


PEEP SHOW: THE MAKING OF A GERONTOLOGIST

Denice Goodrich-Liley; Ph.D., Boise State University, Idaho

As a geriatric social worker, the author spent over a decade working with individuals and families as they prepare for the end-of-life. She was convinced that she knew all that was about to happen, only to discover with her mother's death she had missed the moments of life for seeing only the end. This narrative gives voice to an "Aha moment," revealing the complexity of life beyond the roles occupied by an individual.

Prologue



Giggling sounds, animated expressions, and sudden hushed whispers float from the room. A sea of pillows supports Frances in the hospital bed. At her side, Margaret sits close to the head of the bed. For these friends of a lifetime—nearly sixty years—this is their first face-to-face visit since Frances' diagnosis. Intuitively, both sense only too well that it will most likely be their last. Margaret comes for the day, her daughter having driven her the five hours to see her good friend. The women continue where they had last left off. Margaret has been sending letters, inspirational notes, and quotes throughout the summer, and they have talked by phone a few times. Margaret has visited with all her family and the shared friends of the women. The women sit today talking, summarizing their lives, the early joys, the hurts, and the dreams actually happening as planned or that were surprises. The women fulfill an obligation of their lifelong friendship.

A bedside lunch is served for the two friends, a summer meal of chicken salad on croissants, garden harvests of fresh green beans, raspberry pie, and iced tea. The lunch lasts for hours as the friends eat slowly, as though savoring each morsel. Frances pauses to cough, and then they continue to chat. The mealtime experience continues. A glance into the room reveals the two women eating an apple: in shared sacrament fashion, one bites from the apple and then passes it to the other. This ritual is repeated until the two consume the apple. The talking resumes. When I check

in later, both women sleep. The head of the hospital bed is lowered a little, and a few pillows are removed. Next to the hospital bed, slumped in the chair, her feet strewn across the hospital bed and her hand resting on Frances' shoulder, Margaret sleeps. Satiated, both women enjoy a peaceful moment.

The old familiar bedroom of Frances' daughter is now the makeshift center of the dying woman's world. The hospital bed is positioned in the center of the room to allow her to look out into the house as well as to allow others to be able to look in on her. Her last days are lived out in this arena. Family, visitors, and health care providers all enter into the sunlit room to see Frances. Little do they know a voyeur watches and notes their every word and move.

The Drama: The Beginning

May 1994 came as most Mays, a sign of the nearing end of the school year and the beginning of summer. While this particular May began the same as all Mays might, by the time it ended, my life would be forever altered.

My mother age 68, with no major health concerns, had a terrible cough, thought to be pneumonia, while she was on vacation that month. After returning from vacation, she saw her regular physician the Friday prior to Memorial Day. The doctor ran a few tests, sent her for x-rays, and determined that she had a blood clot in a lower lobe of the left lung. Mother was hospitalized. More tests, more questions. Only three months previously, she

had reported for her yearly physical exam including extensive testing, after which she had been deemed to be in excellent health. Yet, my father was now convinced *something* was wrong. The Tuesday following Memorial Day, the family physician told my parents that my mother's abdomen was full of cancer. "What?" they questioned. "She never smoked, she ate good food, she had no bad habits—was not obese, she did not, she was not..." But, yes, there was something wrong.

One could say I had arrived. Credentials read: "Nearly ten years post Master of Social Work Degree. Additionally, ten years full time—and then some—employment as a social worker with a Geriatric Evaluation and Treatment Team for inpatient and home care, as well as with an ambulatory outpatient clinic." I was six years post graduation with my graduate certificate in gerontology. I had completed the coursework for my Ph.D. in social work and was ABD (all but dissertation), working on my dissertation: "Video Enhanced Discharge Planning Education for the Older Adult."

I had a vast amount of experience with families at the end of life, *how-to* approach: discharge disposition from home to hospital to nursing home, nursing home to hospital, and need for *more* care, 24-hour skilled care, and when no care will change the inevitable. I could discuss a family's need to prepare for death, end of life, lingering life, hovering death, decreased capacity of almost any body function. I was an *official* hand holder, shoulder to lean on, a *voice* who could be called to explore all the *what ifs* at the end of life. Options—coping and caregiving—were all commonplace within my world. I was a professional caregiver and supporter who stayed through to the end. But, somehow, these were simply lines on a vita; an education was about to begin.

At the time of my mother's diagnosis, I lived four hours away. She called me that afternoon and asked that I come home to help.

