



Bringing Palliative Care to SNFs: really?

Shelly Garone, MD, FACP
Assistant Physician in Chief
Kaiser Permanente
North Sacramento Valley

Ms. K

- ▶ 64 y/o woman s/p gastric bypass in 2011
- ▶ Her recall is going in for surgery, and “waking up” weeks later in the ICU on dialysis
- ▶ She has never been home
- ▶ Recurrent complications with a 240-day hospitalization in 2014
- ▶ Moved to my SNF in February of 2015

Ms. B

- ▶ 81 y/o demented lady living at SNF for 7 years
- ▶ History of breast cancer, stroke with PEG for awhile
- ▶ Baseline is max assist for all ADLs, 1-2 words of speech
- ▶ FULL CODE

Mr. G

- ▶ 67 y/o s/p massive CVA
- ▶ Fiancé and friend speak on his behalf, neither wanted POA role
- ▶ Sent to SNF “to get better” 3 weeks after his stroke – nonverbal, hemi-neglect, PEG fed, full code

Ms. C

- ▶ 81 y/o schizophrenic woman, always institutionalized
- ▶ Massive stroke, no DPAHC or previously known wishes
- ▶ No family until sister flies in from England
- ▶ Sister is certain that with proper nutrition, patient will make full recovery

Today

- ▶ We discuss what people hope for
- ▶ We re-define nursing home residents as socially impoverished or marginalized
- ▶ We consider specific populations in which palliative care teams could be of benefit
- ▶ We remember that all clinicians “do palliative care”

Impoverished

- 1. reduced to poverty.
- 2. deprived of strength or vitality.
- 3. (of a country or region) having few trees, flowers, wild animals, etc.

Marginalized

- ▶ 1. to put or keep (someone) in a powerless or unimportant position within a society or group

<http://www.merriam-webster.com/dictionary/marginalize>

Is this both?



Poverty is not only economical

- Social
- Political
- Cultural

And these are largely out of one's control

Social poverty

- ▶ House poor
- ▶ Health poor
- ▶ Time poor

Nursing home residents are

- ▶ Health poor
- ▶ House poor

- ▶ Or socially impoverished

Nursing homes (and residents) are also marginalized



Nursing home residents

- ▶ Eat someone else's menu on a schedule
- ▶ Take meds on a schedule
- ▶ May get response to their needs in the time frame desired
- ▶ May get to pick their own clothes
- ▶ May have their own personal belongings
 - ▶ Underwear, dentures
- ▶ Do have a sense of declining health

Nursing home residents

Do have a sense of declining personhood

As children, we expect....



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- To be safe
- To grow up
- To be healthy
- To achieve our goals
- To always be our SELF

Never growing up sounds ideal



As does aging without physical
change

And not truly dying, or perhaps just
some day magically ceasing to exist

But then there is this thing called
reality

Getting permanently sick

- Means loss of definition of myself
- Means everything is uncertain
- Makes the sun seem clouded over
- Makes the nights longer

Facing death

- Is normally terrifying
- Raises existential angst –
 - Is there something after?
 - Am I good enough to deserve it?
- Raises awareness of challenges to day to day practicalities

If you must live in a SNF, odds are

- ▶ You have a chronic progressive illness
- ▶ You have progressive loss of function
- ▶ You are needing more and more care
- ▶ You may be more symptomatic
- ▶ Your mortality is more visible than someone else's

Thus, we could argue EVERY custodial nursing home patient deserves palliative care consultation

There is opportunity for folks bouncing between SNF and acute as well

- ▶ Too sick to truly leave the hospital?
- ▶ Too “un-fixable” to stay in the hospital?
- ▶ Family demands are un-appeasable
- ▶ Usually, a bigger conversation is lacking

Palliative Care

- ▶ Seeks to maximize personhood despite a body getting sicker
- ▶ Aims to alleviate suffering
- ▶ Understands what the owner of the body wants
 - ▶ I, as a doc, want a normal A1c
 - ▶ My patient, the body's owner, may want cookies and accept consequences
- ▶ Creates care plan aligned to the person's goals

Shelly's definition of Palliative Care

- ▶ If you have to live sick, how can I help you live well?
- ▶ If we cannot accomplish Plan A, what is Plan B?

Starting somewhere

- ▶ Custodial residents who are full code
- ▶ Custodial residents who are losing weight and dropping their prealbumin
- ▶ Skilled residents with readmission to acute
- ▶ Skilled residents with catastrophic illnesses (stroke, sepsis with organ damage, severe trauma) not making recovery

What if I don't have a PC team?

