

RESEARCH BRIEF #109

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Pain Limits Family Caregivers' Daily Activities

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and M. Cary Reid**

KEY FINDINGS

- Over half of all caregivers reported bothersome pain in the previous month, 24% of whom had pain that limited their activities on most or every day in the previous month.
- 40% of caregivers had arthritis, 75% of whom had bothersome pain.
- Caregivers with physical difficulty providing care had a higher prevalence of activity-limiting bothersome pain and arthritis compared to caregivers without physical difficulty providing care.

Millions of people in the United States are caring for older relatives who need support for daily functioning. Family caregivers are the main providers of home care to older adults, especially as the prevalence of Alzheimer's disease and related dementia rises. Caregiving can take a toll on caregivers' physical and mental health, which impacts both their own well-being and their care recipients' health outcomes. However, one critical factor in caregiving has been largely ignored: the caregiver's own pain experience. Limited research suggests that physical pain predicts caregivers' care burden and care-related stress,¹ and caregivers who report pain also report greater challenges associated with caregiving.² This brief summarizes the findings from our [recent study](#) that used data from the latest wave (2017) of the National Study on Caregiving (NSOC) to estimate the prevalence of arthritis and activity-limiting pain among 1,930 family caregivers to older adults. We also assessed the relative prevalence of caregivers' arthritis and activity-limiting bothersome pain by caregiver and care recipient characteristics to identify which caregivers may be at a higher risk for physical pain.

Over Half of All Caregivers Reported Bothersome Pain

A substantial minority of caregivers (40%) had a lifetime diagnosis of arthritis, and 75% of caregivers with arthritis reported bothersome pain, nearly 30% of whom endorsed bothersome pain that limited their activities on most or every day in the last month (i.e., activity-limiting bothersome pain). Regardless of whether they had arthritis, 51% of the

sample reported bothersome pain in the last month, 24% of whom indicated activity-limiting bothersome pain (see Figure 1).

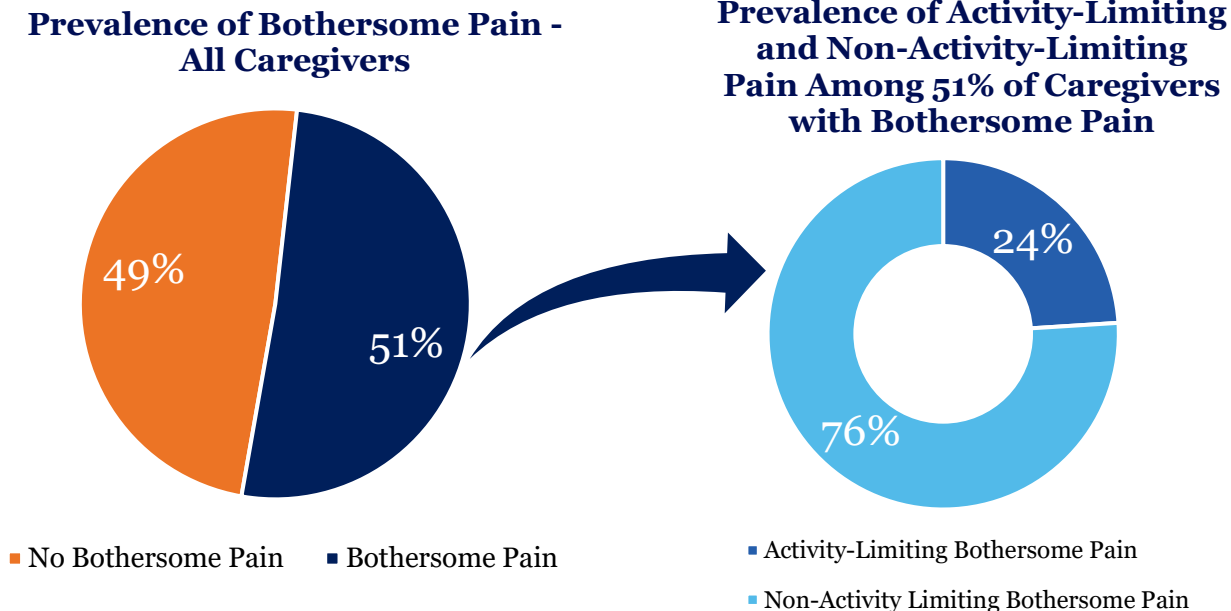


Figure 1: Prevalence of Bothersome Pain among all Caregivers (left) and Prevalence of Activity-limiting and Non-Activity-Limiting Pain among Caregivers with Bothersome Pain (right).

Data source for both figures: National Study of Caregiving, 2017, N=1,930.

Older Caregivers and Caregivers with Physical Difficulty Providing Care Were More Likely to Have Pain

Older age was strongly correlated with arthritis and pain-related disability. Given that caregivers of older adults are often spouses who are themselves older or older children, they may find it challenging to carry out everyday duties effectively and consistently. Caregivers with physical difficulty providing care reported a higher prevalence of both arthritis and activity-limiting bothersome pain versus caregivers without physical difficulty providing care. This finding raises unanswered questions about the certain caregiving activities that may exacerbate existing pain or be associated with the development of new pain conditions.

How Can Clinicians and Communities Support Caregivers?

Arthritis and pain, including activity-limiting pain, are highly prevalent among family caregivers to older adults, and may negatively impact the health of both caregivers and care recipients. As such, among caregivers receiving clinical care, we encourage clinicians to regularly screen for caregiver status, as well as for pain and pain-related disability. Among caregivers who are medically-underserved, we encourage community-based methods of pain care delivery. For example, existing caregiver support services, such as the [Trualta](#) web-based caregiver support platform funded by the New York State Office for the Aging (NYSOFA) and the Association on Aging in New York (AgingNY), could extend their training offerings to include pain self-management techniques for family caregivers with pain.

Data and Methods

Data for this study come from the 2017 round of the National Study on Caregiving (NSOC). We used modified Poisson models to estimate adjusted associations of caregiver and care recipient characteristics with the relative prevalence of arthritis and bothersome pain. For more details on study methodology, readers can access the full paper via [this link](#).

References

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