

1 in 5 North Carolina Adults are Caregivers: Addressing Unpaid Family Caregiver Burden with Supportive Services

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Medical advances paired with expanding home care technology and shorter hospital stays have placed increased responsibilities on family and friends. Yet, most caregivers report they are ill-prepared for their role. There are services and supports specifically designed to assist family caregivers.

Three days stand out from the last 10 years of working with family caregivers in North Carolina. They each began with a phone call. One came at the start of a Monday, one as I was readying to leave for the day, and the third somewhere in the middle. All of them were memorable for their raw desperation, their honesty, and the glimpse they provided into Carolina families and the lives made fragile by caregiving.

The Monday morning call was from someone at a regional organization who had hired a local home care agency to provide overnight weekend respite care to relatives of an older woman. The family was supposed to return Monday morning to relieve the home care worker, but the agreed-upon time came and went. A few phone calls by the home care agency revealed that the family had decided not to come back, ever. They shared that they had done all they could for their grandmother and that it was time for someone else to take care of her.

The end-of-day call was from a woman who was very careful not to give any hints of identity or location. She asked me what would happen if we got a call from a payphone telling us that there was a man home alone in serious need of care. Would someone be sent to take care of him? Would he be okay? I could hear need in her voice and I tried to get more information so we could reach out with possible help, but she would not share. Things she said led me to believe she was the caregiver for her husband, and at the very end of her strength to continue in that role.

The last call was from a woman in her 30s. She had a disabling condition and was no longer able to bathe herself. Her caregiver was a male relative and neither of them were comfortable with him bathing her. She had no one else to help, could not afford to hire someone for this, and did not qualify for public assistance. Every service I mentioned, she replied that she had already tried it and been told no. I spent the rest of the afternoon coming up empty as I looked for

a solution that would preserve this woman's dignity and independence.

Impact on Caregivers

Unpaid family or informal caregivers provide as much as 90% of the in-home long-term care needed by adults [1]. Maintaining and supporting caregiver health and well-being is an overlooked but important public health issue for policy-makers, health professionals, individuals, and families.

A caregiver is an unpaid individual (child, spouse, partner, parent, relative, neighbor, friend) who provides assistance with household chores, medical tasks, personal care, supervision, and activities of daily living to a person with special needs. The individuals receiving the care are often called care recipients.

According to the 2017 Behavioral Risk Factor Surveillance System (BRFSS), one in five North Carolina adults reported giving regular care or assistance to someone with a health problem or disability in the previous 12 months (Figure 1) [2]. Nearly 70% of these caregivers reported providing care for at least six months, and a third of them reported caregiving for more than five years [2].

This same survey showed that about 80% of North Carolina's caregivers are managing household tasks and more than half are assisting with personal care [2]. Regardless of the age of the care recipient, about one-third of the caregivers reported that without their help, their loved one would have to move to an institutional or a long-term care setting [2]. Nationally the numbers are similarly proportioned, with an estimated 65 million American adults providing this kind of assistance. Of these, about 66% (44 million) provided care to an adult aged 50 years or older. In 2013, AARP valued this unpaid labor force at \$470 billion [3]. This figure is nearly double the combined annual costs of home health care (\$43 billion) and nursing home care (\$115 billion) [3].

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Medical advances paired with expanding home care technology and shorter hospital stays have placed increased responsibilities on families. Yet most caregivers report they are ill-prepared for their role. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non-caregiving peers. Both caregiver depression and perceived burden

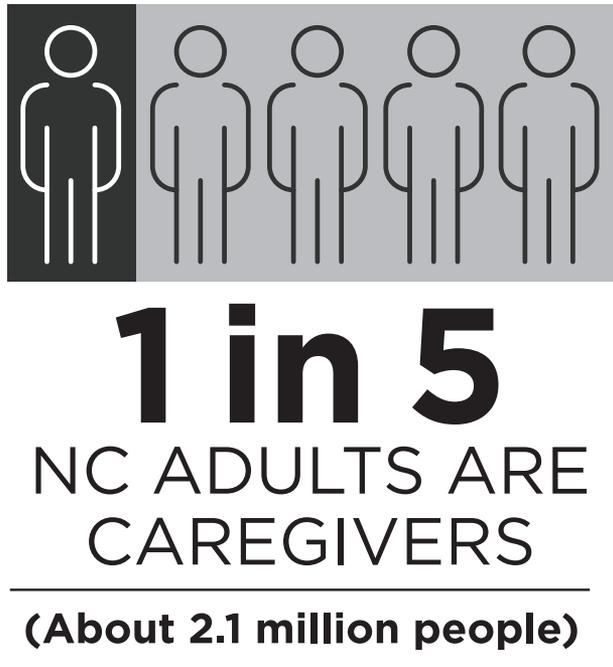
increase as the care receiver's functional status declines [4]. Caregivers who experience chronic stress may be at greater risk for cognitive decline including losses in short-term memory, attention, and verbal IQ [4]. As a response to this increased stress, studies have also shown caregivers to have increased alcohol and substance use and to use prescription and psychotropic drugs more than non-caregivers [4].

Lakis sidebar continued

After speaking with and listening to thousands of caregivers from North Carolina and across the country, it is apparent that their journeys to caregiving are often similar. Their loved one had a fall and a hospitalization and could no longer live alone after rehabilitation; their loved one needs more help due to worsening Alzheimer's disease or related dementia; there was a traumatic brain injury, an accident, or

other health crisis; or, for many care recipients, there was a serious illness diagnosis or simply advancing age, and the progression of the disease or frailty has come to the point that they are seeking help. Very few caregivers or care receivers planned for or expected to be in their situation. Yet it is likely that each of us will be either the caregiver or care recipient at some point in our lifetime.

