

Narratives on Pain and Comfort: Casey's Story

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Pain can be a body-wrenching curse. Yet it is often a life-defining and supporting blessing!

Pain is a distinct physiological event, yet it is also an emotional, social, spiritual, and economic force. Pain in its more destructive form alters lives, changes relationships, and disrupts families.

Quality pain management should not be just a pharmacological response to a medical situation; it must also be a theological, ethical, and societal response to human need. Appropriate pain management is a gift to both the receiver and the provider. As a parish priest, a supervisor of pastoral services, and an ethics resource specialist, I have seen many pain-filled situations that have involved multiples of these dimensions.

Casey's story

Born in 1969, Casey died in 1995, just a few months after his twenty-sixth birthday. Casey was an intelligent, charismatic college student, strong in religious faith, who had few problems ... at least until one day in the summer of 1994. That day he began to suffer extreme pain in his lower stomach and bowels. His mother, a registered nurse, realized that Casey's medical condition was not an ordinary bout of food poisoning or a stomach virus; she rushed him to the emergency department of a nearby hospital. After a quick assessment by the emergency room staff, Casey was given further tests. X-rays revealed a large mass in the lower gut. During the emergency surgery that followed, Casey was further diagnosed with signet ring adenocarcinoma, and a hemicolectomy was performed.¹ The diagnosis also included pelvic metastasis and periaortic lymphatic invasion.

Casey responded positively to his multiple traumas in the first weeks after surgery, soon beginning rounds of chemotherapy and later radiation treatment. He experienced some pain and discomfort that fall, but remained optimistic and active, well cared for by a cancer support team and concerned physicians. With the help of family and friends, he tried to return to college and to resume a fairly normal single adult life. That Christmas was one of the best ever for Casey and his family.

Toward the end of the radiation therapy in spring 1995, swelling in his left leg and groin area worsened as did his pain. Oral medications were augmented by a pain patch and then replaced by an infusion pump in order to provide more consistent pain control. Even when he had to wear a "buddy pack" of pain medication, Casey's attitude remained positive, interrupted only by bouts of greater discomfort and occasional depression.

Casey's condition slowly deteriorated through that spring, resulting in first one and then a second hospitalization. Notations in his chart referred to functional bowel and lymphatic obstruction, edema of the left leg, and enhanced pain management as reasons for both his May and June admissions.

Soon after the second admission, it became clear that Casey's disease was now progressing rapidly. Within days, it was agreed that a do-not-resuscitate status was appropriate. Remarks about pain and comfort measures became more common entries in his chart.

Friends brought guitars, videos, and their unflagging devotion. His pastor and the hospital chaplains listened to him and prayed often with him. Recreational therapists used taped music and other distractions to ease the slow passage of time when he had no visitors. Nurses and occupational therapists sought less stressful ways to position Casey's now gangrenous left leg. Family and friends shared

Journal of Law, Medicine & Ethics, 24 (1996): 292-93.

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their love and support many times in many ways each day.

Casey's primary medication was increased slowly from 20 milligrams per hour of morphine earlier in his disease to 90 milligrams per hour in his last two days. He died late one afternoon surrounded by family and friends, sheltered from the intense agony that would have been his without constant attention to his many dimensions of pain. In Casey's chart, the last progress note penned by his doctor reflected everyone's goal: "Casey died peacefully."

I have not recounted many of the details about Casey's life and death, but some points need more emphasis. The last eleven months of Casey's life began with intense pain and would have ended in great anxiety and unbearable pain had it not been for the interdisciplinary efforts of physicians, oncology staff, cancer support team, chaplains, family, and his faithful friends. Because of the loving compassion of those who cared for him and the various forms of intervention and diversion provided by each, Casey felt very supported in the way his pain was addressed and the various ways his life and approaching death were honored.

Even when resignation to death forcibly replaced his early confidence in recovery, quality pain management allowed Casey to focus on what was important to him. Being able to attend cancer support groups permitted him to

share his story, benefiting both him and others. Honest and open dialogue with his doctors about his condition and frank discussions with spiritual counselors about death and dying empowered Casey to retain some control as his earthly life ended. Because his energy was not totally consumed by the need to deal with constant pain, Casey was able to make meaningful choices and was able to find strength and hope, not in cure, but in wholeness. Casey died peacefully because those around him cared enough to listen to him, to accept and affirm the goals he established for his own pain management, and then to provide consistent and continual care in support of those goals.

Yes, pain is an important part of the created order when it provides a helpful warning; but it can also be a horrible dimension of the dying process. Quality pain management can be God's grace given to those in need by fellow human beings who care. May quality and appropriate pain management be the gift that we always share with all who are suffering.

References

1. Signet ring adenocarcinoma is a tumor that occurs in a high percentage of young colorectal cancer patients.