

3-2013

Taking care of Tootsie: Making a place for nurses.

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Recommended Citation

Owen, M. & Bellot, J. (2013). Taking care of Tootsie: Making a place for nurses. Professional Case Management. 18(2), 86-88, doi: 10.1097/NCM.0b013e31828069ed

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As submitted to:

Professional Case Management

And later published as:

Taking Care of Tootsie

Volume 18, Issue, 2, 86-88,

Doi: 10.1097/NCM.0b013e31828069ed

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Theresa “Tootsie” Smoder, better known as my grandma, always seemed larger than life. She bore eight children in nine years (The “Crazy Eights”), raised them almost single-handedly when her husband died and managed a 160 acre farm. Doing whatever it took to create security and stability for her family, Tootsie worked multiple jobs to feed her brood. She was a social butterfly who always tended to others and modeled the value of caring throughout her life.

Tootsie and I had a special relationship. When I was four years old, my mother decided to pursue a graduate degree. We moved in with my grandmother for the summer so that mom could be close to campus. I distinctly remember attending daycare only one day, faking sick and inventing terrible stories about the teachers so that I could stay home with Tootsie instead. Mom relented and I had a fascinating summer of playing the spoons with the senior center band, pulling carrots from the garden and making strawberry freezer jam. Tootsie would mortify my mother by taking out her dentures and flipping them back in upside-down for my entertainment. She waved her flabby triceps (“angel wings”) to convince me she had special powers. It must have been that summer that cemented my close bond to this amazing woman, as we always spoke easily and freely with each other.

As I grew older, I became involved in Tootsie’s medical management. She would regularly send me copies of her lab reports and medical records. We chatted about her latest cardiology consultation like others might chat about celebrity gossip. Following and safeguarding her health was how we shared our love.

In the back of my mind, I knew that Tootsie was mortal. However, her personality was so strong and vital. No matter how increasingly frail her underlying physiological status became, Tootsie was happy, engaging and ready for “the next big thing.” She saw me through three college degrees, a wedding, two children and helped with the down payment on our first home. It seemed she might live forever, always a force to be reckoned with.

Turning the corner

Three years ago, in a slight concession to her declining health, Tootsie moved from Florida to Michigan to be closer to the Crazy Eights, but still lived independently. Bilateral cataracts sidelined her ability to drive. A portable oxygen tank made it difficult to board the bus. No matter, there was always a will and a way if it meant meeting friends for lunch!

All this verve for life came to a startling halt one July afternoon. Stopping in to check on Tootsie, my aunt discovered that she had been feeling “out of sorts.” She was short of breath, with a racing heart, requiring a trip to the local hospital. Upon admission, Tootsie’s heart rate was in the 200’s and showing no sign of slowing. An astute physician noted, due to a medical error, Tootsie had been taking 3.5 times the intended dose of Synthroid for the previous two weeks.

No one knows quite how this happened. Somewhere between her doctor’s medication order and what was placed in the prescription bottle, Tootsie’s Synthroid dose was drastically incorrect. After six cardioversions, a stay in the intensive care unit, and multiple consultations and tests later, Tootsie was exhausted. She went into irreversible congestive heart failure and resultant fluid imbalance, kidney failure, pneumonia and anemia.

In the final five months of her life, Tootsie went home for a total of 2.5 days. She experienced six hospital admissions at two facilities, involving three intensive care stays, six visits to the emergency department, a cardiac catheterization, five units of blood, an upper endoscopy and a startling number of chest x-rays, EKGs and blood tests. She quickly became deconditioned and spent every day that she was not in the hospital as a resident of the adjoining skilled nursing care facility, determined to regain her independence.

Three months into this journey, just before her 80th birthday, she had had enough. After a half-hearted acknowledgement of the error from her physician, Tootsie informed the Crazy Eights that she was done with medications and interventions. Several of her children threw a party for her, saddened at

Tootsie's decision to "give up," but also happy that she still found joy in living. We all took a deep breath, convinced it was only a matter of days until high potassium or low hemoglobin would end the party. Not to be outdone, Tootsie lived for two more months, truly living life by her own rules. The costs, both monetary and emotional, were astounding.

Humbling findings

Watching from afar, I felt as if Tootsie's course was a nightmare of complications and everything I teach my students to avoid. I taught error prevention and disclosure, how could this possibly happen to our family? What did it mean that I taught good communication skills and I could not even convince her physician to call me? How could it be that all of those lessons I taught about palliative care were lost in the care of my own grandmother?

After she passed, I combed Tootsie's medical records. I was looking for something, anything, to make sense of her final months. What I learned was that no amount of industry knowledge on my part could have saved Tootsie from a textbook case of error, difficult transitions in care and unnecessary intervention. Her case was, simply and sadly, quite typical.

Chronic illness and complexity of treatment

At first glance, the stack of medical records was overwhelming. I was shocked. Could it be true that Tootsie was in and out of the hospital that much in such a short amount of time? Sadly, yes. In 2009, it was reported that 27% of Medicare beneficiaries with congestive heart failure were readmitted to the hospital within 30 days. In that respect, Tootsie was right on target! Further, it is estimated that unplanned, 30 day readmissions account for upwards of \$17.4 billion in Medicare spending per year (Jencks, Williams & Coleman, 2009). To be sure, the complexity of congestive heart failure and readmission has no clear solution. Medications are options for some, not all. Sometimes patients change their lifestyles and behaviors, sometimes they don't. Access to follow-up care has complex issues of its own.

Multiple proposals have been initiated to reduce the costs of chronic disease and avoid inpatient treatment and readmission. The patient-centered medical home model and discharge clinics are just two examples. For years, hospitals have used case managers to help ease the transition out of the hospital. Despite these attempts to combat congestive heart failure and other chronic diseases, the burden and cost of chronic disease continues.

A place for case management

In 2010, the Robert Wood Johnson Foundation and Institute of Medicine joined resources and released “The Future of Nursing: Leading Change, Advancing Health.” The RWJ/IOM report seeks to emphasize the relative merits and traditional education of the nurse to support a system of care coordination, effective communication, seamless transitions, chronic care management, disease prevention and maintenance of wellness.

At present, the American health care system is technology and intervention heavy when population demographics are rapidly changing and intervention is not always the right answer. We have a growing need for a system that instead focuses on addressing chronic disease management, prevention and wellness care. Case managers are well-positioned to support a system with these foci, managing care of the older adult in the community, before inpatient care becomes necessary. Specifically in the outpatient setting, coordinated care that is, by definition, proactive, holistic and comprehensive will help shift the focus of care from acute and episodic to chronic and preventive. Attentive, patient-centered home care or outpatient monitoring by a conscientious case manager would most certainly have resulted in pre-emptive error management and prevented Tootsie’s Synthroid overdose from lasting two weeks.

Could robust care coordination and case management have changed Tootsie’s narrative? We will never know. Would Tootsie have been discharged to her apartment if an astute case manager had assessed that it was not safe, nor practical, and that appropriate home care services had not been arranged? Would a stronger communication system have eliminated the potential for medical error and, in one important instance, allowed prompt treatment of a urinary tract infection in order to avoid readmission?

After scouring her medical records, one thing is clear: Tootsie’s course was hardly unique. Frail elders and chronic disease go hand in hand. What we can do to improve quality and increase thoughtfulness in the care we provide is to begin using our case management resources to their fullest extent. We would be wise to use the preventive, holistic and wellness focus that nurses and social workers are trained for and place them where patients are most vulnerable: discharge, home, outpatient management and readmission. I have no doubt that Tootsie would agree.