

Making Difficult Conversations about Palliative Care Easier and Culturally Sensitive

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Disclosure

- I do not have relevant financial relationships with commercial interests.

Objectives

- Identify the gaps between the way people experience end of life care and how they would like to experience the end of their life.
- Examine the barriers faced by culturally and linguistically diverse communities in discussing palliative care.
- Specify effective and culturally sensitive communication skills for delivering bad news.
- Recommend how to share prognosis with Patients and family.



How would you respond?

–Are you sure we've tried everything?

–There has always been another treatment that worked!

–Are you saying we're giving up?

Do you want us to do everything?

AVOID !!!

MD: All patients admitted need a code status address.
Do you wish to be full code or no code?

PT: I don't know.... I don't want to die.

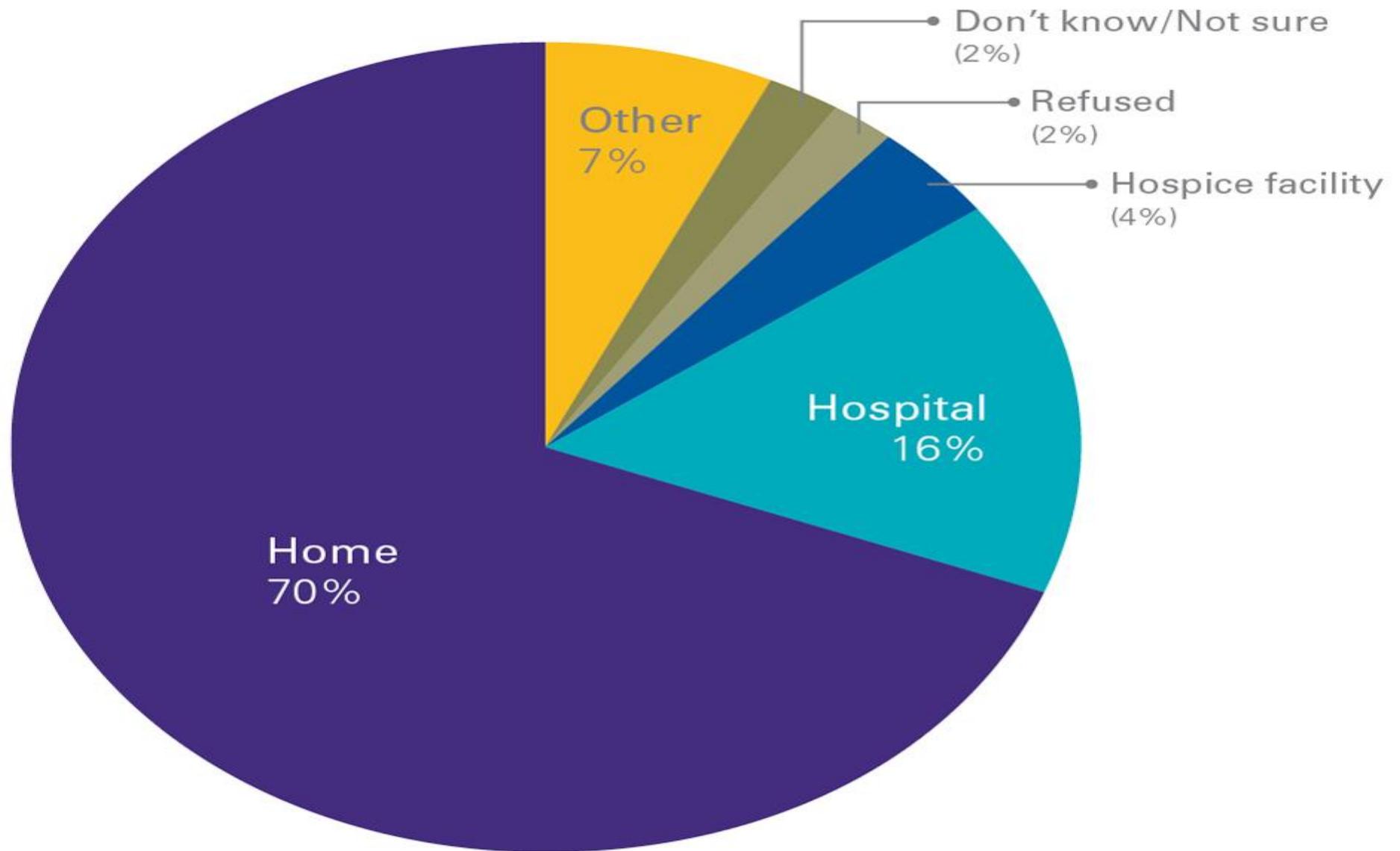
MD: So, do you want us to do everything? Do you want full code?

