Editorial

Bringing Invisible Partners in Care out of the Shadows: Employment Effects of Informal Care Provision in Europe and Implications for the United States

There are urgent calls in the policy advocacy community to expand supports to family and friend caregivers in the United States (called informal caregivers or family caregivers). Advocacy and legislative proposals from AARP and caregiver-specific groups such as the Family Care Alliance and National Alliance for Caregiving, along with Veteran and Military Service Organizations, have led to policy changes in recent years. Two recent policies are of note. The first, passed and implemented in three states to date, is paid family medical leave (PFML) (Brainerd 2016). PFML is paid through payroll taxes as a part of disability policy and allows 6 weeks of paid leave for qualifying reasons, including caregiving. Second, the Department of Veterans Affairs established a national caregiver support program for caregivers of veterans. Besides training and supports such as respite care for all caregivers, more expansive benefits that include a stipend and health insurance are available for qualifying caregivers of veterans from the post-9/11 era who face significant limitations in daily life (Van Houtven et al. 2017). Beyond the direct effects on caregiver tasks and intensity, these policies may have unintended consequences to work behavior and future economic security (e.g., foregone Social Security and Medicare benefits) that should be included in the calculation of their net benefits.

The calls to support the U.S.'s 18–24 million caregivers (Wolff et al. 2016) are not new, but there is more urgency today. Beyond the well-known aging of the U.S. population increasing demand for informal care, demand for informal care will increase because people are living longer with chronic

illness and disability that requires assistance. And because Americans are both sicker and have more trouble than older adults in other industrial nations accessing health care (Osborn et al. 2017), family caregivers help fill the gaps in chronic disease management long before day-to-day assistance is needed in the home. Importantly, there is a limited social safety net to cover the long-term care needs of Americans. Private long-term care insurance is prohibitively expensive for most people, and people do not commonly plan against the risk of needing long-term care (Sperber et al. 2014). Thus, even though recent evidence shows informal care is not the preferred long-term care source by most Americans (Brown, Goda, and McGarry 2012), it will continue to be the default option. Compounding these factors, the Patient Protection and Affordable Care Act of 2010 did not retain the long-term care insurance provision (CLASS Act) but did increase attention to care coordination and transitions of care, which increases demand for family and friends to help. And in non-Medicaid expansion states, demand for informal care will be even higher, given lower access to publicly financed long-term care (Coe, Goda, and Van Houtven 2015; Sommers and Grabowski 2017).

With little traction for expanding formal home care, and the increased expected demand for informal caregivers in coming decades amid numerous concerns that supply will not keep pace, the advocacy community has focused on a more tenable policy goal than expanding formal care: supporting informal care. In 2016, the National Academies of Science, Engineering, and Medicine issued a report, “Families Caring for an Aging America,” which outlines recommendations for caregiver-friendly health care systems, a national strategy for caregivers, and supportive policies (NASEM 2016). AARP has been very successful in pushing forward supportive policies. The Caregiver Advise, Record, Enable (CARE) Act has been passed in 36 states and requires hospitals to record a patient’s primary caregiver’s contact information in the electronic health record (eHR), to inform the primary caregiver when the patient will be discharged, and to provide training about tasks required once home (AARP 2017).¹ As AARP put it, laws like The CARE ACT “offer some basic support — and common sense solutions” (AARP 2017). Even Congress has brought attention to the issue of caregiving with recent testimonials from members about their own caregiving experiences to promote bipartisan

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caregiver support bills (Rubin 2017). Notably, the bipartisan Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, also championed by AARP, was signed into law by President Trump in January 2018. Whereas the law provides no funding for programs, it mandates a national caregiver strategy, including an advisory council report within 1 year of the law's passage, as well as a national strategy issued within 18 months (Jefferson 2018). In general, supportive caregiver policies are expected to expand training of caregivers, to minimize the well-known ill health effects caregivers experience, and to possibly reduce the financial strain of caregiving if work interruptions decrease.

It is into this climate that Kolodziej, Reichert, and Schmitz's article appears in this issue of HSR. The question of how informal care affects work in Europe can inform our thinking about how more generous U.S. policies for informal care may affect U.S. caregiver labor force participation. Besides having an older population than in the United States across Europe, there are also important country-level institutional differences in long-term care financing and design, with Northern European countries having more public financing and access to formal care in the home and nursing home care, as well as policies that directly compensate family caregivers (e.g., Germany). In Eastern and Southern European countries, supports are more modest.

