**Original Research****EFFECT OF COMMUNITY-BASED REHABILITATION ON CAREGIVERS OF PALLIATIVE STROKE AND GERIATRIC PATIENTS: PILOT STUDY**

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ABSTRACT

Introduction: Community-based rehabilitation (CBR) effectively supports palliative care patients, including those with cerebrovascular disease (CVD/stroke), though impacts vary by local resources. Caregiver burden is common among families of palliative patients with cardiovascular and geriatric conditions. This study evaluated a primary health center-based CBR program's effects on both caregiver & patient.

Objective: To describe and assess the clinical and statistical significance of CBR in reducing caregiver burden, improving quality of life (QoL), knowledge, and patient functional outcomes in palliative care.

Material and methods: This retrospective study analyzed CBR data from Universitas Indonesia. Four validated tools were used: Zarit Burden Interview (ZBI), EQ-5D-5L/EQ-VAS (caregiver and patient QoL), caregiver knowledge questionnaire, Barthel Index (BI). Paired pre-post analyses were performed.

Result: Most caregivers cared for post stroke patients. Caregiver EQ-VAS improved significantly (+30.56±39.25; p=0.048). Non-significant but clinically meaningful trends were observed in ZBI reduction (-4.33±8.38; p=0.159) and caregiver knowledge gain (median +7; p=0.050). Patient BI improvement (+1.78±1.30; p=0.073) and patient EQ-VAS increase (median +10; p=0.089).

Discussion: CBR training enhanced caregiver QoL and produced consistent positive trends across functional and psychosocial measures for palliative patients in resource-limited community settings, suggesting clinical benefit and feasibility for primary care implementation despite limited statistical significance.

Conclusion: CBR showed potential benefit in improving caregiver QoL and patient outcomes in primary palliative care. Larger prospective studies are needed.

Keywords: glioblastoma; CAR-T cells; immunotherapy

INTRODUCTION

Palliative care is a holistic approach that improves the quality of life of

patients and their families facing life-threatening illness through

early identification, comprehensive assessment, and treatment of pain and other physical, psychological, social, and spiritual problems, and it is increasingly viewed as complementary to intensive care within a patient-centered model of care.¹ Palliative care is generally delivered through an interdisciplinary approach and can be implemented at any stage of a serious illness, including the chronic phase, episodes of acute deterioration, or at the end of life, and it is not restricted to end-of-life management but may be integrated alongside disease-specific treatments, including those with curative intent, according to the established goals of care.²

In the context of managing individuals with palliative conditions, chronic diseases, or long-term medical needs, the role of caregivers is essential. Caregivers provide continuous physical, emotional, and practical support, often serving as the primary source of assistance in daily care. Although palliative and chronic illnesses differ in their nature, both require substantial caregiver involvement. Palliative conditions are generally life-threatening and

emphasize comfort, symptom control, and quality of life, particularly in advanced stages. In contrast, chronic diseases such as diabetes and hypertension are long-term conditions that require ongoing management to maintain functional status and prevent complications.^{1,2}

Despite these differences, caregiving responsibilities in both palliative and chronic-disease contexts can impose significant challenges, as the sustained demands of care may adversely affect caregivers' physical, psychological, social, and economic well-being. This multidimensional stress, commonly termed caregiver burden, is influenced by the severity and complexity of the patient's condition, limited social support, insufficient access to healthcare services, and inadequate caregiver knowledge and skills.^{1,2}

To address these challenges, a continuum of care approach is essential. In particular, caregiver involvement is key because ongoing assistance and supervision are required to maintain rehabilitation gains and ensure continuity of care at home. Community-based rehabilitation (CBR), delivered

through primary healthcare settings, aligns with this approach by actively involving caregivers in structured training and support, which can enhance patient recovery while potentially reducing caregiver burden.³

MATERIAL AND METHODS

This is a retrospective study analyzing data from a community-based rehabilitation program conducted at Public Health Centers across DKI Jakarta, from July 2022 to December 2024. The palliative CBR program was implemented across multiple districts in DKI Jakarta, including Johar Baru and Cempaka Putih (Central Jakarta) in 2022; Tebet (South Jakarta) in

2023; Grogol and Petamburan (West Jakarta) in 2023; and Pulogadung, Cipayung, Duren Sawit, Jatinegara, Cakung, Pasar Rebo, Kramat Jati, Makasar, Ciracas, and Matraman (East Jakarta) in 2024. The program involved collaboration with 16 public health centers across five municipal health districts in DKI Jakarta.

