



# VOICE OF THE CONSUMER

The Importance of High-Quality and Strong Leadership in Geriatric Care

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Our nation's health delivery system frequently does not meet the unique needs of older adults. Wide gaps remain between evidence-based approaches, nationally recognized best practices, and how care is actually delivered for the many conditions that disproportionately affect this population. There is growing consensus about the essential features of high-quality geriatric care that include attention to common geriatric challenges (e.g. medication management, depression, cognition, falls prevention) and care models that embed interdisciplinary care, care coordination, transitional care, family and caregiver support, and self-care support.<sup>1-3</sup>

The Practice Change Fellows program advances the importance of strong leadership as an important enabler of high-quality geriatric care and promoter of consumer engagement leading to true person-centered care. In 2012, the Practice Change Fellows program joined forces with the Health and Aging Policy Fellows program to produce a report entitled, *Engaging Older Consumers in Health Care Design and Delivery*.<sup>4</sup> This report articulates the value of consumer engagement in the design and delivery of health care: What is it? Why does it matter? What barriers stand in its way? and What practical and policy actions are needed to overcome those barriers?

As a follow up to the consumer engagement report, the Practice Change Fellows sought to give voice to those older adults that have benefited from care models being designed and implemented by our Fellows around the nation. To this end, Deborah Neveleff conducted telephone interviews with older adults or their family members who had received care from these models. We wanted to know if the people who received care thought it was better than previous, "traditional" care they had received, and if they could describe some of the features that were particularly noteworthy or meaningful to them. Specifically, we wanted to learn: What language do older patients and their family members use when describing the care they receive? Which aspects of an improved model are most visible to them? What difference does it make – how do these improvements in care affect their daily lives?

The thirteen interviews included older adults with diverse backgrounds and varied functional limitations, chronic conditions and care needs. Four of the stories focused on transitioning from hospital to home, six on mental health problems, two on end-of-life care, and one on self-management of chronic conditions.

<sup>1</sup>Institute of Medicine. *Retooling for an aging America: building the health care workforce*. Washington DC: The National Academies Press; 2008.

<sup>2</sup>Leatherman S, McCarthy D, The University of North Carolina Program on Health Outcomes. *Quality of health care for Medicare beneficiaries: a chartbook - focusing on the elderly living in the community*. New York, NY: The Commonwealth Fund; 2005.

<sup>3</sup>Engelberg Center for Health Care Reform at Brookings. *Achieving better chronic care at lower costs across the health care continuum for older americans*. Washington DC: The Brookings Institution; 2010

<sup>4</sup>Practice Change Fellows, Health and Aging Policy Fellows. *Engaging older consumers in health care design and delivery: summit report*. 2012.

## TRANSITIONING FROM HOSPITAL TO HOME

For hospitalized older adults, the transition from hospital to home is challenging, and is associated with elevated risk of adverse events. Documented problems with these transitions include confusion about medications, lack of follow-up doctor appointments, missed opportunities for connections with available community-based services, and unplanned readmissions. Older adults were interviewed from three different care transition programs, one in Southern California, one in Houston and one in South Carolina. Each of these programs was designed and implemented by a Practice Change Fellow and were designed to incorporate best practices in geriatric care. Patients were suffering from congestive heart failure, diabetes and other chronic conditions. These individuals largely lived alone and had many worries about being able to live at home safely and remain in the community. In their own voices, they describe the best features of the care transition programs and how their lives have been positively impacted.

