Advance Directives: Are We Expecting More Than They Can Deliver?

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Disclosure

Susan Tolle and the OHSU Center for Ethics in Health Care do not accept gifts from the healthcare industry and have no relevant financial relationships to disclose that would present a conflict of interest.
Objectives:

1. Examine ways that advance directives are effective
2. Review data about the shortcomings of advance directives
3. Explore data about changing perceptions of quality of life as people adapt to living with disabilities
## Differences between Advance Directive & POLST

<table>
<thead>
<tr>
<th></th>
<th>Advance Directive</th>
<th>POLST (Portable Orders for Life Sustaining Treatment)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who is it for?</td>
<td>Everyone 18 and older.</td>
<td>People with a serious illness or who are very old and frail.</td>
</tr>
<tr>
<td>What kind of document is it?</td>
<td>It is a legal document.</td>
<td>It is a medical order.</td>
</tr>
<tr>
<td>Who signs it?</td>
<td>You fill it out and sign it. Also, your health care representative signs it and witnesses or a Notary.</td>
<td>Your doctor* fills it out with your input. Then signs it.</td>
</tr>
<tr>
<td>Do I need a lawyer?</td>
<td>No.</td>
<td>No.</td>
</tr>
<tr>
<td>Who keeps the form?</td>
<td>You keep the original where loved ones can find it. You give a copy to your health care representative and your doctor.</td>
<td>Your doctor’s office keeps it and enters it into the electronic Oregon POLST Registry. They give you a copy that you post at home in a visible place like the fridge.</td>
</tr>
<tr>
<td>Can I change the form if I change my mind?</td>
<td>Yes. You can tear up the old one. Then write a new one where loved ones can find it. You give a copy to your health care representative and your doctor.</td>
<td>Yes. You can ask for an appointment with your doctor to change it.</td>
</tr>
<tr>
<td>What if there is a medical emergency and I cannot speak for myself?</td>
<td>Your health care representative speaks for you and honors your wishes.</td>
<td>The ambulance staff, hospital staff and doctors look for the medical orders in the electronic data base and follow them.</td>
</tr>
</tbody>
</table>

*Doctor means anyone who can sign a POLST form (MD, DO, NP, PA, ND).
In What Ways are Advance Directives Effective?
Effect of Advance Directives on Family Stress

*T Stress measured on Horowitz Impact of Events Scale (Higher score = more stress)

Advance Care Planning Decreases:

1. Anxiety
2. Grief
3. Post-Traumatic Stress

And...

4. Burden on Surrogate Decision Makers

Advance Directives Allow the Appointment of a Surrogate (Health Care Representative/POA)
Shortcomings of Advance Directives
Advance Directives/Care Planning: Clear, Simple, and Wrong

R. Sean Morrison

Journal of Palliative Medicine
Vol. 23, No. 7
June 9, 2020

doi:10.1089/jpm.2020.0272
A 2018 Review of 80 Systematic Review (1600 original articles)

Conclusions:

✓ No evidence of influence on medical decision making

✓ No association with goal concordance

A 2020 Scoping Review of 62 Recent High-quality Articles

✓ No evidence that ACP influenced goal concordant care

✓ No association with subsequent health care use (ED visits, hospitalization or critical care)

Advance Directives’ Negligible Association on Hospitalizations and Hospital Deaths

• Health and Retirement Study

• N=6,122 age 60 & older at death

• 72% advance directives at time of death 2010

Price-Adjusted Total Medicare Reimbursements per Enrollee by Hospital Referral Region (2018)

Inpatient Days per Chronically Ill Medicare Enrollee during the Last Six Months of Life by Hospital Referral Region (2018 deaths)

Deaths among Fee-for-Service Medicare Beneficiaries in Oregon, Washington and the Rest of the United States

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Advance Care Planning and People with Disabilities
Guarding Against Bias in the Care of People with Disabilities
Physician Perception of People with Disabilities and Their Health Care

“82.4% of physicians report that people with significant disabilities have a lower quality of life than non-disabled people.”

Portable Orders for Life-Sustaining Treatment (POLST®):

Guidelines on POLST Use for Persons with Significant Disabilities who are Now Near the End of Life

Developed by the Oregon POLST Coalition and approved by its Education Committee in July 2020
Who is POLST for?

People with serious illness or who are very old and frail and want to set limits on treatment
Advanced Cancer
Advanced Heart Disease
Advanced Dementia
Advanced Frailty
## Top 10 Causes of Death with Proportion of Registered POLST Forms at Death

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>All Natural Deaths (n)</th>
<th>Registered POLST (n)</th>
<th>Registered POLST (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malignant neoplasms</td>
<td>16198</td>
<td>7685</td>
<td>47.4%</td>
</tr>
<tr>
<td>Heart Diseases</td>
<td>13656</td>
<td>5689</td>
<td>41.7%</td>
</tr>
<tr>
<td>Alzheimer’s Disease and Dementia</td>
<td>6850</td>
<td>4246</td>
<td>62.0%</td>
</tr>
<tr>
<td>Chronic lower Respiratory diseases</td>
<td>4181</td>
<td>2015</td>
<td>48.2%</td>
</tr>
<tr>
<td>Cerebrovascular Diseases</td>
<td>3203</td>
<td>1387</td>
<td>43.3%</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>2381</td>
<td>949</td>
<td>39.9%</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>1271</td>
<td>383</td>
<td>30.1%</td>
</tr>
<tr>
<td>Influenza and Pneumonia</td>
<td>892</td>
<td>346</td>
<td>38.8%</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>871</td>
<td>573</td>
<td>65.8%</td>
</tr>
<tr>
<td>Nephritis</td>
<td>793</td>
<td>421</td>
<td>53.1%</td>
</tr>
<tr>
<td>All others</td>
<td>15202</td>
<td>6000</td>
<td>39.5%</td>
</tr>
<tr>
<td>All causes</td>
<td>65498</td>
<td>29694</td>
<td>45.3%</td>
</tr>
</tbody>
</table>

2015-2016 Decedents

Age of Oregonians with POLST at Death

Number of registered POLST form orders for DNR and CPR by age group 2015-2016. CPR, cardiopulmonary resuscitation; DNR, do not resuscitate.

Is POLST Associated with Greater Concordance?
Patient’s preferences recorded as medical orders on a POLST Form and how those orders match with death in the hospital

<table>
<thead>
<tr>
<th>Type of Treatment</th>
<th>% of Decedents Dying in Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort Measures Only</td>
<td>6.4%</td>
</tr>
<tr>
<td>Limited Treatment</td>
<td>22.4%</td>
</tr>
<tr>
<td>Full Treatment</td>
<td>44.2%</td>
</tr>
<tr>
<td>No POLST in Registry</td>
<td>34.2%</td>
</tr>
</tbody>
</table>

Is POLST the Explanation?

To Have Concordance Takes More Than POLST

- Nimble hospice response
- Options in community-based care
- Systems to locate existing POLST forms
An Ongoing Systems Challenge

Do Not Resuscitate. Limited Treatment.
It takes a lot more than documents to have goal concordant care.
Together
We Can Become More
Trustworthy Care Partners
Thank you

ohsu.edu/center-for-ethics