Are you suffering?

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Objectives

• Attendees will understand the 4 levels of suffering.
• Attendees will provide one example illustrative of a patient suffering at each level.
• Attendees will be able to conduct a basic HOPE or FICA spiritual assessment with their patients.
Happiness & Suffering

• Happiness can exist only when suffering is or has also been present.

• Happiness is a choice and we can control our experience of happiness.

• An example...
Anticipation
Behold...
Are you suffering?

- Have you ever asked this exact question?
- Does anyone on the team?
- If not, why not?
- What might you expect as a response to this question?
- Hesitation? Judging? Fear?... Relief?
4 Levels of Suffering

- Physical
- Psychological
- Social
- Spiritual
Physical - Primary Suffering

• Pain, Fatigue, Nausea, diarrhea etc.

• Typically we’re ok with asking about symptoms associated with physical suffering.

• Let’s talk about pain since most see them hand in glove “Pain and Suffering”

• Mrs. Jones on a scale of 1 to 10 with 10 being the worst pain ever...
Physical Suffering

- The Gold Standard of pain assessment is the following: Pain is whatever the Patient says that it is.

- Pain is a **Subjective Symptom** that we still want **Objectively Quantified**.

- For example, **What exactly does a “7” look like to you?**

- What if pain is at an acceptable level to the person? **How do we or do we treat this pain?**

- Do you ever ask why its an acceptable level?
Addressing Physical Suffering

- There are many avenues to address physical suffering – many medications and treatments available.
- Patients and many health care practitioners are hesitant to use “strong” medication.
- Fears: abuse/misuse, tolerance/addiction and various real negative side effects.
- Example: Morphine is also a respiratory suppressant.
Pain & Suffering

- 40+ years of practice. Do we have it right?
- How often is the word addiction used by patients, families and healthcare providers?
- PRN pain medication. Who decides?
- A word on “Last Dose” fears in family members and healthcare professionals
- Are your answers different if your patient is “Dying”?
Psychological Suffering

• Secondary Suffering
• Depression or is it sadness?
• Are they the same or similar?
• How do you assess?
• Is the treatment the same or similar?
• A couple married 65 years, wife dies after a long illness – husband presents to you – says he’s depressed. Do you feel he is sad or “suffering from clinical depression? Do you give a medication? Is there another suggestion?
Psychological Suffering

- Depression – is a clinical diagnosis with identifiable clinical manifestations of a chemical imbalance and treatable with medication... often many, many, many medications.

- Sadness is best treated by listening, understanding, reflection, reorientation, and distraction.
Psychological Suffering

- Panic, anxiety, agitation, anxiousness.
- Before requesting behavioral health assessment – have you considered that dyspnea may be the root cause?
- This is a “Chicken vs Egg” Question.
Psychological Suffering

• Anxiety associated with an underlying medical condition is generally treated well with medication.

• There are a variety of anti-anxiety medications available and when combined with treatment to address the dyspnea success is usually around the corner.

• At the same time, it may be of great help to refer for a behavioral health assessment and supportive care with trained “talk” therapy.
Suffering on a Social Level

- Relationships are at the core of this level of suffering.
- Loss or lack of intimacy
- Lost or diminished role and function in the family unit or the marital dyad.
- Family members quickly transform into nurse/carers
- Caregivers are often “Draftees not volunteers”
- Social Suffering happens slowly, insidiously
Mounting Losses

• Treatment:
  • Acknowledgement is key – identify the real and potential losses.
  • Talk therapy – individual, couple and group
    • Groups with similar sufferers
  • Seek ways to lesson the carer burden
  • Teach – asking for assistance from offerers
Spiritual Suffering

- The “holy” grail
- Hope is near impossible without a belief in something greater than you...
- Remember the Dying can still have hope... hope for pain-free days, hope for relationship healing etc.
Assessing Spiritual Suffering

• Recognize that most individual that you will encounter do have some “spiritual” connection.

• Performing either simple assessment, my indicate a need for a trained chaplain or other skilled religious practitioner to be involved

• Remember Hopelessness lives here.

• Our job is to lift the veneer – addressing spiritual suffering may help the clinicians address the other layers of suffering
Hope Spiritual Assessment

• H--sources of hope, strength, comfort, meaning, peace, love and connection
• O--the role of organized religion for the patient
• P--personal spirituality and practices
• E--effects on medical care and end-of-life decisions
FICA Spiritual Assessment

• **F: FAITH AND BELIEFS**: What are your spiritual or religious beliefs? Do you consider yourself spiritual or religious? What things do you believe in that give meaning to your life?

• **I: IMPORTANCE AND INFLUENCE**: Is it important in your life? How does it affect how you view your problems? How have your religion/spirituality influenced your behavior and mood during this illness? What role might your religion/spirituality play in resolving your problems?

• **C: COMMUNITY**: Are you part of a spiritual or religious community? Is this supportive to you and how? Is there a person or group of people you really love or who are really important to you?

• **A: ADDRESS**: How would you like me to address these issues in your treatment?
Are you suffering?

• What does suffering look like?

• Behavioral Observation:
  • face, eyes, furrowed brow, sweating, stiffness, agitation

• By the numbers
  • temperature, blood pressure, heart and respiratory rate, blood tests

• Ask questions and dig deeper
Are you suffering?

• Questions
  • I can see that you appear to be__________________
  • Or Your _________ is elevated

• If you’re certain - identify it
• and state the observation that you appear to be suffering with...

• Ask are you suffering?
  • Then how can I help you?
  • And then help.
  • I know you know how.
Why? 1st a word about...
Why?

• Suffering is often identified as a key observation and experience by families after the death.

• Achieving the goal of an “Orchestrated Good Death”

• “Good Medical Care” under the ACA begs the inclusion of addressing suffering directly.

• Bad Medical Care is almost always more expensive – and most likely misaligned with the patients goals.
And finally...

- The recent passage of the End of Life Options act (P.A.D.) in California and several other states –was based in large part on the absence of adequate care at end of life and the perception and observation that suffering was seen as an expected part of the dying process.

- The first question in response to a request for P.A.D. should be “Are you suffering?” With a follow-up question being “What in your condition has changed that this is now coming to light?” and then “Can I help you?”
Accessibility

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Resources

http://www.pbs.org/wgbh/pages/frontline/being-mortal/  Being Mortal

www.capc.org  Center to Advance Palliative Care

www.polst.org  National POLST Paradigm

www.coalitionccc.org  Coalition for Compassionate Care of California

www.theconversationproject.org  Conversation Project