 1)

Table 1 Clinical Characteristics of Patients with Central Post-Stroke Pain (N= 44)

Characteristics	n	%
Age		
<60 years	32	72.7
≥60 years	12	27.3
Gender		
Male	30	68.2
Female	14	31.8
Stroke Type		
Ischaemic	40	90.9
Haemorrhagic	4	9.1
Lesion Site		
Thalamic	16	36.4
Extrathalamic	28	63.6
Lesion Side		
Left	16	36.4
Right	18	40.9
Bilateral	10	22.7

The assessment of quality of life (QoL) across multiple domains revealed variations in median scores. The vision domain demonstrated the highest median score (median = 4.0), whereas the social role domain recorded the lowest median score (median = 2.7). Domains such as self-care, language, and mood showed relatively higher median values, while the work and upper extremity function domains presented lower median scores. The broad range between minimum and maximum values across domains indicated variability in QoL outcomes among patients with CPSP.

Quality of Life Domains Among Patients with Central Post-Stroke Pain (Tabel 2)

Table 2. Quality of Life Domains Among Patients with Central Post-Stroke Pain (N = 44)

Quality of Life	Mean ± SD	Median	Min-Max
Energy	3.14 ± 0.84	3.3	1-4.3
Family Role	3.01 ± 0.79	3	1-4.3
Language	3.36 ± 0.73	3.4	2-5
Self-care	3.39 ± 0.84	3.5	1.6-5
Social Role	2.64 ± 0.82	2.7	1-4.2
Vision	3.69 ± 0.96	4	1.7-5
Upper Extremity Function	2.89 ± 0.75	2.9	1-5
Work	2.73 ± 1.04	2.8	1-5
Thinking	2.96 ± 0.77	3	1.3-4.3
Personality	3.28 ± 0.72	3.1	2-5
Mood	3.19 ± 0.78	3.4	1.4-4.4
Mobility	3.01 ± 0.81	3.1	1-4.3

The vision domain recorded the highest mean score (3.69 ± 0.96) with a median of 4.0, whereas the social role domain demonstrated the lowest mean score (2.64 ± 0.82) with a median of 2.7. Domains related to self-care (3.39 ± 0.84), language (3.36 ± 0.73), personality (3.28 ± 0.72), and mood (3.19 ± 0.78) showed relatively higher mean scores compared to other domains. In contrast, work (2.73 ± 1.04) and upper extremity function (2.89 ± 0.75) demonstrated lower mean values. The range of scores across domains indicated variability in QoL outcomes, with minimum values ranging from 1.0 to 2.0 and maximum values reaching up to 5.0 in several domains.

Discussion

The reduction in energy domain scores likely reflected the increased fatigue experienced by patients with CPSP. This finding was consistent with a 2025 Indonesian cross-sectional study, which demonstrated significantly lower energy scores among CPSP patients compared with those without CPSP.[5] Persistent central pain contributed to reduced physical endurance and perceived vitality, thereby negatively influencing overall quality of life.[6]

Lower scores in the family role domain were aligned with findings from a cross-sectional study conducted in Italy.[7] Unpredictable pain restricted patients' ability to participate in family activities, both physically and emotionally.[5,7] Furthermore, CPSP fostered dependency on family members, which altered relationship dynamics and social roles within the household.[8]

In contrast, the language domain demonstrated relatively preserved scores. This finding was consistent with an observational study conducted in Türkiye.[9] This pattern corresponded with the pathophysiology of CPSP, which primarily involved central somatosensory pathways, such as the thalamus and the spinothalamic tract, without direct involvement of cortical language areas.[10] The preservation of language function was clinically significant, as it enabled patients to articulate their pain-related symptoms and needs effectively.[3,11]

The relatively preserved self-care scores were aligned with findings from a study conducted at the University of Birmingham.[12] However, CPSP compromised the comfort and efficiency of self-care tasks, particularly when pain affected extremities essential for daily activities.[5] Previous studies showed that patients with CPSP experienced poorer functional outcomes and lower quality of life scores, including domains related to physical functioning and self-care, compared with patients without chronic pain.[5,7]

Impairment in the social role domain was supported by cross-sectional findings in Italy.[7] Persistent CPSP, often characterized by allodynia and hyperalgesia, prompted patients to withdraw from social activities and environmental interactions, contributing to reduced social participation.[13] The unpredictable nature of pain paroxysms triggered anticipatory anxiety and avoidance behaviors, which further restricted engagement in community and family roles.[12]