- ▶ Many SNFs have amazing staff on site
 - ▶ “Are you serious – can you imagine her after general anesthesia?”
- ▶ SNF staff can be empowered to reach out to families to discuss decline
 - ▶ “I’m worried about him. Are you?”
- ▶ Custodial residents can have hospice services – often hospice teams are willing to help explain those services to the family
- ▶ Experienced SNF docs naturally have conversations about goals and are comfortable changing care plans
 - ▶ “Decline is expected”

Who's job is it to talk about this stuff?

What if the patient asks YOU?

Those conversations don't have to be physician driven

- ▶ Patients question those they most trust
- ▶ ALL health care professionals can answer some questions
 - ▶ RTs know COPD is not going to be better in a year
 - ▶ STs know dysphagia may be permanent
 - ▶ PTs know when walking won't happen again
 - ▶ OTs know when self-toileting won't happen again
 - ▶ RNs know when basic physiology is failing
 - ▶ MSWs know stress in a wife's face when she recognizes the truth in front of her

Our discomfort is palpable to those people we care for



- ▶ We are trained to cure
- ▶ When we cannot, we trained to speak to what we can do
 - ▶ Correct lytes, give abx
- ▶ Our inability to cure is uncomfortable
 - ▶ Which may make us come across as impersonal, uncaring or, worst of all, rude

What do our patients need?

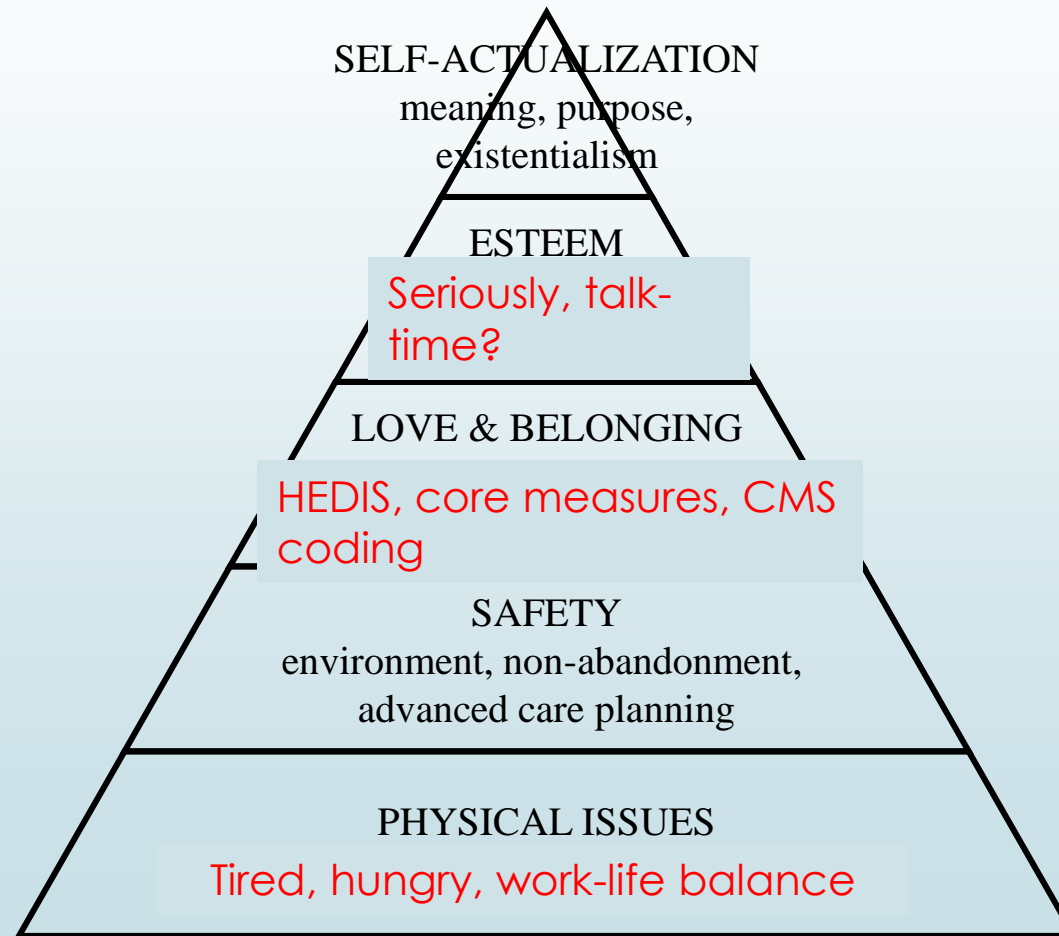
- ▶ Service
- ▶ Compassion
- ▶ Presence
- ▶ Honesty
- ▶ Questions answered
- ▶ Lights illuminating the path of darkness



But they don't listen



Maybe we don't listen either?



What do they need to hear?

