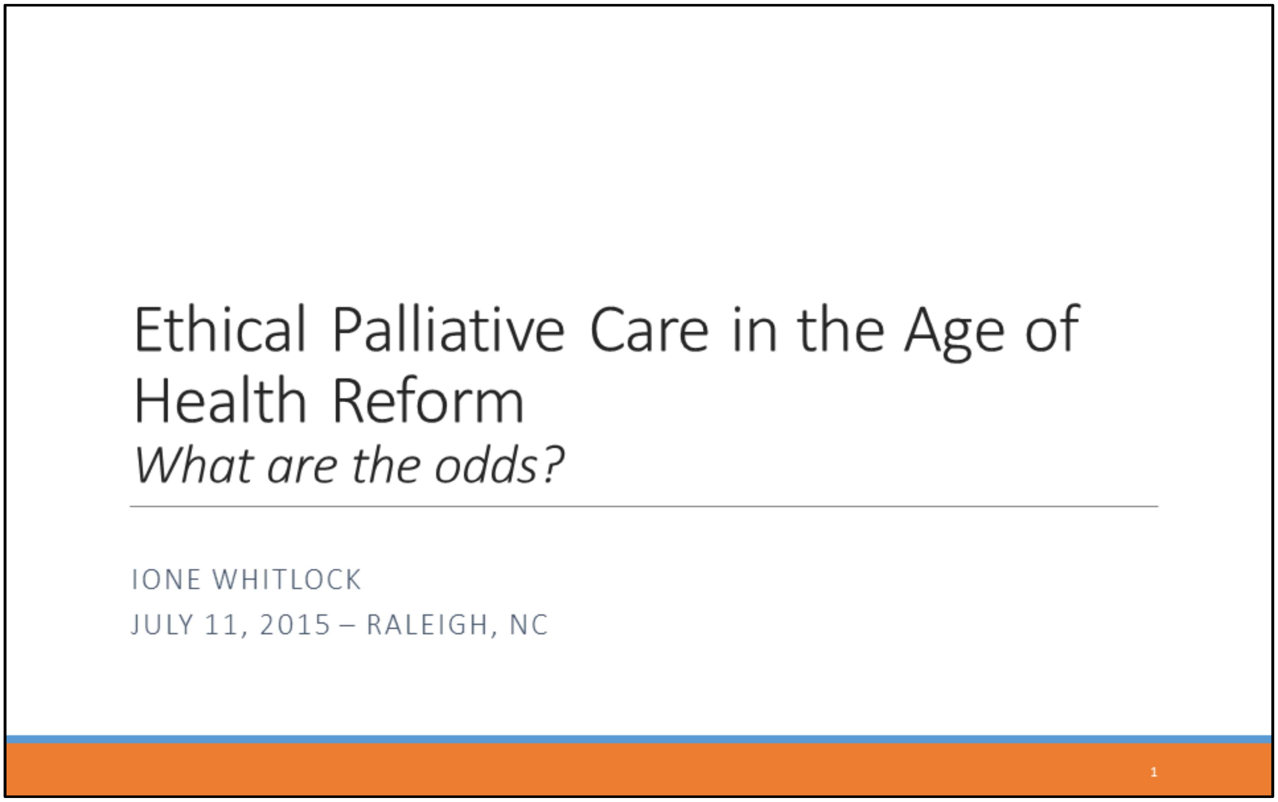


Ethical Palliative Care in the Age of Health Reform

What are the odds?

IONE WHITLOCK
JULY 11, 2015 – RALEIGH, NC

I have heard quite a few people say recently that palliative care is fine if you are referred to ETHICAL palliative care.

That got me to thinking that the problem with a referral to palliative care nowadays is not so much that it is SURE to hasten death, or all the other bad things we hear about, but that we don't really know specifically WHAT a palliative care consult means. Does it mean hospice? Does it mean curative treatment. Does it mean simply covering up symptoms and "letting nature take its course."

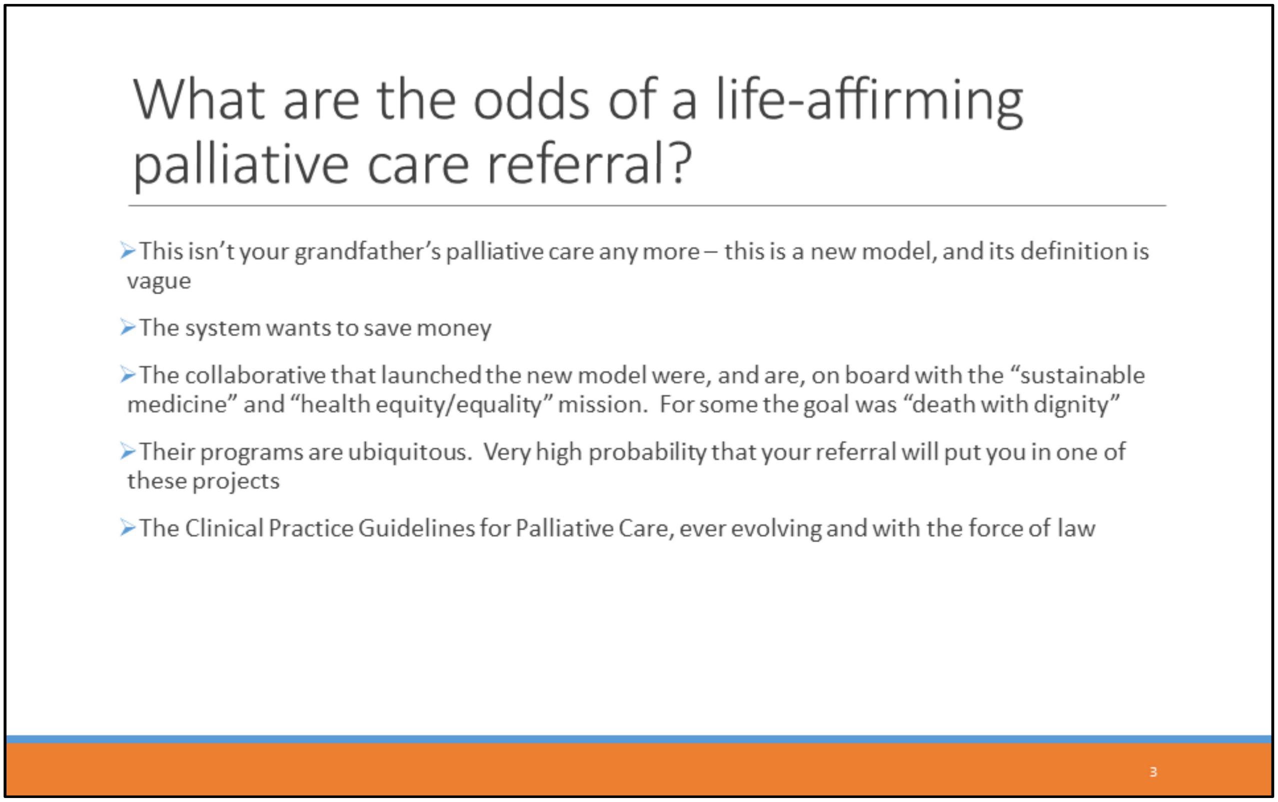
Technically the answer is "all of the above." but Realistically, odds are in favor of the patient being coaxed into withdrawal of life-saving treatment, because realistically, the system is rigged.

Palliative Care: 3-Card Monte of health care referral

You never know what you'll get, but you can bet that the system is rigged.

In fact it reminds me of the 3-card monte games that I used to see on the street corners of New York city many years ago.

