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CLINICAL VIGNETTE

Communication Pitfalls in Managing Patients at the End of Life

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A 28-year-old female teacher with advanced metastatic colorectal cancer presented to the Emergency Department (ED) with abdominal pain, generalized myalgias and weakness. She had a 25 year history of Crohn's disease, previously treated with vendolizumab and adalimumab. She was admitted after imaging found an obstructing abdominal mass and peritoneal carcinomatosis. Liver biopsy revealed poorly differentiated signet ring cell carcinoma and she underwent diverting colostomy. She was initiated on chemotherapy with fluorouracil/ leucovorin plus oxaliplatin **(**FOLFOX) and bevacizumab (Avastin). Her tumor progressed and she sought a second opinion who recommended immunotherapy. She explored options for immunotherapy and several months later travelled outside of the United States to receive six weeks of intrahepatic immunotherapy along with other complementary and alternative medications.

Shortly after completing immunotherapy, she returned to the United States and developed abdominal pain and came to the ED. She was re-admitted with an intra-abdominal abscess and as well as the advanced metastatic colorectal cancer. Initial evaluation was remarkable for abdominal tenderness, hypotension, tachycardia, leukocytosis and hyponatremia. Abdominal Computed Tomographic (CT) scans revealed progression of her tumor in the colon and liver as well as an abcess in the iliopsoas muscle. Sepsis was treated with broad-spectrum antibiotics and she underwent exploratory laparotomy with retroperitoneal debridement of the iliopsoas abscess. Post operatively she developed acute respiratory failure and ST Segment elevation in her anterior chest leads. Emergent echocardiogram revealed a large right atrial mass concerning for thrombus. As she was significantly coagulopathic she was unable to undergo an embolectomy. Palliative care consult was requested. After extensive discussions about her grave prognosis and the option of palliative care measures, she elected to leave the hospital in search of further 'curative options'. After two subsequent admissions for tumor progression and an episode of necrotizing fasciitis, she died.

Discussion

This very sad case raises multiple issues in the care of patients at the end of life and the interface between curative therapy, palliative care and the role of complementary and alternative medicine. Increasingly alternative treatments are being sought by patients with advanced malignancies where traditional Western evidence-based options are not effective or available. Our case highlighted the difficulties in communicating effectively what options were available and the gravity of her prognosis. Every patient has the right to seek treatments they deem appropriate. Health providers are duty bound to convey a prognosis and describe all the options for care in a way the patient and their family members can understand in order to make an informed decision.

Many oncologists are reluctant to recommend complementary and alternative medicine (CAM) treatments for cancer. CAM is defined as a group of diverse medical and health, practices and products that are not usually considered part of "conventional medicine".[1] CAM includes herbalism, spiritual therapy, dietary supplements, biofeedback, hypnosis, acupuncture, homeopathy, naturopathy, east-west medicine, chiropractic, massage, *tai chi*, yoga, electromagnetic therapy, and kinesiology. Studies suggest that oncologists may have difficulty recommending CAM due to lack of efficacy from clinical trials.[2] One study found 39% prevalence of CAM use among cancer patients.[3]

Not surprisingly, this patient's poor prognosis may have led her to pursue other opinions and treatments in an attempt to prolong her life. She clearly suffered complications after each futile treatment. After returning to the United States, she remained hospitalized with a poor quality of life for two months before she died. Masterson proposed a useful guideline to help patients and their families better understand complex prognostic information. They identified five distinct elements of prognostic understanding: understanding of current state of disease, life expectancy, curability, decline trajectory, and available treatment options.[4] It is incumbent on the treating team, including primary care, subspecialist consultants and palliative care physicians to make every effort to help the patient and their families understand these key components as part of the shared decision making process. The work of Masterson and colleagues provides a more comprehensive measure of prognostic understanding than was used in prior studies. After reviewing thirty-four studies of prognostic awareness, it was defined in one of three ways: curability (advanced, incurable, terminal, or life threatening), estimated life expectancy, and treatment intent (curative versus palliative).[5] This study improves our understanding of the multidimensional nature of prognosticating at the end of life.[4] With wider acceptance, it will allow patients and families to grasp prognosis in an understandable way.

