Cancer, Palliative Care and End of Life Planning in Respite

Contra Costa Health Services
Sue Dickerson, RN, OCN
Nishant Shah, MD, MPH

Objectives

- After participating in this workshop, attendees will be able to:
- Identify local barriers to cancer screening, detection, diagnosis and treatment for individuals experiencing homelessness in their community
- Understand how the different strengths and limitations of your respite program can assist with providing respite care for cancer patients
- Plan initiating end of life conversations with patients/clients, discharge planners, shelter/respite staff, and HCH team members to support palliative and end of life care in respite settings.

Introductions

- Sue Dickerson, RN, OCN
- Nishant Shah, MD, MPH
- Go around the room:
  - Name
  - Where you are from?
  - Interest in Cancer Care and Respite

Homelessness and Mortality

- Multiple studies have looked at the increase in mortality of homeless individuals.
  - Age Adujsted Standard Mortality Rate
    - Shelter Population NYC: 3.9 times for men and 4.7 times for women[1]
- 65% of deaths among homeless patient were for acute and chronic medical illnesses including heart disease, cirrhosis, cancer, and pulmonary problems[2]

Cancer Prevalence and Incidence

- Multiple studies on Mortality and Homelessness have listed cancer as an important cause of death.
- No data on age adjusted rates of cancer among homeless indivuduals vs. housed population.
- Risk factors for cancer increased among homeless individuals:
  - Tobacco
  - Alcohol/Hepatitis C
  - HIV/AIDS

Contra Costa Healthcare for the Homeless

- 2012 Total Patients Served: 16,947
- Connected to a larger FQHC system including hospital, 8 outpatient primary care and specialty clinics, and mental health services.
- County owned insurance plan
- 2 county owned shelters including medical respite
- Clinical Services
  - Mobile Vans
  - Shelter based clinics
  - Respite Clinic (FQHC)

Cancer Care and Respite

- Why do we do it?
  - Personal comfort zone
  - You can actually provide care and treatment
  - Stopping the cycle of ER use/Hospital based care
  - Thinking more upstream (motivation to screen people if you take care of people with cancer)
  - Motivation of patients
  - Gives context to AOD and MH

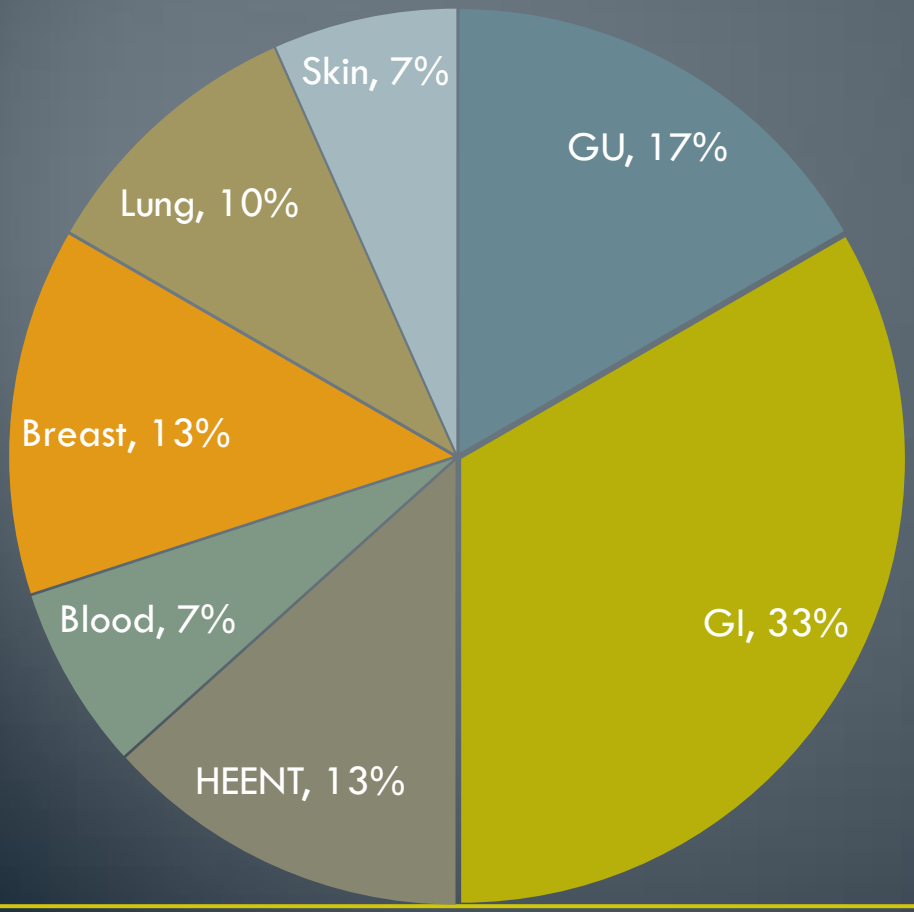
Cancer Screening Contra Costa Healthcare for the Homeless (UDS Data)

