END OF LIFE/PALLIATIVE CARE MODELS AND CHALLENGES IN A MEDICAL RESPITE SETTING

2018 Medical Respite Training Symposium
Phoenix, Arizona
October 1-2, 2018
PRESENTERS

• Brooks Ann McKinney, MSW
  → Head of Vulnerable Population for Cone Health Hospitals

• Kim Despres, RN DHA
  → RN Program Director, Circle the City Medical Respite Programs

• Melissa Brown, LICSW
  → Manager Edward Thomas House Medical Respite, Harborview Medical Center

• Melissa Sandoval, MD
  → Medical Director, Circle the City Midtown Medical Respite Center
LEARNING OBJECTIVES

• Identify different models of care when addressing end of life issues within a medical respite setting.
• Discuss different staffing ideas, and ways to collaborate with other agencies to partner and visit patients on site to facilitate care.
• Identify challenges that may arise in this type of setting, and possible solutions. Also there will be strategies to support self care for clinicians, and ways that staff and consumers can come together to celebrate the lives of ones that pass.
CIRCLE THE CITY

- **Model of Care**
  - Collaborative relationship between hospice and medical respite center
  - Referral is called and faxed through intake line
  - CTC Intake nurse visits patient in person to assess for appropriateness
  - Nursing and social work support from hospice
  - Medications delivered from hospice pharmacy
CIRCLE THE CITY

Admission Criteria

→ Age 18 or over
→ Homeless or imminently homeless
→ Independent in ADLs
→ Psychiatrically stable
→ Does not require medical management for opiate, alcohol, or benzodiazepine withdrawal
→ Does not require secure dementia care
CIRCLE THE CITY

• **Staffing Model**
  → CTC staff provide care 24/7
  → Nurses, respite assistants and providers
  → Hospice nurse visits 2 to 3 times per week to assess patient to determine clinical and equipment needs
  → Hospice social worker visits routinely to assess social needs
  → CTC staff and hospice staff collaborate on meeting needs
CIRCLE THE CITY

- **Staffing Model**
  - As patient nears end of life, patient is placed in private room
  - Hospice nurse increases frequency of visits
  - Medical respite will provide sitters or volunteers to remain at patient’s bedside
  - Medications administered as needed for comfort and pain control
EDWARD THOMAS HOUSE MEDICAL RESPITE

VIDEO – palliative care respite patient
EDWARD THOMAS HOUSE MEDICAL RESPITE

Model of Care

Harborview Medical Center – Downtown Programs

- Edward Thomas House Medical Respite
- Pioneer Square Clinic
- DESC shelter clinic
- Healthcare for the Homeless RNs in shelters and housing programs
- Homeless Palliative Care Team
- Housing provider partners
EDWARD THOMAS HOUSE MEDICAL RESPITE

Model of Care

**Screening** - Must meet basic admission criteria
- Homeless
- Independent in ADL's
- Mobility of 250 feet
- Not a sex offender
- For palliative care patients – determine goal for stay at respite
  - Develop or consolidate treatment plan
  - Diagnostic workup and staging
  - Engagement and building of trust in the healthcare system
  - Engagement with treatment plan and patient development of goals for care
EDWARD THOMAS HOUSE MEDICAL RESPITE

Model of Care

Screening – POLST form and Code status completed

Admission

• POLST/DNAR/DNI
  • Place in medical record
  • Posted above patients bed
  • Posted in main office
• ARNP evaluation and admission orders
• Psychosocial assessment and discharge planning
EDWARD THOMAS HOUSE MEDICAL RESPITE

Model of Care

During respite stay
- Daily nursing visits, ARNP consults prn
- Case management
  - Connection to primary care
  - Connection to the homeless palliative care team
  - Housing search and applications
- Assistance in coordinating transport to all medical appointments
- Patient must remain completely independent in ADL’s
EDWARD THOMAS HOUSE MEDICAL RESPITE

Staffing

- Nursing: daily 7am – 1130pm
- Mental Health Case Managers: Monday to Friday
- ARNP: daily
- Mental Health Specialists: two on shift 24/7
- MA: daily
- Medical Director
EDWARD THOMAS HOUSE MEDICAL RESPITE

