

LIVE UNTIL THE FIRST DAY OF THE MONTH

This narrative reflects on a paradigm case for understanding how in an era of managed care when values and economics appear so indivisible, one health care team united and provided non-costworthy care to a terminally ill patient who needed to live until the first day of the month. The ethical dilemma of treatment effect vs. treatment benefit in end of life decision making becomes a drama. The article chronicles events leading to the first day of the month and underscore the power of story and metaphor in creating common ground and common understanding in patient care.

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THE START

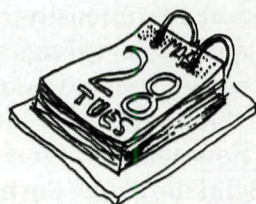
During the middle of a staff meeting, my pager went off. I promptly answered because it was to a number I recognized. It was Dr. Z, a prominent staff oncologist. He said "I have a patient I want you to see." My heart beat a bit more quickly; not once in the four years that I had worked in oncology social work had Dr. Z. consulted me directly. In a polished but firm voice he said that he was transferring his patient (Mr. B), who was actively dying, to the oncology service to which I was assigned. Before I could utter a word Dr. Z asserted that he could no longer "ethically" care for Mr. B, who was asking to be kept alive for financial reasons. "Financial reasons?" I asked. Dr. Z mumbled something about an insurance policy. Before I could inquire further, he asked me to meet with Mr. B and his wife to help them be more reasonable in their requests. I realized that this consult was more than to help a family cope with an impending death. My heart sank. "What a setup! If I don't convince this man to accept Dr. Z's recommendations, then what?" At first I felt defensive, then protective of Mr. B. Curious to learn more about the case's history I hurried to the floor, reviewed the chart and met with Mr. B and his wife.

Mr. B was 51 years old and terminally ill with metastatic lung cancer. He had been admitted on the 22nd day of the month with respiratory distress and bone pain. Mr. B was on medical disability from his job of 2 years with a car manufacturer and would not be fully vested in his retirement benefits until the first day of the month; if he died before then all benefits due his wife would be drastically reduced. Mr. B's wife had never worked outside the home and he was worried about what would happen to her if she did not have his insurance benefits to rely on after his death. Despite aggressive treatment Mr. B's respiratory-condition had continued to deteriorate. On the third day of Mr. B's hospitalization Dr. Z had recommended comfort care only; he told Mr. B, his wife, and two young adult daughters that the cancer was terminal and attempts to prolong life would be futile. Rejecting Dr. Z's recommendation, Mr. B was adamant that he had to live until the first day of the month, even if it meant being put on a ventilator. But after the first, he wanted the ventilator to be taken off.

DILEMMAS

Would honoring Mr. B's request amount to futile treatment and a waste of hospital resources

as implied by Dr. Z? When does a patient have a moral claim to futile or virtually futile health care resources? Was a possible social benefit to Mr. B's surviving family members enough justification to provide what appeared to be medically futile care? If Mr. B were kept alive with ventilator support until the first day of the month, would the team be participating in active euthanasia by withdrawing life-support? I thought, "this could be a nightmare ... how could everyone involved be in agreement?"



THE SEARCH – COMMON GROUND

After meeting with Mr. B and his wife I met with Mrs. B alone. She expressed the wish that her husband would not worry so much about her; she felt that she would survive one way or another and wished he would just focus on his needs. My heart went out to Mrs. B; she presented a mix of emotions including sadness, frustration, fear, and pride. Squeezing my hand, she said, "My husband has always put taking care of me and our daughters number one ... if he needs to do this, then I'll support him all the way, but I just don't want to see him suffer." She then broke into tears. We both knew that her husband would die soon and that this would be his last request.

As I left Mrs. B, my mind

shifted; I wondered how the receiving oncologist and residents would react to Mr. B's request? I caught up with them on rounds and asked to review Mr. B's case with them. They told me that Dr. Z had already reviewed the case with them and that they had seen Mr. B briefly. Fearing that the team may have already been influenced by Dr. Z, I began advocating for Mr. B. To my surprise the staff oncologist turned to the residents and said, "I'll support you if you think you can keep Mr. B alive five more days ... but it will take a huge commitment of your time to manage his care that closely. It's your call." Shuffling their feet in hesitation, the residents looked at each other and nodded in agreement that they would give it their "best shot." I felt so relieved that I almost missed hearing one of the residents say that he feared keeping Mr. B alive that long may be a medical impossibility; Mr. B's cardiac and respiratory status was deteriorating rapidly and adequate pain control would only suppress his respiration further.

