Managing End of Life Care in Homeless Patients with Substance Use Disorder and Mental Illness

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Alameda Healthcare for the Homeless Meeting
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Disclosures

- I work in public health for Contra Costa County
- Nothing to Disclose
Who Am I?
Objectives

- Identify risk factors that make care of homeless patients more challenging at the end of life
- Develop strategies to work with your team and existing resources to help homeless patients manage end of life issues
- Develop patient-centered care plans to manage substance use disorder and mental illness for patients in hospice/end of life
Agenda

- Review why hospice in homeless healthcare is important/vital
- Review challenges to providing this care
- Case Review
- Practical suggestions/solutions going forward
- Questions
People experiencing homelessness are well known to have shorter life expectancy compared to housed individuals. Mortality data suggests average lifespan as young as 50yo. Patients with Substance Use Disorder (SUD) also have increased risk of mortality. Scant studies around SUD and hospice often reviews of SUD and hospice also center on homelessness.
Causes of Mortality

- Increase in both common causes of death as well as population specific causes:
  - Late diagnosis of common and uncommon malignancy
  - Substance Use related diseases
    - Hepatitis C, HIV, etc
  - Untreated or undertreated common chronic conditions
    - DM, CAD, HTN, CHF, etc
Hospice and Homelessness: the good

“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

--Dame Cicely Saunders, founder of the first modern hospice
Hospice and Homelessness: the less good

- These patients can need more patience, understanding, energy
- SUD can make managing symptoms challenging
  - Hospice protocols around SUD can be antiquated
- Untreated or Undertreated Mental Health
- There is often less family to help hospice staff with day-to-day needs
- Trauma to other shelter/respite/homeless clients when patients pass
Local hospice agencies are supportive but less comfortable with our patient population

- Options from local hospice:
  - Pain medications are for pain, not SUD treatment
  - If someone continues to use this can be a reason to discontinue hospice services
  - "For patients with SUD we monitor closely if they are using street drugs so we can offset what we give," "rare cases we have had case conference and stopped orders until the patient is agreeable"
Hospice and Homelessness

- Trauma to other patients in shelter with hospice patients
  - Balance between patient comfort and shelter trauma
  - Shelter allows them to come/go and continue to use much more than SNF
  - Skilled Nursing offers more services, 24/7 care but often cannot come/go or use
Values and Goals

- Why are these cases challenging? Why does it make my stomach feel queasy?
- Moral Distress: when an outcome/action conflicts with our core values
- Values: our internally held beliefs
Values Clarification

- It is important for me for patients to trust my care.
It is important for me to provide compassionate care.
Values Clarification

- It is important for me for patients to be out of pain at end of life.
It is important for me that patients feel heard.
Values Clarification

- Reducing harm to patients is my biggest priority.
It is important for me for patients to live as long as possible.
Values Clarification

- It is important for me to have patients find recovery from substance use.
Values Clarification

It is important for me to have patients reach recovery by end of life.
Values Clarification

It is important for me for patients...
This is HARD!
Case 1 RP

- Metastatic prostate Ca, HIV
- Methamphetamine use disorder
- Reluctant to take any medications, reluctant to any treatment
- Heavy methamphetamine use, refusing hospice

Pt goals: to remain in motel with staff that he considered family
Shelter staff and HCH team were able to create "hospice" without Hospice
- Decreased med burden
- Allowed patient to use safely in shelter
- Regular medical check-ups in his room, focus on comfort – wasn't asking for pain meds (suspect self-treating)
Comfort Care in Motel, eventually transferred to Hospice at Skilled Nursing Facility due to pain control /physical immobility in motel, passed next day.
Lessons

- Flexibility – the patient had strong desire to stay in motel, how can we accommodate that, how is motel (due to covid) easier than shelter
- Addressing his goals/wishes/desires with or without hospice – we can focus on comfort with/without hospice
- Sometimes pain is being addressed in non-typical ways
Case 2: JH

- Lung cancer complicated by heavy alcohol use
- Did not want further treatment of his malignancy, on oxygen, DNR
- Multiple failed admits to skilled nursing for hospice due to continued EtOH use
- Hospice unwilling to supply pain management for symptom control/respiratory distress with ongoing EtOH use
- Had some improvement with naltrexone but limited option due to pain

Pt desires: pain relief, intermittently desiring to stop drinking
Care team meeting with our provider and Hospice team – agreed that HCH staff would hold/monitor narcotics – pt can remain in shelter setting (free to leave, drink, etc) – while enrolled in hospice

Addendum: pt has since graduated hospice, living in an apartment
Lessons

- Often decrease in substance use with adequate pain control, reiterate to hospice

- Utilizing relationship with patient to work with hospice and advocate for continued pain management

- Troubleshooting with hospice agencies – allowing their RNs and providers to feel more comfortable

