PALLIATIVE CARE

Comfort and Dignity at the End of Life

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Disclosure Statement

- I/my immediate family **DO NOT HAVE** relevant financial interest in a product or device, or financial interest/arrangement or affiliations with commercial organizations providing financial support or grants in support of this educational activity, or with any commercial organizations with a financial interest in the subject matter of this activity.

Objectives

In this lecture, we will discuss:

- The definition of palliative medicine and palliative care
- Benefits of palliative care
- Similarity and difference between palliative care and hospice
- Key components of advanced care planning

Good News, Bad News

Death rate: 100%

Myth

You have to choose between quality and quantity of life

Truth

You can have both

Temel et al. *NEJM* 2010;363:733-42
Kavalieratos et al. *JAMA* 2016;316:2104-14
El-Jawahri et al. *JAMA* 2016;316:2094-2103

Live Well and Live Long with Palliative Care

If it was a drug, everyone would get it

Better quality of life

Better mood

Less pain and shortness of breath

Less likely to get invasive care at end of life

Better health for loved ones

Greater satisfaction with care

Live just as long, and maybe longer

Temel et al. *NEJM* 2010;363:733-42
Pantilat *Arch Int Med* 2012;172:1172-3
Kavalieratos et al. *JAMA* 2016;316:2104-14
El-Jawahri et al. *JAMA* 2016;316:2094-2103

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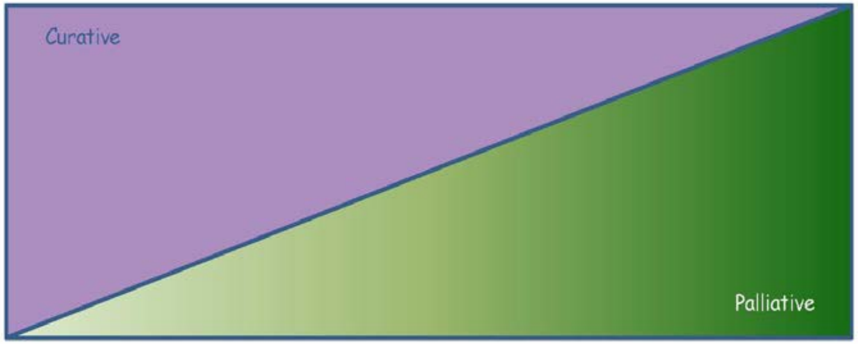
Non-Small Cell Lung Cancer

- **Study in Brief: Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer**

- Studied the effect of introducing palliative care soon after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease
- Randomly assigned 151 qualifying patients to receive either early palliative care integrated with standard oncologic care (PC) or standard oncologic care alone (SC); 107 patients completed the study
- Quality of life and mood were assessed at baseline and at 12 weeks; end-of-life data were collected from electronic medical records
- Results showed that patients assigned to early palliative care had better outcomes than patients assigned to standard care



WHAT IS PALLIATIVE CARE?”

Palliative Care is medical care focused on improving quality of life for people with serious illness

Serious illness

Utilization

Function

- Metastatic cancer
- Heart failure, COPD, ESRD, Cirrhosis and two admissions or ED visits in a year
- Stroke
- Dementia and aspiration pneumonia
- Parkinson’s disease, ALS
- Anyone on a transplant list

“Would I be surprised if this patient died in the next year?”

“Would you like us to do everything possible?”

“How were you hoping we could help?”

Pantilat *JAMA* 2009;301:1279-81

Myth

Talking about what is really going on will destroy hope

Truth

Talking about hope encourages it

Most Important Issues at End of Life

Making sure family not burdened financially by my care: 67%

Being comfortable and without pain: 66%

Being at peace spiritually: 61%

Making sure my family is not burdened by tough decisions about my care: 60%

Living as long as possible: 36%

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California HealthCare Foundation 2011

Myth

The goal is to have a good death

Truth

The goal is to live a good life

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It's OK To Ask
Proper hand hygiene - it's everyone's responsibility.
4:48
CLEAN

- Palliative care helps people with serious illness live well and long Talking about hope will encourage and nurture it
- The goal is to live a good life in the face of serious illness

Cost of dying (Arcadia Healthcare Solutions Report)

- Dying in a hospital costs $32,379
- Dying at home $4760
- Dying with hospice $17,845
- Most people want to die at home
- Most people die in a hospital or nursing home

Occupation and Death

- Physicians are slightly less likely to die in a hospital
- Least likely to die in a facility
- Physicians receive significantly less intensive care than general population
- May be their knowledge of treatment burdens and futility

Hospice and Palliative Care

- PALLIATIVE CARE
- Traditional Medicare benefit
- Anytime during illness, particularly with onset of symptoms
- Compatible with life-prolonging treatment
- Anticipate transition to hospice when appropriate

Hospice and Palliative Care (cont.)

- HOSPICE
- 6 months or less life expectancy
- Defined by Medicare benefit
- Forego life prolonging treatments
- Care provided in homes, inpatient units, and long term care facilities

Hospice and Palliative Care

- Goals are the same
  - Alleviate suffering of patient and family
  - Treat all aspects of pain: physical, emotional, spiritual and social
  - Improve quality of life
  - Help develop goals of care
  - Help patient and family make transition from health and illness to death and bereavement

Advanced Care Planning

Advanced Care planning

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Advanced Care planning

- Most physicians recognize end-of-life discussions are important
- They are waiting for patients to give them a cue
- Patients think doctors will broach the subject if something is really serious
- Medicare paid $16 million for advanced care planning sessions last year

Advance Care Planning (ACP)

- Involves learning about patient's preferences in a life-ending situation
- In 2015 new E/M codes developed
- Can be in or outpatient setting
- 99497-includes explanation and discussion of advanced directives with a health care provider, first 30 minutes
- 99498-each additional 30 minutes
- Paperwork does not have to be completed to bill

Health Care Decisions

- If a patient can make his/her own decisions, the patient should be asked and their wishes should be honored
- State of Arizona Surrogate list
  1. Guardian
  2. Health Care (Medical) Power of Attorney

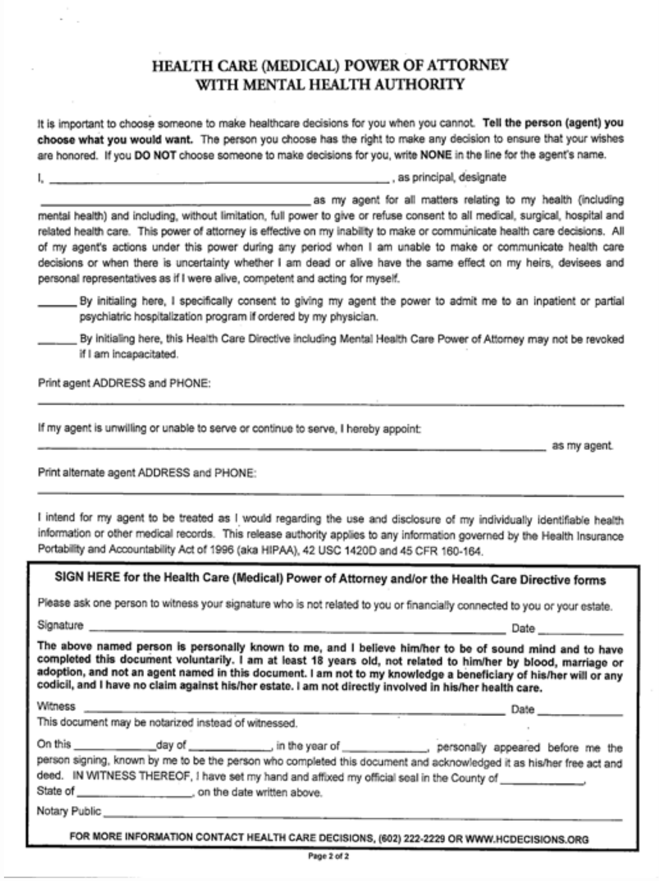
Surrogate List

- The patient’s spouse unless legally separated
- An adult child of the patient, or a majority of adult children
- A parent of the patient
- The patient’s domestic partner if the patient is unmarried
- A brother or sister of the patient
- A close friend of the patient

