Unquenchable Hope: Understanding the Spiritual Underpinnings of End-of-life conflicts for African-American Families in Critical Care

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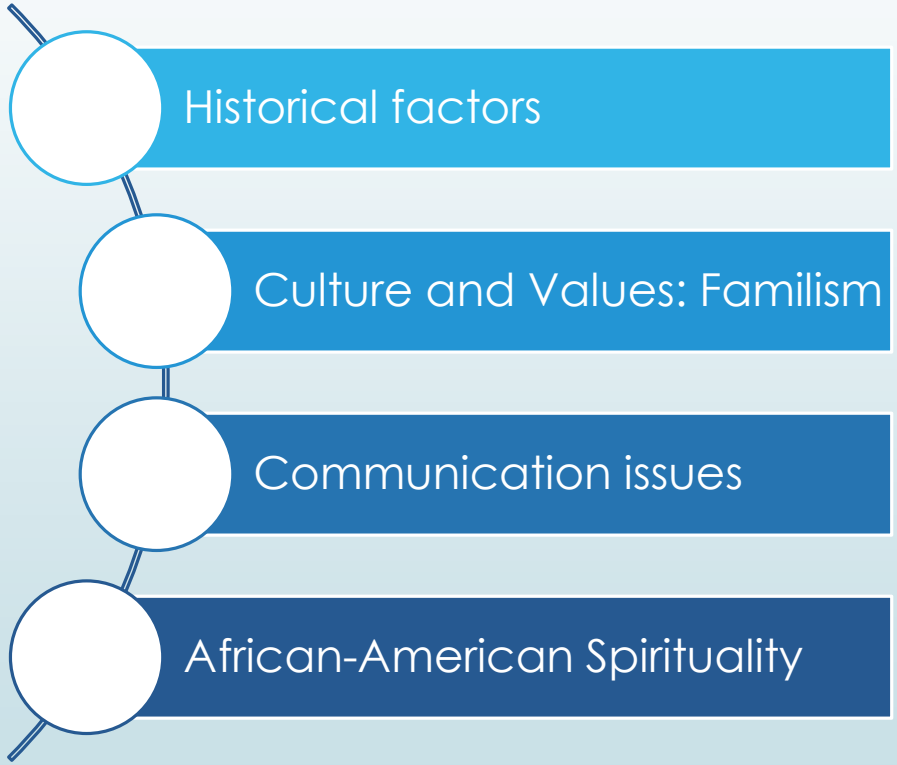
The Problem: "They want 'everything done'"

- Common scenario with African-American family:
  - Physicians have decided that the patient's code status should be changed from full code to DNAR/DNR.
  - Physicians may have determined that the patient is terminally and irreversibly ill and that measures beyond comfort care are futile.
  - An ethics consult may have been ordered.
  - The Palliative/Supportive Care team may be recommending inpatient or in home hospice care.
  - Pastoral care is consulted to help navigate the impasse that may have developed between hospital staff and the family.

Breaking Down the Problem



Patient Quotes

- "As a black man, I am subject to receive less care and attention than a white man, and if I had a living will, they might not care for me at all."
- "Bring Daddy home and we'll move the bed into the dining room and we'll take care of him until he dies. We're not going to keep him in a nursing home and we'll be here until it's over."
- "My doctor never asked me, so I never brought it up."
- "The doctor doesn't really know when someone is going to die. Only the Lord knows. I put my faith in God, and until He says it's time for me to go on to Glory, I want the doctors to do all that they can do to keep me alive."

Sanders, Justin et al. "Factors Impacting Advance Care Planning Among African Americans: Results of a Systemic Integrated Review," 2016

African-American Spirituality: Hope, Survival and Justice

- The role of Religion and The Church:
  - "Positive religious coping and strong religious support from the community are associated with the use of more aggressive EOL care."
    - What are the factors that transform religious coping into aggressive, life-prolonging care?
      - The Role of the Pastor
      - The Role of the Community
      - Suffering and Forbearance in African-American Spirituality
      - Common themes in Evangelical and Prosperity Gospel preaching
      - The power of oral history and anecdotal knowledge

Sanders et al. "Factors Impacting Advance Care Planning Among African Americans."