My perceptions of the *help* needed was for me to share with her what I knew about what to do next, to just be there, to listen, and to rally as good families do in crisis. The decision had already been made: FIGHT this with all our might. The family consulted the only oncologist in their small town. He was to see my parents the next day. However, the primary care physician was a family friend and had already spoken with the oncologist who reviewed my mother's case. The *best course* had been determined. At this time, my mother remained her usual cheerful self, hopeful as ever, simply dealing with just a rather large stumbling block. No one in our family had had cancer, so no one had died of cancer. Clearly this was one of those you-get-treatment-and-get-on-with-living-your-life types of things.

Unfortunately, it was not. In a little over a month, the shift to terminal care had been made. My mother returned home only briefly during this first month. I stayed a few days with my parents after my mother discharged from the hospital, but left so they could have some time alone together. While sitting on the patio the first evening home, my mother began to cry. She spoke of knowing how to live, but of not knowing how to die. This was the only time she voiced a fear, an uncertainty of what lay ahead. She did not want to talk, but just wanted to let it out. During this time my parents celebrated their 50th wedding anniversary privately, as they both wished. My father took my mother out for short trips in the car to see a few friends and my two brothers who lived nearby. My mother bought a wig to prepare for losing her hair. I spoke with her daily; she was so full of hope.

Following the administration of a chemotherapy treatment, my father left my mother in the care of a nurse while he went to bring their car around to get her. The nurse escorted my mother in a wheelchair to the front of the



hospital where my father was to pick her up. In the interim, my mother suffered a stroke, which seemingly went unnoticed by the nurse. My father was insistently clear that this was not his wife of fifty years whom he had left only moments before. Something had happened. My mother was returned upstairs to the hospital. My mother, who lived life to the fullest, would not be jumping this bump or returning quickly to her roles and living her life.

The Middle

My mother's complications moved her care to a holding pattern. She needed to be stabilized and re-evaluated before receiving more cancer treatment. My mother was transitioned to an in-house rehabilitation unit, which was a combination of extended care and rehabilitative services. I complimented myself for doing the best discharge planning, family conferencing, and resource developing of my geriatric social work career. I prided myself on knowing what was coming next, for preparing my father and two brothers and their spouses along the way. During my mother's stay—less than 14 days—I worked full time on her *case*. The local hospital staff appeared grateful not to have another family to deal with. The oncologist would start to talk, and I would interpret for my family what this meant in terms of my mother's care.

My health care career had prepared me for working with the difficult families, physicians, nurses, and outcomes. I found myself overdoing to help everyone to understand what was happening, what one day's tests would tell about the care for the future. I saw what hope looked like from truly rational individuals I knew: they wanted magic. The doctor would speak, and it was as though my family no longer understood the English language. They were sure messages other than what they had heard had been given and that some additional tests could provide different answers. Denial could not accurately describe

my father's state of mind. This rational, pragmatic individual could not understand how the doctor could consider discharging my mother when she could not walk, was now incontinent, seemed to be thinking fuzzy most of the time, and was in such poor health. He had believed my mother would stay until she was better. To him this meant the way she was when she initially came for treatment. At first, it seemed the cancer took a back seat to the crisis of my mother now requiring full-time care. Then the third strike came: the oncologist and family physician concurred that aggressive treatment of the cancer was not an option and that comfort care was the more appropriate course to take.

The art of addressing hospice services with my family was just that—an art: the nuances of discussing *terminal*; the prognosis of less than six months; and the shifting from “We’re-gonna-fight-this-and-win” to “consoling, a retreat of aggressive care” to “compassionate care.” To this day, I know my father never gave up hope for a miracle, a cure, or just a plain mistake, that it was not happening. However, he reluctantly accepted the notion of hospice services, as I had seen in other families, saying only “if it will help your mother.” But the agreement was tentatively held together by “We’ll see if we really need it”—a pledge of day-to-day hope. The logical father I had always known was emotionally lost. He had no role models for the life he was now living.

The Ending

It was a long hot summer. My mother received at-home care for over three months. She left the world gradually, shifting from directing activities to having the day's activities centered around her care and needs. The care was neither remarkable, nor difficult, physically or emotionally. It was just long. I had never participated in day-to-day care, 24/7 as referred to in caregiver support literature. I grew weary of juggling her physical care

needs with the emotional needs of all the rest of the family. The hospice agency assisted in all aspects, but could not take my place as daughter or as experienced geriatric social worker—this was my profession. She died in the early morning, Saturday before Labor Day. My father was at her side—knowing when she took her last breath.

