Increasing Access to Hospice Care for African Americans in the Carolinas:
Kimberly S. Johnson MD MHS
Division of Geriatrics, Center for Aging
Duke Palliative Care
Duke University Medical Center
GRECC, Durham VA Medical Center
Durham, NC

Lessons Learned from Hospice Providers
Kimberly S. Johnson MD MHS
Division of Geriatrics, Center for Aging
Duke Palliative Care
Duke University Medical Center
GRECC, Durham VA Medical Center
Durham, NC

Objectives
• Review potential barriers to hospice use among African Americans.
• Discuss activities of hospice providers in the Carolinas to increase use of hospice care among African Americans in their service area.
• Highlight best practices in increasing service to African Americans.
African Americans Use Hospice at Lower Rates

Why African Americans? Why Hospice?

- **Unmet Needs**
  - Pain Management
  - Communication
  - Overall Satisfaction
- **Higher Costs**
- **Improvements**
  - Pain Management
  - Communication
  - Overall Satisfaction
- **Lower Costs**

African Americans have less exposure to information about hospice

- **Teno et al, JAMA 2004**
- **Rhodes et al, JPSM 2007**
- **Hanchate et al, Arch Intern Med 2009**
- **Welch et al, JAGS 2005**
- **Kelley et al, Health Aff 2013**
- **Baer et al, JAGS 2000**

Have you ever heard of hospice?
- Never
- Heard A Little
- Heard A Lot

<table>
<thead>
<tr>
<th></th>
<th>Whites</th>
<th>Blacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>15%</td>
<td>5%</td>
</tr>
<tr>
<td>Heard A Little</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Heard A Lot</td>
<td>70%</td>
<td>40%</td>
</tr>
</tbody>
</table>

OR = 2.24 [1.17, 4.27]  
Strasser et al, J Pain Med 2009
African Americans have less favorable beliefs about hospice

If I were dying, I would want hospice.

<table>
<thead>
<tr>
<th></th>
<th>Whites</th>
<th>Blacks</th>
<th>P&lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>90%</td>
<td></td>
<td>75%</td>
<td></td>
</tr>
</tbody>
</table>

Does exposure to information about hospice matter?

If I were dying, I would want hospice care.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A Little</th>
<th>A Lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>45%</td>
<td></td>
<td>86%</td>
<td>81%</td>
</tr>
</tbody>
</table>

African Americans are more likely to want life-sustaining therapies

- Want to die in hospital
  - Whites: 18%
  - Blacks: 6%
- Want life-sustaining drugs that make feel worse
  - Whites: 28%
  - Blacks: 15%
- Want potentially life-shortening palliative drugs
  - Whites: 49%
  - Blacks: 74%
- Want mechanical ventilation for 1 week life extension
  - Whites: 24%
  - Blacks: 13%

Barnato et al, JGIM 2009
What do older adults think about hospice?

![Bar chart showing percentage of agreement between Whites and Blacks](chart.png)

Spiritual Beliefs

- Only God can decide life and death
- God is responsible for health
- Religious prohibitions against limiting life-sustaining therapies
- Divine Intervention and Miracles Occur
- Doctor is God’s Instrument

Religious Coping is Associated with Aggressive Care

![Bar chart showing comparison between Low Religious Coping and High Religious Coping](chart.png)
Mistrust in Healthcare System

Perceptions and Reality

What do older adults think about hospice?

Johnson et al, J Pain Palliat Care 2009
Why work to increase hospice use among African Americans?

- Over ¾ of African Americans would want if dying.
- Beliefs change with information about hospice.
- Many have preferences c/w hospice.
- Hospice improves quality.


Is there a role for hospice providers?

In some areas, rates of hospice use are high for African Americans

Rates of Hospice Enrollment for African Americans in the Carolinas
What can hospices do?

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Mistrust</th>
<th>Spirituality</th>
<th>Preferences for Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Education and Outreach</td>
<td>Community Engagement</td>
<td>Partnerships with Churches</td>
<td>Organizational and System Change</td>
</tr>
<tr>
<td>Churches</td>
<td>Diverse Staff and Volunteers</td>
<td>Education</td>
<td>Coupling of Curative and Palliative Care</td>
</tr>
<tr>
<td>Civic Groups</td>
<td>Cultural Sensitivity Training</td>
<td>Hospice Volunteers</td>
<td>Open Access Hospice Program</td>
</tr>
<tr>
<td>Healthcare Institutions</td>
<td>Access to all Healthcare</td>
<td>Chaplains and Pastors</td>
<td>Bridge Programs</td>
</tr>
<tr>
<td>Media</td>
<td>Partnerships</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Survey of Hospices in the Carolinas

