END-OF-LIFE CARE FOR VULNERABLE POPULATIONS

May 3, 2019
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Structural vulnerability

“An individual's or a population groups' condition of being at risk for negative health outcomes through their interface with socioeconomic, political and cultural/normative hierarchies”

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Subtle cultural markers + demographic categories

- Who is invisible to us? Who is left out?
- What patient struggles to work within the existing system? How can this system adapt to better welcome and care for them?
- What are the broader networks of power and policy that impact our patients’ ability to become and stay healthy?
End-of-life care for people experiencing:

- Severe mental illness
- Imprisonment
- Substance use disorders
- Homelessness
End-of-life care for those with severe mental illness

Persons with Severe Mental Illness
- High risk comorbid physical illness
- Avoidance of health care
- Under-reporting of somatic symptoms
- Suboptimal communication with care providers

End-of-life care for those with severe mental illness

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Later diagnosis
Greater burden and severity of disease
Premature mortality

End-of-life care for those with severe mental illness

- Integrate psychiatric evaluation and management into PC/hospice evaluation
- Aim for shared decision-making
- Policy and practice adaptations?
Potential drug interactions

Lithium

Additive anticholinergic side effects
- Clozapine
- TCAs
- Anti-Parkinson meds
- Olanzapine
- Quetiapine
- Scopolamine
- Promethazine
Potential drug interactions

- Olanzapine and haloperidol $\rightarrow$ increased chance of neuroleptic malignant syndrome, seizures

- Methadone
  - Concomitant fluoxetine or fluvoxamine $\rightarrow$ methadone toxicity possible
  - Caution with other potential QT-prolonging meds: haloperidol, quetiapine, fluoxetine, sertraline, venlafaxine
Is there such a thing as terminal mental illness?


End-of-life care for the incarcerated

- The number of inmates 65 years of age and older grew 94 times faster than the overall prison population between 2007 and 2010
  
  Human Rights Watch, 2012

- By 2030 1/3 of all inmates will be 55 or older

  Kaiser Health News 2017
End-of-life care for the incarcerated

State correctional facilities: 4% have hospice programs

47 states have some type of “compassionate release”
“the imprisoned have a constitutional right to appropriate care...this should included ‘dignity-conserving care’”
End-of-life care for the incarcerated

- Increase in Compassionate Release?
- Guiding Responsive Action in Corrections at End of Life (GRACE) project
- Local hospice involvement
  - Serenity Hospice in IL
  - Angola prison in LA – Hospice of Acadiana
EOL care for persons with substance use disorders
4 C’s

COMPULSIVE USE
CONTINUED USE DESPITE
CONSEQUENCES
CRAVINGS
Non-blaming language

Instead of ..... Say ....

Addict ➔ Pt with a substance use disorder
Addicted to _ ➔ Has a ___ use disorder
Addiction ➔ Substance use disorder
Alcoholic ➔ Pt with an alcohol use disorder
Clean ➔ Neg; Free of illicit substances
Dirty ➔ Pos; Active use
Drug habit ➔ Substance use disorder
Drug Seeking ➔ Relief seeking
Relapse rates for drug-addicted patients are compared with those suffering from diabetes, hypertension, and asthma. Relapse is common and similar across these illnesses (as is adherence to medication). Thus, drug addiction should be treated like any other chronic illness, with relapse serving as a trigger for renewed intervention.

Pain management 101

- Rapport/trust
- Dose optimization (ward off pseudo-addiction)
- Screen for and treat Substance Use Disorder
- Consider drug agreement
- Consider urine screen
- Evaluate and treat co-morbid anxiety and depression
Known History of Opioid Use Disorder

- Assess triggers
- Long-acting opioids
- Short prescribing periods
- Consider use of methadone as the long-acting opioid
- Offer treatment for OUD while also treating pain
- Utilize multidisciplinary team
Known History of Opioid Use Disorder

• Addiction Medicine specialist
• If on Methadone Maintenance Therapy aka Medication Assisted Treatment
  • Combine maintenance and analgesic doses, divide total into q8 hr doses
  • Consider using other opioid for breakthrough pain
    • no well established dose conversions methadone to other opioids
    • Be prepared to titrate rapidly
    • Schedule short-acting rather than order prn
  • Must collaborate with MMT prescriber
• Maximize non-pharmaceutical therapies
“Recognize that addiction is a chronic, relapsing illness – and respond with increasing structure and compassion”
Buprenorphine

- Tight binding to mu-opioid receptor
- Prevents other opioids from binding therefore blocks the analgesic and euphoric effects of other opioids

- OUD already on buprenorphine+ pain: Several management strategies based on presumed duration of pain
  - Use short-acting opioids at doses high enough to overcome buprenorphine’s antagonism
  - Change all to methadone and short-acting opioid for breakthrough

