

Informal Caregiver Burden in Southeast Asia's Chronic Disease Transition: A Scoping Review to Inform ASEAN's Care Economy Agenda

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Abstract:

Objective: This scoping review systematically mapped evidence on informal caregiver burden across chronic diseases in Southeast Asia's eleven Association of Southeast Asian Nations (ASEAN) countries between 2013 and 2023, examining geographic distribution, burden dimensions, determinants, and policy implications.

Material and Method: Following PRISMA–ScR guidelines, PubMed, Web of Science, and Scopus were searched for peer-reviewed studies on burden among the informal caregivers of patients with chronic diseases in ASEAN countries. Two reviewers independently screened records, extracted data, and conducted quality appraisal using the Mixed Methods Appraisal Tool (MMAT). Data were synthesized narratively, guided by Pearlin's Stress Process Model and mapped to ASEAN's 2024 Care Economy Declaration pillars.

Results: Fourteen studies from five countries were identified: Indonesia, Malaysia, Singapore, Thailand, and Vietnam. Six ASEAN members (Cambodia, Lao PDR, Myanmar, Brunei, the Philippines, and Timor–Leste) had no published research. Five burden domains appeared consistently: financial strain, caregiving workload, limited social support, emotional distress, and physical health decline. Determinants included care recipient factors, caregiver factors, family context, and structural factors. Burden was associated with caregiver anxiety (25.0–68.0%) and depression (10.0–56.0%).

Conclusion: Evidence concentration in upper-middle-income countries reveals critical research gaps. Supporting informal caregivers through integrated primary care interventions, social protection expansion, and research capacity

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building in underrepresented countries is foundational to achieving Universal Health Coverage by 2030 and advancing health equity in Southeast Asia.

Keywords: ASEAN, caregiver burden, chronic disease, informal caregiver

Introduction

Chronic non-communicable diseases account for two-thirds of deaths in Southeast Asia and 44.0% of healthy life years lost, yet formal long-term care infrastructure remains severely limited^{1,2}. Family caregivers, who are predominantly women, fill this gap, providing unpaid care while absorbing financial, emotional, and health costs that health systems neither recognize nor support. This invisible workforce sustains Southeast Asia's healthcare capacity as the region confronts the dual epidemiological challenges of rising noncommunicable disease (NCD) prevalence and persistent infectious disease burden³.

Growing policy momentum signals regional recognition of this issue. The Association of Southeast Asian Nations (ASEAN)'s 2024 Declaration on Strengthening the Care Economy commits member states to recognize, reduce, and redistribute unpaid care work⁴, while recent reviews identify family caregiver support as a priority for Asia's aging societies⁵. However, existing evidence to operationalize these commitments remains fragmented.

Current systematic reviews either concentrate on high-income countries⁶⁻⁹ or aggregate data across broad Asian contexts^{5,10}, masking Southeast Asia's distinct structural configurations. A recent report noted that 60.0–80.0% of laborers in ASEAN work in informal job markets without social protection¹¹, while primary care systems remain structured for infectious rather than chronic disease management³, and nuclear family structures increasingly replace extended households despite persistent filial expectations¹². Yet no comprehensive synthesis has examined caregiver burden patterns across the region's

diverse chronic disease and health system contexts. Such evidence is increasingly necessary as ASEAN member states seek to operationalize care economy commitments within health systems dominated by informal care and chronic disease needs.

This scoping review systematically maps the evidence on informal caregiver burden across chronic diseases in Southeast Asia's eleven ASEAN countries between 2013 and 2023. Informal caregivers are defined as family members who provide unpaid care to people with chronic diseases. The review examines the regional evidence landscape, including which countries and disease contexts are represented, the dimensions of caregiver burden assessed, the measurement instruments used, and the structural and sociocultural factors reported to shape caregiving experiences. By characterizing patterns and gaps in the existing literature, this review provides evidence relevant to chronic disease caregiving in Southeast Asia.

Material and Methods

This scoping review followed the framework by Arksey and O'Malley¹³, refined by Levac et al.¹⁴. Reporting adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)¹⁵. The Population-Concept-Context (PCC) framework defined the population as informal family caregivers of patients with chronic diseases, the concept as caregiver burden, and the context as Southeast Asian countries. The protocol was not registered because this scoping review involved the iterative refinement of eligibility criteria and analytical focus in response to a heterogeneous

and underexplored regional evidence base, consistent with established scoping review methodology.