PT: Yes, I guess so....

MD: Okay, full code.

How Do People Die in CA?

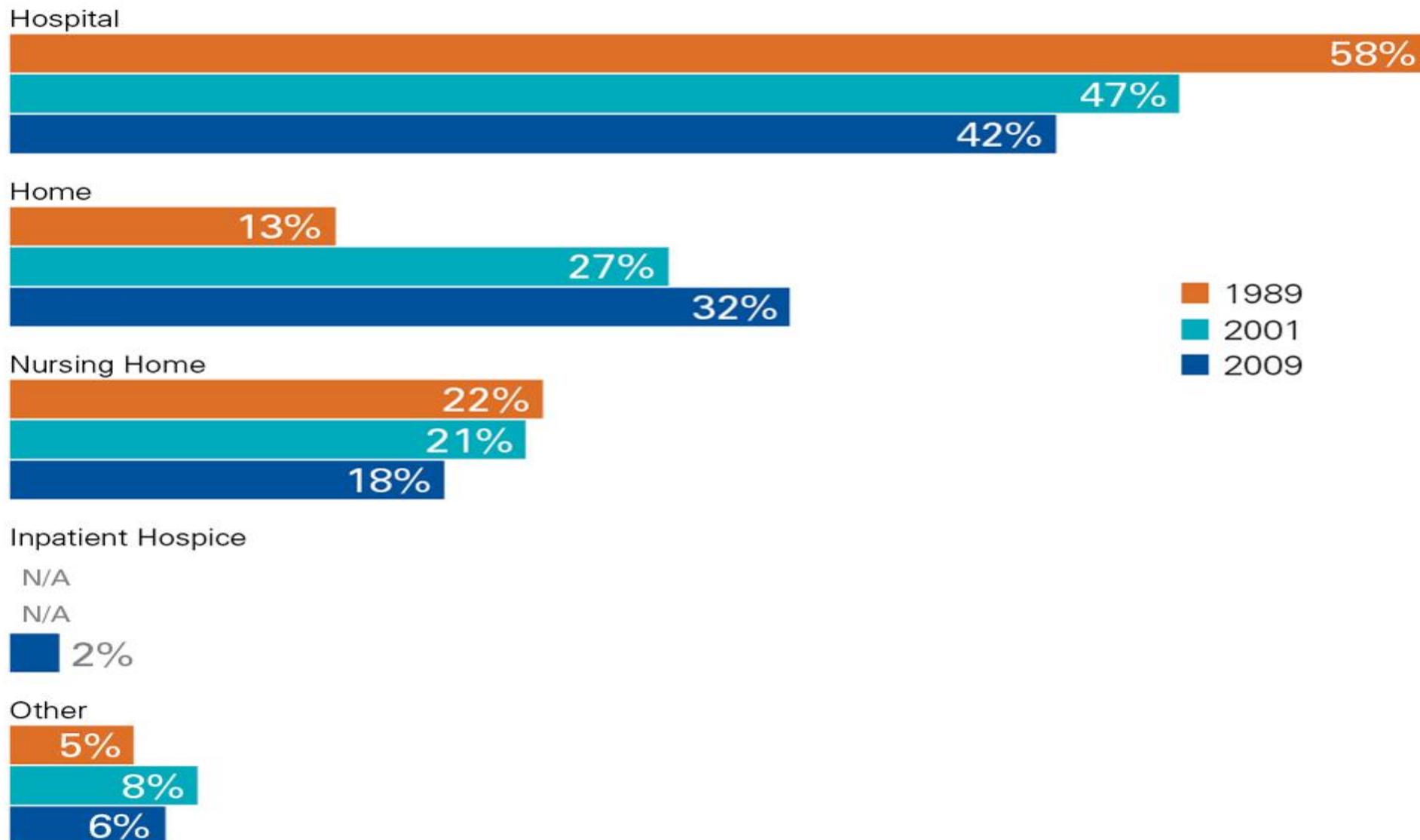
Preferred Location of Death, California, 2011



Note: Segments may not add to 100% due to rounding.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Location of Deaths, California, 1989, 2001, 2009



Source: State of California, Department of Public Health, Death Records, 2011.

