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Taking Care: Community, Family, and Dying in Place

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Introduction

Some time ago, early in my practice in Austin, a patient, well aware that she was dying of her cancer, talked to me about how she wanted to die. She would be looking out at the woods behind her house with her family near, still sensing the pulse of life around her. Her wishes were realized and we can say she "died in place." As important as it is to fulfill our wishes about the circumstances of our death, this often does not happen. Circumstances conspire to impede our wishes and we die in the hospital or in pain, or more often than necessary, both. Yet, as we shall see, it does not have to be this way.

That we have preferences about how we die is not in doubt. We have seen this in how we describe our deaths. On a day last summer (August 4, 2010) the following appeared on separate patients in the Statesman obituary column: "... were at her side when she died . . .," "... died peacefully . . . with his family by his side . . .," "... passed peacefully . . .," "... passed away at his home . . .," "... passed away with her family by her side . . .," and "... passed away peacefully at home."¹ These sentiments are supported by a national survey of more than 2,500 Medicare-age patients that indicated 86% wanted to die at home; only 9% wanted to die in the hospital.^{2,3} Yet we know that, for patients with cancer specifically, this is not how things play out. A recent report of the Dartmouth Atlas Project showed that 29% of Medicare-age patients dying of cancer die in the hospital. Twenty-four percent were admitted to the intensive care unit in the last month of life. Additional indicators of aggressive care were identified: chemotherapy in the last 2 weeks of life, low hospice admission rates, and late hospice admissions (3 days or less before death). Moreover, project data indicate that aggressive care in these cancer patients does not mean better care.⁴ A recent article by Temel et al reinforced this point.⁵ In this study of patients with lung cancer, one group received standard care and the other group received standard care plus consultation directed toward symptom control and quality of life. This latter group received less aggressive care with fewer hospitalizations and more hospice enrollments. Notably, in this

group, symptoms were better controlled and family satisfaction was better. And these patients lived at least as long.

Austin is not immune to these concerns. In Austin, 23% of patients with cancer die in the hospital. The number of days in hospital in the last 30 days of life is 4.4, compared with a national mean of 5.1. Days enrolled on hospice are 10.6, compared with a national mean of 8.7. Chemotherapy in the last week of life was 7.8% of patients, compared with a national mean of 6%. Our practice, Texas Oncology, looked at its own experience during this same time frame.⁶ Seventy-five percent of patients were enrolled in hospice at the time of death, with 57% dying at home and 28% dying at Hospice Austin at Christopher House (a free-standing inpatient hospice). More than 80% of these patients had pain well controlled. For patients not on hospice who died in the hospital, the last measurement indicated poorly controlled pain in 37.5%. A hospice enrollment of 3 days or less was associated with more severe pain levels.

A critical issue in this tension between wished for and actual place of death appears to be communication. A study of oncologists done in 2002⁷ indicated that 37% of oncologists discussed do-not-resuscitate orders at the time of diagnosis, 41% only when treatment was not working, 10% just before hospice referral, and 12% a few days or hours before death. In contrast, 90% of patients want to talk about advance care planning at the time of diagnosis and want to discuss this while they are still well.⁸ The consequence of this disconnect between oncologist action and patient desires is a misperception by the patients as to the likelihood of cure and predictable outcomes. Recent studies by Wright et al⁹ and Temel et al¹⁰ indicate that this situation can be improved by honest discussion about the goals of care.

The cancer community has recognized these shortcomings, and medical schools now more regularly offer courses in communication. There are also programs, such as Respecting Choices¹¹ and Oncotalk,¹² available to practicing professionals to help structure and add comfort to these discussions. Yet, the most critical aspect of improving com-

munication regarding cancer and other life-limiting disease may be empowering patients. In this age of easy access to information, one can be well aware of disease status. A recent consensus panel identified conditions in which assessment of quality of life and patient choices are paramount¹³: incurable cancer with limited life expectancy, frequent hospitalizations for a chronic illness, a decline in the ability to live actively or care for oneself, and increasingly complex care and requirements for support. In addition, ASCO has released a care guide for patients with advanced cancer.¹⁴ In it are a number of questions to ask the cancer care team: What is the diagnosis and what does that mean? What are my chances? What are the options? What is the goal of treatment; is there a chance of cure or only control of disease for a period of time? Only patients can know how a treatment will affect their life and what compromises will be necessary to receive that treatment. For patients with incurable disease, the ideal communication model is to have an informed and questioning patient and family and a cancer care team that is truthful and transparent about treatment choices, risks, and benefits.

So, our cancer patients in Austin generally receive less aggressive care at the end of their lives than those in the majority of other areas in the country. This is associated with more hospice care and likely more comfort and better quality of life. We are fortunate to have an extensive hospice community and professionals interested in comfort-directed care and caring for those with life-limiting illnesses. We have a 30-year history of access to hospice care and we have a free-standing inpatient hospice facility.¹⁵ Yet many communities do this better. There is more we can do.

