Caring for Persons Experiencing Homelessness and Facing End of Life

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Overview

- Goals of Care
- Demographics, Diagnoses
- Advance Care Planning
- Management
- Models of Care
- Case Studies with Table Conversation
- Recommendations

Goals of Care in Homeless Setting : Same as any other end of life setting

- Providing best care at end of life requires that providers assist their patients in clarifying their priorities and establishing goals of care
- Patients maintain a sense of control by taking an active part in their treatment
- These are individual choices that may be different from those of the care team but should be respected and honored


AZ
Happy Birthday

Choices regarding various treatment options

- A major choice is when to stop attempts at curative treatment and elect comfort care only
- For some goal is to prolong life to the greatest extent possible, for others a greater priority is placed on comfort, independence, avoiding hospitalization, not having to move from where they stay, etc.
- Some find suffering intolerable and seek to hasten death.

Examples of Patient Choices

- Withdrawal of life-sustaining treatments such as chemotherapy, dialysis, ventilator support, pacemaker or AICD activity
- Cessation of food or fluids
- Palliative sedation
- “Death With Dignity” legal in seven states.
- Rights of both patients and providers to act according to own ethical and religious beliefs should be respected

Ability to discuss death openly…

- End of life conversations often difficult for both providers and patients
- Respect for the dignity and value of the individual person should be the basis for all conversations about end of life treatment options.
- More difficult for some cultures than others

Options for Integrative, Complimentary and Alternative therapies

- Many patients interested either for belief in cure or for symptom control.
- Examples are Traditional Chinese Medicine, acupuncture, massage, meditation, prayer, guided imagery, laughter therapy, yoga, healing touch, Reike, aromatherapy, nutritive therapy or herbal supplements
- Important to balance support for patient decision with avoiding endorsement of some treatments which are not evidence-based, particularly if patient holds belief of potential cure

Management

Pain and Symptom Management

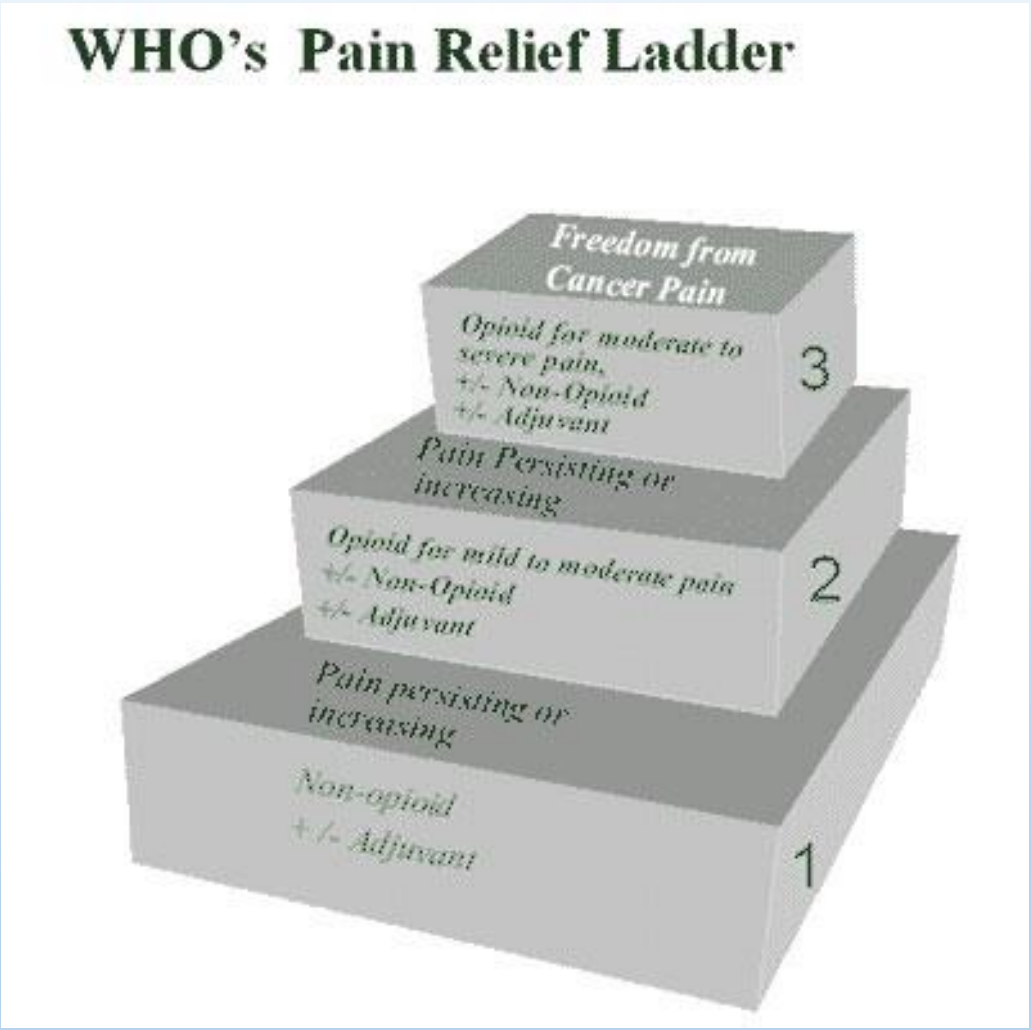
- Symptom management is one of the main ways to provide comfort and dignity to patients at end of life
- Primary focus should be on symptom prevention as much as possible, and then on prompt treatment when symptoms do occur.
- As patients get sicker they will have more problem visiting outpatient provider settings to seek help for symptom control. Hospice and palliative care teams have many advantages, but one is that the team will go to the patient's living environment to help with symptom management.
- Patient's support network very important when caregiving needed. Many persons experiencing homelessness are isolated.


