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COMMENTARY

From Describing Family Caregiver Burden to Developing Supportive Solutions

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Abstract: Family caregiver burden, the physical, emotional, and financial strain experienced by informal caregivers, has been well documented for nearly a century. Early 20th-century observations highlighted the toll of caring for chronically ill relatives, noting how prolonged care could strain family relations and even lead to disintegration of family life. Since then, an ever-expanding body of research has repeatedly confirmed that family caregivers across diverse conditions and cultures commonly experience high levels of burden. In recent years, numerous studies have been published with the aim of *exploring* or *identifying* caregiver burden. Framed within the broader debate on research waste and low-value research, this commentary argues that a continued emphasis on merely documenting family caregiver burden risks yielding diminishing returns. We contend that for many caregiving contexts, the evidence base is already substantial that caregiving can be profoundly demanding; with the exception of some understudied populations and contexts, further proof of burden adds little new knowledge. Instead, the pressing need is for research that develops and tests solutions to alleviate burden. We call for a refocusing of research toward designing, implementing, and evaluating interventions, supports, and policies that can genuinely lighten caregivers' loads. Our viewpoint is not to dismiss the significance of caregiver burden, but to urge the field to rebalance research priorities, using evidence-based, actionable strategies. As a commentary supported by an illustrative, non-systematic review of the literature, this article is intended to stimulate critical reflection and research priority setting rather than provide a comprehensive evidence synthesis. Its observations should therefore be interpreted as indicative of broader trends rather than as definitive empirical estimates of the field.

Keywords: informal care, essential care partner, caregiver support interventions, research waste, research agenda, priority setting

Introduction

For decades, the challenges faced by informal family caregivers, those who provide unpaid care to chronically ill or disabled relatives, have been a subject of extensive research and concern.[1] The cumulative literature has painted an unequivocal picture: caregiving often comes at a high personal cost to the caregiver.[2] Physical exhaustion, emotional distress, social isolation, and financial strain are recurrent themes in caregiver studies.[3–6] So ubiquitous are these findings that "caregiver burden" has become a standard concept in health and social care discourse. We argue that this knowledge is well established in many settings and that incremental nuances rarely yield actionable new insights. Instead, we advocate for a pivot in research priorities, away from repeatedly characterizing the burden, and toward developing solutions that address the needs of caregivers.

This critique can be situated within the broader literature on research waste and low-value research.[7–9] From this perspective, the problem is not that caregiver burden is unimportant, but that once a phenomenon has been repeatedly and consistently documented, further descriptive studies should be justified by their likely incremental contribution to knowledge, practice, or policy. If additional studies mainly reproduce already well-established conclusions without generating actionable implications, they risk representing low-value use of limited research resources. Our concern, therefore, is not with caregiver burden research as such, but with the continued prioritization of descriptive studies that may add little beyond what is already known.

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Background: Historical Perspective on Family Caregiver Burden

It is important to acknowledge that family caregiver burden is not a new discovery of modern gerontology or health services research. Scholars and clinicians as far back as the early 20th century observed the profound toll that caregiving could exact on families. In 1929, American physician Ernst Boas addressed what he termed the *tragedy* of chronic illness in the home.[10] Boas described how the relentless demands of caring for a chronically ill family member could lead to the "strained relations" among relatives and even the "disintegration of the family unit", as financial resources were depleted and caregivers became physically exhausted.[10] He argued that without external support, the burden on families was often untenable. This plea foreshadowed today's calls for better community and health system assistance for caregivers.

Not long after, one of the first rigorous community surveys of old-age caregiving was conducted in the United Kingdom. In 1948, J.H. Sheldon published *The Social Medicine of Old Age*, reporting on a detailed inquiry into the lives of elderly people and their families in Wolverhampton.[11] Sheldon found that the majority of frail older individuals were cared for at home by spouses or adult children, usually daughters. He documented that this care was typically managed "within [the family's] own resources" and could be a "very heavy burden on younger members of the family," especially daughters who provided around-the-clock nursing care with little to no respite. Sheldon noted many caregivers were, as he put it, "at the limit of their tether". His report not only highlighted caregivers' physical and mental strain but also called attention to the "hidden cost" of community care being borne by families. Importantly, Sheldon's findings led him to recommend practical relief measures, such as providing domiciliary services (eg home helpers) and short-term care facilities to give family caregivers much-needed breaks.

