

# Chronic disease care: Family helpers play key roles, but feel left out by providers

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People with diabetes, heart failure and other chronic diseases often live independent lives, without a traditional 'caregiver.' But many of them have a family member or friend who plays a key supporting role in their health care.

A new study finds that many of these [health](#) supporters' wish they could understand their loved one's condition better, or get more involved in helping them navigate a long-term illness. But it also reveals that many aren't getting the information or access from [health providers](#) that could help them do that better.

In a paper published in the journal *Families, Systems and Health*, a team from the University of Michigan and University of Pittsburgh reports the results of a national survey of more than 700 adults who said they helped at least one adult [family](#) member or friend manage a common [chronic illness](#). The survey focused on those who assisted with tasks related to medications, medical appointments, health care forms and cooking healthy food.

The results suggest that there's a pent-up need for health care teams to involve such supporters more in their loved ones' care, if the patient is willing.

"A lot of people who are providing this kind of care don't think of themselves as caregivers, but the average adult with chronic illness gets a lot of support from family and close friends," says Ann-Marie Rosland,

M.D., M.S., who co-led the study while at U-M.

"Past studies have shown the people with chronic conditions who have more support from family and friends are more successful in managing their health," she says. "So it's important to understand more about what these health supporters are actually doing, and what they need from [health care providers](#)."

## **Time and effort - at home or from afar**

The team, based at the U-M Institute for Healthcare Policy and Innovation and the VA Center for Clinical Management Research, explored data from health supporters who helped at least one adult loved one manage at least one chronic condition from a list that included diabetes, heart diseases, [chronic lung diseases](#), depression and arthritis.

On average, these health supporters spent two hours a week helping their loved ones with health matters, the majority of them doing it outside the patient's home and half from a distance of more than 20 miles away.

Just over 20 percent went into the examination room at their loved one's health appointments, and an equal percentage spoke to their health provider on the phone.

The supporters were a mix of patients' parents, spouses, siblings, other relatives and friends; just under 7 percent were the patient's adult children. Most were over age 50. Many health supporters reported helping with issues critical to patients with chronic disease.

Nearly half said they had talked with their loved one about the side effects of their medication, and nearly a third said they had talked about problems paying for those medications - both key issues that can cause people with chronic illness to cut back or stop taking important

medicines that can ward off problems in the long term. Three-quarters had talked to their loved ones' about bothersome symptoms such as pain.

"We were surprised by the extent to which these chronic disease health supporters are in a position to be able to provide support for key aspects of health care, and the sheer amount of help they provide," says lead author Aaron A. Lee, Ph.D., a postdoctoral fellow at the VA CCMR. "But we were also surprised by their concerns about not being involved" in their loved ones' care by health providers.

For instance, 41 percent of the respondents said they didn't feel they knew enough about their loved one's condition and treatment regimen to be able to help them as much as they needed. And only about 12 percent worried that they were getting too involved in their loved one's health.

## **Connecting with health providers - or not**

The researchers then focused on the 45 percent of supporters who said they had had contact with their loved one's health providers.

While more than two-thirds of these supporters said that their loved one's [health care](#) providers had answered questions for them, just under half said those providers had involved them in decisions about their chronically ill loved one's health or suggested ways they could help. And about a third said providers had not been willing to share information with them, perhaps missing opportunities for the providers to hear about side effects and symptoms they'd noticed.

Rosland notes that providers may shy away from involving non-caregiver [family members](#) in these ways because of time constraints or concerns about privacy - or because they never asked the patient if someone close to them helps support them.

Just asking this question, and asking whether the patient wants to bring that person to an appointment or allow the doctor or nurse to talk to them, is an important first step, she says. The federal health privacy law, called HIPAA, allows patients to designate individuals who are allowed to receive information about their condition and care.

## **Improving communication**

With online access to individual medical record and appointment systems becoming more common, this kind of access can help even family members who live miles from their loved ones be effective health supporters, Rosland notes.

But providers' office staff and others must be trained to ask patients if they want to grant someone access or the right to receive information in other ways. Such questions could even be added to the screening questionnaires that increasingly ask patients about 'social determinants of health', and other aspects of their lives that could affect their ability to care for themselves.

Patients who are competent to manage their own care should always have the right to decide what kind of family involvement they want, Lee and Rosland note. That includes young adults whose parents helped manage their chronic conditions when they were minors, but now have the legal right to make their own decisions about whether they still want that involvement.

For patients with complex health conditions who desire family involvement in their care, "health insurers could consider reimbursing providers for phone or in-person encounters with patients' family members," says Rosland.

Providers that receive additional payments for population management

or care coordination could use some of those resources to coordinate care with health supporters who are playing key roles in chronically ill patients' health management.

Once family members and friends are involved in a patient's chronic disease management, they may need training and support to help them have the most positive impact on patients, the researchers note.

For instance, learning how to talk to a parent about her diabetes, or help a spouse manage his heart failure-related medicines, could improve the quality of the support family members can give. Lee is studying the impact of communication styles used by family members on the health outcomes of patients, and Lee and Rosland are leading studies in the VA to examine the best ways to design this type of training.

**More information:** Aaron A. Lee et al, Family members' experiences supporting adults with chronic illness: A national survey., *Families, Systems, & Health* (2017). [DOI: 10.1037/fsh0000293](https://doi.org/10.1037/fsh0000293)

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