

UNDIGNIFIED DYING: "May His Memory Be for a Blessing"*

Sam was one of my first clients when I was a case manager for a program that served the frail elderly. I believe my work helped ease some of the pain of his last year. Yet, there were issues about dying that were very difficult for me to address. As I pushed myself to analyze this experience, I found another challenge: coming to terms with work that was good, but imperfect. While I feel vulnerable publicly sharing my struggle, I believe that this narrative offers valuable lessons for me, as well as, closure.

by Madeleine Rose,

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Offended by our first encounter, I tried to dump Sam as a client. But my supervisor thought otherwise, and I became his case manager for three years. His dying left indelible memories, provoking reflections about my role and the uncertainties of navigating the blurry zone between life and death.

The case management program aimed to help frail, elderly, low-income persons avoid or postpone entry into skilled nursing facilities. Teams of social workers and nurses did assessments and provided access to resources such as Meals on Wheels, transportation assistance, and aides to do household chores. However, as I learned, case management involves more than linking people with services (Soares and Rose, 1994). Often, individuals and families refuse or sabotage needed services. Frailty stirs up conflicts about dependence and autonomy, disappointments and difficulties in family relationships, fears about death and dying. Sam and I plunged into this emotional whirlpool.

As the new social worker at the agency, I took over the caseload of a worker who recently left. Sam was assigned to me; neither of us had much choice. Systematically, I telephoned my clients to introduce myself and set up an appointment to meet.

Sam's response included crude remarks about female breasts. Painfully self-conscious, I was so embarrassed I was immobilized. When I ended the call, I headed directly to my supervisor and asked that he be reassigned. Wisely, she refused and reminded me not to take his words personally; after all, he had never seen me. Instead, his inappropriate comments provided vivid information about his troubled social interactions. Aching from loneliness, he chased people away. While I needed to set limits on obnoxious jokes and language, my initial task was to form a relationship with him. And that I did.

I first saw him at the office. This was not typical—usually I went to a client's home for an initial assessment or meeting. However, I thought the formal office situation would discourage lewd talk and I wanted others nearby to bail me out of a possibly sticky situation. He was a big man, tall with a prominent belly. I didn't like to look at him, and when I think back, sadly, I realize I was stingy with the comforting hugs that I often gave to my elderly clients. I may have held back because of my initial discomfort and concern that he might sexualize our interactions. But his stained and soiled clothes also kept me at a distance. His husky voice boomed a cheery hello. He

*From a saying often used at the end of a Jewish memorial service (Nuland, 1994).

seemed grateful to be invited to the office and quickly entertained me with a joke—this time, nothing obscene. As I recall, I don't think that was ever again a problem. He joked about not wanting to go to Egypt—to see the Nile. And then checked, "Did you get it? Senile, don't want to be senile." I would hear this joke and his fear many more times.

He laughed loudly at his jokes—a hearty laugh accompanied by a big toothless grin. Not far behind the laugh rolled tears. Other times it would be indignant tirades about the aide who didn't do what he wanted. Followed by tears. That's how it was. Hurt crouched behind boisterous banter or gusts of rage.

He called me often to talk—maybe two or three times a week. He would find an excuse, a new joke or fresh outrage. I responded with measured steps leading us to the place where his voice became small, then quiet. I would reach into the silence and hear his anguish, a wail emanating from wounds past and present. I gave him words for the pain, and we would pause to listen, while he released muffled sobs. Communicating the pain to someone who cared seemed to calm and steady him.

Sam was in his 80s and struggled with diabetes—he had lost the battle for his leg a few years ago. He maneuvered unsteadily on the wooden prop that replaced the amputated leg. Short of breath, he blamed the wooden leg that had lately grown heavy. He couldn't walk more than 10 feet without stopping for air. But he went each day to see his wife, Sylvia, in her nursing home.

Not that he saw much, for he was practically blind. The sight was gone completely in one eye, and he only saw shapes and glimmers of light through the other. It was his hope to see again that got him into this last skirmish. The surgery he feared and postponed many times beckoned as a chance to be free. If he could see again, he would drive, go to a restaurant, clean his apartment—without needing other people. He would bring his wife back home.

Rescue her, that's what he wanted to do. Like a storybook knight with a white horse, stride in, swoop her in his arms and carry her off. Instead, he limped in daily, cane in one hand, her favorite chocolate milk shake in the other, to visit her.