- Ms. M's son passed away and she faced severe financial difficulties; eventually, she was hospitalized with congestive heart failure. "After my hospitalization, I was in pretty bad shape," she recalls. "A social worker came to the hospital to see me and asked me if I wanted to go to assisted living or go back home. I wanted to go back to my home. She helped me go back and forth to see my doctor, made sure my light bill was paid, and checked to be sure my medications were okay. All of it was so valuable to me because it meant I could go home. At the time, I had no one to turn to. This program improved my life and I sure would recommend it to anyone."
- Mr. L was hospitalized for heart failure and wanted to return home safely. "This program helped me a lot," he says. "I wanted to go home, but I had concerns about being able to care for myself. This program helped me get my doctor's appointments and get my medications all straightened out. The case manager reminded me about my symptoms and taught me how to watch out for my health. The case manager also helped me get insurance. Since this program, my life has improved. I can do a lot of things I wasn't able to do for myself before, like know how to take my medicine and check my weight every day. They gave me a pill box and a little book to help me keep up with my appointments. I would not have been able to come back home safely without this program. It got me on my feet again."
- Mr. G, whose 76-year-old father was hospitalized for a week, believes that the care transitions program had a meaningful impact on his father's ability to return home safely. "My father went into diabetic shock and I called an ambulance to bring him to the hospital," he remembers. "On the second or third day of his hospitalization, I met with the care transitions social worker. She arranged different services for us. For example, his shoulder hurt and she arranged a physical therapy appointment. After discharge, the social worker visited my dad and called him a few times, and she also called me periodically to ask about how he was recuperating. She provided us with diabetes information, and she made sure that he was getting the care he needed; for

example, she recommended an in-house nursing service and physical therapist. This was a positive experience compared to his other discharges.”

- Mr. G received care transition services when he was admitted to the hospital and diagnosed with heart failure. “I wasn’t feeling too good, but I knew I had to get back to my house and take care of myself,” he says. “Someone came to visit me to help me get back on my feet again and guide me through things. She told me what to do, like get some rest, get some exercise by walking back and forth, what foods to eat, and how to handle certain situations. She explained how to take my medications, and also sent a physical therapist to help me walk. If not for this program, I’d probably have gone to the hospital again. I could be dead and gone, but this program saved my life.”

## MANAGING MENTAL HEALTH ISSUES

The strong link between physical and mental health is well documented. Thus, it is no surprise that many seniors find that their medical conditions are accompanied by – and even exacerbated by – mental health issues. Depression is a particularly common experience for seniors, who are often emotionally burdened by issues such as declining health, financial problems, and the passing of loved ones. Unfortunately, many seniors do not have access to mental health services, or are reluctant to accept such services due to the perceived stigma associated with mental illness. Fortunately, there are effective treatments that can be incorporated into ongoing care by clinicians working in a variety of settings, thereby reducing the barriers posed by access and stigma. Three Practice Change Fellows -- a nurse, a social worker and a physician located in New York, Chicago, and Baltimore -- drew from the evidence to implement interventions that improved depression diagnosis and treatment for the seniors they serve. What follows are the stories of six seniors who describe how receiving mental health care has improved their lives. The first three patients received help from trained, adult mental health nurse specialists who practice in a home health agency. The fourth story describes services provided by a clinical social worker and tailored for Spanish-speaking older adults, many of whom are trauma victims. The final two stories relate the experiences of two patients in a primary care clinic.

- Mr. D had an automobile accident leading to a five-month recuperation in a rehabilitation center, a difficult time that was then followed by his brother’s death and hospitalization for a cardiac condition that required the implantation of a stent. “I told the hospital social worker that I was depressed and had trouble figuring out how to take all my pills, so she recommended sending a visiting nurse to my home,” he recalls. “At first, I was reluctant to let the mental health specialist into my home because I was anxious, depressed, and tired of seeing doctors and nurses. But I opened the door and let her in. By talking to her, I found that I was venting out some problems that were bothering me, and our conversation was very helpful. She offered very practical advice. She made so many suggestions, such as going to community centers and taking walks – even if it was just to the corner – on a nice day. She told me to get out and see people.

At the same time, she helped me with my medications and helped me find a maid service to clean my home. Her visit made me feel more alive, and I felt much better. This service definitely improved my life. She helped me regain my health and got me out into the world again.”