Vintage 13
Moonshine

Pain Control

- Multiple studies indicate that pain is often untreated or undertreated
- Accurate assessment is crucial to developing a good plan
- Many standardized tools exist. Can use these tools, or simpler ones
- A patient should always be encouraged to describe their pain in their own words, and **a patient's description of pain intensity should always be considered accurate.**
- Providers should use every means possible to control pain while avoiding unnecessary side effects

WHO's Pain Relief Ladder



Three General Types of Pain

- **Visceral pain** is frequently described as poorly localized, cramping or squeezing. It is common in cancer patients who have abdominal metastases such as biliary or colonic obstruction. Adjuvant therapy aimed at the source of the pain is frequently added to opioids.
- **Neuropathic pain** is often described as burning, has a radiating character. Tricyclic antidepressants or anticonvulsants are often added as adjuvants.
- **Somatic pain** is usually well-localized. Source is skin or musculoskeletal, usually responds to anti-inflammatory agents. Bone pain frequently cannot be controlled on narcotics alone.

Opioids

- Remain the treatment of choice for pain at end of life.
- Providers should be comfortable making dosage conversions to switch from one opioid to another and when treating a patient with hepatic or renal dysfunction.
- When multiple doses are required per day a long-acting agent is usually started, with short-acting used for treatment of breakthrough pain.
- Different dosage forms may be needed (tablets, liquids, patches, suppositories, gels) in challenging situations
- Use lowest dose needed to control pain, avoiding effect called “opioid-induced hyperalgesia”

Concerns Regarding Abuse

- In today's medical environment, all providers have heightened concern about potential abuse/diversion of prescribed opioids.
- This environment presents special challenges for persons experiencing homelessness who have serious illnesses and a legitimate need for opioids to control pain.
- Challenges include finding a safe place to store their medications, and becoming vulnerable targets for those who would wish to steal them.
- When meds are stolen, providers are hesitant to issue new prescriptions, even when knowing there is a legitimate need.

End of life pain control in patients with substance use disorders

- Higher doses of opioids may be required because of pre-existing tolerance. May need to switch drugs, add adjuvants, use other modalities for pain control.
- Providers must be able to distinguish between behaviors stemming from inadequately treated pain ("pseudoaddiction") and "drug-seeking behavior."
- Pseudoaddiction symptoms will resolve when the pain is adequately treated. Drug-seeking behavior is likely to persist.
- **Always assume inadequately treated pain until proven otherwi**se.