Preventive Health Screening & Services			
Year	**2010**	**2012**	**2013**
Cervical Cancer Screening	33.0%	36.4%	41.4%
Colorectal Cancer Screening	-	-	38.6%

Respite Care: Cancer Care

Year	Number of Patients Admitted into Respite	Number (%) with Diagnosis of Cancer	Number (%) with primary purpose Chemo/XRT
FY 2011-2012	155	1 (0.6%)	1 (0.6%)
FY 2012-2013	136	12 (9%)	6 (4%)
FY 2013-2014	177	18 (10%)	12 (7%)
FY 2014-Feb 2015	108	12 (11%)	10 (10%)

Cancer Types for Patients with Primary Purpose of Admission Cancer Treatment



Diagnosis	Number of Cases
Breast	4
Liver	3
Lung	3
Rectal	3
Prostate	2
Renal	2
Skin	2
Throat	2
Bladder	1
Colon	1
Esophageal	1
Gallbladder	1
Gastric	1
Laryngeal	1
Leukemia	1
Lymphoma	1
Mouth	1

Care Team and Continuum of Care

- Respite Nurse Coordinator
- Respite Community Health Worker
- Clinic Team – CHW, RN, and FNP
- Mental Health FNP
- Mental Health Specialist
- AOD Health Specialist
- Mental Health Transition Team (MFT on site)
- Housing Specialist/Case Manager
- Driver
- Shelter Staff

Respite Admission Process

- Hospital Discharge Planners Fax/Phone Nurse to assess patient for admission
- Criteria for Admission: Functional, independent, no daily nursing needs
- Respite = support, meets the basic needs so patients can contemplate their cancer diagnosis and engage in treatment plan.

Purposes of Admission

- Assisting with follow-up
- Awaiting Medical Procedure
- Chemo/XRT
- Connect with Mental Health Services
- Decompensated Medical Illness
- Medical Management and Teaching
- Post-operative Recovery
- Pre-operative Care
- Reconditioning/Rehab
- Respiratory Support/Rest

Linkage to Services

- Medical Imaging, Tests
- Pharmacy
- Primary Care Medical Home
- Transportation – ACS, Shelter Van, Vouchers (Discharge Hospital)
- Substance Use Services
- Mental Health
- Education
- Medication teaching, use, compliance, side effects

Assessment for Cancer Care in Respite

- Cancer Diagnosis/Stage
- Primary Care Physician
- Insurance
- Cancer Treatment Location
- Cancer Treatment Care Plan
- Pain Management
- Treatment Care Modalities
- Patients Self Care Risk Factors
- AOD history and current status
- Behavioral Health Needs
- Social Support
- Palliative Care/End of Life Needs

Cancer Staging

- Staging describes the extent or severity of a person's cancer. Affects treatment plan and prognosis.
- The TNM staging system is based on the size and/or extent (reach) of the primary tumor (T), whether cancer cells have spread to nearby (regional) lymph nodes (N), and whether metastasis (M), or the spread of the cancer to other parts of the body, has occurred.
- Based on:
  - Physical exam
  - Imaging
  - Surgery/Pathology reports

http://www.cancer.gov/cancertopics/diagnosis-staging/staging/staging-fact-sheet

Treatment Care Modalities

Importance of understanding treatment options on long term homelessness

- Self care options
- Hygiene
- Infection risk
- PICC Line vs. Port placement
- Toxicity of chemo and storage/safety issues

What is the patients priority?

- Sue Dickerson: Experience as a Cancer Center Nurse transitioning to Homeless Care
  - Experience of seeing patients with differing priorities while undergoing cancer care
  - Experience of counseling patients in Respite and understanding their cancer diagnosis and determining priorities for care, housing, social needs, family, support, etc.
- Can someone make an informed choice about the treatment if they are living on the street?
- Being in respite gives the patient a chance to make their cancer treatment a priority.

Group Activity

- Divide into group of 4-6 people
- Introduce the patient (i.e. Referral from the Hospital)
- What questions do you have for the discharging hospital: 10 min to discuss and share (is this patient appropriate for respite)
  - Concerns
  - Clarifications
  - Social concerns
  - Medical concerns
  - Mental Health concerns

Group Activity F/U

- **Present the Chart, Role play**

- How to assess functional ability?
  - Talking to D/C planner, Nurse, or Provider
  - Visiting the patient
  - High risk issues: Seizure, cognitive issues, TBI, severe mental health (behavioral disturbances), ADL's, has patient been out of bed, used the bathroom, review current meds (how much pain meds are they on?)

Group Activity F/U

- Develop a respite care plan (Admission Purposes and Linkage Services), i.e. what does the patient need? What additional information do you need?
- **In your group fill out the worksheet in regards to the care plan - 30 min**
- Return to the group and present the following information:
  - What services are most important for this patient and are you able to provide this to the patient?
  - Anticipate the length of stay in relation to length of treatment?
  - How long can you sustain supporting this patient? What barriers can you anticipate to supporting treatment?

