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COMMENTARY

"How can I be a caregiver for a second time?" A call to action to acknowledge and support *experienced* family caregivers

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Nearly a decade ago, user Heatherrose logged onto a CareChat forum hosted by the US-based *Caregiver Action Network*[1] and made a new post titled, "How Can I Be a Caregiver for a Second Time?" This user proceeded state:

> I took care of my father for many years, and he passed away in 2013. After going through a long mourning period, I started to feel like I was starting a new life. For the first time in years, I was free to pursue my own life. I went from worrying 24/7 about my father and making my father my number one priority, to feeling like I could finally focus on my own life. It looks like that is about to come to an end. I learned that my mother-in-law is going to be moving here. She has Alzheimer's. I will do whatever I can to help out, but I do not want to become a caregiver again… she cannot be alone, and I do not want to become her babysitter. Since my father passed away, I have resumed my career, and I am busy working and pursuing the interests that I could not pursue when I was a caregiver for my father. I feel like I am being selfish for not wanting to be a caregiver for my mother-in-law. I do not want her to become the focus of our lives. I do not want to go back to the stress that I lived for so many years. I am afraid that having my mother-in-law living nearby will end up putting a huge strain on my marriage. I don't know what to do. All I know is that I cannot go back to that life.

This post echoes sentiments of a substantial sub-group of American family caregivers who have engaged in multiple caregiving roles across adulthood. It is well known that the US population is aging.[2] With it, the number of older persons living with chronic, progressive illnesses (e.g., organ failure; cancer; Alzheimer's disease, other related dementias) who are in need of regular care to support activities of daily living is projected to continue to expand.[3] Responses to combined "population aging and shrinking" involve creative efforts to preserve older adults' functioning, autonomy, and quality of life while encouraging family networks to provide care in the home rather than transitioning care recipients to formal care institutions.[4] The result is an increasing reliance on family caregivers, who dedicate months or years of their life, plus financial resources and other assets, to the care of one or more family members or close others. For example, nearly a quarter of US caregivers in 2020 were providing care for more than one care recipient simultaneously—up from 18% in 2015.[5] The percentage of those who are providing care to one family member or close other in the present, and have also been caregivers in the past (i.e., sequentially rather than simultaneously), is likely even higher.

Across multiple family caregiving roles, caregivers may accrue some specific advantages (e.g., learned caregiving "skills"[6]) that ease their transition into subsequent caregiving roles. It is also possible that some former caregivers "self-select" into subsequent caregiving roles, thus entering new roles autonomously and, in turn, harboring a sense of mastery with cascading benefits for the care dyad.[7] But decades of research on the tolls of

TABLE 1 Template for collecting data on past and present family caregiving.

Instructions: We'd like to know a bit more about any other caregiving experiences you have had throughout your life. Besides your care for *[study-specific care recipient or patient]*, can you provide some information about additional family members, friends, or close others you have provided care for in your life, in the past or present? You could have been the primary caregiver, meaning you were the person in your family providing the most care, coordinating the care, and/or spending the most time with the person. You could also have been a supporting caregiver, helping other caregivers in your family or social circle without being the primary caregiver. Please review this list. For any person you have been a family caregiver for in the past or present, please place a checkmark in the first box to the right of that person's description. Then, fill out the other boxes in the row to the best of your ability.

	Place a check in this box if you've been a caregiver for this person	**Year caregiving began**	**Year caregiving ended. If you are still a caregiver for this person, write "present"**	**Cause of death, if this person has died. If not, leave blank.**	**Check this box if you were the primary caregiver for this person**
Your first spouse, romantic partner, or significant other	☐	*text box*	*text box*	*text box*	☐
Your second spouse, romantic partner, or significant other	☐	*text box*	*text box*	*text box*	☐
Mother, step-mother, or guardian	☐	*text box*	*text box*	*text box*	☐
Father, step-father, or guardian	☐	*text box*	*text box*	*text box*	☐
Maternal grandmother	☐	*text box*	*text box*	*text box*	☐
Maternal grandfather	☐	*text box*	*text box*	*text box*	☐
Paternal grandmother	☐	*text box*	*text box*	*text box*	☐
Paternal grandfather	☐	*text box*	*text box*	*text box*	☐
Brother	☐	*text box*	*text box*	*text box*	☐
Sister	☐	*text box*	*text box*	*text box*	☐
Child with physical/mental/developmental disabilities into adulthood	☐	*text box*	*text box*	*text box*	☐
Friend	☐	*text box*	*text box*	*text box*	☐
Different relative (describe)	☐	*text box*	*text box*	*text box*	☐
Other person (describe)	☐	*text box*	*text box*	*text box*	☐
Other person (describe)	☐	*text box*	*text box*	*text box*	☐
Other person (describe)	☐	*text box*	*text box*	*text box*	☐

family caregiving echo the sentiments in Heatherrose's CareChat forum post and suggest that learned skills from prior care roles can be undermined by overstimulation of allostatic systems[8]: a compounding of physical, psychological, financial, career, and social stressors[9] that arise during prior caregiving roles and can persist even after caregiving roles have ended.[10–12] Simultaneously, many caregivers report that they feel they had "no choice" but to support care recipients whom they were geographically or emotionally close to,[13] likely preventing agentic self-selection across multiple caregiving roles. While stressors stemming from individual caregiving roles can be manageable, former caregivers like Heatherrose tell us that management may occur through compartmentalizing some desires, like pursuit of careers and personal hobbies, until being able to "shift back to normal" when caregiving ends.[14] Other stressors, such as grief responses, may peak during advanced illness or in the wake of the loss of a care recipient and be managed through dedicated time to process after the care recipient has died.[15,16] Left unaddressed, stressors may instead compound and result in substantially increased vulnerability as adults enter into subsequent caregiving roles.