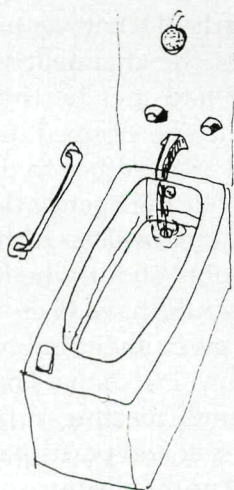


Countless times he told me how Sylvia would brighten when she saw him. He would greet her and tell her she was beautiful and that he loved her. Each day he asked her to marry him and she accepted. Until the afternoon was over and it was time for him to leave she would plead for him to take her home. But he could not. She claimed she didn't love him anymore and

withdrew. He returned home defeated.

Punishing himself, he no longer slept in their bed—he squeezed onto the narrow, naugahyde couch in the living room. He referred to himself as "broken and incomplete," no longer a "whole person." It tore him apart to know he could not bring his wife back home. He couldn't even take care of himself. Fingers gnarled from arthritis, he couldn't button his shirt or change his socks. He was ashamed that when no one was there to assist him, he slept in his shirt and wore soiled clothes. Balancing on one leg, he could not bathe or shower without help. He learned to request, even demand certain services. Our agency hired aides for household and transportation assistance. But it was humiliating to be naked and helpless in front of a stranger. So he didn't bathe for months.

I was rather proud of my work with him. Although tempted many times, I tried not to respond to his angry outbursts and complaints about his caregivers by dismissing him or them. Instead, as he would tell me stories of how people infuriated him, I listened to a man raging against his dependency on strangers or worn out family. I engaged him by addressing the determination and the strength he mustered to be with his wife; I also recognized the severe frustration and loss in his struggle to maintain independence and dignity. Sometimes, I had a hard time figuring out how to react. I admired his refusal to be defeated by a weakening body; yet, I did not want to support unrealistic fantasies



such as being able to bring his wife back home. I helped him find a place to talk about his wishes, yet not be lured by false beliefs. With this goal we inched along together.

He was conflicted about eye surgery. Cataracts, glaucoma, cataracts compounded by glaucoma by macular degeneration. I don't remember the exact medical conditions any more. Sam vacillated between dreams of restored vision and dread that the doctors might take away the shapes and wisps of light he still discerned. The doctors carefully cautioned that cataract surgery might provide incremental improvement at best. No guarantees. After months of shopping for a doctor, Sam scheduled surgery.

In our last conversation, ostensibly to discuss transportation arrangements, Sam sounded anxious. He briefly opened and shut the door to his fears, while I was unable to keep it ajar. He could not admit to being frightened about the upcoming surgery. Yet, he said that he was scared for his wife and what would happen

to her if there were any problems. He worried that no one would look in on her. I think he was trying to extract a promise from me, that I would visit her. But I had never met her, and given the nature of the program's funding, people in nursing homes could not be on our caseload. Still, I was tempted to reassure him falsely. Hearing me hesitate, he mustered his bravado voice and declared: "The surgery would be a success."

His family wasn't available to take him to the hospital. Although children and grandchildren lived nearby, they mobilized only sporadically for Sam. I felt uneasy anger then and experience it again now, more than eight years later, as I write. Countertransference? Probably. My parents died in middle age. I never saw them with wrinkles and gray hair. I never heard them clap with pride as their grandchildren performed at school recitals. Nor was I faced with burdensome care-giving needs that strain the relationships of adult children and parents. When I work with the families of elderly clients, I must guard against misplaced anger and envy about fantasized family relationships. I remind myself that when adult children resist forceful societal pressures to caregive, a troubled family history might lurk in the background. Not surprisingly, my conversations with Sam's daughter revealed a past colored with resentment and grievances. Unfinished issues that dying would resurrect.

As the case manager, I hired a just-above-minimum-wage aide to drive Sam to the hospital and bring him home on Friday, the scheduled day. With the

governing DRGs this was considered routine outpatient eye surgery. But, surgery isn't routine for a terrified, 80 year old diabetic man. Sam never returned home. Something went wrong. No one's fault, perhaps. A bad gamble. He didn't wake up as expected from the anesthetic. Not able to breathe on his own, Sam was plugged into a ventilator.