Why is Delivering Serious News Hard?

- ✓
- ✓ We feel sad ourselves
- ✓ We don't know the right words to say
- ✓ Emotions are strong and we don't know how to respond

Communicating News about Serious Illness is Difficult because...

- Unable to deal with intensity of response
- Fearful of reaction
- Don't want to take hope away from patient
- Illness as an indication of failure
- The task is unpleasant
- Lack of training
- Stress
- Feeling of inadequacy
- Requests by family to withhold information
- Takes time
- Personal fear

Why are Empathic Communication Skills Important?

- ✓ Strong emotions can impair information processing and reasoning
- ✓ FMRI shows brain activation of amygdala (fight or flight) rather than frontal cortex (decision making) in stressed state
- ✓ As little as 40 seconds of emotional support by clinicians is associated with decreased anxiety among patients making difficult medical decisions

Why its important

Emotional Adjustment to Illness

Impacted by Two Factors

How
patient
told the
news



How clinician
responds to
the emotion
provoked by
the news

Butow PN et al Cancer 1996

Omne-Ponten M et al J Clin Onc 1994

Why It Needs to be Done Well

- Groundwork for *Care Plan* decisions
- Result in negative psychological consequences
 - Depression and Anxiety (patient & family)
 - PTSD symptoms (patient & family)
 - Diminish hope (patient & family)
 - Prolonged grief (family)

Why It Needs to be Done Well

- Successful delivery can result in:
 - Decrease in patient anxiety and depression
 - Increased hope
 - Increase in healthcare worker's satisfaction

Remember

Many patients and families remember more about *how bad news was communicated* than **anything else** about their care.



Can Empathic Communication Skills Be Taught?

- ✓ “Duke researchers show doctors can learn empathy”
- ✓ 1-hour lecture on communication skills and a CD-ROM training program on communication skills
- ✓ Doctors in the intervention group used more empathic statements and were more likely to respond to negative emotions empathically
- ✓ Patients of intervention doctors reported greater trust in their doctors than did patients of control group

“There was a big difference between those who came in listening and those who came in knowing.”

-- Mother whose son died of ALS

What We Will Learn

- ✓ REMAP protocol for delivering serious news
- ✓ “NURSE” statements for responding to emotion
- ✓ “I Wish” statements for responding to emotion
- ✓ Ask-Tell-Ask

R.E.M.A.P

- R Reframe
- E Expect Emotion
- M Map Out
- A Align
- P Plan

R.E.M.A.P

- Reframe
 - Why status quo is not working
 - “There is something I’d like to put on our agenda for today”
 - “We are in a different place now”
 - “This is a point where some treatments can do more harm than good”

ASK-TELL-ASK

ASK-TELL-ASK

- **Ask** current understanding
 - “Tell me what you understand is going on with your illness?”
 - “What is your understanding of what your future might look like”
 - “What have the other doctors told you?”

R.E.M.A.P

- Expect Emotion
 - Respond empathically either verbally or non-verbally
 - Verbal: “This is really hard information to hear” or “This is really hard stuff”
 - Emotion means they heard the reframe

R.E.M.A.P

N.U.R.S.E.

- N Naming “This is overwhelming” “This is shocking”
- U Understanding “It is understandable that this would be devastating to you”
- R Respecting “I am impressed by how much you love your dad”
- S Supporting “I’ll be there for you” “Our team will be there for you”
- E Exploring “Tell me more” “It will help me to know more about ...”

Non-Verbal Signs of Empathy

- Touch
- Nodding
- Silence
- Eye contact

NURSE: Acronym for Expressions Empathy

- **N**ame the emotion
“Many people would feel angry if that happened to them, I wonder if you have felt that way?”
- **U**nderstand the emotion
“Although I personally have never gone through what you are going through, I do understand this must be hard for you”
- **R**espect the patient
“I am so impressed with the strength you displayed while getting chemotherapy”
- **S**upport the patient
“I will continue to be here for you”
- **E**xplore the emotion
“Tell me more about what the chemo means to you”

R.E.M.A.P

- Mapping the future
 - Ask for permission: “Can we talk about what we do now?”
 - “Given this situation, what’s most important for you?”
 - “As you think about the future, what concerns you?”