- Buprenorphine monotherapy for pain?
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**Sublingual (addiction treatment only)**

- Sublingual tablets (Zubsolv, generic): buprenorphine + naloxone
- Sublingual tablets (Subutex): buprenorphine
- Sublingual film (Suboxone): buprenorphine + naloxone

**Buccal film**

- Bunavail: Buprenorphine+naloxone

**Subdermal implant**

**Transdermal (pain only)**

**Injectable formulation**
Homelessness 101

CAUSES

HEALTH, MORTALITY
TABLE 1
Total Number of People Experiencing Homelessness in Wisconsin Point-in-Time Count, 2014–2016

<table>
<thead>
<tr>
<th>Regions</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance of State</td>
<td>3,569</td>
<td>3,597</td>
<td>3,445</td>
</tr>
<tr>
<td>Milwaukee County</td>
<td>1,499</td>
<td>1,521</td>
<td>1,415</td>
</tr>
<tr>
<td>Dane County</td>
<td>777</td>
<td>771</td>
<td>629</td>
</tr>
<tr>
<td>Racine County</td>
<td>210</td>
<td>168</td>
<td>196</td>
</tr>
<tr>
<td>Totals</td>
<td>6,055</td>
<td>6,057</td>
<td>5,685</td>
</tr>
</tbody>
</table>
Jefferson County, WI

153 people experienced homelessness

5% Experiencing Homelessness
73% Total Population
14% Hispanic/Latino

<1% of Wisconsin’s total homeless population

16% have a disability
Compared to 7.5% of the general population

47% were children

24% were 25 - 34 years old

Single Adults: Families: 84%
Waukesha County, WI

765 people experienced homelessness

Experiencing Homelessness
- African American/Black: 31%
- Caucasian: 52%
- Hispanic/Latino: 10%

Total Population
- 1.5%
- 93.4%
- 4.7%

- 4% of Wisconsin’s total homeless population
- 54% have a disability
  Compared to 6.1% of the general population

- 31 veterans
- 45% were 35 - 59 years old
Rates Among Homeless

Mental Illness
- About 1 in 4
- 26%

Substance Abuse
- About 1 in 3
- 35%
Access to care

- Affordability
- Acceptability
- Accessibility
- Adequacy of supply
'What is a life worth?': Doctor passionate about palliative care for the homeless

Published on: 12 March 2011 | Last updated on: 15 March 2012

Providing End-of-Life Palliative Care for the Homeless

by Eric Allen Conner, on 21 March 2012, 2:12 PM

The homeless deserve a good death too

Everyone deserves a dignified end to life, however, for those homeless and dying, a good death is not guaranteed. The latest rough sleeping survey for England, calculated on one night every autumn, revealed last month, the 2016 number of rough sleepers, estimated to be 418k, is up 15%, from the summer 2015 total (Department for Communities and Local Government). Last year, the UK government announced plans to cut funding to the services providing accommodation for the homeless (Naomi, 2016).

When circumstances force people into homelessness, they are often in a situation which worsens their wellbeing. The charity reports that 40% of homeless people have problems in comparison to only 10% of the general population. Furthermore, 15% of physical health problems do not receive the help they need (Naomi, 2016).

Public Health England reports that the longer people remain within the healthcare system, the more these problems multiply, and the higher the cost (Crisp, 2011). With homeless individuals reaching the end of life in the UK, the care services needed, will likely increase. It is imperative that the expanding population find themselves in a situation where the palliative care services can do its work (World Health Organization, 2008).

The first for online search results for homeless and palliative care were specific to homelessness and care. A Google search for “homeless care” returns a result of 23 million. The “homeless and palliative care” returns a result of 1.5 million. This is an important gap, given the number of homeless people seeking end-of-life care and how to provide support for homeless individuals at the end of life.

Hospice Houses for the Homeless Fill a Growing Need in an Aging Society

1st May 2017

"Homeless and Dying in Arranged End of Life Alone"

By Betty R. Armell, PhD, RN

As Homeless Persons Near the End of Life

"Nowhere else will take him" – Palliative care and homelessness

News

Dying on the Streets: As the Homeless Age, a Health Care System Leaves Them Behind

By Bob Tedeschi, STAT Online News, 02/17/2016
What do we know?

*Attitudes/Preferences re EOL care*

- EOL care out of their control
- Concerns: loss of control, dying anonymously, disposal of body, not getting adequate pain relief.
- Often want ANY compassionate caregiver at time of death (rather than family member)
- Surrogate decision makers are most often NOT related
- They EXPECT poor care at EOL

What do we know?