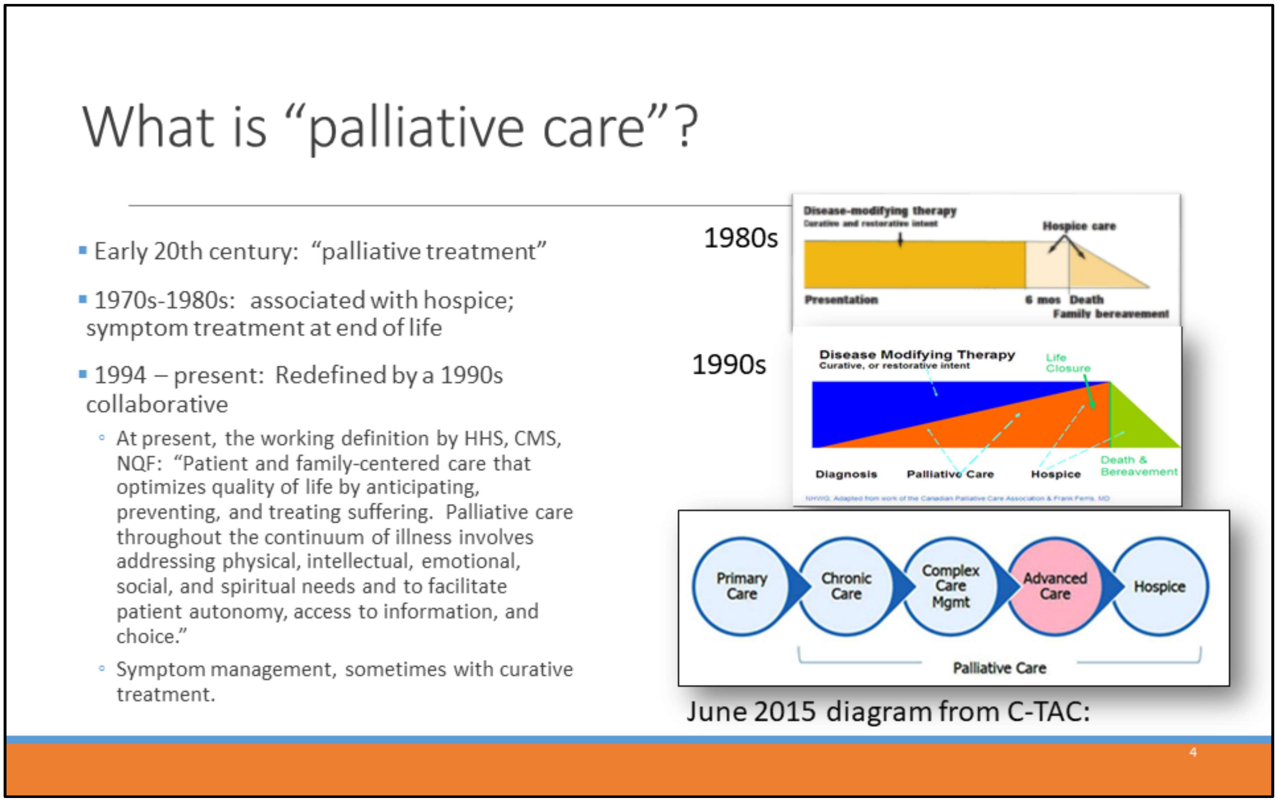
There's the possibility of life-protecting treatment, but more than likely the system is rigged against you.



What are the odds of a life-affirming palliative care referral?

- ➢This isn't your grandfather's palliative care any more – this is a new model, and its definition is vague
- ➢The system wants to save money
- ➢The collaborative that launched the new model were, and are, on board with the "sustainable medicine" and "health equity/equality" mission. For some the goal was "death with dignity"
- ➢Their programs are ubiquitous. Very high probability that your referral will put you in one of these projects
- ➢The Clinical Practice Guidelines for Palliative Care, ever evolving and with the force of law

I'll focus on about five things where I think the odds are working against us.
--this isn't your grandfather's palliative care



What is “palliative care”?

- Early 20th century: “palliative treatment”
- 1970s-1980s: associated with hospice; symptom treatment at end of life
- 1994 – present: Redefined by a 1990s collaborative
  - At present, the working definition by HHS, CMS, NQF: “Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”
  - Symptom management, sometimes with curative treatment.

June 2015 diagram from C-TAC:

Let’s look at the definition.

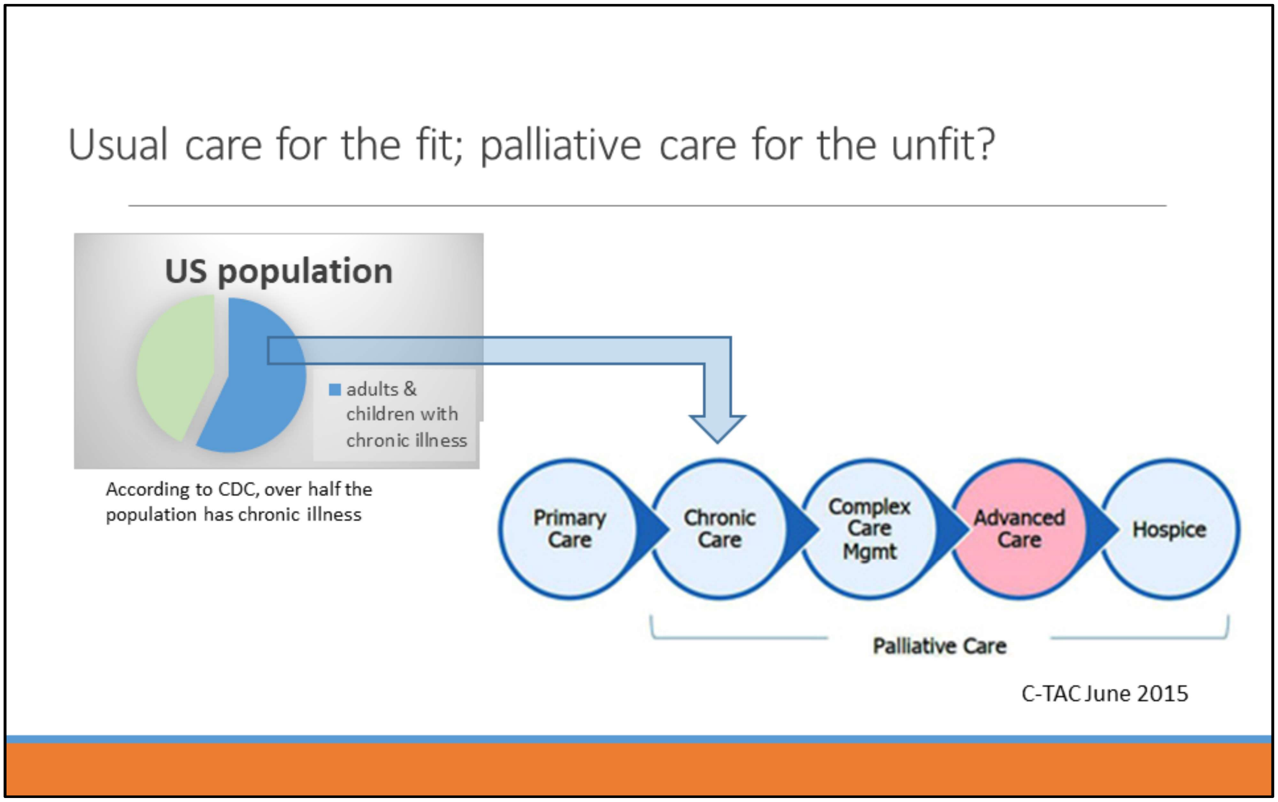
Originally the term “palliative treatment” referred simply to SYMPTOM TREATMENT.

