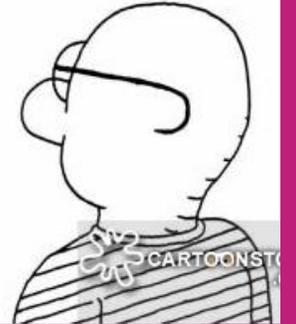


Are you being served? Addressing the medically underserved in our community.

TAKE A
NUMBER



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Commissioner: Commission for Case Manager Certification



Your Presenter

Michael J. Demoratz, PhD, LCSW, CCM, CSA has over 35 years experience in end of life and senior care along the entire healthcare continuum. Nationally recognized as a subject matter expert in end-of-life care, presenting at hundreds of conferences, publishing numerous articles and a book Dying 101: A Short Course on Living for the Terminally Ill. Was recipient of the Distinguished National Case Manager of the Year in 2001 by the Case Management Society of America (CMSA). He contributes regularly to a body of work on suffering and end of life care- which can be found here: <https://www.linkedin.com/today/author/mdemoratz>

Presently, serves on the Boards of both the **Coalition for Compassionate Care of California** and as a elected commissioner for the **Commission for Case Manager Certification**.

Objectives

- ▶ Identify who represent the medically underserved.
- ▶ Address implications and strategies for Advanced Care Planning when a family member blocks direct access to the identified patient.
- ▶ Identify non-clinical causes including cultural, linguistic and socioeconomic barriers and the impact on ED use and re-Hospitalization.

An Ideal World

- ▶ Better education of patients, physicians, and healthcare professionals regarding end of life issues free of Cultural Bias and Linguistic insensitivity
- ▶ Discussion of illness and likely prognosis between patients, physicians and families, facilitated by (awesome) healthcare professionals
- ▶ Cooperative relationship in advanced care planning with patients/families and physicians as part of a normal course of treatment (ideally in the MD office)

Generalizing...

"The cultural and health information presented is intended as a guide, not a rulebook. No strict profile of a particular patient's customs, practices, beliefs or communication styles should be drawn solely on the basis of the information presented. In an effort to avoid stereotypes, please note that membership in a particular culture does not mean that any individual member will necessarily reflect the customs, traditions, and beliefs generally associated with that culture."

That said. I know I may offend someone today - please know its not intentional, the experience I will impart has been mine working within the confines of a culture as a curious anthropologist. The presentation reflects this - some items will resonate with your experience others may not.

The Medically Under-served

- ▶ Not necessarily poor - though limited financial resources does not help -their situation
- ▶ Most often non-English speakers
- ▶ Culturally traditional
- ▶ Often elderly with chronic and or serious conditions
- ▶ Primary caregivers are mostly adult children who may be culturally traditional as well
- ▶ Patients/families express fear, suspicion, paranoia, resistance.
- ▶ Low utilization of hospice and palliative care services - don't see this as a problem - since acute/aggressive care is covered,
- ▶ Patients usually stoic don't complain - are hesitant and suffer in silence.
- ▶ Families think this is standard care.

Physician EOL Conversation Styles

- ▶ Physicians fall into several categories -
 - ▶ Similar Cultural background, Traditional values
 - ▶ Similar Cultural background, Westernized
 - ▶ Dissimilar culturally - hesitant to address EOL
 - ▶ Dissimilar culturally - willing to address EOL
- ▶ Low utilization of hospice and palliative care services - also don't see this as a problem - since acute/aggressive care is covered.

The Vietnamese Community

- ▶ The program is located in Westminster, California adjacent to Garden Grove and Fountain Valley between the 3 cities there are nearly 100,000 individuals
- ▶ The agency site provides a continuum of care - home health and hospice
- ▶ 75% of staff are bi-lingual/bi-cultural, native Vietnamese speakers.
- ▶ The Vietnamese population is generally accepting of acute care and skilled home health services. They trust recommendation from their physicians and will generally follow without question.
- ▶ One area where it seemed to drop off is in hospice. This included resistance of medical staff to refer patients of their own until being VERY sure they needed it.

The population served

Rich History of Immigration into the US.

1975 - ending of the Vietnam war. These individuals tended to be well-educated and professionals who supported the pro-western government of South Vietnam

1978-79 - these individuals were those who became disenchanted with communism and their poor living standards, often less educated.

