Difficult Decisions Regarding Living Arrangements and Health Care: Cultural Dilemmas

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On Lok Lifeways

- Over 1200 participants
- Multicultural populations speaking 30 different languages
- 7 centers in the Bay Area (SF, East Bay, South Bay)
- 67% female, 33% male
- Mean age 81.5
What Makes a Good Team?
Characteristics of a Good Team

• Clear leader of the team
• Appropriate systems for communication within the team
• Personal rewards, training and development
• Structure and resources
• Appropriate skill mix
• Team climate
• Individual characteristics
• Uniform vision
• Quality and outcomes of care
• Respecting and understanding roles

(Ten Principles of good interdisciplinary team work by Susan A. Nancarrow, Andrew Booth, Steven Ariss, Tony Smith, Pam Enderby and Alison Roots 2013)
Advantages of Working in IDT Context

• Comprehensive service to larger number of patients with more complex needs
• Complexity of skills and knowledge
• Continuity of care

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Challenges of Decision Making in IDT

• Difference in Risk Tolerance
• Difference in personal and professional view of a problem by IDT members
• IDT culture/ bias
The Dimensions of Staff Culture

INDIVIDUAL

ETHNICITY / LANGUAGE

PROFESSIONAL

IDT / CENTER

PACE
Challenges of developing a compromise- and the best treatment plan

Physical vs Psychological Wellbeing
On Lok Terms

- **Participant** = Patient or client
- **RCFE** = Residential care facility for the elderly = Assisted living
- **SNF** = Skilled nursing facility
- **IDT** = Interdisciplinary team
- **POLST** = Physician’s Orders for Life Sustaining Treatment (Official document to indicate healthcare wishes)
- **ADLS** = Activities of daily living (toileting, bathing, dressing, hygiene, etc.)
- **IADLS** = Instrumental activities of daily living (shopping, paying bills, meal preparation, etc.)
- **Functional mobility** = manner in which people are able to move around in the environment while doing ADLs (e.g. sitting, standing, bending, transfers, walking, climbing)
IDT Cultures and Perspectives

• Role of PCP as part of the IDT

• Two case studies to examine the cultures, factors, and perspectives that influence IDT decision-making
Case of Mr. C
Case of Mr. C

Primary Care Provider’s Perspective:

Determining the Appropriate Placement for Mr. C
85 y/o divorced Caucasian male veteran living alone in the community:

- Parkinson’s disease
- Severe unstable heart failure (CHF)
- Mild Cognitive Impairment (MCI)
- History of Stroke
- Frequent recurrent falls resulting in significant injuries
- Over 20 other complicated medical conditions!
Factors that Influenced IDT Decision-Making for Placement of Mr. C

- Medical necessity
- On Lok resources
- Medical Ethics
  - Autonomy: Right to self-determination
  - Beneficence: Duty to do good
  - Nonmaleficence: Duty to do no harm
Medical Necessity

- Frequent exacerbations of heart condition (CHF)
- Severe right ear infection
- Hematoma inside left thigh
- Recurrent falls
- Recurrent pressure ulcers
- Cervical neck fractures
Modified Treatment Plan for Mr. C

• Increased **DHC** attendance
• Added, increased, and maximized **home care** for ADLs/IADLs
• Increased **clinic** visits
• Increased **specialist** visits
• Implored **family** to be more involved
Placement Options Considered

1. Remain independent in own home

2. Assisted living in RCFE

3. With skilled nursing needs at Skilled Nursing Facility (SNF)
Autonomy: Right to Self-Determination

• Decision-making capacity

• Goals of care

• Home: Identity as Father/Provider

• Participant’s own culture, values, and belief system
Beneficence: Duty to Do Good

• IDT goal to make decisions that will bring about the most holistic good to participant

• Each IDT member’s decision is influenced by their professional role
Nonmaleficence: Duty to Avoid Harm

Which placement option would allow the IDT to follow the principle of nonmaleficence while also following the principles of autonomy and beneficence?
Recommendation for RCFE (Assisted Living) placement for 24/7 supervision to maintain safety and assistance with ADLs and IADLs
Case of Mr. C

Mental Health Clinician’s Perspective:

Determining the Appropriate Placement for Mr. C
Case of Mr. C
Referral for psychotherapy:

Diagnoses:

1. Major Depressive Disorder, Recurrent, Mild
2. Generalized Anxiety Disorder
Most significant symptoms:

- Depressed mood
- Diminished interest and pleasure in any activities
- Anxiety
- Irritability
- Fatigue
- Difficulty with attention and concentration
- Feelings of worthlessness
Who is this person, really?
Case of Mr. C

Since RCFE is suggested:

• Hopelessness and Helplessness are deeper.
• Disappointed. Frustrated.
• Wants to die. Doesn’t care.
Case of Mr. C

“You are on their side. You don’t care.”

