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Advance Care Planning and Communication with Patients with Neurodegenerative Disorders

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Disclosures

- No relevant disclosures

Objectives

- Demonstrate importance of advance care planning and communication skills in the care of patients with neurodegenerative disease
- Provide tools to improve delivery of this care
- Review practical implementation

Identifying the Need

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A Familiar Story

- 75-year-old with 15-year history of Parkinson's Disease (PD)
- Hospitalized with aspiration pneumonia, intubated
- Ileus with subsequent poor absorption of dopaminergic agents

- Palliative Care consulted
- Family shares that they were told patient's PD was "treatable" and he would "die of something else first"
- Family distressed by needing to make sudden decisions without patient's input

Historical Perspective

A NUMBER of s
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proach to the can
ing the issue of dis
sis.

Of 442 physician

For editori
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the mail in 195
always or usually
while 69% said the
never tell the pati
generally did not r
known, exception

In Oken's[3] survey of 219 phys
at Michael Reese Hospital, bas
questionnaires and personal
views, 90% generally did not i
the patient. Although more
three fourths of the group cited
cal experience as the major det
nant of their policies, the data b
relationship to length of exper
or age. Many showed inconsistencies
in attitudes, personal bias, and resist-
ance to change and to further
research, suggesting that emotion-
laden a priori personal judgments
were the real determinants of policy.
Underlying were feelings of pessi-
mism and futility about cancer.

As shown in Table 1, 98% reported
that their general policy is to tell the
patient. Two thirds of this group say
that they never or very rarely make
exceptions to this
sharp contrast wit
which showed tha
not tell the patien
that they never o
exceptions to this

Thus, as in 1961, it appears that
personal and emotional factors are of
major importance in shaping policy,
perhaps even more so in the present
study. Subsequent to the general
inquiry, "How did you acquire your
policy?" it was specifically asked if
personal issues were determinants.
Seventy-one percent of the 1961
survey and 92% of the current survey
reported that personal elements were
involved. Again, as in 1961, these

Do Patients Want to Talk About This?

Table 2. Percentage Responding "When Should your doctor discuss . . . ."

	At the Time of Diagnosis	During the Next Few Visits	Only When the Disease Worsens	Wait Until I Ask	Never	Unsure
Treatment goals and options	73.2	19.9	4.1	1.6	0	1.2
Symptoms and treatment side effects	73.9	19.7	3.6	2.4	0	0.4
Involving family in disease discussion	56.6	17.3	7.2	15.3	1.2	2.4
Advance care planning documents	25.2	24.8	19.5	12.6	5.7	12.2
Life expectancy	23.8	14.1	25.0	23.8	2.0	11.3
Planning for end-of-life care	13.0	14.2	39.3	20.2	1.6	11.7
Family communication about end-of-life care	12.5	13.3	43.1	17.3	3.2	10.5
End-of-life care options	12.1	9.3	48.4	16.9	0.8	12.5

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[7] Tuck et al

Does Presence of Neurologic Disease Affect Treatment Preference?