R.E.M.A.P

- Align with the patient's values
 - As I listen to you, it sounds the most important things are (x,y,z)

R.E.M.A.P

- Plan medical treatments that match patient values
 - Here are the things we can do now that will help you do those important things. What do you think?

Goal Setting



I WISH ...

- Can serve as a way to verify bad news:
 - I wish I had better news.
 - I wish we had a treatment that would cure you.
- No “buts necessary” it is implied in the “ I wish statement. If needed say “I wish **and**”
- Hope for the best while preparing for the worst

Truth-telling and Maintaining Hope

- False hope deflects from other important issues, such as final goodbyes, finishing projects, reflecting on life, etc.
- Instead, find hope to achieve realistic goals
- Patients more often die in their place of choice, bereavement less difficult with advance care planning

Hope and Terminal Prognoses

- Repeated studies indicate patient and caregiver desire for clear and honest information about their illness
- Clear information results in improved hope, reduced anxiety
- As patients get closer to death, many want fewer details while caregivers crave more.

Hope and Prognostic Disclosure

Mack JW, et al J Clin Oncol 2007;25:5636-42.

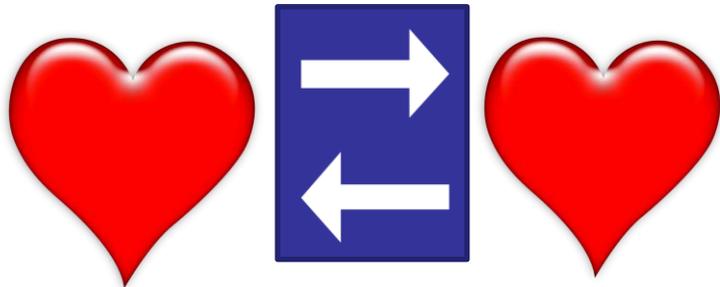
- Hope and communication survey at Dana-Farber Cancer Institute and Children's Hospital in Boston
- No negative effects of prognosis disclosure found
- High quality communication ↑ communication related hope (OR 6.58)

CONCLUSION: “Although physicians sometimes limit prognostic information to preserve hope, we found no evidence that prognostic disclosure makes parents less hopeful. Instead, disclosure of prognosis by the physician can support hope, even when the prognosis is poor.”

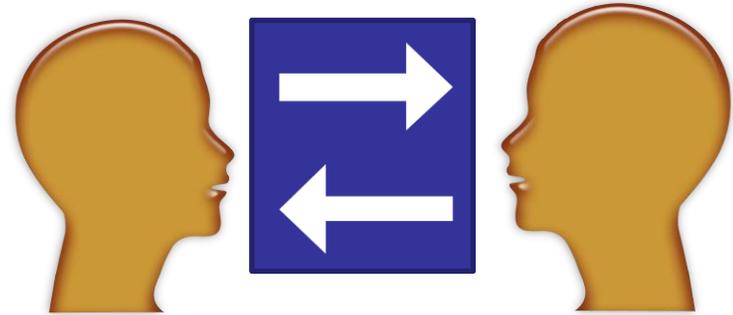
What do Patients and Families Want?

- Information tailored to them
 - When they are ready
 - As much as they want
 - At the level they can understand
- Anticipatory guidance
- **Empathy**
- Affirmation
- Non-abandonment

Heart-Head-Heart



**Feeling, Caring,
Empathetic**



**Thinking, Doing,
Explaining, Fixing**

Uncertainty

- Acknowledge it
 - Survival, physical function, cognition
 - Difficult emotions
 - Discuss signs that indicate improvement or worsening
- Counter with commitment and non-abandonment

What We Discussed

- ✓ REMAP protocol for delivering serious news
- ✓ “NURSE” statements for responding to emotion
- ✓ “I Wish” statements for responding to emotion
- ✓ Ask-Tell-Ask

Summary

- If communicating bad news is done poorly, patient and family members may never forgive us.
- However, if we do it well, they will never forget us.