Monday, I received the news in a telephone call from the doctor. This was not the eye surgeon, but the attending physician. Sam, a Medi-Cal (Medicaid) patient, was in a university teaching hospital. Sam's internist had retired; the new doctor didn't know Sam well and was not on the staff of this hospital. The doctors now responsible for his treatment and for participating in crucial meetings about his quality of life and death, didn't know him. They were strangers who had never talked with Sam, nor heard him joke or agonize about his wife. In a controlled voice the doctor informed me that Sam was in a coma, most likely irreversible. The doctors predicted "a permanent vegetative state"—a prognosis announced cautiously, after deciphering flattened lines from the EEG readings and repeated attempts at 24 and 48 hours to stir the unresponsive patient. The doctor indicated that there was a decision to make regarding whether or not to keep Sam on the ventilator. He asked me if I would help to gather relevant family members for a meeting with the hospital bioethics committee. Shaken, I agreed to help and then hung up.

I sat for a long time, trying to contemplate Sam as they

described him—almost brain dead. I cried as I thought about him lying motionless in a hospital bed, unable to will himself out the door, as he had willed himself to visit his wife. That night I had difficulty sleeping and tried to find words for my own pain. Sitting at my computer, I wrote an essay about Sam, our relationship, and his predicament. The next morning, still very upset, I brought the essay to our weekly staff meeting. As I read it aloud, the other social workers, nurses, and supervisors cried with me. We worked with a frail, elderly population and death was not uncommon. We had permission to care and to grieve. But clients' deaths were rarely so gut wrenching. Often, we could comfort ourselves with the knowledge that we had helped during the last part of life. But this was different. Sam wasn't dead; yet, he had lost the capacity to think and to convey his wishes. I felt guilty, for I had grown close to Sam and helped him to prepare for this surgery. And now, I wasn't sure what Sam would want us to do.

Sam had entered that four dimensional space between life and death—where laws, ethics, religion, and technology render perspective. His brain showed no cortical activity which means no language, no thought, no awareness, no capacity to interact. Part of his brain stem continued to function, allowing rudimentary reflexes. According to the law, brain death is death, even if the heart continues to beat (Nuland, 1994). Technically not brain dead, Sam was close enough that the ventilator could be turned off. He would die with the hospital, doc-

tors, and family protected. This would not be active euthanasia or assisted suicide, still legally off-limits to the medical profession in the United States. Turning the ventilator off would allow dying to finish. But the family would have to make this decision.

In conjunction with the hospital social worker, a meeting was arranged within a few days to discuss Sam's plight. Seven family members attended—his daughter and her husband, their two daughters and spouses, and Sam's teenage grandson. Although I had previously met Sam's daughter and son-in-law, this was my first introduction to the other family members. I remember thinking of the irony of the family gathering to discuss Sam's dying, knowing he felt hurt that they were not available enough when he wanted their company and their help. There was another irony. Although I had previously talked individually with some of the family members, I had not attempted a family meeting prior to this crisis. I had met with the daughter several times, after calling to introduce myself and to explain our agency's role. Hearing references to her conflicted and stressful relationship with Sam, I had encouraged her to come to the office to talk about her caregiving dilemmas. Without hesitating, she accepted the offer. She felt angry and yet concerned about her father who needed help, yet was demanding and difficult to please. His temper was a familiar memory from her childhood. She was also having marital problems—her husband sounded a lot like her father—very critical,

particularly of whatever time and resources she channelled to her father. I had met her husband twice when he stopped by unannounced at the office to demand angrily that the agency do more for his father-in-law. Although I have doubts about whether this family would have been willing to meet given their ambivalence about Sam, I wish that I had pursued a family meeting earlier with Sam present and participating.

Another irony soon became apparent. Sam lived on the modest income available through SSI. With money from state and federal funding, our agency provided him the supplemental services that allowed him to live independently—taxi coupons to visit his wife, an aide to drive him to the doctor, someone to clean his apartment and shop. But budget restrictions limited the extent of these services and they barely met his needs. Once hospitalized, expenditures for Sam increased exponentially. I couldn't help but think that these funds would have been better spent while Sam was conscious and struggling to survive on his own.

The meeting with the bioethics committee took place in a hospital conference room. It was located in a separate wing from the intensive care unit where Sam lay connected to tubes that fed him and machines that breathed for him and monitored and recorded his bodily functions. People entered the conference room nervously and sat in the circle of chairs arranged by the hospital ethicist, a man with degrees in both medicine and law. The attending physician and resident walked in together and

joined the other hospital staff—a social worker, nurse, and chaplain. The family members were solemn and generally composed, although Sam's daughter became tearful several times. The subdued atmosphere underscored the weighty decisions to be discussed.