By the early 1960s, the concept of caregiver burden had entered the lexicon of medical research more explicitly. In 1963, Grad and Sainsbury published a landmark study *Mental Illness and the Family* in *The Lancet*, which is often credited as the first to formally quantify family burden as a variable.[12] In their work with families of psychiatric patients, Grad and Sainsbury distinguished between two components of burden: (1) Objective burden, referring to observable practical difficulties and economic impacts on the family (such as lost income, disruption of household routines, and deterioration in caregivers' health); and (2) Subjective burden, referring to the caregiver's internal experience, such as feelings of stress, guilt, anger, sadness, or perceived strain. This nuanced definition was further refined by Hoenig and Hamilton in 1966, but Grad and Sainsbury's study essentially established that "burden" was a measurable outcome in its own right.[13] Since then, the distinction between objective and subjective burden has informed caregiver research, and multiple questionnaires and scales have been developed to assess caregiver burden in various caregiving contexts.[14,15]

Methods: Illustrative Literature Scan

To illustrate publication growth and the persistence of descriptive caregiver burden research, we conducted two brief, reproducible PubMed searches on January 12, 2026. These illustrative scans were not intended to be systematic or exhaustive and do not support firm conclusions about the entirety of caregiver research. Rather, it was used to identify recurring patterns in a targeted sample of recent publications and to inform the commentary's argument about research priorities.

First, we examined annual publication counts for the query ("caregiver burden") AND (("family") OR ("informal care")). Second, we conducted a targeted, non-systematic search of original research articles published in 2025 in nine open-access healthcare journals: BMC Geriatrics, BMC Health Services Research, BMC Nursing, BMC Public Health, BMJ Open, Nursing Open, PLoS ONE, SAGE Open Nursing, and the Journal of Multidisciplinary Healthcare. The journals were selected pragmatically to represent general health, nursing, public health, and health services research outlets that regularly publish caregiver-related work. The search was performed using the following caregiver-related title/abstract terms: "respite care", "informal care*", "unpaid care*", "lay care*", "family care*", "spousal care*", "parental care*", "kinship care*", "family member care*", "next of kin", "care partner*". Records were screened by one author and grouped descriptively into (i) studies whose primary stated aim was to assess caregiver burden and (ii) studies with broader aims that nevertheless reported caregiver burden as a key finding. No formal review software or quantitative synthesis tools were used, as the purpose was illustrative rather than systematic.

Results: Illustrative Observations from Recent Caregiver Research

In the early 2000s, only a few dozen papers per year could be identified on caregiver burden. By 2013, annual publications on this topic had exceeded 100, and by 2025 they surpassed 500. This trend reflects both the expanding visibility of family caregiving in health research and a growing body of intervention-oriented studies seeking to mitigate burden. Nevertheless, a substantial proportion of publications continues to revisit the same fundamental descriptive question: "How burdened are caregivers?".

In our search in nine open-access healthcare journals for 2025, we identified 56 original research articles whose primary stated aim was to assess or identify the burden experienced by family caregivers in a particular disease or setting. In addition, about 30 studies had more general aims such as "to explore the lived experience of family caregivers" or "to describe the situation of informal caregivers," and unsurprisingly these too reported that caregivers were burdened (often highlighting the same themes of stress, emotional exhaustion, etc., as key findings). In total, 86 studies across these nine journals in 2025 alone essentially reiterated the existence or extent of caregiver burden, often adding little incremental insight beyond reinforcing well-established conclusions about the demands of caregiving. This pattern suggests a degree of saturation in observational caregiver research. At this point of diminishing returns, additional studies yield more repetition than revelation.

Compounding this saturation is the proliferation of measurement tools related to caregiver burden and closely related constructs. Numerous scales have been developed to quantify aspects of caregiver strain, burden, stress, and quality of life. For instance, a recent scoping review described 21 different instruments used to measure the quality of life of informal caregivers of people with dementia.[16] These ranged from generic health-related quality-of-life surveys to caregiving-specific questionnaires. Tellingly, the review concluded that none of these instruments was clearly superior. This plethora of tools underscores the point that the field has been very focused on measuring the caregiver experience. Our own 2025 literature scan noted at least 16 studies just in that year devoted to the psychometric evaluation of caregiver burden scales (eg, validating a translated version of a burden inventory or comparing two scales). While refinement of measurement can be valuable, one must ask: do we need so many ways to measure what is essentially a consistently observed phenomenon? If the scientific community broadly agrees that family caregiving often entails substantial burden, developing ever more fine-grained instruments to quantify it may be yielding progressively marginal benefits. At a certain point, further measurement precision does not necessarily translate into better caregiver support in practice.