Health Care Decisions

- If no one can be identified, the attending physician can make a decision after consulting with an ethics committee
- 2 physicians can make decisions
- Only the patient, a guardian or MPOA can make the decision to withdraw the artificial administration of food or fluid
- All other medical treatment decisions can be made by the appropriate decision-maker

Health Care MPOA Form



HEALTH CARE (MEDICAL) POWER OF ATTORNEY WITH MENTAL HEALTH AUTHORITY

It is important to choose someone to make healthcare decisions for you when you cannot. **Tell the person (agent) you choose what you would want.** The person you choose has the right to make any decision to ensure that your wishes are honored. If you **DO NOT** choose someone to make decisions for you, write **NONE** in the line for the agent's name.

I, ____, as principal, designate

______________________________________ as my agent for all matters relating to my health (including mental health) and including, without limitation, full power to give or refuse consent to all medical, surgical, hospital and related health care. This power of attorney is effective on my inability to make or communicate health care decisions. All of my agent's actions under this power during any period when I am unable to make or communicate health care decisions or when there is uncertainty whether I am dead or alive have the same effect on my heirs, devisees and personal representatives as if I were alive, competent and acting for myself.

______ By initialing here, I specifically consent to giving my agent the power to admit me to an inpatient or partial psychiatric hospitalization program if ordered by my physician.

______ By initialing here, this Health Care Directive including Mental Health Care Power of Attorney may not be revoked if I am incapacitated.

Print agent ADDRESS and PHONE:

____

If my agent is unwilling or unable to serve or continue to serve, I hereby appoint:

____ as my agent.

Print alternate agent ADDRESS and PHONE:

____

I intend for my agent to be treated as I would regarding the use and disclosure of my individually identifiable health information or other medical records. This release authority applies to any information governed by the Health Insurance Portability and Accountability Act of 1996 (aka HIPAA), 42 USC 1420D and 45 CFR 160-164.

SIGN HERE for the Health Care (Medical) Power of Attorney and/or the Health Care Directive forms

Please ask one person to witness your signature who is not related to you or financially connected to you or your estate.

Signature ____ Date ____________

The above named person is personally known to me, and I believe him/her to be of sound mind and to have completed this document voluntarily. I am at least 18 years old, not related to him/her by blood, marriage or adoption, and not an agent named in this document. I am not to my knowledge a beneficiary of his/her will or any codicil, and I have no claim against his/her estate. I am not directly involved in his/her health care.

Witness ____ Date ____________

This document may be notarized instead of witnessed.

On this ____________day of ____________, in the year of ____________, personally appeared before me the person signing, known by me to be the person who completed this document and acknowledged it as his/her free act and deed. IN WITNESS THEREOF, I have set my hand and affixed my official seal in the County of ____________, State of ________________, on the date written above.

Notary Public ____

FOR MORE INFORMATION CONTACT HEALTH CARE DECISIONS, (602) 222-2229 OR WWW.HCDECISIONS.ORG

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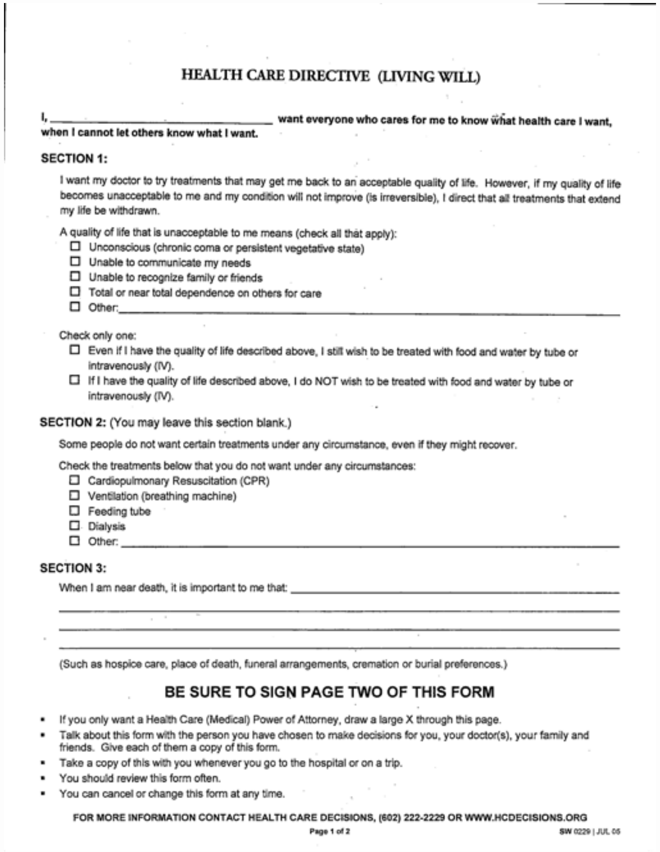
Living Will



HEALTH CARE DIRECTIVE (LIVING WILL)

I, ______________________________ want everyone who cares for me to know what health care I want, when I cannot let others know what I want.

SECTION 1:

I want my doctor to try treatments that may get me back to an acceptable quality of life. However, if my quality of life becomes unacceptable to me and my condition will not improve (is irreversible), I direct that all treatments that extend my life be withdrawn.

A quality of life that is unacceptable to me means (check all that apply):

☐ Unconscious (chronic coma or persistent vegetative state)
☐ Unable to communicate my needs
☐ Unable to recognize family or friends
☐ Total or near total dependence on others for care
☐ Other: ____

Check only one:

☐ Even if I have the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
☐ If I have the quality of life described above, I do NOT wish to be treated with food and water by tube or intravenously (IV).

SECTION 2: (You may leave this section blank.)

Some people do not want certain treatments under any circumstance, even if they might recover.

Check the treatments below that you do not want under any circumstances:

☐ Cardiopulmonary Resuscitation (CPR)
☐ Ventilation (breathing machine)
☐ Feeding tube
☐ Dialysis
☐ Other: ____

SECTION 3:

When I am near death, it is important to me that: ______________________________

____

____

____

(Such as hospice care, place of death, funeral arrangements, cremation or burial preferences.)

BE SURE TO SIGN PAGE TWO OF THIS FORM

- If you only want a Health Care (Medical) Power of Attorney, draw a large X through this page.
- Talk about this form with the person you have chosen to make decisions for you, your doctor(s), your family and friends. Give each of them a copy of this form.
- Take a copy of this with you whenever you go to the hospital or on a trip.
- You should review this form often.
- You can cancel or change this form at any time.