By the 1980s the term “palliative” became associated with hospice.

But around 1994 a variety of influential groups collaborated to change palliative care – to redefine it as a “philosophy of care” and to broaden the target population to anyone with chronic debilitating conditions.

The 1990s produced a new model of care, based on a model that was introduced in Canada years ago. On the top is a view of traditional hospice within traditional medicine. In the traditional model, curative and **restorative** treatments are maintained until the patient enters hospice.
By contrast, the New Model introduces palliative care at the onset of a diagnosis, and gradually tapers off restorative treatments, replacing the life-supporting treatment with palliative care.

The bottom diagram is from a report released just a week or two ago, clearly illustrating that palliative care should begin at the onset of any chronic condition, as part of chronic care.



Usual care for the fit; palliative care for the unfit?

US population

adults & children with chronic illness

According to CDC, over half the population has chronic illness

Primary Care

Chronic Care

Complex Care Mgmt

Advanced Care

Hospice

Palliative Care

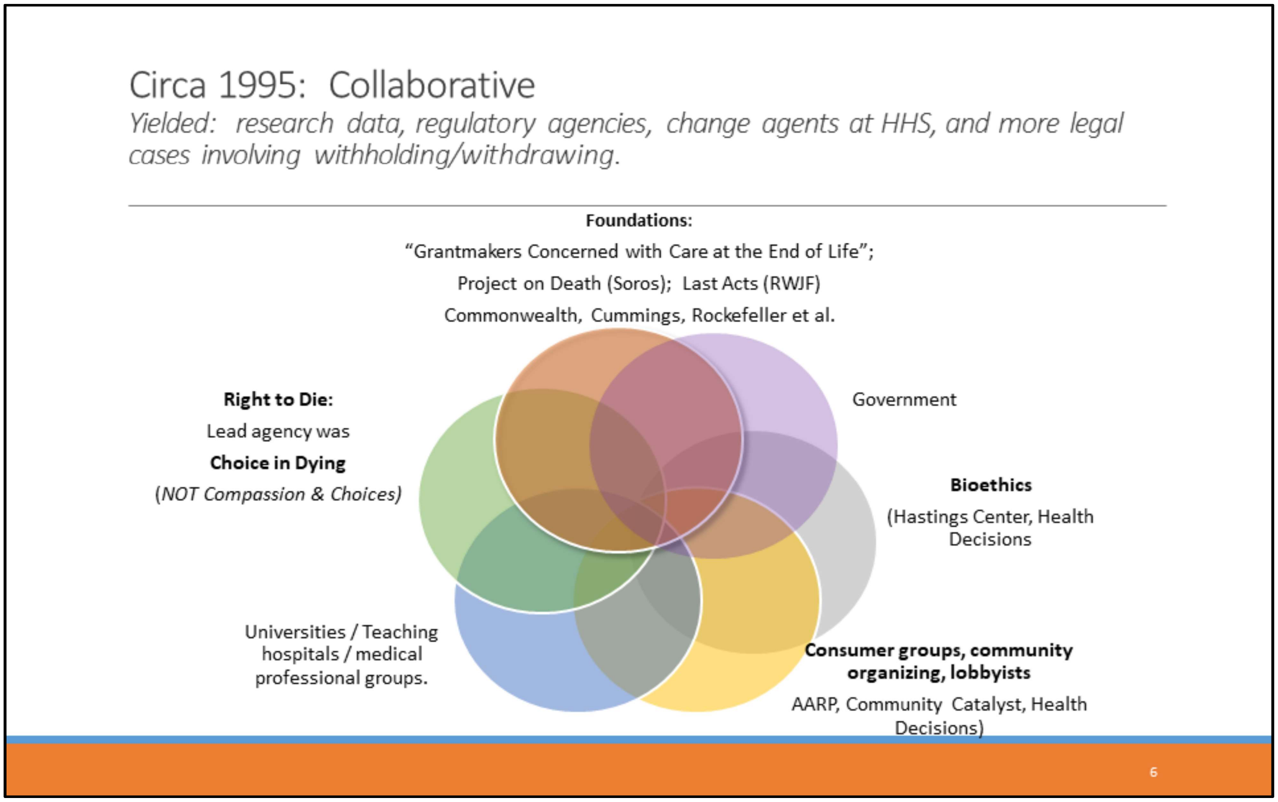
C-TAC June 2015

That means that just over 50% of the US population would fall into the palliative care category. According to the CDC, about half of all adults and about 7% of children have chronic illness.

About a quarter of the population has what is being termed “MCC” – or multiple chronic conditions.

So the system is rigged to send almost anyone into palliative care.

This is the new model. It isn’t your grandfather’s palliative care any more.



Circa 1995: Collaborative

Yielded: research data, regulatory agencies, change agents at HHS, and more legal cases involving withholding/withdrawing.

Foundations:
"Grantmakers Concerned with Care at the End of Life";
Project on Death (Soros); Last Acts (RWJF)
Commonwealth, Cummings, Rockefeller et al.

Right to Die:
Lead agency was
Choice in Dying
(*NOT Compassion & Choices)*

Government

Bioethics
(Hastings Center, Health Decisions

Universities / Teaching hospitals / medical professional groups.

Consumer groups, community organizing, lobbyists
AARP, Community Catalyst, Health Decisions)

This is a diagram that I developed a number of years ago – very abstract – to give the sense of which entities came together in what I call "the collaborative" in the 1990s.

RWJF was actively involved in the Clinton push for health reform, and Soros and a number of the other foundations made it clear their objective was redistribution of healthcare resources, in addition to aid to the dying. Bioethics, universities, lobbying and consumer groups were all involved.

Two types of policy activists:

PRO "ASSISTED SUICIDE"

Celebrates legal assisted suicide in Oregon, Washington, etc.

Compassion & Choices (Hemlock Society)

