



**ARMA/AOMA JOINT
PHYSICIAN TASK
FORCE ON END
OF LIFE CARE
2016-18 Final Report**

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1. SUMMARY AND RECOMMENDATIONS

The Joint ArMA/AOMA Physicians Task Force on End of Life Care was established in 2016 to address current care for Arizonans at the end of life and those with serious and/or life-threatening illness, physician knowledge of end of life issues and care, and needs for education of Arizona physicians on these issues. The Task Force included about 25 physicians in many specialties, including Primary Care, Palliative Care, Hospital and Emergency Medicine and several medical subspecialties. It met monthly and completed the following:

- A comprehensive reference list was compiled.
- Testimony was heard on a variety of topics relevant to end of life (EOL) care.
- Surveys were conducted of medical schools and residency programs in Arizona showing that medical schools devote time to EOL issues, but that most Residencies and Fellowships **do not specifically address EOL care**. Efforts to specify such training should occur starting in IM/ FP residencies and then to fellowships in medical and surgical subspecialties. Successful models do exist within Az.

A survey was designed and emailed to 8,000 physicians, with over 500 responding. The survey examined knowledge, skills and involvement in end of life issues, desire for further education as well as views toward POLST (Physician Orders for Life Sustaining Treatment) and MAID (Medical Aid in Dying).

Major Findings of Physician Survey

1. Counseling of patients regarding end of life options occurs too infrequently

- Only 50% of the time when end of life was near.
- Routinely in only 37% of older patients.
- Perceived patient/ family unreadiness was seen as the major deterrent to having these conversations.
- Physicians with training in EOL were less deterred.

2. “Good deaths “are encountered too infrequently

- A good death was defined as death expected, family present, symptoms controlled, patient’s wishes followed.
- Respondents reported that their patients currently experience “good deaths” less than 50% of the time.

3. Lack of training in EOL care is a barrier

- Most physicians reported not having received training in EOL care.
- 40% indicated an interest in additional training.
- Those with more education found EOL more professionally satisfying and experienced “good deaths” more often.
- Most endorsed the need for public education.
- Despite the availability of Medicare approved CPT codes for end of life counseling, only 15% of physicians used them.
- Although Palliative Care has emerged as a medical specialty in the past 10 years, and is available in most hospitals, only 55% of respondents reported referring terminally ill patients or those diagnosed with serious life limiting illnesses.

4. POLST: most physicians are supportive and welcome additional training

5. Medical Aid in Dying was supported by 53% of respondents; opposed by 27%; and 20% were undecided

**Education for physicians and other providers and general public on End of Life Care initiated;
Relevant statistics on EOL care to be compiled**

- The Task Force collaborated with Arizona Hospital and Healthcare Association(AzHHA) on a grant, which was awarded to AzHHA by the Lovell Foundation, for education of Physicians and other providers (Nurses, Physician Assistants, Social Workers) and the public, in end of life issues, and to compile relevant statistics on EOL care in Arizona. Train the Trainer sessions have been initiated and are starting to reach providers and public around Arizona with CME and incorporation into resident/fellowship training.
- With input from the Task Force, AzHHA will proceed to compile and analyze relevant Arizona data on EOL care that allows a comparison to other states.
- A statewide conference on EOL care is planned under the grant for 2019

Review of MAID by ArMA Committee on Medical Ethics

At the request of the Task Force, the ArMA Ethics Committee was convened to review the issue. The committee was divided on whether the practice was an ethical way of relieving suffering near the end of life. It was unable to reach a consensus on whether or not to recommend that ArMA change its position from “opposed” to “neutral”. (see report in Appendix)

POLST initiatives approved by ArMA and AOMA leadership

The Task Force reviewed information on Physician Orders for Life Sustaining Treatment (POLST), including a pilot Program in Northern Arizona. These are different from Advance Directives, because they require a conversation between a seriously ill or frail patient (in the last year of life), and his/her provider resulting in informed shared decision making that is documented and results in a portable medical order. Arizona is working with The National POLST Paradigm to implement this evidence-based patient and family centered approach to ensure patients receive only the medical treatments that align with their goals of care. Arizona’s current statutes do not align with evidence-based, patient-centered care and will require legislative changes to remove barriers and support statewide adoption of POLST. The Task Force endorsed POLST, and made enabling legislation a goal. Resolutions were submitted to ArMA and AOMA and approved.

Moving forward: taking the lead on changing how the public and physicians view death and dying.

- Having accomplished its objectives, the Task Force will suspend regular meetings, but continue to work with the AzHHA on educational efforts and to monitor progress and to advocate for legislation on POLST.
- It will disseminate results of its findings in a variety of forums including articles in Arizona medical journals and *Pulse*, ArMA’s new online publication, and presentations at professional meetings.

- It will take ongoing efforts over many years to implement these findings and recommendations to change the culture, from one that avoids dealing with death and dying, to one that recognizes that death is part of life and that living fully and having a “good death” are achievable for most individuals, but it requires better planning and improved communication.
- Physicians should play an active role in this culture change by availing themselves of training opportunities to enhance communication with patients with serious life limiting illness and nearing end of life: to clarify goals of care, outline disease trajectory and explore options and patient wishes.
- ArMA and AOMA --the organizations that represent physicians --should lead in providing education to the medical community and to the public on end of life care and support the need for Advance Care Planning for older individuals and those diagnosed with serious life limiting illnesses. Finally these organizations should use their legislative advocacy to promote POLST to assure that patient wishes for end of life care are elucidated, communicated and followed by first responders, hospitals and physicians.

Summary of Recommendations

- 1. Publicize results of the physician survey widely**
 - a. Craft messages for the public and for physicians regarding the need to plan ahead to consider end of life wishes
 - b. Encourage both physicians and the public to engage in conversations about goals of care when life is limited., and as part of routine care for older patients.
 - c. Work to remove insurance barriers to EOL care
- 2. Publicize Physician training sessions and educational sessions on EOL issues on the ArMA weekly newsmagazine, AOMA publications and medical society bulletins**
 - a. Engage with primary physicians, hospitalists and training programs to reach residents and fellows
 - b. Engage with medical subspecialists, with a peer champion to encourage thoughtful consideration about goals of care conversations, using other members of the health care team
 - c. Publicize the role and availability of Palliative Care
- 3. Publicize and inform physicians and the public about POLST and why it is a good idea for patients in the last year of life to clarify wishes and make accessible as part of the medical record and to caregivers and accessible to first responders.**
- 4. Advocate for legislation for POLST in collaboration with the AzHHA and AOMA.**
- 5. Reconsider ArMA’s official position on Medical Aid in Dying in the event of pending legislation on the issue, in recognition of shifting views toward this practice in Arizona and nationally as an ethical way of ameliorating suffering for some patients at end of life.**
- 6. ArMA and AOMA in partnership with AzHHA should monitor and advocate for federal legislation to improve EOL care (see appendix item 1)**

2. SURVEY OF AZ PHYSICIANS

End of Life Care Survey of Arizona Physicians

Posted By [AZPulse](#) on Mar 28, 2018, *Written By:* Ronald S. Fischler, MD, FAAP and Timothy C. Fagan, MD, FACP
ArMA/ AOMA Joint Task Force on End of Life Care

The Task Force on End of Life Care was established by the Arizona Medical Association (ArMA) and Arizona Osteopathic Medical Association (AOMA) in 2016, to evaluate care and make recommendations. It has involved about 25 physicians from a variety of specialties and locations across Arizona.

A survey was designed to determine how Arizona physicians regard aspects of End of Life (EOL) care; specifically, attitudes toward end of life discussions; knowledge and access to Palliative Care (PC); interest in further education on EOL issues; attitudes on Medical Aid in Dying (MAID); and attitudes on POLST (Physician Orders for Life Sustaining Treatment).

The survey was conducted by email, sent to 8,000 members of ArMA, AOMA, Pima County Medical Society (PCMS), Maricopa County Medical Society (MCMS) and the Arizona Chapter of the American College of Physicians (AzACP), and several specialty societies, and a link was published in the journal Arizona Physician. The survey was conducted from October through December 2017, and a professional pollster was engaged to assist in design and analysis. Funding was provided by a private donor, AzACP, and PCMS.

Respondents were physicians interested in EOL issues, and who were willing to complete the survey, most of whom were members of professional medical organizations.

Demographics

- Geography
 - 58% Phoenix
 - 25% Tucson
 - 17% rural/other town
- Age
 - 22% 25-45 years
 - 50% 46-65
 - 28% 66+ years
- Gender
 - 32% female
 - 68% male
- Specialty
 - 36% Primary Care
 - 26% Internal Medicine subspecialty
 - 11% General Surgery or Surgical subspecialty
 - 6% Pediatrics or Ob-Gyn
 - 5% Palliative Care
 - 18% Other
 - 68% routinely engage in EOL
- Practice Setting
 - 29% Hospital
 - 33% Clinic/Office
 - 9% Hospital and Clinic
 - 16% Academic
 - 6% integrated system (FQHC, ACO)
 - 7% Other
- Training in Palliative Medicine
 - Significant 19% (including 5.5% PC specialists)
 - Limited 29%
 - None 52%
 - Experience with End of Life care
 - 68% routinely engage in EOL

Responses

There were 588 responses, of which 466 completed the entire survey (and therefore formed the basis of the analysis). The margin of error was 4.5%.

1. Most surveyed physicians reported feeling comfortable with most aspects of EOL care: discussing advanced directives, delivering “bad news,” discussing change in care from curative to comfort, assessing decision making capacity, pain management, and deciding when a patient is appropriate for palliative care. 18% reported feeling less than comfortable with pain management.
2. Surveyed physicians reported discussing EOL issues when a patient receives a terminal diagnosis (57%), when prognosis worsens (49%), when death is imminent (46%) and routinely with older patients (37%).
3. While a third of physicians do not feel deterred, about 50% believe that family issues (expectations, discord among members or patient readiness) constituted barriers to having these discussions. Notably, physicians with more training in palliative care were less deterred (22% vs 52 %)
4. Although Medicare approved two Current Procedural Terminology (CPT) codes for end of life counseling in 2016, 85% of surveyed physicians had not used them.
5. Referral to palliative care or hospice was reported by 55% of respondents for patients with a terminal illness. Those with more training in EOL care were more likely to refer.
6. Barriers to referral for PC were substantial: 50% viewed families as not ready; costs/insurance concerns were cited by 36%; lack of available PC specialists was reported by 29%. Younger physicians (under 45) were more likely to report that patients did not want to discuss options (66% vs 32%). ER doctors and those in rural areas commented on the lack of palliative care support.
7. For purposes of the survey, a “good dying experience” was defined as: expected death, symptoms controlled, family present and family wishes in accordance with the patient’s wishes. How often do surveyed physicians encounter a “good dying experience”? Overall a good death was observed less than 50% of the time. Physicians with the most training reported “good deaths” more often (77% of the time).
8. Professional Satisfaction with EOL care:
56% of respondents reported that EOL care was fulfilling and 9% reported that it was frustrating. More training in EOL care was associated with higher levels of satisfaction.
9. Interest in additional training:
42% were interested in additional training for themselves.
67% stressed that education for the public on end of life issues was very important.
10. Most surveyed physicians (66%) supported Physician Orders for Life Sustaining Treatment (POLST), which is transportable medical orders for terminally ill patients in the last year of life. POLST are used to document patient wishes and apply to all settings. 76% of respondents want more education about POLST and 58% believed they would use it in practice.
11. Medical Aid in Dying. These laws, which have been passed in Oregon, Vermont, Montana, Washington, Colorado and California, allow terminally ill patients who are residents of the State, to make two oral and one written request to a physician to prescribe a medication, which the patient self-administers. Physician participation is voluntary and liability protection is provided. 53% of respondents were in support (33% strongly in support), while 27% were opposed (18% strongly). There were robust comments on both sides of the issue.

While a majority of physicians surveyed reported comfort with care of patients near EOL, over 40% were interested in further education – especially in pain management and palliative care.

This survey showed clear benefits of education: those with more education in EOL care were more likely to view patients as receptive to EOL conversations, make greater use of palliative care consultants, saw fewer barriers to referral, and reported higher levels of professional satisfaction.

Professional and Public Education on EOL is now available in Arizona.

Excellent training modules have been developed for physicians on how to have EOL conversations. Besides CME for practitioners, training in EOL care should be addressed formally in Residency training for all physicians, who are likely to encounter patients near the end of life.

One of these programs, developed by Ariadne Labs, is being launched in Arizona under a grant from the Lovell Foundation to the Arizona Hospital and Healthcare Association (AzHHA). A two-hour training module uses role play to teach participants how to provide information sensitively and to manage the emotional responses of patients. It has been proven effective. For further information about training for providers contact Karen Beckford at AzHHA, kbeckford@azhha.org.

Most physicians in the survey saw public education on EOL as vitally important to help patients feel informed and empowered regarding end of life wishes. Free tools are available online to enable patients to start conversations with loved ones. Public education is also beginning to occur around Arizona under the Lovell Grant to AzHHA. To find out about public education or to volunteer to assist in your area, contact Karen Beckford at AzHHA, kbeckford@azhha.org.

A complete survey report will be published in the next few months. We will be authoring a series of articles on related topics in this publication and other Arizona medical society publications. We look forward to continuing the conversation.

Dr. Fischler is a pediatrician from Scottsdale who chairs the ArMA/ AOMA Joint Task Force on End of Life Care. Dr. Fagan is an internist from Tucson that led the survey committee of the Task Force and serves on the Board of ArMA.





Resources:

1. Lakin, et al. *Health Affairs*. 2017, 36:1258-1264
2. www.conversationproject.org

Az Survey: Snapshot of Results





Conducted by ArMA/AOMA Joint Physician Task Force on End of Life Care 2017

<h1>Arizona Physician Survey on EOL</h1> <p>Conducted by ArMA/AOMA Joint Physician Task Force on End of Life Care 2017</p>				<h2>Recommendations</h2>
<h3>Attitudes</h3> <p>57% discuss EOL w/terminal diagnosis 46% discuss EOL when death is imminent 37% discuss EOL routinely with elderly 85% have not used CPT codes for EOL counseling 50% view patient/ family unreadiness as principal deterrent to having EOL conversations Those with EOL training less deterred(22%) 16% feel uncomfortable in pain management 56% report EOL care was fulfilling</p>	<h3>Palliative Care</h3> <p>55% make a referral to Palliative Care (PC) for patients with terminal illness Barriers to PC referrals: • 50% say family not ready • 36% Cost/Insurance concerns • 29% Lack of PC specialists • 52% report no training • 42% want training • 50% observe "Good Deaths" • 77% of those with PC training observe "Good Deaths"</p>	<h3>POLST Attitudes</h3> <p>66% fully support POLST in Arizona 23% are unsure 3% oppose POLST 58% likely to use POLST in their practice 77% are interested in education and training on POLST(86% among those who care for patients at EOL)</p>	<h3>MAID Attitudes</h3> <p>53% support MAID 27% oppose MAID 20% undecided 47% view MAID as slippery slope 37% view it violates oaths to administer lethal dose ArMA ethics committee divided on MAID 2018 Official ArMA position is opposed</p>	<p>Provide physician education on communication skills</p> <ul style="list-style-type: none"> • Primary Care • Hospitalists • Specialty focus • Do team based training <p>Educate the public on EOL issues</p> <p>POLST has broad support and is met with interest</p> <ul style="list-style-type: none"> • Provide education & training

Survey Sample

- Email survey sent to 8,000 members of ArMA, AOMA AzACP, MCMS, PCMS; Oct – Dec 2017; Results shared 3/2018
- 588 responses; 466 completed entire survey; margin of error 4.5%
- Funding provided by private donor; professional pollster engaged
- Population Sampled: Physicians interested in EOL issues
- Demographics: 22% 25-45 years; 50% 40-65 years, 28% 66+ years
- Geography: 58% Phoenix area, 25% Tucson; 17% rural/other
- Specialty: 36% Primary Care, 26% Internal Med, 11% Gen Surgery, 6% Pediatrics/OB, 5% PC, 18% Other
- Practice Setting: 29% Hospital; 33% Clinic/Office; 9% Both; 16% Academic; 13% Other
- Training in Palliative Care: 19% Significant; Limited 29%; None 52%
- **68%** care for patients near EOL

Selected Quotes from AZ Survey Open Ended Questions

Patients with terminal illnesses in this society where individuals bear a significant financial burden of responsibility who have decided they have come to peace with their illness should not be trapped in their life. Some chronic illnesses may provide such poor quality of life without acute decompensations significant enough to result in death, resulting in a prolonged process. This drawn out process prevents patients from having the control of inviting their loved ones to join in their last moments due to the likely low likelihood that their children live locally and the high cost of travel. A controlled dying process also allows family members and care givers to appropriately plan their grieving process as well as arrange finances associated with death. Generally, it's good to be allowed to live, but it's good to be allowed to die as well. After all, we are supposedly the land of the free, right?

Expectations of general public regarding terminal illness, severe sudden illness, especially in the elderly patient need to be addressed if we are to contain costs and provide meaningful care. As an ED physician, I find that often the patients I spend the most time and resources on to try to "save" per family request to "do everything " are the one's that I know from the beginning have little to no chance of meaningful recovery. Other patients care gets delayed, nursing and ancillary services are unable to tend to other patients. These patients end up with multiple painful procedures and go to ICU and the die or go to hospice in a day or two anyway. But our society and media expect that everyone can be "fixed". I feel guilty when a dying patient's family demands I continue to resuscitate them because they don't understand that the problem cannot be fixed and the patient will never recover. Usually these families have never discussed death and dying

Reforming ALTCS so that hospice patients can receive immediately upon enrolling in hospice if they have Arizona Medicaid. I have seen such suffering from lack of availability of placement options for dying patients. It is immoral and inhumane.

I think that basic palliative care practices, such as the POLST, should be in place prior to aid-in-dying legislation. 99% of patients who get good palliative care do not utilize aid-in-dying, so we should put our efforts into improving palliative care services before enacting aid-in-dying legislation.