FIGURE 1.



The Financial Impact of Caregiving

In addition to the significant emotional toll reported by caregivers, there is also often a financial toll. The majority of caregivers provide this assistance without any payment for their services. There are very limited situations in which family members—particularly parents and caregivers of children with complex medical needs—are paid by state and federal programs for hours of assistance to a loved one, but for family and friend caregivers of older adults, this funding is often not available.

According to a 2016 national AARP study, more than three in four (78%) family caregivers incurred out-of-pocket costs as a result of caregiving (Figure 2) [5]. This study found that caregivers spent, on average, nearly \$7,000 on caregiving expenses that included home modifications, paid care at home, and transportation [5]. To cover caregiving expenses, family caregivers reported tapping into personal savings (30%), reducing retirement savings contributions (16%), or dipping into existing retirement savings (11%) to cover out-of-pocket caregiving costs [5]. Those caring for an adult with dementia reported nearly twice the out-of-pocket costs of those caring for someone who does not have dementia [5].

When caregivers are facing financial needs, they often turn to federal and state-funded programs. There is often confusion between Medicaid and Medicare and what help their loved one can receive. These programs are designed to cover medical needs, and the majority of daily caregiving tasks are custodial and not medical in nature.

North Carolina has several Medicaid waivers that allow the state to deliver its own Medicaid-funded programs in a way that differs from the standard federal program. These

programs may have unique eligibility requirements that are more conducive to assisting both the caregiver and care recipient with serious illness, physical disability, and intellectual and developmental disabilities. Supports from these waiver programs can be provided as an alternative to out-of-home placements for individuals who would typically need this higher level of care. For more information about NC Medicaid, caregivers should contact the county Department of Social Services in which the care recipient lives.

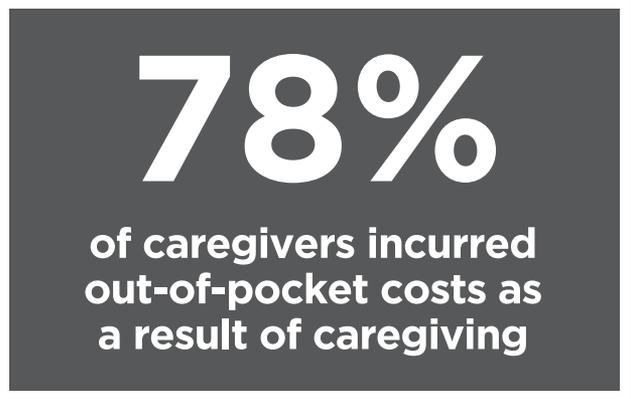
About 2 million North Carolinians are enrolled in Medicare, with about 18% of these enrollees under age 65 and qualified based on disability [6]. It is possible to be dually eligible for both Medicare and Medicaid. For more information about Medicare, caregivers should contact the North Carolina Department of Insurance's Medicare and Seniors' Health Insurance Information Program (SHIIP) at 855-408-1212.

Resources for Caregiver Support

Research has demonstrated that there are positive approaches that can help caregiver health and well-being. The Family Caregivers Alliance recommends the following potential strategies that can be adopted where caregivers interact with health care and be paid for with private or public funds: 1) an assessment of family caregiver needs that leads to a care plan with support services; 2) caregiver education and support programs; 3) respite to reduce caregiver burden; 4) financial support to alleviate the economic stress of caregiving; and 5) primary care interventions that address caregiver needs [4]. There are local public and private services based on these positive approaches available to help ease caregiver burden and offer limited support. Most of the services are offered at no cost to the caregiver, but there may be waiting lists or additional eligibility requirements.

Three specific programs for caregivers administered by the NC DHHS Division of Aging and Adult Services include the Family Caregiver Support Program, Project CARE, and the North Carolina Lifespan Respite Project. The Family Caregiver Support Program, in partnership with the state's 16 Area Agencies on Aging and local partners, provides con-

FIGURE 2.



nection to support groups, caregiver education events, information and referral, respite care, and other supports to help with the care of a loved one at home for caregivers of older adults and older adult caregivers of children [7]. Funding for this program comes primarily from the federal government through the Older Americans Act. Project CARE (Caregiver Alternatives to Running on Empty) offers information and assistance, care consultation, and respite to caregivers of a person diagnosed with Alzheimer's disease or a related dementia [8]. There are six regional offices to serve North Carolinians. Funding for this program comes from the North Carolina General Assembly. The North Carolina Lifespan Respite Project and its advisory team seek to increase respite and support options for caregivers of persons of any age with special needs [9]. This project also operates a small respite voucher program when funds are available through federally funded grant assistance.

There are also myriad other services and supports specifically designed to assist family caregivers. These supportive services are available through statewide or regional non-profit disease- or disability- specific support organizations, home care and hospice providers, adult day care and adult day health providers, Veterans Affairs services to support the care of a person who served in the US military, volunteer organizations, faith-based supports, and benefits within the NC DHHS for specific caregiving populations across the lifespan.

Recent federal legislation impacting caregiver assistance includes the January 2020 enactment of the RAISE Family Caregivers Act to develop and maintain an integrated national strategy to support family caregivers, expand Medicare reimbursement for several services that benefit family caregivers, and give permission to Medicare Advantage plans to include supportive services. Emergency funding related to COVID-19 includes the Stafford Disaster Relief and Emergency Assistance Act, which allows Older Americans Act funding to be used to support caregiver-related disaster efforts; the CARES Act, which will provide funding to family caregiver support programs nationally;

and the Supporting Older Americans Act of 2020, which continues funding for the RAISE Act and activities of the RAISE Council and makes caregiver assessments mandatory. NCMJ

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