Dying Without A Home

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Disclosures

• Adam Schoenfarber has no relevant financial interests to disclose.
• Pam Adams has no relevant financial interests to disclose.
Objectives

• Participants will develop an understanding of the changing face and shifting demographics of homelessness in the United States.
• Participants will develop a toolkit of best practices for end of life patient and family care in homeless individuals.
• Participants will develop mezzo- and macro-level strategies to advocate and navigate agency challenges with the homeless population.
A Disclaimer About “Giving Up”

Ending Homelessness among Older Adults and Elders through Permanent Supportive Housing

STATE OF THE HOMELESS 2017
Rejecting Low Expectations: Housing is the Answer
Jorge Case Presentation

- 45-year-old, bilingual, Latino man of Dominican descent
- Hospice dx of laryngeal cancer with mets to the tongue and jaw
- Mute due to surgical removal of larynx, tongue, and lower jaw
- Admitted to 16-bed hospice residential unit
- Prior to admission, resided at a homeless shelter for men with mental illness
- Diagnosed with depression
- Socially isolated
Carl Case Presentation

- 65-year-old Catholic Caucasian male
- Hospice dx of End Stage Cardiac Disease
- Ambulatory, periodic episodes of apnea
- Honorably discharged from the Army, saw combat in Vietnam, fully service connected
- Living in the Staten Island Ferry Terminal, had previous poor experience with DHS shelters
Values: Which would you prefer?
What is the definition of "homeless?"

• According to the US Department of Health & Human Services, a homeless individual is:
• “an individual who lacks housing (without regard to whether the individual is a member of a family), including an individual whose primary residence during the night is a supervised public or private facility (e.g., shelters) that provides temporary living accommodations, and an individual who is a resident in transitional housing ... A homeless person is an individual without permanent housing who may live on the streets; stay in a shelter, mission, single room occupancy facilities, abandoned building or vehicle; or in any other unstable or non-permanent situation.”

(Public Health Service act Of 1944, 2013)
What is the definition of "homeless?"

“Additionally, the Department of HHS has determined that the definition may also include an individual who is ‘doubled up,’ a term that refers to a situation where ‘individuals are unable to maintain their housing situation and are forced to stay with a series of friends and/or extended family members. In addition, previously homeless individuals who are to be released from a prison or a hospital may be considered homeless if they do not have a stable housing situation to which they can return.’”

(Gaston, 1999)
Definitions continued

- **Chronically Homeless**: Continuously homeless > 1 year, or four episodes of homelessness in three years
- **Continuums of Care**: Local planning groups responsible for coordinating services for homeless population
- **Unsheltered Homeless**: Primary nighttime location is a public or private place not intended for sleeping

(AHAR, 2017)
Homelessness By the Numbers

- Homelessness increased for the first time since 2010
- 63,495 People in NYC homeless shelters in December 2017
- **553,742 Nationwide on a given night in January 2017**
- 384 days: average length of stay in shelters for single adults
- 557 days: average length of stay in shelters for adult families

(Coalition for the Homeless, 2018; HUD, 2017)
Homelessness by State 2017

(AHAR, 2017)
Demographics

• Race
  • 47% White
  • 41% African-American
  • 7% Multiethnic or mixed race
  • 5% Latino/a or Hispanic

• Gender
  • 61% Male
  • 38% Female
  • <1% Transgender, Genderqueer, Non-binary, Nonidentified

(AHAR 2017)
Demographics (continued)

- **Age**
  - Under 18 years: 21%
  - 18 years - 24 years: 10%
  - 24 years and older: 70%
  - 2014 median age: 50 years

- **Illness rates**
  - Not captured by AHAR
  - Mortality rates by age 2-5x higher than adults who never experience homelessness

(AHAR, 2017; Fazel et al, 2014)
Institutional Factors of Homelessness

- Economic Contexts
  - Limited vacancy in affordable housing
  - Rent prices: Increased 19% between 2000 and 2014
  - Income: Average income down by 6.3% between 2000 and 2014
  - Population growth which exceeds anticipated projections
  - Unemployment due to the recession
  - Bankruptcy due to medical bills and lack of or inadequate healthcare coverage

- (Routhier, 2017)
Relationship Between Income and Housing

The percentage of American full-time minimum-wage workers who can afford to rent a 1-bedroom apartment in any U.S. state without being burdened is 0.1%.

“Afford” is defined as ability to pay < 30% of income on the cost of housing

(National Low Income Housing Coalition, 2017)
Trauma-Informed Practice

Trauma (physical, emotional, or sexual) is both a cause and a consequence of homelessness.

