

"YOU KNOW WHAT TO DO...YOU'RE A SOCIAL WORKER!" A DAUGHTER'S PERSPECTIVE OF END-OF-LIFE CAREGIVING

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This narrative is an account of what happens when a daughter who is a social worker is faced with her most difficult challenge: preparing for and witnessing her father's death. The author describes the challenges of acting as both daughter and social worker and how using social work skills and family experiences assisted her with caring for her father. Despite her knowledge and skills, the author believes she learned more about life and death from her father during his last days.

Introduction

Whenever my family experienced difficulties, my mother's favorite response to me would be, "You know what to do. You're a social worker." Those words carried with them the assumption that, as a social worker, I had the training, knowledge, and skills to handle any crisis, even those within my own family. However, not until I faced a family crisis—the critical illness and subsequent death of my father—did I really know what to do and how to handle the situation. While nothing can ever fully prepare anyone for the loss of a loved one, this narrative describes the social work skills I used to assist my mother in caring for my father during his illness and subsequent and untimely death. Yes, I used my social work skills, but other factors—including my role as a daughter, my spirituality, and my African American cultural tradition—also helped me to handle my father's death. This narrative is an account of my father's final days and what happens when a daughter who is a social worker is faced with her most difficult challenge, preparing for and witnessing her father's death.

Prologue: Family and Cultural Tradition of Caregiving

For women, caring is seen as almost a genetic trait or family inheritance that passes from one generation to the next. As my parents' only daughter, I assumed that it would become my responsibility to care for them. According to Stoller and Cutler (1992), "...daughters are more likely to assume the

caregiver role because of cultural norms that support gender role socialization" (as cited by Rozario, Chadiha, Proctor, & Morrow-Howell, 2008, p. 320). I think I was better prepared and understood what I would have to do as a caregiver for my father because I had witnessed other family members provide care to older, ill relatives. As an adolescent, I saw my maternal grandmother care for her ailing and dying mother. Although I was a preteen, my grandmother's devotion to caring for her mother set an empathetic and strong example to me of my role as a daughter and a potential caregiver.

Later in college, I had another opportunity to watch caregiving first hand. My aunt cared for my paternal grandmother with humor, compassion, and enduring devotion. When my grandmother suffered several strokes that required her to be hospitalized, my aunt was there daily, and she was there when my grandmother passed away. I was very concerned about my aunt as she had been my grandmother's primary caregiver for so many years; I knew the constant caring must have taken a toll on her emotionally and physically, and I shared my concerns with my mother. At the time my mother informed me that caring does take a toll, but, "We're family... we care for each other no matter the circumstances..."

My mother's words remained with me as I grew older and I understood that I would some day inherit the caregiving role for my parents. My family shared very traditional African-American values, including a strong family orientation and belief in caring for our

elders. In African-American families it is a common practice for children to provide care for their elders (Dilworth-Anderson & Anderson, 1994; McAdoo, 1993). Further, "Researchers note that African-American families have strong filial bonds" (Rozario et al, 2008, p.321) White, Townsend and Stephens (2000) suggest that "African-American families generally accept that family members should care for an aging relative..." (p.725). As an adult, I chose to live near my parents because I knew that I would be available to care for them if needed.

My maternal grandmother and paternal aunt were incredibly strong African-American women who provided me with living examples of how to care selflessly and with devotion until death ended their roles as caregivers. Their experiences and my mother's words, "You know what to do," were constant reminders of my responsibility to care for my parents.

Daughter as Caregiver

In December 2006, my opportunity to act as a caregiver came sooner than expected. I am always overwhelmed in December, and December 2006 was no exception. My children had their school assignments; my daughter had volleyball practice, and my son had basketball games. To add to my family commitments, I had to prepare for work. I looked forward to working on my computer all day Saturday when the phone rang before 8:00 a.m. It was my mother, informing me that she needed me to come over to her house and take my father to the hospital. I knew my father was sick, in fact my mother had taken him to his primary physician a few days earlier, and he had been prescribed medication. I questioned my mother, "What's going on? I thought Dad was feeling better." My mother told me that it appeared that his condition was not improving and what initially seemed like a minor cold and cough had become a non-stop cough that interfered with my father's ability to sleep and eat.