- Ms. S had a mastectomy and is undergoing chemotherapy, an experience which has made her “very depressed,” she says. “Even though my physical problems eventually lessened, I found that I was still depressed. My visiting nurse thought it would be best to talk to a psychiatric nurse to help get me through this. She has been very encouraging throughout my chemotherapy treatments, which are a struggle – even worse than the surgery. She makes certain practical suggestions to get me through the side effects of treatment, but more than that, she is just extremely comforting, understanding and sympathetic. She gives me a lot of her time. Her help has alleviated my depression symptoms. After a chemotherapy treatment I still feel down, but when she comes to see me, I feel ‘up’ again. She gives me hope that things will eventually get better.”
- Ms. N originally had a visiting nurse to help her with medical issues, but she has found that behavioral home health services have helped her immensely. “I have a lot of issues. I am disabled and in a wheelchair, and I have money problems. It was getting very scary and everything felt overwhelming. Even though I have a lot of medical issues, the doctor said I am really not that sick, but I felt like I was going to die every minute. He decided that it’s my nerves. One of the nurses asked if I had ever considered having someone come in to speak to me about my worries. I started a regimen of antidepressants, and a mental health specialist came to see me. We discussed what’s bothering me. When I talk it out, she makes a lot of sense and I feel much better about everything. I have friends who are sensitive and caring as well, but she is a medical professional and so she has practical advice that I respect. She puts me at ease. My friends can’t do that.”
- Sra. V found the support she needed through a Spanish-language trauma treatment program. Several of Sra. Vazquez’s family members passed away within a short timeframe and she was unable to attend any of the funerals, which were held in Mexico. “I felt like I was starting to forget them, which was very distressing for me,” she says through a translator. “After all this happened, I held my feelings inside and everything began to weigh on me very heavily. I felt physically and emotionally sick. I was like a wilted plant. I found the group counseling to be very helpful. This helped me get rid of the things I had been holding inside and helped me lift myself up more. For example, we did exercises on concentration and meditation that helped me feel more peaceful. Counseling also helped me to relate to other people who also had troubles. Before, I never wanted to be in the company of others, and I felt isolated. Now, I am very active with my neighbors. The group has really affected my life in a positive way.”
- Ms. P recalled feeling “a lot of stress” in her life. Fortunately, her physician had initiated a new service that folded mental health screening and treatment into the primary care setting. “The doctor talked to me and she gave me some questionnaires to fill out. She told me to stop worrying so much and gave me some medication, which is working

pretty well. I take my medication every day, on time. The most valuable thing has been that she talked to me, because she was very sensitive to me and my concerns. She is a good doctor. She gave me good advice. It was better than talking to my family or my friends. My life has improved because before, I didn't want to do go out, but now I go places with my grandson, like out to dinner."

- Ms. L was depressed because she was "dealing with the same situation for a long, long time," she said. "Nothing ever improved, and I realized that my circumstances were going to continue as they were. I did not see any way out of it, and I did not know how to cope with the situation. I felt very depressed, and my depression deepened even though I put on my 'game face' for others around me. Ultimately, I couldn't hide it anymore, and eventually I didn't want to do anything but sit. I even contemplated the idea of ending my life, but I realized that I would be doing harm to those around me who I loved. When I went for a visit to the doctor, she increased my antidepressant medication and arranged for me to talk to a therapist right away. With these interventions, I was able to learn to cope with the situation and change my thinking. My quality of life is now much better. I have come to the realization that certain things cannot be changed and I am more accepting of that fact. I am more engaged in my life now and more able to focus on myself rather than my worries. I don't know how many years I am going to be on this earth, but I am going to try to enjoy the time I've got."

## MAKING END-OF-LIFE DECISIONS

Conversations about care goals for people with advanced illness often occur when a specific decision needs to be made in a crisis, rather than as a proactive effort to understand and document patient and family preferences for all types of care, including end-of-life care. As a result, even when comfort-focused care can best meet the patient's desires; palliative approaches are often not adopted until death is imminent. One Practice Change Fellow – a physician trained in geriatrics and palliative care in Maine -- created a system to facilitate conversations between patients, families and providers so that patients' wishes regarding care interventions could be expressed and documented into the care plan. She systematized the use of the Physician Orders for Life-Sustaining Treatment (POLST) form and developed a process by which the form is used to guide conversations with patients and their families about care choices. Two individuals describe how this approach improved the quality of their parents' end-of-life care and brought peace-of-mind to them and their families.

