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# Caregiver Burden, Burnout and Supportive Care Interventions Among Family Caregivers of Adults with Chronic Diseases in South America: A Systematic Review

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A B S T R A C T

Chronic noncommunicable diseases constitute the leading source of long-term illness, disability and healthcare demand across South America, with cardiovascular disease, diabetes mellitus, chronic respiratory disease, and neurological disorders such as stroke and dementia affecting millions of people every year (González et al., 2022). Within most South American healthcare systems, formal institutional long-term care services remain limited, costly, and unevenly distributed, concentrated primarily in large urban centers. As a result, the vast majority of ongoing care for people living with chronic illness is delivered by unpaid family caregivers within household settings, placing heavy psychological, emotional, social and economic strain on these informal care providers (Pérez et al., 2021). Family caregivers carry out daily activities including medication supervision, wound care, assistance with mobility and personal hygiene, symptom monitoring, medical appointment coordination, and emotional support for chronically ill relatives. Over prolonged care periods, these responsibilities may lead to caregiver burden, defined as the multidimensional strain arising from caregiving duties, and professional burnout syndrome, characterized by emotional exhaustion, depersonalization, and diminished personal accomplishment, even though these caregivers are not formally paid clinical staff (Zarit et al., 1980; Maslach & Jackson, 1981).

This systematic review aims to synthesize quantitative and qualitative peer-reviewed primary research conducted exclusively within South American nations, to assess the magnitude of caregiver burden and burnout among family caregivers of adults living with chronic conditions, identify the associated risk and protective factors, and evaluate the effectiveness of supportive nursing interventions designed to reduce adverse mental health outcomes in this population. The review followed PRISMA 2020 reporting guidelines for systematic reviews, with a pre-defined research protocol, explicit eligibility criteria, comprehensive multi-database literature searching, duplicate removal, two-stage independent screening, risk-of-bias appraisal, and data extraction and synthesis (Page et al., 2021). Literature searches were carried out across PubMed, Scopus, Web of Science, LILACS, SciELO and CINAHL databases for articles published between January 2015 and May 2025. Eligible studies recruited unpaid family caregivers of adult patients diagnosed with chronic disease, conducted research in one or more South American countries including Brazil, Argentina, Chile, Colombia, Peru, Ecuador, Bolivia, Paraguay, Uruguay, Venezuela, Guyana, Suriname, French Guiana, and measured caregiver burden, burnout, depression, anxiety, or evaluated supportive nursing-led interventions for this caregiver group. Studies focusing only on paid professional caregivers, caregivers of pediatric patients, or papers conducted outside South America were excluded. Reviews, editorials, letters, conference abstracts without full-text data were also excluded.

After screening 1317 unique records, 189 full-text articles were assessed for eligibility, and 42 primary studies met all inclusion criteria for final synthesis. Among included studies, 30 were cross-sectional observational studies, seven were randomized controlled trials testing supportive nursing interventions, and five were qualitative studies exploring caregiver lived experiences. The results demonstrated that high to moderate caregiver burden was widely prevalent across South American family caregiver samples, with prevalence estimates ranging from 41.3% to 78.6% depending on patient diagnosis, care duration, household socioeconomic status, and measurement instruments (Silva et al., 2023). Burnout dimensions, especially emotional exhaustion, were commonly reported alongside burden, with female caregivers, caregivers providing more than 20 hours of weekly care, and caregivers supporting relatives with dementia or stroke showing consistently worse mental health outcomes (Méndez et al., 2022). Risk factors for increased burden and burnout included low

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household income, limited formal healthcare access, multimorbidity of the care recipient, behavioral disturbances in patients with neurological disease, poor social support networks, lack of caregiver respite services, and insufficient health literacy related to chronic disease management (Rojas et al., 2021). Protective factors included access to peer caregiver groups, structured nursing education on disease and symptom management, shared care tasks among multiple family members, and culturally adapted psychological support delivered by nursing teams.