Insurance companies benefit by hastening the death of seriously ill patients, and once this is a legal option it has the opportunity for misuse. It can also be misused by unethical doctors. I had a family member who was in remission, and who was inappropriately declared DNR and labeled as "dying from malignancy"--in an effort to cover up a medical error. We transferred her care, and she lived cancer free for 8 years. Had there been an option, I fear it would have been misused.

Some conditions are very difficult to watch as physicians when we cannot change the course of suffering. The conversation in the community at large is very important to help all of us decide how to approach end of life care. As a hematologist, I see a lot of suffering around cancer therapy and prolongation of suffering. I would like to see more people talk about alternatives to "go for a cure no matter what" because some suffering is worse than death, especially after bone marrow transplant that results in GVHD and a long painful death. It's a good thing to talk about this for all of us.

Thank you for addressing this topic in a progressive manner, 2) ensuring healthcare is truly patient-centered means that these options need to be available and ultimately supporting patients' as they assess treatment options or choices for palliative care. 3) this also requires ensuring patients have access

to specialists in this area and truly have primary care providers that actively include these services in their practice.

Public education is key. Death is a part of life. Too often that fact is completely ignored and patients and their families come ill prepared to adequately deal with a serious/terminal illness.

Oncologists need to refer pts to hospice/palliative care much sooner in the disease process and not leave this up to the pcp. The oncologists have a vested interest in keeping pts on therapy which is futile.

I am an Emergency Physician. I am usually the first person to discuss these things with terminal patients despite them having Primary Physicians and Oncologists!!!!!!!!!! It is appalling that this important duty gets dumped on ED Docs who are rushed and have no prior relationship with the patient or family. The worst offenders are Oncologists. These issues should be part of every Primary Care and Heme Onc practice BEFORE the patient winds up in the ER!!!!!!

I work in the Emergency Department, so many of the patients are admitted and have the follow-up discussions and discharge planning completed with the inpatient team. In the emergent setting, we can work with families to change a patient's status to DNR/DNI or move to a comfort care trajectory and sometimes can get our case management team to help find placement with inpatient or home hospice, but most of those discussions happen outside of the Emergency Department. We can help move the trajectory for goals of care in that direction, but it's often provider dependent - based on level of comfort or what they feel falls into the purview of Emergency Medicine. Clearly, so me of us are more progressive in that regard.

I am comfortable with death and dying as part of my medical practice. I am more concerned about the use of palliative care in an unbalanced presentation where pts are given dismal prognostic information from the palliative care provider that may not be accurate, or advised to join palliative care for the financial benefit of involved parties (ie, risk groups saving money by not treating a condition).

The single most helpful thing we could do is educate the public. As a critical care physician I prolong the dying process in futile cases on a regular basis due to lack of patient and family understanding of what "full code" means. When I meet with them in the ICU after a family tragedy they are in a state of shock. It is difficult for them to understand what I am saying and make decisions in that state.

Patients have no idea how likely they are to recover from a code arrest. They only know what they see on TV/movies where 97% of patients recover after seconds of CPR and wake up! Education must be done that this is not a realistic expectation and most of the time people die when they code, especially those with a long-standing illness.

Even though I am a Catholic, and a physician, I think that if death is inevitable, there is little benefit in prolonging it with medical technology, in order to gain a few more days or weeks of life that will be mostly miserable. As a person, I would like to have the option to die at home, with a physician's help, legally, if I am terminally ill and I am suffering., should I choose to do so. I should not have to travel to another state. The option should apply to all of us, with the proper safeguards, as has already happened in Oregon.

As a practicing physician, I realize that many people (including physicians) fear dying more than anything else. People do not want to think about death or talk about it with anyone. Yet, dying is an expected and natural part of our life cycle. It is certainly less common than a hundred years ago because of improved medical care. However, it now seems that dying in the 21st century has become equated with failure or because of a mistake by some physician or insurance company that does not authorize a test or treatment. It seems there is a pervasive yet unspoken attitude that enough money will buy you life and time on earth in this culture. Death has become optional and negotiable. Spiritual and emotional concerns do come into play because they are too painful to think or talk about. Avoidance and denial help to kick the proverbial can down the road to the next subspecialist who can offer a treatment. I really believe these attitudes and practices are harmful to patients and physicians. What can each of us do? Would education for patients and physicians help? Would stronger data than we currently possess on complex conditions, comorbidities, and treatments make a difference and help with discussions and decisions? Would the development of a "quality of life vs. quantity of life" index be useful in conveying information to patients and families? Would a law requiring all adults to possess an advance directive in order to carry health insurance spur conversation and thought on these issues? We owe it to our patients and ourselves to improve the way we talk about death and ensure humane and compassionate care in the end.

Care needs to be taken regarding prognosis. Medicine can be insidiously seductive for practitioners. For example, I received several terminal diagnoses, yet am still alive 30 years since the last one. Also, my wife has been told she would die within days on five-six different occasions since we have been married. Her last "terminal" prognosis occurred seven (7) years ago and came from a panel of MDs at the Cleveland Clinic.

The one thing that all patients (and all persons) have in common is death. We all won't have the same disease journeys, but we will all die. There are enough doctors trying to prolong life, but sometimes they are so focused on prolonging life that they forget about the soul of the person. I am proud to be a palliative care specialist, so I can help as many persons as possible experience a good death. I am strongly in favor of medical aid in dying, and would be willing to provide lethal prescriptions, assuming the legal, medical, and psychological requirements have been met.

Dying is part of living. Any competent adult patient should be able to choose the death that is best for them and their situation, regardless of underlying illness. Who better able to help patients with this than trained physicians? Current official opposition to this (e.g. AMA, state laws, etc.) is only based on people pushing their own, poorly thought-out "morals" onto others who deserve better.

I see horrible suffering from terminal illness. Families suffer watching loved ones slowly die. It is an emotional and financial strain. People who have decision making capacity w terminal illness should be able to choose to end their suffering when it is too much.

It is not the right thing to do. Doctors who want to be trusted that they care for and value life should not be agents of willfully accelerating death. Just because something is possible does not mean it should be done.

Not enough physicians and advanced practice clinicians know exactly what palliative care is. They think it is end of life care which it is not. Even the title of this survey is misrepresentative. Palliative care is about helping patients with serious illness live better. It is also difficult for me to answer these questions as they are worded since palliative medicine is my specialty and it is 100% of what I do.

3. MEMBERS OF TASK FORCE

Members

- Ron Fischler MD, Pediatrics; Honor Health, Task Force Chair, Phoenix
- Paul Stander MD, Geriatrics/Palliative Care; VA Phoenix /Education Chair, Phoenix
- Tim Fagan MD Internal Medicine (retired), Survey Chair/ Policy Co-Chair; ArMA Board; Tucson
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- Chip Finch DO Emergency Medicine Honor Health, Education and Policy Co-Chair
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- Ingrid Garvey ArMA Staff
- Susan Brown ArMA Staff
- Pete Wertheim AOMA Executive Director, Phoenix

Liason

- Sandy Severson VP Arizona Hospital and Healthcare Association (AzHHA) Director Thoughtful Life Conversations; Administrator Lovell Grant

4. SERIOUS ILLNESS CONVERSATION GUIDE

Serious Illness Conversation Guide

CLINICIAN STEPS

☐ Set up

- Thinking in advance
- Is this okay?
- Hope for best, prepare for worst
- Benefit for patient/family
- No decisions necessary today

☐ Guide (right column)

☐ Act

- Affirm commitment
- Make recommendations about next steps
 - Acknowledge medical realities
 - Summarize key goals/priorities
 - Describe treatment options that reflect both
- Document conversation
- Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding

What is your understanding now of where you are with your illness?

Information preferences

How much information about what is likely to be ahead with your illness would you like from me?

FOR EXAMPLE:

Some patients like to know about time, others like to know what to expect, others like to know both.

Prognosis

Share prognosis as a range, tailored to information preferences

Goals

If your health situation worsens, what are your most important goals?

Fears / Worries

What are your biggest fears and worries about the future with your health?

Function

What abilities are so critical to your life that you can't imagine living without them?

Trade-offs

If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family

How much does your family know about your priorities and wishes?

(Suggest bringing family and/or health care agent to next visit to discuss together)

Draft R4.3 5/22/15

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Talking with your clinician about the future

At your scheduled visit, your clinician would like to talk with you about your illness, your goals and wishes, and planning for the future. This is an important part of the care we provide for all of our patients.

Our team likes to start talking about this when patients are doing okay. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Patients who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

Before your next meeting

Please prepare for your conversation by thinking about these things:

- What would you like to know about your illness and what is likely to be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- What are you afraid of about your illness?
- What kinds of medical care do you not want?
- What do you think it would be like to share these thoughts with your family?
- If you haven't already identified a health care proxy, who would be able to fill that role?

Please bring to your visit:

- If you have a health care proxy form that is not on file at the hospital, *please bring a copy*.
- If you have a living will or advance directive, *please bring a copy*.

If you don't have these documents or have questions about them, talk to your clinician.

Why is this important?

Thinking about and sharing your wishes will give you more control over the care you get. It will also help prepare your loved ones to make decisions for you if you can't make them at some point in the future. Knowing what you want will ease the burden on your family of making hard decisions for you if you can't speak for yourself.

Talking about the future won't change your ongoing care

Talking about the future won't change the plans we have made so far about your treatment, unless, of course, you want to. We will keep providing the best possible care to control your disease.

You may find it helpful to bring other people to your next appointment

You can choose to bring the person who is your health care proxy or other family members to your next visit so they can be a part of the conversation. You can also bring your nurse practitioner, social worker, or chaplain if you like. Please let your clinician's office know if you would like to bring others to the appointment.

We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions.



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Serious Illness Care Program

Reference Guide for Clinicians

Key Ideas for successful discussions about end-of-life care:

► Principles

- Patients want the truth about prognosis
- You will not harm your patient by talking about end-of-life issues
- Anxiety is normal for both patient and clinician during these discussions
- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- Giving patients an opportunity to express fears and worries is therapeutic
- Titrate conversations based on patient's responses (especially anxiety)

► Practices

Do:

- Give a direct, honest prognosis when desired by patient
- Present prognostic information as a range
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears, and concerns
- Make a recommendation ("Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend....")
- Document conversation

Do Not:

- Talk more than half the time
- Fear silence
- Give premature reassurance
- Provide factual information in response to strong emotions
- Focus on medical procedures

APPENDIX

Federal Legislation in Support of Improving End of Life Care

We recommend ARMA support ongoing efforts at the federal level to address the issues of workforce and education to increase overall access to palliative care for all. We support PCHETA, the Palliative Care and Hospice Education and Training Act (H.R. 1676 and S. 693). This would expand opportunities for interdisciplinary education and training in palliative care, inform patients and health professionals about the benefits of palliative care and the services available to support patients with serious or life-threatening illness, and direct funding toward palliative care research to strengthen clinical practice and health care delivery.

We also recommend support for Patient Choice and Quality Care Act of 2017 (H.R. 2797 and S. 1334). This creates a new Medicare model for Advanced Illness Care and Management to enable eligible individuals to voluntarily engage in team-based planning to align their goals of care, values, and preferences with their care. It facilitates increased coordination and alignment between public and private sector quality measures. It improves Medicare's existing coverage for ACP services by allowing appropriately trained or experienced clinical social workers to provide ACP services, and ensures copay costs are not a barrier to patients. It also ensures patients and providers have needed support tools and that advance directives follow patients across clinical settings and states.

Finally, we recommend consideration of support for other pertinent federal legislation, including Medicare Choices Empowerment and Protection Act of 2017 (H.R. 3181/ S. 1530) allowing a financial incentive to Medicare beneficiaries to complete an advance directive, Credit for Caring Act (S. 1151) allowing tax credit for caregivers, Rural Access to Hospice Act (S. 980) affecting payment reform increasing access to rural hospices, Veterans Caregivers Act of 2017 (S. 1618) for assistance for veterans' caregivers, Independence at Home Act of 2017 (S. 464) to increase access to home-based interdisciplinary primary care to Medicare beneficiaries, Alzheimer's Caregiver Support Act (S. 311) increasing caregiver training and support for patients with Alzheimer's, Removing Barriers to Person-Centered Care Act of 2016 to establish an alternative payment model for patient-centered care for Medicare beneficiaries with advanced illness, and the Compassionate Care Act which would support a national campaign to inform the public of the importance of life care planning and an individual's right to direct and participate in health care decisions.

Emmalee Kennedy MD

5/8/2018

ArMA/AOMA End of Life Physician Task Force

Physician Survey

January 11, 2018

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Introduction

- **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”

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Introduction

- **Methodology (cont.)**
 - More likely to be those who are engaged with or are interested in EOL issues
 - More likely to be primary care than “all physicians in Arizona”
 - More likely to be in palliative medicine than “all physicians in Arizona”
 - We have 5% reporting that they are specialists in PM
 - Just keep “those who are not in the room” in mind and consider whether they are:
 - As engaged in EOL care
 - As confident or comfortable with these issues
 - As interested in education, resources

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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 $\pm 4.5\%$ 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”)

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Research Goals

- **Set out to examine:**
 - **Physician attitudes towards End of Life (EOL) discussions**
 - **Physician knowledge of, and access to, Palliative Care**
 - **Physician interest in education on these issues**
 - **Physician attitudes on Medical Aid in Dying (MAID) and POLST (Physician Orders for Life Saving Treatment)**

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Executive Summary

- **Those who are specialists in Palliative Medicine (PM) are more comfortable with patients in End of Life (EOL) situations and generally find their practice fulfilling and are more likely to feel that patients have “a good dying experience”**
- **There is wide interest in education and training among others, particularly those who have limited training already (and ‘frequently’ encounter EOL issues), as well as among younger physicians**

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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

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Executive Summary

- A majority support MAID by a 53%-27% margin
 - Recall that we have no way of speculating on the views of physicians who did not take this survey, i.e. those who are less engaged in EOL issues
- Support is strong for POLST in Arizona (66%-3%)
 - 35% are “very” interested (and 42% are “somewhat” interested) in further training on POLST

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Profile

- **Palliative Specialty/Training**
 - ✓ 5% PM Specialists
 - ✓ 13% Significant training in PM
 - ✓ 29% Limited training
 - ✓ 52% No formal training
- **Often are you caring for patients in EOL situation**
 - ✓ 31% Frequently
 - ✓ 37% Sometimes
 - ✓ 22% Rarely
 - ✓ 10% **Never** (not asked questions 3-14 about EOL care in their practice, began with perceptions of "Good Dying Experience")

Note:

- ✓ Our sample of physicians 25-65 was more likely to say they "frequently" see patients in EOL situations, those over age 66 were more likely to say "rarely"
- ✓ Physicians in a hospital/academic setting (41%) are more likely than those in an office setting (27%) to say they "frequently" see patients in EOL situations.

Q1. Which of these best describes you: You are a specialist in palliative medicine | Significant training/CME, but not a specialist in palliative medicine | Limited training/CME in palliative medicine | No formal training/CME in palliative medicine

Q2. How often are patients in your care who are in a later stage of a terminal illness or are in a stage of their life where they need to consider options for their final stages of life?

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Profile

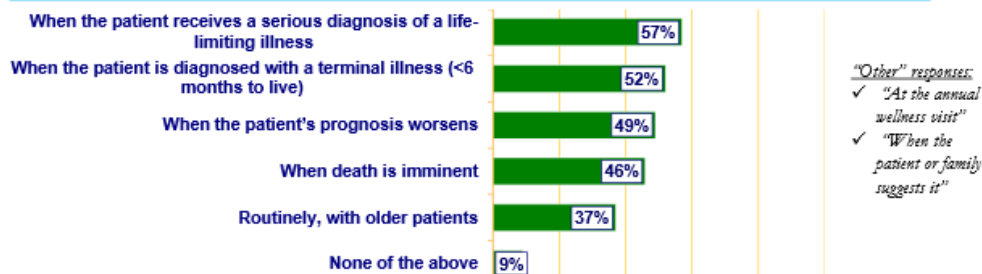
- **Specialty**
 - ✓ 36% Primary Care
 - ✓ 3% Pediatrics
 - ✓ 3% Ob/Gyn
 - ✓ 26% IM Subspecialty
 - ✓ 11% Surgery or subspecialty
 - ✓ 21% Does not apply
- **Geography**
 - ✓ 58% Phoenix area
 - ✓ 25% Tucson area
 - ✓ 7% Other City
 - ✓ 10% Town/rural area
- **Facility**
 - ✓ 29% Hospital
 - ✓ 33% Clinic
 - ✓ 9% Split time about evenly
 - ✓ 16% Academic center
 - ✓ 3% IHDS
 - ✓ 3% FQHC/Rural Health
 - ✓ 5% Does not apply
- **Age**
 - ✓ 22% Age 25-45
 - ✓ 50% 46-65
 - ✓ 28% 66 or older
- **Gender**
 - ✓ 32% Female
 - ✓ 68% Male

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Landscape

11

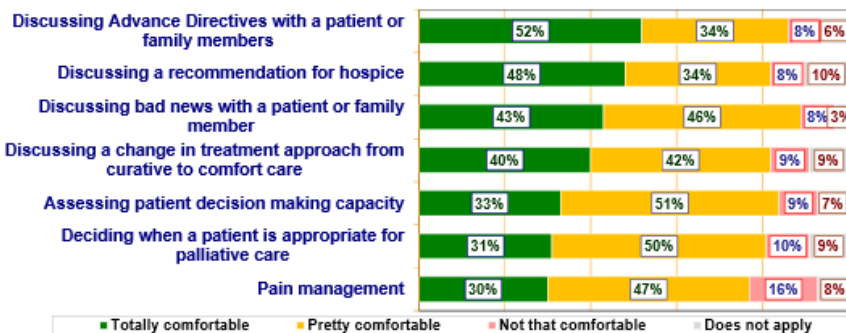
- Two-in-five (37%) “routinely” discuss EOL issues with patients, versus between 46%-57% who do so when the patient’s situation is considerably worse.
- 60% of those who ‘frequently’ care for patients in EOL situations discuss these issues “routinely”, versus 36% of those who do so ‘sometimes.’
- Physicians 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).