Later that day, Mr. B's primary resident sought me out to tell me that Mr. B's condition was worsening. Anxiously, he said that he didn't want to have to intubate Mr. B and then be faced with having to withdraw life-support. Looking directly at me he said, "Please contact Mr. B's employer ... let's make sure his understanding of his company's regulations are accurate. If it is, then try to persuade his employer to make an exception to the rules." The resident seemed very hopeful, more than I was. But I agreed to give it "my best shot."

After obtaining Mr. B's consent I called his human resource representative who confirmed that Mr. B had to live until the first day of the month to collect fully on his benefits; the representative went on to tell me that he had explained this numerous times to Mr. and Mrs. B. Nevertheless, I asked and then pleaded for an exception to the rules emphasizing that this would relieve the pressure of a time line and free Mr. B to focus on being with his family in his final days. My plea for help did not move the human resource person; bureaucratic and inflexible, he expressed neither compassion nor regret but merely quoted policy. Even more frustrating was the newly uncovered fact that an employee would be totally vested in his/her benefit package after being out for three months on a medical disability which Mr. B had been, but the three months were accrued from the first day of month; Mr. B had stopped work in the middle of the month, so his three months did not start being accrued until the first of the following month. That such a technicality could have such a tremendously negative impact on a person's life seemed so unfair! Next, I called Mr. B's union office to see if someone would advocate for him. Although sympathetic, the union representative said that this was a negotiated contract and that there was nothing he could do to help Mr. B. I was given another corporate office number but that call also was to no avail.

Feeling frustrated, if not inadequate, I reported back to the residents that the corporation was inflexible and indeed, Mr. B

had to live until the first day of the month to be fully vested in his benefits. They listened, then vented their frustrations about how absurd such inflexibility was and carried on about bureaucracy in general. One resident said he had been dreaming about buying a particular vehicle made by Mr. B's employing corporation but swore he'd never buy this vehicle now! After expressing their anger and disappointment, it seemed that the residents settled in with renewed resolve to fight to keep Mr. B alive five more days to the first day of the month. Upon recollection, it seemed that the bureaucracy had become the enemy, perhaps a metaphor for death.

THE COUNT-DOWN, FIVE DAYS TO GO:

Day One: As supportive players in Mr. B's story the residents began to tell their own stories in relation to Mr. B's struggle. Mr. B's primary resident shared with me that the same manufacturing corporation had treated his grandfather very poorly years ago and told about how this had hurt his grandparents and his family. I found myself captivated by their sharing of hopes and dreams of having a family and about how they would want to be remembered. The residents also talked about their hope that they could help Mr. B beat the odds stacked against him thus enabling him to leave his family the legacy of a productive life vis a vis his pension, health benefits, and life insurance. I remember being intrigued by the team's conversation, particularly how it seemed to shift from confronting the bu-

reaucracy (as a metaphor for death) to the enduring quality of one's legacy (as a metaphor for life).

Day Two: The nurses' station hummed with activity. In the midst of all this I quietly watched as the residents pulled calculators and poured over lab results and resource books trying to make the minute adjustments that might optimize Mr. B's condition. Throughout the day I observed how they talked frequently and at length with Mr. B and his wife about his condition and their attempts to forestall impending death. It struck me that I had never before experienced physicians relating their technical, medical treatment so directly to a patient's story. As the social worker, it typically is my role to ensure that a patient's voice is heard, that his/her story is not lost among other stories and that the care provided is respectful to the patient's narrative. In Mr. B's case, the residents seemed to be assuming this role; while this was gratifying to observe I must admit it also felt a bit unsettling in terms of my role.

Day Three: The residents and the care team were managing to keep Mr. B viable without putting him in the Intensive Care Unit (ICU); but his room was beginning to look like a mini-ICU with all the respiratory monitoring they were doing. Residents, nurses, and respiratory therapists were constantly strategizing with one another about possible technical interventions that might help keep Mr. B alive. I reflected on the phenomena of the almost military approach to treatment that physicians sometimes take in

cancer care, which is often experienced by patients and families as distancing them from their physicians (Sontag 1989). However, in Mr. B's case such strategizing seemed to further unite the team with Mr. B and his family. Just when everyone thought Mr. B was unresponsive, he'd open his eyes and whisper, 'What day is it? What time is it?' His will to survive until the first day of the month seemed to energize the residents and the team; they marveled at him and talked with me about how they did not want to let him down. I was amazed at the intensity of their efforts and of the feelings evoked in staff as they worked to keep Mr. B alive. I remember beginning to worry how the staff would cope if Mr. B did die before the first day of month.

