African American Culture and Dying
An Interdisciplinary Conference

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CC: Altered Mental Status

- 57 yr old African America female with known Stage IV nonsmall cell Ca of Lung
- Recently admitted for new onset sz dso from new brain lesions
- Worsened MS described as more somnolent
- Brought to TMH for evaluation
**Medical History**

- Poorly differentiated metastatic carcinoma likely Giant Cell lung primary with mets to adrenals and liver s/p 2 cycles of carboplatin and pemetrexed
- HTN

**Surgical History**

- Partial hysterectomy for fibroids
- Cholecystectomy
- Hernia repair x 2
History

- **Family History**
  - Positive for malignancy

- **Social History**
  - >50 pack year smoking history quit 5 years ago
  - Denies alcohol or recreational drug use
  - Lives alone
History

- On admission to TMH she was found to be postictal and was started on Decadron and phenytoin
- For chronic worsening abdominal pain, patient was started on IV Morphine gtt
- Patient’s MS improved
- Patient and team had extensive discussions and patient continued to be CMO
- Hospice was consulted and patient transferred for symptom control
History

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 unable to obtain with MS
 NKDA

Medications:
- Dexamethasone 8 mg IV BID
- Ativan 2 mg SQ/IV q6 hours and q20 mins PRN for sz activity
- Scopolamine TD q72 hours
- Morphine 5mg/hour SQ/IV with 5 mg bolus q 15 minutes PRN
Physical Exam:

- BP 104/67 128bpm 20 afbrile 91% on O2 NC
- Cachectic and lethargic, arousable with verbal stimulation
- Pupils were pinpoint, no icterus
- mmm
- CTAB, Tachycardic without m/g/r
- +BS no organomegaly
- No edema/cyanosis/clubbing
- Neuro exam limited but noted moving all extremities spontaneously
- Skin-heels with callous
Inpatient Hospice Course

Day 1

• Px continued to be lethargic and family demanded to decrease Ativan dose despite risk for sz
• Family expressed disagreement with POC, hydration and medical regimen
• Ativan was decreased and family educated and given support
• DTR as DPOA
Inpatient Hospice Course

Day 2

- Patient’s MS improved
- Able to answer questions with yes/no
- Family continued to be vigilant of every medication being administered
- Family meeting with MD done
- Hospice services and concerns were addressed
Concerns:

- Sedation is interpreted as drastic functional decline (previously “up and about”)
- NO nutrition because of sedation ?IVF
- Miscommunication between transfers from TMH and Hospice regarding “the promise of continuing previous meds/intervention
- Goal: to take px home
- “Patient is a fighter”-wants her to fight dse
- “Is this a place to die? Do we sedate to die?”
Family meeting minutes

- Concerns, expectations as well as scope of responsibilities were carefully explained
- Medications adjusted
- Family discussion regarding EOL care encouraged once px more awake
- For now, patient is DNR
- Chaplain support, Reike and music tx arranged
Inpatient Hospice Course

Day 3

- Patient more awake but noted discomfort and increased anxiety
- Goals of Care were clarified
- Px is not interested in artificial hydration/nutrition
- Px agreeable to be sedated if it came to a point that this is necessary for her comfort
- Delegated any of her daughters to make decisions for her if she is incapacitated
Inpatient Hospice Course

- Over the next few days, the patient continued to decline with increasing abdominal pain, confusion, development of oral thrush and skin breakdown.
- Morphine pump was increased but the family disagreed and wanted the dose to remain at the current dose with only breakthrough doses.
- Patient continued to manifest pain despite lethargy.
Inpatient Hospice Course

- Patient continues to express clearly stated wishes to members of the team as regards to her care (Comfort tx, no pain over alertness and longevity)
- Family members present were divided into accepting of her wishes and some irate
- Staff continued to educate and support family
- With staff, px expresses “wanting to go” but needed support to tell her family
Inpatient Hospice Course

- As patient declined family insisted on their POC to team including discontinuation of medications that brought about complications
- Family feels medical team is failing patient and complains about staff (about POC and attitude towards family)
- During lucid intervals, patient interchanged between her making decisions versus family decisions
Finally on Day 26 patient informed staff that she would like to be comfortable and she revoked delegating daughter for decision making in her behalf.

Px acknowledges difference between her and her family regarding EOL status.

Medications were adjusted and px was d/c to home with hospice.
QUESTIONS

 Who is responsible in deciding for patient care?
 What are the conflicts involved in decisions about patient care?
 What is the role of medical team in terms of reconciling goals of care between px and family?
 How does cultural disparity play a role in EOL care?
 If there is no resolution between players in terms of unifying GOC, who can assist?
Advance Care Planning

- An essential component of EOL care
- Includes discussing preferences, values and contingencies for EOL care
- Exploring px’s wishes reg after-death issues
- Not a static document but an ongoing process and an opportunity to engage pxs and family
Advance Care Planning

- In a study of 200 elderly from 4 ethnic groups
  - 57% of Korean Americans and 45% of Mexican Americans believe family as primary decision maker
  - 24% of African Americans and 20% of Eastern Europeans
- Importance of cultural sensitivity and cultural competence among physicians
Advance Care Planning

- For pts lacking decision-making capacity
  - Generally appropriate to turn to family
  - Predicting pt preferences is difficult
  - Surrogate-pt agreement is often limited even if done beforehand
Advance Care Planning

- Family members may have conflicts of interest or disagree with one another.
- Considering known medical facts about the px, refocusing on px’s values and preferences is an effective way to achieve consensus.
- Substituted judgement.
- Distant family and unpredictability of physician can make decision making difficult.
Advance Care Planning