1979 Orderly Departure program - allowed for safe, legal exit to those joining family already in the US.

1987 Amerasian Homecoming Act - included children of US Servicemen and their Vietnamese mothers, as well former South Vietnamese military officers and political detainees.

Focusing on the 1975-79 Era group

- ▶ Many of these individuals are now in their 70, 80's and up. They are the most revered in the community for many reasons including one often unspoken reason - these are the individuals who risked everything to come to the US and bring their families to a better life.
- ▶ If not for them it is possible their children and grandchildren would not have survived. Their families are especially grateful to these elders as they are the living history and now facing end of life.

The Potential Pilot Study Population

- ▶ Non-English speaking Vietnamese seniors/ considered culturally traditional
- ▶ Adult Children may also be traditional due to their age and lower level of assimilation into Western society.
- ▶ Primary Physicians often Vietnamese and traditional as well
- ▶ High utilization of ER for anxiety related SOB
- ▶ Non-cancer diagnoses - CHF and COPD
- ▶ Average LOS on Hospice 24 hours

Re-educating Staff

- ▶ ACP & POLST: Key tools for Initial Palliative Care Consult
- ▶ Advance Directives - document for ANYONE over the age of 18, regardless of condition or diagnosis. The most important feature is that **it LEGALLY identifies an individual to make decisions.**
- ▶ POLST - **Medical Orders** to accompany the patient across the continuum, completing the POLST is the first real step in providing Palliative Care, since if YOU follow the format - YOU will obtain key information about the patient and family desires and goals of care and the development of a patient centered treatment plan as it relates to their serious illness care.

Advance Directive: In Cultural Context

- ▶ Most important thing for the case manager to remember - completing an Advance Directive legally identifies a decision maker.
- ▶ *If that's all it does, this may be a very significant accomplishment for some.*
- ▶ *However - within the immigrant community - Even after you've identified one person expect them to still need to consult with many family members over important decisions - some family may still be overseas. Decisions can take time.*

POLST in a Cultural Context

- ▶ Yes, No, and maybe...
- ▶ A properly completed POLST/MOLST will guide your treatment recommendation and care plan.
- ▶ This includes: Patient choices about CPR, Intensity of Medical Treatment, & Artificially administered nutrition (& hydration)
- ▶ If you have answers to these 3 areas - you will know a great deal more than with an Advance Directive alone.
- ▶ Again, this may be a very complex form for a surrogate decision maker to complete given the ramifications of the decision (patient could die)

The Impact of Words

“Supportive Care” – Softening the impact of the Word chosen

The **gentler** word “**supportive**” instead of the word “**Palliative**” *for the case manager these words and concepts should be Interchangeable in your mind.*

Important to acknowledge that using words closely associated with “end of life” may prevent patients and their families them from accessing valuable services.

Our purpose is to ensure that misunderstanding language does not interfere with our desire to reduce suffering and improve quality of life for those we serve.

Simple Consumer Definition

Supportive Care:

“Really Good Medical Care”

(Provided at the “Right time, in the right location and in a Cost-effective manner”)

Responding to the questions... this is a major challenge.

- ▶ Doctor to Family member:
 - ▶ I would like to refer you to Palliative care.
- ▶ Family member to Doctor:
 - ▶ Oh that's nice can you tell me what is palliative care?
- ▶ Doctor to Family member:
 - ▶ Hmm well, er, oh, ah, it's just like hospice- kinda right before...er ah you know
- ▶ Observing Case Manager:
 - ▶ (thought bubble above their head) - OMG! Yikes! Wrong answer!

The Potential Supportive Care Population

- **In assessing our patient population currently on skilled home health service with a diagnosis of CHF or COPD. We found no surprise that the majority of these patients met the basic Medicare criteria for hospice.**
- **Refusing Hospice – was commonplace since families felt it was giving up and the patient would die faster... they have many examples of this.**
- **Patients and families associate Hospice with Death. In translation to Vietnamese - Hospice translates to “Hospice” people and hear the word and stop listening.**
- **Physicians would hesitate to bring up hospice since the family would become upset and accuse the doctor of giving up on their family member.**
- **Physicians concerned about liability (families suing). Though MSW’s report patient families rarely sue over an expected death.**

Addressing the Re-admission challenge

- ▶ ER utilization and Hospital re-admission and the impact on hospitals - and with accountable care - everyone is impacted.
- ▶ Why do patients (any) come to ED?
- ▶ What happens before they get there...
- ▶ How are we assessing suffering?
- ▶ What is suffering?
- ▶ What is the care needed regardless of what they want or don't want?
 - ▶ Can you articulate that to a patient?
 - ▶ Would you allow a patient to refuse oxygen?

