AAFP GLOBAL HEALTH SUMMIT

Primary Health Care and Family Medicine: Health Equity for All

Palliative Care in Indigenous Communities

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Objectives

1. Increase comfort delivering patient-oriented, culturally humble palliative care to indigenous and native populations.
2. Reduce barriers and care disparities related to palliative and end of life care for indigenous and native populations.
3. Devise strategies for creating care networks in their communities, and understand when the consultation of a palliative care specialist is indicated.

Disclaimer

The views expressed in this presentation do not necessarily represent the views of the United States Public Health Service, the Indian Health Service, or the United States Government.

Case

- 68 yo Apache F with cirrhosis from auto-immune hepatitis.
- Clinic visits extremely difficult
  - Home visit after work
- Sharp and vibrant just a few weeks ago
  - Now nearly unresponsive on a hospital bed in a crowded living room
- Coughing up secretions, grimaces with any movement
- House smells of burning herbs, several family members in traditional Apache clothing, cross made from cactus spines above the fireplace.

What do you do?

- Can you bring up death?
- Who do you address when you're speaking?
- Can you talk about comfort measures?
- Can you sit on their couch?

Overview

- Cultural issues
- Symptom management
- Care coordination
- Considerations abroad

Cultural Humility

- Process of openness and self-awareness
- Not a discrete set of facts
- Active engagement and curiosity
- Evidence based strategies

Death in China

- Longstanding cultural traditions hold death discussions as extremely taboo…
- But a major population study in 2003 found just the opposite.
- Changing cultural norms?
- Cultural norms not applicable to every person?

Native Americans and Hospice

- Enroll at 1/10th the rate of the general US population
- Cultural preference, or access to care?
- Misconceptions of hospice services

Impacts on Palliative Care

- How physical vs. psychological/pain is processed
- Feelings on death/dying
- Where death should occur
- Individual vs. family decision making
- Organ donation

Core elements of Palliative Care:

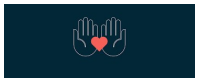
- Palliative vs Hospice
- Assessing and treating physical symptoms
- Psychological, social, cultural, and spiritual aspects of care
- Serious illness communication issues
  - Advanced care planning
- Care coordination
  - In and out of hospital
  - In (and occasionally out) of hospice

Navigating These Issues - What Works

- Physician training in cross-cultural interactions
- Improved physician-patient communication
- Easy to read materials in native language
- Patient navigators
- Multidisciplinary care teams
- Subspecialist palliative consultation
- Integration of spiritual support

Culturally appropriate care

- Cultures themselves are fluid and heterogenous
  - Individuals within them vary further
- Starts with a good connection
  - Physician-patient trust is an extremely common theme in research
  - Home visits go a long way
  - Consider offering personal contact information
  - Can't undo past injustices, but a personal bond



Communication

- Minimize misunderstandings
  - Cultural and linguistic
  - Professional interpreters when available
- Health literacy
  - Potential gaps exacerbated by extreme stress
- Visual aids
  - Even a chest xray print out
- Addressing patient
  - Permission to discuss new information/care plans
  - Respectful by cultural norms
  - Ask them

Communication

- Speak slowly
- Sit down
- Start with eye contact, but heed social cues
- ~~We'll cross that bridge~~
- ~~Prognosis~~
- ~~Benign~~
- Days to weeks, weeks to months, months to years
- Best case, worst case, most likely
- "Other people in this situation."

Communication

- Remind patient about your confidentiality
- Remind patient that we work for them, and want their goals addressed
- Avoid setting up dichotomy between clinician and patient cultures

Needs assessment

- Start with learning about the patient as a person
- Open ended questions to assess cultural and care preferences
  - *What do I need to know about you as a person to give you the best care possible?*
  - *What else do you want me to know about you and your friends/family that will help me take good care of you?*
  - *Are there things that I should know about your family background, religious beliefs, or community that would help me take better care of you?*
  - *How important is religion (or spirituality) in your life?*
  - *Can you tell me anything about your customs or spiritual beliefs that might affect your health care?*
  - *Some patients have spiritual or religious beliefs that prevent them from having certain tests or treatments, such as blood transfusions. Do you have any specific concerns?*