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

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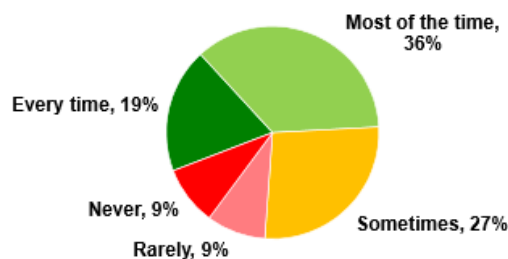
- Between 30%-50% of physicians are “totally” comfortable addressing a range of EOL care issues, with the lowest level of comfort regarding pain management, deciding on palliative care and assessing patient decision making capacity.
- Comfort levels are considerably higher for those with higher levels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



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

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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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- Nearly three-quarters report they can refer (72% and 70%) to palliative care or hospice in the hospital (72%) or outpatient facilities (70%).
 - Among those who 'frequently' see patients in EOL situations, 88% say they can refer in the hospital and 81% say as such for outpatient.
 - 79% of physicians in a hospital setting say they have access to palliative care specialists in the hospital versus 69% of those in an office; 70% of each say they have access for non-hospital patients.

Access to palliative care or hospice in the hospital

Yes, 72%



Access to palliative care or hospice for non-hospital, outpatient

Yes, 70%

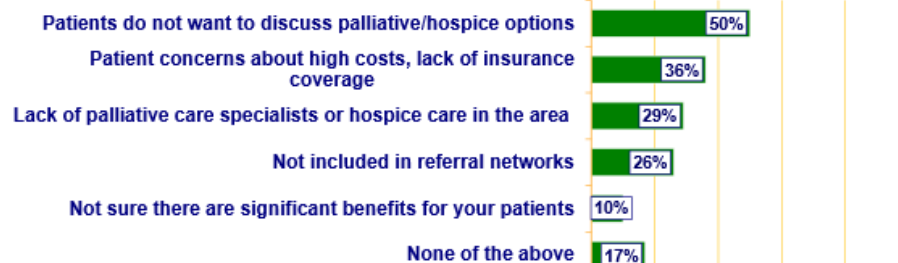


Q12: Do you have one (or more) palliative care specialists, or hospice, that you can refer to for your patients in the hospital?

Q13: Do you have one (or more) palliative care specialists, or hospice, that you can refer to for your outpatient, non-hospital patients?

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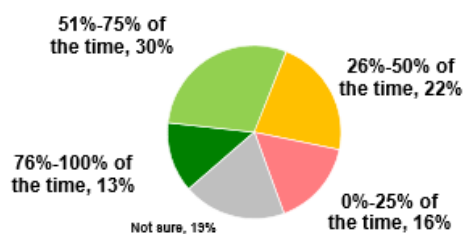
- Patient unwillingness to discuss end-of-life care issues, followed by concerns about cost and coverage, are seen as the primary barriers to these referrals.
 - Specialists in PM agree that patients' attitudes are a barrier, but are less likely than others to cite concerns about high cost.
 - Physicians age 25 to 45 are much more likely with 63% than 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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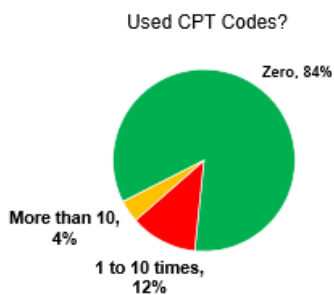
- There is little consensus as to how often patients have a “good dying experience.”
 - Among those who ‘frequently’ deal with patients with EOL issues, 58% believe a good dying experience happens at least half the time; among specialists in PM, 77% say as such, and among those with at least some formal training 65% believe as much.
 - Physicians in a hospital are split 41% to 42% on whether a good dying experience happens at least half the time or less often, versus physicians in the office setting who say so by a 48% to 33% margin.



Q13: A “good dying experience” has been described as having the following conditions: expected death, symptoms controlled, family members present, family’s wishes in accordance with patient’s wishes. If you had to estimate, about what percent of the time does this “good dying experience” actually happen for your patients?

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- 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.



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=57)

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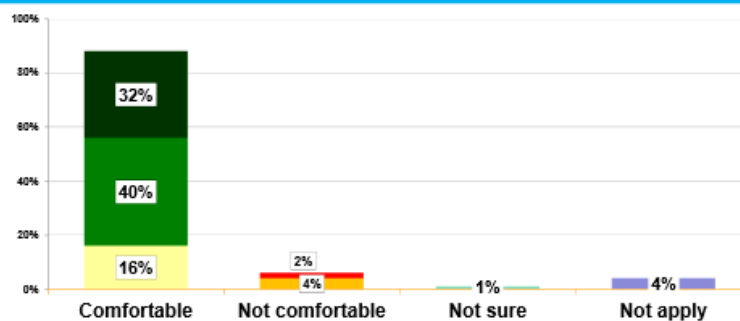
- One-third (34%) say that they do not feel deterred from having conversations with patients about end-of-life care issues, while 28% cite “family expectations” and 22% cite “patients” not being ready.
- Among those with some formal training, 52% do not feel deterred versus 38% of those with limited 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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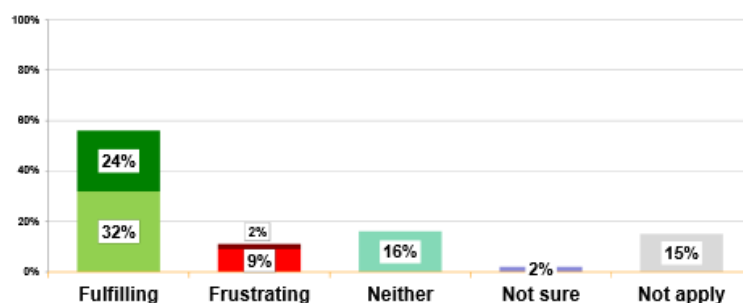
- Three-quarters (72%) are “completely” (dark green) or “mostly” (light green) comfortable, with another 16% “somewhat” (yellow), having EOL discussions.
- Specialists in PM are far more likely to say they are “completely” comfortable, followed by those with at least some training (others tend to say “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.)

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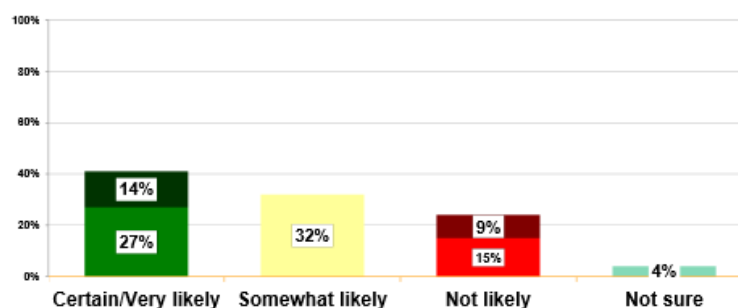
- Overall, 56% say their experiences treating patients at the end of life are either “very” (dark green) or “somewhat” (light green) fulfilling.
- Those who are specialists in palliative medicine are far more likely to say “very” fulfilling versus “somewhat” fulfilling.
- Among those who ‘frequently’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

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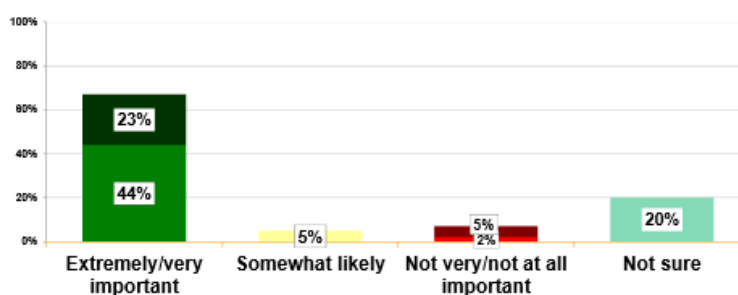
- Two-in-five (41%) say they would be “certain” or “very likely” to use webinars or other resources, with another 32% “somewhat” likely to do so.



Q21: Some have suggested that physicians, and particularly primary care physicians, need support and ongoing training through their careers on talking to patients about their plans and priorities for end of life care. How likely would you be to utilize webinars, trainings, connection to expert resources, connection to peers or other such resources focused on helping providers better address end of life care issues with their patients?

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- Two-thirds (67%) say it is “extremely” or “very” important that there be greater education of the public around EOL care, while just 7% say “not very” or “not at all.”
- Among those who ‘frequently’ care for patients in EOL situations, 81% say “extremely” important (with another 15% saying “very” important).
- Those age 25 to 45, as well as females and physicians in the hospital, are more likely to say “extremely” important as well.



Q22. Some have also suggested that there needs to be greater education of the public around end of life care, such as a public awareness campaigns on the need to have conversations about difficult issues with your doctor, or the importance of Advanced Directives and health care Power of Attorney, etc. How important is this type of public awareness and education in your view?

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Introduction to MAID

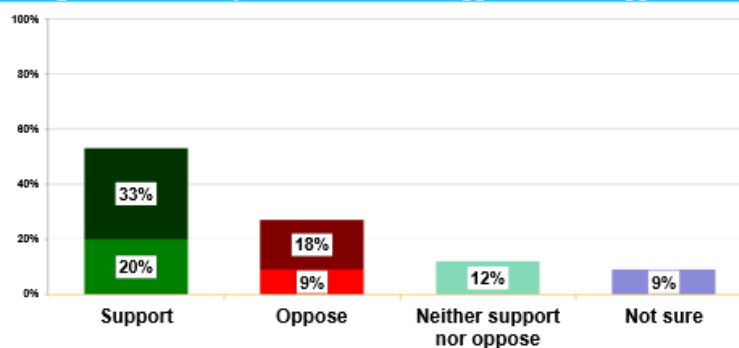
"These questions will ask you about Medical Aid in Dying.
Medical Aid in Dying is the clinical process whereby a terminally ill adult with sound decision-making capacity may ask for and receive a prescription medication they may self-administer to hasten death.

The California medical aid in dying law contains the following criteria and safeguards, including:

- The Primary physician and a consulting physician agreeing that the patient has a terminal illness;
 - 2 oral requests and one written request for a lethal prescription, with at least 15 days between the first and second oral requests;
 - Proof of California residency;
 - Counseling/Psychological evaluation if there is a question as to the patient's ability to make an informed decision;
 - Informing the patient immediately prior to receiving the medication of the right to rescind the request;
 - Extensive documentation requirements.
 - Liability protection for physicians who choose to prescribe the medication.
- There is no mandate for all physicians to participate in Medical Aid in Dying"

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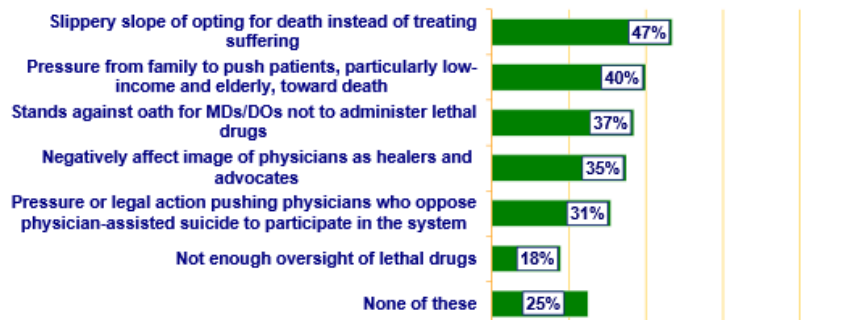
- A majority of physicians in our survey report that they support MAID, versus 27% who are opposed (including 33% who “strongly” support and 18% who “strongly” oppose).
- Among those who ‘frequently’ encounter patients in EOL situations, 49% support and 30% oppose, similar to the 51%-27% margin among those who ‘sometimes’ do; among those who ‘rarely’ or ‘never’ do, 62% support and 21% oppose MAID.



Q23: Do you support or oppose Medical Aid in Dying being legal in Arizona (modeled after the California Law), neither support nor oppose, or are you unsure at this time?

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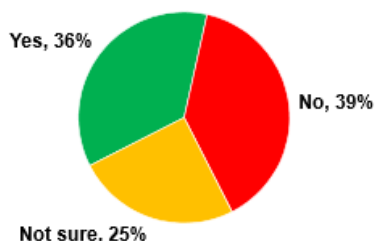
- After seeing a list of potential concerns, between one-third and one-half are concerned with a range of potential impacts of MAID in Arizona, while relatively few are concerned about “oversight of lethal drugs.” One-quarter (25%) say “none” of these.



Q25: The following is a list of some concerns that have been expressed by some physicians about laws legalizing Medical Aid in Dying. Please check any concerns that you also share, and please comment in the space provided.

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- Approximately one-third (36%) say they would be willing to write a prescription for a lethal dose, while 39% said they would not and 25% are unsure at this time.



Q26: Personally, would you be willing to write a lethal prescription for a terminally ill patient if all legal requirements were met?

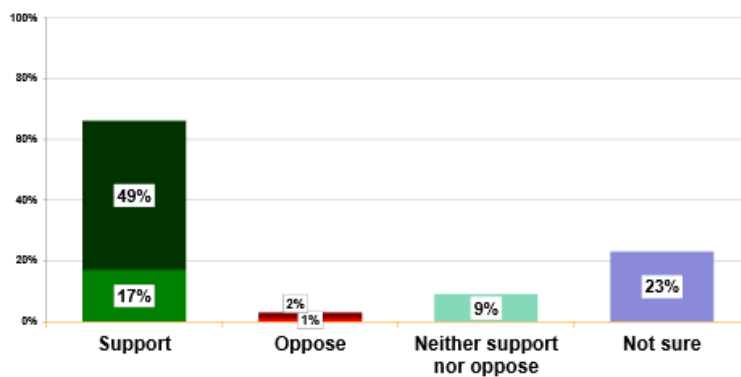
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Introduction to POLST

"POLST (Physician Orders for Life Saving Treatment) 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."

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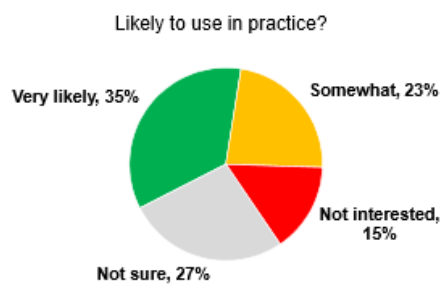
- Fully 66% support POLST in Arizona, while just 3% are opposed (and the remainder neither support/oppose or are unsure at this time).



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

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- 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.



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

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Conclusions and Recommendations

31

Conclusions

- Value of education, training is clear
 - Higher comfort levels with EOL care
 - Greater frequency of referrals to PM/Hospice
 - More likely to say they see “good dying experiences”
- Desire for education, training in specialties that touch these issues with their patients on a regular basis, especially those who have had limited training
 - Younger physicians broadly are also more open to training and education
- Core barriers
 - Patient, family attitudes
 - Cost and access to palliative services, hospice

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Recommendations

- **Education**
 - **Physicians**
 - **Convene different specialties**
 - **Provide training, resources**
 - **Public, patient messaging**
- **Advocacy**
 - **Access, coverage for all patients who need these services**
 - **Value of these services**

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Recommendations

- **MAID has majority support, but one-quarter (of the physicians we surveyed) are opposed, and a greater number have concerns**
 - **Clarification/information about the California experience (and other evidence) might be welcome for those still on the fence, or “softly” in support or opposition**
- **POLST has broad support and is met with specific interest in seeing further education and training**

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MEMORANDUM

TO: Ronald Fischler, Mandy Weaver, Tim Fagan
ArMA/AOMA End of Life Task Force
FR: Benjamin Kupersmit
RE: Survey Research Proposal
DT: January 11, 2018

As a supplement to the presentation, we are providing the following (more detailed) Strategic Recommendations to help spur further discussion and planning:

I. Physicians and EOL Care

A. Physician education, training, webinars, toolkits for practices, etc.

1. "At the annual wellness visit"...this should be universal among PCPs/FPs. "Are you waiting for the patient to take the lead? You might wait a long time" message to spur action and "frame" the campaign.
2. Clearly interest in ideas for engaging patients, families in these conversations
3. Make resources available through their medical societies
 - Short, to the point, and useful
 - Promote them with a table at the conferences/meetings as appropriate
4. Opportunities for mentoring from older to younger physicians

B. Convening

1. Primary care with specialties (oncology, palliative, etc.) on the way PM, hospice fit into a "team based approach" to help bring about more "good dying experiences"
2. PM specialty needs to do a better job explaining its function and benefit to other physicians
 - Hospice providers might be well served by educating physicians about how they manage patients and the role of prescription drugs in particular
3. ED with other physicians

C. Advocacy

1. Payers, hospitals to recognize the value of palliative care and hospice and the overall importance of EOL care and conversations in driving better outcomes, higher patient satisfaction, etc. over time
2. Legislators, to raise awareness of these issues in the broader context of EOL care

II. Public education campaign

- A. Goal: is to “set the table” for the annual visit conversation, so patients expect and know that these conversations are happening and are common/expected at a certain age (reduce the stigma)
- B. Approach: Patient literature in the office that would support this message (ideally backed with a substantial effort in paid or earned media, including social media)
- C. Need to identify the stakeholders that would support such an effort in the EOL provider community, as well as among public health or patient advocacy organizations (or others)

III. MAID

- A. This is not an election, not a “majority wins” question
- B. Need to have a strategy for each med society, component society (as well as the Task Force) if voters or the legislature passes MAID
- C. Recommendations/thoughts
 1. Have trusted (evidence-based) information sources are available to physicians
 2. Identify and respond to concerns – especially about protections for patients and physicians – as best you can
 3. Be prepared with recommendations for legislators, regulators and other stakeholders who will be turning to medical societies for expertise, guidance

IV. POLST

- A. Very popular, should have broad support for passage
- B. Solid initial base of physicians who work in EOL issues
 1. Will be seeking training and resources (webinars, FAQs, etc.)
 2. Perhaps could be explained a bit more clearly moving forward with better “marketing” language for that website/set of resources

Articles Published or Pending

End of Life: The importance of the Doctor/Patient Conversation

By Paul E. Stander, MD, MBA, FACP, and Ron Fischler, MD, FAAP

More patients want greater control about their care at the end of life.