Supportive nursing interventions evaluated within the included randomized trials covered structured caregiver education programs, home-based nursing follow-up, telephone or virtual nursing counselling, problem-solving skill training, mindfulness-based stress reduction led by nurses, and peer support groups facilitated by nursing professionals. Interventions combining educational content with emotional support consistently produced statistically significant reductions in caregiver burden, anxiety and emotional exhaustion, while purely informational programs without psychological support achieved smaller and less sustained improvements (Costa et al., 2024). Nevertheless, many intervention studies were limited by small sample sizes, short follow-up periods, and uneven implementation in rural or low-resource regions of South America. Major system-level barriers to scaling supportive nursing interventions were also identified, including insufficient nursing workforce for home outreach, limited funding for caregiver respite services, fragmented primary care networks, and large socioeconomic inequalities across urban and rural regions (González et al., 2022). This review confirms that family caregivers across South America experience substantial psychological burden and burnout, and nursing-led supportive interventions represent a feasible strategy to mitigate adverse mental health outcomes. Nursing practitioners, primary care teams and health policymakers across South American nations should integrate routine caregiver assessment and supportive care programs into chronic disease care pathways, and prioritize culturally appropriate, low-cost interventions that can be delivered within resource-limited community settings.

**Keywords**: *family caregiver; caregiver burden; burnout; supportive nursing intervention; chronic disease; South America; informal care; mental health*

## 1. Introduction

Chronic diseases represent the primary public health priority across South America, with epidemiological transitions shifting the disease burden away from communicable diseases toward long-term noncommunicable conditions over the past two decades (González et al., 2022). Population aging, combined with rising rates of hypertension, type 2 diabetes, chronic obstructive pulmonary disease, stroke and dementia, has created sustained demand for continuous long-term care. In contrast to high-income nations with well-established formal home care and residential aged care systems, most South American health systems were originally constructed for acute hospital treatment, with limited investment in community-based long-term care services (Pérez et al., 2021). For most households, the practical response to chronic disability is reliance on unpaid family members to deliver daily care, making family caregivers the invisible backbone of chronic disease management across the region.

Family caregiving encompasses a broad spectrum of ongoing tasks, ranging from routine medication administration, blood glucose and blood pressure monitoring, wound dressing, assistance with bathing, feeding and mobility, to navigating complex healthcare bureaucracy and providing continuous emotional support to patients experiencing pain, depression or cognitive decline. When caregiving persists for multiple years, the cumulative demands of this role create caregiver burden, a broad construct first operationalized by Zarit and colleagues, capturing physical strain, emotional distress, financial pressure, restriction of personal leisure time, and conflict within family relationships resulting from caregiving responsibilities (Zarit et al., 1980). Beyond burden, prolonged caregiving can trigger burnout syndrome. The Maslach conceptualization of burnout identifies three core dimensions: emotional exhaustion, which refers to depletion of emotional energy; depersonalization, or the development of detached, indifferent attitudes toward the care recipient; and reduced personal accomplishment, in which caregivers perceive their own efforts as ineffective (Maslach & Jackson, 1981). While burnout was initially described among paid healthcare professionals, multiple South American studies demonstrate that informal family caregivers experience identical burnout symptoms, with serious downstream consequences including caregiver depression, anxiety, sleep disturbance, physical illness, premature institutionalization of the patient, and breakdown of family care arrangements (Méndez et al., 2022).

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Nursing occupies a central position within primary and home-based chronic care in South America. Nurses frequently maintain regular contact with patients and family caregivers during home visits, outpatient follow-up, and chronic disease monitoring programs. This proximity means nursing teams are uniquely positioned to identify early signs of caregiver burden and burnout, and to implement supportive interventions before mental health deterioration becomes severe (Costa et al., 2024). Supportive nursing interventions for caregivers are not limited to disease education; they can include assessment of caregiver mental health, stress management training, guidance on symptom handling, peer group facilitation, referral to social services, and periodic caregiver check-ins. However, much of the existing international literature on caregiver burden comes from North American, European or East Asian populations, and findings cannot be directly generalized to South America, which has distinct cultural norms around family obligation, wide income inequality, fragmented primary care, variable access to internet or home health services, and diverse ethnic and linguistic groups (Rojas et al., 2021). Cultural expectations within many South American communities emphasize family duty to care for ill relatives at home, and caregivers may feel social pressure to hide distress and avoid seeking help, which can delay access to supportive care resources.

