PALLIATIVE AND ADVANCE CARE PLANNING AMONG AFRICAN-AMERICAN HIV-POSITIVE INJECTION DRUG USERS: A Mixed Methods Exploration

ALLYSHA C. MARAGH-BASS, PhD, MPH
SARINA R. ISENBERG, MA
AMY R. KNOWLTON, ScD, MPH
BACKGROUND

- Palliative care (PC) is designed to improve quality of life and functioning among individuals with serious chronic and/or terminal illnesses

- Advanced care planning is the process of communication between individuals and their healthcare agents to understand, reflect on, and plan for when individuals are not able to make their own healthcare decisions

- Few studies have explored PC and ACP interests and preferences for end of life care among disadvantaged African American (AA) populations with serious chronic conditions
  
  - Particularly AA living with HIV
Due to advancements in treatment, HIV-positive individuals are living longer, but with increased impairment and complex palliative and advance care planning needs.

Palliative care interests and preferences for end of life care in disadvantaged AA populations are understudied, including those living with HIV.

Purpose of the present study was to explore:
- (1) preferences for care at end of life
- (2) knowledge of palliative and advanced care planning
- (3) inclusion of informal caregivers in palliative and advanced care planning decision-making
Method – Inclusion Criteria

- Parent study: NIH-funded study entitled “AFFIRM study: Sustaining palliative care to drug users with HIV/AIDS & health disparities”

- Inclusion criteria for main participants (Indexes):
  (a) 18 years of age of or older
  (b) documented HIV seropositive status
  (c) current or former injection drug use (PWID)
  (d) current use of antiretroviral therapy (ART)
  (e) willingness to invite a supporter to participate

- Indexes were recruited via: community sampling, targeted recruitment, HIV clinic affiliated with Johns Hopkins Hospital
METHOD – STUDY APPROACH

- Concurrent, embedded convergent mixed methods design
  - Simultaneous qualitative in-depth interviews and survey instruments
  - Interviews conducted with small sample of participants from larger study. Integrated analysis and interpretation

- Interviews: 60 minutes, semi-structured approach
  - Topics: Knowledge of and preferences for PC and ACP

- Surveys: 45-60 minutes, Baseline, 6mth, 12mth follow-up
  - Constructs: Knowledge of and Preferences for PC and ACP, having heard of Medical Orders for Life Sustaining Treatment (MOLST), Demographics
METHOD – DATA ANALYSES

~Quantitative analyses~
- Univariate frequencies for variables on baseline sample
- Bivariate (chi-square analyses) to look at associations including: PC and ACP, gender, age, insurance, informal caregiver rel’n
  - Factor analyses to assess internal consistency of measurement scales
  - Responses/scales categories collapsed as necessary (e.g. Strongly Agree/Agree)
  - Conducted using STATA Version 14.0

~Qualitative analyses~
- Inductive interview coding (codebook built from raw data, not a priori)
- Grounded theory and constant comparison approach\(^9\)
  - Working hypothesis generated by textual analysis of social context
  - Conducted using ATLAS.ti Version 7.0

PALLIATIVE AND ADVANCED CARE PLANNING AMONG AFRICAN-AMERICAN HIV-POSITIVE INJECTION DRUG USERS
RESULTS – DEMOGRAPHICS

- Mean age: 53 (SD: 6.1 years)
- Participants were predominantly Male (55.1%), African American (97.1%), with public insurance (98.5%)
- Approximately half had received mental health counseling in the past year, and reported frequent or constant pain in the last month with severity of 6 to 10 on average
- Most were virally suppressed (85%), and had not used emergency medical services in the last 5 years (60.9%)
- Illicit substances most used in the past month: Cocaine (14.5%), Marijuana (10.1%), Injection drugs (7.6%)
RESULTS – CARE PREFERENCES

- Strongly Agree/Agree
- Strongly Disagree/Disagree

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Strongly Agree/Agree</th>
<th>Strongly Disagree/Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live at home with assistance from a home health aide</td>
<td>77.80%</td>
<td>22.20%</td>
</tr>
<tr>
<td>Live at home with assistance from a partner, family or friends</td>
<td>11.60%</td>
<td>88.40%</td>
</tr>
<tr>
<td>Live in a long term care facility such as a nursing home</td>
<td>78.80%</td>
<td>21.40%</td>
</tr>
<tr>
<td>If heart stopped, would NOT want CPR</td>
<td>67.80%</td>
<td>32.20%</td>
</tr>
</tbody>
</table>
### RESULTS – $\chi^2 \ (N = 276)$