Other symptoms

- Respiratory Symptoms (Dyspnea or “Air hunger”): Most effective pharmacologic treatment is opioids. Some patients may benefit from oxygen, although this presents a problem for some homeless persons who are staying in shelters.
- Neurologic Symptoms: Most common, often seen toward end of life, are agitation and delirium. These symptoms can cause distress not only for patients but for caregivers and health care providers. Delirium can have reversible causes such as medications, imbalance of electrolytes or infections. Both are treated with medications, usually lorazepam or haloperidol.

Bleeding

- Bleeding occurs in about 10-20% of patients with advanced cancers, and varies in character with the location of the cancer.
- When there is a risk of catastrophic bleeding, such as with end-stage disease in the GI tract or cancers in the lung, it is important to establish goals of care and plan for this eventuality with patient and caregivers. Advance Directives should address whether or not emergency services would be summoned, hospitalization or aggresive therapy undertaken.
- In congregate environments such as shelters or Respite Centers, plans should be made to minimize the effect of such a traumatic event for other residents or staff.

GI Symptoms

- Management of symptoms frequently requires dietary modifications, really difficult for someone who lives on the street
- Nausea and vomiting are frequent, sometimes as a result of chemotherapy or radiation, side effect of medications, or caused by disease itself. If cause can be identified therapy can be tailored to that etiology
- Constipation often occurs as side effect of opioid therapy. Need to be proactive about treatment, frequently pharmacologic since dietary fiber, fruits and vegetables often not available.

Anorexia (Loss of Appetite) and Cachexia (Weight Loss)

- Very common symptoms near end of life, although persons who have had inadequate access to food because of homelessness may be malnourished even before their illness, so more vulnerable to decline in muscle mass.
- Frequent cause of anxiety and guilt in families and caregivers.
- There are some medications that may be of limited usefulness, such as steroids that may also help with bone pain or nausea. Cannabinoids have been shown to increase appetite in AIDS patients, but not with cancer-associated anorexia.

Recommendations Regarding Symptom Management

- Encourage local shelters to permit adaptations in routine for patients with life-limiting illness who may require daytime rest, oxygen concentrators, secure locations to store controlled medications, etc.
- Investigate options for assisting patients who require opioid therapy and choose to remain in street environments. May mean providing storage for personal belongings
- Patients with need to use opioids to control their pain and who are at risk for opioid abuse, diversion or theft may need modifications in opioid prescribing, such as smaller quantities at more frequent intervals, a lock-box to store medications, and dosage adjustments.

Recommendations…

- Priority for prescribers is adequate pain control. Never assume “drug-seeking behavior” until pseudoaddiction (inadequate pain control) has been ruled out.
- Recognize that patients who obtain their food from congregate dining rooms, discarded or inexpensive sources may have difficulty modifying their diet to relieve GI symptoms. They may need education as well as extra support in identifying resources to obtain and store food.
- When Respite Centers are present in a community and able to care for patients with terminal illness, providers must still discern when and if patients need to be transferred to an in-patient hospice unit for symptom management

Recommendations

- Anticipate the impact of the dying process on other residents of a Respite Center, shelter or other congregate environment who may witness a seizure, bleeding or the death itself.
- Preparations should be made to provide emergency management and supportive care when these incidents occur. If a hospice agency is involved they may be able to assist in the process and provide emotional support and grief counseling to affected residents and staff.

Management

Substance Use and Mental Health

Effects of life-limiting illness on mental health or substance use disorders

- Fear and anxiety may exacerbate symptoms in individuals with mental health disorders who are facing end of life. Many homeless individuals specifically identify the fear of dying alone or anonymously.
- Dependency on alcohol or other drugs does not disappear in the setting of a terminal illness.
- In most cases, the stress of dealing with the illness exacerbates the reliance on the drug of choice

Harm Reduction Approach

- This approach is essential to increase access to care and enhance quality at the end of life.
- Includes practices that prioritize withdrawal management and ensure access to medication-assisted treatments when appropriate
- When withdrawal management is not an option, patients are still entitled to and afforded pain management. All healthcare providers should advocate fo pain management across all treatment settings for patients, regardless of the patient's addiction status.