I will never forget that meeting. The ethicist took charge, asking each of us to introduce ourselves and identify our relationship to Sam. He asked the doctors to describe Sam's current medical condition, prognosis, and treatment options. The doctors emphasized the unlikelihood that Sam would ever regain consciousness. Clearly, the agenda focused on helping the family decide whether Sam should remain on the ventilator, or whether it should be turned off, allowing him to die. The chaplain knew that Sam was Jewish, but wanted to know more about his beliefs and whether he followed orthodox religious practices. According to his daughter, Sam was not religious; however, as her husband responded, it became evident that this was a source of tension between Sam and his orthodox son-in-law, who now attempted to impose his views about religion and medical intervention. The chaplain commented that in most religions there is leeway regarding the use or withdrawal of life supports such as respirators. The social worker acknowledged that families may feel conflicted about end-of-life decisions. In a dramatic query the ethicist asked each family member and me: "What decision do you think Sam would make?" He cautioned us to dis-

tinguish between our personal views and what we believed Sam would want. Silently, I remembered Sam's terror of senility, yet his unrelenting determination to see his wife and bring her home. After the family members said they weren't sure what Sam would want, it was my turn. With dismay I conceded that I, too, did not know.

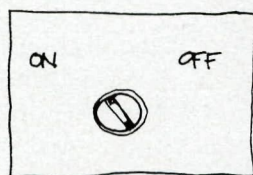
The ethicist directed the doctors and nurse to elaborate on the implications for Sam if he remained on the respirator or if it were slowly turned off. He actively sought to debunk illusions people held. Dying, prolonged by the respirator, would not be an idyllic slumber. To continue using the respirator, the tube placed down Sam's throat and into his windpipe would remain in place. The machine would pump air into a body that would shrivel and contort with muscles stiffened into contractures from lack of use. There would be milestones along the way to death. Decisions about continuing tube feeding—the change from the temporary nasogastric tube to a more permanent and invasive tube that would go directly into the stomach or small intestine. Pneumonia, euphemistically referred to at "the old person's friend," would require a decision. Untreated, it could lead to death within a short time. Antibiotics could further delay death. Kidney failure and

decisions about dialysis—more tubes and machinery. Death would come sooner if the family ordered the ventilator turned off. Usually, this would not be an abrupt process; rather, the dial would be turned down slowly and the person, medicated against pain, would cease to breathe and die within a short time.

The meeting drew to a close after the family indicated that they needed time to make a decision. No one pressured them; in fact, they were encouraged to talk among themselves and to be in touch with the hospital staff as questions and concerns emerged. Of course, not making a decision was a directive to continue the respirator.

The family had so many unfinished issues pertaining to Sam that they remained unable to make a decision actively. Sam lingered for six more months. According to the hospital staff, the family rarely visited, finding it too painful to look at him. As predicted, he developed pneumonia. The family authorized antibiotic treatment. When his kidneys failed, they considered but rejected dialysis. He died soon after.

My formal role ended with Sam's hospitalization, for our program's services were earmarked for people living at home who were at risk of losing their independence. I did go to the hospital one more time to visit him, motivated by concern, curiosity, and a desire for closure. I found it almost unbearable to see this proud, boisterous man curled into a fetal position, catheterized, diapered, and connected to tubes. His sporadic involuntary move-



ments startled me. His unresponsiveness made termination one-sided and incomplete.

Although Sam's life petered out in a most undignified way, I imagine he would be pleased to know he made a lasting impression on me. I bring the disquieting memory of our experience to my teaching, professional work, and personal life. I believe my work encouraged and comforted Sam as he faced many painful losses, yet I found it difficult to help him and his family come to terms with his impending death. Looking back, I wish I had discussed with Sam his end-of-life choices. I am still struggling to explain why I did not. Certainly, the context has changed—this was a less commonly addressed issue eight years ago; patients were not routinely advised of their right to complete an advance directive. Also, cataract surgery, scheduled on an outpatient basis, is not considered major surgery, thus not demanding acknowledgment of substantial risk. I desired to be supportive of Sam's gamble and wanted to avoid upsetting him by confronting his denial and stirring up his anxiety—and mine. Lingering issues about the premature deaths of my parents perhaps made me skittish about another loss. Yet, denial and avoidance left Sam, for whom feeling in control was crucial, completely out of control in the last part of his life.

Sam's dying occurred in old age; yet at any age, injury or illness may bring us to the brink of death. Recasting dying as part of life encourages us to clarify our choices. To help our clients' voices be heard, we cannot dodge our

own discomfort. Parallel to our clients, we must confront our pain and fears about death. Then, faced with end-of-life decisions, as professionals and as family members, we can listen, speak with certainty, and let go. □

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