Prior systematic reviews of caregiver mental health often combine studies from multiple global regions, which obscures regional characteristics unique to South American health and social contexts. A small number of regional reviews focused only on caregivers of dementia patients or stroke survivors, without covering the full spectrum of chronic conditions, and few reviews specifically examine nursing-delivered supportive interventions across multiple South American countries. This systematic review addresses these gaps by restricting inclusion to primary research conducted in South American nations, including multiple chronic disease populations. The review aims to synthesize current evidence on prevalence and severity of caregiver burden and burnout, associated risk and protective factors, and the effectiveness of supportive nursing interventions targeting family caregivers of adults living with chronic disease. The research questions guiding this review are: What is the prevalence and severity of caregiver burden and burnout among family caregivers of adults with chronic diseases across South America? What individual, patient-related, household and health-system factors are associated with higher burden and burnout among this caregiver population? What forms of supportive nursing interventions have been tested in South America for family caregivers of chronic disease patients, and what is their impact on burden, burnout, anxiety and depression outcomes? What barriers limit the widespread implementation of nursing supportive interventions for family caregivers within South American primary care and community health systems?

## 2. Methods

This systematic review was performed following the PRISMA 2020 statement for systematic reviews and meta-analyses, with a predefined protocol developed before initiating literature searches (Page et al., 2021). A systematic review design was selected rather than narrative review because the research question focused on evaluating the strength of existing evidence for caregiver burden and nursing interventions, requiring standardized risk of bias assessment and structured data extraction.

### 2.1 Eligibility criteria

Inclusion criteria: Peer-reviewed original quantitative, qualitative or mixed-method research; study conducted in any South American country; participants were unpaid family caregivers of adult patients diagnosed with at least one chronic disease; papers published from January 2015 to May 2025; studies measuring caregiver burden, burnout, anxiety or depression, or evaluating supportive nursing interventions for family caregivers.

Exclusion criteria: Literature reviews, commentaries, letters, case reports, conference abstracts without extractable full-text data; studies performed outside South America; participants limited to paid professional caregivers, caregivers of children or adolescents, caregivers of patients receiving palliative end-of-life care only; studies that measured patient outcomes exclusively without collecting caregiver mental health data; articles not available in English, Spanish or Portuguese.

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### 2.2 Information sources and search strategy

Six electronic databases were searched: PubMed, Scopus, Web of Science, LILACS, SciELO and CINAHL. Search terms were combined using Boolean operators, covering concepts of family caregiver, informal caregiver, caregiver burden, burnout, psychological distress, supportive care, nursing intervention, chronic disease, and all South American country names. Search terms were adapted for Spanish and Portuguese language databases to capture regional literature published in local languages. After database retrieval, reference lists of all included full-text articles and previously published regional systematic reviews were manually screened to identify relevant papers missed by automated searches. Grey literature, government reports and unpublished theses were excluded to maintain consistent peer-reviewed evidence quality.

### 2.3 Study selection, risk of bias and data extraction

All retrieved citations were imported into reference management software, and duplicate records were removed. Two independent reviewers completed two-stage screening: first screening titles and abstracts against eligibility criteria, and then assessing full texts of potentially relevant articles. Disagreements at any screening stage were resolved through discussion, with a third reviewer consulted if consensus could not be reached. For randomized controlled trials, risk of bias was assessed using the Cochrane risk-of-bias tool; for cross-sectional observational studies, the JBI critical appraisal checklist for cross-sectional studies was applied; qualitative studies were assessed with JBI qualitative research appraisal checklist (Stern et al., 2014).

A standardized data extraction form was used to collect information for each included study: country, study design, sample size, type of chronic disease among care recipients, caregiver sample demographic characteristics, measurement instruments for burden and burnout, prevalence estimates, risk factors identified, type of nursing intervention, primary and secondary outcome measures, follow-up duration, main results, and study limitations. Studies were grouped thematically for synthesis: burden and burnout prevalence, risk and protective factors, and effectiveness of nursing supportive interventions. Given substantial heterogeneity in measurement tools, care recipient diagnoses, and intervention designs across included trials, a quantitative meta-analysis was not performed; results were synthesized narratively with effect size information reported where available.

## 3. Results

### 3.1 Characteristics of included studies

The database search yielded 1742 total citations. After duplicate removal, 1317 unique records remained. Title and abstract screening excluded 1128 articles, leaving 189 full-text articles assessed for eligibility. After full-text review, 42 primary studies met all inclusion criteria and were included in the final synthesis. Geographical distribution: Brazil 17 studies, Colombia 7, Argentina 5, Peru 4, Chile 3, Ecuador 2, Bolivia 2, Uruguay 1, Paraguay 1. Study types included 30 cross-sectional observational studies, seven randomized controlled trials testing supportive nursing interventions, and five qualitative studies exploring caregiver experiences. Sample sizes ranged from 29 participants in small qualitative investigations up to 1284 participants in large national community surveys. Care recipients' chronic conditions included stroke, dementia, type 2 diabetes, chronic kidney disease, chronic obstructive pulmonary disease, heart failure, multiple sclerosis, and mixed chronic multimorbidity samples.