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SW 0229 | JUL 05

Case study: Trauma

- 46 year old male involved in MVA
- Multiple injuries including ICH, TBI
- Undergoes early trach/peg
- Patient weaned to trach collar
- Very poor neurologic recovery
- Wife requests hospice care

Case Study: Trauma

- Meeting with PCT
- No hospice diagnosis as tube feeds can not be stopped
- Grieving wife goes to court to obtain guardianship
- Patient then transferred to Hospice

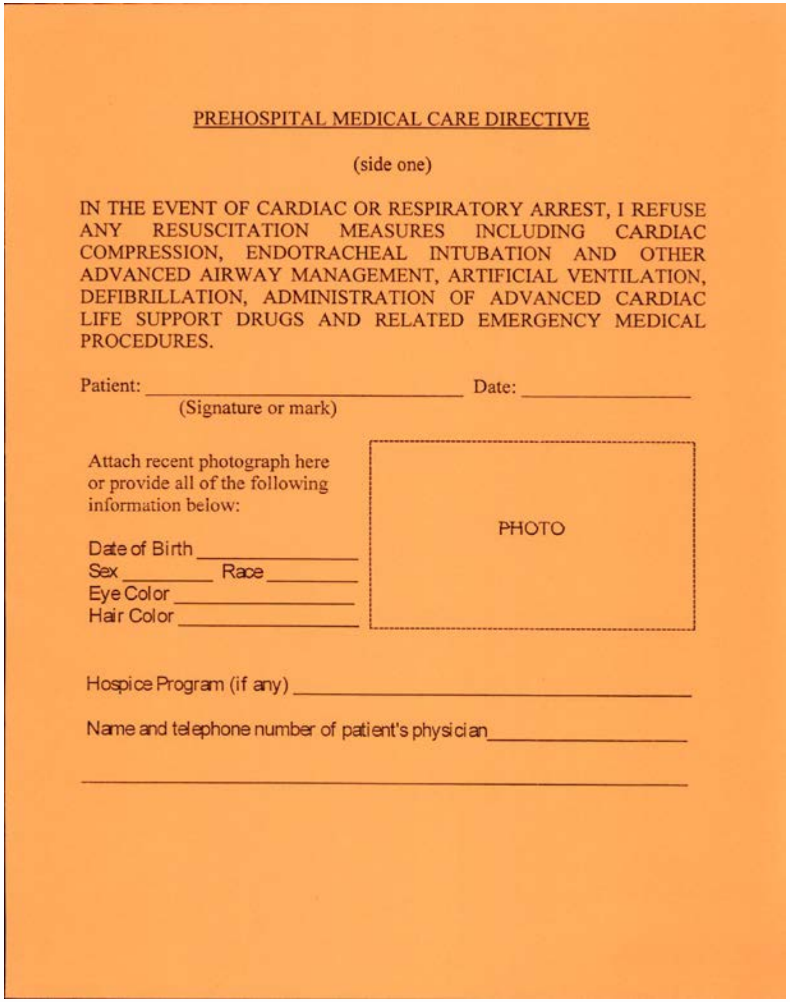
Code Status

DESPITE WINNING LOYAL FOLLOWERS, BOTH "GREYHOUND'S ANATOMY" AND "DOGGIE HOWSER, MD" WERE CANCELLED AFTER ONLY ONE SEASON...

Code Status

- Should be discussed with hospitalizations or diagnosis of serious or incurable illness
- 40% who receive CPR in the hospital will survive immediately after the code arrest
- 10-20% of those patients will survive to discharge
- Should be a goals of care discussion: cure, prolongation of life, and symptom control

Prehospital Medical Directive



PREHOSPITAL MEDICAL CARE DIRECTIVE

(side one)

IN THE EVENT OF CARDIAC OR RESPIRATORY ARREST, I REFUSE ANY RESUSCITATION MEASURES INCLUDING CARDIAC COMPRESSION, ENDOTRACHEAL INTUBATION AND OTHER ADVANCED AIRWAY MANAGEMENT, ARTIFICIAL VENTILATION, DEFIBRILLATION, ADMINISTRATION OF ADVANCED CARDIAC LIFE SUPPORT DRUGS AND RELATED EMERGENCY MEDICAL PROCEDURES.

Patient: ______________________ Date: __________
(Signature or mark)

Attach recent photograph here
or provide all of the following
information below:

Date of Birth __________
Sex ______ Race ______
Eye Color __________
Hair Color __________

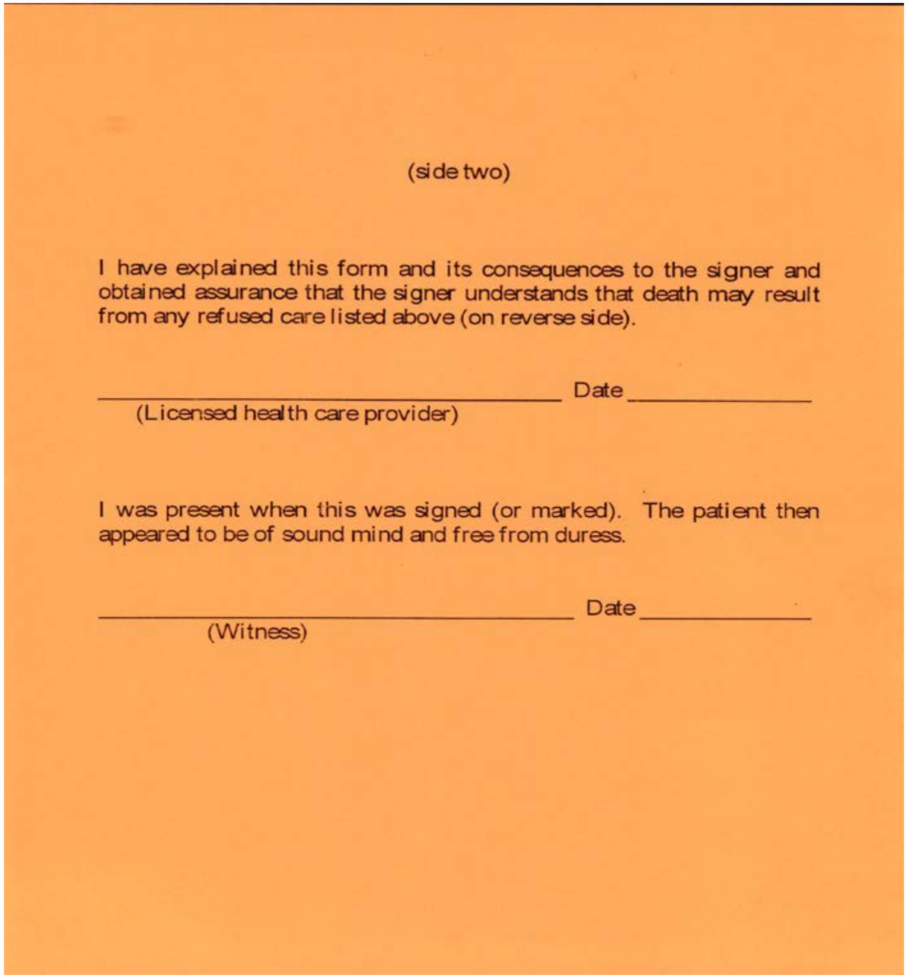
PHOTO

Hospice Program (if any) ____________________

Name and telephone number of patient's physician __________

____

Prehospital Medical Directive



(side two)

I have explained this form and its consequences to the signer and obtained assurance that the signer understands that death may result from any refused care listed above (on reverse side).