- **Completing Advance Directives**
  - 30% completed AD, up to 50% if counselor-guided
  - Completers reported a significant decrease in “worry about death”

- **Preferences re CPR**
  - 88.6% request CPR (62% in general population)

**Implications?**


# Symptom burden

<table>
<thead>
<tr>
<th>Pain</th>
<th>Dry mouth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worrying</td>
<td>Depressed mood</td>
</tr>
<tr>
<td>Paresthesias</td>
<td>Difficulty concentrating</td>
</tr>
<tr>
<td>Lack of energy</td>
<td>Irritability</td>
</tr>
<tr>
<td>Cough</td>
<td>Anxiety</td>
</tr>
<tr>
<td>SOB</td>
<td>Drowsiness</td>
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</tbody>
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What DON’T we know?

■ Where does death occur?
■ Do rough sleepers want shelter at time of death? Any shelter?
■ How many avoidable hospital days or readmissions are for care of homeless persons as they near death?
■ How many hospice agencies provide specialized care to this population? ....Will do street rounds?
■ How many inpatient hospice facilities have designed specialized (low threshold, harm reduction) services for this group?
■ Are symptoms (pain!) able to be well-controlled on the street?
Homelessness and EOL care: Barriers

- I can’t find anyplace to lie down during the day.
- I can’t smoke in hospice.
- They won’t give me pain medication because they think I’m an addict.
- I don’t trust them to help me.
- They don’t know what to do with someone like me.
- We’re ALL dying out here.
- I’m too busy trying to live; I don’t have time to think about dying.
- If I ask them for help, I have to play by their rules.
- If I go to the nursing home, I’ll never see my buddies.
- It isn’t safe for me to keep meds with me.
**Desires:**
- To choose where they die and who is with them
- To be pain-free
- To engage with their religion/spirituality
- To have dignity
- To have a good QOL for as long as possible
- 80% prefer to die at home or in familiar surroundings

**Tasks:**
- Develop a renewed sense of personhood and meaning
- Bring closure to personal and community relationships
- Bring closure to worldly affairs
- Accept the finality of life and surrender to the transcendent
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Services designed/delivered under these assumptions:
- **family and friends** provide needed care
- there is a safe and **stable residence** where dying days will occur
- people have access to publicly funded health services OR have the ability to pay for extra services needed

End of life counseling and planning
Supportive services: spiritual, psychologic
Expert symptom management
Compassionate caregiving
Help discovering and navigating care options
System Barriers

- Difficult to identify people who need EOL care
Source: Murray, S.A. et al.*

- **Cancer** (n=5)
- **Organ failure** (n=6)
- **Physical and cognitive frailty** (n=7)
- **Other** (n=2)
Homelessness?

Source: Murray, S.A. et al

- Cancer (n=5)
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Homelessness?
System Barriers

- Difficult to identify people who need EOL care

- Challenges in prescribing pain medications
* Locate safe storage or administration sites
* Need lock-box?
* Naloxone and safety plan
System Barriers

- Difficult to identify people who need EOL care
- Challenges in prescribing pain medications

- Shelter staff/outreach workers often don’t have special training on helping during this process
System Barriers

- Difficult to identify people who need EOL care
- Challenges in prescribing pain medications
- Shelter staff/outreach workers often don’t have special training on helping during this process
- Shelters aren’t conducive to the care and environment needed
Place

- **Hospitals**: seen as inflexible, oppressive systems of institutional control
  - *Limitations on freedoms*
  - *Surveillance, lack of control (information)*

- **Clinics/physician offices**: represent paternalistic medical power
  - *Influenced amount of information patient willing to disclose*
  - *Patient attempts to right the power imbalance: avoiding care, not heeding medical advice*
  - *Setting exacerbates sense of mistrust, exclusion, vulnerability*

- **Palliative Care Unit**: “space of no return”

Giesbrecht M et al, *Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life* Health and Place 53 Sept 2018, 43-51
“Many participants lived their entire lives outside the mainstream health system; making them live their final days in that system only added to their suffering”

“Anti-therapeutic places of health care... amplify discomfort, fear, anxiety, and harm, which resulted in disproportionate and undue hardship”

Giesbrecht M et al, Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life Health and Place 53 Sept 2018, 43-51
System Barriers

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- Challenges in prescribing pain medications
- Shelter staff/outreach workers often don’t have special training on helping during this process
- Shelters aren’t conducive to the care and environment needed
- Palliative care and hospice personnel may have little knowledge or experience in
  - Trauma-informed care
  - Harm-reduction practices
  - Low-threshold approach to service delivery
TRAUMA
Trauma

“an event, or series of events, that causes moderate to severe stress reactions. Traumatic events are characterized by a sense of horror, helplessness, serious injury, or the threat of serious injury or death...affecting those who suffer injuries or loss.”
Underactivated Prefrontal Cortex: Executive functions, thought