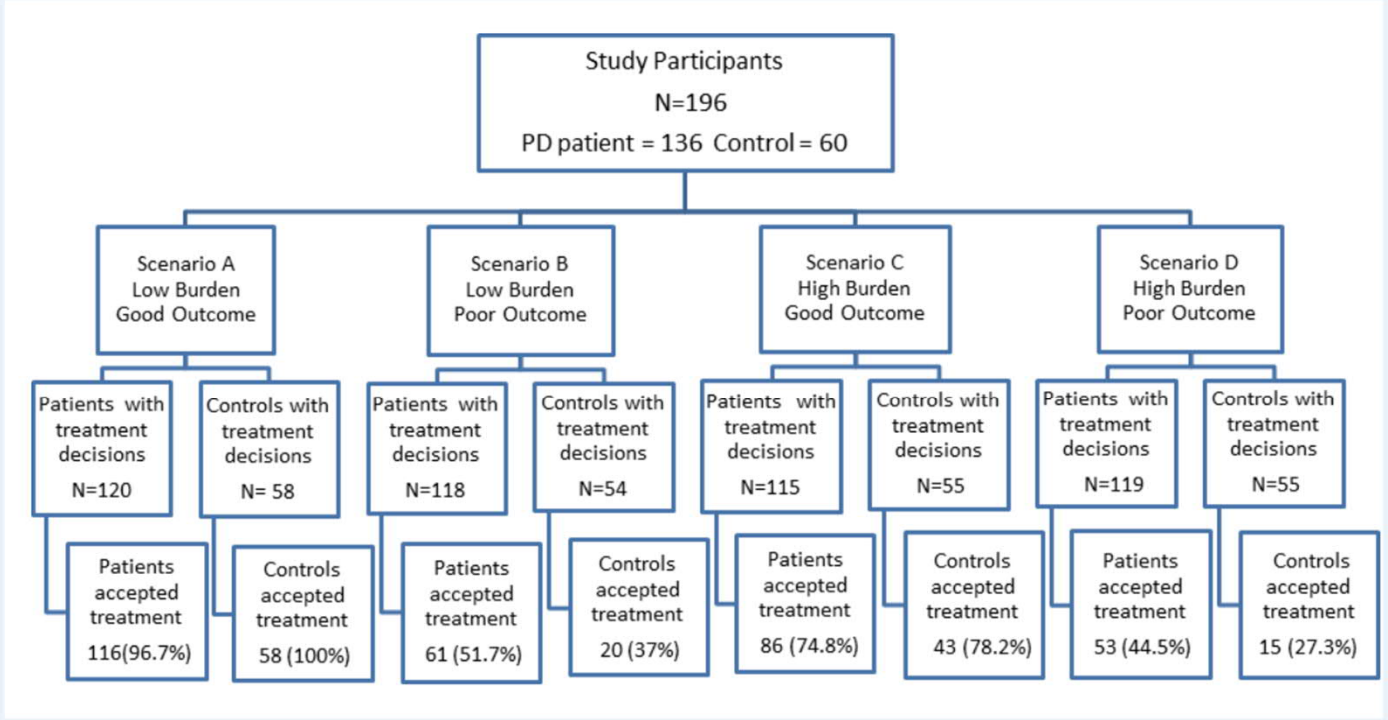

Figure 1 Treatment preference to each scenario. The number of participants who made treatment decisions and accepted treatment under each scenario are listed.

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TABLE 3 Predictors for Treatment Preferences of Parkinson's Disease Patients

Scenarios	Parameters	Odds Ratio	95% Confidence Interval	*P* Value
Scenario B*				
Low burden	Religion vs. free thinker	7.43	1.97–28.07	0.003
Poor outcome	Motor score >17 vs. motor score ≤17	2.51	1.14–5.50	0.022
Scenario C*				
High burden	Religion vs. free thinker	6.93	2.23–21.43	0.001
Good outcome	Married vs. others[a]	6.93	2.23–21.43	0.001
Scenario D*				
High burden	Chinese vs. non-Chinese	0.29	0.10–0.79	0.016
Poor outcome	Knowledge about PD high vs. low	0.37	0.17–0.80	0.012
	Motor score >17 vs. motor score ≤17	3.05	1.35–6.90	0.008

Li et al

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Shared Decision Making

Pergamon

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0277-9536/97 $17.00 + 0.00

SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO)

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Patient and Clinician Perspective Vastly Different

Patient, Caregiver, and Oncologist Report of Prognostic Discussion Processes

	N(%)								
	Patient			Caregiver			Oncologist		
	First recurrence	Second or more	Total	First recurrence	Second or more	Total	First recurrence	Second or more	Total
Was prognosis discussed?									
Yes			3 (17.6)			8 (47.1)			10 (58.8)
No			14 (82.4)			9 (52.9)			7 (41.2)
Was curability discussed?									
Yes			4 (23.5)			9 (52.9)			12 (70.6)
No			13 (76.5)			8 (47.1)			5 (29.4)
Were EOL goals discussed?									
Yes			3 (17.6)			6 (35.3)			6 (35.3)
No			11 (64.7)			11 (64.7)			11 (64.7)
I don't know			3 (17.6)			0			0
Have you ever discussed prognosis or life expectancy with oncologist?									
Yes			7 (41.2)			5 (29.4)			13 (76.5)
No			10 (58.8)			10 (58.8)			1 (5.9)
I don't know			0			2 (11.8)			3 (17.6)

Note: EOL = end-of-life

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Walsh et al

Unique Challenges in Neurological Diseases

- Cognitive impairment is seen in the majority of progressive neurologic diseases
- Decision making capacity can be affected prior to a diagnosis of dementia

- Advanced age can equate to multiple medical comorbidities
- Acute decline to critical illness can occur

Abu et al

What Should We Be Doing?