A comprehensive search was conducted in Web of Science, PubMed, and Scopus between January and March 2024. The search was conducted in Web of Science, Scopus, and PubMed, as these databases provide broad multidisciplinary and biomedical coverage. Together, they capture a substantial proportion of peer-reviewed literature relevant to caregiver burden across clinical, public health, and social science domains. Search terms combined three core concept groups: informal caregiving (e.g., informal caregiver, family caregiver, unpaid caregiver), chronic disease (e.g., chronic illness, non-communicable disease), and caregiver burden (e.g., burden, stress, distress, impact), together with country-specific terms for all eleven ASEAN member states. The full syntax is presented in the supplementary file.

Two reviewers (ANK and MK) screened all the records independently and recorded results in an Excel spreadsheet, which served as the main data management tool. Duplicates were removed before screening by title and abstract. Citation chaining was used to identify additional studies that met the inclusion criteria. Full-text eligibility assessments were conducted independently by both reviewers, and discrepancies were resolved through discussion until a consensus was reached. Covidence was used to assist with database management and screening processes. Both reviewers independently extracted data using a standardized Excel form.

Inclusion criteria were peer-reviewed studies published from 2013 to 2023 that presented qualitative, quantitative, or mixed-methods data on caregiver burden among the informal caregivers of patients with chronic diseases in Southeast Asian countries. This review focused exclusively on Southeast Asia's eleven ASEAN member states as a policy bloc with collective commitments, including the 2024 Declaration on Strengthening the Care Economy.

The region also faces a distinct epidemiological transition, creating unique caregiving contexts³.

The timeframe captures recent evidence from the period of increased regional focus on NCDs, following the 2011 UN High-Level Meeting on NCDs, while aligning with ASEAN's current policy cycle leading to the 2024 Care Economy Declaration and 2030 UHC targets.

Exclusion criteria were studies that explored caregiver experiences indirectly, such as those focusing on only the patients' or healthcare professionals' perspectives, studies conducted outside Southeast Asia, grey literature, systematic reviews, and articles not published in English.

Quality appraisal was conducted jointly using the Mixed Methods Appraisal Tool (MMAT, version 2018)¹⁶. This method was selected because the review included studies with heterogeneous designs, including quantitative, qualitative, and mixed-methods approaches. Although the majority of included studies were quantitative, MMAT provides a standardized and consistent framework for appraising methodological quality across different study designs, facilitating comparability within a single review. Appraisal outcomes inform interpretation rather than exclude studies.

Consistent with scoping review methodology, data synthesis focused on descriptive and thematic mapping rather than causal inference. An inductive narrative synthesis approach was used to identify recurring concepts related to caregiver burden across included studies, allowing context-specific burden mechanisms to emerge from a heterogeneous and underexplored Southeast Asian evidence base without constraining findings to predefined categories¹⁸. Themes and burden domains were iteratively developed through cross-study comparison and reviewer consensus. Subsequently, these inductively derived themes were organized using Pearlin's Stress Process Model¹⁷ to enhance conceptual clarity and coherence, rather than to impose causal explanations. Finally, the mapped

domains and determinants were categorized descriptively according to the four pillars of ASEAN's 2024 Declaration on Strengthening the Care Economy (Recognize, Reduce, Redistribute, and Reward) to facilitate policy interpretation.

Results

The PRISMA flowchart (Figure 1) summarizes the search and selection process. From 408 records, 243 titles and abstracts were screened, 55 full texts were reviewed, and 14 studies met the inclusion criteria. The included studies (Table 1) represented five Southeast Asian countries: Indonesia, Malaysia, Thailand, Singapore, and Vietnam, with no eligible studies identified from the remaining ASEAN countries. Most studies employed quantitative designs and were predominantly cross-sectional, with sample sizes ranging from 13 to 340 participants.