Non-Clinical Causes for Hospital Readmission Contributing to the *Medically Underserved*.

- ▶ Just a few things YOU cannot control
 - ▶ Cultural differences
 - ▶ Language/comprehension
 - ▶ Literacy/understanding
 - ▶ Physical/Social/Financial factors

Non-clinical causes continued

- ▶ Cultural differences **ABCDE**
 - ▶ **A**ttitudes of patients and families
 - ▶ **B**eliefs
 - ▶ **C**ontext
 - ▶ **D**ecision-making style
 - ▶ **E**nvironment

Non-clinical causes continued

- ▶ Language/comprehension (**teach back**)
 - ▶ Preferred Language spoken
 - ▶ First language
 - ▶ Response style (**example**)

Non-clinical causes continued

- ▶ Literacy/understanding
 - ▶ Severely limit medical jargon - use their words for their condition
 - ▶ Reduce your language to at least 5th grade level
 - ▶ Remember: People of all backgrounds may smile and nod understanding rather than be embarrassed that they don't know what you said.

Non-clinical causes continued

- ▶ Physical/Social/Financial Resources
 - ▶ Physical - lack of caregiver support
 - ▶ Social/Emotional - poor coping skills
 - ▶ Financial - Lack of \$\$

Back to the Pilot Study

- ▶ Patients currently on home health - (Medicare only)
- ▶ Average age 85 and Non-English speaking - Vietnamese
- ▶ All were represented by a family member (spokesperson) patients did not participate in the conversation.
- ▶ Diagnosed with CHF, COPD or both (met clinical Medicare criteria for hospice)
- ▶ Stable home setting - adequate family resources.
- ▶ Multiple ER visits previous 6 months for SOB/Anxiety

Back to the Pilot Study

- ▶ Patients were given a choice to have this team but were first told the following - you have been assessed by the MD and found to meet criteria for additional “support” which will not cost anything additional.
- ▶ Of those screened 40 patients were identified and assigned to the Supportive Care team - this team consisted of an MD, RN and MSW.
- ▶ New consents were not signed as patients being provided care under home health.
- ▶ It seems “Support” translate well into Vietnamese.
- ▶ Families were advised they would have additional staff visits who would assess the progress of the patient.
- ▶ @ 2Weeks - the MSW made contact by phone to family to assess how things were going and made arrangements to come out to do another home visits at 4 weeks.

Pilot Study results

- ▶ @ 4 Weeks 15 patients agreed to Hospice - but first it was presented to family in the following manner - We've noticed that your patient appears to have less anxiety and complaints of SOB, has not felt the need to go to ER, feels care is good at home. Is that how you see the care at this point?
- ▶ “We want to share with you another program that your family member meets criteria for - you've probably heard of the program but I would like to share this with you now. It's a program called hospice. The care that we have been providing your family member is very similar to “hospice” care. The difference would be under hospice you would receive even more home visits, mentioning bath aides and chaplains as well as current staff, the medicines and supplies would be paid for by hospice as well.
- ▶ The goal would be for your family to remain at home and receive all care in the home and not need to ever return to the hospital.
- ▶ At this point we would state- if you felt that care was not being adequately provided in the home you could revoke and return to the hospital only would have to revoke from the hospice program.