When I arrived at my parents' house, my father did not appear to be his usual happy self. In fact, he looked very ill. I had to close the front door to his house because he was unable to do so due to his pain. He had a hard

time getting into my car and I had to gently place the seat belt on him. I immediately assumed the role of a "double-duty caregiver," professionals that work in the social service or medical profession who also serve as caregivers to their family members (Ward-Griffin, Belle Brown, Vandervoort, McNair, & Dashnay, 2005). My professional and non-professional roles began to blur as I did an initial assessment of his condition. "Daddy, how long have you been feeling like this? Where is the pain? What did your doctor say the other day? Have you been taking your medicine?" Seeing my father, who had always been a very active person who played sports throughout his life, grimace in pain was especially hard for me to accept. I remember as a child going to his basketball games and watching him coach my brother's little league team. As he grew older he maintained his physical health, even walking daily and shooting baskets with his grandchildren. After being diagnosed with a severe form of rheumatoid arthritis, his activity level had been reduced, but not to the level I was now witnessing in my car.

At the emergency room, the receptionist asked my father his symptoms and the list was detailed and exhaustive. I could hear the pain in his voice. As we waited in the emergency room, he admitted to me and another patient in the waiting room that "I just don't feel like myself anymore." Hearing my father describe himself in that manner made me feel helpless. I wished I could have waved the magic wand that would restore my father's health and sense of vitality. Requesting a wheelchair from the triage nurse during her examination, I reemphasized for the nurse my father's medical conditions and his need to be seen as soon as possible due to the intensity of his chronic pain. When I attempted to hold his hand, he recoiled because my touch was painful to him. Despite my request for my father to be seen immediately, we had a long wait in the emergency room. Each minute added to my sense of anxiety and concern for my father.

Finally, after being admitted to a hospital room in the emergency department, I sat with my father, and he showed glimpses of his usual self by joking with the nurses and talking with me. As he downplayed his pain and his

symptoms, I started feeling a little better about my father's condition. Perhaps he was just experiencing another severe rheumatoid arthritis flare-up that would be solved with a pain killer. Then he began coughing and I realized that in my rush to see him admitted to alleviate his pain I had forgotten to report his cough. I immediately found his nurse and told her about the cough. She reassured me that it probably wasn't anything major but she would notify the attending physician. When the physician appeared I notified him of my father's cough and he assured me that the cough was a secondary problem, but he would take chest x-rays to be on the safe side.

I felt a little better after my father's rheumatologist consulted with the emergency room physician and it appeared my father's pain could be alleviated. But there it was again: the unrelenting cough. I immediately went to the nurse's station and reminded the head nurse that my father never was taken to the X-ray department to have his chest X-ray taken. Within a matter of minutes a technician came and wheeled my father away for the exam. Trying to keep a positive outlook on my father's condition, I believed that the X-ray results would be routine and after receiving a few more shots of pain medication he would be released from the hospital and back to his normal self.

The physician assisting my father in the emergency room that day appeared younger than I and not as experienced as some of the other physicians. The physician's youthfulness concerned me because I wanted my father to receive the best medical care possible, especially since he was experiencing so much pain. I knew and trusted my father's primary-care physician, but I had never met the emergency room physician and he would be responsible for diagnosing and deciding my father's treatment plan. About 30 minutes after the X-rays had been completed, the emergency room physician had an opportunity to review them. I sat anxiously, watching the physician look at my father's X-rays, and I noticed a puzzled look on his face. He immediately grabbed one of his colleagues to come over and look at the X-rays. Now I was alarmed and tried not to show my concern to my father

who was lying there watching me. I could tell by the expressions on the physicians' faces and their conspiratorial whispering that my father's X-rays were not "normal" and that this routine trip to the hospital was more serious than I had anticipated.

The physician came over to us and explained that it appeared that there was fluid in my father's lungs—a mild case of pneumonia probably, nothing too serious—but my father would have to be hospitalized for further observation. My father, who was usually compliant with his physicians' wishes, began to put up an earnest protest: "I don't want to stay this time... just let me go home!" I was patient and tried to reason with him: "Dad, I know that you want to go home, but if you go home now and get sicker, Mom can't help you and you'll just end up back in the hospital again. Please listen to the doctor; he's trying to do the best thing for you." My father remained steadfast in his desire to leave the hospital: "I still want to go home; I don't want to stay here!" I attempted to compromise with my father by suggesting that I speak with my mother about his desire to go home against physician's advice, and I told my dad that if my mother was willing to let him return home, I'd take him. Of course, when I reached my mother by telephone, she refused to let my father leave the hospital, and I returned to notify my father and the emergency room physician, who appeared relieved that my father would be admitted. I sat there with my dad and reiterated that everyone wanted him well and the best place for him to get the proper treatment and become well was at the hospital.

