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New Report Finds That Spouses Who Are Caregivers Are More Likely Than Other Caregivers to Perform Demanding Medical/Nursing Tasks

Yet They Are Less Likely to Get Support from Family or Friends Or to Have Support from Home Visits by a Health Care Professional

NEW YORK, NEW YORK April 14, 2014—The United Hospital Fund and AARP Public Policy Institute issued a report today showing that spouses who are caregivers not only perform many of the tasks that health care professionals do—a range of medical/nursing tasks including medication management, wound care, using meters and monitors, and more—but they are significantly more likely to do so than other family caregivers, who are mostly adult children. Nearly two-thirds of spouses who are family caregivers performed such tasks (65 percent), compared to 42 percent of nonspousal caregivers. *Family Caregivers Providing Complex Chronic Care to Their Spouses* was produced with support from the John A. Hartford Foundation.

Despite these demanding responsibilities, spouses were less likely than nonspousal caregivers to receive inhome support from health care professionals; 84 percent of spousal care recipients received no professional health care on site, compared to 65 percent of nonspousal care recipients. Compounding the challenge, spouses were also less likely to receive help from family or friends or home care aides: 58 percent of the spouses reported no additional help from others, compared to 20 percent of nonspouses. This lack of support elicited special concern from the authors: "'Taking care of one another' in an era of complicated medication regimens, wound care, and tasks associated with complex chronic care is a challenge that no one should have to face alone," they state in the report.

In addition, spouses who are caregivers were on average a decade older than nonspousal caregivers (median age 64 versus 54). They were also poorer, less likely to be employed, and less educated than nonspousal caregivers.

Family Caregivers Providing Complex Chronic Care to Their Spouses, a publication in the "Insight on the Issues" series, summarizes the new findings drawn from additional analysis of data based on a December 2011 national survey of 1,677 family caregivers, 20 percent of whom were spouses or partners. Earlier findings were published in the groundbreaking PPI/UHF report Home Alone: Family Caregivers Providing Complex Chronic Care and in an earlier publication in the "Insight on the Issues" series, Employed Family Caregivers Providing Complex Chronic Care.

"The challenges spouses who are caregivers face are daunting," said Susan Reinhard, Senior Vice President and Director of the AARP Public Policy Institute and co-author of the report. "Nearly three-quarters of the spouses they care for were taking five or more medications, which are not easy to coordinate. And some of these medications were administered in nonpill forms, including injections and infusion pumps, with greater frequency than one might expect."

The report notes that it is unclear why spouses receive less help, hypothesizing that it could be choice, lack of awareness about resources, financial limitations, or fear of losing independence. The report calls for additional research to help tailor interventions that support but do not supplant the primary bond between spouses.

"As a former spousal caregiver, I certainly understand the desire to take care of all of a spouse's needs," said co-author Carol Levine, Director of the Families and Health Care Project for United Hospital Fund. "But the care that is needed and the responsibilities thrust upon family caregivers by our health care system—typically, without adequate support—are more than any family caregiver, particularly an older spouse, can handle alone."

Sarah Samis, Senior Health Policy Analyst at United Hospital Fund, was the third author of the new publication, along with Susan C. Reinhard and Carol Levine.

There are more than 42 million unpaid family caregivers in the United States.

Family Caregivers Providing Complex Chronic Care to Their Spouses is available athttp://www.uhfnyc.org/publications/880975 and http://www.aarp.org/home-family/caregiving/info-04-2014/family-caregivers-providing-complex-chronic-care-to-spouses-AARP-ppi-health.html. The earlier report Home Alone: Family Caregivers Providing Complex Chronic Care is also available, athttp://www.uhfnyc.org/publications/880853 or www.aarp.org/homealone. The earlier "Insight on the Issues"

publication *Employed Family Caregivers Providing Complex Chronic Care* is available athttp://www.uhfnyc.org/publications/880949 or http://www.aarp.org/home-family/caregiving/info-11-2013/employed-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.html.

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