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have cognitive impairments that make them forget their medication. Further, older women and their physicians may recognize that the absolute survival benefit of treatment decreases with shorter life expectancy, so the balance of benefits and side effects becomes less favorable for women who are older and/or have life-limiting comorbidities. Younger women may be less willing to accept the menopause-like side effects the drug can cause. But more research is needed to really understand what causes women to stray from their treatment plan, says Partridge.

“There are lots of reasons why people don’t take their drugs, some of which are modifiable,” she explains.

For instance, people who often forget their medication may benefit from pill diaries or pill boxes to help them keep track of dosages, Partridge points out. Scheduling refills to coincide with other regular activities (monthly bill paying, quarterly oil changes) is another suggestion she offers patients. Refill reminders from pharmacies and insurance companies can also help women stick with their medication. Financial assistance programs from drug companies and other sources can help women who otherwise might not be able to afford their full course of treatment.

Side effects are another area where effective interventions are available, Partridge says. Hot flashes may be helped by vitamin E or SSRI antidepressants. The musculoskeletal complaints common to aromatase inhibitors can be addressed with NSAID pain relievers. Vaginal dryness can be ameliorated with over-the-counter remedies.

But patients and doctors need to talk about these issues if they hope to address them, Partridge says. Patients need to mention such problems to their doctor, and doctors should ask patients, too.

“I think on an individual level, the best thing a physician can do is consider the possibility of nonadherence and ask patients in a nonjudgmental way, ‘How’s it going, are you remembering to take it, is it causing problems?’” she says. “The more communication there is, the better we are able to identify problems with adherence and intervene.”

END-OF-LIFE CAREGIVING OFTEN LIKE A FULL-TIME JOB

Caring for a loved one at the end of life can require as much time as a full-time job, according to a recent study. This intense level of caregiver involvement points to the importance of incorporating such caregivers into the health care plan for dying patients, according to researchers from the Johns Hopkins Bloomberg School of Public Health.

“In three-quarters of the cases of disabled older adults who die, there is a family member involved and typically providing high levels of assistance,” observed lead researcher Jennifer L. Wolff, PhD, Assistant Professor of Health Policy and Management. “I think our medical system needs to better recognize and support family members’ important contributions to patient care.”

Wolff and her colleagues analyzed data from the 1999 National Long-Term Care Survey and its Informal Caregivers Survey. Their findings were published in the *Archives of Internal Medicine* (2007;167:40–46).

The study included 1,149 primary informal caregivers, mostly spouses (41.5%) and children (39%), of people with severe chronic disabilities who needed assistance with activities of daily living (bathing, dressing, eating, toileting, etc.), as well as household tasks (shopping, laundry, cooking, money management, etc.). The caregivers were stratified according to whether the person they were caring for died within the following 12 months or not. Although the study did not stratify care recipients according to disease, the cohort did include cancer patients, who were disproportionately represented in the group of patients who died, Wolff said.

Caregivers of a person who died within 12 months reported spending a mean of 43 hours per week helping their loved one. The vast majority (84.4%) provided daily assistance. End-of-life caregivers commonly reported problems such as interrupted sleep, providing care when they themselves did not feel well, and worry over leaving their ill loved one alone. Compared with caregivers of patients who survived, bereaved caregivers also reported more emotional (28.9%

versus 14.6%, $P < 0.001$) and physical strains (18.4% versus 10%, $P < 0.05$). Yet less than 5% of caregivers reported using services like support groups or respite care to help ease the caregiving burden.

Experts in caregiving say it's no surprise that caring for a dying loved one takes so much time, particularly if that person is dying of cancer. Cancer caregiving is most intense when a patient is first being treated and at the end of life, said Youngmee Kim, PhD, Director of Family Studies at the American Cancer Society (ACS). Family members are the primary source of support for cancer patients, and the tasks required of caregivers can be very complicated because cancer typically involves an acute phase that requires intensive involvement of family caregivers with little advance notice and training.

It's also no surprise that caregivers didn't take more advantage of services intended to help them, said Greta Greer, MSW, ACS Director of Survivor Programs. It can be difficult and time consuming for caregivers to correctly identify, and then locate, the services their loved ones need; there are few resources, even educational materials, geared to help caregivers learn what they need to know, she said. Many would benefit from the services of a case manager or oncology social worker who could assess the needs of their loved one to determine what services should be provided, along with cost and coverage options.

"Informal caregivers don't know what questions to ask or where to go for information," she explained. "They need help with communication skills, information-seeking skills, and self-advocacy or negotiating skills. And they need emotional support to ensure they understand the importance of self-care as a caregiver. Right now the system isn't set up to provide this as a matter of routine; it's hit or miss at best."

Physicians and other professionals on the cancer care team can be valuable sources of this type of information, said Kim. Other caregivers can also help, said Greer, who directs the ACS Cancer Survivors Network (CSN), an online community for cancer survivors, caregivers, and others affected by cancer.

"A lot of people join CSN to find other people who have been there for that very reason—to get that 'What do I do?' question answered and get practical tips about what helped them," she noted.

Although end-of-life caregivers reported more challenges and burdens than caregivers of people who were not dying, they were no less likely to report emotional rewards from their caregiving duties, Wolff and her colleagues report. Around 70% of end-of-life caregivers agreed or strongly agreed that caregiving "makes me feel good about myself" and "enables me to appreciate life more."

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