Caregivers were mostly women, commonly spouses or daughters. Caregiving contexts included chronic kidney disease, diabetes, frailty or multimorbidity, stroke, and chronic obstructive pulmonary disease. No studies focused on hypertension or cancer caregiving. Half of the studies were rated as high quality. Common limitations included convenience sampling, hospital-based recruitment, and cross-sectional design.

Measurement and reporting of caregiver burden

The Zarit Burden Interview (ZBI) was the most frequently used instrument, applied in both the 22- and 12-item forms. Other instruments included the WHOQOL-BREF for quality of life, HADS for anxiety and depression, and the WPAI-GH for productivity loss. Several studies used researcher-developed questionnaires or scales without reported validation. Qualitative studies used semi-structured interviews or phenomenological approaches to explore caregiving experiences.

Reported burden levels varied by setting. Studies from Indonesia and Thailand reported a predominance of low to moderate burden in several samples. Singaporean

studies reported a higher prevalence of perceived burden, with Chan et al.²⁹ finding that caregivers frequently scored above the ZBI-12 threshold (71.8%), and Kang et al.²⁰ observing an increase in moderate-to-severe burden (from 13.0% to 28.0%) over one year.

Dimensions of caregiver burden

Through inductive narrative synthesis, we identified five core burden domains across the 14 studies. These domains represent the convergence of quantitative findings and qualitative themes derived from caregiver interviews. The five domains are: financial strain, caregiving workload, limited social support, emotional distress, and physical health decline.

Financial strain was reported in four studies. Thai and Vietnamese caregivers described difficulties meeting treatment-related costs, while Malaysian caregivers reported income loss and increased household spending during caregiving.

Caregiving workload was commonly described, particularly among caregivers of homebound or functionally dependent patients, where physical assistance and constant supervision were frequent tasks.

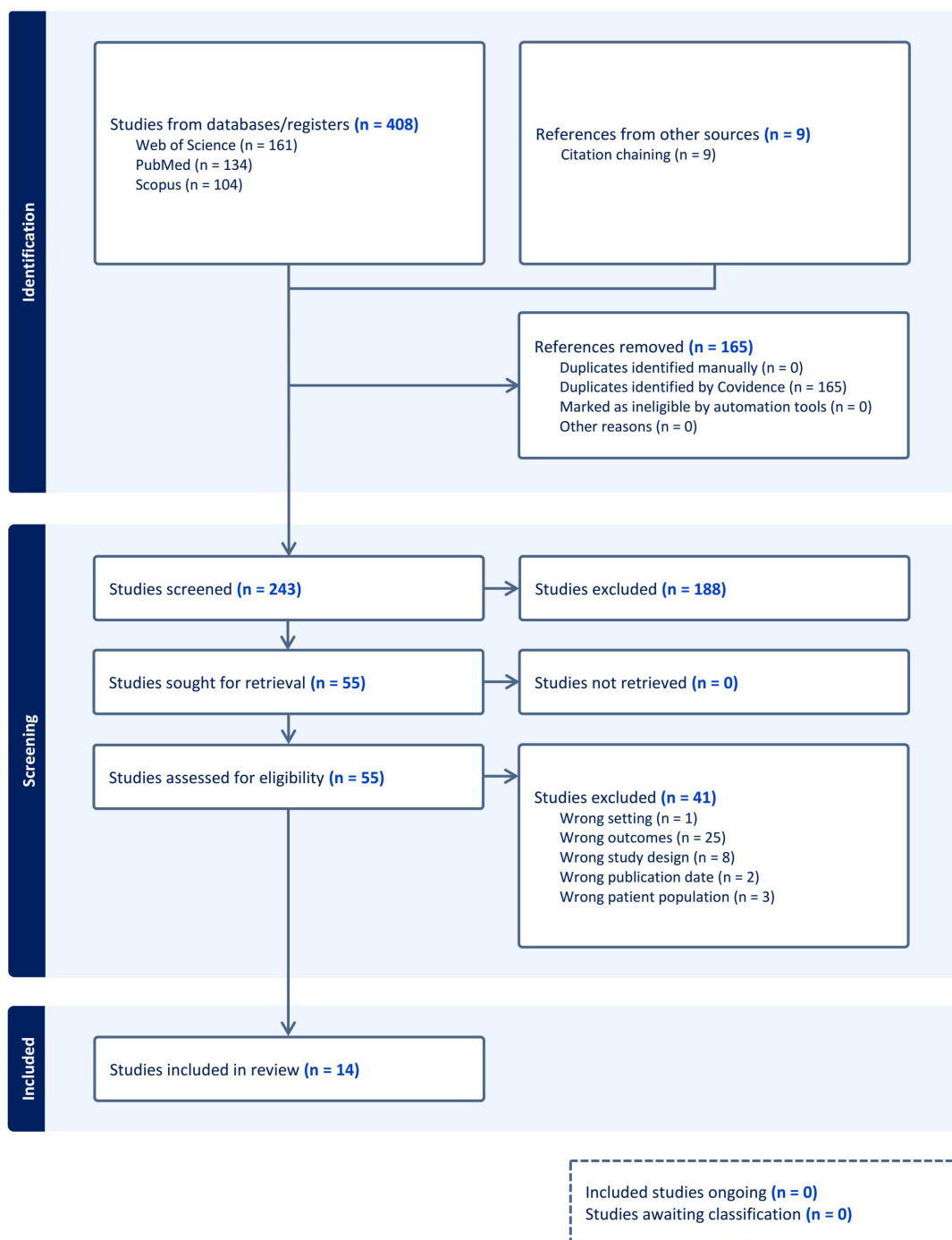
Lack of social support appeared across qualitative and quantitative reports, with caregivers indicating reluctance to seek external help and describing practical barriers to accessing support.