The study is part of a monitoring and evaluation program for Palliative - CBR, a collaboration between DKI Jakarta Provincial Health Service and Physical Medicine and Rehabilitation (PM&R) Department, Faculty of Medicine, Universitas Indonesia. The whole Palliative - CBR process was described in Figure 1.

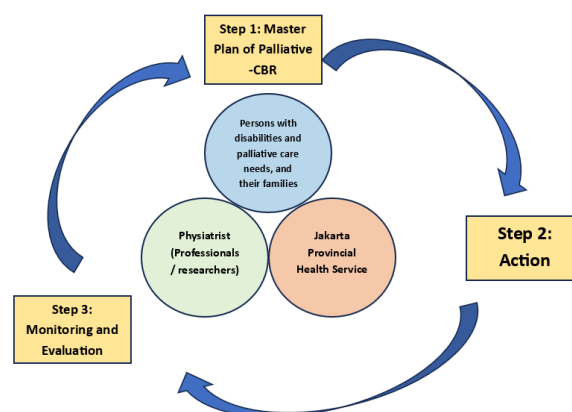


Figure 1 Overview of the Palliative Community-Based Rehabilitation (CBR) Program Across Primary Health Centers in DKI Jakarta

The program conducted of three steps that includes:

1. Master plan of Palliative - CBR

DKI Jakarta Provincial Health Service chose CBR thematic and location after comprehensive analysis in regional palliative service existed. The designated regional public health centers prepared their cadres and palliative patients for community visits.

2. Action

Various CBR activities included community visits, focus groups, and reflective meetings. Basic rehabilitation services for palliative patients were conducted by caregivers that were supervised by health cadres and regional public health. Caregiver, health cadres and public health officers received CBR training by physiatrists from PM&R Department, Faculty of Medicine, Universitas Indonesia.

3. Monitoring & Evaluation

Several focus group discussions were conducted in 2025 to evaluate CBR collaboration in previous years. Secondary data related were undertaken. These data were interpreted as defined in this study.

Thirty-three caregivers aged ≥ 18 years, literate, and providing ≥ 1 hour daily palliative care received basic rehabilitation training. Data was excluded if the patient death ($n=1$) and incomplete data, yielding a $n=9$ cases for analysis. Ethical approval was obtained from the Faculty of Medicine, Universitas Indonesia (No. KET-164/UN2.F1/ETIK/PPM.00.02/2026)

Four validated tools were used: the Indonesian Zarit Burden Interview (22 items, 0–88; higher scores indicate greater burden; sensitivity 75%, specificity 83.6%), EQ-5D-5L quality of life (5 domains and EQ-VAS 0–100), a 25-item caregiver knowledge questionnaire covering deconditioning detection, mobilization, ADL, and nutrition, and the Barthel Index (BI) for patient

ADL independence (0–20). Recorded baseline and 1-month follow-up assessments were retrospectively analyzed using home-visit documentation, self-completed questionnaires (with guidance), and patient assessments. Informed consent was obtained and confidentiality was assured.

Data were analyzed using IBM SPSS Statistics. Data distribution was assessed using the Shapiro–Wilk test to evaluate normality. Demographic data were presented as frequencies and percentages; descriptive statistics were expressed as mean

and standard deviation for normally distributed data and as median and minimum–maximum values for non-normally distributed data. For paired (pre–post) comparisons, the paired t-test and Wilcoxon signed-rank test were used for normally and non-normally distributed data, respectively.

RESULTS

Nine caregiver-patient pairs had complete data to be analyzed. The characteristics of the participants are shown in Table 1.

Table 1 Characteristic of the caregivers

	N (%)
Gender	
Male	1 (11.1)
Female	8 (88.9)
Age Group	
Adult (≤ 60 years)	6 (66.7)
Elderly (> 60 years)	3 (33.3)
Relations with Patients	
Partner	2 (22.2)
Child	5 (55.6)
Mother	1 (11.1)
Relatives	1 (11.1)
Participate in Synchronous Training	
Yes	2 (22.2)
No	7 (77.8)
Comorbidities of the patients	
CVD	8 (88.9)
Geriatric syndrome	1 (11.1)

Among the nine patients, eight had cerebrovascular disease comorbid, and one had a geriatric syndrome, all

managed palliatively. The relationship between caregivers and patients was predominantly children,

with some being partners. CBR training targeted caregivers and also benefited patients.

CBR training effects on both caregiver, and patient are shown in Table 2 and Table 3. A statistically significant improvement was seen in caregiver EQ-VAS (mean difference 30.56, $p=0.048$). Clinically

meaningful but non-significant changes ($p \geq 0.05$) included improved caregiver knowledge (median gain +7, $p=0.050$), reduced caregiver burden (ZBI mean difference 4.33, $p=0.159$), improved patient BI (mean difference 1.78, $p=0.073$), and increased patient EQ-VAS (median +10, $p=0.089$).

