

END-OF-LIFE DECISION MAKING: RESULTS OF A STUDY OF BURDENS EXPERIENCED BY SURROGATE DECISION-MAKERS

Summary outline adapted from: Braun, U. K., Beyth, R. J., Ford, M. E., McCullough, L. B. [Michael E. DeBakey VA Medical Center, Houston Center for Quality of Care and Utilization Studies, Houston, TX], "Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End-of-Life Decision Making," *Journal of General Internal Medicine* 23, no. 3 (March 2008): 267-274 [--see Table 4 on p. 270].

I) Burden of EOL decision-making

A) Personal context:

1) Psychosocial:

- a) Loss of a loved one**
- b) Taking a loved one's life in one's hand**
- c) Guilt of feeling one never does enough**
- d) Depression**
- e) Role reversal/role change**

2) Financial

3) Physical: self-neglect of own health from stress of caregiving

B) Family context:

- 1) Being the one in a position of trust who has to make the decisions, sometimes alone without other family members' participation and/or support**
- 2) Stress/struggle, especially if family is discordant**
- 3) Potential blame by family for (treatments) decisions, and for other decisions (like when to call/not to call family to hospital)**
- 4) Feeling the need to be strong for pt, even though they don't feel strong**

C) Clinical context:

- 1) Deciding under conditions of uncertainty (–about outcomes of certain treatments / Is continuing treatment sufficiently beneficial?; –about patient's preferences)**
- 2) Having to decide quickly/under pressure**
- 3) Feeling a lack of control, e.g., don't know how to stop intensive care, ventilator, feeding tubes once started**

II) Factors that affect the burden of EOL decision making

A) Factors that increase burden:

1) Problems with doctor-patient communication

- a) Time**
- b) Trust**
- c) Miscommunications: reliance on jargon, language barriers**

2) Organizational factors

- a) Discontinuity of care (rotations)**
- b) Restrictive visiting hours**

3) Chances of achieving an acceptable functional outcome at an acceptable cost

- a) Assuring comfort and quality of life**
- b) Desire for aggressive therapy if it doesn't unacceptably sacrifice functional independence/cognitive capacity**

B) Factors that decrease burden

- 1) Decision 'making' versus 'reporting' a decision**
- 2) Trial of intervention**
- 3) Faith/religion/spirituality**
- 4) Social support: family, friends, church members**