- Early introduction of conversations regarding values and medical decision making
- Early establishment of surrogate decision maker

Limitations to Practical Implication

- Time

- Provider comfort/training
- Cultural expectations/differences
- Stigma

Communication Tools

Normalize Conversations Early

- Start by asking permission!
- “I ask all of my patients this – if you couldn’t talk to me and I needed to make a decision about your health care, who should I talk to?”
- “Have you ever thought about things you might not want if you were to become very ill? For example, some patients are ok with the ICU and want us to ‘do everything,’ but others are not ok with certain things.”

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Focus on Values

- What defines “quality of life” for this patient? Their family unit?
- Spiritual history can be valuable
- Recognize your own biases!

Recognize Emotions/Explore

- NURSE acronym
  - Name
  - Understand
  - Respect
  - Support
  - Explore

- “Tell me more….”

Smith RC
Back AL et al

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Revisit Longitudinally

- Priorities change overtime
- Interventions may play a different role as disease progresses
- Healthy people underestimate quality of life in patients with ALS – this can be true of patients early in disease as well

Lulé et al

SPIKE

- **Setting up** the interview
- Assessing the patient's **perception**
- Obtaining the patient's **invitation**
- Giving **knowledge** and information
- Addressing the patient's **emotions** with **empathetic** responses

 Baile et al

REMAP

- Reframe
- Explore emotion
- Map values
- Align with values
- Propose a plan

 Childers et al

Practical Implications

What if a MPOA is Not Available?