<table>
<thead>
<tr>
<th>Variable</th>
<th>N=80</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Free-standing</td>
<td>55.3</td>
</tr>
<tr>
<td>Home-Health Based Hospital Based</td>
<td>23.7</td>
</tr>
<tr>
<td>Hospital Based</td>
<td>21.1</td>
</tr>
<tr>
<td>Not-for-Profit</td>
<td>71.1</td>
</tr>
<tr>
<td>Annual Budget</td>
<td></td>
</tr>
<tr>
<td>&lt; 1 million</td>
<td>21.1</td>
</tr>
<tr>
<td>&gt; 4 million</td>
<td>48.7</td>
</tr>
<tr>
<td>Average Daily Census</td>
<td>59</td>
</tr>
</tbody>
</table>

How concerned are you about the % of African Americans served by your hospice?

- 41.3% Not at all/Not Very
- 17.4% Somewhat
- 41.3% Very/Extremely
Lesson 1: You need a plan

The hardest part of any job is getting started

- Gather support and form a team
  • Senior leadership, volunteers, community leaders
- Set some measurable goals
- Develop strategy to accomplish those goals
- Measure impact of your work (short & long-term)

Caring Connections African American Outreach Guide

Hospices in the Carolinas are working to reach African Americans

• Set goals to increase service to African Americans
• Specific strategies to reach African Americans
• Senior leaders participate in efforts
Lesson 2: Establish Community Partnerships

Think Inside and Outside of the Box

• Reach out to important organizations in the African-American Community
• Don't forget the importance of healthcare providers
• Media and Marketing

Community Outreach Practices

<table>
<thead>
<tr>
<th>Nursing homes</th>
<th>Churches</th>
<th>Physicians</th>
<th>Hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civic groups</td>
<td>Fraternities, sororities, Kiwanis clubs, chamber of commerce</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Businesses</td>
<td>Barber and beauty shops, funeral homes, restaurants, grocery stores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Service</td>
<td>Meals on Wheels, Senior Centers, Free Clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organizations</td>
<td>NAACP, day care centers, libraries, Women's groups, support groups</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9/9/2015
### Lesson 3:
What you look like matters some...

*Does staff race matter?*

It helps to have African-American staff
But it is hard.....

Over half of hospices were concerned about the low proportion of African-American:

- RN's
- Social Workers
- Chaplains
- Board Members
- Volunteers
Try to hire diversely

Over half of hospices had tried to recruit African-American staff:

– RN's
– CNA's
– Social Workers
– Board Members
– Volunteers

Lesson 4:
Maybe how you care for patients matters more...

Lesson 5:
Your service is your best advertisement
OR
Words can help or hurt
The Importance of Word-of-Mouth

• People Talk......

Lesson 6:
Be flexible when you can.

Admission policies vary among hospices in the Carolinas

<table>
<thead>
<tr>
<th>No Primary Caregiver</th>
<th>No PCP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wants hospitalization</td>
<td>IVF</td>
</tr>
<tr>
<td>XRT</td>
<td>Chemo</td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td></td>
</tr>
</tbody>
</table>

34 35 36
Conclusions

- Many hospices in the Carolinas are engaged in practices to increase service to African Americans.
- Hospices often engage in outreach/education to community organizations, directed marketing, and attempt to recruit diverse staff.
- More flexible admission practices and greater community outreach may increase service to African Americans.

Resources

- Caring Connections African American Outreach Guide
- NHPCO Inclusion and Access Tool Box

How can I help others and make a difference beyond my community?

- National Study of Hospice Providers
- Goal: To identify best practices among hospices in serving African Americans.
- What’s involved? Online form and 30-minute interview about your hospices’ practices
- Who can participate? Hospices in any of the 50 states and DC. It doesn’t matter about your current service to African Americans.
How can I help others and make a difference beyond my community?

• Benefits to participating hospices?
  – Access to 2 free webinars and small incentive
  – 3 hospices will win $1,000 via random drawing
  – State org in state with highest participation rate will receive $1,000

• How do I learn more?
  kimberly.s.johnson@dm.duke.edu

Acknowledgements

• Carolina’s Center for Hospice and End of Life Care
• Hospices in Carolinas
• Research Team
  – James Tulsky MD
  – Karen Steinhauser
  – Maragatha Kuchibhatla
  – Alana Bennett

  kimberly.s.johnson@dm.duke.edu