After my mother arrived at the hospital, I gave my father a kiss and said, "I love you Daddy. Get better!" I did not know it at that time, but that would be the last conversation that I would have with my father...

Worrying about my father's condition and my mother's health, in addition to caring for my own family and working, compromised my own health. As a result, I caught the flu and was unable to visit my father in the hospital over the next few days, but I received daily updates on his condition from my mother, my aunt, and the nursing staff at the hospital. My father was on a ventilator and was in and out

of consciousness. Despite his condition, I firmly believed that he would return home by Christmas to be with our family. My mother and I even started to discuss the type of care he might need when he returned home and how we would ensure that he received the proper care and rehabilitation.

One Sunday, three weeks after my father was hospitalized, my mother was told by my father's pulmonary specialist that his lungs were in the process of failing. She contacted my husband to inform us of the dire nature of my father's prognosis and to tell us to come to the hospital immediately. After he hung up the telephone, he told me to sit down before relaying to me the gravity of my father's condition. I cried, then immediately called my mother and told her that I would meet her at the hospital.

Once at the hospital we met with the pulmonary specialist who informed us of my father's treatment options and his grave prognosis. My mother was strong and steadfast in her decision to allow nature to take its course. Her only request was that my father "...not suffer anymore, or be in pain." I agreed with and supported my mother's decision because I understood that my father's quality of life would never be the same and that for several years prior to this hospitalization, he had been ill and experiencing intense pain. It still was not an easy decision to make, and I was overwhelmed by feelings of sadness and helplessness. I did not want my father to continue to suffer, but I was not ready to let him go. I felt like the English poet, Dylan Thomas, in his poem *Do Not Go Gentle Into That Good Night*. I wanted to tell my father:

*Grave men, near death, who
see with blinding sight
Blind eyes could blaze like
meteors and be gay,
Rage, rage against the dying of
the light.*

*And you, my father, there on the
sad height,
Curse, bless, me now with
fierce tears, I pray.*

*Do not go gentle into that good
night.*

*Rage, rage against the dying of
the light*

(Thomas, 1952).

For me, the whole experience was surreal. I could not believe what was happening, how a routine visit to the emergency room could end like this for my father. I also remembered how he had resisted staying in the hospital; perhaps he knew that he was not going to return home.

Even hearing the physician's diagnosis and seeing my father on the ventilator, unconscious, could not prepare me for the reality that my father was dying and that our family would never be the same. As our family members that were there with us at the hospital broke down into tears, I knew that I would need to be strong to help my mother through this very painful time. I had always been the one in the family who disliked going to hospitals, funerals, and cemeteries, and now I would experience my father's passing. And even though I felt I understood death and dying from an academic standpoint, as I stood in the hospital with my mother, I felt unprepared to experience death in such a personal manner. I could not believe it! I visited my father in the ICU room, protected by gloves, a gown, and a mask, and held his hand. The only thing I could say was, "Thank you, Daddy. I love you!" I still could not believe that my father would not be making a miraculous recovery and walk out of the hospital doors.

Daughter as Social Worker

My mother's refrain, "You're a social worker....you know what to do," was fresh in my mind as I immediately started to help her. Although I am one of three social workers in my family, I was the only one at the hospital to assist my mother. My father's younger sister, my aunt and a social worker, lived 3,000 miles away. My younger cousin, also a social worker, visited my father on the Sunday we learned my father was critically ill, but was too emotional to return. So, I knew that I would be the one my mother would rely on. However,

being daughter and social worker was emotionally draining. I felt conflicted—I wanted to cry and deal with my own emotions, but I also knew that my mother would expect me to serve as liaison between her and the medical staff. I was used to my role as family social worker because my mother always requested that I assist her when my father had medical crises. As a result, I was familiar with his medical history and felt confident interacting if needed with his physicians. Perhaps if I hadn't been a social worker, my mother would choose to talk to the hospital social worker. But my mother trusted me, and I was willing use my social work knowledge in my caregiving role.