Given known trends in caregiver demographics, disproportionate repeated reliance on marginalized caregivers (e.g., women, persons with low socioeconomic status, individuals who identify as racial or ethnic minorities) is increasingly likely. Indeed, the sole respondent to Heatherrose's CareChat forum post described the phenomenon of taking on multiple family caregiving roles as "being sucked into… the caregiver-meatgrinder." In our call for increased research and policy attention, we have opted to adopt a more neutral (but perhaps less sensational!) term to describe this phenomenon: we define this sub-group of family caregivers as *experienced caregivers*, a term which we believe acknowledges and accounts for both the cumulative advantages and disadvantages of multiple care roles, most of which are yet to be systematically determined.

Since Heatherrose's CareChat post went live in 2014, there has been little research attention toward this critical sub-group of family caregivers. Acknowledgment of experienced caregivers seems more common in web forums and blog posts (see Rita File's blog description of 'serial' caregivers,[17] or Michele Houck and Elizabeth Miller's video-based discussion[18]) or manifests as research on "sandwich generation"

TABLE 2 Template for collecting data on anticipated future family caregiving.

Instructions: Next, think for a minute about the future. Do you anticipate that you will be a caregiver to any family, friends, or close others in the future, not including people you are already a caregivers for now? If so, please choose the individuals you think you might care for in the future by placing a checkmark in the box.

	Place a check in this box if you anticipate that you will be a caregiver for this person in the future but have never been a caregiver for them in the past.
Your first spouse, romantic partner, or significant other	☐
Your second spouse, romantic partner, or significant other	☐
Mother, step-mother, or guardian	☐
Father, step-father, or guardian	☐
Maternal grandmother	☐
Maternal grandfather	☐
Paternal grandmother	☐
Paternal grandfather	☐
Brother	☐
Sister	☐
Child with physical/ mental/ developmental disabilities into adulthood	☐
Friend	☐
Different relative (describe)	☐
Other person (describe)	☐
Other person (describe)	☐
Other person (describe)	☐

caregivers (i.e., adults, particularly Baby Boomers, who care for children and older parents simultaneously[19,20]). Trajectories of family caregiving over the life course, including patterns that characterize experienced caregivers, have been introduced,[21] but not widely adopted to structure research programs. As a result, experienced caregivers remain hidden in plain sight, with no accurate estimation of their prevalence, nor practices that account for their unique needs, nor tools to identify those most at-risk for negative outcomes for themselves, their care recipients, or their families, nor evidence on which to base caregiver-relevant health policies. In fact, we conducted search of projects listed in the National Institute of Health (NIH) RePORTER project repository (2007-present), in which we entered relevant terms from scientific literature and public forums (i.e., experienced caregiver, concurrent caregiver, repeat caregiver, compound caregiver, serial caregiver, second-time caregiver, dual caregiver, and multi-generational caregiver). Three individuals reviewed the titles and abstracts for each search result to determine if the project related to experienced caregivers, as defined in this article. Despite robust funding efforts for caregiving research (i.e., 5603 separate “hits” for funded projects related to “family caregiver” search term), no projects in our search focused on prevalence, outcomes, or support resources for experienced caregivers.

We call for an increase in focused, person-centered research on experienced caregivers: initiatives that spotlight their stories, burdens, strengths, needs, and hopes for the future. We also call for researchers collecting data from family caregivers to document their simultaneous and sequential caregiving roles, recording how many individuals these caregivers have already provided care for in the past, are currently caring for, and anticipate caring for in the future. These questions would be asked in addition to related demographic questions about marital status or number of children the participant has, which are already commonly asked in caregiving studies. In some studies, these characteristics may be important determinants of caregivers' reported health, wellbeing, strengths, or even the effectiveness novel interventions. We call for development of systematic tools to gather this type of data. As a start, we have provided two simple, questionnaire-style tools used successfully in our existing research[6] for collecting data on past/ present caregiving experiences and anticipated future caregiving experiences (see Tables 1 and 2, respectively). These new foci and additional data collection efforts can critically inform policy and practice, helping us identify and draw strategic boundaries around our presently limitless dependance on family caregivers.

> *“We call for an increase in focused, person-centered research on experienced caregivers: initiatives that spotlight their stories, burdens, strengths, needs, and hopes for the future.”*

While increasing human longevity is evidence of successful public health initiatives, longevity brings with it new sets of public health concerns that require equal attention from researchers, care services, and policy makers. Worldwide, we are relying on family caregivers to provide functional, social, and financial support to bridge healthspan and lifespan gaps, even as the ratio of healthy to ill adults is projected to shrink. This disparity has been described as a “policy/ demographic impasse,”[21] and has undoubtedly resulted in the growth of populations of experienced caregivers. Now, it is our responsibility to dedicate resources to identifying, understanding, and supporting these experienced caregivers, because caregivers like Heatherrose deserve, at minimum, tailored, accessible, evidence-based responses to their requests for support.

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E. L. Mroz led concept development, literature review, and writing. All author supported concept development, writing, and editing. All authors approved the manuscript before submission.

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