End of Life Care at the Barbara McInnis House

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Objectives

- Learn about the collaboration between the Barbara McInnis House and the Palliative Care Service at Massachusetts General Hospital and how that collaboration helped to grow our EOL program
- Understand the burden of symptoms among dying homeless adults
- Learn how to use the palliative performance scale to estimate prognosis
- Review some protocols that can help staff do this difficult work while improving quality of care for patients
- Discuss ways to help support staff and the community in their grief

Fears about death

- Dying anonymously-un-memorialized
- Fractured relationships
- Death anxiety
- Not being treated with respect
- Lacking control with regard to EOL decisions
- Having care imposed on them

(*Song, J of Gen Int Medicine,2007*)

BMH/MGH Palliative Care Collaboration

- “Train the trainer” model
- Build local expertise
- Champions who receive additional training in advanced palliative care topics –curriculum around advanced care planning, determining prognosis, symptom management
- Development of protocols and models
- Research

Research

- Examined the care of patients receiving EOL care at BMH
  - Interviewed patients
  - Retrospective chart reviews for deceased patients
  - Interviews with interdisciplinary staff
  - Survey of attitudes concerning death, EOL care and symptom burden in terminally ill patients

Symptom Burden

- Pain (70%)
- Lack of energy (75%)
- Paresthesia's (60%)
- Cough (60%)
- Dry mouth (60%)
- Shortness of breath (55%)
- Difficulty concentrating (50%)
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- Irritability (50%)
- Depressed mood (50%)
- Anxiety (50%)
- Drowsiness (50%)
- Feeling ashamed, embarrassed or degraded at least a few times a month (30%)

(Tobey, et al. In progress)

Palliative Performance Scale

%	Walking	Activity/ Disease	Self-Care	Intake	Conscious	days
70	Reduced	Can't do Job Some Disease	Full	Nl or Reduced	Full	145
60	Reduced	Unable House Work Significant Disease	Occasional Assistance	Nl or Reduced	Full or Confusion	29
50	Mainly Sit/Lie	Unable Any Work Extensive Disease	Considerable Assistance	Nl or Reduced	Full or Confusion	30
40	Mainly in Bed	As Above	Mainly Assistance	Nl or Reduced	Full/Drowsy /Confusion	18
30	Bed Bound	As Above	Total Care	Reduced	Full/Drowsy /Confusion	8
20	As Above	As Above	Total Care	Minimal Sips	Full/Drowsy /Confusion	4
10	As Above	As Above	Total Care	Mouth Care	Drowsy or Coma	1
0	Death	-	-	-	-	

Sample End of Life/Comfort Care Orders for EOL Patients at BMH

- **Sample End of Life Care/Comfort Care Orders for EOL Patients at BMH**
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- *Pain Control and/or control of dyspnea:*
- Standing order: Morphine sulfate (concentrate) 20 mg/ml oral soln 0.25 ml by buccal mucosa q 6 hours.
- PRN order: Morphine sulfate (concentrate) 20 mg/ml oral soln may give 0.5ml by buccal mucosa q1 prn air hunger or pain
- Acephen 650 mg supp 1 supp pr q 6hrs prn pain and fever. give if unable to take po form
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- *Delirium/Agitation*
- Haloperidol lactate 2 mg/ml conc 0.5 ml by mouth every 8 hrs (standing). for agitation
- Lorazepam 2 mg/ml soln 0.25 ml by buccal mucosa bid anxiety. may have 0.25 ml by buccal mucosa q3h prn anxiety
- Chlorpromazine hcl 25 mg/ml soln 1 ml im q 4hrs prn agitation. should be used as last resort. do not give w/o first consulting with MD
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- *Oral Secretions*
- Levsin 0.125 mg tabs 1 tab by sublingual q 4hrs prn oral secretions
- Albuterol sulfate (2.5 mg/3ml) 0.083% nebu 1 vial via neb q 1-2 hours prn sob (in addition to scheduled dosing.)