Medicine, and cancer medicine particularly, exists on the interface of the human condition and science. The profession will always be distinguished by its human side—showing compassion, expressing empathy, detecting nonverbal clues, fostering confidence and comfort, framing meaningful discussions. Yet, it is science that continually informs and complements our interactions. This is evident by these recent studies. There is critical information to share so that we and our family members, when the time comes, will die in place. Both professionals and patients can take a more active role in communication, information sharing, documentation, and transparency.

And there is one more thing. A key component of a discussion on goals of care depends on a fair understanding of treatment choices. Atul Gawande, in a *New Yorker* article,¹⁶ felt it important to note that “hospice is not the difference

between treating and doing nothing . . . [it is there] . . . to help people with a fatal disease have the fullest possible lives right now.” There is an often-expressed tendency among physicians and patients to think that when there are no more technologic answers to care, there is nothing more to do. Yet the last days and weeks of a life may be the most intensely lived of all. There is a need to have the way one’s life ends reflect the meaning of the way that life was lived. There are at least issues of comfort, dignity, relationships, spirituality, finance, and legacy. These considerations became real to me with the death of my mother. Her lung cancer was diagnosed when her tumor caused a hip fracture. She was treated with radiation therapy for spread to the brain and had a short course of chemotherapy. She enrolled in hospice 2 months before she died, when it became clear there would be no benefit to further aggressive care. In her last few months, she was visited by her three sons and all of her nine grandchildren. She moved into my brother and sister-in-law’s house along with their four children. Her bedroom was a converted study on the ground floor. I was able to stay with my mother for a week while my brother and his family went on a much-needed vacation. As the week went on, she deteriorated rapidly. On the afternoon of her last day, she began to struggle with breathing and restlessness. At the bedside, holding her hand, I said to her that it was OK to go. It seemed to me, as it has to others in the same situation, that her struggle eased, and she died shortly thereafter. All of these things—family gatherings; attention to basic needs; maintaining dignity; arranging visits, volunteers, and sitters; keeping her comfortable but still engaged; and ultimately being present and giving permission—all of these things seemed to be so much more than doing nothing. We had hoped it was doing everything.

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Author’s Disclosures of Potential Conflicts of Interest

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Documentation and Discussion of Preferences for Care Among Patients With Advanced Cancer

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Abstract

Purpose: We sought to describe the documentation, frequency, and timing of discussions about patient preferences for care and to examine patterns of palliative care and hospice use among patients with advanced cancer.

Methods: We prospectively abstracted the medical records of 118 patients receiving care at a Veterans Administration (VA) facility from diagnosis of stage IV disease to 12 months postdiagnosis or death. We used univariate statistics to describe the type and frequency of documentation of patient preferences and palliative care/hospice referral. We calculated the time from diagnosis to the first documentation of preferences and the time from first documentation to death. We compared documentation of patient preferences between decedents and nondecedents using χ^2 tests.

Results: The majority of patients (81%) had some documentation of their care preferences recorded, although decedents were significantly more likely to have had their preferences documented than nondecedents (96% v 60%; $P < .000$). Most (53%) patients did not have a formal advance directive documented in the medical record. The mean time from diagnosis to the first documentation of preferences was approximately 2 months. More than half of all patients (53%) and almost three-quarters of decedents (73%) had a palliative care consultation.

Conclusion: Despite high rates of preference documentation, there remains room for improvement. Providers may need to be helped to identify patients earlier in their trajectory for appropriate palliative care services, and future work should focus on developing useful alternatives to advance directives for adequately documenting patient preferences.

Introduction

High-quality, patient-centered cancer care requires effective communication and coordination regarding preferences and goals of care, across settings and between patient, family members, and the multidisciplinary care team. A critical tool to achieving this is adequate documentation of patient preferences within the medical record, which helps to ensure that patient wishes are communicated and acted on across care settings and providers, and has been shown to increase patient autonomy in decision making and to decrease resource use.¹ Unfortunately, evidence suggests that documentation of preferences among patients with cancer is suboptimal,²⁻⁴ and as a result, providers are often unaware of their patients' preferences regarding treatment.⁵⁻⁸

In addition to adequate documentation of preferences, a growing body of literature has highlighted the relevance of having early and regular discussions about patient preferences to improving the quality of cancer care.^{9,10} Earlier discussions are associated with more preference-concordant care at the end of

life¹¹ and may lead to longer integration of hospice care^{12,13} and fewer aggressive interventions near death.¹² Early discussions about patient preferences may also lead to earlier palliative care use,¹¹ which has been shown to result in significant improvements in quality of life and mood among patients with metastatic cancer, as well as less aggressive care at the end of life compared with standard oncologic care.¹⁴ Such findings have led multiple consensus organizations to formally encourage early and regular communication regarding preferences and goals of care for patients with advanced cancer.^{15,16} To date, little is known about when or how often patients with advanced cancer have these discussions with their providers.

The purpose of the current study was to describe the documentation, frequency, and timing of discussions about patient preferences and goals of care, and to examine patterns of palliative care and hospice use in a prospective, longitudinal cohort of patients with advanced cancer at a large Veterans Administration (VA) medical center.