Offering Social Support may involve…

- Family systems
- Financial assessment/aid
- Coping strategies
- Multidimensional stages of the dying process
- Manifestations of pain
- Modes of alleviating discomfort
- Specialized understanding of ethnic, religious and cultural differences
- Illness-related issues such as decision-making, relationshiup with healthcare providers, death and dying
- Special needs population

Spiritual Components

- Allow for expression of spirituality as defined by the patient, provide for spiritual rituals and support as patients request. Particularly important for those who identify with a given religion.
- Terminally ill patients often experience a spiritual crisis or awakening when coming to terms with their own mortality, sometimes involving a life review process.
- Care providers should use a non-judgmental approach to identify spiritual strengths, facilitate coping mechanisms, help the patient develop a connection to a faith community, or explore the patient's sense of the meaning and purpose of their life.
- People experiencing homelessness may have complicated grief issues, not only around their illness but also related to losses of homelessness

Benefits and Entitlements

- Multiple types of benefits are available though social security, Medicare, Medicaid, the Veteran's Administration, and Health Care for the Homeless services.
- Persons experiencing homelessness should be connected with a benefits or entitlements case manager at the local HCH for homeless-specific resources and care.

Expedited programs for those with terminal illness

- When a person with a terminal illness applies for SSDI or SSI disability benefits the Social Security Administration will process the application quickly under the terminal illness program (TERI)
- The Presumptive Disability program for SSI (temporary benefits for up to six months while the SSA processes a disability claim for someone with selected diagnoses or who is on hospice)
- The Compassionate Allowances program or the Quick Disability Determination (QDD) program (serious illnesses that obviously will qualify for disability)

Models of Care

Street and Shelter Based

Medical Respite

Inpatient

Street and Shelter Based Care

- Mobile Palliative Care Program for Homeless Individuals, Seattle (MPCH)
- Palliative Education and Care for the Homeless (PEACH) initiative in Toronto
- Pros: ability to meet patients where they are, offer services where no other good options exist
- Cons: sometimes difficult to coordinate care

Medical Respite

- The Inn Between in Salt Lake City, Utah
- Circle the City Medical Respite in Phoenix, Arizona

- Pros: wide variation of services provided depending on size and resources of the organization, easier to coordinate care
- Cons: limited beds, harm reduction models?, some patients not comfortable or accepting of the setting

Inpatient

- Laguna Honda Hospital in San Francisco
- Mission Diane Morrison Hospice in Ottowa

- Pros: experienced palliative care teams, comprehensive services
- Cons: limitations on beds available, harm reduction models?, some patients not comfortable or accepting of the setting

Circle the City Medical Respite

- Circle the City Medical Respite
- 50 bed free standing facility in central Phoenix, AZ
- 2 providers in clinic 7 days a week (MDs/DOs, PAs, NPs)
- Staffed 24 hours a day 7 days a weeks by nursing (RNs, LPNs), respite assistants and Security
- Case Management
- Physical Therapy
- Psychiatry consultations once a week
- LCSW specializing in substance abuse

Circle the City
healthcare for the homeless

Faith

- 48 year old woman with breast cancer.
- Admitted to Medical Respite to treat cellulitis of breast
- Over the next weeks, mass enlarged rapidly with ulceration through the skin
- Patient had a history of depression, PTSD and methamphetamine use disorder