Care preferences

- *How much information about what is likely to be ahead with your illness would you like from me?*
- *Is there anyone you would like here while we talk?*
- *How much does your family know about your priorities and wishes?*
- *I have information about your illness. Would you like me to talk with you or is there someone else you prefer me to speak with?*
- *Your family and I are planning to discuss how best to take care of you. Would you like to participate in that conversation, or should we proceed without you?*

Illness/symptom understanding

- *What have other doctors told you about where things are with your illness right now?*
- *How is treatment going for you and your family?*
- *What has been the most difficult part of this? illness for you?*

Treatment planning

- *Given what we've talked about, what is most important to you going forward?*
- *What worries you most about your illness?*
- *As you think about the future, what are you hoping for?*
- *Some people worry about the possibility of dying and have questions about that. How about you?*

Advanced Care Planning

- A conversation more than a signature
- *Is there anyone in your life you trust to make medical decisions for you if you are ever unable to make them?*
  - *What have you talked about in terms of medical care that is important to you?*
  - *Have you written that person's name down on any official forms? Do you have this form? Have you written anything else down?*
  - *Would it be okay if we all talk together?*
- prepareforyourcare.org/ (English and Spanish)
- https://theconversationproject.org/ (14 languages)

Back to our case

- 68 yo Apache F with ESLD and cirrhosis from auto-immune hepatitis.
  - Nearly unresponsive on a hospital bed placed in a crowded living room.
  - Coughing up secretions, grimaces with any movement.
  - House smells of burning herbs, several family members in traditional Apache clothing, cross made from cactus spines above the fireplace.
- Who do you talk to? What do you say?

Symptom Management

- Pain
- Dyspnea/Cough
- Fatigue
- Dry mouth
- Dysphagia
- Aspiration
- Lack of Appetite
- Weight Loss
- Nausea (with or without vomiting)
- Constipation or diarrhea
- Extremity swelling
- Psychological symptoms
  - Anxiety

Pain

- Assess type and likely cause
  - Nociceptive: Injury to somatic structures
    - "Aching, stabbing, throbbing"
  - Neuropathic: Abnormal sensory processing
    - "Unpredictable shooting, burning, numbness, itching"
- No evidence to support any particular opioid over another
  - Either for effectiveness or tolerability
  - So start with the least expensive
  - Renal failure: Consider hydromorphone and fentanyl first
  - Liver failure: Lower dose, longer interval

Nociceptive Pain

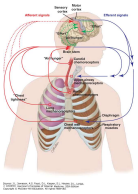
- Most opioids typically short acting (2-4 hours) in standard preparations
- Consider opioid rotation
- Transdermal fentanyl slightly less constipating than other opioids, but rarely first line
- Consider empiric use in patients unable to self report
- Several opioid conversion calculators online

Neuropathic pain

- Associated with depressed mood:
  - First line is SNRI (duloxetine)
- No depressed mood:
  - Gabapentin or pregabalin, consider duloxetine
  - Gabapentin has been associated with more respiratory depression when coupled with opioids
- Topical lidocaine
- Botulinum injection for refractory nerve pain
- Nerve blocks

Dyspnea/Cough

- Extremely common in many terminal illnesses
- Subjective definition
- Multidisciplinary management
  - Relaxation techniques and psychosocial support
  - Modification in activity level/bathroom support/wheelchair use
  - Fan with cool air to face
  - Chest wall percussive therapy
  - Pulmonary rehab when available



Dyspnea/Cough

- Oxygen (for dyspnea) has mixed results
  - Consider consult
- Acupuncture has mixed results
  - More recent data leans positive
- Opioids can improve central perception of breathlessness
- No evidence to support routine use of benzodiazepine
  - Unless anxiety is playing a major role
- Loop diuretics and/or bronchodilators when relevant to disease process
- Consider sedation at end stages

