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“I Can Take Care of Myself!”—When Patients Who Need Home Care Say “No!”

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Home health care is very powerful medicine. Its alchemy takes place at the unique intersection of expert clinical care and informed, independent healing. It is often life-saving and nearly always transformational for both the patient who benefits from it, and the trained experts who deliver its personalized, diverse and highly skilled services.

I have seen home health care restore independence to a 102-year-old woman who wanted nothing more than to carry morning tea to the table herself, so her visiting nurse and physical therapist outfitted her walker with a tray. I've seen home health care deliver relief to a young first-time expectant mother who was overwhelmed by, of all things, a mouse in a mousetrap, which her visiting nurse disposed of safely. I've seen a severely depressed man noncompliant with his prescribed diabetes care—and a smoker, to boot—turn his life around with the help of a patient and persistent home care nurse. “Thank you,” he said on a recent follow-up visit. “I don’t know what I would have done without you.”

Every day on the home care frontlines, I see quality of life transformed and peace of mind restored to countless New Yorkers—especially the frail elderly—in the familiar comfort of their own homes. So I read with special interest a [recent study, which](#) found that 28 percent of 495 eligible patients refused post-acute care services (including home care) when they were offered.

Reasons included a fear of losing control and privacy, concerns about finances, and the belief that family caregivers alone were both skilled and had time enough to do the job. The study, led by my colleague Kathryn Bowles, at the [Visiting Nurse Service of New York's Center for Home Care Policy and Research](#) and the [University of Pennsylvania School of Nursing](#), is part of a report by [United Hospital Fund](#) and the [Alliance for Home Health Quality and Innovation](#), exploring the under-examined issue and ramifications of eligible adults who refuse prescribed home health care.

Knowledge Is Power

According to the study, in most cases, people resist home care to their own detriment. Those who refused home health care were twice as likely as those who accepted it to be readmitted to the hospital within 30 or 60 days, the report found.

So why resist? The report's title speaks volumes: **“I Can Take Care of Myself!”** quoting a typical patient response in refusing care. This refusal, typical as it may be, reflects a misperception of what home health care is all about. Indeed, home care has as one of its central goals creating the conditions in which a patient *can* take care of him- or herself—safely, soundly, and on a path towards greater independence.

Home health care workers, who include nurses, physical and occupational therapists and social workers, use a variety of interpersonal skills and professional expertise to create those conditions, beginning with educating the patient and family caregivers about the illness or injury at hand, and being mindful of symptoms that indicate a worsening condition. For the recently divorced diabetic smoker in his sixties mentioned above, Nurse Huda Scheidelman mixed compassion, tough love and plenty of facts and information about how smoking and failing to take his insulin was preying on his system and cheating him of a chance to live life to its fullest.

Similarly, when Jane Sadowsky-Emmerth, RN, a clinical case manager with the licensed home care agency [Partners in Care](#), arrived to teach her patient with ulcerated colitis how to give herself blood thinner injections, the 30-year-old business executive's face lost all color. "I can't do it," she said. "I just can't give myself a shot." Without the prescribed four daily injections, the patient would need to interrupt her busy work schedule for regular blood transfusions. So, Jane tag-teamed with the patient's husband to administer the shots until the daily ritual became less daunting and the patient was able to handle it herself. "I don't know how you did it," the patient said, "but you've helped me relax and understand that this is how I care for myself now. I can never thank you enough."

Understanding the Human Condition

We know that it's not always so easy for people to accept help, to accept that their current health limitations may represent a new normal. That's why visiting care teams are trained to observe, listen actively and be responsive to patients' needs in a way that goes beyond the physical.

"We're like little home care detectives," says Alicia Schwartz, a nurse with [VNSNY CHOICE](#) Health Plans. The detective work, especially for her elderly patients with multiple chronic illnesses and taking as many as 19 medications, often involves managing medication changes and mitigating side-effects and other symptoms. One patient was so averse to taking medications that she often skipped important blood pressure drugs that had been prescribed after a stroke.

"We see resistance to lifestyle changes, like suddenly having to take a full schedule of medications," Alicia notes. "It's not easy to accept that the best that you are going to feel is not as good as you remember feeling when you were younger, but we work to build trust and to educate our patients so they *can* take care of themselves for as long as possible. For my patient, we worked out a plan so that she could take meds in the morning, after meals, and at night. The plan worked just right."

Just Being There

"Often when I visit one of my older patients, I'll be the only person they see or talk to all day," says nurse Lynn Taylor, who visits patients in their homes across Staten Island. Her goal is to address physical, cognitive and behavioral issues so that her patients have the highest possible level of independence at home and in the community. "We dress wounds and help manage pain and other symptoms, but sometimes I think what's most healing is simply that we show up, listen, and show we care."

The Cost of Refusing Care

The ramifications of refusing home care go beyond personal stories and individual lives impacted. There may in fact be tangible costs when patients refuse or are not offered home health care services, as shown by Dr. Bowles' finding that patients who refused services were more likely to be readmitted to the hospital. At VNSNY, anecdotal evidence consistently shows that patients who accept home health care generally report better quality of life after discharge.

A follow-up report, which recaps an expert roundtable exploring the subject of home care refusals, also contains ideas for closing the gap, including recommendations for improved communication about home health care challenges and solutions, more qualitative and quantitative research into what causes people to refuse in-home care, and policy changes to increase home care access and coordination. It is a comprehensive and extremely timely and thought-provoking investigation.

As America ages and health care evolves and moves away from hospitals toward more community- and home-based care, I hope we will be able to turn the page from a report titled "I Can Take Care of Myself!" to one that borrows a quote from Huda's diabetic patient: "I don't know what I would have done without you."