African Americans’ Perceptions and Recommendations for Palliative Care in an Urban Community

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Background and problem statement

- Palliative care is growing rapidly and recommended early on as part of care for serious illness
- Inadequate treatment of symptoms and suffering associated with serious illness continues
- Disparate access to care for individuals from underrepresented groups
- Disproportionate lack of awareness and utilization of palliative care among underrepresented groups, including African Americans
- Limited provision of information and emotional support for individuals and families
- Growing numbers of older adults in underrepresented groups
- Why African Americans are not using palliative care-particularly in Milwaukee remains largely unanswered.
Project Question and Aims

What awareness, attitudes, and beliefs about palliative care do African American participants from selected Milwaukee area communities describe when participating in focus group sessions facilitated by trained community stakeholders?

The aims of this project are to:
1. Gain genuine understanding of awareness, attitudes and beliefs about palliative care in Milwaukee African American communities.

2. Use findings to develop local initiatives in conjunction with community members to address gaps in palliative care.
Pre-project planning

- Project supports secured
- Office of Research & Sponsored Projects & Institutional Review Board approvals obtained
- Informational, consent, and training materials developed and reviewed
- African American community stakeholders recruited and trained as facilitators
- Commitment to host focus groups and help recruit participants obtained
Facilitator training: Conducting focus groups and palliative care

Curative Focus:
Cure disease; restore health & function

Palliative Focus:
Treat disease symptoms; provide comfort & support

Serious disease diagnosed

Disease worsens

Bereavement Support

Death

Hospice

(Adapted, WHO & ELNEC, 2005)
Methods

• Qualitative study, purposeful sampling technique
• Community sites informed of project
• 4 sites agreed to host focus groups
• Participant recruitment through flyers and word of mouth at host and other community sites
• Registration to participate was open to community area English speaking, African American adults interested in sharing their views
Methods

- 90 minute café style focus groups conducted by facilitator and note taker
  - Welcome and introduction, project description, consents obtained, and ‘ground rules’ discussed
  - Participants’ discussion recorded (written & audio)
  - Participants received small stipend for participation
  - Post-group debriefing for project personnel
Methods (con’t)

- Facilitator-led ‘café style’ focus groups conducted and recorded
- Facilitators and project personnel debriefed
- Written and audio records transcribed and analyzed
- Findings shared with local and state stakeholder groups to guide meaningful ‘next steps’
Analysis

• Post group debriefing for facilitators and project personnel
• Audiotapes transcribed
• Transcriptions reviewed and compared with (written) notes
• Themes identified
• Themes and transcriptions reviewed by project personnel
• Additional qualitative analysis with N Vivo software
Results: Demographics

- Facilitators: 6
- Host sites: 4
- Groups: 11
- Participants: 97 (9-12/group)
- Mean age: 46.6 (Range: 36.9 – 70.8)

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<tr>
<th>DATE</th>
<th>LOCATION</th>
<th>NUMBER OF PARTICIPANTS</th>
<th>AVERAGE AGE</th>
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<td><strong>97</strong></td>
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Results: Key findings in 4 areas

- Sources of support and trust
- Awareness
- Attitudes and beliefs
- Recommendations
Sources of support and trust

• Major sources of support
  • First and foremost: family, friends, pastor and God
  • Less often: health care providers
  • Sometimes: caseworkers
• Variable degrees of trust in systems and providers
Awareness of palliative care

• Aware of the concept of “palliative care”
• The word/term “palliative care” often associated with hospice and end of life care

• Participants’ definitions of palliative care
  “Taking care of someone who can’t take care of themselves.”
  “Taking care of loved ones.”
  “Taking care of someone who is very, very, ill, about to pass.”
  “Hospice care.”
  “24-hour care.”
Awareness of hospice care

- Many participants were aware of hospice care and/or had a family member who had used hospice.
- Hospice was viewed as a place to die.
- Many participants perceived that hospice care was only available to people with “good” insurance.
- Respect was believed to be the most important factor for hospice to benefit the individual and the family.
- Most participants stated they would want to die surrounded by family and loved ones at home.
Attitudes and beliefs: Benefits of palliative care

- Reduces suffering and pain.
- “No one wants to be a burden on their family.”
- Prepares and supports the family.
- Increases access to expensive medical equipment.
Attitudes and beliefs about barriers

- African Americans receive different quality care than others
- Lack of knowledge, “We don’t know about it.” “Black folks are always the last to know about something that is good for them.”
- Inadequate or no insurance – “This is for people who have good insurance.”
- Religion, “I trust in God.”
- Belief in home remedies – *Many of our folks use what their grandparents used to take care of pain...home remedies*
- Desire to die at home without medical team in place.
- Power of attorney prevents family members from making better, more informed decisions about one’s health.
Recommendations: Education, information and care

- Intentional, timely and meaningful change
- More education earlier on and to more people
  - before diagnosis of serious illness
  - for the community: “more groups like this (focus) group”
  - for students and health care providers
- ‘Spread the word’ through
  - brochures, pamphlets, word-of-mouth
  - information sessions at community organizations (churches, nursing homes)
  - media campaigns
- More compassion & respect in patient/family - health care interactions
- More care modeled after community-based hospice program
Dissemination

- Dec. 2013 program & discussion, Marquette University
- Jan. 2014 webinar, Wisconsin Cancer Care Control Network, Palliative Care Workgroup
- Feb. 2014 presentation & discussion, Milwaukee Regional Cancer Care Network
- Feb. 2014 article, Nursing Matters
- May 2014 breakout session, Breast Cancer Conference for Community Health Workers
Limitations

- Qualitative project
- Limited generalizability
Unanticipated outcomes

• Number of people wanting to participate exceeded expectations
• Interest and support from host sites was strongly positive
• Extra focus groups were held to accommodate overwhelmingly positive interest
• Extent and richness of discussion among the groups exceeded expectations
• Project consultant, facilitators and sites interested in future palliative care related endeavors
Next steps

• Continued collaboration with area community, health care, education, and religious organizations about palliative care for African Americans
• Education and use of ‘ready resources’ for community residents and groups about palliative care
• Academic courses and programs for students
• Education for community health workers
Conclusion

- There is a strong interest among community members, community leaders and organizations, and health care providers in improving awareness of, education about, access to, and satisfaction with palliative care for African Americans in our area.
Acknowledgements

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Trained Facilitators
- Olufunmiola Akindogum
- Alicia Ellis
- Shawn Green
- Pastor Roy Lewis
- Felicia Moore
- Monica Payne

Hosting Sites
- COA Youth and Family Services
- Lovell Johnson Quality of Life Center
- Marquette University Health Center
- YMCA of Metro Milwaukee

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