

## **ONC HIE Hearings: MaryAnne Sterling Testimony**

My thanks to ONC and both committees for the opportunity to speak today.

“I am not getting good medical care”. This is how a conversation began with my 82-yr-old mother, a retired nurse, two weeks ago. Culprit #1: lack of response from both her primary care doc and cardiologist after she called them to report an allergic reaction to medication; and culprit #2: a complete breakdown in communication between primary care doc and pharmacy. The pharmacy could not refill critical medications for almost a week, including heart medication, until re-authorized by the non-responsive primary care doc. Just another day at the office for frustrated patients and family caregivers.

The idea that mom’s primary care doc, cardiologist, and pharmacy are even close to working as a team and exchanging information to improve her healthcare is a work of fiction. Frankly, I would be happy if these three critical components of her healthcare ecosystem would simply exchange phone numbers!

I function as the (reluctant) health information exchange for my mother. I am typically pressed into service when I get the 3am phone call that she has been rushed to the emergency room. Here is an example:

Last year at this time, mom fell and crushed her right arm. Invasive surgery to repair her brittle bones with plates and screws was not an option. After 10 days of caring for her in our home (with no sleep), my husband and I successfully got her admitted to an inpatient rehab facility so she could re-learn how to complete her activities of daily living while she healed -- without the use of her dominant arm and hand.

The nurse assigned to her began the intake process by asking the obvious question: what medications are you taking? My mother, heavily medicated for pain and suffering from mild cognitive impairment, was not able to answer this question with the clarity of years past. I quickly stepped in and presented the nurse with a spreadsheet that I had created, a detailed medication list that included important data like drug name, dosage, and time of day administered. The nurse evaded my attempts to hand her this sheet of paper and returned to her tactic of trying to extract the information from my mother. I chimed in when mom faltered and was all but ignored by the nurse. It quickly became clear: since I was not the patient, I had no credibility.

This painful exercise went on for 45 minutes. Ditto for mom’s medical history. Frustrated by this ludicrous behavior, I found some scotch tape at the nurse’s station and taped my spreadsheet to the wall of her room. I was going to be part of the care team by brute force if necessary. After all, I was the one who would be responsible for her continued recovery upon discharge.

I pre-arranged with the staff to be present at a specified date and time when discharge instructions would be communicated to my mother. When I arrived, I found that the nurse had started without me and was halfway through discussing a pile of paper 35 pages deep. My mother's expression indicated that she understood little, if any, of the information being conveyed. I informed the nurse that we would be starting over again and stood my ground when she protested. I suspect they opened a bottle of champagne when we left.

This is just one of countless stories I could share with you, the culmination of almost 17 years of being an only child supporting my aging parents. Combined, my husband and I have 3 out of 4 parents diagnosed with some form of dementia.

In general, I find that attitudes toward family caregivers are extremely guarded, if not hostile, within the healthcare delivery community. It is rare that I find a clinician who welcomes the information and insight I have to offer about mom's health. I find this mind-boggling since I have been my mom's co-pilot through two battles with breast cancer, countless broken bones, and numerous chronic conditions. I can recite her medical history with more clarity than my own.

When I try to gather and organize mom's medical information and test results, I am frequently met by the HIPAA roadblock that is erected in my path. As Jodi Daniel gently reminded me several weeks ago, this was never the intent of HIPAA! In theory, if I could easily access and aggregate the information from all of mom's providers electronically, I could help identify and troubleshoot potential problems more quickly and effectively, before they become a crisis.

But information alone will not address the people and process issues that we currently face. More importantly, we have allowed a culture of intimidation to become ingrained in the fabric of healthcare. We tolerate poor communication, antiquated processes, the complete absence of collaboration, and the use of complex medical terminology that nobody is willing to translate into "normal-human-speak" for patients and family caregivers. Thus far, new regulation and policy have had zero impact on resolving these issues.

A staggering amount of culture change is needed to re-invent our healthcare system and replace it with a collaborative health ecosystem that is patient-and-family-caregiver-centric. Technology is not the problem. We will soon have mountains of technology in place, just waiting for data to begin flowing. But if we do not solve the people and process problems in parallel with the implementation of technology, we will not have removed the biggest roadblocks to improving our healthcare system, my mom will still be waiting for better quality medical care, and the family caregiver will still be the most underutilized resource in healthcare.