Emotional and psychological stress, including anxiety, worry, and feelings of exhaustion, were documented in several studies. Pandemic-related service disruptions exacerbated emotional strain in some samples.

Physical health decline among caregivers, particularly older caregivers, was noted in qualitative accounts and some quantitative measures, with reports of fatigue, headaches, and sleep disturbance.

These five inductively derived domains were subsequently organized using Pearlin's Stress Process Model framework. Caregiving workload reflected primary

Caregivers of Patients with Chronic Disease in Southeast Asia: Burden and Experience



8th March 2024



Figure 1 PRISMA flow diagram of the study selection process

2024 Declaration on Strengthening the Care Economy for subsequent policy discussion. The five domains captured the scope of unpaid care work (Recognize), included modifiable caregiving conditions such as competence and support availability (Reduce), described reliance on family-based care in the absence of external assistance (Redistribute), and documented financial costs borne by caregivers, including income loss and out-of-pocket expenditure (Reward).

Factors associated with caregiver burden

Factors examined in the literature clustered into four categories: care-recipient, caregiver, family/social, and structural factors.

Care-recipient factors: Disease severity, lower functional status, and higher dependence were associated with higher caregiver burden. For example, Srisatidnarakul & Bunthumporn³⁰ reported correlations between lower ADL scores and higher caregiver burden, and Al Muchtari et al.¹⁸ reported associations between patient non-adherence and greater caregiver burden. Caregiver exposure to aggressive behaviors was reported in a subset of cases.

Caregiver factors: Competence and coping style were reported as associated with burden. Lower perceived caregiving competence among caregivers reporting burden²⁹, and reductions in burden following psychoeducation interventions²³. Employment status was also reported as relevant, with working caregivers noting conflicts between paid work and caregiving responsibilities.

Family and social context: Shared caregiving arrangements were described variably, with some studies reporting reduced strain when tasks were distributed and others noting coordination difficulties or conflict. Filial and cultural expectations were common contextual features in caregiving narratives.

Structural and system-level factors: Transportation costs, long travel or waiting times, fragmented services,

and out-of-pocket payments were reported as contributors to the burden. Several studies described pandemic-related service interruptions that increased caregiving responsibilities.

Reported outcomes of caregivers and patients

We synthesized outcomes by integrating data from quantitative studies with experience from three qualitative studies.

Caregiver outcomes

Mental health morbidity varied significantly by setting. Among hemodialysis caregivers assessed with HADS, anxiety prevalence ranged from moderate in Indonesia²¹ to relatively high in Malaysia²⁴ (25.0% and 64.7%, respectively). Depression followed a similar pattern (56.2% in the Malaysian cohort)²⁴. Path analysis confirmed that this burden exerts a downstream effect on quality of life, mediated through anxiety and depression ($p\text{-value}<0.001$)²¹. Qualitative findings provide the context for these psychological morbidities. Across Vietnam, Thailand, and Malaysia, caregivers described how sustained responsibility led to social withdrawal and chronic fatigue, creating barriers to maintaining their own physical and mental well-being.