Fatigue

- Tiredness precipitated by effort
- Consider underlying causes:
  - Anemia, uncontrolled pain, emotional distress, sleep disturbance, weight loss and malnutrition, electrolyte disturbances, infections, endocrine disruption
- Transfusions may be appropriate as part of palliative care
- Cochrane: No evidence to support any particular medication use
- Energy conservation, most important tasks in the AM
- Steroids may be helpful in late stages
  - No evidence to favor any particular one
  - Dexamethasone most widely studied (8mg/day)
  - Hiccups may occur, consider changing steroid
  - Far more serious side effects to consider

Fatigue

- Consider stimulants (methylphenidate and modafinil) for severe fatigue
  - May worsen, precipitate underlying emotional disorders
  - start low, 2.5-5mg twice daily around 6am and no later than 2pm
  - Can be particularly helpful with depression and very short prognosis
- American Ginseng may be helpful
  - Several drug interactions
- Exercise
  - Yoga, Tai chi
- Good sleep hygiene
- Bright light therapy
- Behavioral and psychosocial interventions
- Acupuncture where available

Dry mouth

- Causes: Advanced age, cancer, radiation, anxiety, dehydration, many medications
- Can affect oral intake and lead to further complications
- Improved hydration/humidifiers
- Sugar-free chewing gums or candy
- Mucosal lubricants/saliva substitutes (Biotin)

Dysphagia

- Causes: Nerve degeneration, solid mass, stricture
- Postural adjustments are of limited use
- Remove mealtime distractions
- Optimal eating position
- Schedule mealtimes according to level of alertness
- Consider alternative medication routes
- Speech therapy can be very helpful
  - Important to communicate goals, safest way to comfort feed to avoid an NPO recommendation

Aspiration

- Closely linked with dysphagia
- Can evaluate at bedside
  - Coughing after thin liquid consumption
  - Drooling
  - Wet/hoarse voice
  - Head/neck repositioning while swallowing
- Management is similar to dysphagia
- Antibiotics may be appropriate in cases of pneumonia

Lack of Appetite/Weight Loss

- Does it bother the patient?
- Megestrol acetate
  - Progesterone derivative
  - Low number needed to harm
  - Expensive
- Glucocorticoids
- Canabinoids: Low quality data, synthetic doesn't seem to help
- 5% weight loss is significant

Nausea - Causes

- **V**estibular
  - Cholinergic, Histaminic
  - Scopolamine patch, promethazine
- **O**bstruction (constipation)
  - Cholinergic, Histaminic, likely 5HT3
  - Senna
- dys**M**otility of upper gut
  - Cholinergic, Histaminic, 5HT3, 5HT4
  - Metoclopramide
- **I**nfection, **I**nflammation
  - Cholinergic, Histaminic, 5HT3, Neurokinin 1
  - Promethazine, prochlorperazine
- **T**oxins
  - Dopamine 2, 5HT3
  - Prochlorperazine, haloperidol, ondansetron

Nausea

- Chemotherapy induced: Start with 5HT3 (ondansetron)
  - Otherwise no strong evidence to favor any particular agent
- Guidelines suggest using metoclopramide first
- Some use for synthetic cannabinoids for breakthrough nausea
  - No clinical evidence available yet for cannabis
- Acupuncture, ginger may have some benefit
- Consider malignant bowel obstruction if progressive and associated with pain
  - Survival generally quite short

Constipation

- Cuases: Meds, low-fiber diet, inactivity, age, depression, hemorrhoids, polypharmacy
- Formal definitions, but patient-driven in palliative care
- Check for rectal masses, fissures, sphincter tone, hemorrhoids
- If rectal vault is empty, consider malignant bowel obstruction (CT?)
- Consider senna for all opioid users (no evidence for adding docusate)
- Osmotic laxative next
- GI-specific opioid antagonists available, but expensive and may cause harm

Extremity Swelling

- Fluid retention, gabapentin/pregabalin
- Consider lymph obstruction if unilateral/unilimb
- Can try elevation, compression sleeves/stockings
- Diuretics if causing discomfort

Psychological and Cognitive Symptoms

- Consider electrolyte/nutrient deficiencies, untreated pain, glucocorticoid use, rapidly progressive disease, financial strain

Psychological and Cognitive Symptoms

- Grief vs. depression
- Retains capacity for pleasure?
- Waves vs. constant
- Passive wishes for death vs. intense suicidal thoughts
- Remains forward looking?
- Depression under-recognized in patients with serious illness
- Are you depressed?
- How has this been affecting your mood?