African-American Spirituality: Hope, Survival and Justice

- African and African-American views of God
  - Covenantal Relationship with God
  - God involved in daily life as well as in struggles against injustice:

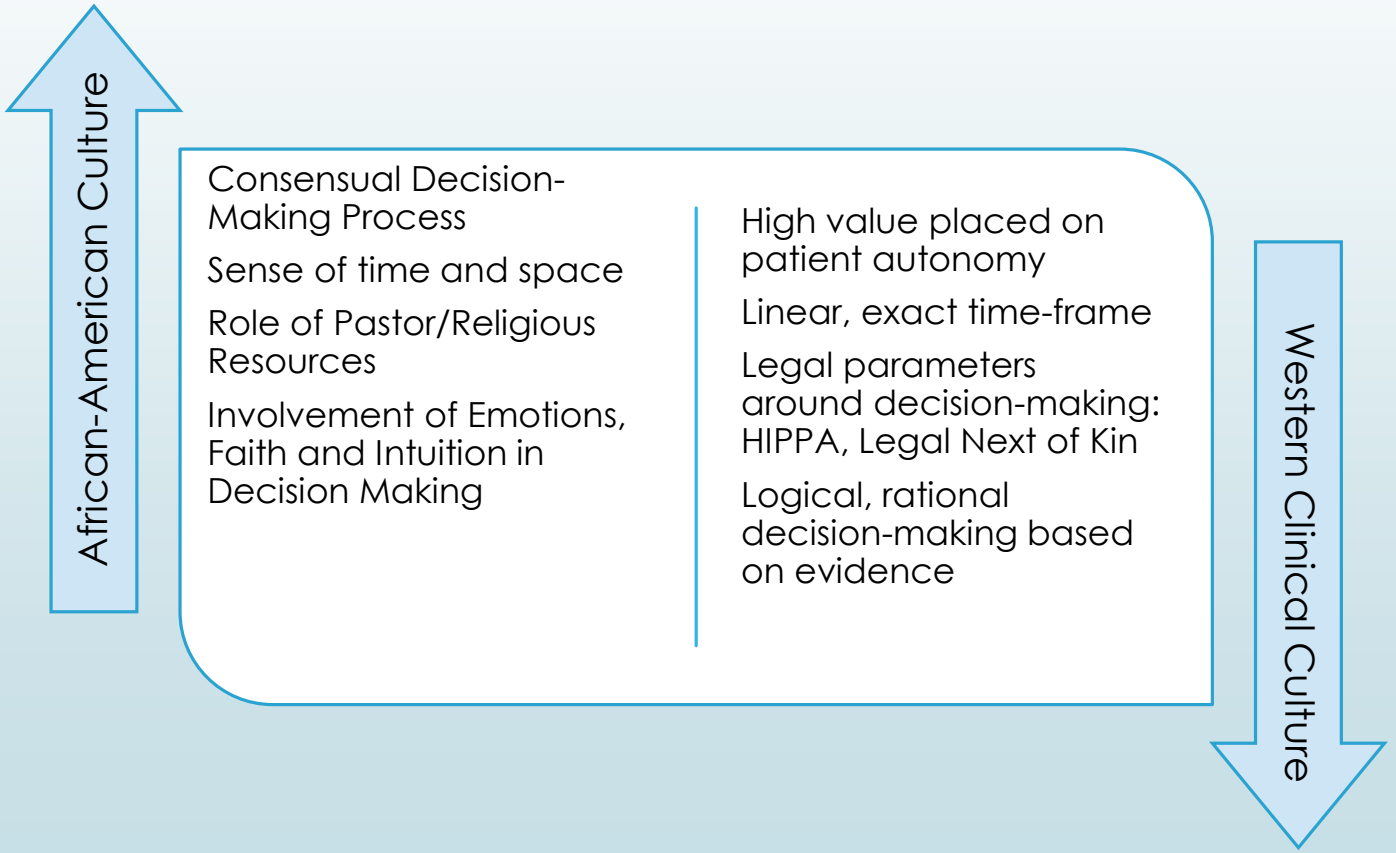
"In short, belief in an ever-present divine power capable of delivering them from any measure of trouble has been characteristic of their faith from the most ancient times up to the present. Thus, like that of their African predecessors, the basic theology of Africans in the diaspora reflected primarily the survival orientation of their racial community."—Peter J. Paris

Patient Quotes

- "We want to put him on the machine regardless of how long because [we] believe faith is so strong it will bring them through."
- "God would not 'put more on you than you can bear.'"
- "We have faith because we live through God. We don't need man-made documents to tell us how to go [die]."
- "We are all going to suffer at some point. Jesus suffered…So if 'not suffering' means dying at home, I'll suffer a little bit because I don't want to die at home.'"

