

‘CARING FOR CAREGIVERS’ MODEL ADDRESSES NEEDS OF THOSE LOOKING AFTER OTHERS

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Imagine being offered a job that will require you to be on call 24/7 every day of the year, with no time off for holidays or illness. You will probably need to cut back on hours at your current job or leave it to take on this new role, which means financial worries, including reduced retirement assets in your future. The new job has no salary attached. In fact, you will be responsible for paying for some aspects yourself. The work is stressful, your physical and mental health may suffer, and you may even be more prone than others to developing serious chronic health conditions as a result. The job can be fulfilling in many ways, but you naturally have reservations. However, because there may be no one else to take this role on, you feel you have no choice but to accept it.

Welcome to the world of the family caregiver.

Because the United States lacks a comprehensive plan for long-term care for older adults, family caregivers continue to be the assumptive long-term care providers for the nation’s aging population. Although many family caregivers find meaning in this role and take it on willingly, they often experience related physical, emotional and/or financial costs. However, thanks to a new initiative started by Rush University Medical Center in Chicago, resources are now becoming available to patients and their caregivers to help improve their well-being.

LANDSCAPE OF THE FAMILY CAREGIVER

Family caregivers in the U.S. are providing approximately 24 hours of complex care per week, with 58% engaging in medical and nursing tasks.¹ Seven out of 10 of these caregivers also experience the practical and emotional burden of managing pain for the person they are looking after.² This care is provided to the best of the caregivers’ abilities, but few have received ongoing training and support from medical professionals. Less than a

third (29%) of family caregivers say that a member of the care recipient’s health care team has asked them about the support they need to provide care, and only 13% say a health care provider asked what they needed to care for themselves.³ This clearly demonstrates the need for more to be

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done to provide assistance to meet those needs.

Clinically significant signs of depressive disorders are present in 40%-70% of family caregivers of older adults, with a quarter to a half of them meeting the criteria for major depression.⁴ Caregivers are frequently strapped for time and energy, so neglect their own care needs, and 40% report experiencing two or more chronic diseases.⁵ These issues are affecting millions of caregivers throughout the U.S., resulting in serious consequences for them as well as the older adults for whom they provide care.

Despite these dramatic findings and the crucial role of caregivers in providing long-term care, health care providers have typically not attended to these needs. Health systems are uniquely positioned to address their needs, given the care recipient's reliance on caregivers for help with making and keeping appointments. Because of this accessibility and thanks to funding from RRF Foundation for Aging, Rush University Medical Center embarked on an effort in 2019 designed to have a two-pronged effect: to change the ways the health system identifies and addresses the needs of family caregivers of older adults, and to provide education and support them to improve their and their care recipients' well-being.

ADDRESSING CAREGIVER NEEDS WITHIN HEALTH SYSTEMS

Intervention begins with identification. The CARE Act, enacted in 44 states and territories, stipulates that caregivers of older adults need to be identified and entered into the medical record upon admission to the hospital.⁶ Rush University Medical Center has expanded this expectation and has established it as a best practice in both its inpatient and outpatient settings. Although most medical record systems do not make it easy to enter this information, Rush has created a work-around to allow this change, explicitly listing the relationship and care provision role with the recipient, and for it to appear on the storyboard in the older adult's medical record so it can be easily viewed by anyone opening their chart. In addition, multiple caregivers who handle different tasks can be noted, with those tasks delineated in the record. The entry may be made or edited by anyone with appropriate access to the record.

Rush also actively encourages providers to view the caregiver and the care recipient as a dyad to be included in discussions about care planning and provision. Caregivers have historically not been included in these discussions, which has led to misunderstandings about what will be done and how. Age-Friendly Health Systems support the use of four evidence-based elements of care for all older adults, known as the "4Ms" (What Matters, Medication, Mentation and Mobility) including a focus on what matters to both the older adult and the caregiver as key components. Rush's approach adds what matters to the caregiver as a key component of addressing the needs of the dyad.

LISTENING AND PLANNING TO PROVIDE SUPPORT

The "Caring for Caregivers" model begins with a referral to the program by anyone inside or outside of the health system, and caregivers may also self-refer to take part. An appointment is set up for the caregiver to meet with a social worker or other mental health professional to get acquainted and to assess caregiver needs with a set of evidence-based tools. By the end of this meeting, a customized intervention plan is established together.

