

# UC San Diego

## Independent Study Projects

### Title

Parental polst preferences for pediatric patients enrolled in palliative home care

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# ISP Submission

Jared Rosen

## *Parental POLST Preferences for Pediatric Patients Enrolled in Palliative Home Care*

### **Background:**

Palliative care and advanced health directives, particularly the Physician's Orders for Life Sustaining Treatment (POLST), play significant roles in the management of seriously ill children and those with chronic medical conditions. Multiple studies have demonstrated improved patient quality of life and family sense of autonomy and control when advance health directives are implemented, yet little is known about actual end-of life-care choices parents make. The goal of this project was to examine parental preferences for end-of-life care among patients enrolled in a pediatric palliative home care program (PPHCP) or hospice who have completed a POLST.

### **Methods:**

A retrospective chart review was performed among patients enrolled in a PPHCP or hospice at a large tertiary care children's hospital from January to July 2015. Data from the POLST, including preferences for medical treatment, demographic data, and health data were extracted from the electronic health record. Descriptive statistics and bivariate analyses were conducted using SASv9.4.

### **Results:**

104 patients were enrolled in PPHCP. Mean age of patients was 7.3 yrs, 59.6% female, 43.3% Hispanic, 67.3% Medicaid. The majority (91.4%) had a diagnosis that was present at birth (e.g., congenital/genetic/neuromuscular) and 8.6% had a later-onset condition (e.g., trauma/oncology). G-tube was present in 84.6%; 11.4% had a tracheostomy. Most families (78%) completed a POLST for their child, with 87.5% selecting Cardiopulmonary Resuscitation (CPR), 86.1% choosing full medical treatment and 85.7% wanting long-term artificially provided nutrition. Parents were more likely to select CPR if their child was in home care vs. hospice (89.6% vs. 60%,  $p=0.05$ ), had a condition present prenatally/at birth vs. later (89.7% vs. 50%,  $p=0.02$ ), and had a G-tube (91.7% vs. 66.7%,  $p=0.02$ ).

### **Discussion:**

The majority of families in PPHCP and Hospice elected full treatment at the end of life for their child, although those on hospice were more likely to elect not to have CPR done, aligning with national trends. However, we found that the primary factor associated with choosing full medical treatment was having a condition present at birth, versus having a diagnosis later in life. This raises intriguing questions about the timing of POLST discussions and how this may influence decisions around end of life preferences. Further evaluation of how phases of grief affect these decisions are warranted.

## ISP Submission Supplemental Tables

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**TABLE 1:** Sample Characteristics: Those who were in the Palliative Home Care and Hospice Service from Jan 2015 to June 2015

	(n=104)
<b>Age (months) (mean, SD)</b>	87.7 (69.2)
<b>Inpatient Days (mean, SD)</b>	13.8 (22.1)
	5 (IQR 16)
<b>ED visits (mean, SD)</b>	1.6 (2.1)
	1 (IQR 2)
<b>Inpatient admissions (mean, SD)</b>	1.3 (1.6)
	1 (IQR 2)
<b>Final Diagnosis group:</b>	
<b>Congenital/Genetic, Neuro/Neuromuscular, Neonatal, Metabolic, Cardiology, Renal</b>	91.4%
<b>Other: Trauma, Onc, GI, ID</b>	8.6%
<b>Level of care:</b>	
<b>Home care</b>	81.3%
<b>Other (Hospice/Palliative)</b>	18.7%
<b>G-tube</b>	84.6%
<b>Vent</b>	6.7%
<b>Trach</b>	11.4%
<b>Insurance:</b>	
<b>MediCal</b>	67.3%
<b>MediCal + Private insurance</b>	28.9%
<b>Other (private alone or other)</b>	3.8%
<b>Sex: Female</b>	59.6%
<b>Vital Status (alive)</b>	100%
<b>Ethnicity: Hispanic</b>	43.3%
<b>Race:</b>	
<b>White</b>	42.3%
<b>Other</b>	40.4%
<b>Asian/Black/Native American</b>	17.3%
<b>Preferred Language:</b>	
<b>English</b>	73.5%
<b>Spanish</b>	20.6%
<b>Other</b>	5.9%
<b>Completed POLST (n=81)</b>	77.9%
<b>Where was POLST completed:</b>	
<b>Inpatient</b>	19.3%
<b>Outpatient</b>	7.0%
<b>Home</b>	73.2%
<b>CPR (yes)</b>	87.5%
<b>How was POLST completed</b>	