The Chorus

You are certain, I suppose, that I lay claim to the champion phrase, “Now that I have walked the walk,” or “Since I have been there, I now know the reality of end of life.” Or perhaps you assume that I now feel I have such great insights about truly knowing what families experience at the end of life. No, I do not have anything that dramatic to say, nor did I experience such.

What I did learn seems so big, yet so obvious—something I had never considered, really, nor knew I did not know: I learned of my mother’s world as I observed her those months with her friends—her interactions, sharing, secrets, laughter, tears, perhaps all uninhibited as a result of the stroke. But more likely, I learned she was living her life as she was dying. Authentic to her world as a human being, she was no longer concerned or bridled with her roles of being a wife, mother, grandmother, faithful church parishioner, and community volunteer. Her focus was not on caregiving to all the world. I was able to see her as a person totally separate from me and the life she had given me.

Many times during those three months, I was an outsider looking in, as though a voyeur at a peep show—my mother apart from me, her family, her responsibilities, and her obligations. Television, movies, and novels are all filled with experiences of children learning of their parents’ secret lives. This was no secret. This was who she authentically was, but her daily life had overshadowed it. I watched, observed her interactions unnoticed. Mother was unaware that I was there or that I was

tuning into what was transpiring. Many of these relationships had been a part of her life for nearly 50 years, some a little less than five years, and others somewhere in between. The friends were not strangers, occasional acquaintances, rare visitors. These women had regular and ongoing contact with one another. They had shared in the course of each other’s family life—the trials and the triumphs. Now they were not concerned with each other’s families; instead, they were focused on my mother and her impending death. I was given the gift of being an observer, not a participant.

To this day, it seems odd that at 35 years of age I had this surreal experience, to have experienced being the cognitive observer rather than the emotionally involved family member. I came to this experience with my mother to provide care. I believed I knew much about the end of life. My years of education, professional work experience, and practical life experience in the area had prepared me for just this type of situation. Entering into this caregiving role, my concern—and that of everyone who knew me—was the emotional toll this experience would take: the reality of going through the process of losing one’s own family member. That was not the impact I felt. I speak not only of the expected emotional toll of this experience, but also of the fact that I was given an awareness of an unexpected loss—my mother—the profound loss of failing to see her complexity, the depth of the person she was—failing to *see* my mother as the whole person she really was. I had understood that death was a loss—the separation of the person from the living. I had repeatedly provided educational format on “caring at the end of life.” I knew this. Through my education and career, I had become steeped in the human behavior literature exploring the theme of separation and individuation in the family.

Prior to this experience, my attention as a geriatric social worker had been on the fam-

ily and comfort of the individual, both physically and emotionally. I had not clearly seen the individual; I had only seen the roles and responsibilities the individual occupied. This experience has shaped my practice and teaching. As the end of a life nears, the depth of human connections, the exploration of all the relationship ties of individuals, and the summation of a lifetime is not merely the passive event of an individual retelling and verbally revisiting his or her life. It is a dynamic process involving many people: the dying person, the family, the informal network. The emotional support system of the individual—those individuals with whom the dying person has varying depths of relationships—rallies not only to provide help, but also so they too can work through what is about to transpire: the loss of a human being. The living will experience a part of themselves dying with the person. The impact of living a full and rich life gives rise to a complicated, multidimensional individual who is dying, leaving the world of the living and all that has been known to them. The survivors, those who will remain, question life's purpose, strive for some sense of equilibrium in sorting out whether they did everything they could do or whether they helped the dying person enough. In this process, they can be at peace with going on living.

Epilogue

Today, I remain profoundly affected by my mother's death. I have the all-too-familiar wishes that she were here to have witnessed my accomplishments, to have a relationship with my children, to lighten my sad days, and to cherish my joys. However, my mother influences me most on a daily basis in my professional life. I know I have a much keener sense of the depth of human existence beyond the narrow confines of the roles we each play. The intricacies of the person go far beyond their family, their circle of friends, the roles they are. Those intricacies

are threads within the tapestry of the person. I have witnessed the presence of a human soul. My mother's death provided me a key-hole perspective, of the delicate balance of the complexity of the individual. We share life, but we are also separate, multidimensional individuals. Each person—no matter how connected we are to each other or how well we think we know one another—is a separate person. This individual is the essence who each of us is. I now shape my work and that of my students to consider that uniqueness in our work with individuals.