My social work skills were immediately put to use. I used my counseling skills, as I listened to my mother talk about the stress of my father's terminal condition and her sadness that he would not recover. I assessed what needed to be done and immediately began to make a mental list of all the family members that needed to be contacted, beginning with my brother. I suggested that the family priest be contacted to see my father. I asked my mother if there were any additional questions she had for my father's physician. I contacted all of my father's siblings to inform them of the gravity of his condition.

As soon as I contacted them, family members and friends began their pilgrimage to the hospital. During that time, I became a facilitator and counselor, communicating my father's medical condition with the many family members present at the hospital and ensuring that their emotional needs were being met. As each new family member entered the ICU, my mother requested that I accompany them to my father's room and be present with them to explain my father's condition and be there to offer emotional support. After each visit to my father's room, I felt saddened and emotionally drained because I could see my father's health declining rapidly, and I was worried that some of our family members would not have an opportunity to be present with my father in the hospital.

Informal Support

As we kept our daily vigil at the hospital, we were fortunate to have family and friends come by and sit with us and help us with errands. It seemed as though the world stopped when my father became critically ill, but it did not. Our family members and friends were my anchors to remind me to eat and to help me complete those daily tasks that I had neglected in order to stay with my mother and father at the hospital. Often they would share some of their positive memories and stories about my father which would help to remind us that my father touched many people throughout his lifetime.

A family friend, Carol, who was a doctor at the hospital where my father was hospitalized, met with us. She was able to alleviate our fears regarding the decision to remove my father from life support and she also explained the process of death to us and answered our questions. Her support and professional expertise was invaluable. I trusted Carol and felt comfortable sharing my fears regarding my father's impending death. Hearing Carol inform us that she knew and trusted my father's physician and the medical staff helped me trust that they would provide my father with competent care as he prepared for death.

Advocacy during a Difficult Time

Due to the long hours at the hospital and because of lack of sleep, by Tuesday, December 12, I felt mentally and physically exhausted. Each minute at the hospital became agonizing. It hurt to see my father languishing away, and it also hurt to realize that his death was imminent as he could not support his vitals without life support. I believe in the sanctity of life and I especially felt that the life of my father—the man who gave me life—was precious and should be given every opportunity to continue. However, looking at my father in his hospital room, unable to think, move, or breathe unassisted, tested my definition of life, especially since my father was a vibrant, energetic, and engaging person. To me life means vitality, the ability to think and to breathe unassisted. In my naïve definition of life, there was no need for medical intervention or

artificial means of support. In some instances, there is a fine line between life and death, and the literature indicates it is not easy defining death (Dickinson, 2005). I could see that extending my father's life by using life support would not restore him to his former health. By December 12, I felt as though the life-support measures were preventing my father from experiencing a gentle death and the afterlife. I also knew that my father had very specific, advanced directives and a Do Not Resuscitate (DNR) order, so I felt that my father had defined the terms of his death. As difficult as it would be to witness his death, I knew that I would obey my father's wishes.

My mother and I also met with and continued to discuss my father's medical condition with his physician. According to Barrett (2006), "African-Americans as a cultural group have been documented to reflect a preference for open communication and discussion with their physicians as means to making decisions about end-of-life care" (p.256). My father's physician performed all the necessary medical examinations, including a lung scan, to ensure that there was no possible medical recovery for my father and that any additional medical efforts would be futile. My mother and I believed the physician when he said that nothing more could be done for my father medically. He was a very gentle, knowledgeable, honest, and compassionate physician. He had even taken the time to consult my cousin Debra, a surgeon in Chicago, regarding my father's medical status. After that meeting, my mother decided the time had come to withdraw my father's life-support system since it was no longer extending his life, merely prolonging his death. My mother showed her enormous strength and courage at that moment. There was no long discussion between her, the doctor, and me. She simply stated, "I know your father told me that he wouldn't want to remain on life support. He's in God's hands now." I felt overwhelming sorrow for my mother at that time because I knew she would be losing the love of her life, her best friend and her support.

