ADVANCE CARE PLANNING IN HOMELESS HEALTHCARE

Laura Kaplan-Weisman, MD and Sara Sansone, MS, MPH, RN
With Casey Crump, MD, PhD and Eve Waltermaurer, PhD

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Presenter Disclosures

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
1. Background
Should we discuss advance care planning in persons experiencing homelessness?
What is Advance Care Planning?

- Health Care Proxy (HCP) / Surrogate
- Code status
- Living will/Advanced Directive (AD)
  - MOLST/POLST
- Organ Donation
- Burial vs. cremation
4 Pathways for Surrogate Decision Making

- **Directed decision making**: specify decisions in advance in writing, such as a living will
- **Delegated decision making**: specify a healthcare power of attorney
- **Devolved decision making**: if no one is specified, family members by default become healthcare proxy
- **Displaced decision making**: court-appointed guardianship or surrogate

BARRIERS TO DISCUSSION:

- There are more immediate & pressing problems
- I don’t have time; patients experiencing homelessness are too complicated
- Patients experiencing homelessness don’t want to discuss advance care plans
  - Too depressing, they are estranged from family or friends
- Due to mental illness, patients experiencing homelessness cannot understand or discuss advance care plans
- Documents will not make it to the hospital; this is not an effective use of clinical time
1. There are more immediate and pressing problems

- The population of elderly persons experiencing homelessness is growing faster than the general US population
- Adults age 50 and above experiencing homelessness are sicker than their peers, have more difficulty with ADLs & IADLs, and have higher morbidity and mortality

2. I don’t have time; patients experiencing homelessness are too complicated

- Homeless adults rarely have the opportunity to discuss and document advance care plans
  - 2% of homeless men in Canada had completed an AD prior to one study

- Persons experiencing homelessness have unique needs and perspectives compared to housed patients

- They worry that they will have lose control over maintaining their dignity and end of life preferences in their future care

3. Patients experiencing homelessness don’t want to discuss advance care plans

- All studies in this limited research area should that persons experiencing homelessness are able and want to discuss advanced care plans
4. Due to mental illness, patients experiencing homelessness cannot discuss advance care plans

- Norris 2005: compared end of life wishes for 229 homeless patients vs 236 physicians vs 111 oxygen-dependent COPD patients in Seattle-cross-sectional survey
- Song 2010: 263 homeless patients in Minnesota- RCT
- Leung 2015: 205 homeless Canadian men in an alcohol harm reduction program- cohort study

*All prospective research studies not performed as part of routine care*
5. Documents will not make it to the hospital; this is not an effective use of clinical time

- Gruzden et al: In adults 65+ presenting to the ED, over 50% have a named health care proxy and over 40% had a living will, but only 4% of the study population have this documented in the hospital electronic health record

- Leung et al 2017: patients who completed an advance directive in a shelter-based study were more likely to have use of an advance care directive documented while hospitalized than those who did not complete an advance directive

Gruzden 2016, Leung 2017
The Case of LR

- 85 yo Spanish-speaking male with Alzheimer’s dementia without a health care proxy
- Formerly homeless, lives in supportive housing program
- New onset asymptomatic, dark diarrhea 3-4x daily, unintentional weight loss x 3-4 weeks
- Barium enema: mass concerning for rectosigmoid neoplasm

Case report slides adapted from “Consent, Dementia, and Surrogate Decision-making: Ethical Challenges in the Context of Homeless Health Care”- roundtable presentation with Mark Fox, MD, PhD, MPH at the National Health Care for the Homeless Conference & Policy Symposium 6/2016
Should we discuss advance care planning in persons experiencing homelessness?
Questions in Advanced Care Planning in Persons Experiencing Homelessness

- What is the size of the population who lacks a health care proxy?
- How can we reduce the size of this population?
- What are the end of life wishes of adults experiencing homelessness?
- How do you ensure that documents make it to the hospital?
2. Methods
CQI Project

- From 4/1/2016-6/6/2017, we sought to discuss and complete HCPs and other advance care directives for IFH homeless patients during primary care visits and focused visits with an RN in an APN/MPH program

- Copies of directives were:
  - Provided to patients
  - Scanned to the EHR
  - Stored at the transitional homeless sites

- In addition, wallet sized HCP cards were given to patients
IFH ADULT HOMELESS PROGRAM

- Drop-in Centers
  - All Angels Church
  - Broadway Presbyterian Church
- Transitional homeless shelters
  - George Daly House
  - Valley Lodge
- SRO
  - The Senate
Documenting Health Care Proxy Status

Does the patient have capacity to appoint a surrogate decision maker?