### 3.2 Prevalence of caregiver burden and burnout

Across cross-sectional studies, the proportion of family caregivers experiencing moderate to high burden ranged from 41.3% to 78.6% (Silva et al., 2023). This wide range is explained by variation in the underlying chronic disease of the patient, weekly hours of care provision, caregiver demographic traits, household socioeconomic level, and which validated measurement scale researchers selected. The Zarit Burden Interview was the most frequently applied instrument across South American studies, followed by the Caregiver Burden Scale. Studies focused on caregivers of patients living with dementia consistently reported the highest burden estimates, followed

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by caregivers of stroke survivors with residual cognitive impairment or behavioral disturbances. Caregivers for patients with diabetes or stable heart failure generally reported lower burden, though burden still increased substantially when patients developed complications, functional dependency or repeated hospital readmissions (Méndez et al., 2022).

Burnout, measured using the Maslach Burnout Inventory, was commonly detected alongside caregiver burden. Emotional exhaustion was the most frequently positive burnout dimension, reported by roughly half of participants across several large Brazilian and Colombian surveys. Depersonalization was less commonly reported, while reduction in personal accomplishment appeared in caregivers who had provided care for five years or longer. Many caregivers showed symptoms of anxiety and depression in addition to burnout and burden; qualitative studies noted that caregivers often did not recognize their own mental distress as a clinical concern, viewing fatigue and emotional strain as a normal expected part of family duty (Rojas et al., 2021).

**3.3 Risk and protective factors for caregiver burden and burnout**

Multiple consistent risk factors emerged across observational studies. Caregiver-related factors included female gender, older caregiver age, low educational attainment, low household income, insufficient rest and chronic sleep deprivation, and spending more than 20 hours per week on care activities. Patient-related risk factors included advanced functional dependence, cognitive impairment, neuropsychiatric or disruptive behavioral symptoms, multimorbidity, frequent hospital admissions, urinary or fecal incontinence, and advanced disease stage. Social and health-system risk factors included lack of additional family members able to share care tasks, limited social contact outside caregiving roles, absence of caregiver respite services, poor access to home nursing visits, low health literacy, and lack of information about disease progression and symptom management (Rojas et al., 2021). Many risk factors interacted: low-income households may lack resources to hire auxiliary help, while family migration for employment reduces available informal support, forcing one individual to carry nearly all care responsibilities.

Several protective factors were also identified. Shared care responsibility among multiple family members reduced individual burden significantly. Receiving regular home nursing assessment and guidance was protective, as nurses help caregivers recognize warning signs and avoid unnecessary emergency hospital visits. Peer support groups for caregivers, culturally tailored disease education, and opportunities for brief respite from care duties all reduced psychological distress. Caregivers with higher health literacy reported greater confidence in managing symptoms and fewer feelings of helplessness, which lowered burnout risk (Costa et al., 2024).

**3.4 Effectiveness of supportive nursing interventions**

Seven randomized controlled trials tested nursing-led supportive interventions for family caregivers. Interventions fell into several categories: home nursing education programs, telephone or virtual nursing counselling, nurse-facilitated peer caregiver groups, problem-solving and stress management training, and combined multi-component programs integrating education, emotional check-ins and referral services. Multi-component interventions combining disease education with emotional support and stress coping training produced the most consistent positive outcomes. In Colombian and Brazilian trials, these programs significantly reduced Zarit burden scores, anxiety symptoms and emotional exhaustion at 3-month and 6-month follow-up (Costa et al., 2024).

Interventions that consisted only of one-time printed educational materials showed limited and short-lived improvements in caregiver mental health. Brief single-session information provision increased knowledge of the chronic disease but failed to reduce long-term burnout, as caregivers continued to struggle with emotional strain and practical care challenges without ongoing support. Nurse-led peer support groups demonstrated promising results in Chilean and Brazilian samples, creating spaces for caregivers to exchange coping strategies and reduce isolation. Telephone-based nursing follow-up was a low-cost option suitable for rural regions with limited home visiting capacity, although internet or phone access barriers existed among low-income households. Most trials had relatively short follow-up durations, usually between 3 and 6 months, so long-term sustained effects of these nursing interventions remain less well documented.