- Know your state laws and institutional rules

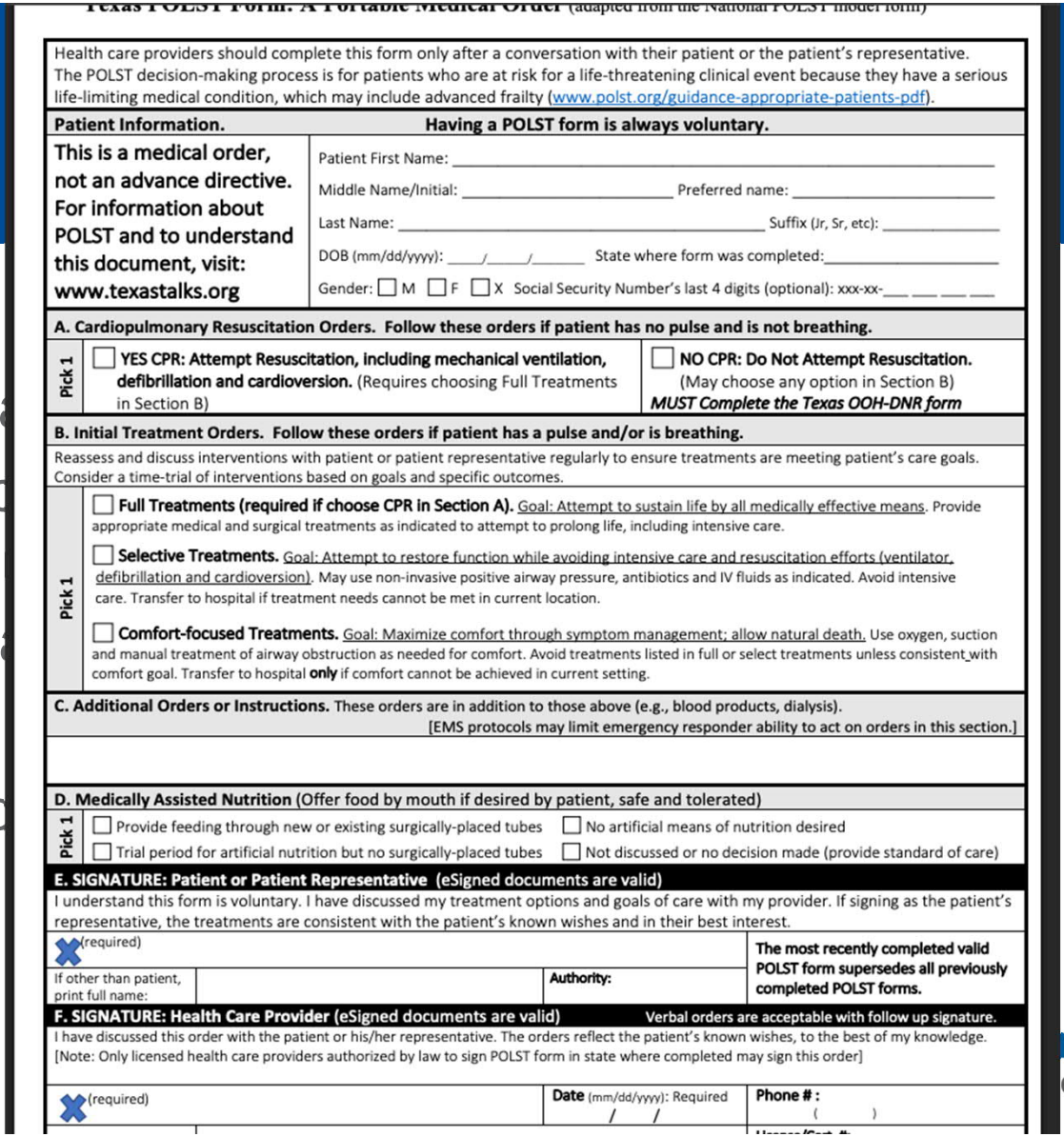
- Spouse
- Majority of Adult Children

”Do I need to talk to a lawyer about…”

- Medical Power of Attorney and Advance Directive to Physicians readily available online
  - Two witnesses
  - Notarize if taking across state lines
- Out of Hospital DNR also available – requires physician certification
- Many patients (and even health care providers) confuse in hospital DNR and OOHDNR

MOST/POLST

- Physician order that
- "Order set" – not lega
- Has been in existenc
  - Not widely adapted i
- Advance directives t
- Can be a guide to co



Texas POLST Form: A Portable Medical Order (adapted from the National POLST Model form)

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients-pdf).

Patient Information. **Having a POLST form is always voluntary.**

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.texastalks.org

Patient First Name: _____

Middle Name/Initial: _____ Preferred name: _____

Last Name: _____ Suffix (Jr, Sr, etc): _____

DOB (mm/dd/yyyy): ____/____/_____ State where form was completed: _____

Gender: ☐ M ☐ F ☐ X Social Security Number's last 4 digits (optional): xxx-xx-___ ___ ___ ___

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1

☐ **YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion.** (Requires choosing Full Treatments in Section B)

☐ **NO CPR: Do Not Attempt Resuscitation.** (May choose any option in Section B) ***MUST Complete the Texas OOH-DNR form***

B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1

☐ **Full Treatments (required if choose CPR in Section A).** Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.

☐ **Selective Treatments.** Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.

☐ **Comfort-focused Treatments.** Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital **only** if comfort cannot be achieved in current setting.

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis). [EMS protocols may limit emergency responder ability to act on orders in this section.)

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated)

Pick 1

☐ Provide feeding through new or existing surgically-placed tubes ☐ No artificial means of nutrition desired

☐ Trial period for artificial nutrition but no surgically-placed tubes ☐ Not discussed or no decision made (provide standard of care)

E. SIGNATURE: Patient or Patient Representative (eSigned documents are valid)

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's representative, the treatments are consistent with the patient's known wishes and in their best interest.

✖ (required) | **The most recently completed valid POLST form supersedes all previously completed POLST forms.**

If other than patient, print full name: | **Authority:**

F. SIGNATURE: Health Care Provider (eSigned documents are valid) Verbal orders are acceptable with follow up signature.

I have discussed this order with the patient or his/her representative. The orders reflect the patient's known wishes, to the best of my knowledge. [Note: Only licensed health care providers authorized by law to sign POLST form in state where completed may sign this order]

✖ (required) | **Date** (mm/dd/yyyy): Required ___/___/___ | **Phone #:** (___) ___

Take Home Points

- Normalize conversations early.
- Ask your patients about their communication preferences and their values.
- Learn structured tools to improve communication
- Individualize conversations and revisit as indicated.

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