- NO
- YES

Has a health care proxy been signed previously?

- NO
- YES

Unbefriended/Adult Orphans/Unrepresented/Isolated

Surrogate if patient lacks capacity

Does the patient have a surrogate to appoint?

- NO
- YES

“Surrogateless”

Sign Health Care Proxy
In the summer of 2017, we conducted a retrospective chart review of documented advance care plans and documents scanned to the EHR.

Inclusion criteria: All patients of the IFH homeless sites who:

a) has their PCP at one of the homeless sites
b) saw their PCP at least twice during the study period
c) aged 40 years or above
3. Results
Advance care directives discussed

- Not discussed: 58%
- Discussed: 42%

Health care proxy status

- Family or friend: 55%
- Surrogateless: 36%
- Declined: 5%
- Not documented as discussed: 4%
- Unable: 2%
- Administrator/SW/PC: 18%
- None: 7%
- Undecided: 9%

$n = 332$

$n = 139$
<table>
<thead>
<tr>
<th>Demographics</th>
<th>Family or friend</th>
<th>Surrogateless</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( n = 77 )</td>
<td>( n = 49 )</td>
</tr>
<tr>
<td>Age</td>
<td>( n )</td>
<td>( n )</td>
</tr>
<tr>
<td>Over 70 years</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>Under 70 years</td>
<td>63</td>
<td>36</td>
</tr>
<tr>
<td>Mean (sd)</td>
<td>64.8 (7.8)</td>
<td>65.8 (8.4)</td>
</tr>
<tr>
<td>Sex</td>
<td>( n )</td>
<td>( n )</td>
</tr>
<tr>
<td>Female</td>
<td>28</td>
<td>19</td>
</tr>
<tr>
<td>Male</td>
<td>49</td>
<td>30</td>
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<tr>
<td>Race and Ethnicity</td>
<td>( n )</td>
<td>( n )</td>
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<tr>
<td>Black Non-Hispanic</td>
<td>29</td>
<td>19</td>
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<tr>
<td>Other Non-Hispanic</td>
<td>5</td>
<td>1</td>
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<tr>
<td>White Non-Hispanic</td>
<td>19</td>
<td>16</td>
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<tr>
<td>Hispanic/Latino</td>
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<td>12</td>
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<tr>
<td>Unknown</td>
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<td>1</td>
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<td>History of Mental Illness</td>
<td>( n )</td>
<td>( n )</td>
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<tr>
<td>Yes</td>
<td>32</td>
<td>25</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
<td>24</td>
</tr>
<tr>
<td>History of Dementia</td>
<td>( n )</td>
<td>( n )</td>
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<td>Yes</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>71</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Family or friend</td>
<td>Surrogateless</td>
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<tr>
<td>--------------------------------</td>
<td>------------------</td>
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</tr>
<tr>
<td></td>
<td>( n = 77 )</td>
<td>( n = 49 )</td>
</tr>
<tr>
<td><strong>n</strong></td>
<td><strong>n</strong></td>
<td></td>
</tr>
<tr>
<td><strong>History of Substance Abuse</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>22 29%</td>
<td>12 24%</td>
</tr>
<tr>
<td>No</td>
<td>55 71%</td>
<td>37 76%</td>
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<tr>
<td><strong>3 or more medical co-morbidities</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>40 52%</td>
<td>20 41%</td>
</tr>
<tr>
<td>No</td>
<td>37 48%</td>
<td>29 59%</td>
</tr>
<tr>
<td><strong>End-stage diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2 3%</td>
<td>1 2%</td>
</tr>
<tr>
<td>No</td>
<td>75 97%</td>
<td>48 98%</td>
</tr>
<tr>
<td><strong>Died by end of study period</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 6%</td>
<td>1 2%</td>
</tr>
<tr>
<td>No</td>
<td>72 94%</td>
<td>48 98%</td>
</tr>
<tr>
<td><strong>Visits with Primary Care Provider</strong></td>
<td>Mean (sd)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11.8 (8.2)</td>
<td>12.7 (9.4)</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>10</td>
</tr>
<tr>
<td><strong>Visits with Social worker/Case worker</strong></td>
<td>Mean (sd)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5.2 (4.9)</td>
<td>8.6 (16.5)</td>
</tr>
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<td></td>
<td>Median</td>
<td>4</td>
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<td></td>
<td>*not provided by IFH at all sites</td>
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</tr>
<tr>
<td><strong>Time in primary care of homeless sites (months)</strong></td>
<td>Mean (sd)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>49.8 (55.4)</td>
<td>67.1 (61.4)</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>28</td>
</tr>
</tbody>
</table>

*Pearson Chi-Square for categorical; t-test for continuous measures.