Day Four (Second Thoughts and the What-If's): Everyone seemed to be getting tired. So close to the goal, but yet so many hours away. So much could happen in the next 48 hours. In contrast to the previous day, the residents seemed to need to talk about whether they were doing the right thing, instead of what they could do clinically. They questioned how far they thought they should go with invasive life-prolonging care, and were worried about how they would handle the situation if Mr. B died just hours or minutes before midnight of the first day of the month. One strategy they came up with, was to make sure that the resident on call the last night of the month knew not to respond to a call from Mr. B's floor until after midnight, unless it was to respond to a pre-arranged number set up with the

nurses. This is just one example of the "what ifs" that the residents faced and processed. The "what ifs" were numerous. What if Mr. B died on the 30th and they falsified the time on the death certificate? Who would catch that? Would they lose their license? Would they be thrown out of the residency program? What if they did have to intubate Mr. B today or tomorrow? Would his wife have to sign a consent form to take him off the ventilator? Would his living will help in facilitating pulling life-supports? What if Mr. B's employer figured out that they had kept him alive just long enough to receive his benefits? Could the corporation deny his wife the benefits then after the fact? I tried to address the "what ifs" but they were overwhelming. I just kept reassuring the residents they were doing the best they could and validated all their efforts. It was a day of uncertainty clinically, ethically, and legally. The hours seemed to creep by.



Day Five, The Last Day of the Month: The last day of the month finally came; everyone was on edge and began counting down the hours. Intense, worried, but determined, the residents talked together about what they could do technically to keep Mr. B viable and alive until midnight. They continued to express fear about Mr. B dying before mid-

night. They also began to express sadness, anticipating that even if Mr. B made it through the day, he would die shortly thereafter. The focus of the medical team began shifting from fighting death to preparing for it and to saying good-bye. There were many good-byes being said on the floor that day; the residents would be switching to other medical services on the first day of the month. Typically residents celebrate going off the oncology service, but these residents were sad to be leaving. On the floors death is often viewed as a failure, as a defeat. Resident physicians tend to experience the oncology rotation as difficult because there is often so little hope of a cure. In Mr. B's case everyone seemed to accept death as inevitable, including Mr. B and his family, but the negotiated goal was to postpone his death. If successful, the team would have met the challenge of bureaucracy and won the battle against death by preserving the legacy of Mr. B's life.

Now there were only hours left to go. Mr. B's family also began talking about letting go; they believed that Mr. B would let go of the struggle to stay alive after he met his goal. I talked with family members about beginning to anticipate the end. They began actively grieving and arranged to spend the night with Mr. B. Their family minister came to sit with them through the night. When I went home about 5:30 p.m. everyone was settled in for the vigil. That evening it was so hard not knowing what was happening with Mr. B; yet, it seemed inappropriate to call in regularly to the hospital to check on Mr. B's

status, so I decided that I just had to wait until morning.

The First Day of the Month: Morning of the first day of the month came. I anxiously called in to the oncology floor. Mr. B was still alive! When I got to the hospital I saw Mr. B's primary resident; he told me that he switched his schedule around to be on-call for the oncology floor on the last night of the month. He said that he was too nervous to sleep so at 12:05 a.m. he went up to Mr. B's room. He said that Mr. B and his family were crying and celebrating that he had made it, but that it was a bittersweet victory celebration since they all knew that Mr. B would be letting go of his fight to survive now that he had met his goal. After talking with his resident, Mr. B opted not to be resuscitated. He also agreed to a morphine drip to control his pain knowing that this might suppress his respiration and thus hasten death. Respiratory monitoring and all blood work was stopped. On that first day of the month, Mr. B's family took turns staying at his bedside as he gradually became less and less responsive. Mr. B died on the first day of the month at 11:30 p.m. with his wife by his side.

CONCLUDING THOUGHTS

As I reflect on the case of Mr. B today I have renewed appreciation for the extent to which health care professionals contributed from their specific disciplines to Mr. B's care. Also, I am reminded of the power of story and of metaphor in the creation of common understandings in

patient care; paradoxically, we health care professionals may have to look upward to find our common ground. As illustrated in the case of Mr. B, unity was found in the metaphors of legacy and bureaucracy — or life and death, respectively. Sharing these metaphors enabled the health care team to acknowledge the vulnerability, strength and interdependence of the human spirit in each of us.

... We invent stories about the origin and conclusion of life because we are exiles in the middle of time. The void surrounds us. We live within a parenthesis surrounded by question marks. Our stories and myths don't dispel ignorance, but they help us find our way, our place at the heart of the mystery. In the end, as in the beginning, there will be a vast silence broken by the sound of one person telling a story to another. (1989, Keen & Valley-Fox, p.128) □

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