Trauma comes with the territory.
Trauma-Informed Practice

- Trauma created by homelessness
  - Series of losses, e.g. community, possessions, security, contact with family
  - Ongoing terror, loneliness, fear, dread, and despair
  - Adjusting to a new and often problematic environment
  - Increased exposure to high-risk situations, e.g. experiencing and/or witnessing physical or sexual assault

(Muller, 2013; Post, 1999)
Trauma-Informed Practice

• Homelessness created by trauma
  • Domestic violence
  • History of physical and/or sexual abuse during childhood
  • Subsequent substance abuse
  • Military service-related trauma and loss

• (Muller, 2013; Post, 1999)
Relationship Between Health and Homelessness

- Poor health can create homelessness
- Chronic diseases are difficult to manage under stressful circumstances and can even worsen
- Acute conditions are difficult to treat when there is no place to rest and recuperate
- Living on the street or in shelters increases risk of communicable diseases and violence
- Medications are often lost, stolen, or compromised
- Focus is on need for shelter, rather than need for healthcare
Homelessness Through a Hospice Lens

- Higher rates of complex comorbidities
- Barriers to interventions that work (Supportive Housing)
  - Lack of clinician knowledge
  - Arduous applications, which may require in-person interviews
  - Limited availability of programs
  - Limited funding, and resources
  - Strict rules and regulations within programs
- The dangers of other clients
- DHS does not want patients to die in shelter

What Happens when homelessness is a choice?
What Makes a Culture

From NASW’s Standards and Indicators of Cultural Competence:

“The word ‘culture’ implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group (Gilbert, Goode, & Dunne, 2007). Culture often is referred to as the totality of ways being passed on from generation to generation. The term ‘culture’ includes ways in which people … experience the world around them. Culture includes, but is not limited to, history, traditions, values, family systems, and artistic expressions of client groups served in the different cultures related to race and ethnicity, immigration and refugee status, tribal status, religion and spirituality, sexual orientation, gender identity and expression, social class, and abilities.”

(NCORD, 2015)
Cultural Humility vs Cultural Competence

“A commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves… a process that requires humility in how [clinicians] bring into check the power imbalances that exist in the dynamics of physician-patient communication by using a patient-focused interviewing and care.”

(Tervalon and Murray-Garcia, 1998)
Barriers to Providing Jorge’s Care

• Probable undiagnosed mental illness, in addition to depression
• Refusal of psychiatric services
• Episodes of decompensation
• Socially isolated
• Triggered by rigid institutional structure
• Attempts to split staff
• Implicit biases of staff (including your own)
Interventions for Jorge

- Familiarity of appropriate treatment modalities for psychiatric diagnosis
- Honor autonomy and self-determination
- Build trust by allowing patient to drive plan of care
- Collaborate and communicate with staff to avoid splitting
- Staff education
- Recognize that strong emotions may be projected at clinicians
- Explore and process countertransference
Barriers to Providing Care for Carl

- Patient admitted and revoked from hospice 5 times
- Elopement
- Incident while on day pass: hospitalized at Non-Contracted IPU
- Guarded and suspicious
- No available cell phone or contact information
- Refused to engage in discharge planning and “bureaucracy”
Interventions for Carl

- Library Books and card
- Map of the neighborhood
- Cared for plants on the unit
- Wallet healthcare proxy card
- Anatomical Donation
Clinical Toolkit

- Explore values, identify roles
  - Generativity vs stagnation
  - Who is a part of your life? How does John/Jane fit in your picture?
  - Explore the timeline, and how a person’s life functions in their setting
- Respect and mark small victories
- Recognize that strong emotions may be projected at clinicians
  - Do not personalize
- Explore and process countertransference
An Open, Curious, Non-Judgmental Stance

- Be aware of biases (your own and your team’s)
- Honor autonomy and self-determination
- Build trust by allowing patient to drive plan of care
- Reframe resistance as ambivalence
- Reassure your patient of their patient rights
- Collaborate and communicate with staff to avoid splitting
What do staff say about homeless clients?
Challenging Bias and Supporting Clinicians

• “You’re lucky Medicaid pays for you to be here.”
• “Be grateful.”
• “He/she refuses to bathe and it’s a health hazard.”
• “I’m not going in until he takes a shower.”
• “I deserve to feel safe here, too.”
Macro-Level Practice

- The INN Between Hospice for the Homeless - Salt Lake City, UT
  - Opened in 2015
  - 148 acutely or terminally ill homeless people served
  - 37 deaths with dignity in a home, rather than in the streets
  - 92% of those served were reunited with estranged families
  - 3 “miracles” in which the person regained their health

(The Inn Between, n.d.)
Macro-Level Practice

- Alpha Project’s Hospice for the Homeless - San Diego, CA
  - Established in 2007
  - Rent subsidy
  - Case management
  - Support services
  - Local hospice providers provide medical care and medications
  - In some cases, housing and stabilization has extended life
Macro-Level Practice

• Joshua’s House - Sacramento, CA
  • Founded by Dr. Marlene Fitzwater and named after her grandson who died in 2014 in the streets of Sacramento
  • Dr. Fitzwater has purchased a warehouse and is converting it into a 20-room hospice unit for terminally ill people
  • Expected to be open by the end of 2018
  • Privately funded
Mezzo-Level Practice and Advocacy

- Adopt an agency culture of harm-reduction
  - Harm Reduction is a natural progression of person-centered care
- Can your agency practice in shelter settings
- Develop Specialized Practice team
- Forge relationships with Continuums of Care
  - For education
  - For discharge planning
  - For referral sources
- Support legislation for medical shelters, and for supportive housing programs
Conclusions

• Homelessness may improve, but will not end tomorrow
• Homelessness is inextricably linked to chronic illness
• Homeless clients are people before they are a population
• Homeless clients carry trauma in their backpacks
Questions and Comments

Questions are guaranteed in life; Answers aren't.
References


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References


Public Health Service Act of 1944, 42 U.S.C. §§254(b)-330(h)(5)(A)
References

