USF UNIVERSITY OF SOUTH FLORIDA
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Why We *Must* Provide Respite Care

“CAREGIVING OFTEN CALLS US TO LEAN INTO LOVE WE DIDN’T KNOW POSSIBLE.” - TIA WALKER

Executive Summary

- Demands for informal caregivers are increasing with the growth of an aging population and high prevalence of chronic diseases causing disabilities.
- Increased demands for informal caregiving can impact caregiver well-being and increase caregiver burden, which in turn, can have adverse health outcomes for the caregiver and care recipient, significantly impacting the capital market, Social Security, and Medicare.
- Funding the National Family Caregiving Support Program (NFCSP) will allow local agencies to provide more respite care hours to informal caregivers in their local communities to lessen caregiver burden. More funding will also improve coordination among NFCSP services to ensure older adults receive information about respite care.

BACKGROUND

The need for informal caregivers is paramount with the growth of an aging population and high prevalence of dementia[1], a disease that currently affects more than 50 million worldwide. Demands for informal caregivers have also risen with the high prevalence and incidence of chronic diseases such as stroke, one of the leading causes of disability in the world[2]. In addition, as health care systems trend towards palliative care to decrease costs associated with hospitalizations, use of intensive care, and emergency visits, a much greater demand has been placed on caregivers to provide care.

These increased demands can come at the cost of caregiver well-being and caregiver burden over time. In fact, research has shown caregivers experience lower levels of well-being compared to non-caregivers[3]. One of the most important factors that impacts caregiver burden is the amount of respite care received. Studies examining the benefits of respite care have shown that caregivers who used respite care had decreases in self-reported caregiver burden over time compared to caregivers who did not utilize respite care[4]. Studies have also found favorable outcomes both for the caregiver and caregiver recipient with increased respite care hours per week[5].

Despite these benefits found with respite care, an extensive evaluation of the National Family Caregiver Support Program (NFCSP)conducted by the Administration Community of Living (ACL)[5,6] reported 63% of caregivers needed more respite care on a frequent basis and for longer periods of time. Moreover, 75% of caregivers who did not use respite care were unaware that this service was available to them, and 50% of

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caregivers reported that respite care information was received too late in the caregiving phase to make a significant impact on their caregiving experience.

Other important areas of concern with respite care involve the lack of homogeneity in respite care limits among Area Agency on Aging (AAA), long waiting lists to initiate respite care, and mandatory co-payment requirements placed by some AAA[7]. These issues exist mainly because of limited funding.

It is crucial to increase knowledge about respite care services that are available to caregivers and to increase funding for these services so that caregivers can receive more, flexible respite hours for longer periods of time. These needs are highly necessary during end-of-life care when caregiver burden may be heightened, and especially true for vulnerable low-income families who may not afford paying the required co-payments to utilize respite care.

POLICY RECOMMENDATIONS

By increasing funding to the NFCSP under the legislation Section 371 of the Older Americans Act of 1965, as amended, Title IIIE, this policy will:

- Provide caregivers respite care for 12-15 hours per week over 1-year time frame. Respite care services are limited to 32 hours over a 3-month period, an amount equivalent to $3500/year. This amount of respite care may not significantly reduce caregiver burden.
- Make sure respite care services across all Areas of Aging Agencies remain free without co-payment requirements for older adults in the communities.
- Remove long waiting lists that delay the initiation of respite care services.
- Improve coordination of NFCSP services to ensure all caregivers can easily receive adequate information about respite care services in their local communities.

POLICY IMPLICATIONS

By advancing this policy into effect:

- Informal caregivers will have improvements in overall well-being with reduced caregiver burden. Lower caregiver burden implies caregivers will be able to sustain their caregiving roles. This has a tremendous effect on our national economy as the economic impact of caregiving exceeds over 461 billion dollars of unpaid labor[8]. These are cost-savings that would have otherwise been spent on direct health care workers through Medicare programs.
- More respite care hours will allow women, who usually take on the caregiving role, to stay gainfully employed by not missing work due to caregiving demands. This in return will improve the capital market and Social Security.
- By lowering caregiver burden with more and easily accessible respite care, caregivers will provide better quality of care to their care recipients. This in turn will have favorable outcomes for care recipients, including lower hospitalization and emergency admission rates, and lower nursing home placements. These favorable outcomes will significantly reduce Medicare costs.

CONCLUSION

Funding to support more respite care services and increased awareness on the availability for this service in local communities will significantly impact not only caregiver burden, but also the national economy by cutting Medicare costs and stimulating the capital market. This policy will ensure care recipients continue to receive better quality and person-centered care.

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