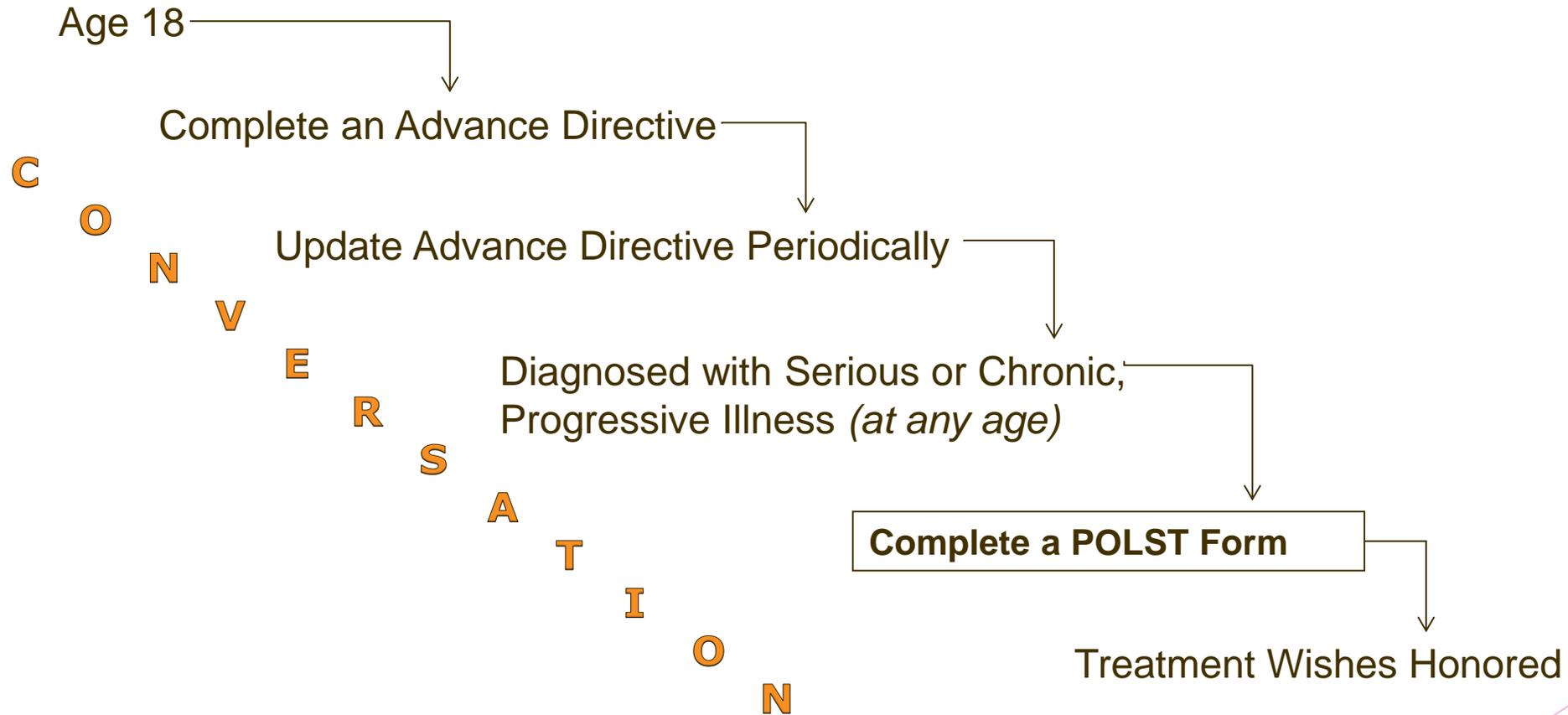
Summary

- ▶ 40 patients agreed to have Supportive team follow.
- ▶ @ 4 weeks 15 patients agreed to Hospice
- ▶ 1 patient revoked went to hospital and returned home on hospice and died
- ▶ LOS increased to 38 days versus 24 hours.
- ▶ @ 12 weeks 25 patients on supportive team - zero ER visits
- ▶ Review lessons learned with your team - regularly.
- ▶ The program recognized a few things early on
 - ▶ Recognize that listening is harder once words associated with death/dying were used.
 - ▶ Alternative terms (in their language) used to state what care actually looked like vs. what it was called was helpful.

A Successful Program

- Should include at minimum the following:
 - Non-crisis presentation of late stage/EOL options in culturally and linguistically sensitive and appropriate language by individuals with training and experience.
 - Understand you may not (never) be able to present the options to the patient – the family will want to hear this information first.
 - Greater access to experienced/trained clinical staff – trained in both Advance Care Planning and goals of care conversations.

Advance Care Planning Continuum: It's about the conversation.



ACCESSIBILITY AND RESOURCES

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- Direct – 949-355-6000 mdemoratz@gmail.com
- *Resources*
- www.coalitionccc.org **Coalition for Compassionate Care of California**
- www.capc.org *Center to Advance Palliative Care*
- www.capolst.org *California POLST*
- www.polst.org *National POLST Paradigm*