Table 2 Caregiver Burden, Quality of Life, Knowledge Before and After CBR Training Program

	Mean $\pm$ SD / N (%) / Median (Min-Max)		Change	Mean Difference (95% CI)	p value
	Pre (N=9)	Post (N=9)			
Zarit Burden Interview	33.44 $\pm$ 15.428	29.11 $\pm$ 14.987	-4.33 $\pm$ 8.382	4.33 (-2.11, 10.78)	0.159 ^a
Caregiver EQVAS	32.78 $\pm$ 24.636	63.33 $\pm$ 27.386	30.56 $\pm$ 39.246	-30.56 (-60.72, -0.38)	0.048* ^a
Caregiver Knowledge	11 (0 – 13)	11 (5 – 20)	7 (-7 – 19)	—	0.050 ^b

*Sig $p < 0.05$, a = paired t-test, b=Wilcoxon Signed Ranked test

Table 3 Patient Barthel Index and Quality of Life Before and After CBR Training Program

	Mean $\pm$ SD / N (%) / Median (Min-Max)		Change	Mean Difference (95% CI)	p value
	Pre	Post			
Patient Barthel Index	4.33 $\pm$ 3.279	6.11 $\pm$ 3.06	1.78 $\pm$ 1.302	-1.78 (-2.77, -0.77)	0.073 ^a
Patient EQVAS	40 (0 – 60)	50 (20 – 60)	10 (-20 – 40)	—	0.089 ^b

*Sig $p < 0.05$, a = paired t-test, b= Wilcoxon Signed Ranked test

The coordinate plot (Figure 2) shows most subjects clustered in the positive-positive quadrant, indicating concurrent improvement in caregiver and patient outcomes (n=6 including L, SA, Sr, WH, SU,

My). A minority showed discordant effects, SI improved only in caregiver outcomes, and ZA only in patient outcomes, one subject (S) showed decline in both domains. Overall, the plot confirms that the

CBR program predominantly caregivers and patients, though produced aligned benefits for variability existed.

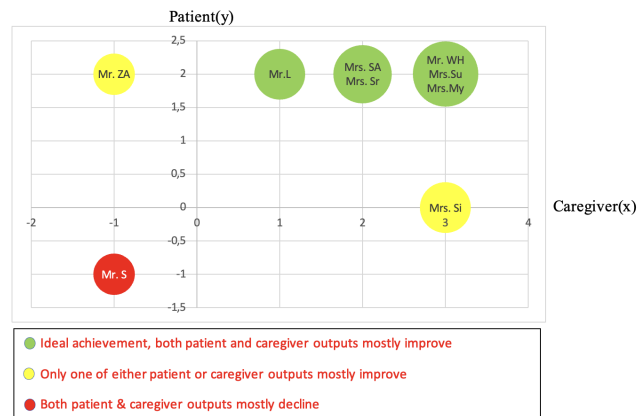


Figure 2 Visualization of Improvement or Decreased Gained of Caregiver Knowledge, Burden and QoL, and Patient ADL and QoL After CBR Training Program

Coordinates represent summed directional changes in caregiver (knowledge, burden, QoL) and patient (ADL, QoL) outcomes, where positive values indicate improvement and negative values indicate decline.

DISCUSSION

This pilot study comprised palliative survivors with cerebrovascular disease (88.9%) and one geriatric syndrome case, reflecting common intersections of comorbidity, and palliative needs in community transitions.^{4,5} Among the nine caregivers, 88.9% were female, which aligns with broader palliative-care and caregiving literature indicating that informal caregiving responsibilities are disproportionately shouldered by women, with estimates across countries showing that 57% to 81%

of caregivers are women and often at the expense of their own physical and psychological well-being.^{6,7} This pattern also reflects culturally assigned domestic and caregiving roles for women in Indonesia, consistent with Bekdemir et al., who reported higher mean Zarit Burden Interview scores among female caregivers compared with male caregivers.⁸

The age distribution of caregivers (66.7% adult ≤ 60 years and 33.3% elderly > 60 years) suggests that caregiving spans mid-life and

older-age cohorts, which may affect capacity for sustained, physically demanding care and increase susceptibility to caregiver burden, particularly because chronic exposure to psychological stress is associated with poorer cognitive function and accelerated cognitive decline. Given the high prevalence of psychological impairments among post-intensive care caregivers, some degree of cognitive impairment may exist, particularly among older caregivers.^{9,10} However, Bekdemir et al. found, in a multiple regression analysis of predictors of caregiving burden, that neither gender nor age were significant predictors of caregiver burden.⁸ The relational structure, predominantly children (55.6%) and partners (22.2%), is consistent with patterns observed in home-based palliative and post-critical settings, where adult children and spouses remain the primary providers of daily care.^{11, 12}