There has been growing interest in end of life care issues in the United States in recent years both in the medical literature and in the popular press. Many individuals in both the medical and lay communities have come to question the “traditional” medical approach that provides aggressive treatment for the elderly and others with serious, life-limiting illnesses, even if such treatment may be largely ineffective or even harmful and potentially prolong suffering while increasing health care costs. The reason that this approach is sustained is multifactorial and driven in part by our highly litigious healthcare environment, fee for service reimbursement that rewards more interventions, and at times, by an inability of patients, families and doctors to accept the inevitability of death.

Numerous surveys and studies have shown that this approach can often be a source of dissatisfaction for many patients, families and providers. Our current situation is fortunately shifting in favor of eliciting the patients’ and families’ goals and priorities about end of life care with a focus on maximizing functional status and quality of life beyond solely prolonging life.

Most people have time to prepare but too few do it.

The leading causes of death and its trajectory have changed dramatically in the past 100 years, with most patients dying from one or more chronic illnesses and often having a slow progressive decline over several years before death. This period offers an opportunity to settle one’s affairs, make peace with important people and plan well enough to achieve a “good death,” often defined as one that is pain and symptom free, surrounded by loved ones and in a comfortable setting outside the hospital or ICU potentially with hospice services. Hospice programs have expanded greatly in the US since they were introduced in the early 70’s, although patients are all too often not referred until days before death.

Eliciting patient and family preferences and priorities is vital in order to successfully navigate the complex and often confusing choices patients face at the end of life with the ultimate goal being a good death. Achieving a good death starts with the awareness that, for the vast majority of patients, death does not represent a failure of medical care but an inevitable consequence of aging and the natural progression of one or more chronic conditions. Both patients and doctors have a lot of control over the choices they make when facing end of life decisions.

Atul Gawande, MD, a Harvard surgeon, noted in his groundbreaking book, *Being Mortal*, the importance of the conversation between physicians and patients to elicit patient wishes about what was most important to them at the end of life. Despite most patients and physicians agreeing that these conversations are important, they happen all too infrequently. There are many reasons for this, including lack of physician training in how to conduct such conversations, lack of time to conduct these conversations, concerns that patients and families may not be ready or will be upset when dealt unwelcome news, as well as concerns about reimbursement. There are now solutions to overcoming each of these barriers.

Only 30% of physicians report having been trained to have these conversations.

To overcome these barriers, Gawande, in conjunction with his quality improvement organization, Ariadne Labs, along with Palliative Care colleagues from the Dana Farber Cancer Institute have developed a structured methodology for training physicians on how to conduct such conversations. They developed a structured, seven-question tool called the “Serious Illness Conversation Guide” and conduct training sessions on the use of this instrument, ideally in the outpatient setting, for patients with a survival prognosis of one year or less. They conducted a randomized controlled trial involving oncologists from Dana Farber and published data showing that the use of this tool increases the effectiveness of serious illness conversations and reduces anxiety of clinicians and patients during these conversations (Bernacki et al, *BMJ Open* 2015; 5:e009032). They published further data demonstrating how formal training of primary care clinicians can increase the frequency of these conversations documented in the EMR (*Health Affairs* 2017;36 1258-1264).

The first steps in the conversation involve explaining the purpose of the conversation and asking permission to proceed, followed by a query of the patient’s understanding of their illness and prognosis (within a range). Identifying candidates for these conversations often comes down to the so-called “surprise” question: “would you be surprised if this patient died within one to two years?” Primary care physicians should also consider offering this discussion to older adults as part of their routine care as well as to those with a diagnosis of a potentially life limiting illness such as cancer, COPD, CHF, CKD, cirrhosis, dementia and other neurodegenerative diseases.

The next steps elicit the patient’s wishes, goals and priorities now that they understand their disease is not curable and life expectancy is limited. Once they articulate what they want and don’t want, patients can address their preferences regarding a variety of possible interventions like CPR, dialysis, tube feedings, et cetera. All this information is then recorded in the EMR or health record in a clearly identifiable location such as “advance directives.” If a patient’s wishes are elucidated, communicated to family and physicians, and documented in the record, there is a much greater likelihood that their wishes will be honored.

Dr. Angelo Volandes, a Harvard hospitalist, has expanded on informed decision making for patients nearing end of life. He has developed videos that illustrate medical procedures and treatments in order to make them real and more understandable to patients. Research found that patients who viewed his videos were more likely to choose less invasive treatments and accept palliative care earlier. Some patients will, after counseling, continue to want all disease-modifying efforts pursued and those wishes need to be respected as well. A Tucson ACO has recently purchased access to these decision-making videos.

Who should initiate the conversation?

One of the challenges of our increasingly complex and fragmented health care system is that specialist clinicians who do not have longstanding relationships with seriously ill patients are often put in the position of having to conduct these conversations during emergent or crisis situations. The primary care physician or outpatient specialist may not be involved during these circumstances so the responsibility for an end of life conversation often falls upon an emergency medicine physician, hospitalist or intensivist who have no prior relationship with the patient and family. These circumstances frequently results in less than optimal conversations and decision making.

The burgeoning field of palliative care is just over 10 years old and can be an extremely valuable resource for serious illness discussions and end of life care. Inpatient palliative care consults are available in most large hospitals but remain a challenge in most outpatient settings and emergency departments. It is therefore incumbent upon primary care clinicians, emergency medicine physicians, hospitalists, Intensivists and specialists who deal with patients with life limiting illness to improve their skills and willingness to conduct serious illness conversations

While some patients will prefer to continue to press on with aggressive intervention regardless of their prognosis, others facing a terminal disease with progressive debility will prefer an approach focused on symptom management and avoidance of potentially painful and hospital-based interventions. This may enable them to say their goodbyes and have time to enjoy their final days in comfort in familiar surroundings with family nearby. A landmark study published several years ago in the *New England Journal of Medicine* showed that, in a cohort of patients with Stage IV lung cancer, the use of palliative care improved quality of life, satisfaction by patients' families and providers, and even prolonged survival (Temel et al, *NEJM* 2010; 353: 733-42).

Physician and Public education on advanced care planning coming to Arizona

While efforts are being taken to increase the frequency with which physicians initiate these conversations, the general public is also encouraged to conduct conversations with loved ones before a crisis occurs. The Conversation Project (www.conversationproject.org) has developed a free online tool for patients that leads them through the steps in the conversation. They also encourage discussions regarding end of life issues at local places of worship (e.g. Conversation Sabbath) and other venues to encourage people to explore issues and concerns about death.

In order to address some of the challenges to end of life care in Arizona, last spring the joint ArMA/AOMA Task Force on End of Life Issues joined efforts with AzHHA and was awarded a generous grant from the Lovell Foundation to improve end of life care in our state. One of the strategies to help achieve this will be to conduct **clinician and public education on end of life care**. Specifically, training will be offered for physicians, nurses, other clinicians, social workers and others on improving communication with patients with serious and life limiting illness.

The Ariadne Labs methodology will form the basis of this training to be offered in two hour sessions across Arizona. These sessions will be conducted by practicing clinicians with use of role plays followed by ongoing follow up and coaching. The training is designed to enable clinicians to conduct these conversations with their patients in an approximately 15-20 minute time frame to make it practical within a busy office-based practice setting.

Public education under the grant will also be offered statewide through the collaboration with community non-profit service agencies and faith based organizations

LOOK FOR PUBLICITY IN YOUR HOSPITAL, MEDICAL ASSOCIATION AND IN THIS JOURNAL FOR ANNOUNCEMENTS ABOUT REGIONAL OFFERINGS. CME CREDIT WILL BE AWARDED and the training is provided at NO COST.

For more information about training for physicians or public, contact Karen Beckford at AzHHA who coordinates this project: kbeckford@azhha.org.

Paul E. Stander MD, MBA, FACP is Associate Chief of Staff for Geriatrics at the Phoenix VAMC and was Chief Medical Officer at Banner Good Samaritan and has worked with Hospice of the Valley for many years. He is Clinical Professor of Medicine at the University of Arizona - Phoenix College of Medicine. Ron Fischler, MD, is a pediatrician in Scottsdale who has held leadership roles at Scottsdale Healthcare and in the Arizona Academy of Pediatrics and Arizona Medical Association and chairs the Joint ArMA /AOMA Task Force on End of Life Care. He is an Associate Clinical Professor at the University of Arizona College of Medicine.

End of Life Care in Arizona - Where Do We Go from Here?

The Joint ArMA/AOMA Task Force on End of Life Issues

D was a 69-year-old male who developed renal cell carcinoma with lung and bone metastases at the time of diagnosis. He was treated with chemotherapy and radiation therapy with partial response and many complications, including serious, and ultimately intractable, pain. I visited every other week and we discussed life, death, and choices. He pursued chemotherapy and other efforts to extend life as long as possible, fully aware of the complications, and made the choice to endure them. He used his time well, but when he could no longer function, and pain was particularly difficult to manage, he enrolled in hospice and died peacefully shortly thereafter with family at his side, approximately two years from original diagnosis. His last question to his oncologist was, "Why didn't you tell me it would be this bad?"

Ron Fischler, MD

Despite his incurable illness and untimely death, Ron's friend was fortunate compared to many Americans who succumb to life-limiting illnesses. He had a friend with medical expertise to help with the complex and confusing choices that patients face at the end of life; however, he died wishing he had better communication with his oncologist. He maintained a large degree of control over the type, amount and settings in which his care was provided, and ultimately died peacefully at home surrounded by loved ones.

Sadly, many Americans experience circumstances where their choices for care at the end of life are unheard or overlooked and often end up dying with poorly controlled symptoms in hospitals or nursing homes. Why does this happen and what can we as physicians in Arizona do to improve end of life care for our patients?

By the late twentieth century the impression that technology could stave off dying became very powerful and

to many in the medical establishment, death became equated with failure, rather than as a natural inevitable part of the life experience. Discussing death or providing a negative prognosis became virtually taboo under the false premise that providing honest information would destroy hope for both patients and their families.

The American health care system remains heavily focused on sophisticated acute inpatient care and is woefully inadequate to address the needs of frail elderly patients with multiple chronic conditions who comprise a majority of those who die in the United States, particularly as the Baby Boomer generation ages. "As an Emergency Medicine physician, I am saddened at how many patients end up in the [Emergency Department] when they would be far more humanely served in a palliative or hospice care setting," states Alan Molk, MD.

A substantial percentage of Medicare spending continues to occur in the last six months of life, often on interventions

that provide little or no benefit, which is neither clinically appropriate nor financially sustainable. There are myriad reasons for this, including “perverse” financial incentives that favor more care, regardless of the chance of benefit; perceived legal risks for physicians who do not acquiesce to “do everything,” even when they believe such efforts are futile; avoidance of advance care planning; and lack of understanding by both patients and physicians alike of the role and benefits of palliative care and hospice and/or the availability of such services.

Jud Tillingshast, MD, a retired critical care specialist reflects, “Addressing the difficult questions surrounding end of life is a daily problem in the ICU. I have seen family members divided and agitated, demanding aggressive care even if it only prolongs a patient’s suffering. We need more physicians (primary care, specialists, hospitalists and critical care) to communicate clearly and sensitively with patients facing a terminal condition, with assistance from the palliative care team, to help families honor the wishes of their loved ones and ideally to do this before a crisis occurs that results in the ICU admission.”

Many of the deficiencies in end of life care in the United States, and possible solutions, were highlighted by the Institute of Medicine in its 2015 report, *Dying in America*. A key message for physicians was to initiate advance care planning discussions as early as possible for individuals with serious illness. This is a role that most physicians fail to address, most often citing lack of time, inadequate reimbursement and inadequate training. Furthermore, when they do conduct such discussions and prognosticate regarding survival, physicians tend to be overly optimistic and overestimate life expectancy in order to not decrease their patients’ hope, which may be well-intentioned but is usually counter-productive.

Cottonwood cardiologist Bruce Peek, MD, states: “How we assist patients and their families during the dying process is just as important as how we assist them to prolong life. Educating patients and families regarding the nature and prognosis of their disease throughout the course of their illness, and eliciting their goals and preferences along the way is essential to what we do.”

The increase in palliative care programs and the recent emergence of hospice and palliative medicine as a recognized medical specialty have been beneficial. “Palliative care is specialized supportive care for people with serious illnesses and is provided by a team of doctors, nurses and other specialists. Unlike hospice care which is indicated for patients with a life expectancy of 6 months or less, palliative Care is focused on providing comfort and appropriate at any stage of a patient’s illness to help with symptom management, address psychosocial and spiritual aspects of illness, and define and meet patients’ and families’ goals of care,” explains Stacie Pinderhughes, MD, Director of Palliative Care at Banner Health. “Numerous studies have demonstrated that the involvement of Palliative Care teams can increase patient and family satisfaction with their care and a landmark study in the *New England Journal of Medicine* demonstrated that Palliative Care services reduced the incidence of depression and actually prolonged survival

in patients with advanced lung cancer.”

Still, major gaps in end of life care persist. Many patients today also want more options as they face the end of life. This has fueled efforts and passage in numerous states of so-called “Medical Aid in Dying” or “Death with Dignity” legislation that provides a legal framework for physicians to prescribe medications by which patients with terminal illness can end their lives.

The Task Force on End of Life Care created by the Arizona Medical Association (ArMA) and the Arizona Osteopathic Medical Association (AOMA) is a multispecialty group of physicians from around Arizona. The mission of the Task Force is to assess the state of end of life care in Arizona and offer practical options to improve care for patients across our state. The group initially prioritized three areas:

1. **Education.** How can we provide effective, convenient and accessible educational efforts for both physicians and the public, and to help physicians increase their skills in end of life care? We also want to determine the level of interest of primary physicians, hospitalists, and specialists in Arizona if such training were made available.
2. **Access to Palliative Care.** How can we assist to increase the availability and accessibility to hospice and palliative care services for patients across Arizona, and to enable advance care planning to occur earlier when it may be more beneficial?
3. **Policy.** Assess Arizona physician attitudes regarding Aid in Dying legislation and other end of life care issues which may be subject to legislative efforts.

The first goal of the Task Force is to gather as many physician views as possible on these issues. To that end, the Task Force will send a survey to as many Arizona physicians as possible. Your feedback will help us transform the care our patients receive at their most vulnerable time in life. As Carla Denham, MD, a psychiatrist and member of the Task Force, observed, “I was not really surprised to learn that conversations about death and dying are often rewarding to patients and their families, since they frequently help to reduce fear and clarify treatment goals. What was surprising was how those same conversations alleviated my own fears as well.”

To learn more about the Task Force and its members, view article references, or to sign up for updates from the group, please visit www.azmed.org/general/custom.asp?page=endoflifecare. ■

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Ron Fischler, MD, is a pediatrician in Scottsdale who has developed a strong personal interest in end of life issues. He has held leadership roles at Scottsdale Healthcare and in the Arizona Academy of Pediatrics and Arizona Medical Association. He is an Associate Clinical Professor at the University of Arizona College of Medicine.

ArMA Ethics Committee Report 2018

Report of the **Committee on Medical Ethics** to the House of Delegates

At the request of the Executive Committee and the Task Force on End of Life Care the Committee on Medical Ethics was convened to specifically address the issue of Physician Assisted Suicide/Medical Aid in Dying (PAS/MAID).

The Arizona Medical Association (ArMA) has a longstanding policy of opposing Physician Assisted Suicide. In 1997 ArMA's Committee on Bioethics produced a Position Paper detailing the basis for opposing PAS. In the 21 years since the Position Paper public opinion and opinions in the medical community have evolved. In a survey of more than 7,500 physicians, representing more than 25 specialties, the Medscape Ethics Report found that in 2010, for terminally ill patients, 46% of physicians were in favor of MAID/PAS and 41% were opposed. In 2016, 57% were in favor and 29% were opposed. The ArMA/AOMA Joint Task Force on End of Life Issues found in a 2017 survey of Arizona Physicians, that 53% were in favor of MAID/PAS and 27% were opposed. Five States, the District of Columbia and Canada have statutes that permit, and strictly regulate, provision of a prescription for a lethal dose of medication.

In this context the Committee on Medical Ethics convened to discuss PAS/MAID to determine if ArMA's policy of opposition should be reconsidered. We recognized that ArMA would not likely take a position favoring PAS/MAID but could potentially adopt a neutral position, neither favoring nor opposing PAS/MAID.

We recognize that PAS/MAID is currently illegal in Arizona. A neutral position would allow representatives of ArMA to present all aspects of the issue in public and legislative settings.

We also observed that many national organizations such as the American Academy of Neurology have a "Code of Conduct" and find that many of their members practice in states where PAS is legal and who are supportive of PAS. This potentially creates a conflict between the national organization and members whose practice falls outside of the established Code of Conduct. As a result, the American Academy of Neurology has rescinded its opposition to PAS.

We observed that those in support tend to use terms such as "Medical Aid in Dying" or "Physician Assisted Death" while those against prefer "Physician Assisted Suicide". The terminology is value-laden.

We clarified that MAID in this context is a synonym for assisted suicide and generally refers to such outside of the hospital environment rather than to the broader context of end of life issues within the hospital.

Similarly, we agreed that active euthanasia is not part of the MAID discussion and the Committee is not addressing or supporting changing ArMA's position on euthanasia.