Challenges and Strategies

• Difficult to find our niche, sometimes the patient is too healthy and other times the patient is too sick
• Once patient is no longer independent in ADLs we must discharge from respite (hospital, hospice, snf, housing with home health)
• Staffing – we accommodate increased need for as long as we can, but are unable to provide hours of 1:1 care
• Pain management
  o Oncologists don’t have daily information on patients that are over-sedated and/or using drugs. They typically won’t provide daily or q three days pain rx
  o Respite providers worry about interaction with chemotherapy agents and medication regimens
Medical Respite in North Carolina

- **Collaborative models of care**
  - Designed for smaller programs
  - Contracts with hospice agencies to come on site/in coordination with primary doc at HCH clinic
  - Hospitals assess for palliative care and refer to resources before discharge to respite program
MEDICAL RESPITE IN NORTH CAROLINA

• **Staffing**
  → All staffing contracted from local hospice agencies and/or home health from local hospitals.
  → In Raleigh, once patient was at last stages, was transferred to nursing facility.
Medical respite in North Carolina

- **Staffing**
  - Home health from local hospital would come and do IV if needed
  - Palliative care staff and chaplain involvement if needed, making sure that other patients in program had support.
  - Meds for pain kept same as others.
Medical respite in North Carolina

- **Challenges:**
  - Lack of clinicians on site, worries if falling
  - Strategies: collaboration is key
  - Started a rose garden for patients who passed away
  - The story of Pops
CLINICAL CONSIDERATIONS

CHALLENGES

• Pain management

• Terminal restlessness (delirium, agitation)
PAIN MANAGEMENT

- Can be complicated by comorbid opioid use disorders

- At the end of life, the patient’s description of pain intensity should always be considered accurate
KEVIN

58 year old man initially admitted to Medical Respite for wound care for a lower extremity ulceration and cellulitis. 30 year history of heroin use.
• 3 weeks later...worsening abdominal pain and vomiting, sent to ED
• 2 week hospitalization, diagnosed with metastatic hepatocellular carcinoma with portal vein thrombosis
• Came back from hospital signed up for Hospice service and on large doses of Methadone and Dilaudid, was very unhappy with pain medication regimen

• Left AMA “I’d rather use heroin than be here”
• Started using heroin again and dropped out of Hospice care
• Lived on the streets for the next 5 months, but still maintained contact with outpatient clinic
• Restarted methadone treatment, eventually readmitted to Respite for end of life care
• Catheter placed to drain rapidly accumulating ascites with ~2L drained daily

• Pain was controlled with Methadone and Dilaudid
  → Methadone 120mg daily
  → Dilaudid 4mg-8mg q 1 hour prn

• Passed 19 days after readmission
TERMINAL RESTLESSNESS

• In advanced illness, confusion and terminal restlessness or agitation are common.
• Can include impaired consciousness, hallucinations, paranoia and disorientation.
TERMINAL RESTLESSNESS

• Important to ensure safety of the patient during this time with consideration to transfer to higher level of care
• Precedes “active dying”
• Usually a few days in duration but can be a couple of weeks
DAWN

52 year old woman with metastatic cervical cancer. Prolonged stay (8-9 months) at Respite for radiation/chemo/surgery, ostomy placement. Discharged to permanent supportive housing
• While living on her own, continued treatment with support from other patients/friends she met at CTC
• After ~1 year on her own, had disease progression, given 1-2 months to live requested to return to CTC on Hospice
• Metastatic disease to liver
• Problems controlling anxiety led to increasing doses of lorazepam
• After 3 weeks, began to have paranoia, perceiving other patients to be banging on walls at night, throwing shoes at her door and threatening her
• Around this time, also reported she felt her body was “shutting down”
• Medications changed with improvement
  → Decreased lorazepam
  → Started quetiapine
• 1 week later, after informing the provider in the morning that she was “so sick but I can’t explain why”...
• She fell in her room sustaining head laceration
• She was evaluated by Hospice Nurse and transferred to an inpatient hospice unit
• Passed away 2 weeks later inpatient hospice
SELF CARE

• Patient Town Hall usually held to announce the death of a hospice patient
• Services arranged usually led by hospice Chaplain
• Patient’s family, outside friends, CTC friends and staff invited to attend and speak
End of Life Care

Clinical Practice Adoptions

Adapting Your Practice: Recommendations for End-of-Life Care for People Experiencing Homelessness (2018) | This document is part of the network’s series of practice adaptations developed by clinicians working in HCH projects.
Q & A