Best practice guidelines suggest clinicians should understand patient's goals of care and preferences for information as part of providing high-quality care.[6] Discussions of goals of care that occur early in the course of treatment are associated with better quality of life, less invasive treatments near death, and reduced health-care spending.[7] Most patients in this study agreed with this assessment of patient's preferences for health information and goals as part of the process of prognostic discussion.

Some question who are the stakeholders in our patients' care? In addition to the patient and providers, the insurance company and hospital also play an integral role. We already know that the US has the highest per capita healthcare expenditures in the world, and hospitals and insurance companies are highly integrated in our healthcare system.[8] All stakeholders should be motivated to disseminate accurate information regarding traditional western cancer care as well as complementary and alternative medicine. Such discussions should occur in the office between the treating physician and patient, and also should also be reinforced by the other stakeholders before a patient seeks off-label therapy, often outside of the United States.

It is not clear to conclude the patient would have suffered less had she not opted for expensive invasive treatment. It is clear, however, that we need better guidelines and standards for cancer treatment discussions in a multidisciplinary environment involving the patient, physicians and other stakeholders including health insurance companies and hospital administration.[9] More research needs to be done to determine the best approach in advising patients who seek alternative medical care,[10] especially in countries where regulations and standards may be lacking.

REFERENCES

1. **US Department of Health and Human Services, National Institutes of Health**. The Use of Complementary and Alternative Medicine in the United States. In: *National Centre for Complementary and Alternative Medicine (NCCAM)*. 2008. https://nccih.nih.gov/research/statistics/2007/camsurvey_fs1.htm. Accessed 27 June 2017.
2. **Tabish SA**. Complementary and Alternative Healthcare: Is it Evidence-based? *Int J Health Sci (Qassim)*. 2008 Jan;2(1):V-IX. PubMed PMID: 21475465; PubMed Central PMCID: PMC3068720.
3. **Bahall M**. Prevalence, patterns, and perceived value of complementary and alternative medicine among cancer patients: a cross-sectional, descriptive study. *BMC Complement Altern Med*. 2017 Jun 30;17(1):345. doi: 10.1186/s12906-017-1853-6. PubMed PMID: 28666435; PubMed Central PMCID: PMC5493839.
4. **Masterson MP, Applebaum AJ, Buda K, Reisch S, Rosenfeld B**. Don't Shoot the Messenger: Experiences of Delivering Prognostic Information in the Context of Advanced Cancer. *Am J Hosp Palliat Care*. 2018 Dec;35(12):1526-1531. doi: 10.1177/1049909118780650. Epub 2018 Jun 12. PubMed PMID: 29895170.
5. **Chen CH, Kuo SC, Tang ST**. Current status of accurate prognostic awareness in advanced/terminally ill cancer patients: Systematic review and meta-regression analysis. *Palliat Med*. 2017 May;31(5):406-418. doi: 10.1177/0269216316663976. Epub 2016 Aug 4. Review. PubMed PMID: 27492160.
6. **Innes S, Payne S**. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med*. 2009 Jan;23(1):29-39. doi: 10.1177/0269216308098799. Epub 2008 Oct 24. Review. PubMed PMID: 18952746.
7. **Miovic M, Block S**. Psychiatric disorders in advanced cancer. *Cancer*. 2007 Oct 15;110(8):1665-76. Review. PubMed PMID: 17847017.
8. **Stub T, Quandt SA, Arcury TA, Sandberg JC, Kristoffersen AE, Musial F, Salamonsen A**. Perception of risk and communication among conventional and complementary health care providers involving cancer patients' use of complementary therapies: a literature review. *BMC Complement Altern Med*. 2016 Sep 8;16:353. doi: 10.1186/s12906-016-1326-3. Review. PubMed PMID: 27609097; PubMed Central PMCID: PMC 5016861.
9. **Emanuel EJ, Fuchs VR**. The perfect storm of overutilization. *JAMA*. 2008 Jun 18;299(23):2789-91. doi: 10.1001/jama.299.23.2789. PubMed PMID: 18560006.
10. **Hyodo I, Eguchi K, Nishina T, Endo H, Tanimizu M, Mikami I, Takashima S, Imanishi J**. Perceptions and attitudes of clinical oncologists on complementary and alternative medicine: a nationwide survey in Japan. *Cancer*. 2003 Jun 1;97(11):2861-8. PubMed PMID: 12767101.