______________________________ Date ______________
(Licensed health care provider)

I was present when this was signed (or marked). The patient then appeared to be of sound mind and free from duress.

______________________________ Date ______________
(Witness)

What the future holds

- Pilot Study in Flagstaff for POLST
- Physician Aid in Dying Acts increasing over the US
- Increased presence of outpatient palliative care services
- State Task Force on End of Life Care in AZ

End of Life Care Survey in Arizona

- Methodology
  - E-mail invitation sent to physicians in ArMA, AOMA, ACP, MCMS and PCMS
  - Self-selection is an inherent challenge with limited resources
    - Nonetheless, the views of hundreds of physicians who deal with these issues directly is valuable
  - Please bear in mind as you review our results:
    - This is a survey "of physicians in Arizona who are members of (ArMA, etc.) who chose to take the End of Life Care survey"

Introduction

- **Methodology (cont.)**
  - **466 Arizona physicians gave a full response to the survey**
    - **Approximately 8,000 emails were sent out, with multiple reminders**
    - **588 began the survey**
    - **Cannot estimate the exact response rate as members can be in more than one organization**
  - **Survey open October 23 to December 31, 2017**
  - **For the sample of 466 members, the margin of error is ±4.5% at the 95% confidence level (in terms of representing the population "of physicians who are interested/involved in EOL issues" and not "all Arizona physicians")**

Profile

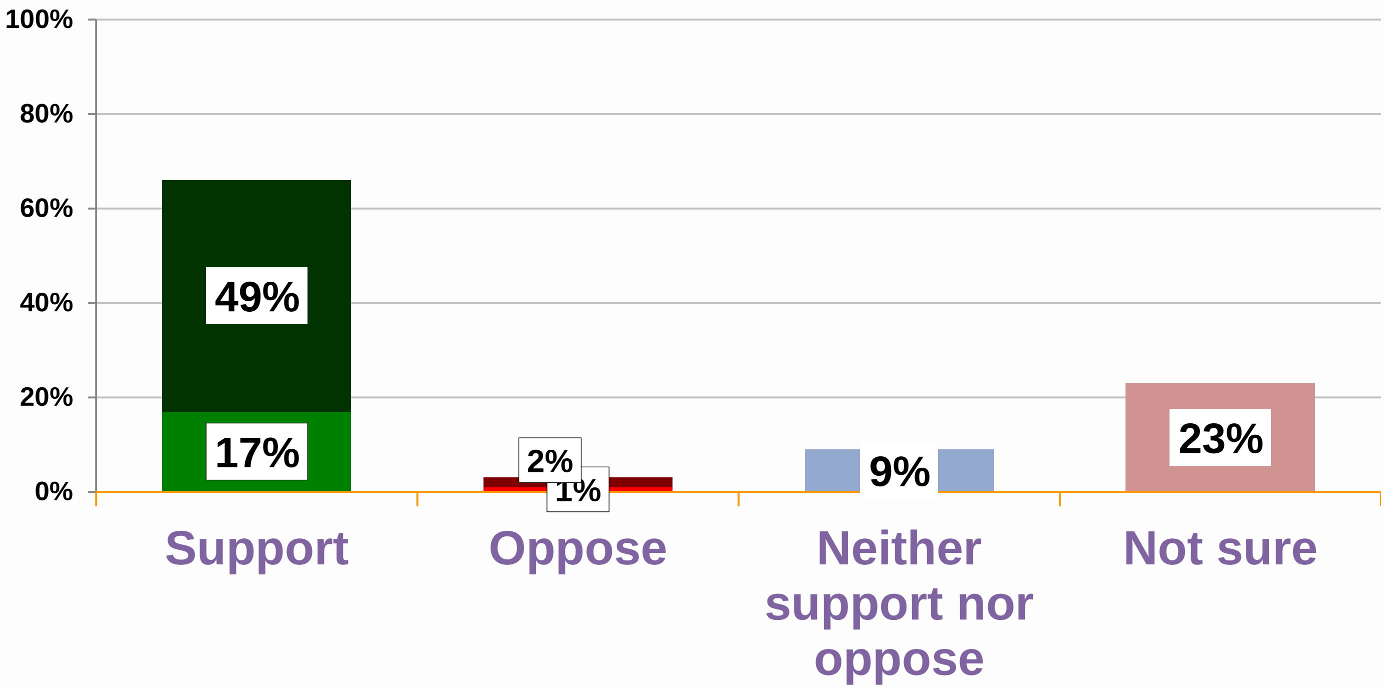
- **Specialty**
  - ✓ **36% Primary Care**
  - ✓ **3% Pediatrics**
  - ✓ **3% Ob/Gyn**
  - ✓ **26% IM Subspecialty**
  - ✓ **11% Surgery or subspecialty**
  - ✓ **21% Does not apply**
- **Facility**
  - ✓ **29% Hospital**
  - ✓ **33% Clinic**
  - ✓ **9% Split time about evenly**
  - ✓ **16% Academic center**
  - ✓ **3% IHDS**
  - ✓ **3% FQHC/Rural Health**
  - ✓ **5% Does not apply**

- **Geography**
  - ✓ **58% Phoenix area**
  - ✓ **25% Tucson area**
  - ✓ **7% Other City**
  - ✓ **10% Town/rural area**
- **Age**
  - ✓ **22% Age 25-45**
  - ✓ **50% 46-65**
  - ✓ **28% 66 or older**
- **Gender**
  - ✓ **32% Female**
  - ✓ **68% Male**

Physician Orders for Life Sustaining Treatment (POLST)

“POLST is a transportable medical order that is being used in 23 states and in pilot(s) in Arizona. A POLST document follows the patient across care transitions, ideally being available upon a person’s presentation to an ED, hospital, or new care setting to use as a starting point for readdressing goals of care and treatment decisions. POLST is only for the seriously ill in the last year of their life and always voluntary.”

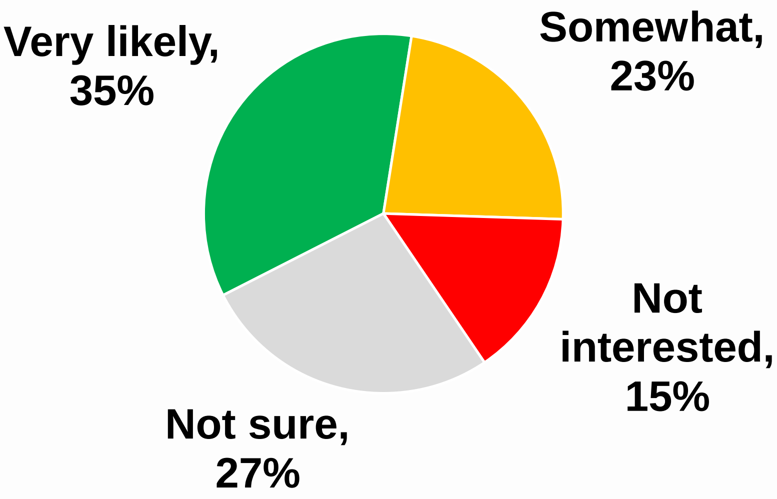
- Fully 66% support POLST in Arizona, while just 3% are opposed (and the remainder neither support/oppose or are unsure at this time).