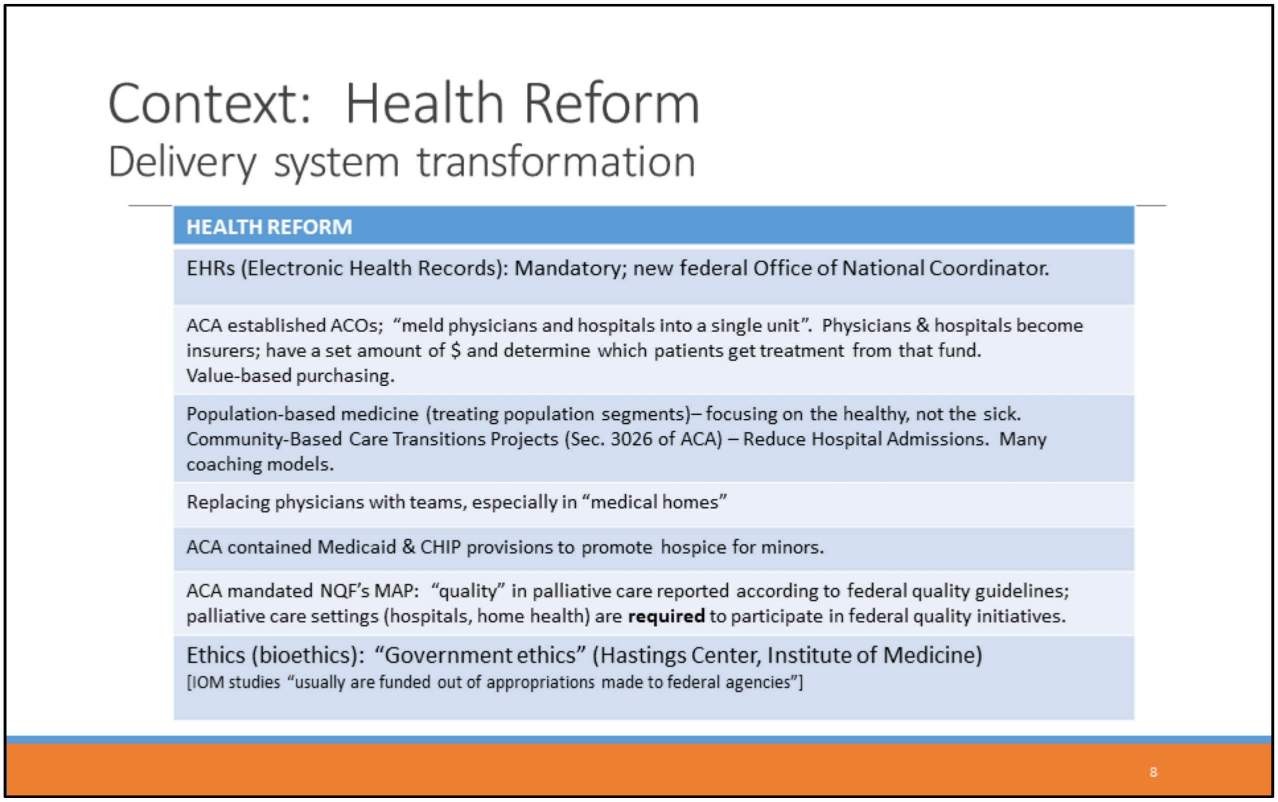
OPPOSES ASSISTED SUICIDE, BUT

Celebrates court decisions on so-called "right" to die (imposed deaths) of Nancy Cruzan, Hugh Finn, Terri Schiavo.

The collaborative included activists who were focused on end-of-life issues. There are generally two types.
There are those who were openly pro-assisted suicide, such as Compassion & Choices. But there is another category that **opposes** assisted suicide but focuses instead withdrawal of so-called futile treatment. I call this category the "Imposed Death" group.

This is a very important distinction for at least two reasons:

- State-level legislation purporting to be anti-euthanasia and/or anti-assisted suicide often contains language that opens the door to withholding/withdrawing ordinary treatment.
- The enemy of my enemy is not always my friend. They have coaxed a lot of pro-life into their camp by presenting a false common ground.



Context: Health Reform

Delivery system transformation

HEALTH REFORM
EHRs (Electronic Health Records): Mandatory; new federal Office of National Coordinator.
ACA established ACOs; "meld physicians and hospitals into a single unit". Physicians & hospitals become insurers; have a set amount of $ and determine which patients get treatment from that fund. Value-based purchasing.
Population-based medicine (treating population segments)– focusing on the healthy, not the sick. Community-Based Care Transitions Projects (Sec. 3026 of ACA) – Reduce Hospital Admissions. Many coaching models.
Replacing physicians with teams, especially in "medical homes"
ACA contained Medicaid & CHIP provisions to promote hospice for minors.
ACA mandated NQF's MAP: "quality" in palliative care reported according to federal quality guidelines; palliative care settings (hospitals, home health) are **required** to participate in federal quality initiatives.
Ethics (bioethics): "Government ethics" (Hastings Center, Institute of Medicine) [IOM studies "usually are funded out of appropriations made to federal agencies"]

So we've looked at this confusing definition of palliative care, and the reasons it was re-developed into a new model.

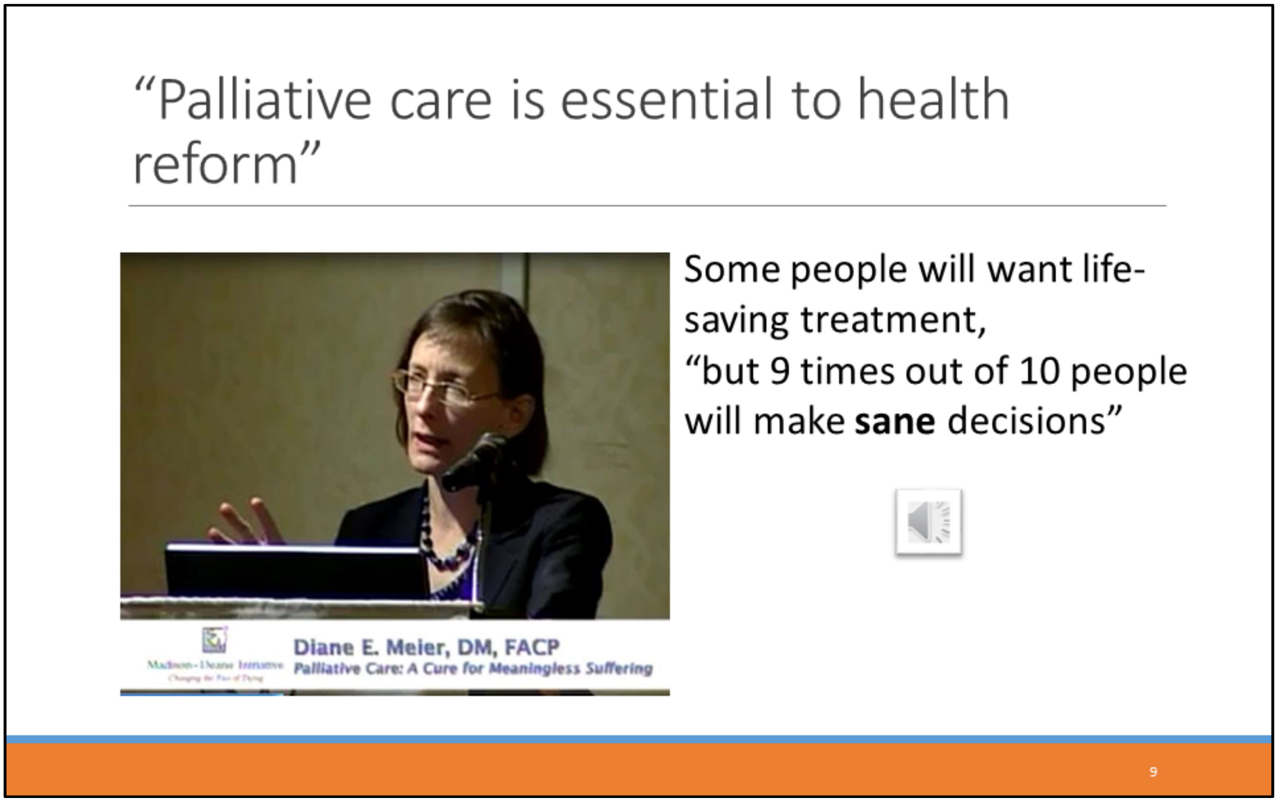
Now let's place that model in the context of health reform, or Obamacare. Health reform is much more than mandated insurance; it's as much or more about transforming our entire healthcare delivery system.

Twila Brase wrote an excellent article that was published in The Hill several months ago, in which she outlined 9 ways the Accountable Care Act and the federal takeover of our healthcare system endanger patients and doctors.

I've listed a few here, and added a few other characteristics. In a minute we'll see how palliative care dovetails with or enables these features

Here are a few features that tend to give "the system" the upper hand:

- Mandated electronic health records, which are used both to collect data for research, and to track a patient through care transitions.
- Accountable Care Organizations which melds physicians and hospitals into a single unit, and forces the physician to decide which of his patients receives treatment from a limited pool of funds.
- Defining Quality based on federal guidelines.



“Palliative care is essential to health reform”

Some people will want life-saving treatment,
“but 9 times out of 10 people will make **sane** decisions”

Diane E. Meier, DM, FACP
Palliative Care: A Cure for Meaningless Suffering

This is Diane Meier, director of the Center to Advance Palliative Care; was with the Senate HELP Committee and at CMS during the passage of Obamacare. She was funded heavily by Robert Wood Johnson Foundation, Soros, and federal funding from the NIH, and more recently by a special fund established by Elizabeth MacCormick – the former nun known for secularizing Manhattanville College.

