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VIEW FROM THE HOSPITAL BED

A Small Kindness

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On August 6, 2009, my vigorously healthy 59-year-old brother-in-law, a beloved husband and father of 2 sons, developed mild right hand clumsiness and slight slurring of speech. This led to a primary care visit and the symptoms were originally felt to be related to working long hours and stress. The symptoms failed to improve and on August 11th, an magnetic resonance imaging (MRI) made a shocking discovery, my brother-in-law had a brain tumor. He was seen in the Neurosurgery department of a major academic center the following day and on August 13th he underwent resection of the majority of the tumor with a pathologic finding of grade IV glioblastoma multiforme (GBM).

During this initial admission, a consultation was obtained from a neuro-oncologist who would then become the principle director of his care. My brother-in-law was crystal clear with his physicians; he wanted honest information about what to expect. From the outset he understood this was an incurable disease, but hoped that with aggressive treatment, he could live for months, possibly even years. He started chemotherapy almost immediately and in early October started a 6-week course of daily radiation. The early weeks went relatively well. He saw his oncologist regularly and stayed in close contact with his oncology nurse. With his engineering background and attention to details, he followed his physician's instructions to the letter; however, despite his very best efforts at compliance and working intensively with physical therapy he was becoming progressively weaker.

In early November, a follow-up MRI appeared to show progression of tumor and on November 12th, a second resection was undertaken. Pathologically, this seemed successful with removal of tumor bulk, but he was left even weaker, particularly on the right side. His symptoms were managed with dexamethasone; however, aphasia and hemiparesis would always reemerge with attempts to taper the drug and his functional status was too poor to allow for further chemotherapy. As his communication ability was becoming more limited, my sister-in-law was increasingly becoming his spokesperson at doctor visits and with phone updates to his oncology nurse.

On January 21, 2010 after working with a home physical therapist, he was making a transfer and became nonresponsive. Paramedics were called, arriving within minutes, but he was found pulseless. Despite a heroic resuscitative effort, he was pronounced dead at a nearby hospital a short time thereafter. A postmortem was not performed and the presumptive cause of death was pulmonary embolism.

His funeral was January 29th.

My brother-in-law and I lived 1600 miles apart and saw each other on only the rarest occasions. When the diagnosis was made, my role changed as I am the only relative within the extended family with medical expertise. Questions were directed to me via e-mails and I did my best using UpToDate and other resources to learn about GBM and relay this information back to the family.

Recently, and in a vicarious way, I was becoming more and more deeply involved. Using the best descriptions of functional status that I could extract from e-mail and phone calls, I estimated his Karnofsky Performance Score as being fairly poor. By way of my e-mails to him and his wife, I was just beginning, ever so gently, to touch on the subject of hospice care at the time of his sudden death.

At the visitation and reception following the funeral, I think I was seen as more than a distant brother-in-law; I was also seen as a surrogate for the medical profession and for his doctors in particular. One message that I got loud and clear, from more than 1 family member was the devastated, abandoned feeling that was emerging in the 8 days since his death. On the morning following his death, my sister-in-law called his physician's office and told his oncology nurse that her husband had died suddenly and unexpectedly the night before. The nurse expressed sympathy and indicated she would relay this information to his doctor and she would personally call back. As of the time I left to return home, that was the last communication any family member had received from anyone involved in his care.

Although the outpouring of community support and sympathy was powerful and touching, not a single condolence card or phone call came from his doctor. I was shocked at the suddenness of his death, but I was also shocked at the complete absence of any communication, any acknowledgement of his courageous struggle against a terrible illness, or of his family's depth of caring and love over these last few months.

I am reminded of an essay by Gregory Kane, MD in *CHEST*,[1] in which he describes a disturbing personal encounter with the following;

"In a personal and memorable patient encounter, I sat and listened while a tearful patient cried at having received no contact from the physician who treated her husband for metastatic lung cancer for a treatment duration of 9 months. As I struggled to comprehend her sense of pain and abandonment, I considered offering as possible explanation that the physician may not have been "on call" at the time of the death and may have mistakenly believed that his partner had offered such a gesture verbally. Before I could respond, however, my patient added that her veterinarian had sent a card when the family dog died. I was speechless."[1]

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TABLE 1. Considerations for Bereavement Letters

Handwritten on a card or stationary.
Timely (within 1-2 weeks of death).
Use sensitive, caring language and avoid cliché.
Acknowledge the family's grief and loss.
Acknowledge the patient's courage or other qualities.
Mention the privilege it has been to work with the patient.
Mention your appreciation of the family's caring.
Avoid "sincerely yours" and end on a personal note such as suggesting your thoughts are with them at this most difficult time.

As Hospitalists, we are gifted and privileged to work closely with patients and their loved ones struggling with the existential and eternal questions of life and death. As we can all well attest from 6 PM family meetings, the unit-of-care extends beyond the patient and certainly includes the loving and caring members of the patient's family and close support system. If we fail to acknowledge a family's bereavement, we run the risk of unintentionally communicating the message that the patient was not important, that their suffering did not matter or that the crushing grief the family may be bearing is somehow insignificant compared to our busy schedules.

I have asked you to join me on this short journey my brother-in-law has taken these last few months in the interest of raising awareness. There are many occasions when a verbal, bedside expression of condolence is very appropriate and completely adequate. There are other times when a condolence letter will better facilitate the closure of the physician-patient-family relationship. This may be intimidating, both the extra work involved and especially the challenge of not knowing what to say. The article quoted above by Dr. Kane is an excellent resource for guidance concerning content, style, and other writing considerations. Using examples, such as a letter from Abraham Lincoln to a girl whose father died in the Civil War, he shows that this essential communication does not have to be lengthy or difficult. Another excellent resource can be found in the *New England Journal of Medicine*; The Doctor's Letter of Condolence.[2] See Table 1 for suggestions to help with bereavement communications.

We are the profession of Hospital Medicine. It is our knowledge, our hope, our compassion, our experience and judgment that often directs care at the end-of-life for many of our patients. We are teammates along with the primary care provider, subspecialty consultants, palliative care specialists and other members of the care team. We have a professional obligation to extend a thoughtful condolence to surviving family members and to contact other members of the care team so that they too may have this opportunity. The responsibility for the final closure rests with us and within this responsibility is a powerful fulfillment of the promise of the practice of medicine.

The condolence note is a small kindness, a part of the art of medicine, a part of our humanness and essential to our vision of patient-centered hospital care.

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