Paris, Peter J. *The Spirituality of African Peoples: The Search for a Common Moral Discourse*, 1995.
Sanders, Justin et al. "Factors Impacting Advance Care Planning Among African Americans: Results of a Systemic Integrated Review," 2016

Cultural Conflict: African-American Culture v. Western Clinical Culture



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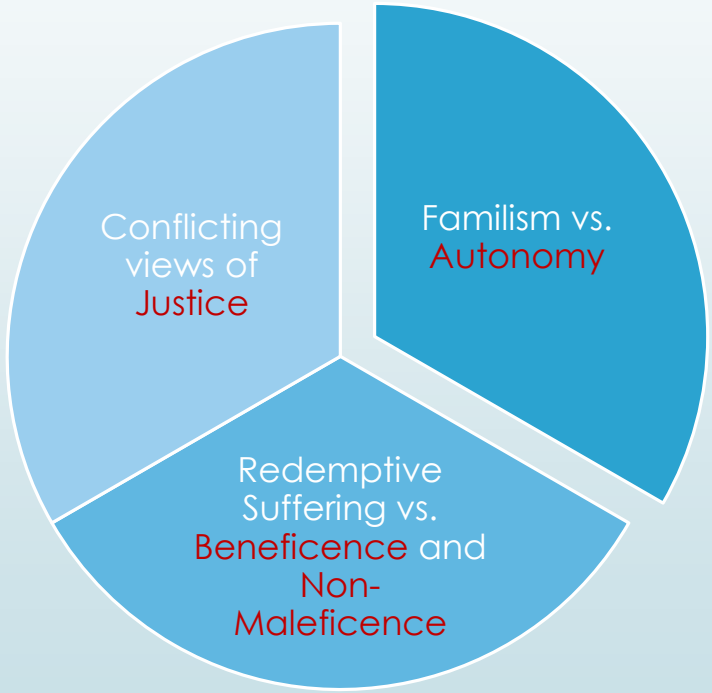


Strategies for Healthy Dialogue: The Chaplain's Role

- Cultural Humility and Chaplaincy
- The Chaplain as Cultural Ambassador
- The Chaplain as Facilitator/Mediator

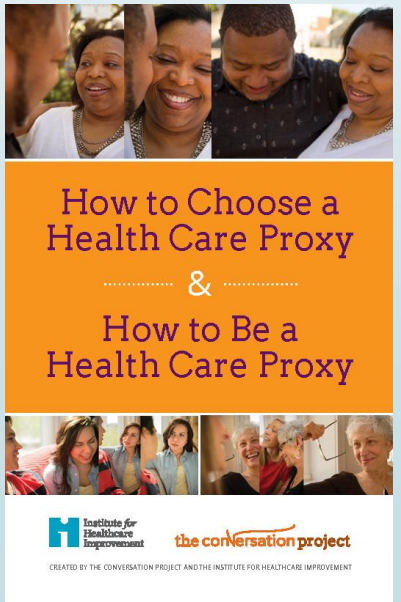
Interdisciplinary Team and Community Strategies

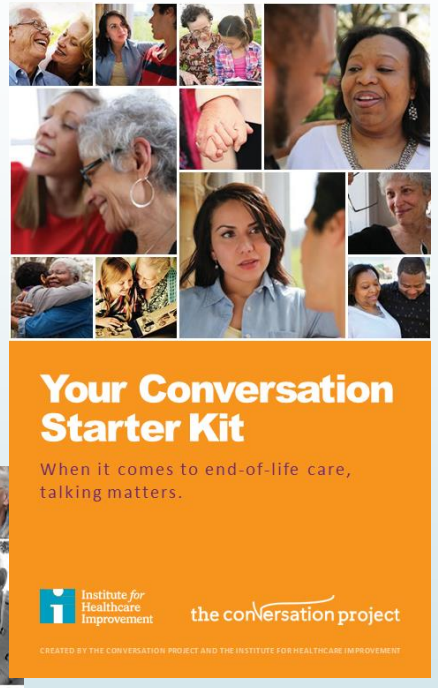
- The Serious Illness Care Project: Ariadne Labs
  - Empowers physicians and nurse practitioners to have important conversations with patients and caregivers about their goals of care and values
  - Encourages earlier end-of-life conversations
  - Includes patient's hopes, fears, wishes, values and spirituality in healthcare planning
  - Empowers patients and caregivers to make significant choices about their future care
  - Helps them to feel heard and cared for by healthcare team
  - Appropriate for inpatient and outpatient settings

