Patient Centered Palliative Care

Karlene Boss DNS

Arum Vang RN

Crystal Levesque LPN

Sumathi Devarajan MD

Objectives

1. The learner will be able to learn nuanced communication tips to interact with patients and families with complex medical needs

2. The learner will become aware of various cultural care needs within various cultural groups

3. The learner will be able to support their staff in dealing with medical and cultural conflicts

Case Mrs. SA

-70 year old lady, accepted for admission into West Hills Health and Rehab for skilled, then ICF transition for sub arachnoid hemorrhage related CVA event from uncontrolled HTN

-Positive Hepatitis C for 20+ years

-hepatic tumor, found incidentally on work up, needing follow up

-on admission, had a tracheostomy tube, feeding tube and Foley catheter, dependent on 2-6 liters of oxygen

Social background

- SA married, was living with husband, emigrated from Pakistan to live in US
- Has 5 adult children living in the US, one daughter , 4 sons
- No belief in allopathic medicine
- Huge change in baseline, from independence to bed bound status with no form of communication

Preferences

- 24 hour family presence
- Wanting to follow naturopathic treatment
- Special dietary needs
- Wanting female caregivers only
- Allow for changes in treatment plans at any time
- Did not want to discuss advanced directives

Challenges for the care team

- Lack of trust
- Not sure how much of truth family wanted to know
- Family perceived only what they wanted to hear
- RN departures
- Quick requests for change in treatment plans
- Wanting non listed naturopathic powders/liquids to be administered by RN's
- Reporting of complaints from family to various boards with ongoing inquiries

Medical standpoint

- Team was able to wean her off all tubes, G tube was left in place for bitter herbal remedies/tea that family was wanting
- Oxygen was weaned to 1-2 liters per nasal cannula
- Mild growth in the liver tumor was seen, slow growing
- Non verbal, right hemiparesis, right knee and UE contractures
- Able to tolerate PO pureed foods (family was providing)
- Neurology consult; Hepatology consult; alternative medicine consults

Communication challenges

- Patient preference not known
- Husband not getting the concept of discussions
- Change of communication channels to daughter, then onto husband
- Son, who actually knew what was really happening, was not engaged in care decisions
- Triangulation within family members
- Favoritism of staff, dealing with kitchen staff directly by family

Team perspectives

- From Crystal LPN
- From Arum RN
- From Karly DNS

Palliative Literature on communication
(Primer of Palliative care, 6th)

- Prepare and plan: Setting, Key stakeholders; agenda setting with pre-meeting huddle
- Find out what the patient and family know and want to know: allow for patient and family to speak; active listening; respect the differing preferences about truth telling
- Complete Medical Review and share information: ‘ warning shot’; small amounts of information sharing; pause frequently
- Respond empathetically
- Identify and resolve conflicts: use “I wish”.. Statements
- Set Goals and Plan for future

Tools- to help with communication

- Kleinman's questionnaire
- *https://implicit.Harvard.edu/implicit*
- "Cultural Competency" a practical guide for medical professionals OMB
- *https://eprognosis.ucsf.edu*
- *https://sgec.Stanford.edu/end_of_life_care.html*
- *"doorway thoughts"*
- *https://Stanford.edu/letter.html*

Cultural component

- "an inclusive approach to healthcare practice in a manner that recognizes the context and complexities of provider-patient interactions and preserves the dignity of individuals, families and communities"

- It is a life long process of examining values and beliefs while developing the above in practice.

More on cultural aspects

- Do not make assumptions…ask
- Find out how they would like to be addressed
- Initially a more formal approach is ok
- Be aware of patient’s non verbal language and your own
- Be mindful of literacy levels, use interpreters
- Take into consideration the trauma and immigration history
- Use open ended questions
- Use teach back method
- ETHNICS (interviewing tool)

Interviewing tool

JAGs 2002

- E-explanation (from patient's perspective)
- T-treatments (all types of treatments tried so far)
- H-healers (prior and present involved in their care)
- N-negotiate (acceptable treatment plans with patients/caregivers)
- I-Intervene (explanation and implementing care plans with evidence)
- C-collaborate (with patient, family, caregivers, community)
- S-spirituality (find out about meaningful spiritual practices at the end of life for patient and families)

Audience perspectives

- How would you have approached this scenario?
- Please share your challenges if any?

Lessons learned

- Extent of truth telling
- Setting the right format for communicating with family
- Spending more time for discussions
- Including other health care resources(Ombudsman, Ethics team at University)
- 20/20 hindsight(wish I had read a lot about cultural communication)

Thank you!