My role as a daughter was to notify all our family members and ensure that they would come to the hospital immediately and to notify

our family priest that my father's condition had worsened. Additionally, my mother requested that I go to the ICU during the process to check on my father. On one hand, I was the scared little girl, terrified about witnessing my father's death. On the other hand, I was still trying to be the brave social worker who knew what to do during a very emotional time. It was difficult but, at my mother's request, I again became a "double-duty" caregiver: a daughter and social worker, using my advocacy skills. According to Ward-Griffin and colleagues (2005), double-duty caregivers often "advocate on behalf of their relatives, especially if they were not in the position to speak for themselves" (p.386). My father was unable to tell the doctor of his need for a peaceful and dignified death, but I wanted to ensure that would happen for him. According to Dickinson (2005), the physician's role at the end of life is critical, and physicians have a responsibility to the dying patient to "mitigate their suffering while allowing them to die" (p.3). I met with my father's physician, asking questions regarding the process of removing his life-support system, advocating for my father's right to die with dignity and in peace.

I wanted to ensure that my father experienced no pain as he transitioned from this world to the afterlife. As a social worker, I was familiar with the term "palliative care," but I had never worked with dying individuals nor had I experienced the process of death first hand. My father's nurse was empathetic and patient with me as I observed him prepare my father for his end-of-life experience. Feeling very anxious and uncomfortable, I was direct and purposeful in my interactions with the nurse. "How are you going to make sure that my father won't experience any pain? Will my family members be able to be with him in his final moments?" The nurse assured me that Father would have a peaceful death surrounded by our family. I was too sad and scared to remain with the nurse or to witness the removal of my father's life-support system. I asked my oldest friend, Kate, to remain with the respiratory therapist as he removed the tubes from my father and to let the family know when to return to my father's bedside.

In the hospital waiting room, the family members present were joined by one of the hospital's chaplains who prayed with us and offered us words of support. I was nervous and anxious as we waited. I wondered if the nurse was ensuring that my father would not feel any pain. I worried about my mother and brother and how they would handle my father's death. I was scared that my father's death would be long and painful. It seemed as though the process was taking forever, but about thirty minutes later, Kate told my family it was time to join my father in his hospital room.

My anxiety and apprehension about witnessing the process of death subsided as I stood with my family members. As I stood near my father, I could only thank him for being the wonderful and loving father that he had been to me. I wondered if he could hear and understand my words. I wanted to make sure that he knew that I loved him and was there at that moment. I felt that it was important that he knew he was not alone as he transitioned from this world to the afterlife. I was prepared to accept God's plan for my father and during that moment, my prayer was that my father would experience no pain. My father passed away peacefully and with dignity and grace in the presence of his loved ones. I could not believe that he passed away so quickly and peacefully. All of my fears of a prolonged and painful death for him were never realized. Immediately following my father's passing, our family members joined hands around his hospital bed and prayed for him and for ourselves. Leaving his hospital room, I felt a calmness and relief that my father did not suffer in death.



Epilogue

My mother's words, "You know what to do. You're a social worker," were my mantra during my father's last days in the hospital. I used my advocacy, counseling, facilitating, and assessment skills during those days. However, I also feel other factors helped me during the

process including family cohesion and spirituality.

Family Cohesion

Having a cohesive and supportive family was also beneficial to me during my father's illness and subsequent death. In my family's African-American cultural tradition, we believe in caring for and supporting each other. A strong family orientation and a family-centered approach to end-of-life care are documented as common values for African-American families (Barrett, 2006). Four years prior to my father's death, my parents and I had discussed how the end of their lives should be handled. At the time of our discussion, I was in denial. My parents had chronic medical conditions but were healthy, happy, and active individuals. Also, our family was known for the longevity of its elders; my paternal grandmother lived to 90 and my maternal grandfather is 92 years old. After the discussion, I felt my parents' deaths would be many, many years into the future.

Knowing and understanding my father's end-of-life desires made it somewhat easier for my mother and me to accept the decisions that were made pertaining to his treatment. I experienced some level of comfort knowing that we were following my father's request not to have his life prolonged. Even though the decision to remove him from life support was my mother's to make, she used a family-centered approach by discussing it with my brother and me and talking to us about our feelings regarding her decision. I appreciated the fact that my mother talked to us about her decision. I was not surprised or angered by the decision because I knew my father's wishes. My brother and I were saddened by the decision, but we also knew that it was what our father requested. We communicated with each other during each step of the process and supported our mother during her difficult decision. I felt as though we were walking through this difficult time together, relying on each other for support and guidance. Our family's cohesiveness and support of each other strengthened me. I believe that I could not have witnessed my father's death without

my family being present with me because we were able to comfort each other.