Patient outcomes

Burden also impacted patient care. In a dyadic analysis of hemodialysis patients in Indonesia, higher caregiver burden (adapted ZBI) was significantly associated with lower treatment adherence ($r=-0.308$, $p\text{-value}=0.011$)¹⁸. This quantitative link mirrors qualitative reports of interpersonal strain, where elevated caregiver stress manifested as tension within the caregiver-patient relationship, complicating care routines.

Discussion

This scoping review maps the evidence of informal caregiver burden across Southeast Asia and reveals three overarching insights: First, burden experienced by informal caregivers is consistently multidimensional across chronic diseases, indicating shared caregiving mechanisms rather than disease-specific challenges. Second, the evidence base of informal caregiving is geographically and methodologically uneven, concentrating in a small subset of ASEAN countries and clinical settings. Third, the findings expose a structural gap between the health system's reliance on family-based informal care and the limited health, labor market, and social protection support available to caregivers. These insights raise concerns about the sustainability of current caregiving arrangements amid epidemiological transition.

Extending existing knowledge on caregiver burden in Southeast Asia

The consistency of burden domains across diseases suggests that caregiver strain in Southeast Asia reflects systemic caregiving conditions rather than illness-specific demands. This convergence indicates that caregiver support policies can be designed around common mechanisms rather than disease-specific programs.

These domains are mutually reinforcing. Structural analyses indicate that upstream factors, specifically financial distress and lack of social support, function as primary drivers that exacerbate daily workload and emotional strain⁹. Consequently, cross-cutting interventions targeting these root causes could yield cascading benefits for caregiver well-being across the chronic disease spectrum. This pattern aligns with the stress process theory while highlighting context-specific drivers related to informal labor markets and limited service integration. By synthesizing these patterns across multiple countries and disease groups, this review moves beyond descriptive burden reporting to

clarify how structural and social conditions shape caregiver experiences in the region.

The absence of evidence from six ASEAN countries reflects structural research capacity constraints in lower-income ASEAN members. International funding mechanisms must intentionally support research capacity building in underrepresented countries to ensure that policy responses reflect diverse contexts rather than extrapolating from wealthier neighbors. Furthermore, the thematic concentration on adult chronic illnesses leaves pediatric caregiving underexamined, while the reliance on hospital-based studies limits understanding of burden in community and rural contexts where formal support is scarcest. Building on how these findings extend the existing literature, the following section examines how economic, structural, and psychosocial conditions interact to produce caregiver burden in Southeast Asia.

Economic, structural, and psychosocial drivers of burden

Economic and structural conditions emerged as upstream drivers of caregiver burden, threatening the continuity and quality of patient care. High medical costs and productivity losses drive households into financial precarity, particularly in Southeast Asia's largely informal labor market¹¹. Employed caregivers frequently faced trade-offs between income generation and caregiving responsibilities, reflecting the absence of paid leave, job security, or caregiver protections^{11,28}. These findings underscore how caregiver burden is shaped not only by health needs but also by labor market structures and social protection gaps.

Structural features of health systems further intensified the burden. Fragmented referral pathways, transportation costs, long waiting times, and limited continuity of care, especially in rural areas, shifted coordination and logistical responsibilities onto families³⁰. These system-level inefficiencies increased caregiving

Table 1 Summary of included studies on caregiver burden in Southeast Asia (2013–2023)