Importantly, Kolodziej, Reichert, and Schmitz (2018), control for the nonrandom selection into caregiving, focusing on the full age range of working age adult children caregivers (20–65), and using data from most countries in Europe, their generous sample size allows them to look at whether male and female caregivers have differential labor market responses. The data source is the Survey of Health, Aging and Retirement in Europe from 2004–2013, modeled after the U.S. Health and Retirement Study. Kolodziej, Reichert, and Schmitz (2018) examine immediate changes in labor force participation for caregivers of older parents who have a demonstrated need compared to noncaregivers. Demonstrated need for care was defined by either receiving some informal or formal help in the home or reporting a disability and is important to keep in mind because many other studies include a broader sample of potential care recipients, for example, not restricting the analysis to those who have disability. The authors find that informal caregiving in the SHARE-represented countries reduces labor force participation on average by 14.0 percentage points.

The empirical approach addresses the fact that adult children face a choice about whether they will become a caregiver or not. The authors use instrumental variables methods to ensure that the effect of informal care on

work is not simply picking up the effect of being less interested in work (or sicker or something else) to begin with. This method pseudorandomizes adult children into “caregiving” or “not caregiving” states, by exogenous features of their family structure: number of siblings and whether a parent is widowed by recent death of the spouse. The inference possible in this approach, as the authors point out, is a local average treatment effect. That is, they estimate the labor market changes among those adult children invoked to provide care (or not) due to the availability of other sources of care in the family.

Examining younger caregivers than most other studies, their findings highlight the limitations of past informal care and work studies, which focus on caregivers 50+. Ten percent of the SHARE caregivers were age 20–29; 23 percent were age 30–39; and one-third were age 40–49. If other studies, including those done in the United States by myself, Coe, and Skira (2013), had examined caregivers in the lower portion of the age distribution, they may have found more significant reductions in labor force participation. On the other hand, younger U.S. workers face incentives to remain in the labor force to ensure employer-sponsored health insurance for themselves and dependents, so the labor force effect could be smaller. As Kolodziej, Reichert, and Schmitz (2018) point out, by covering the full age distribution of workers, they may be uncovering an impact on a country’s welfare hidden in prior work that focused on the 50+ caregivers. Indeed, labor market trajectories may be quite different for early versus late in life caregiving episodes (Miller 2011).

Their model is fully interacted with male gender, and while males appear to be more likely than females to reduce work, which is counter to the expectation that males are more attached to the labor force than females, this finding is not statistically significant. The magnitude of the effect for males may be because more women work in part-time jobs, whereas more men work in full-time jobs. Thus, initiation of caregiving duties for men means that they may have to exit the labor force entirely because a move to part-time work is not an option.

In addition to the above strengths, the key contribution of this paper is the authors examine different labor force effects by different institutional settings along the north versus east and south gradient. The authors find that negative labor market implications of caregiving are more pronounced in Eastern and Southern European countries compared to Northern European countries. Besides cultural differences that may explain this trend, for example, more multigenerational households and less geographic mobility, there are distinctly different policies that support caregivers by the N/E and S gradient. In

the east and south, there are few publicly provided substitutes to informal care. Thus, the overall finding is driven entirely by the Eastern and Southern countries and informal care in Northern European countries has no discernible effect on labor market participation. It is hard to disentangle the income effect (Northern countries are wealthier) from the generosity of long-term care policy effect (Northern LTC benefits are more generous), but it is plausible that the specific policies that support long-term care or the more extensive social safety net in Northern European countries drive their finding.

One must ask, what are the lessons for the United States from this work? Eastern and Southern European country informal caregiver supports are much more akin to the types of supports in the United States (Colombo et al. 2011). We should expect that more expansive policies to support long-term care, such as seen in Northern European countries, if they focus on formal care services, would overall increase U.S. labor force supply among informal caregivers. If supports allow direct payments to caregivers, however, such Germany enacted starting in 1995, then such a policy in the United States may decrease U.S. labor force supply, which is what happened in Germany, at least among male caregivers (Geyer and Khorfage 2017). One factor that may blunt the labor market response to caregiving in the United States, even in the presence of supportive caregiver policies, is the fact that health insurance in the United States is still predominantly tied to employment for those under age 65. Thus, non-elderly U.S. caregivers face an additional barrier to reducing work due to caregiving demands on their time that European caregivers do not face—loss of insurance.

The United States is nowhere close to having the policy supports available in Northern European countries, but what can we learn from the three recent informal care policies described in the introduction about possible spillovers to labor market activities? Would the net change from these policies be neutral, positive, or negative to caregiver work behavior? Thus far, research in the United States that carefully considers causality shows that informal care among caregivers 50+ years old has modest negative effects on work, retirement, and wages, and the impact depends on the type of care provided and the caregiver's gender (Van Houtven, Coe, and Skira 2013; Jacobs et al. 2014). Because U.S. studies have not examined yet the full age distribution of caregivers in a national study, more research is needed to understand the full “caregiving effect” on work, as well as the “policy effect” on work. What might the policy effect be in the United States, with the advent of new policies to support caregivers directly?