I just wanted you to hear her explanation on why palliative care is essential to health reform. Listen carefully.

Palliative care is central to the success of health care reform. And the reason for that is, that [pause] you have [pause] When you take the time to talk to patients and families about what is really happening, to them medically, what the medical treatment options are, and the pros and cons of those treatment options, and you take the time to understand what patients are hoping for in the future, and what their fears are in the future, 90% of the time patients make much more conservative choices.

90% of Medicare patients are fit.
The 10% who are not healthy consume 2/3 of Medicare spending.

"Hospice & palliative care save <u>the system</u> a lot of money"

Diane Meier, MD

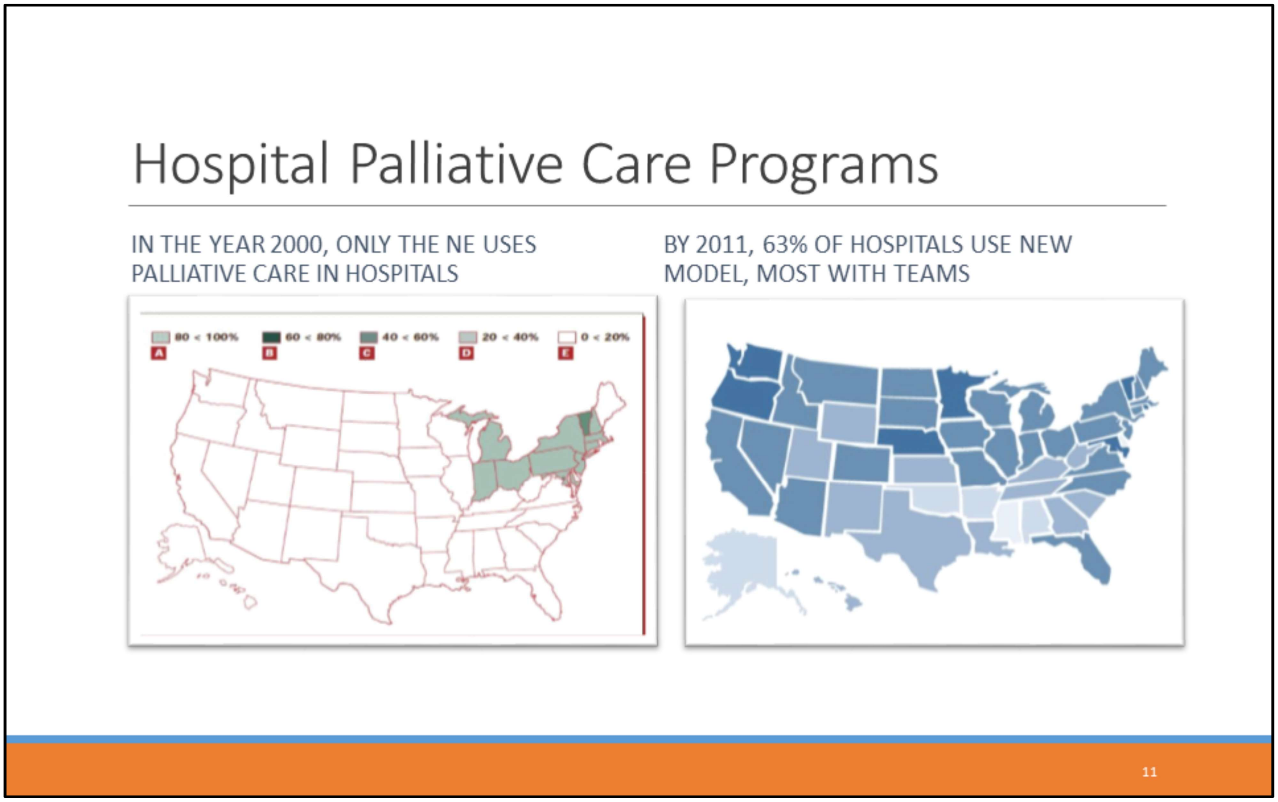
Founder, CAPC
(Center to Advance Palliative Care)

Consultant to Senate HELP Committee
during Obamacare passage

Here she is again. I'll skip the part where she bashes fee for service and claims that fee-for-service is what has ruined American healthcare, and pick up wher she says palliative care will save THE SYSTEM money, and explains where they would find the savings (from the sickest 10% of Medicare patients.)

So they're counting on hospice and palliative care to save the system by cutting spending for the 10% sickest Medicare patients.

The palliative care patient population [is] the 10% of Medicare beneficiaries who have five or more chronic conditions. And that group of Medicare beneficiaries accounts for two-thirds of all spending. OK? So 90% of all Medicare beneficiaries spend almost nothing. They're healthy. They don't need much. The sick Medicare beneficiaries are driving the overwhelming majority of spending. . . .
if we intend to get a handle on costs, and improve quality at the same time, it will not be possible without fully integrated palliative care.



Hospital Palliative Care Programs

IN THE YEAR 2000, ONLY THE NE USES PALLIATIVE CARE IN HOSPITALS

BY 2011, 63% OF HOSPITALS USE NEW MODEL, MOST WITH TEAMS

Just a diagram to show how Meier’s programs expanded across the US.

By 2011 the CAPC brand of palliative care was in over 63% of American hospitals.
[With this program, patients do not automatically stay in the hospital for hospice; many if not most are moved with palliative care to facilities outside the hospital.]

That’s the thing about this new model of palliative care. It’s ubiquitous.

C-TAC

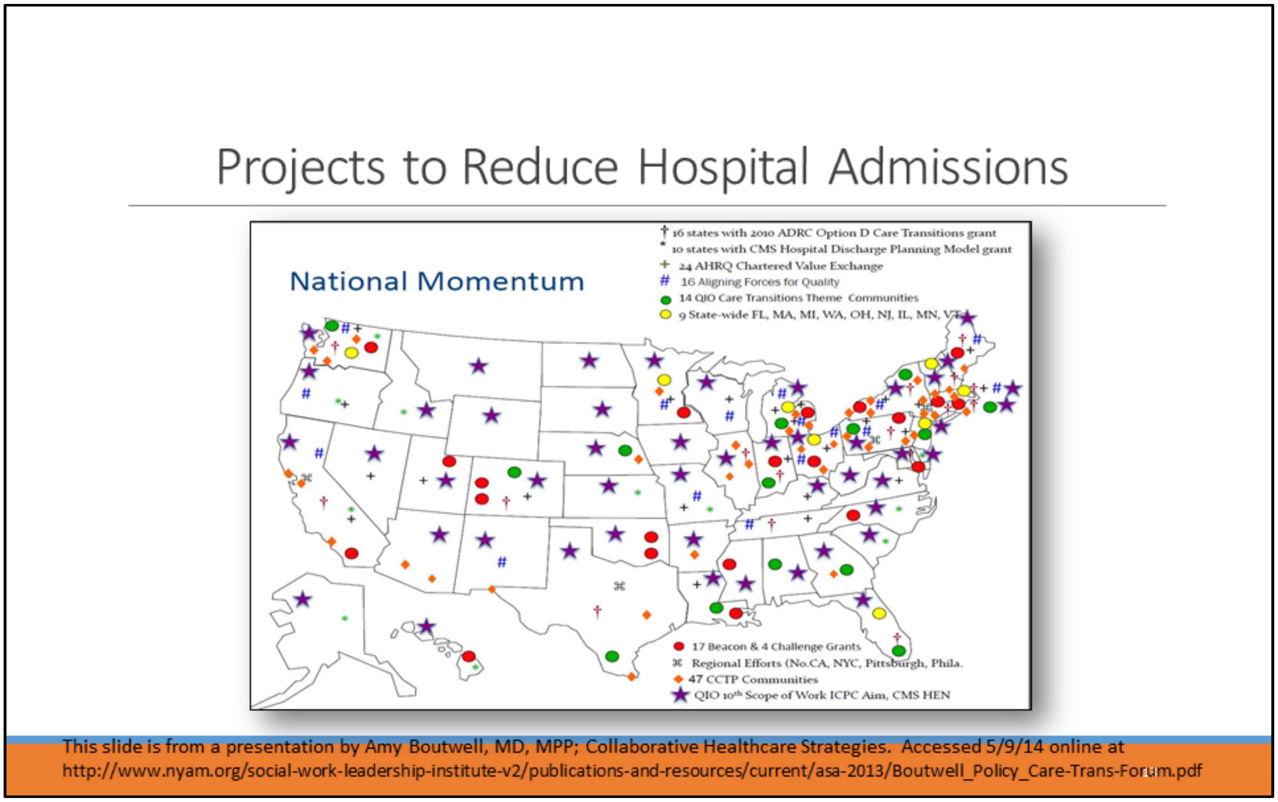
The Coalition to Transform Advanced Care (C-TAC) is a national non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payers. http:/thectac.org. Members include:

Coalition to Transform Advanced Care

12

I’m going to drop the name C-TAC a few times in the next slide or two. In many ways they are picking up where the old “Collaborative” left off. I just wanted you to have a mental picture of who is involved in that.

This is one of THEIR slides with logos of a few of the organizations who have signed on – some are more involved than others. Ascension Health, and Catholic Health Association – through the Catholic “Supportive Care Coalition” – have been very involved in most of the projects. I could do an entire hour presentation on C-TAC alone.

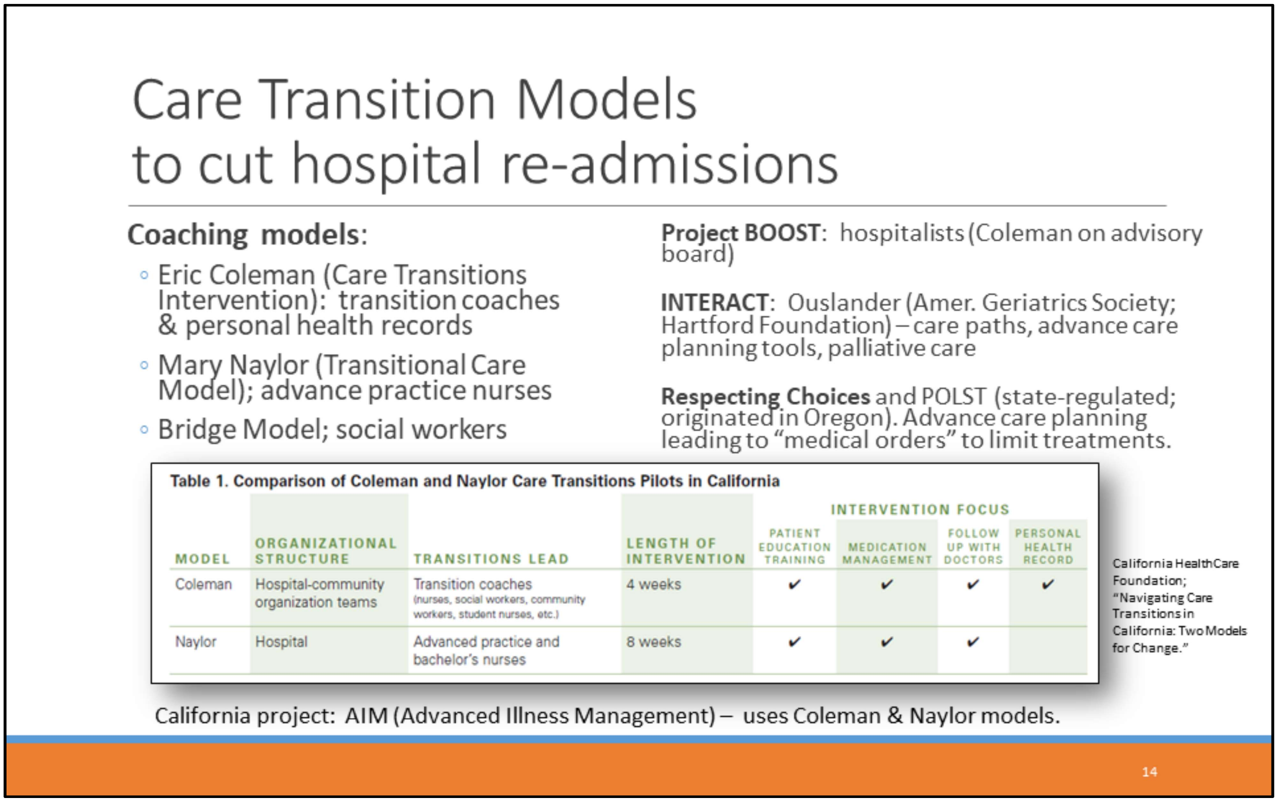


Projects to Reduce Hospital Admissions

This slide is from a presentation by Amy Boutwell, MD, MPP; Collaborative Healthcare Strategies. Accessed 5/9/14 online at http://www.nyam.org/social-work-leadership-institute-v2/publications-and-resources/current/asa-2013/Boutwell_Policy_Care-Trans-Forum.pdf

About two years ago CMS began penalizing hospitals for readmitting too many patients within 30 days of their stay at the hospital. This is causing hospitals to look or ways to transfer some patients to other places rather than admitting them to the hospital. What you see on this map are demonstration projects, most working off of federal funding one way or another, all with the purpose of streamlining the system and reducing hospital admissions. Earlier this year CMS decided there was too much overlap in these efforts, so they planned to narrow the types of programs.

There is a program in most, if not all, of the major metropolitan areas.



Care Transition Models to cut hospital re-admissions

Coaching models:

- Eric Coleman (Care Transitions Intervention): transition coaches & personal health records
- Mary Naylor (Transitional Care Model); advance practice nurses
- Bridge Model; social workers

Project BOOST: hospitalists (Coleman on advisory board)

INTERACT: Ouslander (Amer. Geriatrics Society; Hartford Foundation) – care paths, advance care planning tools, palliative care

Respecting Choices and POLST (state-regulated; originated in Oregon). Advance care planning leading to "medical orders" to limit treatments.

Table 1. Comparison of Coleman and Naylor Care Transitions Pilots in California

MODEL	ORGANIZATIONAL STRUCTURE	TRANSITIONS LEAD	LENGTH OF INTERVENTION	INTERVENTION FOCUS			
				PATIENT EDUCATION TRAINING	MEDICATION MANAGEMENT	FOLLOW UP WITH DOCTORS	PERSONAL HEALTH RECORD
Coleman	Hospital-community organization teams	Transition coaches (nurses, social workers, community workers, student nurses, etc.)	4 weeks	✔	✔	✔	✔
Naylor	Hospital	Advanced practice and bachelor's nurses	8 weeks	✔	✔	✔	

California HealthCare Foundation; "Navigating Care Transitions in California: Two Models for Change."

California project: AIM (Advanced Illness Management) – uses Coleman & Naylor models.

http://www.caretransitions.org/documents/CA_Two_Models.pdf

These are some of the models they use for those projects.