What is the role of a Psychotherapist?

Participant versus IDT?
Case of Mr. C

IDT Dilemmas:

• Home versus Assisted Living
• Body versus Mind and Heart
• IDT versus Family
• Person beneath the body and the disease.
Case of Mr. C

Mr. C Moves to RCFE

• Mr. C’s children are happy
• IDT is somewhat relieved
Mr. C is depressed.
• …is not part of the moving out/in process
• …grieves the loss.
• …hates his new place
• …talks about moving back to his home, another cheaper place or to NJ to be with his siblings.
“I am 85 and all I have is a TV and an electronic piano”

“Can you help me?”
Case of Mr. C

Mr. C is now in a Nursing Home. Nothing has changed.

Is this fair?
Case of Mr. B
Case of Mr. B

Primary Care Provider’s Perspective

Determining How Best to Interpret and Honor Mr. B’s Healthcare Wishes
Mr. B

96 year-old widowed Filipino male living in the community with his family:

• Chronic lung disease
• Advanced kidney disease
• Newly diagnosed **gastric cancer**
• Multiple chronic illnesses!
Factors that Influenced IDT’s Interpretation of Prt’s Healthcare Wishes

• Clinical presentation
• Participant’s wishes
• Participant’s family’s wishes for him
• Medical ethics
  • Nonmaleficence: Duty to do no harm
  • Autonomy: Right to self-determination
Mr. B’s Clinical Presentation

• Mr. B’s Gastric Cancer
  • Stomach mass caused him to bleed internally continuously
  • Stomach mass was obstructive, rendering him unable to eat by mouth
1. Nothing to eat or drink by mouth

2. Hospice
Major Dilemma

Should Mr. B get a feeding tube placed?
2011 POLST: Mr. B’s Healthcare Wishes
Autonomy

• From a cognitive standpoint, Mr. B had decision-making capacity

• However, Mr. B chose to defer all his decisions to his granddaughter, even if he himself disagreed with her decisions
Mr. B’s Family: Granddaughter

- Primary DPOA and decision-maker
- Nurse
- Unwilling to accept participant’s terminal illness and death as inevitable
- Consistently wanted to escalate care with more aggressive interventions and treatments
2014 POLST: Family’s Healthcare Wishes
“You’re killing me! You’re starving me to death!”

~ Mr. B
“I want my life to prolonged as long as possible …except in the following circumstances…in a terminal illness (death expected within 6 months)”

~Mr. B

(from his May 2012 Advanced Directive)
Autonomy Vs. Nonmaleficence

• **For Mr. B: Autonomy** meant following the decisions of his granddaughter

• **For IDT: Nonmaleficence** meant changing goals of care to comfort care and not escalating care at the end of life
IDT’s Final Decision for Mr. B

IDT step aside and follow granddaughter’s healthcare wishes for Mr. B as his utmost desire was to honor his granddaughter’s wishes for him.
Case of Mr. B

Mental Health Clinician’s Perspective:

Determining How Best to Interpret and Honor Mr. B’s Healthcare Wishes
Case of Mr. B

- Frail and fragile Filipino man
- Spoke well about what was happening to him
- Knew what he wanted for himself
“I am tired and I don’t want these treatments.
It hurts. My family will decide.”

~Mr. B
Case of Mr. B

“It’s God’s will.”

~Mr. B
IDT’s Challenges

• Emotional struggle was watching Mr. B go to the hospitals and have heroic interventions performed on him.

• The struggle was having to spend hours on the phone with the family, who we all felt, was almost abusive of this man’s rights.
IDT’s Challenges

• Constantly trying to quickly resolve any issue that would arise, especially additional time demands for Home Care, Clinic, and Social Work.

• These problematic situation took away time from other participants and issues.

• As professionals, we have to “fix things”. It is difficult to step back.
What did we decide?

• We realized that Mr. B’s “Faith in God’s Will” and his trust in his family will not change.

• We accepted that Mr. B’s family did love him and really wanted him to live longer, at any cost.

• We decided to step back and be ready to provide services as and when we were called upon.
Conclusion: IDT decision-making
Conclusion: IDT decision-making

KEEP CALM AND STRUGGLE ON
Conclusion

• Know your bias

• Be able to compromise
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Questions?

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