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Respecting Patient Autonomy, End-of-Life Care Experience, and the Transitional Status

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Transitional Status**

Main Text

Clinical ethics emphasize the importance of patients' autonomy [1]. Today, the need for a patient's involvement in decision-making in daily clinical practice is unquestionable. However, patients' autonomy in end-of-life care often involves various ethical concerns, including their deteriorating decision-making capacity. With evolving end-of-life ethical debate, it has become easier to implement such ethical practices as identifying surrogate decision-makers and recommending advance care planning.

Patients in end-of-life have two options: living and dying. "Status Passage," one of Glaser and Strauss' best publications, states that patients nearing the end of their life are in a "transitional state" [2]. In modern society, the state of being in an ambiguous existence, such as transitional status, is commonly lumped into certain categories so it becomes easy for people to deal with such categories. For example, when a person is accused, people may regard the person as a sinner despite the ruling has not been confirmed. When a patient is in end-of-life, healthcare professionals may treat the patient as a dying despite of living. Dying is a transitional process that fluctuates between living and death. Without careful attention, even healthcare professionals can fail to respect patient autonomy.

Physician cumulative experience in end-of-life care can be negatively correlated with respecting patient autonomy. We conducted a secondary analysis with physicians' end-of-life care experience nationwide survey [3]. In contrast to other variables, we found a clear trend towards family-first decision-making style as physicians' end-of-life experience increased (e.g., assignment of end-of-life patients, patient death and death pronouncements experience) [Table 1]. Through daily practice, the importance of family involvement in end-of-life care can be more evident. However, as D. Sudnow argued in "The Social Organization of Dying," experienced healthcare professionals may exclude dying patients in decision-making without sufficient consideration [4]. As a result of these data, healthcare professionals are warranted to be reflective about respecting autonomy for people in the "transitional status."

References

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Variables	Reference	Should tell the patient First, then family ^{a)}				Should tell the family first, then patient ^{a)}				Should tell the patient, even if the family disagrees ^{a)}			
		OR	95% CI	P-value		OR	95% CI	P-value		OR	95% CI	P-value	
Seniority													
Resident Physician (PGY1-2)	Reference	1				1				1			
Clinical Fellow (PGY3-5)		0.326	0.203	0.525	<0.001	0.882	0.462	1.685	0.704	0.713	0.446	1.14	0.157
Attendant		0.922	0.566	1.502	0.745	0.196	0.058	0.662	0.009	1.418	0.865	2.324	0.166
Age		1.007	0.99	1.024	0.427	0.941	0.898	0.985	0.01	1.022	1.005	1.04	0.012
Sex													
Male	Reference	1				1				1			
Female		0.721	0.46	1.129	0.153	0.566	0.256	1.25	0.159	1.136	0.725	1.782	0.578
Years of Clinical Experience		1.007	0.989	1.024	0.445	0.934	0.886	0.985	0.012	1.02	1.002	1.038	0.03
Marital Status													
Married	Reference	1				1				1			
Unmarried		0.959	0.648	1.419	0.835	1.67	0.867	3.215	0.125	0.743	0.497	1.109	0.146
Own family long-term care experience													
Yes	Reference	1				1				1			
No		1.173	0.71	1.938	0.532	1.323	0.57	3.071	0.515	0.647	0.393	1.067	0.088
Own family bereavement experience													
Yes	Reference	1	0	0	0	1	0	0	0	1	0	0	0
No		0.747	0.45	1.239	0.258	0.382	0.133	1.098	0.074	0.846	0.503	1.422	0.527

Religion														
Yes	Reference	1					1				1			
No		1.003	0.646	1.558	0.988		0.757	0.364	1.577	0.457	1.451	0.93	2.263	0.101
Interest in palliative care														
High	Reference	1					1				1			
Low		1.898	0.967	3.727	0.063		1.545	0.61	3.911	0.359	0.675	0.325	1.402	0.292
Clinical training in palliative care														
Yes	Reference	1					1				1			
No		0.858	0.577	1.274	0.447		0.664	0.363	1.217	0.185	0.669	0.447	1.003	0.051
Number of end-of-life patients assigned	<10 as reference	0.672	0.499	0.906	0.009		1.53	0.961	2.434	0.073	0.768	0.567	1.041	0.088
Number of patient deaths experienced	<10 as reference	0.699	0.524	0.932	0.015		1.581	1.005	2.489	0.048	0.759	0.566	1.019	0.066
Number of death pronouncements	<10 as reference	0.683	0.506	0.922	0.013		2.212	1.366	3.585	0.001	0.799	0.589	1.083	0.148

Footnote, a) Physicians (198 resident physicians, 134 clinical fellows and 96 attendant physicians) were asked about their opinions regarding decision-making pattern for end-of-life patients, using a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The situations were: 1) the doctor should tell the patient first and let the patient decide whether his or her family should be told; 2) the doctor should tell the patient’s family first and then let them decide whether the patient should be told; and 3) assuming that the family has been told and they do not want the patient to be told, the doctor should tell the patient anyway. PGY, postgraduate year; OR, odds ratio, CI, confidence interval.