The relatively preserved vision scores were consistent with findings from a cross-sectional study in Indonesia.[5] This observation was anatomically coherent with the pathophysiology of CPSP, which primarily involved the somatosensory system rather than visual pathways.[14] Intact vision assisted patients in navigating their environment and maintaining spatial orientation.[3,11]

Lower upper extremity function scores were aligned with findings from a cross-sectional study evaluating chronic post-stroke pain.[7] CPSP exacerbated functional impairment through fear-avoidance mechanisms, in which patients limited movement to prevent pain exacerbation. Patients with CPSP exhibited greater upper limb disability compared with those without neuropathic pain, suggesting that chronic pain interfered with motor recovery of affected extremities.[15]

The decline in the work domain was consistent with findings reported in an Indonesian cross-sectional study. Chronic CPSP diminished work tolerance and the capacity for sustained concentration, as persistent discomfort and psychosocial burden negatively affected daily functioning.[5] Even among patients with favorable motor recovery, cognitive barriers, reduced motivation, and self-perceived limitations predicted challenges in returning to work after stroke.[16]

Impairment in the thinking domain was aligned with findings from a 2025 Indonesian cross-sectional study.[5] Chronic pain activity involved neural circuits intersecting with cognitive networks, particularly within the prefrontal cortex, which played a key role in attention, information processing speed, and executive function. Epidemiological evidence supported an association between persistent pain and cognitive decline.[17]

Alterations in the personality domain were supported by findings from studies conducted in Italy.[7] The persistent nature of CPSP contributed to irritability, emotional lability, and reduced stress tolerance, reflecting the psychological burden associated with chronic neuropathic pain.[18] Chronic post-stroke pain was associated with higher levels of psychosocial distress and maladaptive coping strategies.[7]

Disturbances in the mood domain were consistent with findings from a 2025 Indonesian cross-sectional study.[5] CPSP was identified as an independent risk factor for depressive and anxious symptoms following stroke, and patients with chronic pain reported poorer quality of life when mood disturbances were present.[19-20]

The decline in mobility was consistent with studies reporting increased disability among post-stroke patients with chronic pain.[7] Neuropathic pain triggered kinesiophobia and avoidance behaviors, which restricted ambulation and functional mobility. Previous studies demonstrated that fear of movement was associated with reduced physical activity and diminished step counts among stroke survivors.[20]

Clinical Implications

The multidimensional deterioration of quality of life observed in CPSP patients highlighted the limitations of relying solely on pharmacological pain suppression.[5,7] Because chronic neuropathic pain intersected with cognitive and emotional regulation systems, clinical management should incorporate early neuropsychological screening to identify depressive symptoms, anxiety, and maladaptive coping strategies.[17] Furthermore, the role of kinesiophobia in upper extremity disability and mobility decline indicated that rehabilitation programs should integrate cognitive-behavioral approaches and graded exposure therapy.[20]

Significant impairments in social and family roles, along with diminished work tolerance, emphasized the need for structured occupational therapy and family counseling.[16] A proactive, multidisciplinary approach integrating neurology, rehabilitation medicine, psychology, and occupational therapy would optimize functional recovery and facilitate psychosocial and vocational reintegration among CPSP survivors.[7]

Limitations

This study had several limitations. The absence of a control group restricted comparative interpretation of QoL scores. The reliance on univariate analysis limited exploration of statistical associations between demographic variables and QoL domains. The relatively small sample size from a single regional center reduced generalizability. Additionally, although standardized procedures were implemented, the use of guided interviews introduced potential interviewer bias.

Conclusions

CPSP exerted a profound and debilitating impact on the overall quality of life of stroke survivors, extending beyond localized neuropathic discomfort. Although anatomically distinct functions such as vision and cortical language pathways remained relatively preserved, CPSP significantly compromised energy stamina, mobility, and upper extremity function.

The chronic nature of the pain created a compounding cycle of disability that disrupted psychosocial well-being, leading to marked declines in mood, executive cognitive functioning, personality stability, and social role fulfillment. The interplay of kinesiophobia, emotional distress, and functional limitation constituted a substantial barrier to vocational reintegration and functional independence.

Overall, the findings indicated that comprehensive post-stroke management required a holistic approach that addressed both the physical and psychological dimensions of chronic neuropathic pain in order to improve long-term patient outcomes.

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Declaration concerning generative AI and AI-augmented technologies in the compositional process

In the course of preparing this paper, the authors utilized ChatGPT to enhance readability and linguistic quality. Subsequent to utilizing this tool/service, the writers assessed and amended the information as necessary and assume complete accountability for the publication's content.

Declarations of competing interest

This study does not involve any personal, financial, or other conflicts of interest.

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