Interdisciplinary Team and Community Strategies

Advance Care Planning Education: Partnering with Community Clergy

- Hospice Education
- Conversation Sunday
- Organ Donation Sunday
- Health Fairs

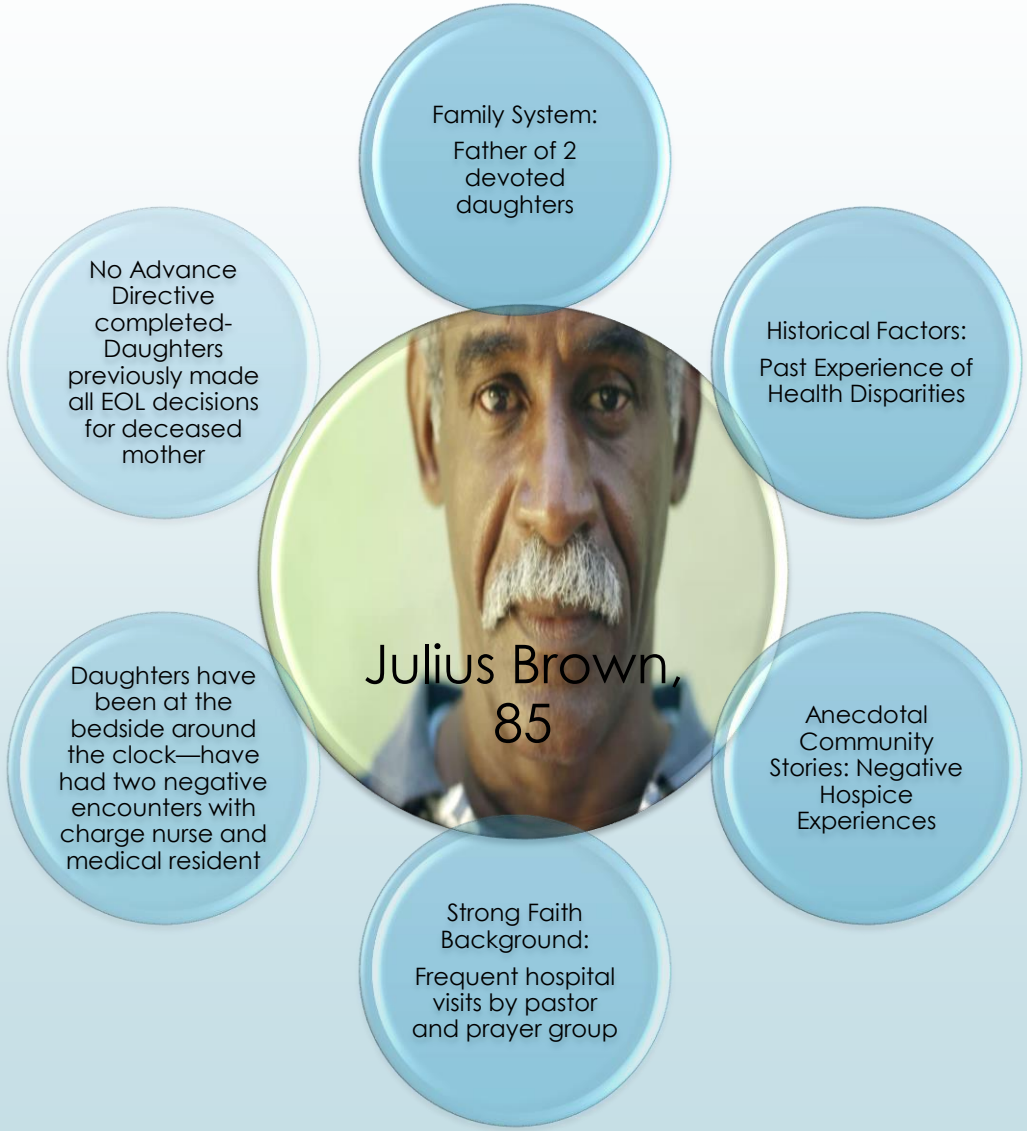




Case Studies

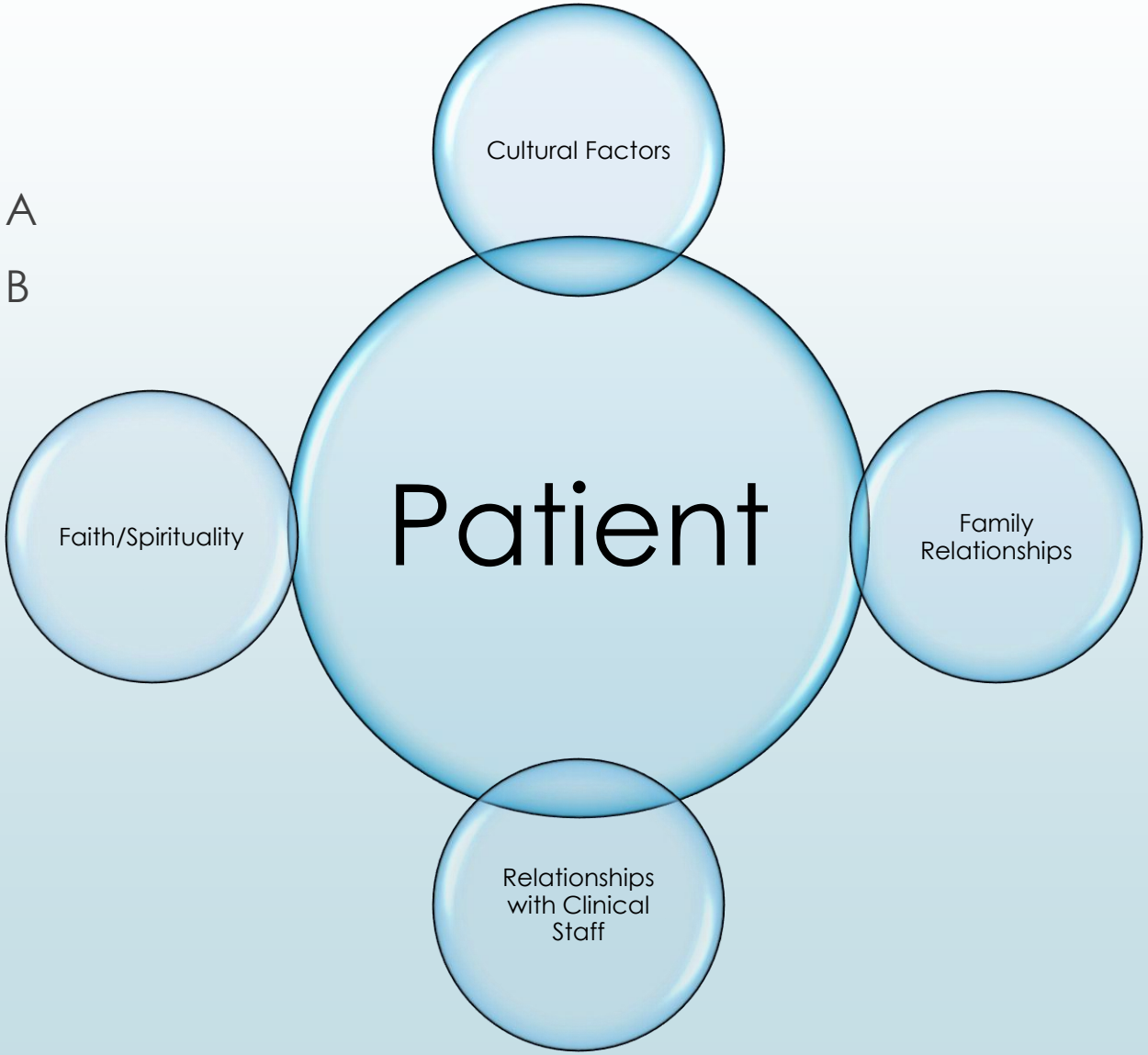
- An 85 year-old African-American male is hospitalized with end-stage Congestive Heart Failure. After being resuscitated three times in the ICU, he begins to experience kidney and respiratory failure. Their long-term primary care physician recommends comfort care and that his code status be changed to DNR/DNAR.
- The patient is widowed and has been cared for at home by his two unmarried daughters. The daughters, after consulting with their pastor, refuse the change of code status. They want "everything done," including dialysis and continuation of mechanical ventilation.
- The Palliative Care team has met with the family twice, but the daughters refuse the offer of comfort care. The nurse practitioner on the team consults the Ethics committee.
- The family meets with the committee, and the impasse continues. The chaplain is called in to meet with the family again, as physicians believe that the patient will continue to decline.

Case Studies: A Closer Look



Group Case Study Activity

- Case Study A
- Case Study B



Discussion

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