Spirituality

Lastly, spirituality and a belief in God helped me during the days of my father's illness and death. For many African-American families, faith and spiritual practices are a fundamental part of life and family values (Turner, Wallace, Anderson, & Bird, 2004). My family is very religious and those spiritual values are part of my identity. As soon as my father was hospitalized, I asked family members and friends to pray for his well-being. At the hospital my family welcomed the prayers and spiritual words of encouragement offered by our family priest and the hospital chaplain. The importance of spirituality for caregivers is acknowledged by White, Townsend, and Stephens (2000) who state, "For African-American caregivers, prayer and faith may raise their threshold for the stresses of caregiving, may act as a buffer when caregiving stresses arise, and may be associated with perceptions of caregiving rewards, such as being blessed by God for their caregiving efforts." Each day prior to going to the hospital, I would go to my church and pray for my father and our family. It was my coping strategy. I am not a physician, so I could not give my father any medical intervention that could save his life, but I could offer my prayers as spiritual intervention. The research of Branch, Torke, and Brown-Haithco (2006) identified one of the essential spiritual values of African Americans as a belief in God's providence especially during crisis situations and an acknowledgment that, "Whatever happens is part of God's plan" (p.1203). Praying allowed me to turn over the stress of caring for my father and family to a "Higher Power" whom I trusted would hear my concerns and guide me during my difficulties. Also, being with the members of my church community helped me to realize that I was not alone, and that gave me a sense of strength. Finally, going to my church gave me a sense of peace, as it reinforced my beliefs that my father who was a very spiritual person, would transition into an afterlife with God.

In addition to my spirituality, I also believed that it was important to have my father's spiritual needs met as he was preparing for his end-of- life experience. The International Work Group on Death, Dying and Bereavement (2006) agree that in addition to providing medical care for a loved one preparing to die, other factors including spirituality must be addressed. They state, "Providing optimal caregiving to a dying...individual...as a family member...involves a complex of cognitive, psychological, social and spiritual factors..." (p. 661). Additionally, the research of Branch and colleagues (2006) acknowledges the salient role of spirituality for African-Americans end-of-life experiences. My father was a deeply religious man who was a dedicated and involved member of his church. Throughout my life he shared with me the importance of spirituality, especially in difficult times. So, as soon as I discovered that my father was gravely ill, one of my first inclinations was to contact a priest who was a friend of our family and knew my father. Despite his obligations to his church, he came to the hospital and prayed with my family. He was also kind enough to sit with me and pray with me in my father's room and offer support to me as I cried. It was comforting to hear the priest talk to me about how my father served his church community and family. Even though my father was gravely ill and comatose, I believe he was comforted during the time our priest prayed for him.

Conclusion

When my father died I lost a friend, a hero, a supporter, and a wise sage. Throughout my life he taught me many invaluable lessons that I will always cherish. During his final days, I believe my mother looked at me to offer assistance because she believed as a social worker I'd know what to do. It was hard to be both daughter and social worker. Truthfully, it was a difficult transition for me to use my social work skills during such a personal time and to balance the emotions I experienced as a daughter. However, I believe those social work skills (assessment, counseling, facilitating, and advocating), coupled with my family and

cultural experiences (tradition of caregiving, family cohesiveness, informal support, and spirituality) provided a foundation for me to assist my father and my family. And yes, even with those skills and family experiences, being present for my father's final days was still a difficult and life-changing event for me.

True, I am a social worker and I should have known what to do, but my father taught me so much more in his final days. I have gained new insights as a result of my experience caring for my father in his last days and being present during his death. Prior to my father's death, I viewed it as a painful and prolonged process and I anticipated it with fear. However, through my father, I learned that death was part of the process of life and that it could be dignified and peaceful. Being able to share such an intimate and emotional experience with my father and my family members has helped my understanding of death. It was a very touching gift that my father gave me in his final days...for I now have a greater appreciation for life and a better understanding of death.

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