Social Determinants of Distress at End-of-Life

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Jason Parviz, DO

Hospice and Palliative Medicine Fellow, University of Minnesota

Disclosures

- No disclosures

Objectives

- Discuss how existential distress can contribute to "total pain" and complicate treatment of symptoms at end of life.
- Discuss how social factors can contribute to existential distress at end of life.
- Discuss how knowledge of prognosis can impact existential distress.
- Discuss some potential interventions for existential distress.

Case

- M is a 58 year-old man with widely metastatic prostate cancer, no other significant medical history. He was established with oncology and outpatient palliative care, but had multiple hospital admissions for uncontrolled pain near the end of his life.
- Social factors: Black, working class. In a long-term relationship with a supportive significant other; despite working full-time she was present in hospital with him a fair amount of the time. Several brothers who lived in the same city. Previous felony conviction.
- Personality: In a word, nice. This actually made it difficult to assess and treat him in some interesting ways.

Initial diagnosis and course

- Initial diagnosis of prostate cancer 12/2018
- Underwent TURP, chemo, radiation and was lost to follow-up for about a year
- Recurrence with spread throughout pelvis and bony and liver metastases 3/2020
- Restarted chemo and radiation, with intent shifting from curative to life-prolongation/symptom improvement
- Started following with outpatient palliative care 5/2020, and was maintained on a relatively low dose of p.o. oxycodone for much of that year.

A flurry of admissions- all for uncontrolled symptoms

- 9/9/2021-9/11/2021
- 10/14-10/17
- 10/22-11/6
- 11/9-11/24 (we'll spend some time here)
- 11/30-12/16 (and here)
- 12/20 ED visit
- 12/22-12/30 (died)

11/9-11/24: a broad overview

- He had significant progression of disease and obstructive uropathy on admission
- Had been on methadone 5mg TID and oxycodone 30mg q4h prn; his pain was still severe
- We treated pain very aggressively, increasing methadone and starting a fentanyl PCA.
- His fentanyl use skyrocketed- at one point he got 6000 mcg over a 24 hour period.
- He also had a number of other symptoms, including intractable GERD/hiccups (likely related to steroids), and had a number of other modalities (drug and non-drug) trialed for his pain and other symptoms.

11/9-11/24 continued

- He underwent TURP/TURBT/stent during this admission, which led to persistent urinary incontinence. This was extremely distressing to him.
- We also had several serious illness conversations with him and his family, he described these discussions as “preying on his mind” later in the course.
- Over time and as the team established a relationship with him, it became clear that much of his pain was “total pain” unresponsive to opioids
  - 11/23 Disclosed to our social worker that his pain “25% physical and 75% emotional.” Also disclosed that he had been robbed at gunpoint for pain meds in late October and did not feel very safe at home.
- He still really wanted to go home, and was weaned to oral regimen of methadone and hydromorphone and discharged

11/30-12/16: admitted again for intractable pain

- Had some issues with nausea and vomiting, as well as delirium. Not clear he was actually getting medications regularly- he had difficulty managing them himself, and his significant other, while very supportive, worked full time.
- He elected to discharge to a SNF on hospice because "I don't want to put my family through any more of this." His disposition was significantly delayed due to his previous felony conviction; it was difficult finding a SNF that would accept him.
- Once he was discharged with hospice, there was concern about care at the SNF, and specifically whether he was receiving medications in a timely fashion. Was noted to be "curled up in pain" on several visits.

12/22-12/30- Death in Hospital

- Was readmitted with intractable pain and terminal delirium. Was clearly actively dying on admission. Was not able to express preferences during this admission.
- Family felt they could not care for him at home due to symptom burden and inability to have someone available 24/7.
- Ultimately he remained in hospital on hospice (GIP status) and died peacefully on 12/30.

Interesting Points

- M’s pain and symptom regimens became very complex, and he received very high doses of opioids at some points.
- The interdisciplinary team was crucial in his care; he disclosed a great deal of what he was feeling and what was distressing him to the social worker.
- In the end it became clear that much of his distress was existential, and probably would have been better addressed in other ways.
- Death in hospital for terminally ill patients is often though of as a “failure” by the medical team. But in this case, both M’s family and the team viewed his death in hospital as the most desirable available outcome. This outcome would not have been available in some other settings.

The kitchen sink

- Oxycodone, fentanyl (PCA and TD), hydromorphone (PCA and PO), methadone (various doses)
- Dexamethasone
- Ketamine
- IV lidocaine (for renal colic)
- Acetaminophen, ketorolac, ibuprofen
- Duloxetine
- Ondansetron, prochloperazine, olanzapine
- PPI, H2 blocker, GI cocktail
- Lorazepam

Sources of existential distress for M

- Approaching end of life
- Rumination on his prognosis (especially after serious illness conversations in hospital). Would he have been better served by NOT having these conversations?
- Dignitary issues, mostly around urinary incontinence.
- Many options that are available to other patients (e.g. hospice in the home or SNF) were more difficult for M due to his socioeconomic status and remote felony conviction.

Social Determinants of Distress

- For understandable reasons, there's not much research into the ways that social factors impact existential distress. How would one study this? Perhaps start with some qualitative methods?
- We know that disparity in the provision of health care continues at the end-of-life. How much of this is due to inequity vs different preferences is questionable, and likely varies by the disparity in question.
- In this case, it's pretty clear that social factors limited what was available to M at the end of his life, and that this increased and complicated his suffering in a lot of ways.

Interventions for Existential Distress

- Counseling and psychotherapeutic interventions are a mainstay. Some specifically address concerns around meaning or spirituality (e.g. Individual Meaning-Centered Psychotherapy).
- Art and music therapy are excellent adjuncts.
- In cases of refractory existential distress, continuous deep sedation until death (palliative or terminal sedation) is an option, albeit a fraught one.
- The new cool thing appears to be psychedelic-assisted therapy, especially psilocybin- early research on this is pretty promising, and there are further studies proceeding currently.

Final Points

- Refractory pain (or other symptoms) may be related to existential distress
- Social difficulties (housing, finance, security, etc.) can be contributory to existential distress, and we should try to have resources available to address these.
- There are useful interventions available for existential distress, and we should probably be using them more and earlier.
- We should attend to the ways that disclosing prognosis can worsen distress.

Thank you for your time!

- Questions?

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