



# Helping the forgotten soldiers of healthcare

By Peter Aran, M.D. | August 17, 2017

As more aging Americans become chronic care patients, a new challenge confronts U.S. healthcare. Unfortunately, it has not gotten the attention it deserves. That problem: educating, guiding and assisting the millions of people who hourly and daily care for our patients once they have been discharged home.

These are not home health nurses or the resurrected “Marcus Welby” physicians you have read about making house calls. These are lay people who have not had one day of formal medical training. You know them – they are your parents, your grandparents, your siblings, your kids, or your neighbors. For non-medical people reading this, “they” might even be you.

The *lay caregivers* I’m talking about aren’t paid to do this crucial job. They’ve never gone to medical school, nursing school, or pharmacy school. It’s not as if someone can wave a magic wand and transform someone who is a shoe salesman, a farmer, househusband or housewife into a nurse or physician with 20 years’ experience.

Yet we in healthcare, and society in general, expect these lay caregivers to care for sick people who only hours, days, or weeks earlier had been patients in

intensive care units, medical-surgical floors, skilled nursing facilities or nursing homes, cared for by trained professionals.

The amazing job lay caregivers do is a testimony to their resiliency – and that of our patients. But they are not fully prepared and trained to accomplish what we ask of them.

How big of a problem is this? Let me give you three numbers to mull over: 40 million, 2.3 million, and 37 billion. The first number, 40 million, represents the number of lay caregivers in the U.S. today, caring for a friend or family member on a routine basis. The second number, 2.3 million, reflects the sub-group of lay caregivers who have had to quit their jobs to perform these caregiving tasks.

And the third number, 37 billion, represents the number of hours that these medical Good Samaritans provided in care to these sick patients with multiple or chronic health conditions this past year.

It is concerning that we have handed off this great responsibility to lay caregivers – in effect, saying, ‘Here’s the ball, now run with it.’

## A cultural shift

We all understand that care extends beyond the walls of doctor's offices, hospitals and nursing homes, and into the home. That's why lay caregivers are a vital part of the continuum of care and should be acknowledged as such.

But expanding the concept of the healthcare team will require an educational and cultural shift. We could start with three ideas:

First, trained caregivers need to come to an agreement about who is responsible for the education of the lay caregiver. Currently, the physician, nurse, and hospital social worker attempt to accomplish this challenging task. Unfortunately, their combined efforts do not always result in the level of understanding that most lay caregivers need and earnestly want.

Lay caregivers need a daily lifeline, whether through care managers, nurse navigators, or other members of our trained caregiver teams. They do not ask, and I am not suggesting, that they be financially compensated. But they want more guidance in how best to provide that care to their loved ones.

And healthcare professionals must ensure that the people lay caregivers are watching – our patients – aren't experiencing un-noticed clinical deterioration or reacting to their multiple medications in adverse ways.

Second, lay caregivers need emotional support. We are appropriately directing more attention to doctor and nurse burnout. But in reality, all of our caregivers, pharmacists, social workers, healthcare administrators are susceptible to this, and certainly our lay caregivers. Much more needs to be done to help them all.

Third, lay caregivers need better care coordination. Hospitals call their patients to check and make sure they understand complicated discharge plans, are taking their medications appropriately, or have a follow-up visit planned. In some cases, a nurse from the doctor's office calls with the same intent. And nurses from payers call to check on how their members are doing.

So it is not unheard of that a patient might get three different calls after leaving the hospital. Healthcare needs to reduce that redundancy and increase communication – particularly for patients with multiple chronic conditions.

That communication should extend through a whole community of support. Home health nurses provide tremendously valuable care, but there are not enough of them to see any but the very sickest patients. What about the rest? Can we better engage the pharmacist? Can we better integrate churches, YMCAs, and other non-governmental organizations as part of our care team? Can we tap into human resources like retired doctors, nurses, and pharmacists?

And if we can, who will coordinate all of this care?

## New models for team-based care

There are already some initiatives in place designed to help. In Oklahoma, doctors, hospitals, nurses, pharmacists, social workers, physician practice administrators, and payers are participating in a number of national care delivery improvement programs predicated on team-based care. These are led by the Centers for Medicare and Medicaid (CMS) and designed to improve coordination of care. Doing this while delivering evidence-based care results in improved patient outcomes and lower costs.

The CMS projects include the Comprehensive Primary Care programs (CPCI and CPC Plus), the Oncology Care Model, the Beacon Community Grants, the Accountable Health Communities' program, and Healthy Hearts of Oklahoma with the Agency for Healthcare Research and Quality.

In addition, many primary care and oncology practices have adopted the tenets of the Patient Center Medical Home movement. All of these programs share certain basic components that would help the lay caregiver:

- Risk stratification, in which the sickest patients are cared for by a dedicated group of nurse navigators who practice "proactive" instead of traditional "reactive" healthcare

- Real-time access to electronic medical records for all caregivers
- Care quality goals agreed to by caregivers and participating payers
- Better engagement for family members who serve as “care extenders” for the traditional lay caregivers who are doing their very best.

Unfortunately, only a small percentage of healthcare organizations take part in these initiatives.

Lay caregivers are too often the forgotten soldiers, and sometimes heroes, of our healthcare system. And their workload is only expected to intensify. By 2037, the number of Americans needing this level of care is predicted to double. But no one is expecting us to have twice as many doctors and nurses in that time.

So the solution to the looming lay caregiver healthcare crisis needs to occur now.

Tonight I want you to look into the mirror before you go to bed. The person you see looking back at you may well be one of those patients needing a lay caregiver in the next 10-20 years. The gravity of that possibility should be sobering to all of us.

And if you don't see this as a problem, go back and look more deeply into that mirror.

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