In discussing PAS/MAID it became apparent that the Committee members were divided in their personal opinions regarding the ethics of PAS/MAID and that it was unlikely that those personal opinions would change with further information or debate.

We addressed the ethical principles of autonomy, beneficence, non-maleficence and justice and that based on these principles reasonable ethical arguments can be made for either position: for or against PAS/MAID.

We discussed the dichotomy of individual ethical belief vs a global ethical position for our profession. While we hold individual ethical opinions, what are our foundational ethical principles that are fundamental and essential to our profession?

Ultimately the discussion focused on the meaning of taking a neutral position and its implications for our profession and for society. Many felt that a neutral position simply recognized the division in physician's opinions regarding PAS/MAID. Some felt that taking a neutral position was equivalent to supporting PAS/MAID and violates our fundamental ethical principles.

We questioned who would notice or be affected by ArMA taking a neutral position. Some felt that the Legislature, and possibly the Arizona Medical Board would interpret a neutral position as favoring PAS/MAID. Most felt the change to a neutral position would have little impact on the Legislature.

Greater concern was directed towards the implications for such a change on our foundational principles. Does taking a neutral position violate values that are fundamental to the practice of medicine? Some expressed concern that taking a neutral position on PAS/MAID risks crossing a slippery slope that could endanger the vulnerable individual or lead to forced participation in PAS/MAID or euthanasia. Others on the Committee felt there was little evidence for this.

Committee members felt regardless of one's position on PAS/MAID, support for a position of neutrality should be seen merely as recognition that physicians are quite divided in their support for PAS/MAID. Similarly, most felt that opposition to policy change should not be seen as reflecting a lack of awareness and sensitivity to the issues involved in the dying process

Ultimately it was moved and seconded to recommend that ArMA take a position of neutrality toward PAS/MAID and the vote ended with eight recommending approval of the motion and eight voting against. Clearly there is no consensus to change ArMA's position nor is there a consensus for firm opposition to PAS/MAID.

Thus, the Committee on Medical Ethics is not making any recommendation for change in ArMA's position toward PAS.

Consideration might be given for ArMA to develop a category for a position where no consensus and reasonable debate exists.

ETHICS IN MEDICINE University of Washington School of Medicine **Physician Aid-in-Dying**

SITEMAP

BIOETHICS TOPICS

CLERKSHIPS

BIOETHICS TOOLS

RESOURCES

[Case 1](#) [Case 2](#)

Article

What is physician aid-in-dying?

Helene Starks, PhD, MPH, Denise Dudzinski, PhD, MTS and Nicole White, MD, MA (2013) Original text written by: Clarence H. Braddock III, MD, MPH with Mark R. Tonelli, MD, MA (1998)

Physician aid-in-dying (PAD) refers to a practice in which a physician provides a competent, terminally ill patient with a prescription for a lethal dose of medication, upon the patient's request, which the patient intends to use to end his or her own life. (For related discussion, see also [End of Life Issues](#).)

What role does language play in discussions of aid-in-dying?

A variety of terms have historically been used to describe when a terminally ill patient uses a lethal dose of medication for the purpose of ending his or her life (or having control over the timing of death). Prior to the passage of the Oregon Death with Dignity Act in 1996, the term most often used was “physician-assisted suicide” (PAS). Those who use this term feel that it is an accurate reflection of the

relationship between doctor and patient and refer to the etymological roots of suicide as “auto-killing” or “self-killing.” The use of this term ties the role of the physician to one that aids the patient in killing him or herself. However, implicit in the understanding of the word suicide is the notion of a premature death that is being hastened out of despair, therefore when mental illness impairs judgment, intervention to stop a suicide is ethically warranted because the person seeking suicide has lost his ability to carefully weigh the benefits and burdens of continued life. Generally speaking, persons who are suicidal are treated as though their decision-making capacity is compromised and health care providers often intervene and provide life- sustaining treatments (including involuntary psychiatric treatment) over the objections of the patient. Therefore, some people, including several national professional organizations*, object to the term suicide for the choice of a terminally ill patient to hasten death, because of the associations between suicide and mental illness. They argue that, unlike the patients with impaired judgment who request suicide, terminally ill patients who request medication under the Act have the capacity to make a rational, autonomous decision to end their lives.

The term “physician aid-in-dying” is used to describe the practice authorized under the Washington, Oregon and Vermont Death with Dignity Acts and is meant to reflect the requirement that eligible persons must be decisionally competent and have a limited life expectancy of about 6 months or less. In this context, the term is meant to reflect that physicians provide assistance to patients who are otherwise going to die, and who seek help to control the timing and circumstances of their death in the face of end-of-life suffering they deem intolerable. While this term evades the mental health connotations associated with the word suicide, people who object to the use of “physician aid in dying” suggest that it could include other

practices that are clearly outside the legal bounds of the three states' Death with Dignity Acts, e.g. a patient who receives assistance in ingesting the medication, which would constitute euthanasia (see below). Here we use the term physician aid-in-dying to reflect the practice that is legal under the Washington Death with Dignity Act.

It is important to note that both terms, "physician assisted suicide" and "physician aid-in-dying" are value-laden and may reflect the speaker or writer's political or ideological support for or objection to the practice. Recent research has detailed the need for open and honest discussion on end of life issues. This discussion should supersede any debate over the use of particular terms or language. Acknowledging the power of both historic and contemporary terminology, will help flesh out both sides of this sensitive and powerful debate.

*The Oregon Department of Public Health, American Public Health Association, American Psychological Association, American Academy of Hospice and Palliative Care, American Medical Women's Association, and the American Medical Student Association have adopted the term patient directed dying or physician aid-in-dying and have rejected the term physician-assisted suicide. Neither term is used in Oregon, Washington or Vermont Death with Dignity laws.

Is physician aid-in-dying (PAD) the same as euthanasia?

No. While both physician aid-in-dying and euthanasia involve the use of lethal medications to deliberately end a patient's life, the key difference is in who acts to administer the medications that will end the patient's life. In physician aid-in-dying, the patient must self-administer the medications; the "aid-in-dying" refers to a physician providing the medications, but the patient decides whether and when to ingest the lethal medication. Euthanasia occurs when a third party administers

medication or acts directly to end the patient's life. Euthanasia is illegal in every state, including Washington.

Some other practices that should be distinguished from physician aid-in-dying include:

Withholding/withdrawing life-sustaining treatments: When a competent adult patient makes an informed decision to refuse life-sustaining treatment, their wishes are generally respected. The right of a competent adult patient to refuse life-sustaining treatments is supported by law. **Pain medication that may hasten death:** Often a terminally ill, suffering patient may require dosages of pain medication that have side effects that may hasten death, such as impairing respiration. Using the ethical principle of double effect as the foundational argument, it is generally held by most professional societies, and supported in court decisions, that this action is justifiable. Since the primary goal and intention of administering these medications is to relieve suffering, the secondary outcome of potentially hastening death is recognized as an expected and acceptable side-effect in a terminally ill patient. **Palliative sedation:** This term refers to the practice of sedating a terminally ill patient to the point of unconsciousness, due to intractable pain and suffering that has been refractory to traditional medical management. Such patients are imminently dying, usually hours or days from death. Often other life-sustaining interventions continue to be withheld (CPR, respirator, antibiotics, artificial nutrition and hydration, etc.) while the patient is sedated. Palliative sedation may occur for a short period (respite from intractable pain) or the patient may be sedated until s/he dies. In the rare instances when pain and suffering is refractory to treatment even with expert clinical management by pain and palliative care professionals, palliative sedation may legally be employed.

Is physician aid-in-dying (PAD) ethically permissible?

The ethics of physician aid-in-dying continue to be debated. Some argue that PAD is ethically permissible (see [arguments in favor](#)). Often this position is argued on the grounds that PAD may be a rational choice for a dying person who is choosing to escape unbearable suffering at the end of life. Furthermore, the physician's duty to alleviate suffering may, at times, justify providing aid-in-dying. These arguments rely on respect for individual autonomy, recognizing the right of competent people to choose the timing and manner of death in the face of a terminal illness.

Others have argued that PAD is not ethically permissible because PAD runs directly counter to the traditional duty of the physician to preserve life and to do no harm (see [arguments against](#)). Furthermore, many argue if PAD were legal, abuses would take place, as the social forces that condone the practice are a slippery slope that could lead to euthanasia. For instance, the disabled, poor or elderly might be covertly pressured to choose PAD over more complex and expensive palliative care options.

For more information on the debate around PAD please see [Euthanasia Pros and Cons](#) . **What are the arguments in favor of physician aid-in-dying (PAD)?**

Those who argue that PAD is ethically justifiable offer the following arguments:

- 1. Respect for autonomy:** Decisions about time and circumstances of death are personal. Competent people should have right to choose the timing and manner of death.

2. Justice: Justice requires that we "treat like cases alike." Competent, terminally ill patients have the legal right to refuse treatment that will prolong their deaths. For patients who are suffering but who are not dependent on life support, such as respirators or dialysis, refusing treatment will not suffice to hasten death. Thus, to treat these patients equitably, we should allow assisted death as it is their only option to hasten death.

3. Compassion: Suffering means more than pain; there are other physical, existential, social and psychological burdens such as the loss of independence, loss of sense of self, and functional capacities that some patients feel jeopardize their dignity. It is not always possible to relieve suffering. Thus PAD may be a compassionate response to unremitting suffering.

4. Individual liberty vs. state interest: Though society has strong interest in preserving life, that interest lessens when a person is terminally ill and has strong desire to end life. A complete prohibition against PAD excessively limits personal liberty. Therefore PAD should be allowed in certain cases.

5. Honesty & transparency: Some acknowledge that assisted death already occurs, albeit in secret. The fact that PAD is illegal in most states prevents open discussion between patients and physicians and in public discourse. Legalization of PAD would promote open discussion and may promote better end-of-life care as patients and physicians could more directly address concerns and options.

What are the arguments against physician aid-in-dying (PAD)?

Those who argue that PAD is ethically impermissible often offer arguments such as these:

- 1.**Sanctity of life:** Religious and secular traditions upholding the sanctity of human life have historically prohibited suicide or assistance in dying. PAD is morally wrong because it is viewed as diminishing the sanctity of life.
- 2.**Passive vs. Active distinction:** There is an important difference between passively "letting die" and actively "killing." Treatment refusal or withholding treatment equates to letting die (passive) and is justifiable, whereas PAD equates to killing (active) and is not justifiable.
- 3.**Potential for abuse:** Vulnerable populations, lacking access to quality care and support, may be pushed into assisted death. Furthermore, assisted death may become a cost-containment strategy. Burdened family members and health care providers may encourage loved ones to opt for assisted death and the protections in legislation can never catch all instances of such coercion or exploitation. To protect against these abuses, PAD should remain illegal.
- 4.**Professional integrity:** Historical ethical traditions in medicine are strongly opposed to taking life. For instance, the Hippocratic oath states, "I will not administer poison to anyone where asked," and I will "be of benefit, or at least do no harm." Furthermore, some major professional groups such as the American Medical Association and the American Geriatrics Society oppose assisted death. The overall concern is that linking PAD to the practice of medicine could harm both the integrity and the public's image of the profession.

5. Fallibility of the profession: The concern here is that physicians will make mistakes. For instance there may be uncertainty in diagnosis and prognosis. There may be errors in diagnosis and treatment of depression, or inadequate treatment of pain. Thus the State has an obligation to protect lives from these inevitable mistakes and to improve the quality of pain and symptom management at the end of life.

Is physician aid-in-dying (PAD) illegal?

Physician aid-in-dying is legal in Oregon, Washington, and Vermont, where voter-approved initiatives or legislative action have legalized aid-in-dying under very specific circumstances. A Montana lower court has also determined that physician aid-in-dying is permitted under Montana's State Constitution; this decision was upheld by the Montana State Supreme Court in December 2009.

In other states, without specific legislative authority or a court decision, physician aid-in-dying would most likely be considered illegal, and in many states is explicitly illegal. The citizens of Oregon passed Measure 16, the Oregon Death with Dignity Act, on November 16, 1994 by a margin of 51.3% to 48.7%.

Opponents immediately challenged the law and it was not enacted. In response, the Oregon Legislature referred Measure 51 (a law to repeal Measure 16) for a public vote. That measure was defeated by 60% of the votes in 1997. Thus, physician-assisted dying has been legal in the state of Oregon since 1997. In November 2008, the citizens of Washington state passed I-1000, The Washington State Death with Dignity Act (DwDA) by a margin of 57.8% to 42.2%, and it went into effect on March 5th, 2009. On May 20, 2013, PAD was legalized in Vermont when the governor signed a bill that was passed by the state legislature. Similar legislation was been introduced in 2013 and 2014 in Connecticut, Hawaii, Kansas,

Massachusetts, New Hampshire, New Jersey and Pennsylvania; none of these states has yet to approve these bills.

The laws in all three states have strict patient eligibility criteria, limiting access to competent, legal residents of the state over age 18, with a terminal illness (defined as an estimated life expectancy of 6 months or less) that is confirmed by two independent physicians. There is a requirement for two oral requests with a 15-day waiting period in between, as well as a written request that must be witnessed. Prescriptions may be written no less than 48 hours after the receipt of the written request. Patients must be able to self-administer the medications (i.e., have the mental and physical capacity to take the medications on their own). Providers may decline to prescribe medication under the Act.

Several major court decisions have been made regarding this issue. In the case of [Washington v. Glucksberg](#), the plaintiffs argued that prohibitions against suicide impinged on an individual's right to liberty, as stated in the due process clause of the 14th Amendment. The Ninth US Circuit Court of Appeals upheld this argument, but this decision was later overturned by the United States Supreme Court. In another case, [Vacco v. Quill](#), the Second Circuit Court found a New York law prohibiting assisted suicide was in conflict with the equal protections clause of the 14th amendment, which says that no state shall "deny to any person within its jurisdiction the equal protection of the laws." The Court held that competent patients were being treated differently than incompetent patients. The US Supreme Court declined to find a federal constitutional right to "assisted suicide", and made a legal distinction between refusal of treatment and PAS. The Court also left the decision of whether to legalize PAS up to each individual state.

There have been high-profile cases related to specific incidents of aid-in-dying. One involved Dr. Timothy Quill (of *Vacco v. Quill*) who was investigated but not indicted for his participation in the suicide of a patient after he published his account of the incident. Another involved Dr. Jack Kevorkian who claimed to have assisted over 100 patients in death, and was acquitted on murder charges on multiple occasions. In November 1998, he and his patient, 52 year-old Thomas Youk, who suffered from Amyotrophic Lateral Sclerosis (ALS-otherwise known as Lou Gehrig's Disease) appeared on the TV show 60 Minutes where Dr. Kevorkian administered a lethal injection. As a result of the show, Kevorkian was tried for first degree murder in Oakland County, Michigan. Prosecutors argued that, in administering a lethal injection to Youk, his actions constituted euthanasia rather than PAD. Kevorkian was convicted of second degree murder in 1998, sentenced to a 15-25 year term of which he served 8 years, and was released in 2007.

What does the medical profession think of physician aid-in-dying (PAD)?

Surveys of individual physicians show that half believe that PAD is ethically justifiable in certain cases (Cohen et al., 1994). However, professional organizations such as the American Medical Association have generally argued against PAD on the grounds that it undermines the integrity of the profession.

Surveys of physicians in practice show that about 1 in 5 will receive a request for PAD sometime in their career (Back et al., 1996; Meier et al., 1998). Qualitative research has shown that requests for PAD bring up sensitive issues and emotions. Physicians stated that the discussion around these issues was lengthy and included patient and physician concerns about depression, pain and symptom management, issues of control, and exploration of the fear of abandonment (Back et al., 2002; Dobscha et al., 2004; Ganzini et al., 2000, 2001).

What should I do if a patient asks me for physician aid-in-dying (PAD)?

One of the most important aspects of responding to a request for PAD is to be respectful and caring. Virtually every request represents a profound event for the patient, who may have agonized over his situation. The patient's request should be explored, to better understand its origin and to determine if there are other interventions that may help ameliorate the concerns that motivated the request. In most cases, there are alternatives in palliative and hospice care that likely will address most of the patient's concerns. Palliative care physicians recommend the following process for evaluating and responding to requests (Emanuel, 1998; Quill & Arnold, 2008a, 2008b).

- 1.Wait to directly respond to the request until you have explored the reasons for the patient's request. Discuss various ways of addressing the patient's pain, suffering, hopes, and fears. If time permits, tell the patient that you would like to talk more about this at a subsequent appointment. That gives both you and the patient time to prepare for a fuller exploration of PAD as well as other palliative treatments, hospice, etc.
- 2.Evaluate for depression or other psychiatric conditions and treat appropriately.
- 3.Assess the patient's decision-making competence.
- 4.Engage in discussion surrounding the patient's diagnosis, prognosis, and goals for care. Make sure to assess patient understanding.

5. Evaluate patient's physical, mental, social, and spiritual suffering. Be sure to take into account the patient's support system as well as personal and professional pressures and stressors.
6. Discuss all alternative options, such as palliative care and hospice.
7. Consult with professional colleagues regarding the patient's situation. Where appropriate, ask for help from a palliative care specialist to assure that all options have been explored.
8. Help the patient complete advance directives, DNR orders and POLST forms, as appropriate and ensure that preferences are followed.

What if the request for physician aid-in-dying persists?

If a patient's request for aid-in-dying persists, each individual clinician must decide his or her own position and choose a course of action that is ethically justifiable and legally permissible. It is useful to carefully reflect on and think through where you stand on the issue and be prepared to openly discuss your position with the patient, acknowledging and respecting difference of opinion when it occurs.

Patients who ask for PAD-in states where it is legal or illegal-understand that physicians will have different opinions about what they can and should do. The most important thing is to be clear and transparent about your position. Even in states where it is illegal, some physicians will decide to help their patients, particularly when patients are enduring unbearable suffering. While we cannot condone this practice, we must recognize its occurrence and the reasoning behind it. No physician, however, should feel forced to provide assistance if he or she is

morally opposed to PAD.