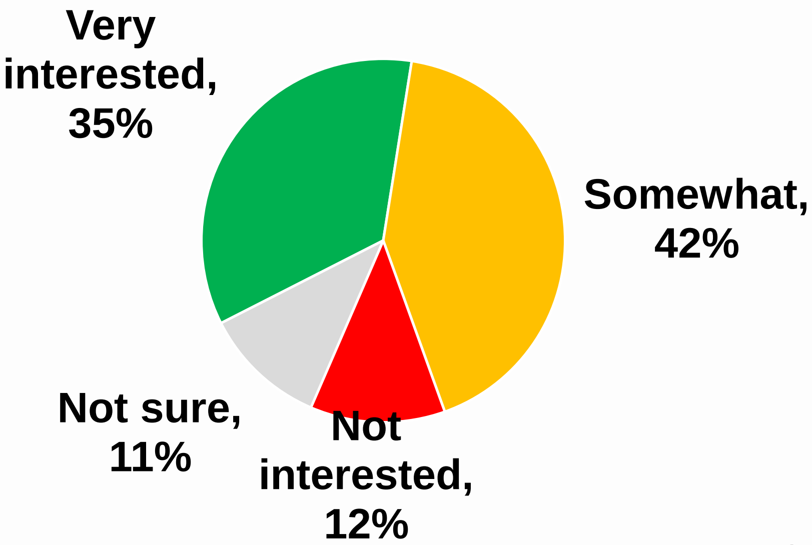
Q27: Do you support or oppose POLST for patients in Arizona, neither support nor oppose, or are you unsure at this time?

- One-third (35%) are "very" likely to use POLST in their practice, with another 23% "somewhat" likely to use it; among those who 'frequently' see patients in EOL situations, 52% are "very" and 22% are "somewhat" likely to use it.
- Slightly more physicians are interested in education and training on POLST, with 35% "very" and 42% "somewhat" interested overall; among those who 'frequently' see patients in EOL situations, 46% are "very" and 40% are "somewhat" interested.

Likely to use in practice?

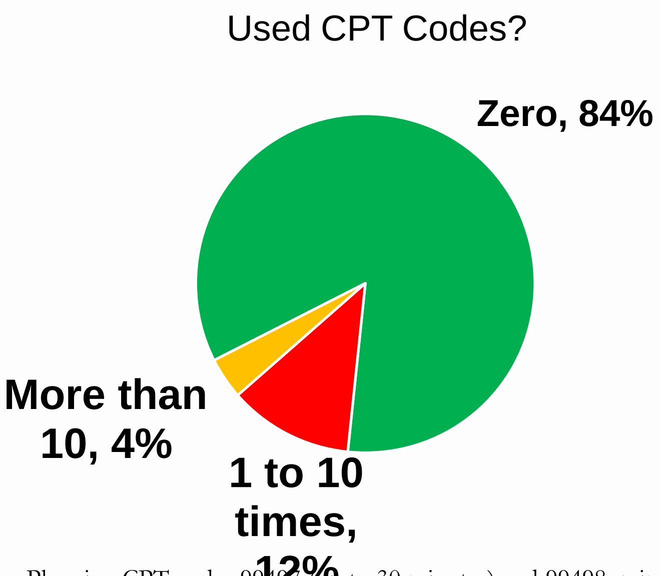


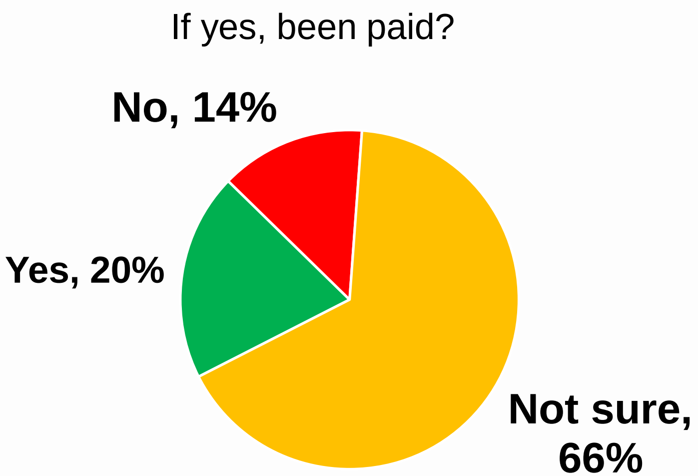
Interested in education/training?



Q28: How likely are you to use POLST in your practice?
Q29: How interested are you in having additional education/training on POLST?

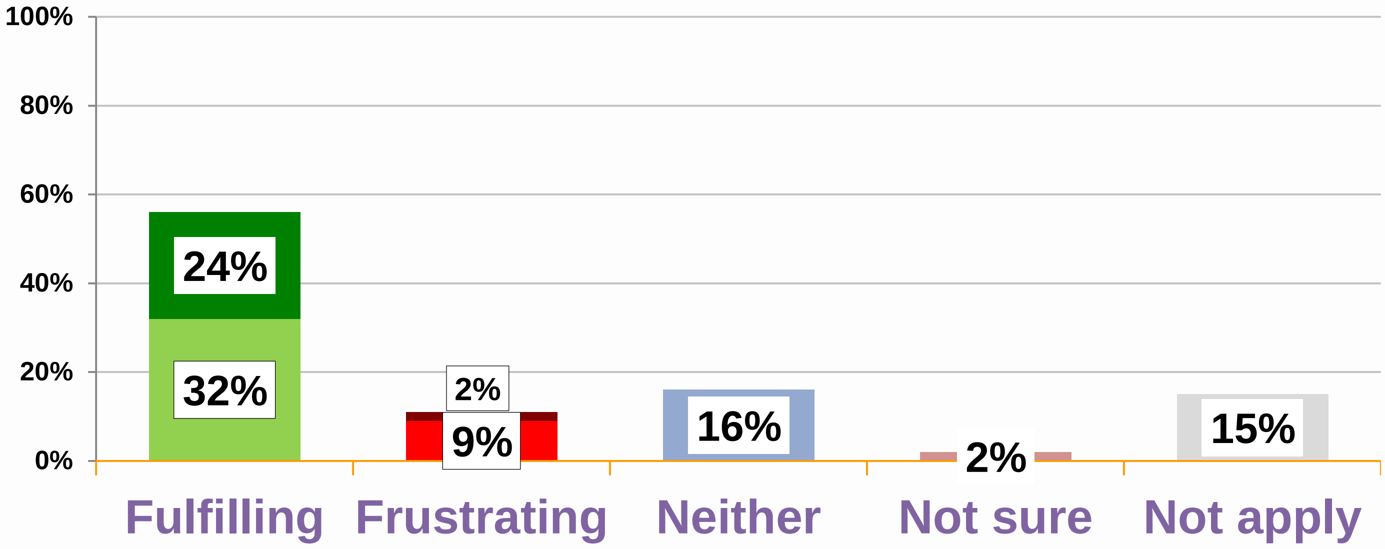
- Overall, fully 85% say they have never used specific codes for end-of-life care, and few of these are aware they have been paid for using them.
  - Among specialists in PM, 47% say they have not used these codes, and among those who say they ‘frequently’ deal with patients at the EOL, 78% say they had not used these codes.


Used CPT Codes?


If yes, been paid?