- Ms. M's mother, who had dementia, moved to an assisted living facility when her father couldn't care for her any longer. "That was very upsetting to her. She seemed haunted – she knew something was wrong, but couldn't figure it out. Eventually, she developed pneumonia, and as a hospice nurse, I know that pneumonia can be a gift. But when I talked to her doctor about maybe not giving her the antibiotics, the doctor looked at me like I was crazy. My mother was given three different courses of antibiotics. She recovered and continued with her life, which seemed pretty harrowing." "After learning

about the POLST form, Ms. Morin asked the geriatrician, who was her mother's new doctor, to arrange a family meeting with her, her dad, and her sisters." "We each said what we needed to say. My dad was initially uncomfortable with choosing non-treatment. But my sisters supported me in what I was trying to communicate, which was the gift of allowing my mother to have a natural death, and my father eventually saw the value in this. My sister, who was the power of attorney for my mom, said, 'I've heard Mom say that she didn't want to be kept alive and in a nursing home.' She validated my beliefs, which was very valuable to me. I don't think we would have had this kind of conversation if it hadn't been for POLST. I wish this conversation had happened much earlier." Ms. Morin's mother passed away in March 2009, and to this day, she says would recommend the program to anyone. "I think that lots of people have strong feelings about their quality of life, expectations and wishes at end-of-life. But if those wishes aren't discussed and documented, they might not be met."

- Ms. R and her family also had a goal of care conversation about the needs and desires of her mother, who is 83, has dementia and has been living in a nursing home since she had a stroke in Spring 2011. "In the nursing home, we had the good fortune to meet a physician who introduced us to the POLST process. We all have advance directives, but I had never heard of POLST before. When I saw it, I recognized that this was very important in terms of making sure my mother's wishes were followed because the form helped me define in a concrete way what those wishes were. The doctor met with me and my partner, my father, and my brother and sister-in-law from California to review the form in order to ensure that we all agreed that the form reflected my mother's wishes. This process gave everyone a chance to talk about it and agree on our approach to my mother's care." Ms. R feels that POLST has been so valuable because it has given her a sense of comfort. "I like to plan ahead as much as possible, but of course these situations cannot be planned," she said. "The goal of care conversation has made me feel tranquil, even though there is hardly anything about this situation that is tranquil or comforting or predictable. At the moment my mother is okay, but if she takes a turn for the worse, I know what to do to meet her wishes and my whole family is in agreement."

## CHRONIC DISEASE SELF-MANAGEMENT

The majority of seniors suffer from one or more chronic conditions – such as diabetes, congestive heart failure, and hypertension – that often require extensive self-manage activities. Living with chronic illness requires these individuals to cope with emotional challenges, negotiate expectations placed upon them by their care team, and attend to lifestyle changes in diet, exercise, and medication management. A program developed by a Practice Change Fellow in Riverside, California facilitates access to Stanford University's evidence-based Chronic Disease Self-Management Program, an evidence-based program that has been repeatedly shown to improve self-management skills and health outcomes.

- Mr. and Mrs. S participated in the Stanford self-management program and enjoyed it so

much that they signed up for a second session. “We needed to get out and exercise and learn about the right foods to eat,” says Mrs. S. “Each week, the program covered a different topic that was important for our health, like exercise, diet and medications. They covered everything we seniors need to be aware of. The program encouraged us to develop a healthier lifestyle. My husband has a pacemaker and he has had a stroke and double vision, and it is hard for him to get around, but he can walk, so this program prompted us to get out there.” Mrs. S says the program helped her and her husband improve their quality of life. “It emphasized that if we need to see the doctor, we should go, rather than just living with our aches and pains.” Mrs. S added that the program was very enlightening and was more helpful than other methods of patient education for seniors, such as written materials or advice from doctors. “The classes made the message more meaningful,” she says. “When you just read about something, you really don’t pay attention to it. But the class leaders, by sharing details of their lives, really prompted us to make changes in our lives.”

## CONCLUDING THOUGHTS

The Practice Change Fellows program has commissioned this report with an explicit focus on the voices of older people whose lives were touched in impactful ways by the work of the Fellows. Care improvements instituted by the Fellows have improved the lives of thousands of older adults and their family members; these stories represent a small sample of the meaningful, real-life impact of the Practice Change Fellows Program.