Contents of the Palliative Care Cart

- Palliative Care Cart & Freezer
- Towels/ washcloths
- Aloevesta foam cleanser/ barrier cream
- shampoo,body wash/peri wash
- Mouth care sponges with a plastic stick
- wash bucket
- comb
- Good razor+ shaving cream ???electric
- Thick blue chux
- Fan
- Air mattress
- Eye drops
- Skin lotion
- Lip balm
- Sheets
- Pillows
- Shroud
- Heel protecting booties
- Johnnies
- Good depends...the ones with the straps, not the pull ups
- Bed pan
- Urinal
- Wipes
- Snacks: yogurt, jello, ice cream pudding
- Radio/ CD player
- Stationary/ writing pad
- Call bell
- Phone in the room
- Good air mattress to prevent skin breakdown
- Foley Catheters
- Hamper
- Bible
- Inspirational books
- Gatorade

Check List for Post Mortem Care

- Place body in supine position with bed flat.
- Place pillow under head.
- Close patient's eyes.
- Place small towel under chin to close mouth.
- Remove IV and other tubes(catheter) unless autopsy is to take place.
- Remove soiled dressings, ostomy bags and replace them.
- Wash soiled areas of body.
- Place ABD's (disposable pads) to the perineal area to absorb any stool or urine released as the sphincter muscle relaxes.
- Remove watch, jewelry and all possessions, give it to the nearest relative if possible.
- Put a clean gown on the patient.
- Leave the wrist identifications band in place
- If the body is to be viewed, replace top linens and tidy the room.
- Care for dentures and eye glasses, leave/put dentures in patient's mouth.
- Gather personal effects and give to the family or supervisor for safekeeping.
- Put away or dispose equipment and supplies used.
- If body is not to be viewed, place body in shroud
- Fill out tags and place on toe and on outside of shroud

Mr. C

- 62 year old man with advanced terminal pulmonary fibrosis, not a candidate for lung transplant based on functional and nutritional status, as well as lack of insurance and housing.
- Born in Peru, had been in shelter in Boston for 15 years working on and off as a landscaper. Had to stop working due to breathing problems.

Mr. C

Chief Complaint had been Dyspnea: Patient was oxygen dependent. Attempted to help patient focus less on his "numbers:" sat, pulse, BP, etc.

Dyspnea was worsened by a tension pneumothorax.

After discussion on 3/28 we shifted focus of care to comfort care with goals of avoiding hospitalization unless unable to manage symptoms in respite, mitigating anxiety, constipation, pain, urinary retention

Mr. C

- Patient had a friend from the shelter, a fellow patient of BHCHP, who was his HCP. We allowed his friend to visit 24/7

Mr. C

- 4/2 Mr. C asked for an injection to “stop his suffering” He became unable to walk due to inability to catch his breath
- At this point we made a call to Dr. Wilson from the Palliative Care team at MGH
- Recommendation to add standing ativan, increase seroquel and start comfort care
- Later that night patient said “ I can’t breath, I want to die, maybe tonight”
- Another call placed to Dr. Wilson when we felt that we couldn’t achieve comfort, she recommended IM Thorazine

Mr. C

- Symptoms were managed with a combination of morphine, ativan, and neuroleptics (initially haldol, eventually thorazine). Starting at 9pm on 4/2 pt. was comfortably sedated and unresponsive, occasionally moving arms and legs. He passed away peacefully at 7:25am on 4/3

Padre Nuestro

Padre nuestro que estás en
los cielos
Santificado sea tu Nombre
Venga tu reino
Hágase tu voluntad
En la tierra como en el cielo
Danos hoy el pan de este día
y perdona nuestras deudas
como nosotros perdonamos
nuestros deudores
y no nos dejes caer en al
tentación
sino que líbranos del malo.

Memorializing Mr. C

- Graveside Memorial with people who cared for him
- Letter sent to his hometown in Peru
- Space for staff to grieve and debrief

Caring for the Caregivers

- The staff of the Barbara McInnis House who had become close to Mr. C were offered group and individual counseling
- A larger meeting with all staff was held to review Mr. C's death and discuss what went well and where we could improve