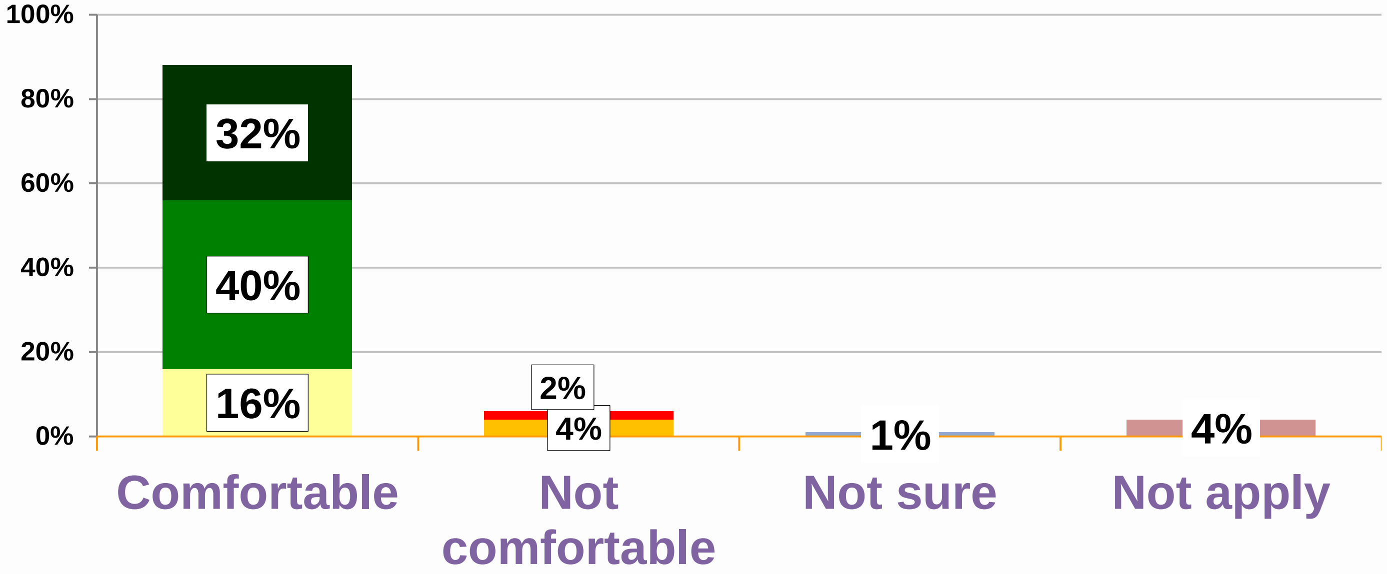
Q16: Advance Planning CPT codes 99497 (up to 30 minutes) and 99498, reimburse physicians for having conversations regarding end of life care with their patients.
Q17: IF YES: Have you been paid for these? *(n=81)*

- Overall, 56% say their experiences treating patients at the end of life are either “very” (dark green) or “somewhat” (light green) fulfilling.
  - Those who are specialists in palliative medicine are far more likely to say “very” fulfilling versus “somewhat” fulfilling.
  - Among those who ‘frequently’ encounter EOL care issues, 31% say “very” fulfilling and 40% say “somewhat” fulfilling.



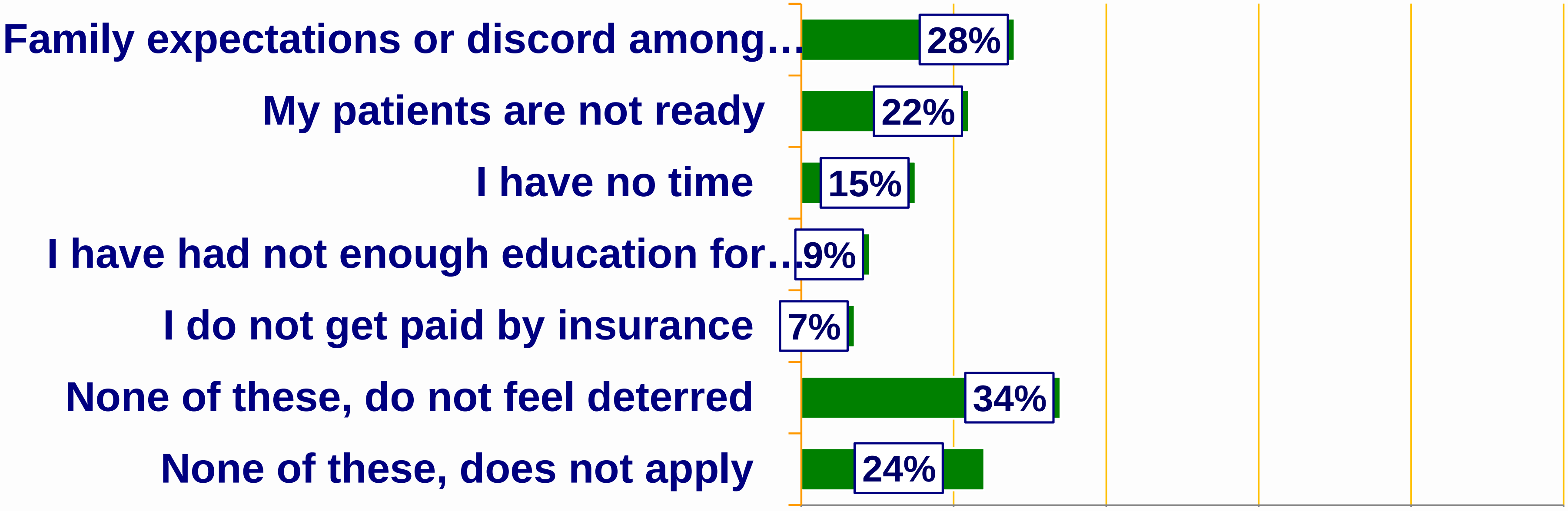
Q20: Do you find that your experiences providing care at the end of life generally more of a fulfilling and satisfying part of your practice, or generally more of a frustrating and draining part of your practice? Or do these terms not really capture your experiences for you?

- Three-quarters (72%) are “completely” (dark green) or “mostly” (light green) comfortable, with another 16% “somewhat” (yellow), having EOL discussions.
  - Specialists in PM are far more likely to say they are “completely” comfortable, followed by those with at least some training (others tend to say “mostly” comfortable or “somewhat” comfortable).
  - Physicians age 25 to 45 are less likely to say they are “completely” comfortable than those over the age of 46 as well.



Q19: In general, how comfortable are you with having conversations with patients and their families regarding end of life care? (Please reflect as honestly as possible as you consider your response, as we are trying to establish a baseline for our education and outreach efforts.)

- One-third (34%) say that they do not feel deterred from having conversations with patients about end-of-life care issues, while 28% cite "family expectations" and 22% cite "patients" not being ready.
  - Among those with some formal training, 52% do not feel deterred versus 38% of those with limited training at 25% of those with no formal training.



Q18: Do any of the following obstacles deter you from having these conversations? Please check all that apply, and feel free to add any comments.