Following CBR training, caregiver burden measured by the Zarit Burden Interview decreased, with mean scores declining from 33.44 ± 15.43 to 29.11 ± 14.99 , $p=0.159$) and although

the reduction was not statistically significant, a trend toward clinical improvement was evident and consistent with the coordinate analysis showing that most subjects experienced parallel gains in caregiver and patient outcomes. This aligns with previous evidence that community-based rehabilitation (CBR) can ease family burden, especially among working caregivers, and that educational interventions yield moderate reductions in caregiver strain even in small samples.^{13,14} Semere W et al. also reported similar non-significant burden trends, underscoring the need for caregiver-optimized strategies in palliative interventions, mirroring our findings that burden was not solely tied to patient outcomes but influenced by broader psychosocial and contextual factors.¹⁵

Caregiver-reported quality of life, as reflected in the EQ-VAS, increased significantly by 30.56 ± 39.25 , supporting evidence that rehabilitation-palliative care improves informal caregivers' quality of life, and the mean difference exceeded the minimal

clinically important difference (MCID) of 7.5 points, confirming its clinical relevance.^{7,16} Caregiver knowledge showed a non-significant improvement (median gain +7 points, $p=0.050$), consistent with systematic reviews indicating that educational programs produce moderate knowledge gains and trends toward burden reduction even in small samples.¹⁴

Patient functional status showed a non-significant trend toward improvement on the BI (from 4.33 ± 3.28 to 6.11 ± 3.06 ; mean change $+1.78\pm1.30$, $p=0.073$), with the confidence interval crossing zero, indicating that the true effect may range from no meaningful change to potential improvement and reflecting uncertainty in the estimate. The mean BI change also exceeded the distribution-based MCID approximated using the Standard Error Measurement (SEM), which was 1.45 points, indicating a clinically meaningful gain in patient ADL (Table 3).¹⁷ These trends align with CBR literature showing that community programs improve ADL function in chronic stroke survivors,

though larger samples are needed to confirm statistical significance.¹⁸ Patient quality of life also showed a non-significant but clinically meaningful trend toward improvement (EQ-VAS median +10, $p=0.089$), consistent with MCID-based evidence and CBR literature indicating that community rehabilitation programs enhance patient well-being alongside caregiver skill development.^{16,19}

The coordinate plot (Figure 1) confirms concurrent benefits from the CBR program, with most subjects ($n=6$; L, SA, Sr, WH, SU, My) clustered in the positive-positive quadrant, indicating aligned improvement in patient and caregiver outcomes; a minority showed discordant effects (SI improved only in caregiver outcomes; ZA only in patient outcomes), and one subject (S) showed decline in both domains. This pattern is broadly consistent with prior study, where CBR was designed to improve outcomes for people with schizophrenia and their caregivers.²⁰ Prior study about caregiver analysis showed a greater

tendency to reduce work due to caregiving at 6 months (OR 2.40).²¹

These findings suggest that CBR training delivered through primary-care centers can serve as a feasible, low-resource intervention to bridge the gap between hospital-care discharge and long-term community-based palliative management, particularly in comorbidity-heavy cohorts.^{4,5} The predominantly female, spouse/child-based caregiver structure underscores the need for policies that recognize and support informal caregivers, including access to training, respite, and psychosocial services, to sustain the caregiving capacity essential for palliative care trajectories.^{6,7}

As a retrospective pilot study, this analysis relied on previously collected program data, limiting control over confounding variables and completeness of follow-up. The main limitation was the limited 1-month follow-up period, which may not capture sustained long-term outcomes. This community-based study conducted exclusively at

primary health centers also could not capture acute hospital-based trajectories.

Home-visit implementation was uninsured, restricting scalability. Further prospective studies with larger sample sizes and longer follow-up are required.

CONCLUSION

CBR significantly improved caregiver quality of life and showed clinically meaningful trends toward reduced caregiver burden, improved caregiver knowledge, and better patient ADL and quality of life among predominantly female caregivers of palliative patients with CVD or geriatric comorbidities. As a low-resource intervention, CBR appears feasible for primary health centers to bridge hospital discharge to community palliative care. Next study with better design is needed to confirm these findings and determine clinical impact.

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