- Future goal: values workshop/clarification around SUD with local hospice agencies
CM

- Hemolytic Anemia, Restrictive Cardiomyopathy
- Cocaine Use Disorder
- Followed all shelter rules, often getting weekend passes
  - Would use while on weekend passes, come back decompensated
- Well connected to health team: oncology, cardiology, HCH
- Oncology kept recommending 2nd, 3rd line treatments – didn’t see patient declining at shelter
Outcome

Patient died of unintentional OD in motel

- Family was able to visit before her passing
- Never enrolled in hospice
Lessons

- Care Coordination
  - Oncology in outside health system (cardiology, HCH, and PCP all able to communicate frequently around patient goals and wishes while oncology often remained overly hopeful)
  - Patient constantly asking us “what do you think is best?” – conflicting responses
  - Reminder to other care team we often know these patients best
How did Covid change things?

- Covid changed everything in our work
- Shelter > Motels
  - Hospice became more doable in motels for patient centered care but also felt riskier with locked doors
- Increase in non-covid death
  - Almost 50 individuals passed away in motels of NON-COVID related causes
    - Some OD, many more of chronic disease
  - Patient and staff trauma
Hospice in Covid

- Less options for hospice and skilled nursing
- Staffing shortages both with HCH, shelters, and hospice
What can we do to improve things?

- Communication
  - Patient
    - ACP
  - Hospice
    - Collaboration meetings
  - Primary care
    - Care conferences for high risk patients
Advanced Care Planning (ACP)

- More studies looking at homeless ACP than that of individuals with SUD
  - Similarities with SUD

- HCH teams know these patients, don’t defer to PCP or hospital
  - Upon intake into medical respite or even shelter – adv care planning conversation with MD/NP/PA or MH clinician
  - Goals, code status, important family members to contact
  - DOCUMENT in the EMR – emergency family/friends, wishes, etc
Common Patient Concerns

- Isolation/Anonymity
  - Will anyone know if I die?
  - What will happen to my body?

- Advanced Directives
  - Less likely to have advanced directives documented
  - More likely to want full code

- Role of family
  - Who a patient identifies for decisions
  - Not always blood relative

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**Physician Orders for Life-Sustaining Treatment (POLST)**

- **Cardiopulmonary Resuscitation (CPR):**
  - If patient has no pulse and is not breathing:
    - If patient is **NOT** in cardiopulmonary arrest, follow orders in Sections B and C.
  - **Attempt Resuscitation/CPR** (Selecting CPR in Section A requires selecting Full Treatment in Section B).
  - **Do Not Attempt Resuscitation/DNR** (allow natural death).

- **Medical Interventions:**
  - If patient is found with a pulse and is breathing:
    - **Full Treatment** - primary goal of prolonging life by all medically effective means.
      - In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
    - **Trial Period of Full Treatment.**
  - **Selective Treatment** - goal of treating medical conditions while avoiding burdensome measures.
    - In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV medications, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
    - **Request transfer to hospital only if comfort needs cannot be met in current location.**
  - **Comfort-Focused Treatment** - primary goal of maximizing comfort.
    - Relieve pain and suffering with medication by any route as selected; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. **Request transfer to hospital only if comfort needs cannot be met in current location.**

**Additional Orders:**

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**HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY.**
Pt: NR

- Metastatic Lymphoma with large necrotic axilla wound requiring frequent, time intensive dressing changes
- Significant methamphetamine use disorder
- No family involvement until patient dying, wanted to help – hospital discharged to sister’s house on hospice
- Hospice discharged pt from their services due to “agitation and continuing to use methamphetamine”

- Pt desires: scared, desired to be “out of pain”
Outcome

- Outcome: patient able to be transferred to Zen Hospice Project in SF
- Zen Hospice Project
  - “living facilities”, with 24/7 care
  - Harm reduction model
  - Started in the 80’s around AIDS
  - Closed due to finances in COVID
Lessons

- Harm reduction works!
- Benefit of Advanced Care Planning
- Reaching out to family sooner
Overall Lessons

- Recovery and Sobriety *can* but does not *have* to be the goal at the end of life
  - Decreasing pain and anxiety often decreases illicit substance use in the end of life
  - Substances other than opiates can be someone’s way of self-medicating, offering opiates can decrease other use

- Ownership of the relationships we have made with our patients
  - Having conversation early/often around goals, wishes, important people

- Continue to collaborate and educate hospice agencies around substance use disorders and harm reduction
What is your HCH practice around hospice? What’s worked? What hasn’t?

Do you offer POLST/code status forms for clients in shelter?

How do you communicate with hospice around these issues?

How do you communicate with Primary Care or Oncology (predominately) on these issues?

Is there pushback to harm reduction?
Questions
Most grateful to our clients and patients that have taught us everything we know.