Delirium

- Non pharmacologic measures mainstay to prevent and treat
- Hypoactivity or agitation can predominate or interchange
- Haloperidol (1st generation antipsychotic) and 2nd generation antipsychotics (quetiapine most sedating) for when behavior is dangerous

Anxiety

- Can be difficult to separate from depression or delirium
- Psychotherapy
- Exercise
  - Even passive range of motion
- Caffeine/alcohol intake
- Sleep evaluation
- SSRI when mixed anxiety/depression
- SNRI when associated with chronic pain
- Benzos
  - Half-life and side effect accumulation
  - Lorazepam

Insomnia

- Extremely common, often coexisting with other exacerbating conditions
- Aggressively manage other symptoms
- Adjust med timing when steroids or stimulants can't be avoided
- Environment and personal factors
  - Egg-crate/memory foam
- Impacts on caregiver

Insomnia meds

- Atypical antidepressants (mirtazapine)
  - Sedative at 7.5mg to 15mg doses. Useful when anxiety is playing a role.
- Nonbenzodiazepine hypnotics (zolpidem, etc)
  - Safer than benzos for patients with respiratory issues
  - Less likely to precipitate tolerance than Benzos
  - Higher fall risk
- Sedating antidepressants (trazodone)
  - Limited data, slightly controversial
  - Studied at 12.5mg to 50mg, no significant adverse effects at those

Insomnia meds

- Selective melatonin receptor agonists (ramelteon)
  - Limited data, probably safe and effective, $15/tab in US
- Benzos
  - Rapid tolerance, withdrawal potential, cognitive impairment/falls, CNS depression
- Diphenhydramine
  - Side-effect to benefit ratio too high for routine palliative use
- Melatonin
  - Good studies have not shown effect, but expert opinion favors it
  - Low risk, cheap

Existential distress

- Loss of sense of self
- Often contributes to somatic symptoms
  - Important to think of when symptoms difficult to control, medications rapidly escalating
- Important to use team members to help address
  - Especially spiritual care
- Be present, listen

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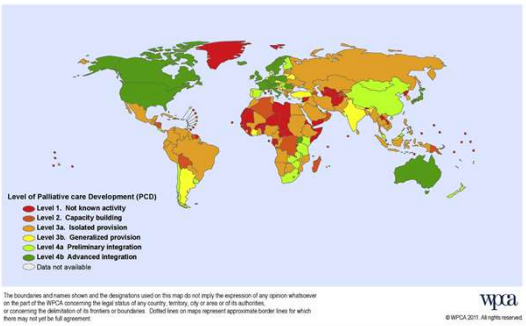
- What symptoms need to be addressed?

Care coordination

When to refer/consult

- Refractory pain or other symptoms
- Very high opioid doses
  - Managing patients with terminal illness and addiction
- Management of complex depression or spiritual suffering
- Conflict between patient desires and prudent medical care
- Conflict among family members
- Requests about assisted dying
- Any time you have a question



Building local care coordination

- Reach out to available resources
  - Therapy : PT/OT/Speech
  - Case management/social work
  - Chaplain/spiritual leaders
  - Home health
  - Nearest hospices
  - Nearest palliative care team for phone consultatio..