What are the attending physician's duties and responsibilities under the Washington Death with Dignity Act?

1. Confirm the following eligibility criteria:

Washington State resident
Age 18 and older
Competent (able to make and communicate an informed decision to health care providers)
Terminally ill (incurable, irreversible disease expected to cause death within six months, as determined by the attending physician and a consulting physician)
Able to voluntarily express his or her wish to die

2. Assure that it is an informed decision, which means the patient has an appreciation of the relevant facts, after being fully

informed about the following:

Medical diagnosis
Prognosis
Potential risks associated with taking the prescribed medication
Probable result of taking the prescribed medication
Feasible alternatives including, but not limited to, comfort care, hospice care, and pain control

2. Evaluate the patient's request: Assess reasons, Explore and recommend alternatives (palliative care, hospice, pain/symptom management, psychosocial and/or spiritual counseling, palliative sedation).

3. Counsel patient about the following: Opportunities to rescind request at any time. Recommend notifying next of kin. Importance of having another person present and not taking medications in a public place.

4. Refer to a consulting physician, who reviews the medical record and interviews the patient to confirm the diagnosis, and confirm that the patient is competent and is making a voluntary request.
5. Refer to a counselor if concerned about a psychiatric or psychological disorder or depression causing impaired judgment.
6. Work with pharmacists to prescribe/get medications.
7. Document all steps in the medical record.
8. Sign the death certificate. List the underlying terminal disease as the cause of death.
9. Send a copy of the dispensing record to DOH within 30 days.

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2017 Annual Report: Joint Task Force on End of Life Issues

Joint Task Force on End of Life Issues

Arizona Medical Association // Arizona Osteopathic Medical Association
Annual Report
May 15, 2017

Report

This Task Force was established in the spring of 2016 by both organizations' governing bodies and via resolutions. Members (about 25 MD's and DO's) were recruited based on experience and interest in end of life care from around Arizona in both practice and academic settings.

The **rationale for a Task Force** was based on a number of important recent developments including:

1. Institute of Medicine's Report on *Dying in America* (2014)
2. Atul Gawande's *Being Mortal* (2014)
3. JAMA's Jan 2016 issue entirely devoted to issues related to End of Life care
4. Medicare's authorization to pay for end of life counseling (2016)
5. Legislation in Colorado (2016) and California (2015) legalizing Medical Aid in Dying and corresponding change by their State Medical Associations' position of opposition to such laws to a position of neutrality.

The Task Force defined its **Mission**:

To review care for individuals with serious, life limiting illness along with those at end of life. The Task Force will identify strengths, unmet needs, and make recommendations that provide practical solutions to improve care for these individuals in Arizona.

The **Task Force met monthly** from Oct 2016-May 2017 both in person and via telephone. Its **Steering Committee** met monthly before each Task Force meeting. The Task Force heard testimonials from its members based on their experience, and created three workgroups based on the priorities identified:

1. Education for physicians and public
2. Access to Palliative Care
3. Policy (such as POLST and Medical Aid in Dying)

We heard reports from each of these **workgroups** on:

1. Status of education in Medical Schools and Residency programs
2. A comprehensive community / physician / hospital initiative in Northern Arizona to implement POLST (Physician Orders for Life Sustaining Treatment)
3. Pro and con views from prominent physicians on Medical Aid in Dying.

We issued a **publication, communication vehicle and grant application**:

1. Article about Task Force activities in the new statewide medical journal, *Arizona Medicine*, that reaches all 18,000 physicians in Arizona (March 2017)
2. Web page and blog as part of ArMA's website (<http://www.azmed.org/page/endoflifecare>)
3. Lovell foundation grant application in partnership with the Arizona Healthcare and Hospital Association for a comprehensive statewide education effort for both providers and the general public across Arizona over a 4 year time frame (notification expected in July 2017).

We surveyed allopathic and osteopathic **medical schools** in Arizona and **primary care residency programs** in Maricopa County

1. A survey of curricula at Arizona's Medical Schools found that most contained substantial training on end of life issues
2. A survey of primary care residency programs in Maricopa County suggested that most do **not** have specific curricular objectives or time allotted to end of life care issues

The Task Force has the following **future plans**:

1. Another year of meeting to deepen the discussion of key issues identified and to **research further for relevant statistics** to benchmark Arizona's experience in end of life care with national data, before making recommendations to ArMA and AOMA.
2. Conduct a **survey** of physicians in Arizona regarding:
 - a) Their views of end of life care in Arizona
 - b) Their confidence and satisfaction in providing such care
 - c) Their perceived need for training to improve their skills in end of life care
 - d) Their perceived access to palliative care services for their patients
 - e) Their views on Medical Aid in Dying
3. The Task Force will engage a qualified **pollster** to conduct this survey and has raised funds for this purpose held in the ArMA Foundation. The Task Force will conduct this survey over the summer and analyze results in the fall of 2017. It will base further efforts at education and policy based on the findings of the survey.
4. The Task Force will explore ways of encouraging and providing **training** on end of life care in **residency programs** around the state and through **CME programs for practicing physicians**, including sponsoring a conference on end of life care and trying to engage with physicians in primary care and specialties like oncology, cardiology, nephrology, emergency medicine, hospital medicine and critical care medicine through their respective specialty organizations.
5. The Task Force is recommending that ArMA /AOMA provide **fiscal support** for its activities in their budgets for 2017-2018. The Task Force has submitted resolutions for ArMA/ AOMA:
 - a) One regarding fiscal support for its planned activities
 - b) Support for implementing POLST in Arizona
6. The Task Force will continue to look for ways to encourage and develop greater **access** to Palliative Care Services to all patients across Arizona in both inpatient and outpatient settings
7. The Task Force will also request ArMA **Ethics Committee** to reconvene to revisit prior positions (1996) on Medical Aid in Dying
8. The Task Force will continue to reach out to physicians around Arizona who are engaged in activities related to **improving care** to patients near the end of life and engage in collaborative efforts to improve professional and public education on issues related to end of life care.

MEMBERS OF TASK FORCE:

Ron Fischler, M.D.*	Pediatrician Scottsdale Chair
Dan Aspery, M.D.	VP/Medical Director, Blue Cross Blue Shield Phoenix
Jeanette Boohene, M.D.	Palliative Medicine Scottsdale
Carla Denham, M.D.	Psychiatry Phoenix
Tim Fagan, M.D.*	Internal Medicine, Survey Committee chair Tucson
Chip Finch, D.O.*	Emergency Medicine, Education workgroup chair
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Mandy Weaver*	Project Mgr (retired Exec Dir AOMA)

* denotes member of Steering Committee

Appendix

This section includes documentation of testimonials regarding end of life care in Arizona as offered by members of the Task Force that speak not only to the problems they see, but also to possible solutions. They will form the basis for next year's discussions and for the planned survey of Arizona physicians. Additionally, the reports on POLST in Arizona, on education for students and residents and a compilation of the best articles on end of life care are included as well as the article from [Arizona Physician](#) regarding the Task Force activities.

Recommendation: The Task Force recommends that additional efforts and grant funds be used to compile additional relevant statistics on end of life care in Arizona that can be used as a comparison with U.S. data and as a benchmark for efforts to improve care to this population.

Dying in Arizona: Testimonials from Members of the Task Force

All too many patients with chronic debilitating diseases do not have the conversation about advanced directives with their families and doctors and wind up in a crisis in the ER

Alan Molk M.D. ER Physician Banner system

I am saddened by how many terminally ill patients (an everyday occurrence in my ER) wind up in a medical crisis in the ER when they would be far more humanely served in a palliative or hospice setting

The ICU is also a common place where terminally ill patients are sent because families have not yet dealt with the terminal nature of the illness and discussed a treatment plan and advanced directives. It is costly and invasive, adding to a patient's suffering.

Jud Tillinghast, M.D. retired critical care /pulmonary physician Scottsdale

Addressing the difficult questions surrounding end of life is a daily problem in the ICU. I have seen family members divided and agitated, demanding aggressive care even if it only prolongs a patient's suffering. We need more physicians (primary care, hospitalists, specialists and critical care specialists) to communicate clearly and sensitively with patients facing a terminal condition, with assistance from the palliative care team, to help families honor the wishes their loved ones and ideally to do this before a crisis occurs that results in an ICU admission.

The view of a neurologist who deals with a variety of terminal scenarios. What remains to be clarified is whether patients achieve a "good death" in each?

Michael Powers, M.D.

The scenarios confronting neurology are quite diverse. In the acute setting we see the families of those with severe strokes or with cardiac arrests and severe hypoxic brain damage. There the family needs the intervention and the family often determines the level of support, especially in the absence of advance directives.

For the more gradually progressive conditions I would divide them between those such as Alzheimer's disease and severe Parkinson's disease where cognitive function is quite impaired vs conditions such as ALS where the body is failing but cognitive function is relatively preserved. There the patient can direct the level of their intervention. If they decline long term ventilation (which is common) then we can usually be successful in utilizing hospice services to keep them from suffering due to ventilatory failure. This typically requires use of sedatives or opioids to eliminate air hunger.

Sometimes the issue of tube feeding arises, such as in ALS or other disorders where swallowing is impaired. Most will accept PEG placement to prevent starvation with the understanding it does not artificially prolong life in that setting.

Brain tumor patients can be diverse depending on the extent physical and cognitive function is impaired. In my general experience it is possible to provide comfort measures to prevent suffering for most who are dying from neurological disorders.

Palliative care-- if started earlier-- could avoid needless suffering and hospitalization and procedures at the end of life.

Rama Kunkle, D.O. Palliative Care Specialist Honor Health / Lincoln

I was recently taking care of a patient that was end stage heart failure. She had been struggling with shortness of breath and required paracentesis for fluid management with increasing frequency. Although followed by her PCP and Cardiologist, she was admitted to the hospital for respiratory distress the day before she was to meet with hospice. Her daughter said to me that she wished that her mother had palliative care services earlier in her disease process for support and symptom management. Patients and their families often want this support. The presence of outpatient palliative care services is growing and can provide a valuable service to our patients.

Counseling patients honestly is a big part of providing care for patients with chronic and ultimately terminal illnesses and revising/ updating prognosis and treatment options with input from the patient and family as the disease progresses

Bruce Peek, M.D. Cardiologist, Cottonwood

How we assist patients and their families during the dying process is just as important as how we assist them to prolong life. Educating patients and families regarding the nature and prognosis of their disease throughout the course of their illness and eliciting their goals and preferences along the way is essential to what we do.

Palliative care is a relatively new specialty now available in many larger hospitals to assist physicians and patients make the transition to comfort based care; outpatient palliative care is more limited in availability.

Stacie Pinderhughes M.D. Banner Palliative Care

Palliative care is team based, specialized medical care for people with serious illness. A team of doctors, nurses and other specialists provide patients relief from symptoms, pain, and stress of any serious illness. The goal is to improve quality of life for patient and family during any stage of serious illness.

Jeannette Boohene, M.D. Palliative Care, Cancer Center of America, Phoenix

From the most recent Center to Advance Palliative Care (CAPC) report on this for 2015 (four years of data from 2011 to 2015)

One-third of U.S. hospitals report no palliative care services of any kind, and access to palliative care in community settings (home, nursing home, assisted living) is limited for people who are not hospice-eligible. Additionally, the presence of a palliative care program in a hospital does not necessarily mean that seriously ill patients needing palliative care actually receive palliative care services. As a result, most people with serious illness are unlikely to receive the care they need throughout their course of illness. Making palliative care available to the much larger population of the seriously ill who are neither hospitalized nor hospice-eligible is perhaps the single largest opportunity to improve value in the U.S. health care system

*Palliative Care penetration is highest in New England, Pacific and mid Atlantic states >75%, and lowest in West South Central (Arkansas 32%) and East South Central states (Mississippi 29%). **Arizona is 68% and moved from a grade C in 2011 to a grade B in 2015.***

Hospice referrals happen too late; Palliative care is often not available outside of a hospital

John Manfredonia , D.O. Regional Hospice Medical Director , Kindred, Tucson

Palliative Care has made considerable progress in the last several years, but the palliative model has been predominately hospital rather than community based. There have been a few successful community models but they usually require financial supplementation. Overall, the work force is inadequate to handle the growing need/demand and reimbursement has been inadequate Hospice: About 1/3 of patients entering hospice die in less than a week, insufficient time to achieve a "Good Death". The barriers to early referral include physicians and patient / family perceptions and poor communication within the healthcare system

What can be done? Physicians, patients and their families need to better understand the consequences of their decisions. Look at all possible scenarios, the good and the bad. The old adage of living longer does not always equate with living well...in hospice it is about attempting to live (well) until the time of death.

CME: Overcoming Doctors' reluctance to having conversations with patients about end of life planning.

Patty Mayer, M.D. Palliative Care Banner, Mesa

There is much criticism that doctors can't or won't have these conversations with patients. What I have observed is doctors do want to have end of life conversations but can be uncomfortable doing so simply because they lack training in this area. This is why I hear: "I'm no good talking about death!" My response is: "I can teach you! Just as you could teach me to sew a laceration, administer chemotherapy, or adjust a ventilator. All these things are learned skills; they do not come without training."

Most of our medical training emphasizes curing patients, not assisting them with options when they are seriously, critically or even terminally ill. Having difficult conversations is a teachable skill, and most physicians and medical students are eager to learn. As a group they are bright, inquisitive, hard-working quick studies.

I have personally taught these skills to many professionals over the years with overwhelmingly positive responses. Imparting these tools to doctors improves their comfort and satisfaction, which in turn enhances the patient experience.

For some patients, Medical Aid in Dying offers an important end of life option

Evan Kligman, M.D. Family Physician and Geriatrician, Tucson

In my 15 years providing palliative and hospice care, I have experienced situations where such care was insufficient and for which medical aid in dying would have given certain terminally ill patients and their loved ones a degree of comfort and sense of being in control with dignity.

Living wills can't see all events and need provisions for revision as a disease progresses

Lisa Stearns M.D. Cancer Pain specialist Scottsdale

My mother was diagnosed of lung cancer a year before her death. She suffered from hyponatremia, cachexia and severe pain from vertebral compression fractures. When I went to see her one day, I discussed her condition and the obvious suffering she had endured. I gave her permission to quit to which she replied "really?" and then "thank you." She had dinner with her friends, called in my sisters and died peacefully in her sleep two weeks later. Following her death, my father was distraught and lost. He developed progressive dementia and died eight years after her death. I had to ask a psychiatrist to evaluate his competency after several distressing events. He moved to Montana into a skilled nursing facility to be near my sister. The year of his death, when my sister was out of town for an extended period, he was beaten by a caregiver on several occasions and had boiling water poured on his legs because he "was naughty." Following the burning episode, another caregiver notified us by text of what was happening and shared pictures of his bruises and burns. Upon moving him to a new facility, he withdrew and became more confused. He suffered two falls with subdural hematomas, resulting in aspiration pneumonia and finally death. As MPOA communication was poor and disjointed. It was difficult to get the whole story unless my sister was in town to evaluate his condition. His physician was reluctant to follow his living will and requested that he be transported to the hospital on several occasions. I had to remind him that my father was terminal in the sense that he was living a life which he had stated was without quality and purpose. Hospice care was supportive but sparse when it came to the actual caregiving. Had my sister not been a nurse and her husband a physician, it would have been difficult to stop the interventions from trying to save my father's life. I had to remind his physician and nurses that it was his wish not their personal beliefs which should guide his care.

Even though I navigate death scenarios for a living, doing it for family, has been one of the hardest challenges I have encountered as a physician.

In a study published in Community Oncology: we found that 86% of patients who came to our office for pain related to cancer, never had an end of life discussion with their physician. Of those, 95% were happy to have the conversation with the provider and completed a medical power of attorney and advanced directives.

Today, we discuss end of life planning with all patients and require a medical power of attorney be established at the first visit.

Families that come together and have good communication with the medical team and each other can create a “good death” experience

Tim Fagan, M.D, retired palliative care internist Tucson

My mother was active with no significant chronic medical issues at age 86. She lived in Prescott, Arizona which has very good to excellent medical care.

We had not discussed end of life issues and she had no advance directive, but the family knew how she had lived her life.

She called me in Tucson one morning at about 6:30 AM. She had a sudden onset of severe shortness of breath, and she asked me what to do. I advised her to go to the ER immediately.

In the ER, her chest X ray revealed a near whiteout. A transthoracic echo revealed previously unknown mitral regurgitation, but the quality did not allow a good assessment of severity. She was severely hypoxic and was presumed to have pneumonia. She was treated with IV antibiotics, intubated, sedated and hospitalized in the ICU, where she was connected to the usual 10 or so tubes.

She lived with her husband, and my wife and I drove to Prescott that day. Her other 2 children and their spouses live in Prescott. All of her grandchildren arrived within the next 2 days.

She did not improve, and a transtracheal echo revealed that she had ruptured her chordae and had a flail mitral leaflet. Thus, she had overwhelming pulmonary edema, rather than pneumonia.

The only option for effective treatment was transportation to Phoenix, open mitral valve replacement, with a high risk of operative mortality, and prolonged rehabilitation.

Due to sedation, she was unable to speak to us, but we all spent most of several days at her bedside and talked to her. The entire family agreed, that, knowing my mother, even in the absence of an advance directive, that she would not want the transportation, operation and rehabilitation.

All of her tubes were removed and she died peacefully within a few minutes.

In many respects this was a good death. She suffered minimally, her dying was not prolonged, the entire family had the chance to say goodbye. The family all agreed on what she would want, and she died surrounded by her husband and family.

An advance directive, particularly one that specified no intubation or artificial ventilation, would have simplified her death, but the family would not have had a chance to say goodbye.

