



PALLIATIVE CARE CASE OF THE MONTH

“The Use of Narrative Medicine in Existential Distress”

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Case: Ms. S.T. is a 26-year-old woman with metastatic colorectal carcinoma who is admitted to the hospital with worsening abdominal pain. Imaging of the abdomen and pelvis demonstrates further progression of her cancer despite second line palliative chemotherapy. In addition to abdominal pain, she reports decreased appetite and nausea. No family is at bedside.

Despite aggressive titration of IV dilaudid via a PCA, she continues to report excruciating pain and frequently asks the nurses for higher doses of opioids. On evaluation, she spends the first few minutes describing her pain in great detail, but the subject quickly changes to other forms of distress. She spends a lot of time talking about her fear of dying, about how her cancer has taken over her life. She describes her dream to be the first person in her family to graduate from college, and her hopes to provide a better life for her family. She speaks passionately of her desire to help others, and her distress at not being able to help herself. She is angry at her cancer, at her doctors for not catching it sooner, and at God for “abandoning” her. Her parents are deeply religious and tell her that “things are in God’s hands,” but hearing this only makes her more upset. When discussing her concerns and general distress, her pain seems to fade into the background, and she only pushes her PCA once in the hour visit.

A multi-modal and interdisciplinary approach is put in place to help address her existential distress and total pain. The chaplain visits regularly, family and friends are encouraged to visit; psychiatry is involved to address concerns of depression. She wonders if there is a way to help give back, and take her mind off of things while in the hospital.

Discussion: Existential distress is quite common at the end of life, with some studies suggesting that 50-80 percent of terminally ill patients experience troubling thoughts about death, and only a minority achieve acceptance. While general consensus supports a multi-disciplinary approach to addressing existential distress, some more specific strategies exist such as cognitive existential group therapy, dignity psychotherapy, and meaning-centered group psychotherapy.

Another strategy is the use of narrative medicine through reflective writing. In fact, some studies have even shown benefits of emotional disclosure through patient narrative on pain and well-being scales, showing that narratives with higher emotional disclosure resulted in a significant decrease in pain and an increase in well-being scores.

Recognizing that a person’s illness is part of his life story acknowledges that we are all part of a larger life narrative – the story of ourselves, of our relationships, our love and suffering. We tell stories on a daily basis, whether consciously or subconsciously.

But in the setting of illness, personal narratives and identities often crumble. Rita Charon and others argue that narrative medicine is a model for empathy, and is beneficial not only to our patients, but to ourselves as well. Palliative care experts use narrative medicine often on a daily basis – giving patients and family members time to explore their illness through storytelling, and eliciting their goals and values in the process.

A specific technique in narrative medicine is the generation of a reflective piece through the 55-word story. The premise is simple: write for ten minutes about any topic or concern, and then spend another 10 minutes narrowing down the narrative to 55 words, cutting out the unnecessary words. This is a quick, and often very powerful, reflective tool. For patients searching for a legacy project, the exercise of writing – whether through an exercise like the 55-word story, or through journaling or some other form of expression – can serve this purpose as well.

Resolution of Case: Ms. S.T. decided that journaling would be a way to express her frustrations, but at the same time share her life lessons with her siblings and other young adults living with cancer. In this regard, she felt like it would be a good legacy project and a way to further give back at the end of her life. She often spent hours a day writing in her journal, and found that this helped ease her mind and took her thoughts away from her pain. She made it her goal to publish her journal so that it could continue helping others long after she had died.

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Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the *Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, beeper 412-647-7243 pager # 8513, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644 –1724, Interventional Pain 784-4000, Magee Women’s Hospital, beeper 412-647-7243 pager #: 8510, VA Palliative Care Program, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children’s page 958-3844. With comments about “Case of the Month” call Dr. Robert Arnold at (412) 692-4834.*