Additional Considerations Abroad

- Advanced directives may not have legal status
- Opioids can be difficult to obtain, and prohibitively expensive
  - 15% of world uses 94% of opioids
- Colombia is the only low/mid income country with legal protections on physician assisted death
- Global death burden is highest around progressive non-malignant disease

Palliative Care and Hospice Abroad

- WHO Priority
- Worldwide Hospice Palliative Care Alliance
  - http://www.thewhpca.org/
  - Global Atlas on End of Life Care
  - Palliative care toolkit: improving care in resource poor settings
- 40 million people in need of palliative care
  - Less than 50% have access to it
    - 2% of children
  - Vast differences in access by country

Conclusions

- Cultural humility is difficult, but best practices exist
- Symptom assessment and treatment varies by patient and environment, but is within the scope of Family Physicians
- Palliative care resources vary widely, partnerships help

References

- Bernacki RE, Block SD. Communication about serious illness care goals: A review and synthesis of best practices. JAMA Intern Med 2014; 174:1994.
- Bruce Finke, Theresa Bowannie, and Judith Kitzes. Palliative Care in the Pueblo of Zuni. Journal of Palliative Medicine.Feb 2004.ahead of printhttp://doi.org/10.1089/109662104322737403
- Currow, D., Agar, M., Smith, J., & Abernethy, A. (2009). Does palliative home oxygen improve dyspnoea? A consecutive cohort study. *Palliative Medicine*, *23*(4), 309–316.
- *Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA 2002; 287:2253.*
- Davis, Mellar P. et al. A Systematic Review of the Treatment of Nausea and/or Vomiting in Cancer Unrelated to Chemotherapy or Radiation. Journal of Pain and Symptom Management, Volume 39, Issue 4, 756 - 767
- *Domer T, Kaur JS. Palliative practice in Indian health. S D Med 2008; :36*
- *Hallenbeck, James. The Causes of Nausea and Vomiting (V.O.M.I.T). Fast Facts #5. https://www.mypcnow.org/fast-fact/the-causes-of-nausea-and-vomiting-v-o-m-i-t/*
- Lynch T, Connor S, Clark D. Mapping Levels of Palliative Care Development: A Global Update. Journal of Pain and Symptom Management, 45(6), 1094-1106. https://doi.org/10.1016/j.jpainsymman.2012.05.011
- *Mücke M, Mochamat, Cuhls H, et al. Pharmacological treatments for fatigue associated with palliative care: executive summary of a Cochrane Collaboration systematic review. J Cachexia Sarcopenia Muscle. 2016;7(1):23-27. doi:10.1002/jcsm.12101*
- *S D Passik, et al. Oncologists' recognition of depression in their patients with cancer. Journal of Clinical Oncology 1998 16:4, 1594-1600*
- *Quigley C. Opioids in people with cancer-related pain. BMJ Clin Evid. 2008;2008:2408. Published 2008 Jul 31.*
- *Quill TE, Abernathy AP. Generalist plus specialist palliative care - creating a more sustainable model. N Engl J Med 2013; 368:1173.*
- *Sabatino CP. Advance Care Planning Tools That Educate, Engage, and Empower. Public Policy Aging Rep 2014; 24:107.*
- *Sixty-seventh World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (Accessed on January 26, 2016).*
- *Sudore RL, Landefeld CS, Barnes DE, et al. An Advance Directive Redesigned to Meet the Literacy Level of Most Adults: A Randomized Trial. Patient Educ Couns 2007; 69:165.*
- *Sudore RL, Schillinger D, Katen MT, et al. Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trail. JAMA Intern Med 2018; 178:1616.*
- *Sudore RL, Boscardin J, Feuz MA, et al. Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trail. JAMA Intern Med 2017; 177:1102.*
- *Tanimukai, H., Murai, T., Okazaki, N., Matsuda, Y., Okamoto, Y., Kabeshita, Y., … Tsuneto, S. (2013). An Observational Study of Insomnia and Nightmare Treated With Trazodone in Patients With Advanced Cancer. American Journal of Hospice and Palliative Medicine®, 30(4), 359-362. https://doi.org/10.1177/1049909112452334*
- Tse, C. Y., Chong, A., & Fok, S. Y. (2003). Breaking bad news: a Chinese perspective. *Palliative Medicine*, *17*(4), 339–343. https://doi.org/10.1191/0269216303pm751oa
- Uptodate,com