INSTITUTE TO ENHANCE PALLIATIVE CARE

PALLIATIVE CARE
CASE OF THE MONTH

Her Way or No Way

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Case: Grace was a strong-willed and faithful African-American woman who loved to have things her own way. Throughout her struggle with cancer, her physicians came to know and respect her strength and independence. Yet somehow, the strong will that was praised throughout her cancer treatment presented challenges at the end of her life.

During the 19 months after diagnosis, 20% of Grace's days were consumed by outpatient treatments, appointments, and lab/radiology testing. Grace was admitted to the hospital for only seven days in these nineteen months. As the cancer progressed, she experienced extreme suffering, including repeated bowel obstruction, infections, surgical procedures, pain, fistulas, and anorexia. In the last six months of her life, Grace spent 73 days in the hospital (40% of the six month period), including one 40-day stay that included 20 days in long-term care. Grace was consistently approached, if not "hassled," during these admissions regarding her wishes regarding life-sustaining treatments and code status. Grace was extremely faithful to her religious beliefs. When approached with bad news, or the need to make decisions, she would refer to her belief in God and wanted to continue to press on with aggressive measures, taking great comfort in knowing that "it was in God's hands" and that the health care team was merely "carrying out his work." Prior to every discharge, she would be asked to consider hospice care. Grace continued to decline making these choices. Instead, she would reference her faith and remind us that "miracles happen." She desired treatment, surgical intervention, and artificial nutrition. At times, Grace was angry with the health care team because of these persistent conversations. She was clear that she wanted to come back to the hospital each time and never felt as though her care at home was lacking. Grace's family was protective and staunchly advocated for her wishes. Ultimately, Grace's cancer declared itself as she presented to the hospital one last time. In the emergency room, Grace and her family were asked one more time to consider the consequences of her wishes for aggressive care. Grace was minimally responsive and her family acknowledged that her comfort was now paramount. While her family declined aggressive measures, Grace was admitted and her family continued to carry on her faith in miracles. In fact, just hours before she died, her Pastor introduced himself and said was there to say a blessing when the miracle came. More than a dozen loved ones sang hymns at her bedside and prayed aloud while she quietly slipped away.

There, literally surrounded in a cramped hospital room, Grace died the way she wanted to. While many of us propose that a home death is a "good death," we must all stop to remember that it's not "our" death to decide. In this case, Grace died the way she lived, her way or no way. In fact, when she was admitted this last time, Grace told her physician not to worry, that "she would go home on Monday." Just forty-eight hours later, on a quiet Monday evening, Grace's faith was as evident in her death as it was throughout her life.

Discussion: The influences of ethnicity and spiritual beliefs on end-of-life care have been well studied and documented in the literature. Specifically, African-Americans are more likely to request life-sustaining therapies at the end of life and are less likely to participate in advance care planning. Prevalent beliefs in the community include the belief that only God has the power to make life/death decisions, strong beliefs in divine intervention, and that healing is influenced by spiritual beliefs and practices. Grace's case reminds us to consider the uniqueness of the individual, the person behind the decisions, and that it is not for us to make assumptions regarding what is "best" for people at the end of life.

References:

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