- Variance in wishes
- Often places physicians in the center of a triangular conflict
- To balance considerations of professionalism, patient autonomy and integrity of family
Conflicts
Conflicts

- Defined as “a dispute, disagreement, or difference of opinion related to management of px involving more than one individual and requiring decision or action”
- 78% in 102 consecutive cases
- Clinician-family conflict in 48%
- Clinician-clinician conflict in 48%
Common Examples of Conflict

- Family vs Clinician
  - Daughter prefers life sustaining tx for px
  - MD thinks this will increase px suffering

- Husband uncertain about px’s wishes
  - MD feels husband is inconsistent when discussing px’s wishes

- Wife does not believe prognosis
  - MD believes wife is in denial

- Husband does not trust that clinician is acting in px’s best interest
  - RN thinks family is not acting in px’s best interest
Common Examples of Conflict

✧ Clinician vs clinician
  ✧ Specialist wishes to continue intervention
  ✧ Palliative MD wishes to focus on QOL and px goals

✧ MD wants to continue tx based on small chance of cure
  ✧ RN wants to focus on QOL based on large chance of failure

✧ MD thinks medical decisions are his responsibility
  ✧ RN thinks her input is excluded
Common Examples of Conflict

- **Family vs family**
  - Dtr thinks she knows px wishes best
  - Son thinks med options not exhausted
  - Wife accepted imminent death of husband
  - Dtr just arrived insists on not giving up

- **Patient vs Clinician**
  - Px wants to try another chemotx
  - MD thinks this is futile
  - Px wants to live independently
  - MD thinks she needs ALF
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African American Culture and EOL
EOL in Black and White

- Family of African American decedents were 60% less likely to report excellent or VG care.
- More problems with communication with MDs, being informed, and receiving support for family members.
- 60% less likely to have DPOA or signed living will and in addition were 70% compared to whites to have had specific wishes about tx.
- Similar rates regarding respect and coordination of care.
EOL in Black and White

- African Americans approaching EOL rely more on trusted family members, friends to speak for them regarding medical decisions
- Oral communication rather than written particularly important for this group
- Financial burden with EOL care
Palliative Care, Advance Directives and African American Cultural Beliefs and Practices

- Significantly less likely to complete AD and more likely to express concerns about hospice
- Hospice philosophy-core values of dominant white culture: independence, individual rights, acknowledgement of death, focus on QOL and fear of receiving too much care at EOL
- Inconsistent with non-anglo-american cultural attitudes about planning EOL
Palliative Care, Advance Directives and African American Cultural Beliefs and Practices

✧ Caring for and being cared for by a family member is a valued way to express respect and dignity for loved ones and takes precedence over independence.

✧ Decision making styles also varies.

✧ In contrast to hospice focus on individual’s right to make EOL decisions, African Americans trust in families to make best EOL care decisions.
Palliative Care, Advance Directives and African American Cultural Beliefs and Practices

- Use of AD is less in this culture and many feel they will receive inferior care if such documents are signed.
- Hospice req that both px and family acknowledge impending death, a concept often runs counter to African American spiritual beliefs.
- A reluctance to plan death due to belief that death is only acceptable when it is God’s will.
Palliative Care, Advance Directives and African American Cultural Beliefs and Practices

- Hospice’s focus on quality rather than quantity also conflicts their belief in longevity and the redemptive nature of suffering.
- Hospice is equated to giving up that counters belief that longevity is intrinsically good.
Palliative Care, Advance Directives and African American Cultural Beliefs and Practices

- Long and often justified mistrust in medical system
- Pxs and families mostly are not accepting of prognosis and do not acknowledge that px is dying
- Lack of knowledge and access to hospice and services
- Reluctance to go outside network
Barriers

- Study done by Yancu showed similar results except lack of trust does not appear to be a major barrier, most believe hospice provides equal care to all racial groups
- Lack of diversity among hospice workers is problematic
Barriers

- Effective service delivery models designed to reach increasingly ethnically diverse population is still lacking
- We need to develop a culturally sensitive, evidence-based, educational training tool for health care professionals, hospice teams, family caregivers to broaden knowledge and understanding of cultural beliefs and attitudes surrounding EOL care
Among African Americans, several studies suggest that qualitative data would be an invaluable tool to extend palliative care’s outreach to this population.
When Conflict Cannot Be Resolved

✦ Bringing in an outside person may help diffuse tension, depersonalize the issues and identify new solutions
✦ Seeking assistance from Ethics, Risk Management or Palliative Care
✦ Transfer of Care
The End
End of Life Care in Black and White: Race Matters for Medical Care of Dying Patients and their Families; Lisa Welch, PhD, Joan Teno and Vincent Moe PhD

Barriers to Hospice Use and Palliative Care Services Use by African American Adults; Cecile Yance PhD, Deborah F Farmer et al.

Damage Compounded: Disparities, Distrust and Disparate Impact in End of Life Conflict Resolution Policies; Mary Ellen Wojtasiewicz, et.al

What’s Race Got to Do With It? Ramona Rhodes, Et. Al

Supporting Family Caregivers at the End of Life “They Don’t Know What They Don’t Know; Micahel Rabow, Joshua Hauser, Jocelia Adams

Using clinical empowerment to teach ethics and conflict management in antemortem care: A case study; W. Clay Jackson MD DipTh, James Wilde, Jr MD, Jackson Williams

Dealing With Conflict in Caring for the Seriously Ill “It was Just Out of the Question”; Anthony Black MD, Robert Arnold

Ethnicity and Attitudes Toward Patient Autonomy; Leslie Blackhall et. Al

Health care professional’s accuracy in predicting patients’ preferred code status; Barbara Morris