Group Activity F/U

- Patient arrives to Respite
- Face-to-Face Intake: **Role Play**
  - Inform patient of Admission Purpose
  - Orientation to the respite program/shelter
  - Complete intake process
  - Review discharge information
  - Med reconciliation
  - Insurance issues, ID
  - **Elicit patients concerns**
  - **Start building trust**
  - Set up provider visit within 2-3 days

Addressing Common Barriers

What common barriers to care do you see in your respite setting?

- Insurance
- Pain management
- Coping with a new diagnosis
- Taking ownership of care plan can be distressing to the patient

Motivational Interviewing

- Motivational interviewing techniques
  - Empathic Listening
  - Open ended questions
  - Affirmations
  - Reflections
  - Summary statement
- Hospitals are a controlled environment. Instead of doing things TO the patients, we prefer to do things WITH the patient.
- As care givers, we are comfortable taking control of the medical problem.
- Re-do **Role Play**

Trauma Informed Care

- Trauma History
- Sharing can be distressing. How do you give patient the space to share.
- Using the entire care team to “listen” to the patient, when the patient is ready to disclose concerns, it may not be to a specified team member
- **Self care for providers**

Group Activity

- We welcome anyone to share any patient/personal stories
- Additional Case Studies

Treatment Care Plan

- Implement admit purposes:
  - Plan to meet weekly to update where are we with things.
  - Reinforce advice numbers/persons to call.
  - Delegate tasks – who on your team does different tasks (appts, insurance, transportation).
- Treatment starts:
  - At this point, people have trust and understand the purpose
  - The oncology team may not know what is going on behind the scenes
  - Focus changes to reactive issues that come up (side effects, legal issues, family issues, relapse, etc)
  - Workload is often shared with the oncology clinic, social work within the system of care and the HCH team.

Treatment Care Plan (cont)

- Help re-establish social support.
  - Often times family will step into assist with going to appts, transportation, but rarely will offer housing.
  - What is the patient willing to do around their social support.
  - Support may come from respite/shelter (staff and residents).
- Reassess admission purposes:
  - Especially if patients are re-admitted.
  - At each return to respite, reassess needs and purpose (may change to palliative/hospice care)
  - SNF (higher level of care)
  - Pain control needs
- Appointments – missed appts are not an issue, however, med compliance can be an issue.

Ensuring Successful Treatment

- **Med compliance** – some people aren't used to taking meds, need to take meds before side effects/symptoms occur
- **Utilization of ER/Inpatient services** - need to provide a warm handoff, patients won't advocate for themselves around side effects/symptoms.
- **Substance Use** – Often times reduced use during treatment, will not let it interfere with care plan, or they have more advanced disease.
- **Mental Health** – Depression may improve, find a purpose around pursuing cancer treatment. Doing something about their problem.

Tolerating chemotherapy

- Side effects (Nausea rare in patients with history of alcoholism)
- Patients tolerate treatment very well
- When side effects occur, patients may wait until symptoms are very severe before disclosing them or presenting for care.
- Insight into side effects due to chemo
- Functional Status while on Chemo/XRT

Palliative Care

- Hospice vs. Palliative Care
- Goal of treatment is comfort and not cure or extending life.

Palliative Care

- Request a palliative care consult for the chronically ill, hospitals need permission from us to get the palliative care consult. Patient is aware of the need more than we are. It is important to having the conversation started in the hospital.
- Addiction, trauma, mental illness, reconnect to family, forgiveness, healing past trauma may begin after the palliative care consult

Palliative Care Counseling

- Counseling patient on goals of care and treatment plan
- Is palliative care a permanent choice? What would be a reasons to reconsider goals of care?
- How would goals change if housing plan changed? Social support? Sobriety achieved?

AODS and Palliative Care

- Is Alcoholism, Meth use, Cocaine addiction a terminal disease?
- What would it look like to treat addiction from a palliative care approach?

When to Consider Palliative Care?

- Any diagnosis can qualify for a palliative approach to care.
- Severe Cardiopulmonary Disease, COPD, Heart Failure, Cirrhosis, Cognitive Decline, Substance Use, etc.
- Consider after repeat admissions to the hospital

Documenting Patients Wishes

- POLST: Helpful when communicating within health systems, EMS, hospital providers
- 5 wishes: Very patient centered, but must pay to use these forms
- Institute for Healthcare Advancement: Low literacy forms

Many forms are state specific

References

1. Barrow et al. Mortality among homeless shelter residents in New York City. American Journal of Public Health April 1999: Vol. 89, No. 4, pp. 529-534.
2. O'Connell JJ. *Premature Mortality in Homeless Populations: A Review of the Literature,* 19 pages. Nashville: National Health Care for the Homeless Council, Inc., 2005.