If the caregiver is experiencing physical difficulties or a lack of confidence related to care tasks, skill-building meetings with physical therapists, occupational therapists, nurses, dietitians, pharmacists or social workers are available to assess concerns and address identified needs. Planning meetings may also be initiated to include the caregiver and the care recipient in working with the health care team on current and future care plans.

In addition, up to five sessions may be held with family-therapy trained mental health professionals — referred to as "Planning for What Matters" sessions — to assist the care recipient and/or the caregiver alone with expanding the care team, communicating effectively with each other and the health care team, exploring what is valued most by both parties and mapping out ways to support each other currently and in the future. Care plans for what is needed now and for what will be anticipated with disease progression are included, and extended family and friends who can support the dyad may be brought in to discuss their participation in the plan as well.

OUTCOMES

Program engagement begins with the mental health professional and the caregiver completing a set of evidence-based tools, including the shortened version of the Burden Scale for Family Caregivers⁷; the Patient Health Questionnaire-9 to assess depression⁸; and the General Anxiety Disorder-7 to assess anxiety.⁹ Once the caregiver has completed the recommended interventions, follow-up assessments occur at one, three and six months post-intervention. Initial results using paired sample t-tests [a statistical test that is used to compare the means of two groups] indicate statistically significant reductions in all three measures at one and three months, and significant reductions in self-reporting of burden at six months. (See Figure 1 on page 62.)

Additionally, outcomes have been explored to see if caregivers' participation in the program is

associated with changes for care recipients in the number of hospital admissions, length of hospital stays and emergency department visits when comparing these six months prior to and six months after caregiver participation using paired sample t-tests. When looking only at changes in Rush care recipients' hospital use, preliminary results indicate statistically significant reductions in all three measures with more clinically significant changes seen when the pool is limited to care recipients who had any inpatient or emergency department visits (see Figure 2 on page 63). These types of findings are of particular interest to health system administrators due to associated financial penalties for instances of high rates.

EXPANDING THE CARING FOR CAREGIVERS MODEL

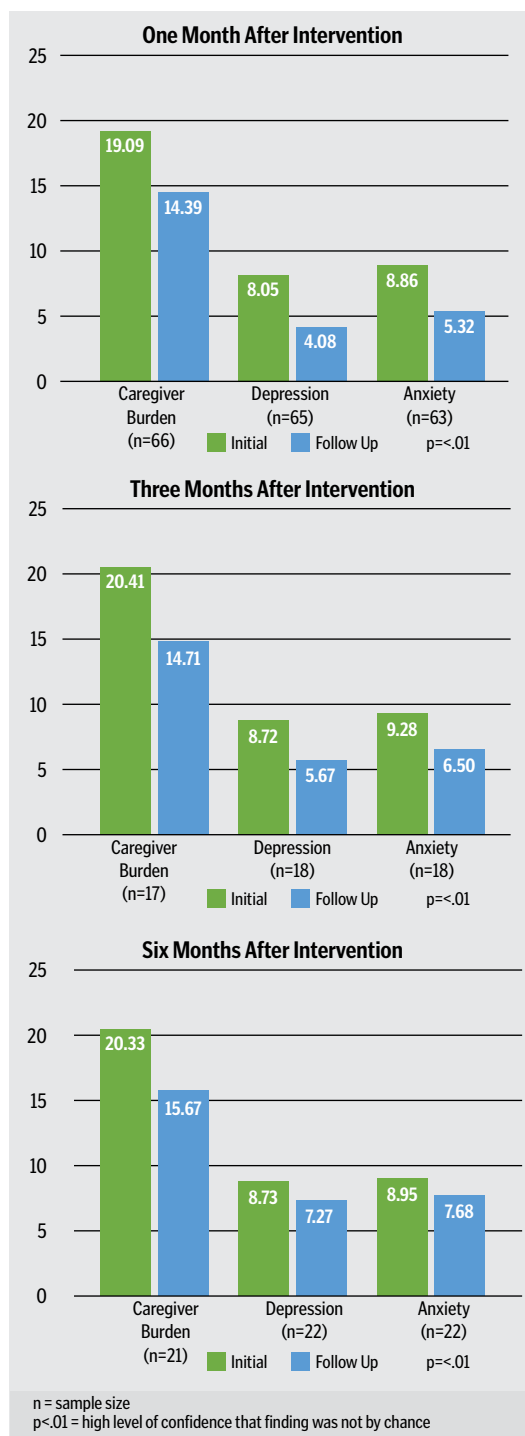
Beginning in 2020, thanks to a grant from The John A. Hartford Foundation, Rush University Medical Center began working with the Institute for Healthcare Improvement to prepare expansion of the Caring for Caregivers model throughout the country as part of the Age-Friendly Health System movement, an initiative started by the foundation and the Institute for Healthcare Improvement in partnership with the American Hospital Association and CHA. Six pilot sites began testing the model within their health systems to determine the facilitators and barriers to implementation, and the data collected is being explored to make needed updates to the model and related materials.