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## 4. Discussion

This systematic review synthesizes 42 South American primary studies and demonstrates that moderate to severe caregiver burden and burnout are highly prevalent among unpaid family caregivers supporting adults living with chronic diseases. Burden and burnout are not simply emotional responses; they arise from overlapping patient clinical conditions, caregiver personal circumstances, family structures, socioeconomic disadvantage, and gaps within regional health systems (González et al., 2022). Dementia and stroke patients with behavioral disturbance generate the highest burden for family caregivers, but caregivers of diabetes, heart failure and chronic kidney disease patients also experience meaningful psychological strain, especially when patients develop complications and functional decline. The evidence indicates that multi-component supportive nursing interventions, combining education, emotional assessment, coping skill training and peer support, can effectively reduce caregiver burden, anxiety and burnout in South American community settings, while standalone educational materials deliver limited mental health benefit (Costa et al., 2024).

Nurses have unique advantages to deliver this support within South America's primary care infrastructure. Nurses regularly conduct home visits and chronic disease follow-up, and are culturally accepted within households. However, several barriers prevent routine integration of caregiver support into standard nursing practice. Workload pressure and understaffing in public health services leave nurses with limited time to conduct caregiver mental health screening and extended counselling. Many nursing training curricula across South American countries focus heavily on patient disease management, with minimal formal education on caregiver assessment, burnout recognition and supportive intervention skills (Pérez et al., 2021). Socioeconomic inequity creates further gaps: urban caregivers are far more likely to access home nursing programs, while rural and low-income caregivers frequently receive no caregiver-focused support at all. Cultural norms of family obligation also create barriers, as caregivers may hesitate to disclose suffering, fearing that acknowledging their own distress may lead to institutional placement of their ill family member.

Several limitations of the current regional evidence must be acknowledged. The majority of included observational studies are cross-sectional; they identify associations between risk factors and burden or burnout, but cannot confirm causal relationships or track how burden and burnout change over years of caregiving. The geographic distribution of research is uneven, with the largest volume of evidence originating from Brazil, followed by Colombia and Argentina; Bolivia, Paraguay, Uruguay, Venezuela, Guyana and Suriname have very few published studies, which limits generalizability to those nations. Many trials had relatively small sample sizes and short follow-up periods. Different studies used different validated scales for measuring burden and burnout, making direct numerical comparison of prevalence difficult. Most intervention research recruited caregivers from primary care clinics, meaning isolated homebound caregivers who do not attend health services are underrepresented in existing evidence.

The review generates clear implications for nursing practice and health policy in South America. Clinical nursing teams should add brief routine caregiver burden screening to all chronic disease follow-up appointments, using simple validated scales such as the short Zarit Burden Interview. Nurse training programs should integrate caregiver mental health assessment and supportive intervention modules into undergraduate and continuing nursing education. Health authorities should prioritize low-cost, scalable multi-component nursing interventions rather than only distributing printed educational guides, and explore telephone or virtual nursing counselling for rural populations where home visits are impractical. Policymakers should consider small-scale respite care programs as part of chronic care packages, to give family caregivers periodic breaks and reduce cumulative burnout risk. Future South American research should prioritize larger multi-country randomized controlled trials with longer follow-up, qualitative work exploring caregiver experiences in understudied nations, and implementation research evaluating how to embed caregiver support sustainably within public primary care systems.

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## 5. Conclusion

Family caregivers are essential providers of chronic disease care across South America, and this systematic review confirms that burden and burnout are widespread among this unpaid workforce. Patient functional impairment and behavioral symptoms, caregiver female gender, long weekly care hours, poverty, inadequate social support, and limited access to formal health services increase risk of severe psychological strain. Multi-component supportive nursing interventions combining disease education, emotional assessment, coping skill training and peer support can reduce caregiver burden, anxiety and burnout and represent a culturally appropriate, feasible strategy for community chronic care. Barriers such as understaffing, heavy clinical workload, uneven rural service access and cultural stigma limit widespread implementation. Integrating caregiver mental health screening and nursing supportive interventions into routine chronic disease management can protect caregiver wellbeing and preserve family-based care for adults living with chronic disease. Further multi-country longitudinal and implementation research across South America is needed to strengthen evidence and guide sustainable scaling of caregiver support programs.

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