

Work, Data and Storytelling: An Interview with Barbara Sutton, APRN, ACHPN

In order for the home-based primary care (HBPC) movement to grow, healthcare providers need to be excited about the possibilities, and trained to provide home-based services. The daughter of a cardiologist who occasionally provided house calls, Nurse Practitioner Barbara Sutton has long understood the importance of seeing patients in their homes.

We've been lucky enough to talk with Barbara several times. We find her commitment to HBPC, and her observations about the changing medical field, inspirational. We recently talked to Barbara about some of the challenges the field faces, and what motivates her to keep working towards the goal of making home-centered care available to everyone.

What do you see as the biggest barriers to providing home-based primary care?



The biggest barrier is a lack of societal and industry support. The financial challenges of health care are a big deal. Often times, medical management and surgical management are equivalent in outcome, but doctors and hospitals make money off of surgical management and not medical management. We do things to people because they're quick fixes.

Patient expectations also play a roll. For two generations now we've trained people to call 911 and get fixed, or to ask your doctor about pills. People expect quick fixes, and as a society, we aren't willing to pay for the things that will help people stay in their home. Unless we're willing to change the way we look at people, it's going to be hard.

Here's an example. For a brief time I worked for a for-profit community based palliative care company. A conversation I had with a case manager drove home the thought process I'm in rebellion against.

The patient was an ex-drug addict, living in downtown Chicago. She was in her 60s, very poor, and oxygen dependent. When the company took over her care I called to say, "We need to get her more oxygen."

The patient lived on the second floor of the building and had to take two buses to the grocery. So each grocery trip involved stairs, two buses, and blocks of walking. The bus rides alone took her 40 minutes, which used up one oxygen tank. So, when she

goes to the grocery, she needs to take two tanks. Because she has to carry the tanks, she can only buy a limited amount of groceries, meaning more frequent trips.

When I explained all of this, the case manager asked, "Why does she have to go shopping so often?"

The mindset is that she should consolidate her shopping. She's a high-cost patient and that's how they come at it, which is backward. We're shortchanging care and endangering health.

Naturally, the patient went to the ER because she didn't have enough oxygen. It would have cost less, and improved her quality of life to give her another oxygen tank, or even, pay for her to take a cab to the grocery store.

When you extrapolate that mindset, you see why we're in trouble. We have to change our thinking on this.

What gives you the most hope for the future of home-centered care?

The biggest hope is that there are more and more people who really want to help people in their homes. Healthcare professionals are looking around and looking at the best ways to take care of people. Hospice care keeps people at home better than any other program. Home healthcare keeps people where they want to be as they age. As stories come out, as we tell our stories about our moms and dads and our patients and how they're helped by someone coming to the house, that's what helps.

The other help is that we're keeping data, which is huge! The VA does great work with keeping the data and it helps. It looks like a lot of money to send a doctor and a social worker to see someone, but by keeping the data, we can see that we're actually saving money by not telling people to go to the ER.

Work, data, and storytelling, they give me hope.

How has working in home healthcare changed you personally and professionally?

Being in homes has made me appreciate people. It is awe-inspiring to meet the maintenance man who brings food to a bedridden woman with mental illness, or the daughter who sacrifices her life to care for her dad, or to see the courage needed to care for your dying wife and care for and prepare the kids, or the elderly couple married 65 years who are so much in love. It is truly an honor to be able to help people do that. When the healthcare system sees people, it is at a hard time, and it is difficult to think of them as young and vibrant. To imagine them in love, holding a baby, working, living. In their home I can see the pictures, the artwork, the furniture, the travel, even the colors they love.

Being able to look at who they were before I see them is humbling. I met a couple that had been professional dancers. He was the only one who could guide her so she could walk, because he used a cue from their career. I've met a National Geographic photographer, authors, poets, teachers, doctors, nurses (horrible patients and I anticipate being one of the worst), moms and dads, engineers, pilots, and more.

I met a man caring for his dying wife. When I asked the standard "how long have you been married?" he answered 60 some years, then asked me to guess how long they had known each other. They had been born in a remote African village where their parents were missionaries. He was one day older than she was. He was literally losing his life long friend. I got to support him through that.

I have become more political as I see the challenges faced every single day by patients and their families. Healthcare is so dependent on our elected officials, from insurance coverage to caregiver support to equipment to medications and everything else. We have to step up and fight for their rights and dignity, and educate others to do the same.

I go home every day knowing that I have an amazing job, and I do make a difference for people. Their choices are not always what I would choose, and I worry about the outcome for some, but I know that I help people really think about what they want, what kind of medical care they want, how it will affect them, and share that with their families.

Sometimes the best thing I can offer is a hug, a touch, or a few words of support.

So, how has making house calls changed me? It has made me:

- More humble and appreciative of people in general, and of my family.
- More political, so more of us can do this for more people.
- More careful of myself, so that I can keep on doing this without burnout.
- More proud of what I do, knowing that I make a difference every day, and that small things are huge at the right time.

If you find Barbara as inspiring as we do, be sure to [watch](#) a segment of our interview with her.