<table>
<thead>
<tr>
<th>Variables</th>
<th>p-val</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex and Physical functioning</strong></td>
<td>.008</td>
</tr>
<tr>
<td>55.6% of males reported Good or Excellent Health, vs. 39.7% of females.</td>
<td></td>
</tr>
<tr>
<td><strong>Sex and Care preference to live at home with help from family, partner, or friends</strong></td>
<td>.037</td>
</tr>
<tr>
<td>36.4% of females strongly agreed, vs. 22.4% of males.</td>
<td></td>
</tr>
<tr>
<td><strong>Sex and Relationship to health proxy</strong></td>
<td>.000</td>
</tr>
<tr>
<td>7.9% of males reported parent was their proxy vs. 34.7% of females. 28.3% of males reported siblings vs. 11.6% of females.</td>
<td></td>
</tr>
<tr>
<td><strong>Sex and Frequency of including main supporter in treatment decisions</strong></td>
<td>.029</td>
</tr>
<tr>
<td>46.9% of females reported always including main supporter in decisions, vs. 28.9% of males.</td>
<td></td>
</tr>
<tr>
<td><strong>Education level and Having ever heard of MOLST</strong></td>
<td>.000</td>
</tr>
<tr>
<td>57.9% of those with less than high school education vs. 13.4% of those with some college education reported having never heard of the MOLST.</td>
<td></td>
</tr>
<tr>
<td><strong>Preference for long-term care facility and having ever heard of MOLST</strong></td>
<td>.002</td>
</tr>
<tr>
<td>Those who agree/strongly agree with this care preference were less likely to have ever heard of MOLST (26.1% vs. 15.1%, respectively).</td>
<td></td>
</tr>
<tr>
<td><strong>Interest in learning about Maryland healthcare law and assistance deciding medical care and care preference to live at home with healthcare aide</strong></td>
<td>.086</td>
</tr>
<tr>
<td>Among those who agree/strongly agree with this care preference, individuals were more likely to be interested in learning about MD healthcare law (25.8% vs. 11.3%, respectively).</td>
<td></td>
</tr>
</tbody>
</table>
### Results – Main Qual Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example quotes</th>
</tr>
</thead>
</table>
| Knowledge of health care mandates and palliative care | “Well no actually, I haven’t of those forms, per se. What R_____ was—he had mentioned it, I’m not quite sure if—now this is just last.. this is just in April. So I’m assuming that they may have had that form by then, **but his family was real adamant, you know**.. I’m not quite sure if he actually had a Maryland MOLST or whatever. What I do know is that there were a lot of friends that were there, but **his family he must have discussed this with, because they had let the providers know** this was his wish, and they must have had the ammunition. …….”  
“Palliative care? Well I don’t really know much about palliative care. I’ve heard it in our support groups.. and actually it’s funny, **because that was on one of the discussions, on one of the pamphlets that I was supposed to go to**, and I really don’t have a clue of what the palliative care is. |
<p>| Avoidance of end of life discussion             | “I don't know. No, not right now. I'll probably need to, but I've not…If I'm diagnosed with cancer or something, active cancer, I would discuss it, you know, my last will and testament and stuff. So I got to do GYN Sunday-- I mean Wednesday. I go back to them and see what they're going to do about what they found last year and really face it. <strong>I didn't want to face it last year, so I put it off for a whole year after they told me I had cancerous polyps in my anal and in uterus.</strong> So I have to deal with that. I put it off for long enough, so it's something I got to deal with.” |</p>
<table>
<thead>
<tr>
<th>Theme</th>
<th>Example quotes</th>
</tr>
</thead>
</table>
| Managing pain and impact on quality of life | “Well, my pain-- my lower back pain stops me from doing a lot of things. Like for instance, I can't do a lot of my housework like I want to. I have to stop, then start, then stop, then start doing a little, doing, you know, like that. And it's no telling how long-- I could be in bed sometimes three or four days in a row with my pain.”  

“But the pain that I had is so consuming, it's like it takes my mind. I mean, I'm one that can't handle pain. You know, I just don't like pain. I'm scared of pain, you know? So I don't even want to feel it. And I know it's coming if I don't do anything, put anything in my body to-- and it keeps me in the house. Now I would be really afraid to go outside, because it's like I can't function the way I use to because I don't-- and I mean, and it's became like a habit, whereas, though, I'd rather be handling the pain out.” |
| Desire for long life                       | “Just I stay stable and I keep getting better. That's the best what I would like for my health. Stay healthy as I can... As long as I can. That's what I would want, just live long as I can.”                                                                                                                                                                           

“A long healthy, positive life. That I may live along with this disease I have. And maybe they'll find a cure for this. And since I've been on meds I've been all right. My viral load was 25,000 copies of the white cells and that is undetectable. And I've been on my meds since last year. That's a big change.” |
OTHER CONSIDERATIONS

Study Strengths:
- AFFIRM: recruitment of a hard-to-reach vulnerable population
- Potential to establish new pathways in palliative and advance care planning in a vulnerable HIV-positive, substance-using population
- Prioritizes healthcare engagement and needs among African American PLHIV

Study Limitations:
- Nearly 100% Insurance status (lack of variance)
- Baseline timepoint only (cross-sectional)
- Small sample size
CONCLUSIONS

- Many complex care needs in this population
  - Pain management
  - Active substance use (often to cope with pain)

- Even with access to care, AAs and PWID may be at risk of poor health outcomes
  - Women and men may differ across various PC and ACP dimensions
  - Health care mandates unheard of, despite recent healthcare access
  - Strong preferences for life-sustaining treatments (quantitatively) and desire for long life (qualitatively)

- Future directions:
  - Dyadic-level intervention
  - Family-level health education
  - Healthcare provider training in HIV PC and ACP
Thank You

- Funding acknowledgments
  - National Institutes Nursing Research
  - JHU Center for AIDS Research

- Questions and comments are welcomed
  - Contact email: arobinson21@bwh.harvard.edu
REFERENCES