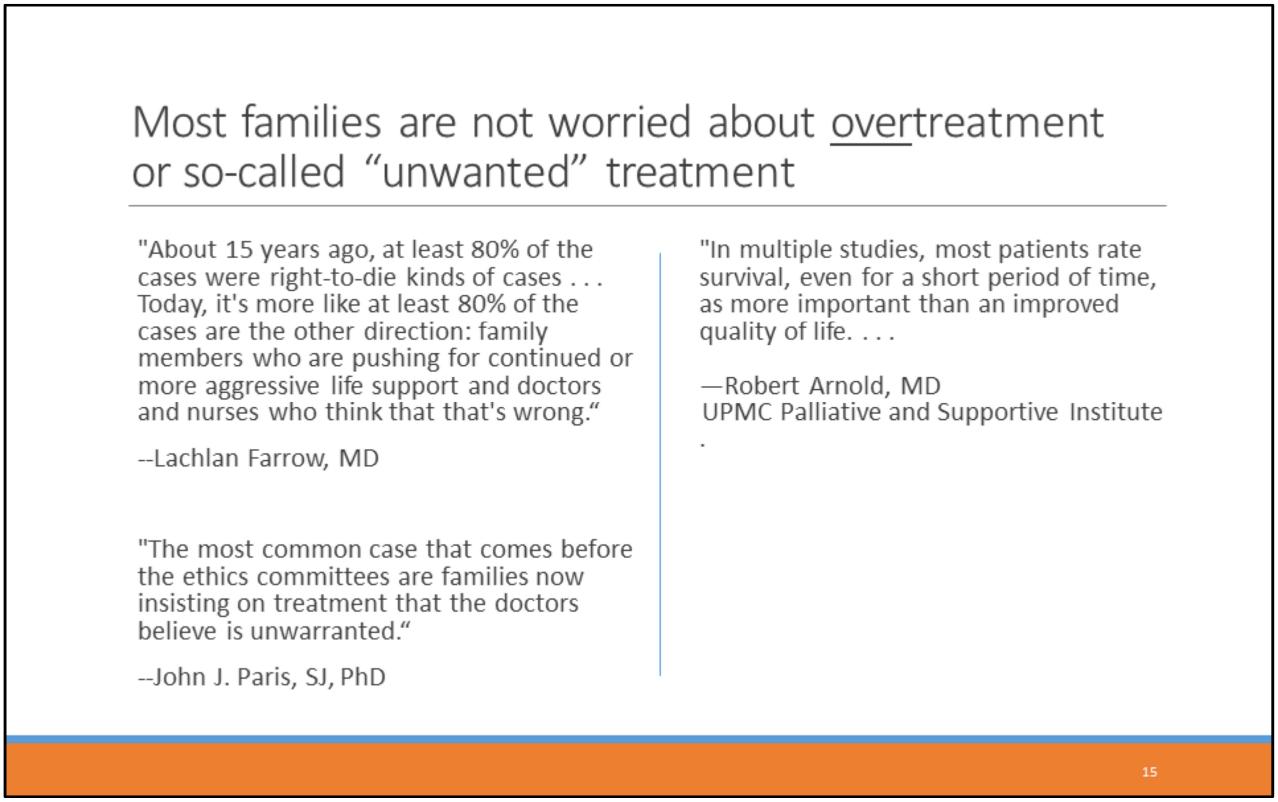
One of the most prominent care transitions projects is in California. Brad Stuart, the physician who designed and leads the project, is on the board of C-TAC, and won a multi-million-dollar grant from CMS to expand his model for national use.

His project – AIM (Advanced Illness Management) – uses the Coleman and Naylor models, and has been successful in reducing hospital admissions and moving patients into hospice and palliative care.

You'll see that though a primary care physician is supposedly involved, the structure is organized around a TEAM, and the "transitions coaches" are not physicians, and in many cases not even professionals with advanced medical degrees. Notice that Coleman's model, in particular, works with community-based groups.

C-TAC is using AIM as the basis for their Community Action Project which launched in Alameda County, California, and is being replicated in Detroit and other communities. The Community Action Project works with community based organizations, including community-organizing groups affiliated with PICO (and maybe Gameliel?) I think Stephanie will elaborate on this project in her talk up next.

On the right side of this slide are some other models that are often employed in combination with the Coleman/Naylor models. Notice that all these models involve advance care planning.



Most families are not worried about <u>over</u>treatment or so-called “unwanted” treatment

"About 15 years ago, at least 80% of the cases were right-to-die kinds of cases . . . Today, it's more like at least 80% of the cases are the other direction: family members who are pushing for continued or more aggressive life support and doctors and nurses who think that that's wrong.“

--Lachlan Farrow, MD

"The most common case that comes before the ethics committees are families now insisting on treatment that the doctors believe is unwarranted.“

--John J. Paris, SJ, PhD

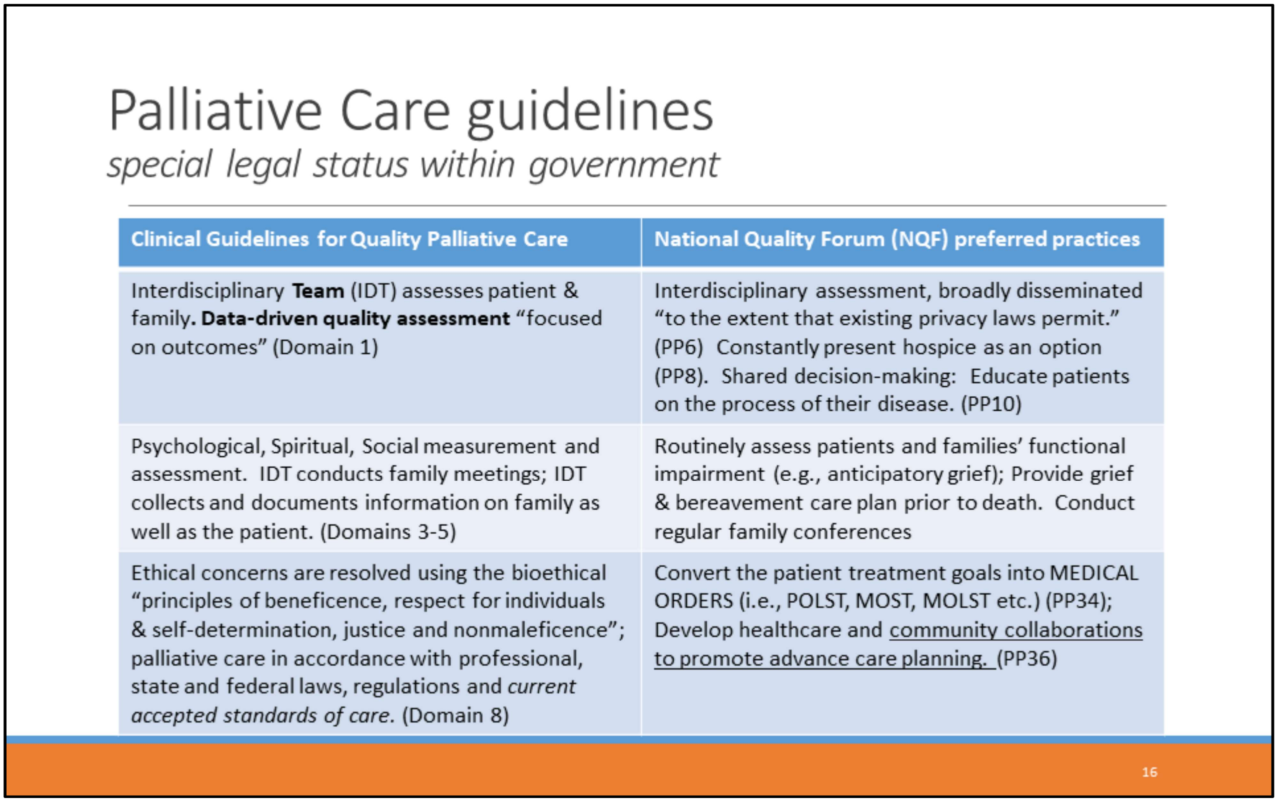
"In multiple studies, most patients rate survival, even for a short period of time, as more important than an improved quality of life. . . .