→ Poor concentration, problem solving

Overactivated Amygdala: Fear

→ vigilance, fear, don’t feel safe, trouble sleeping

Overactivated Anterior cingulate Cortex: emotional dysregulation

→ can’t manage emotions
Effects of trauma

- Lack of trust → disconnection, lack of sense of safety, relational difficulties
- Disempowerment
- Difficulties with problem-solving, critical thinking, emotional regulation
- Higher rates DM, CA, CVD, respiratory Dz, mental health issues
- Survival imperative
- Self-medication
Trauma and homelessness

- SHIFT study: 292 families, 30 mo
  - 79% mothers had experienced trauma in childhood
  - >66% experienced physical assault as an adult
  - 50% met criteria for PTSD
Trauma-informed care principles

- **Safety** – Ensuring a physically and emotionally safe environment for the client
- **Trustworthiness** – Establishing trust and trustworthiness, making client responsibilities and tasks clear and maintaining appropriate professional boundaries
- **Choice** – Emphasizing and encouraging consumer choice and control
- **Collaboration** – Focusing on a collaborative approach and sharing power with the client
- **Empowerment** – Stressing the development of client empowerment and skill building
Harm-reduction principles

- Individual’s decision to use is accepted
- Individual is treated with dignity
- Individual is expected to take responsibility for his or her own behavior
- Individuals have a voice
- Reducing harm, not consumption
- No pre-defined outcomes
Models of EOL care for those experiencing homelessness

Street and shelter palliative care
- Ottawa Mission: Podymow
- Harborview Medical Center Mobile Palliative Care Program for Homeless Individuals
- PEACH: Toronto
- Alpha project: San Diego

Palliative Care or Hospice services in a respite facility
- Barbara McInnis House: Boston
- The Inn Between: Salt Lake City

Stand alone hospice homes
- Diane Morrison Hospice: Canada
- Joseph’s House: DC
- Hildegard House: Louisville
- Welcome Home: Chattanooga
- Abbie Hunt Bryce Home: Indianapolis
- Sarah House: Santa Barbara, CA
- Balm of Gilead: Birmingham, AL
- Cost 30% of hospital stay/day
- Dr Peter Centre, Vancouver
Mobile Palliative Care Program for Homeless Individuals (MPCH)

- 25% reduction in days spent in the hospital for individuals after six month enrollment in the MPCH program

- Emergency room visits dropped by more than 50% after program implementation
  - 344 visits 6 months prior, 158 visits 6 months post
PEACH: Palliative Education and Care for the Homeless

PEACH (Palliative Education And Care for the Homeless) is a Supportive & Palliative Care service of the Inner City Health Associates (ICHA), aimed to meet the pain & symptom, psychosocial and goals of care needs of homeless and vulnerably housed patients with life-limiting illness. The service is offered in collaboration with mobile health teams and shelter settings.
Solace: Community, Comfort, and Care at Life’s End

Madison, WI

Goal: Comprehensive Palliative Care and End-of-Life services to those who are homeless

Social Model Hospice Home: care for 4 nearing death

- Paid caregiving staff
- Large cadre of volunteers: supportive services
- Hospice services from outside
- “Surrogate family”
- Values-based: deep respect, compassionate presence, celebration of the varieties of human expression
THE GOAL

People without a home will have their preferred degree of shelter, symptom management, companionship, and compassionate supportive care during their dying process.

Current review articles:

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- Kindermann, A and O’Connell JJ, Palliative Care for Homeless Persons, UpToDate, www.uptodate.com, updated June 18, 2018
Homelessness
and end of life care

Practical information and tools to support the needs of homeless people who are approaching the end of life, and those who are bereaved

Peter Kennedy, Christina Saraf and Wendy Greenish

US Social Model Hospice Homes w special focus:
- http://www.josephshouse.org (Joseph’s House, Washington DC)
- http://www.sarahhousesb.org (Sarah House, Santa Barbara)
- https://tibhospice.org (The Inn Between, Salt Lake City)
- http://www.welcomehomeofchattanooga.org (Welcome Home, Chattanooga TN)
- http://hildegardhouse.org (Hildegard House, Louisville KY)
- http://www.solacehome.org (Solace Home, Madison WI)

Canada Social Model Hospice Home:
- https://ottawamission.com/hospice/ (Ottawa, ON, Canada)
- http://www.drpeter.org/en/ (Dr Peter Centre, Vancouver)

Street services:
- Toronto: http://www.icha-toronto.ca/programs/peach (Toronto, Canada)
- Seattle: https://medicine.uw.edu/news/palliative-care-homeless (Harborview, UW, Seattle)
Pain resources:

- [https://www.mypcnnow.org/blank-bhvai](https://www.mypcnnow.org/blank-bhvai)
- [https://www.mypcnnow.org/blank-zi1e3](https://www.mypcnnow.org/blank-zi1e3)
- [https://www.accp.com/docs/bookstore/psap/p7b05.sample03.pdf](https://www.accp.com/docs/bookstore/psap/p7b05.sample03.pdf)
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