Authors, Year	Country	Study Objective	Sample & Setting	Methods/Design	Disease / care Context	Measurement/ assessment tools	Key Findings	Quality (MMAT)
Al-Muchtari et al., 2023 ¹⁸	Indonesia	Examine association between caregiver burden and patient compliance in CKD	n = 67 family caregivers (82.1 % female, mostly spouses/children); outpatient unit	Cross-sectional	CKD (hemodialysis)	ZBI-adapted Caregiver Burden Scale; Montgomery-Borgatta Scale ³³	Moderate-high burden in 53.7%; burden negatively associated with patient compliance (p=0.011)	3/5
Chan et al., 2023 ²⁸	Singapore	Evaluate psychosocial predictors of caregiver burden	n=188 caregivers (65.0% female, median age 62 y); tertiary hospital	Cross-sectional	Multimorbidity	ZBI-12; Caregiving Competence Scale; MOS Social Support ²⁷	71.8% perceived burden; lower competence and social support associated with higher burden (p<0.001)	4/5
Hashim et al., 2022 ³¹	Malaysia	Identify caregiver burden among parents of chronically ill children	n=230 caregivers (80.0% mothers); pediatric wards	Cross-sectional	Mixed pediatric chronic diseases	PedsQL™ Family Impact Module	High worry and fatigue domains; burden not correlated with caregiver demographics	3/5
Huyen et al., 2023 ²⁸	Vietnam	Explore challenges and coping strategies of family caregivers	n=21 caregivers (mean age 63.9 y); rural community	Qualitative ethnography	Type 2 Diabetes	Semi-structured interview guide	Main stressors: exhaustion, loneliness, financial strain; shared caregiving reduced burden	5/5
Mamom & Daovisan, 2022 ²⁷	Thailand	Identify enabling factors for caregiver burden	n=30 caregivers (63.0% female); home-based palliative care	Qualitative (TISM)	Palliative care	In-depth interviews	Financial distress and workload linked to burden; social support moderated effects	3/5
Mukhti et al., 2022 ²⁶	Malaysia	Explore caregiver burden and coping during COVID-19 pandemic	n=13 caregivers (62.0% female); rehabilitation centers	Phenomenological qualitative	Stroke	Semi-structured interviews	Increased strain due to service disruption; adaptive coping via faith and problem-solving	5/5
Pinyoponpanish et al., 2022 ¹⁹	Thailand	Assess violence against caregivers and effects on burden and depression	n=123 caregivers (74.0% female); community setting	Cross-sectional	Older adults with chronic illnesses	ZBI-22; PHQ-9; HITS; MSPSS	28.5% experienced violence; higher burden and depression (p<0.01)	4/5
Pio et al., 2022 ²¹	Indonesia	Examine relationships among burden, anxiety, depression, and QoL	n=104 caregivers; hospital dialysis unit	Cross-sectional	Hemodialysis	ZBI-22; HADS; WHOQOL-BREF	Burden negatively correlated with QoL via anxiety and depression (p<0.001)	4/5
Kristaningrum et al., 2021 ²²	Indonesia	Assess correlation between caregiver burden and diabetic patient health	n=327 caregivers; primary-care centers	Cross-sectional	Diabetes mellitus	ZBI (version unspecified); SF-12	91.4% low burden; lower burden linked to better patient health (r=-0.333, p<0.001)	4/5
Rehman et al., 2021 ²⁵	Malaysia	Evaluate economic and productivity burden of COPD caregivers	n=127 caregivers; tertiary hospital	Prospective cohort	COPD	WPAL-GH; EQ-5D-5L	21.6% social activity limitation; burden reduced productivity and QoL	3/5
Shukri et al., 2020 ²⁴	Malaysia	Determine predictors of anxiety and depression among caregivers	n=340 caregivers; hemodialysis centers	Cross-sectional	CKD (hemodialysis)	HADS; WHOQOL-BREF; Social Support Scale	64.7% anxiety; 56.2% depression; poor QoL and burden predicted anxiety (p < 0.05)	3/5

Table 1 continued

Authors, Year	Country	Study Objective	Sample & Setting	Methods/Design	Disease / care Context	Measurement/ assessment tools	Key Findings	Quality (MMAT)
Srisatidharakul & Bunthumporn, 2020 ³⁰	Thailand	Identify barriers to care and caregiver impacts	n=124 caregivers+243 elders; home setting	Mixed-methods	Home-bound elderly	ADL Index; Structured Questionnaire	Poor care access increased financial and emotional burden	2/5
Kang et al., 2019 ²⁰	Singapore	Examine longitudinal changes in caregiver burden and QoL	n=44 caregivers; peritoneal dialysis program	Longitudinal	Peritoneal dialysis	ZBI-22; WHOQOL-BREF; LC-GAD ²⁴	Moderate-severe burden rose 13.0→28.0%; psychological QoL declined over 1 year	2/5
Isworo et al., 2019 ²³	Indonesia	Evaluate psychoeducation's effect on caregiver burden	n=36 caregivers; community diabetes program	Experimental	Diabetes mellitus	Family Burden Scale; SDSCA; HbA1c	Psychoeducation significantly reduced caregiver burden (p-value<0.01)	1/5

