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Conceptualizing surrogate decision making at end of life in the intensive care unit using cognitive task analysis

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ABSTRACT

Background: Surrogate decision makers (SDMs) face difficult decisions at end of life (EOL) for decisionally incapacitated intensive care unit (ICU) patients.
Purpose: To identify and describe the underlying psychological processes of surrogate decision making for adults at EOL in the ICU.
Methods: Qualitative case study design using a cognitive task analysis interviewing approach. Participants were recruited from October 2012 to June 2013 from an academic tertiary medical center's ICU located in the rural Northeastern United States. Nineteen SDMs for patients who had died in the ICU completed in-depth semistructured cognitive task analysis interviews.
Discussion: The conceptual framework formulated from data analysis reveals that three underlying, iterative, psychological dimensions (gist impressions, distressing emotions, and moral intuitions) impact an SDM's judgment about the acceptability of either the patient's medical treatments or his or her condition.
Conclusion: The framework offers initial insights about the underlying psychological processes of surrogate decision making and may facilitate enhanced decision support for SDMs.

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Introduction

Surrogate decision makers (SDMs) are typically family members who are entrusted with the authority to make health care decisions for decisionally incapacitated patients, including those who are dying in the intensive care unit (ICU; Beauchamp & Childress, 2012). Surrogates are expected to make decisions for patients that approximate as closely as possible those choices patients would have made were they able (Beauchamp & Childress, 2012). Yet, evidence strongly suggests that making decisions based on concordance between patients' preferences and SDMs' beliefs about those preferences is not realistic (Moorman & Inoue, 2013; Shalowitz, Garrett-Mayer, & Wendler, 2006; Sharma et al., 2011; Song, Ward, & Lin, 2012). Additionally, the SDM role can be extraordinarily burdensome (Melhado, 2011), and at least a third of SDMs experience negative psychological aftereffects that persist months to years

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after the death of patients (Wendler & Rid, 2011). These psychological aftereffects can include depression, anxiety, and guilt about whether or not they made the "right" decision (Melhado, 2011; Wendler & Rid, 2011).

Although the outward decision-making behavior of SDMs has been well described (Meeker & Jezewski, 2009), there is a gap in what is known about the psychological processes undergirding SDMs' behavior. Understanding these underlying psychological processes may offer a picture of SDMs' decision-making processes that better predicts and explains the psychological burden during and after the experience. Innovations in the area of naturalistic decision making, which focuses on decision making as it occurs in real-world settings, have resulted in the development of interviewing techniques that are well suited to elicit the psychological processes of decision makers (Crandall, Klein, & Hoffman, 2006). One such technique is called cognitive task analysis (CTA).

First emerging in the 1980s, CTA represents a family of research methods that have been used in applied cognitive research and have shown validity and usefulness in diverse areas including health care, aviation, military, and firefighting (Crandall et al., 2006; Hoffman & Militello, 2008). Interviewing techniques have emerged from CTA that aim to elicit the psychological processes of decision making when individuals are in situations of high stress, uncertainty, and limited time (Crandall et al., 2006). These CTA interviewing techniques prompt participants to develop a general time line of events leading up to a specific decision. After this, they are asked to recall in as much depth as possible their moment-to-moment thoughts and feelings at key points in the time line. Table 1 lists cognitive aspects of decision making and corresponding generic interviewing prompts examined by CTA interviewing techniques (Crandall et al., 2006).

To better understand the underlying psychological processes of surrogate decision making, we used a CTA interviewing approach to identify and describe these processes in a cohort of recent SDMs of adults who died in the ICU.

Methods

Subsequent to institutional review board approval, study participants were recruited from October 2012 to June 2013 from an academic tertiary medical center's general ICU located in the rural Northeastern United States. Eligibility criteria included adults aged >21 years self-identifying as a primary decision maker for a dying ICU adult patient aged >21 years. Clinical resource coordinators and social workers identified decisionally incapacitated patients in the ICU who were approaching end of life (EOL) and their family members who were acting as the patient's SDM. Surrogates were informed generally about the study, and, if they were willing to be contacted by the principal investigator (PI) to learn more about the study, they were asked for their contact information.

Surrogates were contacted by the PI a minimum of 8 weeks after a patient's death to allow for bereavement. The PI interviewed eligible, willing SDM participants at either their homes ($n = 7$), the PI's research office ($n = 8$), a location of their choosing ($n = 1$), or over the telephone ($n = 3$). After signing an informed consent and completing a short demographic data form, an in-depth, semistructured interview was conducted using a CTA interviewing protocol adapted from Crandall et al. (2006). The CTA semistructured interview protocol consisted of three "sweeps": (a) developing a time line of events, (b) deepening or in-depth exploration of key moments, and (c) "what if" queries. The first sweep aimed to construct a time line of the

Table 1 – Aspects of Decision Making and Cognitive Task Analysis Interview Probes (Crandall et al., 2006)

Decision-Making Aspect	Cognitive Task Analysis Interview Probes
Cues	"What were you seeing, hearing, smelling, noticing, etc.?"
Options	"What courses of action were considered or were available to you? How was this option chosen and others rejected? Was there a rule you were following in choosing this option?"
Analogs	"Were you reminded of any previous experience?"
Goals and priorities	"What were your specific goals and objectives at this time? What was most important to accomplish at this point?"
Mental models	"Did you imagine the possible consequences of this action? Did you create some sort of picture in your head? Did you imagine the events and how they would unfold?"
Information-seeking	"What information did you use in making this decision or judgment? How and where did you get this information, and from whom? What did you do with this information?"
Experience	"What past experiences were necessary or helpful in making this decision?"
Situation assessment	"Suppose you were asked to describe the situation to someone else at this point. How would you summarize the situation?"
Decision making	"What let you know this was the right thing to do at this point in the situation? What kinds of pressure was involved in making this decision?"
Guidance	"Did you seek any guidance at this point in the situation? How did you know to trust the guidance you got?"

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