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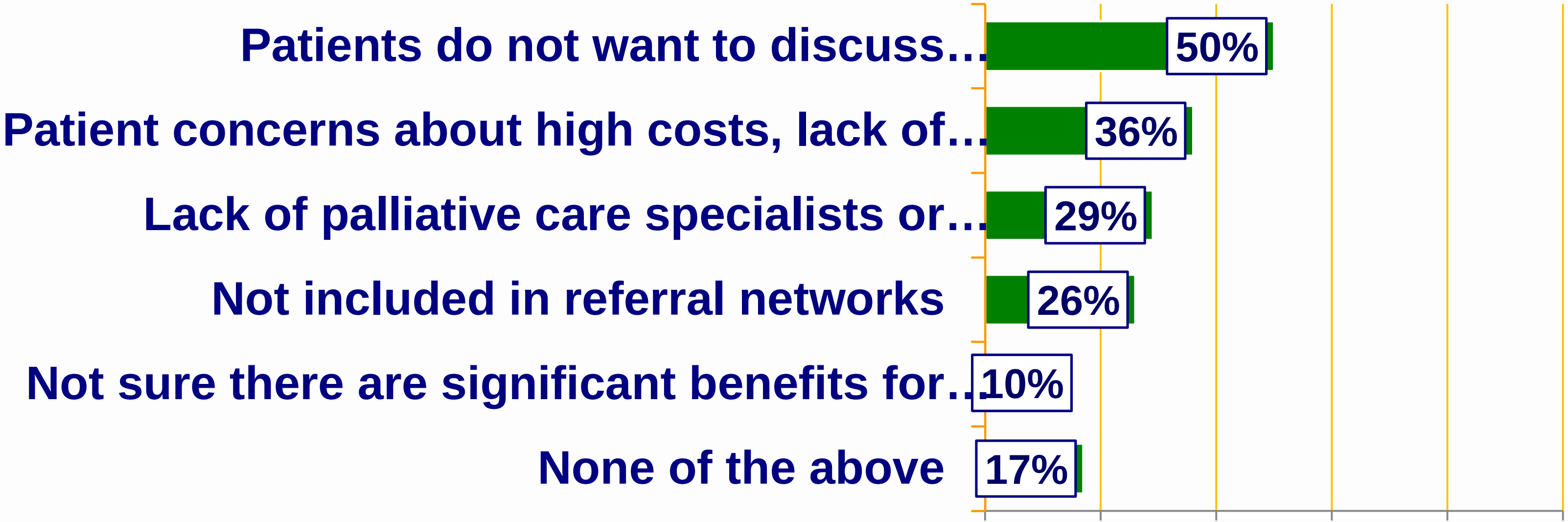
- Patient unwillingness to discuss end-of-life care issues, followed by concerns about cost and coverage, are seen as the primary barriers to these referrals.
  - Specialists in PM agree that patients' attitudes are a barrier, but are less likely than others to cite concerns about high cost.
  - Physicians age 25 to 45 are much more likely with 63% then those 46 to 65 with 52% and those 66 and over with 32% to say patients do not want to discuss.
  - Lack of specialists is more likely to be seen as a barrier by hospital physicians and those under age 45.



Q14: Which of the following do you see as barriers to physicians referring patients to a palliative care specialist (or bringing one into the 'care team' for that patient)? Please check all that apply.

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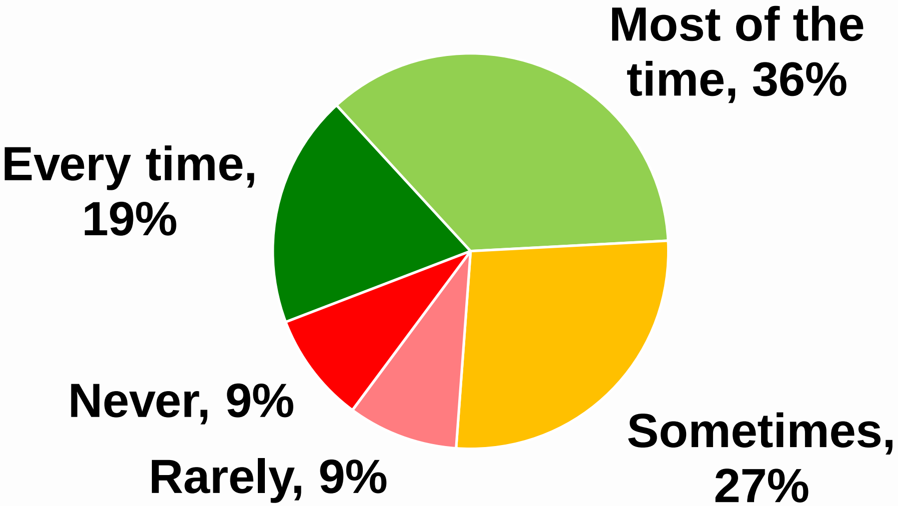
- A majority (55%) refer to palliative care or hospice “every time” or “most of the time” in cases a patient is diagnosed with a terminal disease.
  - Among those who ‘frequently’ see patients in EOL situations, 71% say as such, versus 54% of those who say “sometimes.”
  - We see considerably higher levels of referral among those with at least “limited” training in EOL care, versus those with “none.”



Q11: In cases where a patient is diagnosed with a terminal disease, how often do you refer patients to a palliative care specialist (or work with a palliative specialist on your care team) or hospice care ?