Faith

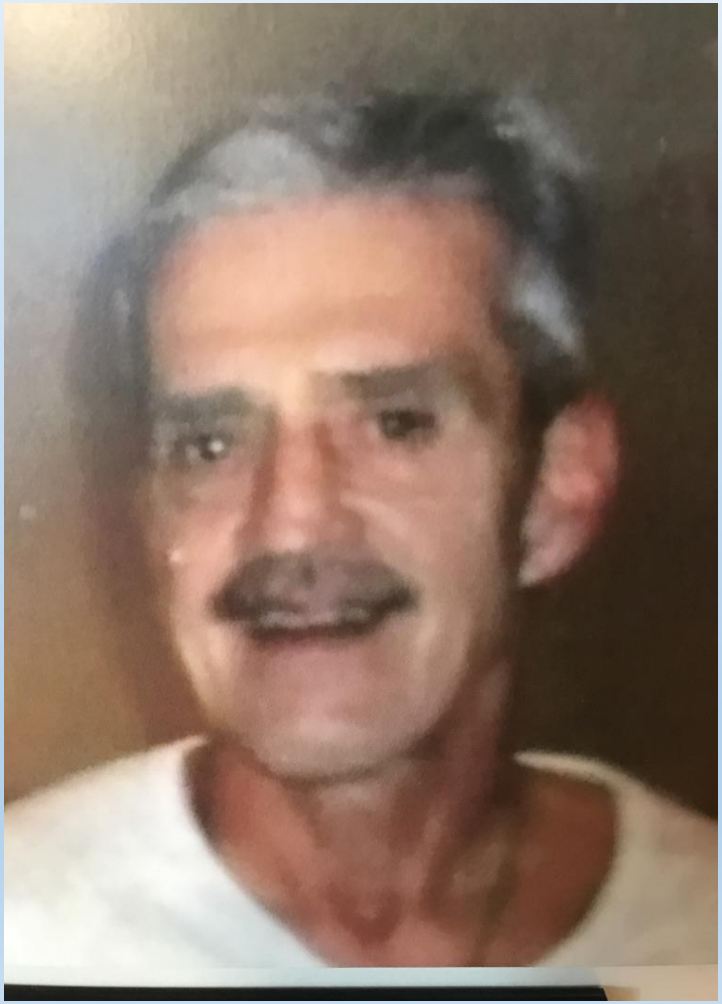
- Over the next two months, she began chemotherapy with noticeable decrease in size of tumor and plan was for mastectomy soon.
- She struggled with the site of her breast, scrubbing furiously at the fungating mass, often causing bleeding and increasing the local irritation
- Had many unprocessed feelings of anger and regret
- Emotionally labile while at Respite and declined many services offered
- Was ambivalent about continuing chemotherapy vs going on Hospice
- Left AMA twice to smoke meth

Faith

- Followed up intermittently in clinic thereafter asking for wound care supplies and pain medications, she reported she was being abused by boyfriend on the streets
- Was referred to Hospice of the Valley inpatient and left AMA several times.
- She stopped chemotherapy and ended up hospitalized 2 times for complications from metastatic disease (pleural effusions)
- Died 7 months after initial presentation

Kevin

- 58 yr old man initially admitted to Medical Respite for lower extremity ulceration and cellulitis, and reported abdominal “cancer”.
- Has history of Hep B and C and heavy heroin use currently on methadone



Kevin

- Worsening abdominal pain and vomiting 3 weeks into stay, sent to ED, after two week hospitalization, diagnosed with metastatic hepatocellular carcinoma with portal vein thrombosis

Kevin

- Came back from hospital signed up for Hospice serviced and on large doses of Methadone and Dilaudid, was very unhappy with pain medication regimen
- Argumentative, verbally abusive to staff and had many altercations with other patients
- Left AMA two days later

Kevin

- Started using heroin again and dropped out of Hospice care
- Living on the streets, but still maintained contact with outpatient clinic
- Considered for readmission to Respite two additional times in the interim but was not accepted

Kevin

- Accepted back into Respite January 11, 2017
- Pleurx catheter was placed to drain rapidly accumulating ascites with 2L drained daily
- Pain was controlled with Methadone and Dilaudid
- Passed away January 29th at 11:15pm

Michael

- 50 yr old man referred to Medical Respite from Maricopa County HCH clinic after being diagnosed with metastatic colon cancer

Michael

- Admitted for chemotherapy support, he was not a surgical candidate
- Multiple issues treated: candidal esophagitis, ongoing back and abdominal pain, pulmonary embolism, progressive neuropathy from cumulative effects of chemotherapy
- Trip to Colorado to visit his children and grandchildren whom he had not had contact with for over 10 years

Michael

- Stayed at Medical Respite from October 2015 to June 2016
- Discharged to permanent supportive housing
- Maintained contact with our outpatient family clinic
- Progression of metastatic disease noted on PET CT 11/2016
- Developed post obstructive pneumonia end of November
- Died at home with hospice services 12/12/2016

Discussion

- Unique examples of care
- Difficult scenarios
- Self Care for staff
- What could we be doing better?