- ▶ What's "normal"
- ▶ What COULD happen
- ▶ What IS LIKELY to happen
- ▶ What IS NOT LIKELY to happen
- ▶ That the "right" decision is the one that feels right
- ▶ That we will create a care plan aligned to their carefully considered decision

86 y/o with COPD



- ▶ Normal is daily cough, progressive loss of energy and stamina, recurrent exacerbations
- ▶ Complete respiratory failure could (or could not) happen
- ▶ Recurrent exacerbations and steroid dependence are likely to happen
- ▶ Returning to the health enjoyed 10 years ago is not likely
- ▶ Choices include looking only at exacerbations without context of larger disease “You’ll be good as new” vs planning for progressive decline

92 y/o with dementia



- ▶ Normal is progressive loss of person and basic physiological functions
- ▶ Slowing of decline could happen
- ▶ Falls, infections, malnutrition and weight loss will happen
- ▶ Recovery to pre-trauma state will not likely happen
- ▶ Choices include denying underlying dementia and just fixing issues in isolation as they arise, or planning for the next decline

The time to talk is when the patient asks,
“when am I getting better?”

OR

When you're truly worried

What it boils down to

- ▶ Functional decline
- ▶ Unintentional weight loss
- ▶ Impaired cognition
- ▶ Accumulated organ system diseases
- ▶ Metabolic markers:
 - ▶ hyponatremia
 - ▶ serum prealbumin
 - ▶ blood cell counts (lymphopenia, then anemia)
 - ▶ cholesterol

So what do you say?

- What is your understanding of the situation?
- What potential choices and outcomes do you have?
- What are your fears?
- What are your hopes?
- What trade-offs are you willing to make? Not willing to make?

All health care workers can speak

- ▶ You seem less able to do things like you could a few months ago
- ▶ I'm worried that you're still losing weight
- ▶ Mr. Jones, your wife's persistent confusion and forgetfulness worries me
- ▶ Mrs. Smith, the doctor is seeing some lab abnormalities that he does not like
- ▶ If this does not end up the way we're hoping it will, do you have a contingency plan? What I call Plan B?

Your role may simply be firing the warning shot

This lets patient and family know that we are worried...

and that we CARE

Starting to talk

- ▶ Mandates that we follow-up
 - ▶ We cannot say, “I’m worried,” and drop it
- ▶ Acknowledges that our patient / family may not be ready to hear us
 - ▶ We cannot abandon them
 - ▶ “Can we see how this next week goes and re-address my worries afterward, if I still have them?”
- ▶ Does NOT condemn the patient to worsen or die

“I could be wrong...”



Ms. K

- ▶ 64 y/o woman s/p gastric bypass in 2011
- ▶ Moved to my SNF in February of 2015
- ▶ Now lives on TPN, will never again consume food orally, has nowhere else to move to
- ▶ Repeatedly noncompliant with her care, but when she creates a new problem for herself, works to heal it
- ▶ Clear that her goal is restorative
 - ▶ I can still laugh

Ms. B

- ▶ 81 y/o demented lady living at SNF for 7 years
- ▶ FULL CODE
- ▶ Yelling and hitting at staff
- ▶ I called her son to ask about new psychotropic medication
- ▶ I also asked “tell me how this POLST came to be,” and if it made sense to him to have her full code
- ▶ He agreed to DNR, limited intervention

Mr. G

- ▶ 67 y/o s/p massive CVA
- ▶ Sent to SNF nonverbal, hemi-neglect, PEG fed, full code
- ▶ Fiancé could say that he would NOT want to be dependent and agreed that a DNR made more sense, as a code blue would guarantee worsening injury to his brain
- ▶ Fiancé felt he could improve further and wished for ongoing rehab
- ▶ Now living custodially at SNF, able to walk short distances, swallow some textures, speak some words
- ▶ Fiancé visits every day – life is not over, just different

Ms. C

- ▶ 81 y/o schizophrenic woman, massive stroke
- ▶ No family until sister flies in from England
- ▶ Sister turns out to be incapacitated herself
- ▶ Patient continues at SNF with PEG, progressive decubiti, nonverbal, minimally conscious

Life is not over, it is different

- ▶ SNF residents deserve every attempt to maximize their personhood we can afford them
- ▶ They are not at SNF by choice, 99% of the time
- ▶ As their underlying medical illnesses progress, they must have goals clearly defined, Plan A and Plan B delineated, and a point at time when hospice is appropriate

As a SNF / Palliative Care doc

- ▶ I can minimize physical suffering
- ▶ I can help my patient (and her family) understand what is permanent and progressive
- ▶ I can hear her opinions for which treatment choices are meaningful to her

If I can make my patient smile and have a better afternoon, I've done my job

Comments or questions?