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<b>Full treatment</b>	86.1%
<b>Selective treatment</b>	11.1%
<b>Comfort focused treatment</b>	2.8%
<b>Artificial Nutrition</b>	
<b>Long-term</b>	85.7%
<b>Trial period</b>	10%
<b>None</b>	4.3%

**TABLE 2:** Factors associated with filling out the POLST

		p-value
<b>Ethnicity</b>	74.6% (Non-Latino) vs. 82.2% (Latino)	0.35
<b>Sex</b>	83.3% (male ) vs. 74.2% (female)	0.23
<b>In Home care vs. hospice</b>	78.1% (Home Care) vs. 75.0% (hospice)	0.84
<b>Diagnosis Group</b>	80.0% (congenital) vs. 55.6% (later onset)	0.09
<b>G-Tube</b>	77.3% (Yes)vs. 81.3% (No)	0.72
<b>Vent</b>	71.4% (Yes) vs. 78.4% (No)	0.67
<b>Trach</b>	83.3% (Yes) vs. 77.2% (No)	0.63

**TABLE 3:** Factors associated with saying YES to CPR

		p-value
<b>Ethnicity</b>	84.6% (Non-Latino) vs. 90.9% (Latino)	0.42
<b>Sex</b>	84.8% (male ) vs. 89.7% (female)	0.53
<b>In Home care vs. hospice</b>	89.6% (Home Care) vs. 60.0% (hospice)	0.05
<b>Diagnosis</b>	89.7% (congenital) vs. 50.0% (later onset)	0.02
<b>G-Tube</b>	91.7% (Yes) vs. 66.7% (No)	0.02
<b>Vent</b>	100% (Yes) vs. 86.8% (No)	0.44
<b>Trach</b>	87.5% (Yes) vs. 87.5% (No)	1.00

**TABLE 4:** Factors associated with saying YES to Medical Interventions – Full treatment

		p-value
<b>Ethnicity</b>	57.3% (Non-Latino) vs. 62.2% (Latino)	0.64
<b>Sex</b>	66.7% (male ) vs. 54.8% (female)	0.23
<b>In Home care</b>	61.5% (Home Care) vs. 37.5% (hospice)	0.18
<b>Diagnosis</b>	63.2% (congenital) vs. 22.2% (later onset)	0.02
<b>G-Tube</b>	61.4% (Yes) vs. 50% (No)	0.39
<b>Vent</b>	57.1% (Yes) vs. 59.8% (No)	0.89
<b>Trach</b>	58.3% (Yes) vs. 59.8% (No)	0.92

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**TABLE 5:** Factors associated with saying YES to Artificial Nutrition

	p-value
<b>Ethnicity</b>	0.48
<b>Sex</b>	0.67
<b>In Home care</b>	0.21
<b>Diagnosis</b>	0.83
<b>G-Tube</b>	<b>0.01</b>
<b>Vent</b>	0.63
<b>Trach</b>	0.30

**TABLE 6:** Healthcare utilization associated with POLST completion

	Tests of significance
<b>relationship to # ED visits</b>	beta = 0.90 (S.E. 0.48, t value 1.88, p-value 0.06)
<b>relationship to # hospital admissions</b>	Beta = 0.15 (S.E. 0.37, t value 0.41, p-value 0.68)

**Table 7:** Rationale given for parents not completing POLST

reason_not_filled	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<b>Foster parents</b>	1	4.76	1	4.76
<b>Mom not present for visits</b>	1	4.76	2	9.52
<b>Mom refuses</b>	1	4.76	3	14.29
<b>NONE GIVEN</b>	1	4.76	4	19.05
<b>Not discussed</b>	1	4.76	5	23.81
<b>Parents don't agree</b>	2	9.52	7	33.33
<b>family refuses</b>	5	23.81	12	57.14
<b>foster parents</b>	2	9.52	14	66.67
<b>mom refuses</b>	3	14.29	17	80.95
<b>none given</b>	3	14.29	20	95.24
<b>parents do want all life p</b>	1	4.76	21	100.00