Another noteworthy finding from our scan was the number of study protocols published in 2025 that propose to assess caregiver burden yet again. We found at least 7 protocol papers outlining new observational studies intended to survey caregiver burden in various contexts (eg, "burden among caregivers of patients with X disease in Y region"). These studies are likely to conclude – as countless before them – that caregivers are indeed burdened and that this is an important issue. Such conclusions have become increasingly formulaic. For example, many research articles begin by stating something akin to: "Caregiving imposes substantial psychological and emotional burdens on family members" as established background, and then proceed to conduct yet another study "to explore the psychological distress" of caregivers in a particular cultural setting. In one recent study of dementia caregivers in China, the authors opened by acknowledging the well-known fact that "dementia caregiving imposes substantial burdens on family members," yet the study's stated aim was to delve into the psychological distress experienced by these caregivers in a particular cultural context.[17] Unsurprisingly, their conclusions reiterated that caregivers felt overwhelmed and conflicted. While these outcomes were certainly valid, they were largely implied by the study's own premise that caregiving is burdensome. This kind of redundancy occurs when the background of a paper establishes the problem and the findings simply reinforce the same problem. It epitomizes why further repetitive burden studies have diminishing utility.

Discussion: Implications for Future Family Caregiver Research

A reasonable starting premise for contemporary family caregiving research is that caregivers frequently experience substantial burden. This burden is shaped by interacting health, social, and economic determinants and is observed across countries and care contexts. From this premise, the research question should not be whether burden exists, but which

targeted strategies can reduce it. These strategies are likely to include promoting caregiver self-care, delivering psychosocial and educational interventions, strengthening formal support systems, and coordinating action across public, private, and non-profit sectors to improve caregiver well-being and the quality of care they can provide.[18,19] With this as a baseline, research can build cumulatively by testing, refining, and scaling solutions rather than repeatedly re-establishing the same descriptive conclusion.

Encouragingly, thought leaders in the caregiving field have begun articulating a forward-looking research agenda. In 2020, a conference of over 50 caregiving experts convened to establish consensus on family caregiving research priorities for the next decade. The outcome of this summit was a list of ten top-priority topics, none of which were simply to explore caregiver burden.[20] Instead, the priorities highlighted areas such as: improving caregiver support interventions across the illness trajectory, addressing the needs of diverse caregiving populations (eg, considering cultural, ethnic, and socioeconomic differences), leveraging technology to assist caregivers, integrating family caregivers into healthcare teams and decision-making, and examining the long-term health effects of caregiving on caregivers themselves. This reflects a clear shift from problem description to problem solving.

Building on such frameworks and our analysis of the literature, we propose several broad categories of research that appear most needed. The areas where additional inquiry can translate into better support for caregivers:

1. Intervention Development and Testing: There is a pressing need for rigorous studies (especially randomized trials or implementation studies) of interventions designed to reduce caregiver burden or improve caregiver well-being. These interventions can be psychoeducational, psychosocial, respite-based, or technology-enabled. Systematic reviews suggest that multi-component interventions tend to yield modest but significant reductions in caregiver burden and distress[21,22] implying that better-designed or more intensive interventions could achieve larger impacts.
2. Supportive Care Integration in Health Systems: Research should explore models of care where supporting the family caregiver is treated as a standard component of healthcare delivery, including caregiver assessments in clinical practice and caregiver-focused services embedded in healthcare.
3. Policy and Economic Research: Studies should examine how laws and economic supports (eg, caregiver stipends, paid leave, tax credits, respite entitlements, subsidized home care) affect caregiver outcomes, using comparative and quasi-experimental methods where possible.
4. Positive Outcomes and Resilience: Research into resilience and caregiver gain can inform strengths-based interventions, without minimizing the real hardships of caregiving.
5. Streamlining and Harmonizing Measurement: Rather than creating more scales, the field should converge on core outcome sets that matter for caregiver support research and enable meaningful synthesis across studies.

Conclusion

Descriptive research established long ago that family caregiving is frequently associated with substantial burden. At this point, repeatedly documenting that caregivers are stressed and strained offers diminishing returns. The more urgent scientific task is to generate evidence for interventions, services, and policies that can reduce caregiver burden and improve caregiver well-being. A rebalancing in research priorities, from reiterating burden to testing solutions, is essential if caregiving research is to produce tangible benefit for the families who provide the majority of long-term care in communities worldwide.

Ethics

There were no living persons involved in this study. The analysis is based on data not reducible to individual persons.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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