A big problem continues to be resistance by patients to considering palliative care until they are worn down by the ravages of their disease; but a powerful therapeutic relationship with a primary physician can be helpful to families

Akash Shah M.D. FP PGY 3 St Joseph's Hospital Phoenix

My story revolves around a patient I first saw on my surgery rotation the day after he had an SMA dissection and resultant colectomy. Soon after he developed short gut syndrome and was resigned to being on IVF almost 14 hours a day to stay ahead of the volume loss. Because the patient did not have a doctor and there were no GI specialists who specifically saw post colectomy pts, I volunteered to start seeing him in clinic. I saw almost every 1-2 weeks and I was able to build a very strong relationship with him and his wife. He had follow up with surgery but the only treatment option for him was a full bowel transplant and that required a move to the East Coast and family did not want to consider that option. Therefore, I saw him and helped manage his pain/anxiety/depression/stomach cramping/short gut on a weekly basis with sporadic follow up with specialists. I tried numerous times to bring up the topic of hospice or palliative care and patient abjectly refused every time. After months of this back and forth and continued deterioration of pts physical and mental health, we got a point with his pain management that our clinic was no longer comfortable managing the amounts of benzos/opioids he was getting and we had to send him to pain management as they were still refusing a palliative/hospice evaluation. Then I find out about a week later that the family accepted hospice and the pt finally passed away within a few days. This experience taught me the value of establishing a relationship with pts beyond just their medical issues and delving into their personal story. I learned first hand the kind of difference I could potentially make in pts and their families lives doing palliative type medicine.

One of the major problems in the current health care system is that patients lose contact with their primary physicians when they become very ill and enter the hospital and enter the world of hospitalists, intensivists and specialists. Whose role is it to counsel them regarding prognosis, and options and elicit their wishes and address fears and concerns?

Heather O'Toole, M.D. Family Physician Honor Health

As an FP, I often lose contact when patients are at the end of life. If they enter a long term care facility, they may switch to the primary care doc at the facility. If they go on hospice, they usually switch to hospice for all their needs.

The impact that I can make is when they are battling with chronic diseases early on when we can discuss advanced care planning and also if they have a new terminal diagnosis, such as cancer. I see oncologists pushing for treatment that seems futile to me, so it is helpful to have a conversation with patient and family in my office to let them know it is okay if they don't want everything proposed to them. Palliative vs curative is important to discuss. We spend a lot of time discussing quality of life as well and what their goals are. Patients don't often understand the options given by a specialist, so I will see them back, review the consult notes and explain things in a manner that is easier for them to understand. Patients may get into a spiral of multiple specialists, conflicting treatments with potential side effects, and confusion about their diagnoses and I can help to view the big picture and make sure that their treatments are not causing more harm than good.

I do a lot of Medicare Annual Wellness Visits, where we do discuss their wishes. I would like to see more education of the primary care physicians and providers on the best way to go about these discussions though.

Overcoming resistance by patients' families and doctors to having a conversation regarding end of life wishes in a culturally sensitive way is being demonstrated in a pilot program in Northern Arizona. POLST (AZ MOST) codifies and makes available end of life choices to those that need to know.

Emmalee Kennedy M.D. Medical Director NAH Palliative Care – Flagstaff Co Chair Thoughtful Life Conversations program

As a practicing palliative care specialist, I see many patients and families struggle with the unforeseeable choices they face during a serious illness. Medically and functionally frail people are admitted to the hospital, seeming to have no insight into how sick they are or what they may face in the near future. Patients in the ICU are very frequently confused and unable to make decisions. Not uncommonly, we see families struggle with what the patient would want. Without having a conversation about what is important to their loved one or considered a good quality of life, these families can be torn apart with blame and anger. Advance directives (health care powers of attorney and living wills) are very helpful, but they are often filled out when a person is in good health. It is difficult to predict choices in future situations.

AzMOST is a helpful tool for people with advanced illnesses to help communicate health care choices pertaining to their current situation. AzMOST stands for Arizona Medical Orders for Scope of Treatment. It is a bright pink form that is a medical order signed by both a health care provider and the patient after a conversation about the medical situation. The conversation gives patients the information they want and need to make important choices about treatment they may need in the near future. These forms are considered the standard of care for communicating a patient's choices in more than 38 states. They allow a patient and their provider to work together to make a treatment plan that is right for what is important to that patient. It also helps everyone involved know the right thing to do in a medical crisis, from the patient's primary care doctor, nursing home, or hospital to EMS or an ER doctor. When the person's health has a change, the form helps start a new conversation and may be updated or changed at any time. Arizona has tried to fill this communication gap through the Prehospital Medical Care Directive, commonly known as the Orange Form. Unfortunately, this form still leaves gaps, especially when patients want to specify in more detail their level of hospital transfer, invasive or noninvasive ventilatory support, or artificial nutrition.

As the principal investigator for the main AzMOST pilot, I have seen a high level of engagement, with patients filling out the form about 75% of the time when offered. We serve a large population of Native American patients, primarily Navajo. We often hear physicians decline to have code status or goals of care discussions with patients because it is culturally taboo to discuss end of life care or DNR. However, we have shown that when the conversation is done in a culturally sensitive way, our Navajo patients (in fact all Native patients) engage in this conversation as often as non-Native patients, and a significant number choose to set future limits on care, such as a DNR order. We have also found major issues remaining with communication of these forms (infrastructure and patient understanding) as well as health care knowledge gaps. In order to improve end of life care, we must first have high quality conversations with patients and their families and the best possible access to palliative care. We must ensure wide spread access to palliative care education for all providers, including education specifically on the communication skills needed to have these discussions.

Models for early palliative care are emerging that are well accepted by patients and providers alike.

Gobi Paramandaram M.D. Hospice of the Valley Out Patient Early Palliative Care Pilot

A recent Kaiser/Economist Survey showed that 71% of Americans say that they would prefer to die at home than in a hospital or nursing home but a smaller share (41%) expect to do so, demonstrating gaps between their wishes and expectations. Early Palliative Care interventions could help in diminishing that gap by eliciting conversations about death and dying prior to a crisis situation. At Hospice of the Valley we've developed a home Palliative Care program where a trained team meets patients in their own environment with the goal of developing a relationship and eliciting people's end-of-life wishes and documenting those over time.

We've even seen patients that are not specifically on a dying trajectory, but instead living with chronic illness and yet finding themselves lost in the current medical milieu of doctor visits, frequent medical testing and recurrent hospitalizations. Our interdisciplinary team conducts home visits to educate patients about their disease process, coordinate communication, and elicit goals that allow them to stay at home and out of the hospital and/or nursing home.

Current Status: Education for Physicians in End of Life Care in Arizona

(Education workgroup: Chair Chip Finch D.O., Jeanette Boohene, M.D.; Carla Denham, M.D.; Alan Molk, M.D.; Tom Neuman, M.D.; Akash Shah, M.D.; Jud Tillinghast, M.D.; Sarah Wypiszynski MS IV, [i](#)

Education for Medical Students on End of Life Care in Medical Schools in Arizona (survey by Sarah Wypiszynski MS IV UACOMP)

Both allopathic and osteopathic medical schools in Arizona were surveyed for curriculum devoted to end of life care issues. All had substantial educational components across all 4 years, including communication of difficult situations, advanced care planning, medical ethics and hospice/palliative care. It utilized professional patients to simulate difficult communications with patients and families.

Training in Residency programs (Maricopa Co.)

Survey by Akash Shah MD PGY-3 FP St Joseph's Hospital, Phoenix.

I reached out to 7 programs in the Valley (5 Family Medicine and 2 Internal Medicine). Only two programs indicated that they have formal curriculum time allocated to end of life issues. All residents do receive varying degrees of training and exposure but few programs have specific milestones that are tied to existing competencies in this particular area. Most have geriatrics rotations.

There are no formal requirements for residency training per the Residency Review Committee milestones in this specific area. Each year residents and their faculty mentors fill out milestones for the ACGME. The six core competencies for residency per the ACGME are: Patient Care, Medical Knowledge, Practice-Based Learning and Improvement, Interpersonal and Communication Skills, Professionalism, Systems-Based Practice. Under each of these areas, there are sub milestones which can address more specific markers of resident training, some of which can be program specific. While going through the Family Medicine milestones, I have realized that sub milestones can be added to any of the core competencies. For example, family meetings at the end of life (usually done during the ICU rotation) can be used as a sub milestone under the Interpersonal and Communication Skills, as well as Patient Care. Another program utilized Objective structured clinical examinations to practice giving patients and their

family bad news and then tied that to the Medical Knowledge, Professionalism, and Interpersonal and Communication Skills milestones. These are a few examples of what can be done to improve end of life training throughout the Valley to improve resident training and education in this vital area.

Training for practicing physicians (CME)

Arizona Academy of Family Medicine included topics on end of life at this year's annual conference, as did the Arizona Osteopathic Medical Association's Annual Convention.

Recommendation: Greater efforts should be made to encourage medical associations of the various specialties to include topics on care at end of life and to publicize these on ArMA website/ e-news

Recent Surveys (Hartford Fdn 2016) indicate that although most physicians believe that conversations with patients regarding end of life wishes are important, most do not have them. A number of barriers have been identified lack of time, lack of training, personal discomfort, fear of upsetting patients, lack of payment) Effective training modules have been developed elsewhere and local palliative care physicians are available and willing to provide training to colleagues. Medicare now authorizes payment for end of life counseling.

Recommendation: Training should be offered to all physicians who encounter patients nearing the end of life including: by primary physicians, hospitalists, ER, ICU, specialists. Efforts should be made to find ways to overcome resistance by physicians (and patients) to having these conversations.

Policy Changes to Improve End of Life Care

Policy change workgroup: Paul Stander MD, Chair; Jim Dearing, D.O.; Ron Fischler, M.D. Emmalee Kennedy MD; Heather O'Toole, M.D.; and Bruce Peek, M.D.

1. POLST (Physician Orders for Life Sustaining Treatment/ AZMOST) Presented by Emmalee Kennedy MD Palliative Care Flagstaff and member, Thoughtful Life Conversations (Az HHA)

AZ Statutes Today

- Arizona Statutes Related to Health Care Directives
 - Living Will (A.R.S. § 36-3261 et. seq.)
 - Health Care Power of Attorney (A.R.S. § 36-3221-2)
 - HC Directive Conflicts (A.R.S. § 36-3209)
 - A Mental Health Care Power of Attorney
 - Pre-Hospital Medical Care Directive (A.R.S. § 36-3221-2)

National POLST Update on Names

Arizona Legal Review & National POLST Recommendations

- Statutory Changes
 - Seek amendment of A.R.S. § 36-3209(B)
 - Seek amendment of A.R.S. § 36-3205(C) to grant providers immunity from civil and criminal liability and disciplinary action if the provider makes decisions based on the patient's known wishes
 - Add reciprocity language

- Regulatory Changes
 - Work with ADHS to address concerns regarding order authentication. Request a rule change to permit hospital employees to accept AzMOST/POLST form that is not signed by a medical staff member so orders can be implemented without delay

Defenses of POLST

- Ensures patient autonomy
- Standardizes documentation
- Optimizes communication (to diminish anxiety and disputes among families)
- Minimizes the use of unwanted interventions
- Simplifies decision making
- Promotes consistency of care across care settings
- Decreases interventions and cost of care at the end of life

POLST Success

- Oregon Study: Location of Death and POLST Orders
- 58,000 deaths reviewed, 31% had POLST in Oregon registry
- Patient treatment choices honored, including avoiding dying in hospital

Why POLST/ AzMOST?

- People value autonomy (supports PSDA 1990)
 - Many fear death that comes too slowly and too late
- Patient wishes often are not known.
 - The Advance Directive (AHCD) may not be accessible.
 - Wishes may not be clearly defined in AHCD
 - The AHCD is not a physician order
- Allows healthcare providers to know and honor wishes during serious illness

POLST Benefits

- Promotes informed patients & surrogates
 - Gold Standard
- Promotes quality care through informed end of life conversations and shared decision making
- It's voluntary
- It is an interactive process with patient/family and/or surrogate and HCP
- Concrete medical orders that must be followed by HCP
- Transportable orders that follow patient from care setting to care setting
- Complements the AHCD
- Provides guidance for treatments and triggers additional conversations
- Addresses legal concerns when patient is incapacitated and provides clarity for providers and families
- Encourages completion of POA
- Can be nulled, reversed, updated
- Incorporates the importance of comfort

POLST Opportunities

- POLST Tool has limitations
 - Complex, needs provider education and time to review and complete with patient/family or surrogate
- Patient must be appropriately selected and medically informed, as well as surrogate
- Misconceptions of POLST and frank opposition in Arizona
- Will require change in legislation
- Will require structure and process development

Recommendation: Task Force recommends ArMA's legal/ advocacy staff explore the feasibility of moving POLST legislation forward for Arizona

2. Medical Aid in Dying

The Task Force heard an ethics panel presentation held at ASU (Ethics at Twilight: Medical Aid in Dying) and from Rebecca Thoman MD (Minnesota) and David Grube MD (Oregon) with Compassion and Choices, an advocacy group in favor of this option; it also heard from Zuhdi Jasser MD, who is opposed to physician involvement

Recommendation: At this point the Task Force recommends surveying Az physicians on their attitudes and recommending that the ArMA Ethics Committee reconvene to review old policies (1996) regarding this topic

Key References for Physicians: Death and Dying; Care at End of Life

Institute of Medicine Report: Dying in America 2014

<https://iom.nationalacademies.org/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

[https://www.nationalacademies.org/hmd/~media/Files/Report Files/2014/EOL/Key Findings and Recommendations.pdf](https://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf)

Byock, Ira

Dying Well 1997

The Best Care Possible 2012

NYT opinion piece comparing Dr to patients on their end of life practices

http://well.blogs.nytimes.com/2016/06/30/at-the-end-of-life-what-would-doctors-do/?_r=1

Kubler Ross, Eliz 1973 On Death and Dying

Moyers, Bill A Death of One's Own 2000 <http://billmoyers.com/content/a-death-of-ones-own/>

Gawande, Atul 2014 Being Mortal

Volandes, Angelo "The Conversation" 2015

Warraich, Haider Modern Death: How Medicine Changed the End of Life 2017

The Conversation Project <http://theconversationproject.org/>

Free online toolkit that provides step to step guidance how to have the conversation w/ loved ones about their wishes for end of life care

Stanford Letter Writing Project description

<http://www.nytimes.com/2016/09/07/well/family/writing-a-last-letter-before-you-get-sick.html?smprod=nytcore-ipad>

Oliver Sacks MD Reflections

upon learning he is dying of cancer My Own Life

<http://www.nytimes.com/2015/02/19/opinion/oliver-sacks-on-learning-he-has-terminal-cancer.html>

the joy of old age <http://nyti.ms/16VBMcg>

my periodic table <http://nyti.ms/1MMna3z>

(viewing death as Sabbath like rest)

http://www.nytimes.com/2015/08/16/opinion/sunday/oliver-sacks-sabbath.html?_r=0

Leonard Cohen His last words (song)

<https://www.leonardcohen.com/video/you-want-it-darker-lyric>

Clety et al; "Please do Whatever it Takes to End our Daughter's Suffering" Pediatrics:137:1 Jan 2016

JAMA 2016 Jan Vol 315 no 3 entire issue devoted to death and dying issues

(see pdf file below)

A PIECE OF MY MIND A Final Course.pdf

A PIECE OF MY MIND Hope Is the Thing With Feathers.pdf

A PIECE OF MY MIND What Would Mom Want.pdf

A Policy Prescription for Hospice Care.pdf

Death in the United States Changes From 1969 to 2013.pdf

Death, Dying, and End of Life.pdf

Euthanasia.pdf

Physician-Assisted Death in Canada.pdf

Physician-Assisted Dying A Turning Point.pdf

Quantity and Quality of Life Duties of Care in Life-Limiting Illness.pdf

Responding to Patients Requesting Physician-Assisted Death Physician Involvement at the Very End of Life.pdf

The Liberty to Die California Enacts Physician Aid-in-Dying Law.pdf

The Problems With Physician Orders for Life-Sustaining Treatment.pdf

Toward Better ICU Use at the End of Life.pdf

Why Physicians Should Oppose Assisted Suicide.pdf

Kalanithi, Paul *When Breath Becomes Air* 2016

Lee, Barbara "Oregon's experience with Aid in Dying" Ann NY Acad Science 1330:94-100 2014 (See PDF file below)

Shared Decision Making in end of life decisions:

http://www.nytimes.com/2016/09/15/well/live/helping-patients-make-the-right-decisions.html?_r=0

On VSED (voluntary stopping eating and drinking)

<http://www.nytimes.com/2016/10/25/health/voluntarily-stopping-eating-drinking.html?smprod=nytcore-ipad&smid=nytcore-ipad-share&r=0>

On the shift toward Aid in Dying Laws and the resistance by physicians

<http://www.nytimes.com/2016/11/05/opinion/on-assisted-suicide-going-beyond-do-no-harm.html?smprod=nytcore-ipad&smid=nytcore-ipad-share>

<http://www.nytimes.com/2017/01/16/health/physician-aid-in-dying.html?smid=nytcore-ipad-share&smprod=nytcore-ipad>

Focus group surveys of physicians around the country on

strategies to improve participation in end of life conversations by physicians

<http://www.johnahartford.org/newsroom/view/advance-care-planning-poll>

barriers to having advanced care planning conversations

from surveys of 700+ physicians from across us.

<http://www.johnahartford.org/newsroom/view/advance-care-planning-poll>

POLST: current legislative guide

<http://polst.org/wp-content/uploads/2017/01/2014.02.20-POLST-Legislative-Guide-FINAL.pdf>

Medical Aid in Dying: Ethics Arthur Caplan MD

http://www.medscape.com/viewarticle/874168?src=WNL_bom_170213_MSCPEDIT&uac=108831EZ&impID=1288438&faf=1

Medscape survey: Assisted Death Physician Support continues to Grow Dec 29, 2016

https://www.dropbox.com/s/ki0lh7yvdrd0afm/2017_02_18_15_47_16.pdf?dl=0

Gostin, L; Roberts, A Physician Assisted Dying: A Turning Point?