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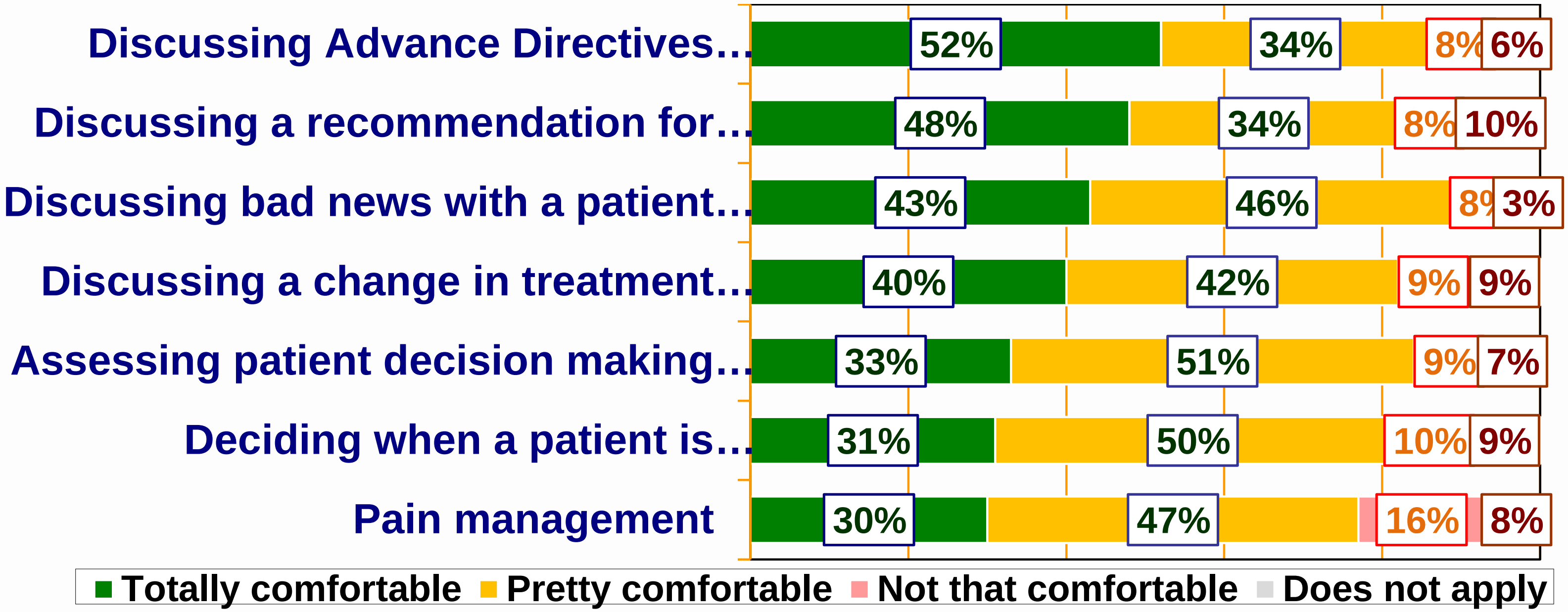
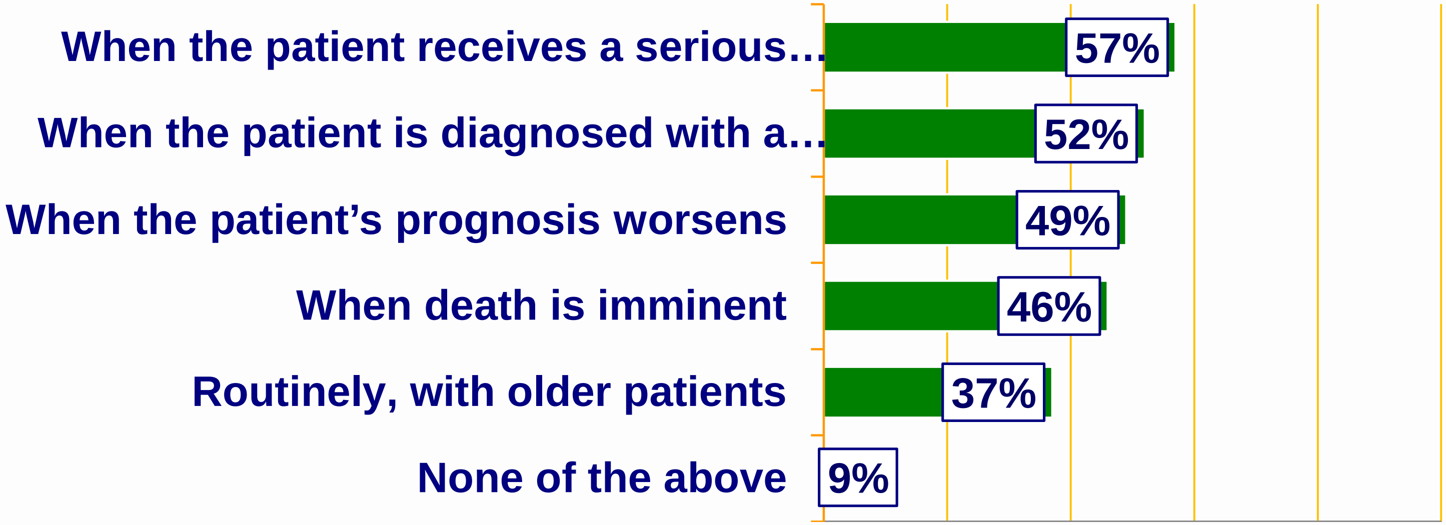
- Between 30%-50% of physicians are “totally” comfortable addressing a range of EOL care issues, with the lowest level of comfort regarding pain management, deciding on palliative care and assessing patient decision making capacity.
  - Comfort levels are considerably higher for those with higher levels of training in EOL issues.



Q4-10: How comfortable are you carrying out the following in your practice?

- Two-in-five (37%) “routinely” discuss EOL issues with patients, versus between 46%-57% who do so when the patient’s situation is considerably worse.
  - 60% of those who ‘frequently’ care for patients in EOL situations discuss these issues “routinely”, versus 36% of those who do so ‘sometimes.’
  - Physicians in an office setting (43%) are more likely than those in a large facility (31%) to say “routinely.”
  - 49% of primary care doctors say they do so routinely versus 33% of specialists (while we see very little differences on the other factors).



“Other” responses:

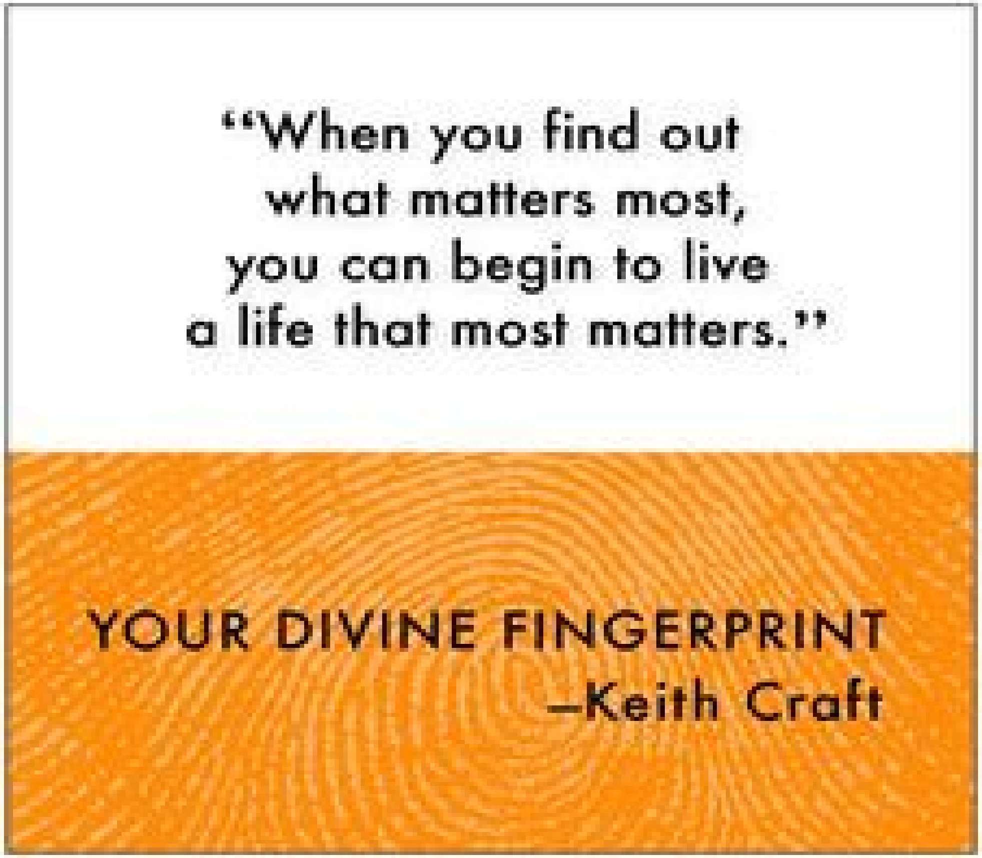
- ✓ *“At the annual wellness visit”*
- ✓ *“When the patient or family suggests it”*

Q3: In your practice, when do you typically discuss end of life issues with patients? Please check all that apply.

Executive Summary

- There is also a strong desire to see patient and public education efforts (from literature in offices to advertising campaigns) on EOL issues
  - Top barrier to better EOL care is seen as family/patient discomfort
  - Also concern with cost and network access
    - Very few are using CPT codes

Questions?



"When you find out
what matters most,
you can begin to live
a life that most matters."

YOUR DIVINE FINGERPRINT
–Keith Craft