PFMLA

There are few evaluations of the Paid Family Medical Leave Act (PFMLA) effects on caregiver work. An early evaluation found “no evidence to suggest that likely caregivers experienced changes in leave-taking, employment, or labor force participation after the implementation of the California or New Jersey programs,” and that the main explanation was low uptake of the benefit (Morefield et al. 2016). Other analyses using actual participants are needed to examine trade-offs between informal care and work directly. A recent evaluation of California’s PFML policy by Arora and Wolf (2017) showed that “paid family leave reduced nursing home use by 0.65 percentage points, or in relative terms, an 11% decline in nursing home use.” They carefully addressed the threats to validity from the nonrandomized setting. Presumably, the mechanism through which nursing home use fell was that increased flexibility at work allowed family members to continue providing care and also prevented pay disruptions. Although not tested, the channel by which this occurred was presumably from more informal care. Examining labor market retention among caregivers directly is an important next analysis.

VA PROGRAM OF COMPREHENSIVE ASSISTANCE TO FAMILY CAREGIVERS

In a recent evaluation of the Program of Comprehensive Assistance to Family Caregivers (PCAFC), the program for post-9/11 caregivers, participating caregivers reported lower perceived financial strain compared to caregivers who did not participate (Van Houtven et al. 2017). The evaluation did not examine labor market effects of the policy. If the stipend and availability of health insurance led to labor market exits, then one needs to look at whether exits were temporary or permanent. If program participation helps facilitate a veteran’s recovery, or allows a caregiver to invest in education, then the caregiver may later re-enter the labor force. Re-entry also likely depends on the veteran’s ability to regain independence. Considering veteran recovery highlights how complicated the “spillover” picture can be of any policy: PCAFC may increase some care recipients’ own labor force participation, for example, through use of VA’s supportive employment program. However, for severely injured veterans, it is likely the caregiver may face a permanent or many-year exit. Thus, the net benefits of this policy need to consider the income effect,

the recovery effect for the veteran, the well-being effect on caregivers, and the work effect on caregivers.

These three highlighted policies illustrate that any new caregiver support policy will have unique effects on caregiver behavior and work behavior, and these changes in behavior need to be considered to assess net benefits. Skira (2015) authored the preeminent study of caregiving and work in the United States and found that informal care reduced labor force participation among adult daughters. Her policy simulations showed that paid and unpaid leave policies were much more effective at keeping a higher proportion of adult daughter caregivers working full time after an intensive caregiving episode, but that a more modest number remained intensively caregiving. By contrast, a generous (\$27,000) caregiver allowance was very effective at keeping a large proportion of adult daughters intensively caregiving, but the trade-off was that there was an accompanying substantial reduction in the proportion of them who remained working full time. For reference, in the VA PCAFC program the annual tax-free stipend ranges between \$7,000 and \$28,000. These trade-offs should not be ignored given competing goals of the labor sector to increase female labor market participation and goals of health sector to minimize cost of long-term care provision (Van Houtven, Coe, and Skira 2013).

In addition, to evaluate proposed policy supports for caregivers, there is an urgent need for researchers to delve deeper into identifying who fares the worst from caregiving. Who fares the worst on the labor market and accompanying increasing economic insecurity? Who leaves for the short-term versus permanently? A continuing focus on gender, but combined with other features of vulnerability, such as poverty or underinsurance, is critical. These questions are paramount to design optimal policy mechanisms that address goals of equity and fairness. For example, while 50 million Americans have taken Family Medical Leave Act leave since 1993, 78 percent of those who need leave do not take it because they say they cannot afford to take unpaid leave. What about other support structures? What differential impacts might respite care programs, consumer-directed programs where patients can pay the caregiver directly, or pension credits for caregivers have on work behavior and welfare, and whom would these policies differentially benefit? Detailing the winners and losers is an important gap in existing European and U.S. studies, and this knowledge is needed to inform targeting of policy interventions.

ACKNOWLEDGMENTS

Joint Acknowledgment/Disclosure Statement: This was an unfunded commentary written at the request of HSR; however, I am grateful for funding from the Center of Innovation for Health Services Research in Primary Care (CIN 13-410), research assistance from Katherine E. M. Miller, and helpful comments from my coauthor, Josephine Jacobs, Ph.D.

Disclosures: None.

Disclaimer: None.

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NOTE

1. The CARE Act could also have modest spillover effects on reduced caregiver labor force participation by demanding a greater role in post-discharge care coordination with the caregiver, which future evaluations should keep in mind. Because work disruptions would depend on sick leave and duration of follow-up period after discharge, it is unclear whether the policy would be negative or neutral on work behavior a priori.

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