—Robert Arnold, MD
UPMC Palliative and Supportive Institute
.

Incidentally, The assumption that patients and families fear so-called life-prolonging treatment is a myth.

In candid moments, a few members of what I have termed the collaborative movement have revealed their real problem: that in fact the public usually wants to give life a chance if at all possible. The “<u>quality</u> of life” imperative is not as important to them as it is to the bioethicists.

The point here is that models such as these care transitions projects are UBIQUITOUS. There is slim to no chance of finding a hospital – or now a nursing homes or home health – that doesn’t have a palliative care team focused on goal-setting and quality of life.



Palliative Care guidelines

special legal status within government

Clinical Guidelines for Quality Palliative Care	National Quality Forum (NQF) preferred practices
Interdisciplinary **Team** (IDT) assesses patient & family**. Data-driven quality assessment** "focused on outcomes" (Domain 1)	Interdisciplinary assessment, broadly disseminated "to the extent that existing privacy laws permit." (PP6) Constantly present hospice as an option (PP8). Shared decision-making: Educate patients on the process of their disease. (PP10)
Psychological, Spiritual, Social measurement and assessment. IDT conducts family meetings; IDT collects and documents information on family as well as the patient. (Domains 3-5)	Routinely assess patients and families' functional impairment (e.g., anticipatory grief); Provide grief & bereavement care plan prior to death. Conduct regular family conferences
Ethical concerns are resolved using the bioethical "principles of beneficence, respect for individuals & self-determination, justice and nonmaleficence"; palliative care in accordance with professional, state and federal laws, regulations and *current accepted standards of care.* (Domain 8)	Convert the patient treatment goals into MEDICAL ORDERS (i.e., POLST, MOST, MOLST etc.) (PP34); Develop healthcare and community collaborations to promote advance care planning. (PP36)

And then there are the Clinical Practice Guidelines for Quality Palliative Care, that supposedly guide the palliative care clinician.

Again, the cards are rigged against the clinician who wants to practice ethical medicine.

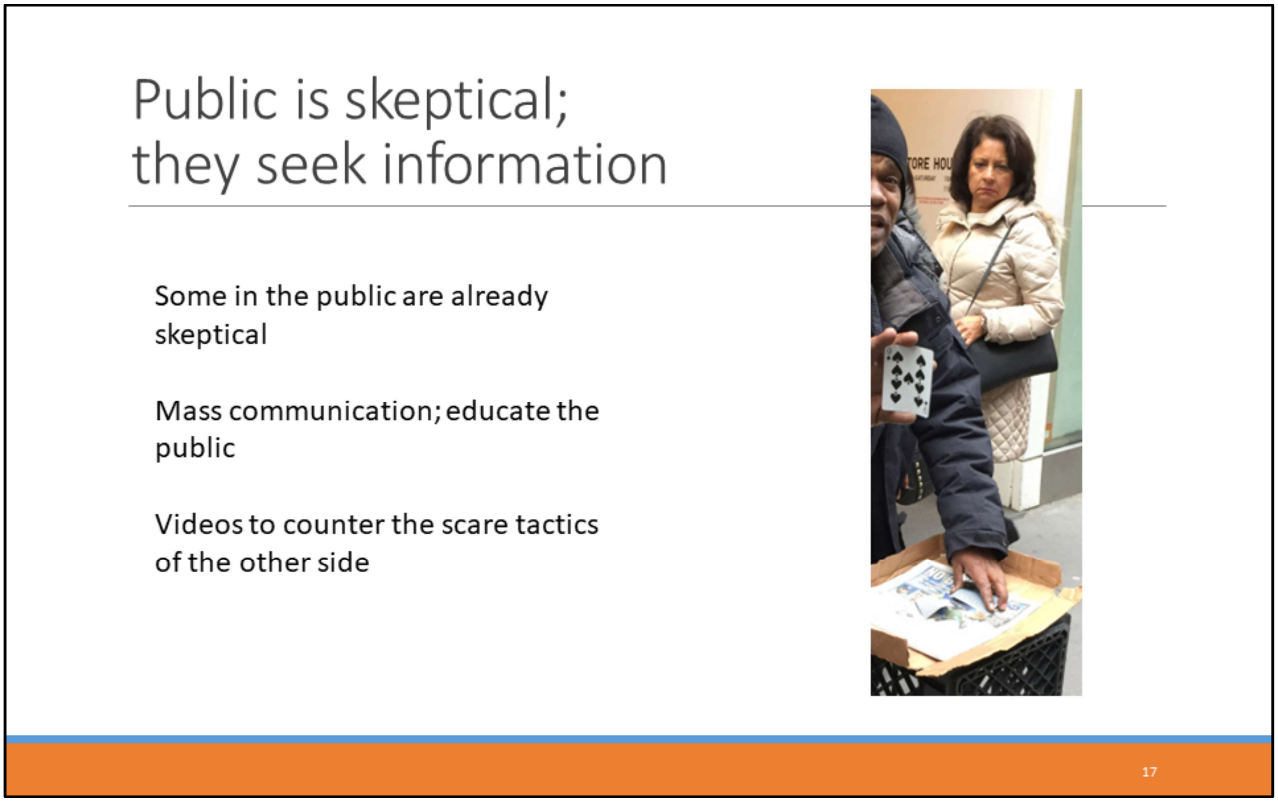
Again we see the mandate for TEAM-based care. Data-driven quality assessments – meaning that quality of life is assessed by predetermined checklists that pseudo-scientifically evaluate the patient's quality of life, and suggest the next course of action.

As "voluntary consensus guidelines", they have special legal status within the federal government. Government regulators have a natural tendency to use such standards in setting regulations for industries, like healthcare, whenever possible. The guidelines, then, have the force of law.

The Clinical Guidelines can also be used as performance standards to regulate the industry. The Guidelines as well form the basis of a set of Preferred Practices that were issued by the National Quality Forum. The Preferred Practices call for the Interdisciplinary Teams to use POLST, and to meet frequently with families to "provide information, discuss goals of care . . . and the benefits and burdens of potential interventions."

The guidelines were created about a decade ago by about 20 people from the collaborative – most of whom were from the "imposed death" group of so-called right-to-die groups. The Guidelines are in their Third Edition, and have evolved to reflect "current standards" and to dovetail with recommendations from the bioethicists at the Institute of Medicine and from other bureaucratic entities.

Looks like once again The System has stacked the deck against ethical medicine; in favor of imposed death.



Public is skeptical; they seek information

Some in the public are already skeptical

Mass communication; educate the public

Videos to counter the scare tactics of the other side

So back to the 3-card monte. What can we do to protect people?
Educate.
The public is already skeptical, which is why C-TAC is so determined to get them on board with community organizing and lobbying.

I’d love to see video campaigns of our own, to counter the scare tactics of the other side. For example, while the other side is spreading scary images of patients hooked up to machines and feeding tubes, I’d like to see more pictures like this next one.

With the PEG

This was my father, four months after he had a life-threatening accident.

I was told “you have to understand, Miss whitlock, your father is 90, and he has severe dementia. Studies show feeding tubes do not extend the lives of dementia patients.”

Fortunately, we didn’t cave to the pressure. He was given a PEG. Dad lived almost two years – long enough to have some good visits with family, drives around town, singing with friends, and to see his great-grandson born.

That’s quality of life.