ADL=activities of daily living, CKD=chronic kidney disease, HADS=hospital anxiety and depression scale, MMAT=mixed methods appraisal tool, MSPSS=multidimensional scale of perceived social support, PHQ-9=patient health questionnaire-9, QoL=Quality of Life, SDSCA=summary of diabetes self-care activities, TSM=total interpretive structural modeling, WHOQOL-BREF=world health organization quality of life-BREF, ZBI=Zarit burden interview

Table 2 Geographic and disease distribution of evidence

ASEAN Country	Income Level	Number of studies	Diseases studied	Study settings
Singapore	High	2	Dialysis, Multimorbidity	Hospital (2)
Indonesia	Upper-middle	4	DM, CKD	Hospital (3), Community (1)
Malaysia	Upper-middle	4	CKD, COPD, Stroke, Pediatric chronic Disease	Hospital (4)
Thailand	Upper-middle	3	Multimorbidity, Palliative care, Frailty	Hospital (2), Community (1)
Vietnam	Lower-middle	1	DM	Community (1)
Cambodia	Lower-middle	0	–	–
Lao PDR	Lower-middle	0	–	–
Philippines	Lower-middle	0	–	–
Timor Leste	Lower-middle	0	–	–
Myanmar	Low	0	–	–
Brunei	High	0	–	–

DM=diabetes mellitus, CKD=chronic kidney disease, COPD=chronic obstructive pulmonary disease, Lao PDR=The Lao people's democratic republic

Table 3 Policy-relevant findings matrix

ASEAN 2024 care economy pillar	Evidence from this review	Implementation gaps identified	Recommended actions
Recognize unpaid care work	64.1% caregivers are women; average 30–89 hrs/week	Time–use surveys exist (UNESCAP 2022) but don't capture chronic disease burden dimensions	Integrate disease-specific burden assessment into national surveys
Reduce caregiver burden	5 burden domains consistent across diseases; psychoeducation reduced burden (Isworo 2019)	Only 1 intervention study; most evidence descriptive	Pilot integrated caregiver training within primary care; evaluate effectiveness
Redistribute care responsibilities	70.0% report inadequate support; filial piety prevents help-seeking	Formal respite care largely absent; informal labor markets lack protections	Extend paid care leave policies; develop community-based respite programs
Reward care work	Financial strain universal; USD 217.92 annual indirect costs (Rehman 2021)	No SEA countries offer caregiver allowances for chronic disease care	Explore cash transfer pilots; extend social protection to informal caregivers

UNESCAP=United Nations Economic and Social Commission for Asia and the Pacific, SEA=Southeast Asia

stressors related to care recipient demands and disease-related tasks. Financial strain represented secondary stressors linked to role strain and economic pressures arising from caregiving responsibilities. Social support functioned as a moderating factor, with insufficient support

reported across multiple studies. Emotional distress and physical health decline were reported as caregiver outcomes associated with sustained caregiving demands.

The same domains were also categorized descriptively according to the four pillars of ASEAN's

workload and compounded emotional strain, illustrating how health system design can directly influence caregiver well-being^{32,33}.

Psychosocial factors operated both as risk and protective mechanisms. Caregiving competence and problem-focused coping were consistently associated with lower burden, highlighting modifiable determinants amenable to intervention²⁹. Conversely, the caregivers' own health status showed a bidirectional relationship with burden: poorer baseline health increased vulnerability, while sustained caregiving demands further eroded physical well-being^{21,28}. This reinforces the need to recognize caregivers not only as support providers but also as individuals with independent health needs.