*not provided by IFH at all sites.
Code status, if good chance of recovery

- Full code: 59%
- Full except specific interventions: 1%
- DNR/DNI: 4%
- DNI only: 13%
- Declined: 1%
- Undecided/thinking about: 1%
- Unable: 4%
- Defers to surrogate: 9%
- Not documented as discussed: 1%

In event of irreversible brain damage

- All care: 40%
- All care except specific interventions: 9%
- Withdraw care: 6%
- Withdraw care after trial: 9%
- No intervention/No invasive care: 2%
- Declined: 5%
- Undecided/thinking about: 16%
- Unable: 8%
- Defers to surrogates: 1%
- Not documented as discussed: 1%
Care of the body after death

- Burial: 32%
- Cremation: 29%
- Declined: 14%
- Undecided/thinking about: 15%
- Unable: 4%
- Defers to surrogate: 4%
- Not documented as discussed: 2%

Organ donations wishes

- Yes: 32%
- No: 26%
- Declined: 14%
- Undecided/thinking about: 14%
- Unable: 2%
- Defers to surrogate: 14%
- Not documented as discussed: 11%
<table>
<thead>
<tr>
<th></th>
<th>Norris 2005</th>
<th>Song 2010</th>
<th>Leung 2014</th>
<th>IFH 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Care Planning Discussed</td>
<td>n= 229</td>
<td>n= 70</td>
<td>n= 103</td>
<td>n= 139</td>
</tr>
<tr>
<td>Participation Rate</td>
<td>76%</td>
<td>27%</td>
<td>50%</td>
<td>42%</td>
</tr>
<tr>
<td>Family/friend as health care proxy</td>
<td>65%</td>
<td>87%</td>
<td>61%</td>
<td>55%</td>
</tr>
<tr>
<td>Critical care if in current health/ reasonable chance of recovery</td>
<td>60-89%</td>
<td>49%-yes, 29%-defer to surrogate, 21%-other/blank</td>
<td>94%</td>
<td>60%</td>
</tr>
<tr>
<td>Critical care if in permanent coma</td>
<td>23-31%</td>
<td>9%-yes, 19%-other/blank</td>
<td>36%</td>
<td>7% yes, 23% not discussed/unsure</td>
</tr>
<tr>
<td>City</td>
<td>Seattle</td>
<td>Minneapolis</td>
<td>Toronto</td>
<td>New York</td>
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<tr>
<td>Type of Study</td>
<td>Cross-sectional survey</td>
<td>RCT</td>
<td>Cohort study</td>
<td>Retrospective chart review</td>
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</table>
4. Conclusions & Next Steps
Take home points

■ 1st study to establish feasibility of discussing advance care planning in clinical practice in homeless healthcare
■ Over 1/3 of patients were surrogateless
■ No significant demographic differences were found between patients with surrogates and the surrogateless
■ Homeless team staff members can serve as health care proxies to reduce the surrogateless rate

**We need more research to better understand advance care planning and the prevalence of surrogateless in the homeless population**
Tips for discussions with patients

- Normalize the conversation
- Divide discussions over multiple visits
- Work as a multidisciplinary team
- Use wallet cards
- Identify 1 patient per day for conversations
- Complete documentation correctly
- Identify appropriate documents for your state
- Emphasize choosing a surrogate who will follow your wishes - does not have to be next of kin
Reducing the size of the unbefriended/surrogateless population

- Individual volunteer advocate programs
- External committees of trained volunteers
- Partner nursing home staff with patients
- Nonprofits build relationships with patients and serve as “conservators” in the future

*Discuss & document health care proxies and advance directives
*Homeless healthcare team members can serve as healthcare proxies
Ensuring documents are transmitted to the hospital

- Health care proxy wallet cards
- Sending documents to local hospitals prior to illness
- Improve EHR interoperability
- Include advance care planning documents in RHIOs
- Expand advance care directive registries
  - eMOLST/ePOLST registries should include all patients & documents

https://www.nysemolstregistry.com
"I’m afraid I still have more questions than answers."
References


References


References


“Medical Orders for Life-Sustaining Treatment Registry.” New York State Department of Health. [https://www.nysemolstregistry.com/Account/Login?ReturnUrl=%2f]


