INFUSING CULTURAL HUMILITY INTO ADVANCE CARE PLANNING

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ADVANCE CARE PLANNING:

The act of communicating one’s wishes around future medical care either verbally or in writing. Common documents:

• Advance health care directive or a living will
• Durable power of attorney for health care
• Physician’s Order for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) form

ACP is a process in which a patient's current condition and prognosis are reviewed, their wishes for information regarding their illness are elicited, likely medical dilemmas are presented, and options are discussed. (Detering & Silveira, 2016).
THE OVERARCHING GOAL

ACP may include the completion of an advance directive or POLST form, although this is not the primary intent of ACP discussions. Rather, the intent of ACP is to ensure that patients receive care that is aligned with their goals and values.
The IOM’s report, *Dying in America*: “advance care planning is essential to ensure that patients receive care [that] reflects their values, goals and preferences...advance planning and medical orders are needed to ensure these preferences are honored.”

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1991</td>
<td>Congress enacts the Patient Self-Determination Act</td>
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<td>2006</td>
<td>The National POLST Advisory Panel, later known as the National POLST Paradigm Task Force (NPPTF), convened to establish quality standards for POLST Paradigm Forms and Programs and to assist states in developing the POLST Paradigm.</td>
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<td>2012</td>
<td>The California Health Care Foundation (CHCF) reported that 82% of people believe it is important to have their end-of-life wishes in writing.</td>
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<td>2014</td>
<td>Medicare begins reimbursement for ACP discussions in the inpatient and outpatient settings.</td>
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<td>2016</td>
<td>The State of Oregon creates nation’s first POLST form.</td>
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A CHCF survey in 2012 found that 82% of people believe it’s important to put their end-of-life wishes in writing.

When we engage in ACP with our patients, it is essential to keep in mind the inverse of this statistic: if 82% believe it is important, presumably 18% of people do not.

This critical detail should inform our policies and approach to ACP.
HOW WE OUGHT TO BEGIN

1. We ought to move away from a presumption that all patients need an advance care plan, gently contesting it with our colleagues.

2. When we engage in the work of ACP with our patients, we need an approach that both allows for the uniqueness of each individual within a cultural group and promotes curiosity by the health care provider to inquire about each patient’s values.

3. Such an approach begins with the provider exploring his or her own set of values and beliefs about advance care planning and medical decision-making. This is an approach known as cultural humility.
‘Cultural humility’ is defined as a constant and lifelong process of self-reflection and self-critique whereby the provider learns about another’s culture only after an examination of his/her own beliefs, values, and cultural identities (Anderson Juarez, et. al, 2006).

This approach challenges health care providers to move away from identifying personal values—especially specific beliefs about advance care planning—as ‘the norm.’

It also creates space to acknowledge the presence of two perspectives: the provider’s and the patient’s, and allows for the opportunity to recognize both as valid.
CULTURAL COMPETENCY VS. CULTURAL HUMILITY
To infuse advance care planning with cultural humility, we should complete the pre-requisite task of thoughtful examination of the values at play.

Advance care planning is not a values-neutral endeavor; the very act of it is rooted in Western bio-ethical values. Only by understanding these value-laden roots will we be able to generate more inclusive and effective policies and practices around this delicate work.
THE FOUR VALUES

1. Patient Autonomy/Self-Determination
2. Informed Decision-Making
3. Truth-Telling
4. Control over the Dying Process

(Johnstone and Kanitsaki, 2009)
Differing Values

In many minority ethnic groups, family sovereignty and family-determination supersede individual-sovereignty and self-determination as the preeminent principles guiding decision-making at the end of life.

(Johnstone and Kanitsaki, 2009)
COMPARING ACP TO GOALS OF CARE CONVERSATIONS

When we invite our patients to participate in advance care planning, let us promote it as optional. After all, *advance* care planning is referencing medical interventions that are to be attempted (or avoided) in the future.

This voluntary characteristic is quite different from an emergent ‘goals of care’ conversation that must take place, for example, in the Intensive Care Unit.

When we are willing to acknowledge ACP as optional, we may be better prepared to accept a patient’s decision to opt out of it.
AN ILLUSTRATION: CALIFORNIA’S POLST FORM

<table>
<thead>
<tr>
<th>INFORMATION AND SIGNATURES:</th>
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<tbody>
<tr>
<td>Discussed with:</td>
</tr>
<tr>
<td>□ Advance Directive dated _____________, available and reviewed</td>
</tr>
<tr>
<td>□ Advance Directive not available</td>
</tr>
<tr>
<td>□ No Advance Directive</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My signature below indicates to the best of my knowledge that these orders are consistent with the patient’s medical condition and preferences.</td>
</tr>
<tr>
<td>Print Physician/NP/PA Name:</td>
</tr>
<tr>
<td>Physician/NP/PA Signature: (required)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Patient or Legally Recognized Decisionmaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.</td>
</tr>
<tr>
<td>Print Name:</td>
</tr>
<tr>
<td>Signature: (required)</td>
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</tbody>
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<tr>
<th>Mailing Address (street/city/state/zip):</th>
<th>Phone Number:</th>
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*For Registry Use Only*

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011 or 10/1/2014 are also valid*
THE BENEFITS OF ADVANCE CARE PLANNING

We know family members have reported experiencing less distress when they know their loved ones’ preferences at the end of life. (Detering, et al, 2010).

We know it is far easier to follow care preferences outlined on a Physician’s Order for Life-Sustaining Treatment (POLST) form than to attempt to elicit a patient’s wishes from a distraught family in the Emergency Room.

Understanding the benefits, it is incumbent upon us to make a strong case for ACP to our patients. This is an essential part our work as social workers in health care.
THE RISK: ACP BENEFITS AS BLINDERS

Some health care providers may cite these benefits and the goals of honoring patients’ wishes, whatever those wishes may be, as reasons why everyone “should” complete advance care planning.

“Why wouldn’t a patient want to participate?”
IDEAL POLICIES FOR ADVANCE CARE PLANNING

We should put in place policies and practices that ensure we offer an advance care planning conversation and assistance with accompanying ACP documents to 100% of our patients.

“The traditional objective of advance care planning has been to have patients make treatment decisions in advance so that clinicians can attempt to provide care consistent with their goals. A better objective for advance care planning is the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions.”

(Sudore & Fried, 2010)
WHEN WE ENCOUNTER THE 18%

Grounded in cultural humility, we can respect when patients decline an invitation to an advance care planning conversation.

1. We can advocate for patients to the medical team and/or health system in honoring these opt-outs.

2. Let us shift our focus from advance care planning form completions to ascertaining and documenting the name of their trusted surrogate. If your state has a Next-of-Kin Law, educate the patient about their default surrogate and how to appoint someone else if s/he wishes.

3. Let’s provide anticipatory guidance to the patient. Let’s encourage these patients to have a conversation with their designated decision-maker and their family, offering to facilitate the conversation for them if they’d like.
ACTIVITY: APPLYING CULTURAL HUMILITY TO ACP
REFERENCES


9. Kaiser Permanente Image Library; Microsoft BING image library with common creative licenses.
FROM THE LIST:

- TED Talks
- Having two last names
- Hummus
- Unpaid Internships
- New Balance shoes
- 80's Night
- Religions their parents don’t belong to
- Yoga
- Threatening to move to Canada
- Coffee

My proposed addition:
- Advance Care Planning