Social support emerged as the most consistent buffering factor, yet its availability was often limited^{24,27,29}. Cultural norms emphasizing filial responsibility motivated caregiving but simultaneously constrained help-seeking, creating a paradox in which moral obligation increased burden²⁸. This dynamic distinguishes Southeast Asian caregiving contexts from settings where formal care services are more accessible and socially accepted^{34,35}.

Implications for ASEAN's care economy agenda

ASEAN's 2024 Declaration on Strengthening the Care Economy represents a regional policy milestone, committing member states to recognize, reduce, and redistribute unpaid care work⁴. Translating this commitment into effective policy for chronic disease care, however, requires context-specific evidence. This review yields three implications for operationalizing the care economy agenda across ASEAN health systems.

First, caregiver burden in chronic disease contexts extends well beyond time spent caring. Policies that focus solely on caregiving hours risk underestimating the true costs borne by families¹². Integrating caregiver assessment into routine chronic disease management using validated

and culturally adapted tools would support recognition while enabling early identification of high-burden situations.

Second, reducing caregiver burden requires addressing structural drivers^{11,30}. Extending social protection mechanisms to informal caregivers, improving care coordination within primary care, and reducing access-related barriers in rural settings are likely to yield broader benefits than isolated disease-specific interventions. Workplace flexibility provisions for caregivers of the chronically ill could further mitigate work-care conflicts and support sustained economic participation.

Third, redistributing care responsibilities depends on strengthening community and formal support systems. Evidence of widespread unmet support needs suggests opportunities for low-cost interventions, including peer support networks, caregiver training, and linkage to existing social services. Finally, persistent financial strain across studies underscores the importance of reward-oriented policies, such as income protection, transport subsidies, or caregiver allowances, particularly for low-income households.

Implications for future research

The current evidence base remains insufficient to fully inform equitable care economy policies across ASEAN. Future research should prioritize intervention studies evaluating integrated caregiver support models, particularly within primary care and community settings. Greater use of implementation science approaches would strengthen the understanding of feasibility and scalability in resource-constrained contexts. Harmonizing caregiver burden measurement across countries would further enable regional monitoring and policy learning aligned with the 2024 Care Economy Declaration.

Study limitations

This scoping review has several limitations. First,

evidence was concentrated in five of eleven ASEAN countries, limiting generalizability to lower-income and underrepresented contexts; however, identifying these gaps aligns with the review's aim of mapping inequities in the regional evidence base. Second, most of the studies included were cross-sectional and hospital-based, restricting causal inference and underrepresenting community and rural caregiving experiences, where structural barriers are often greatest. Third, intervention evidence was scarce, with only one quasi-experimental study, limiting guidance on effective support models.

In addition, comparability across studies was affected by heterogeneity in caregiver burden measurement, particularly variation in ZBI versions, cut-off scores, languages, and the use of non-validated instruments. Moreover, the review included only English-language publications, which may have excluded some locally published studies. However, most health research in Southeast Asia is published in English; thus, the potential omission of relevant data was considered minimal. Finally, the exclusion of grey literature may have resulted in the omission of programmatic or policy reports, but the review intentionally focused on peer-reviewed evidence to ensure methodological consistency and comparability.

Conclusion

This scoping review demonstrates that caregiver burden among families caring for people with chronic diseases in Southeast Asia is a multidimensional challenge shaped by economic, psychosocial, and structural factors. Despite diverse disease contexts, five core burden domains: financial strain, caregiving workload, limited social support, emotional distress, and physical health decline, appeared consistently, indicating shared mechanisms across conditions. Yet the evidence base remains uneven and largely absent from rural, community, pediatric, and lower-income contexts.

These findings have direct implications for ASEAN's care economy agenda. Caregiving in Southeast Asia remains predominantly family-based, operating within health systems designed for acute and infectious care and labor markets dominated by informality. Supporting caregivers therefore requires strengthening primary care systems to recognize and address caregiver needs, reducing structural and financial barriers to care, and building context-sensitive evidence across all member states. By situating caregiver burden within chronic disease management and health system design, this review provides region-specific evidence to translate ASEAN's 2024 Declaration on Strengthening the Care Economy into actionable pathways that support Universal Health Coverage, advance gender equity, and build resilient health systems capable of managing the region's growing chronic disease burden.

Conflict of interest

The authors declare no competing interests.

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