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Tropical Spastic Paraparesis and End of Life Care

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The benefits of shared decision making in medical management are well established, but implementing its principles is often a difficult task. It involves extended conversations with patients, with obstacles including cultural and language barriers. Such barriers can be difficult to overcome, particularly with decisions involving death and end of life care.

A 73-year-old Haitian woman with history of spastic hyper-reflexic paraparesis, recurrent urinary tract infections (UTI) and chronic hyperkalemia presented to the emergency room with her daughter for back pain and dysuria, following a year-long history of multiple hospitalizations for pain and UTIs. She had worsening confusion, poor appetite, and occasional upper extremity trembling. Examination revealed a demented patient with abdominal tenderness and 3+ hyper-reflexic paraparesis of the lower extremities. Labs showed leukocytosis and hyperkalemia with a polymicrobial urine culture growing ESBL E. coli and Pseudomonas aeruginosa for which she was started on meropenem. Transtubular potassium gradient indicated renal tubular acidosis as a cause of her hyperkalemia and treatment with fludrocortisone corrected her potassium. Despite almost a week of treatment there was little clinical improvement; the patient was bed-bound and had poor appetite. Given her significant disability, testing for HTLV in the CSF (indicative of tropical spastic paraparesis) was performed, and came back positive. The patient's condition and prognosis as well as the family's values were discussed throughout, and as the burden of her chronic disease became evident, the consensus was to maintain comfort and request additional care through hospice. Thus, she was referred to hospice for symptom palliation, and she passed away surrounded by family two weeks later.

The lack of adequate communication with this patient and her family over several hospitalizations initially resulted in a care plan that was not aligned with the patient's values and understanding of her prognosis. Although her urine cultures were repeatedly treated with antibiotics, there was no meaningful recovery and this likely contributed to the development of her multi-drug resistant bacteria. With the current shift toward personalized medicine, it is important to involve a multidisciplinary team that includes the patient, family, and physicians to make collaborative decisions. Such an approach contributes to holistic care and outcomes better aligned with patient values; improved patient quality of life, better family perceptions of the healthcare system and lower potential costs from readmissions.

Biography

Hala Sheikh-Mohamed is currently doing her Internal Medicine Residency at the University of Central Florida/HCA consortium and hopes to pursue a fellowship in Hematology-Oncology in the near future. Dr. Sheikh-Mohamed is passionate about the early diagnosis and management of triple negative breast cancer but has unfortunately experienced limited early integration of palliative care services for patients undergoing treatment for these aggressive cancers. Dr. Sheikh-Mohamed hopes to work towards establishing a more standardize incorporation of early palliative care services that will address the early symptom burden, quality of life, and end of life care needs of all medical oncology patients.

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