Comparison between various states laws, and shift in physicians' opinions

<https://www.ncbi.nlm.nih.gov/pubmed/26784764>

Palliative Care:

Health Affairs Blog: End of Life and Serious Illness

www.healthaffairs.org

[How Can we Increase the Use of Palliative Care in Medicare? Feb 13, 2017](#)

Family satisfaction w/ end of life care when referrals are made earlier

- <http://jamanetwork.com/journals/jama/fullarticle/2482326>

On teaching teens about death education (much like sex ed) using "go wish" cards

<https://www.nytimes.com/2017/02/18/opinion/sunday/first-sex-ed-then-death-ed.html?smprod=nytcore-iphone&smid=nytcore-iphone-share>

5/8/2018

ArMA/ AOMA Joint Physician Task Force on End of Life Care

2016-18

ArMA | AOMA Joint Task Force End of Life Care

Task Force Composition

- About 25 physicians from Phoenix, Tucson, Cottonwood , Flagstaff 5 DO's 1 Med student, 1 resident
- Primary Care, Specialties (Palliative Care, Cardiology, Oncology, Pulmonary / ICU)
- ER
- **Mission:** *to review EOL care in Arizona and make recommendations*

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Task Force Activities

- Compiled reference list for physicians
- Conducted Phone Surveys of medical schools and residency programs in Arizona
- Heard testimony from members on relevant issues affecting EOL care
- Collaborated w/ AzHHA on Lovell Grant
- Designed and implemented survey of over 500 Arizona physicians Oct –Dec 2017

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Goals of Physician Survey

To Explore Physician:

- Attitudes toward End of Life discussions
- Knowledge of and perceived access to Palliative Care
- Interest in education on EOL issues
- Attitudes on Medical Aid in Dying
- Attitudes on POLST (Physician Orders for Life Sustaining Treatment)

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Az Physician Survey: Methodology

- Email invitation ArMA, AOMA, ACP, MCMS, PCMS
- Questionnaire developed and pretested
- Professional pollster engaged
- 8000 sent w/ several reminder emails
- Oct-Dec 2017
- 588 responses/ 466 completed
- Margin of error 4.5 %
- Population sampled: "physicians who are interested in EOL issues who completed the survey"

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Profile of Respondents

- Specialty
 - 36% Primary Care
 - 26% IM Subspecialty
 - 11% Surgical specialty
 - 5% Palliative Care
- Facility
 - 29% Hospital
 - 33% Clinic
 - 16% Academic
 - 6% Integrated system (FQHC, ACO)

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Profile of Respondents

- Geography
 - 58% Phoenix area
 - 25% Tucson area
 - 17% Rural/ other
- Gender
 - 32% Female
 - 68% Male
- Age
 - 22% 25-45yr
 - 50% 46-65yr
 - 28% 66+

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Amount of Training in Palliative Medicine

- Specialist in Pall Med 5.5%
- Significant training 13.5%
- Limited training/CME 29%
- No formal training 52%

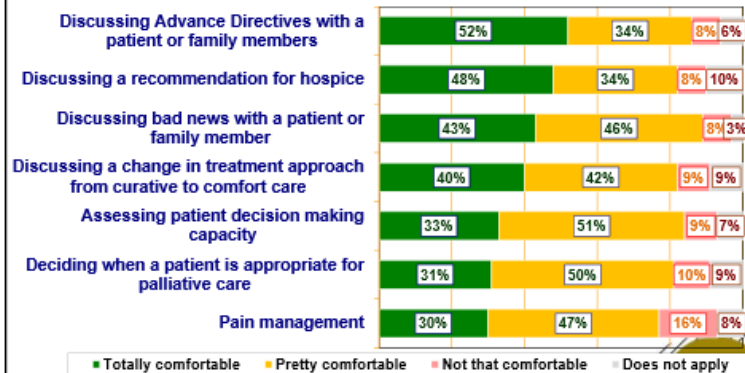
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How often do you encounter patients at EOL ?

68% of sampled physicians routinely care for patients near EOL

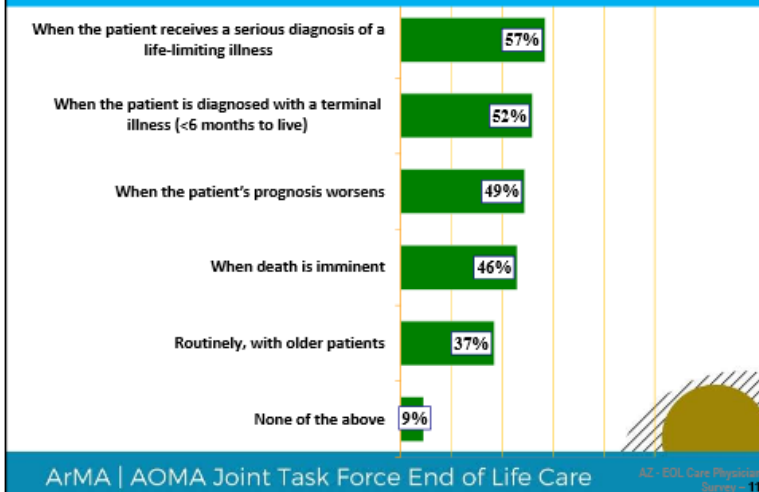
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How comfortable are you with skill sets needed for EOL care?

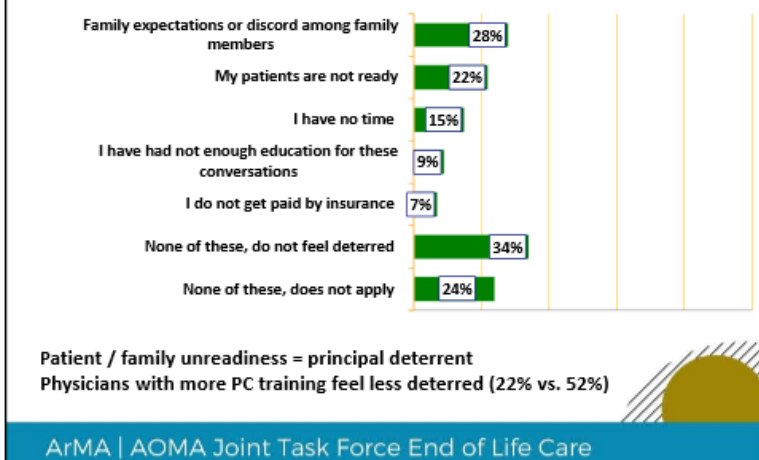


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When do you discuss end of life issues with patients?



What deters you from having these conversations?



How often have you used CPT codes for EOL counseling?

- 85% have **not** used CPT codes for end of life counseling funded by Medicare in 2016

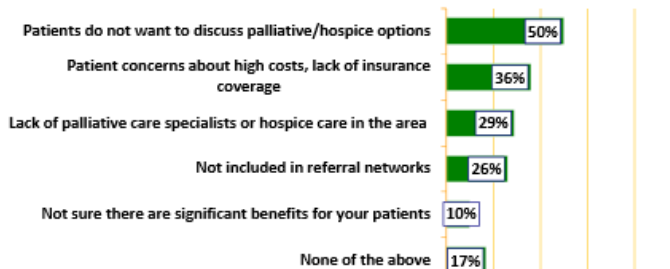
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Referral to Palliative Care

- 55% refer if patient dx w/ terminal disease
- More refer if they see EOL patients frequently and if they've had training

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Barriers to Palliative Care Referral



- Younger physicians (<45) say patients don't want to discuss options (66% vs 32%)

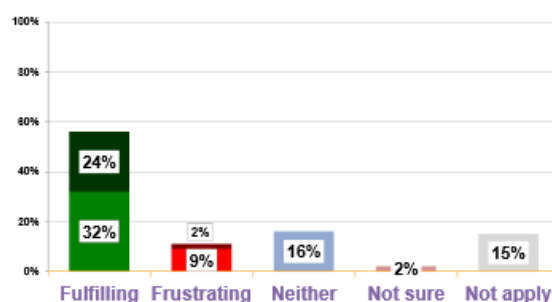
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How often do your patients have a good dying experience?

- Good dying experience= death expected, symptoms /pain controlled; family present, family wishes in accord with patient's
- Most report this happens about ½ of the time
- Responses vary by degree of experience/training (the more experienced physicians report a higher percentage of patients having a good death)
 - Palliative Care specialists 77%
 - Some training 65%
 - Overall 58%

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Physician satisfaction in EOL care



56% of surveyed physicians find EOL care fulfilling
Training and experience assoc w/ higher satisfaction
9% found EOL care frustrating

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Education / CME for EOL Care

- 42% very likely to use webinars or other
- 67% strongly favor Public Education
- Physicians with more education in EOL care more likely to view patients as receptive to EOL conversations, make greater use of pall care consultants and see fewer barriers to referral and report higher levels of professional satisfaction

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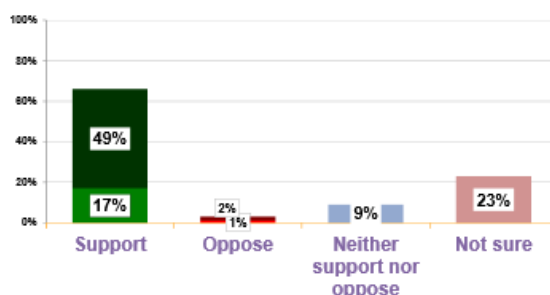
POLST

Physician Orders for Life Sustaining Rx (used in 23 states)

- Transportable medical order used to document patient wishes in the EMR and for use by prehospital first responders
- May be completed by health care proxy if the patient is not competent
- For terminally ill patients during the last year of life
- Updated if clinical circumstances change
- Available to all settings: home, nursing home

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Strong Support for POLST in AZ



66% support POLST in AZ

76% want education about POLST

58% believe they will use it in their practice

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POLST: Collaboration in 2019

- ArMA (4000+ physicians)
- AOMA (1000 + DO physicians)

Have passed resolutions from Task Force on POLST 2017, 2018

Join efforts with AzHHA in 2019 legislative session?

Education on POLST a priority

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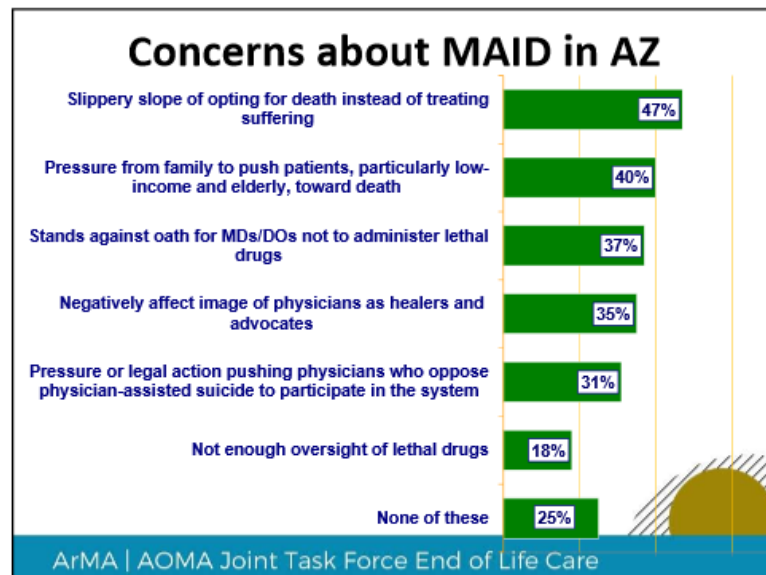
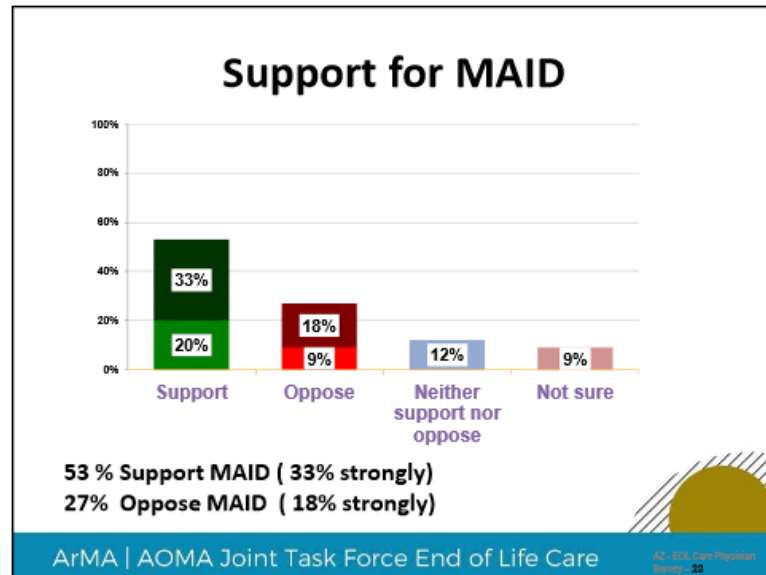


Medical Aid in Dying

- Oregon 20+yr, California , Colorado , Vermont, Montana , Washington, Hawaii, DC, Canada
- California law
 - 2 physicians concur in dx of terminal illness and psych evaluation if question of competency
 - Proof of residency
 - 2 oral and 1 written request 15 d apart; right to rescind
 - Physician participation voluntary/ liability protection for those that participate
 - Participating physician prescribes barbiturate which the patient must self administer

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Policy : US Views of MAID are Shifting

- **AZ sample 2017:** 53% support / 27 % oppose (18% strongly) 20% undecided
- Nationally 57% support /29% oppose/ 14% undecided (Medscape 2016 N=7500)
 - 2010: 46 % in favor / 41 % opposed

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Medical Aid in Dying

- AMA to discuss policy 2018
- ArMA policy officially opposed
- ArMA Ethics committee 2018 divided on whether to change ArMA policy to “Neutral”
 - Most of the PC physicians on the Task Force were in favor as a way of alleviating suffering
 - Oregon 20 yr 0.3% of deaths
- No law likely to move forward in Arizona soon

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Survey: Major Findings

- Counseling of patients too little too late
 - Only 50% of the time even, when EOL is near
 - Only 37% of the time routinely in older pts.
 - Only 15% using CPT codes for EOL counseling
 - Perceived family unreadiness the most frequent deterrent to conversations
 - Physicians with EOL training less deterred

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Training on Sensitive Conversations— How do we engage more physicians ?

- Solicit Champions in each field to carry the message
- Mentoring role for senior physicians
- Primary Care/ Hospitalists
- Specialists
- Include Team (nurses, SW, etc.)
- Focus on how this role helps patients and improves satisfaction
- Incorporate into curriculum for residencies/fellowships

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Physicians Strongly Support Education for the Public

- What should the message be?
 - Living fully and dying peacefully are achievable but require planning and communication with your physicians and your family
 - Ask your physician about your disease, its likely course and treatment options available with risks and benefits for each--Informed patients are empowered patients
 - Prepare Advance Directives,(POLST) and appoint a proxy (durable power of attorney for health care)

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Physicians Role: Important and Evolving

- Care for the patient thru the end of life
- Provide information and guidance to patient/family
 - On the nature of the disease and likely trajectory
 - Options/ risks / benefits
- Consider Palliative Care team to address :
 - What does comfort care look like?
 - Elicit patients goals, wishes, fears
 - Jointly complete Advance Directives/POLST

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Physician Engagement

- Task force of 25 +
- Survey: Nearly 600 gave long thoughtful responses to open ended questions
- Topic on agenda of the medical associations: ArMA, AOMA, MCMS, PCMS, ACP
- Topic for discussion ACEP, ACP state conferences
- Participation with AzHHA

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Changing the Culture around EOL

- From avoidance of death/ dying to viewing EOL as part of life...
- Hospice has done a wonderful job making the very end of life comforting
- Palliative care can help make the last years comfortable and meaningful
- Informed patients can avoid “over medicalizing” a natural process
- A team of physician nurse, SW, chaplain with support from PC and Hospice can be effective and improve satisfaction of patients and providers

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An Oncologists' View

"Some conditions are difficult to watch as a physician when we cannot change the course of suffering. The conversation in the community is very important to help all of us how to approach end of life care. I see people with cancer therapy and see prolonging suffering as worse than death. It's a good thing to be able to talk about for all of us." (from open comments: Arizona physicians survey 2017)

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Task Force Members

- Ron Fischler MD Peds HH Chair
- Paul Stander MD Geriatrics/ PC VA/ Education
- Tim Fagan MD Int med (retired) Survey/ Policy
- Gobi Paramanandam MD PC HOV Statistics
- Chip Finch DO ER Educ/ Policy
- Alan Molk MD ER Educ/ Professional / Public
- Greg Mayer MD ASU Health Solutions/ PC
- Jud Tillinghast Pulm/ ICU (Retired) HH
- Emma Lee Kennedy MD PC Flagstaff
- Bruce Peek MD Cardiology Cottonwood
- Evan Kligman MD Ger Tuc
- Stacie Pinderhughes MD PC Optum
- John Manfredonia DO Hospice Tucson
- Bree Johnston MD PC Banner Tucson
- Tom Fitch MD PC/ Onc Mayo
- Jeanette Boohene MD PC HH
- Rama Kunkle DO PC HH
- Chikal Patel MD PC Banner
- Patty Mayer MD PC Banner
- Michael Powers MD Neuro(retired) Ethics chair
- Bunnie Richie DO Neurology
- Heather O'toole FP HH
- Lisa Stearns MD Pain Management HH
- Sarah Wypiszynski MD FP HH
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- Gretchen Alexander MD Psych MC
- Phil Keen MD Path
- Dan Aspery MD BC/BS
- Akash Shah MD FP/PC Resident
- Mandy Weaver Coordinator
- Ingrid Garvey ArMA Staff
- Susan Brown ArMA Staff
- Pete Wertheim AOMA ED

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