A three-year continuation grant from The John A. Hartford Foundation — which began in October 2022 — is allowing this work to move forward. The importance of including caregivers in age-friendly care is being promoted by the Institute for Healthcare Improvement through their marketing and communication efforts, and ways to include caregivers in the care provision of older adults is being discussed in their Action Communities, which include individuals from participating Age-Friendly Health Systems and offer information and facilitate discussion among members.

Rush University Medical Center will offer opportunities for health systems to establish Caring for Caregiver model programs at their sites and will assist with tailoring the model's interventions to the needs of interested systems and their patient/caregiver populations. Presentations at conferences, workshops and trainings, learning communities offering information and peer support, and meetings with individual health systems will be held to help health care systems learn about the

Figure 1: Caregiver Outcomes

Measured results indicate a reduction in caregiver burden, depression and anxiety among those initially assessed who took part in the Caring for Caregivers program.



Source: Rush University Medical Center

model, assess for readiness to integrate the model into existing programs and services, garner active support from leadership, promote the program and gather and assess outcomes to adjust the intervention as needed.

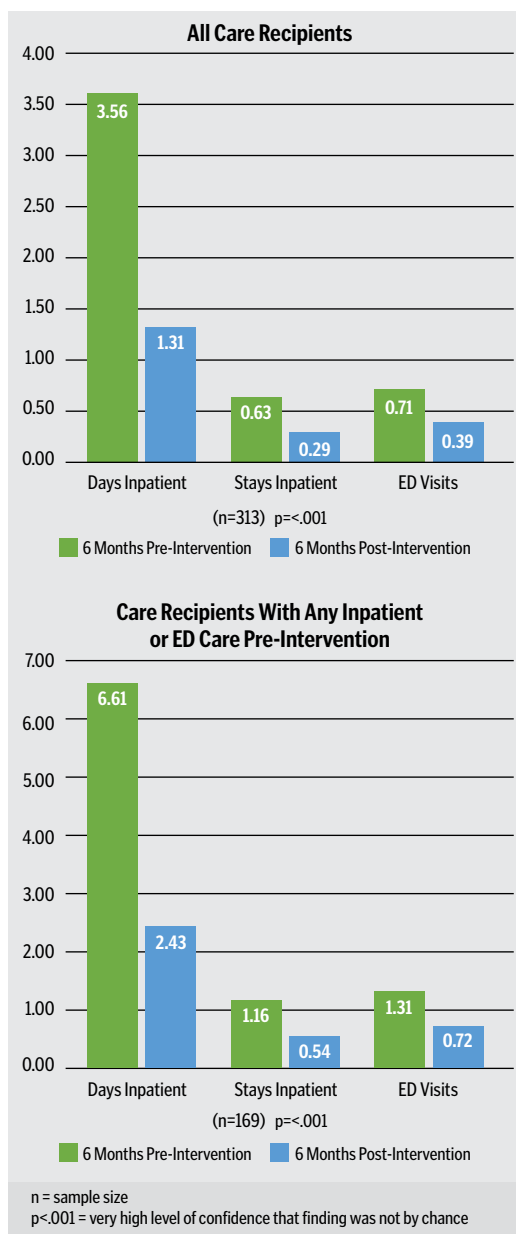
The Caring for Caregivers model is being offered to sites free of charge nationwide, and recruitment for the program has begun. For more information and implementation at your site, please contact Diane Mariani, Program Manager, at Diane_Mariani@rush.edu.

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NOTES

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Figure 2: Care Recipient Outcomes



Source: Rush University Medical Center

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