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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—Identify and describe the underlying psychological processes of surrogate decision-making for adults at EOL in the ICU.

Method—Qualitative case study design using a cognitive task analysis (CTA) 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 semi-structured CTA interviews.

Discussion—The conceptual framework formulated from data analysis reveals that three underlying, iterative, psychological dimensions: gist impressions, distressing emotions, and moral intuitions impact a 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 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).

While 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 demonstrated validity and utility 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 timeline of events leading up to a specific decision. Following this, they are asked to recall in as much depth as possible their moment-to-moment thoughts and feelings at key points in the timeline. Table 1 lists cognitive aspects of decision-making and corresponding generic interviewing prompts examined by CTA interviewing techniques (Crandall et al., 2006).

In order 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 age >21 years self-identifying as a primary decision maker for a dying ICU adult patient age >21 years. Clinical resource coordinators (CRCs) 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, semi-structured interview was conducted using a CTA interviewing protocol adapted from Crandall, Klein, and Hoffman (2006). The CTA semi-structured interview protocol consisted of 3 "sweeps": 1) developing a timeline of events; 2) deepening, or in-depth exploration of key moments; and 3) "What if" queries. The first sweep aimed to construct a timeline of the participant's SDM experience noting the sequence and duration of events, actions, perceptions, and decisions. Oriented by the timeline from the first sweep, questions in the second sweep were used to understand in depth what participants were thinking and feeling at key moments in their SDM experience. Questions in this sweep were adapted from those listed in Table 1. The third sweep posed "What If" queries, such as hypothetical situations ("If a [key feature] of the situation were altered, what impact would it have had?") and potential aids ("What information might have been helpful?"). After completion of the interview, all participants received a \$30 Visa gift card as a token of appreciation.

Interviews were digitally-recorded, transcribed verbatim by a professional transcriptionist, checked for accuracy, and uploaded into HyperRESEARCH Version 3.0.2 software (Researchware, Inc., Randolph, Massachusetts) to assist with coding and organization of the raw data. Consistent with CTA, the analysis followed a qualitative case study approach (George & Bennett, 2005; Yin, 2009) and used within and across case comparison techniques as described by Miles, Huberman, and Saldaña (2014).

Data analysis ensued upon transcription of the first interview and consisted of an iterative process that included case summarizing; coding of raw data; and corroborating findings with the study team and through member checking. A case summary was composed by the PI after an initial reading through each individual transcript in order to facilitate immersion into the data and to synthesize key points from the interview. The PI reread and coded transcripts progressing through two coding cycles: first cycle provisional coding and second cycle pattern coding (Saldaña, 2013). In the initial provisional coding cycle, the first five interviews were coded according to a priori aspects of decision-making listed in Table 1. As analysis progressed through the remaining interviews, second cycle pattern codes were inductively generated within each of the aspects of decision-making to better reflect the raw data. All remaining interviews were then coded according to the pattern codes including recoding of the initial 5 interviews. Pattern codes were then grouped into the larger psychological dimensions in the final framework (Figure 1).

To corroborate findings and establish trustworthiness, co-investigators were convened every 2 to 4 weeks throughout the entire data collection and analysis process. Three of the 4 co-investigators were qualitative methods experts (DW, MB, BC), including a premier CTA expert (BC). Two of the 4 were content experts in the areas of decision-making, ethics, and EOL (MB, PG). The co-investigators critically examined the data collection and the analysis process and provided feedback on the emerging codes and categories. After consultation with the research team, unanimous consensus was reached that data saturation had been met after 17 interviews. Two additional interviews were completed wherein no new insights emerged. Member check forms asking about participants' impressions of the preliminary findings were mailed in July, 2013 to 17 agreeable participants. Nine member check forms were returned and responses indicated support for the findings.

Findings

Sample

The sample consisted of 19 participants who served as primary surrogate decision-makers for 19 adult patients who died in the ICU (Table 2). Interviews occurred an average of 70.3 days after the patient's death. Mean age of SDMs was 59 ± 11 years (range, 38–76), 53% (n=10) were female, 100% (n=19) were white, 53% (n=10) were widowed, and 36% (n=7) had a college education or higher. The sample represented a diverse range of religious affiliation: 32% (n=6) were Protestant; 32% (n=6) had no religious affiliation; 21% (n=6) were Catholic; 10% (n=2) were "Other"; and 5% (n=1) were Buddhist. Just over half of decedents were the SDM's spouse (53%, n=10) while another 32% (n=6) were the SDMs' parents. Table 3 shows that decedents (n=19) for whom SDMs made decisions had a mean age of 67 ± 12.9 years (range, 33–85), 47% (n=9) were female, and 100% (n=19) were white. Just over half, or 58% (n=11) of SDMs reported that patients had designated a durable power of attorney for healthcare and the same number reported that patients had completed a living will.

Major Psychological Dimensions and Their Key Constituent Elements

The conceptual framework emerging from our analysis is depicted in Figure 1. In this framework, SDMs' made internal decision judgments before openly expressing these decisions to the healthcare team. These internal decision judgments were impacted by three primary psychological dimensions: 1) gist impressions, 2) distressing emotions, and 3) moral intuitions. We report and discuss each separately, however, we emphasize that these dimensions and their constituent elements are not mutually exclusive and nor are they exhaustive of all psychological variables that likely impact surrogates' decision-making processes.

The internal decision judgment—Prior to outwardly expressing decisions to the healthcare team about the patient's care, all SDMs reported making an internal judgment about the degree to which one or more medical treatments or the general condition of the patient was acceptable or unacceptable. For many SDMs, these internal judgments were directed at the acceptability of the patient's overall physical condition:

...that's when I saw him. In that moment, I knew it was time. I just said [TO THE ICU PHYSICIAN] "He's gone through enough." (SDM28)

...to restore her life to sucky didn't seem like a good plan to me. (SDM30)

In other cases, these judgments were oftentimes targeted at the acceptability of the medical treatments. These treatments could be ones that were either currently in use (e.g. intravenous vasopressive medications) or treatments that not yet initiated (e.g. starting dialysis) but were proposed by the healthcare team:

...It would have just been more procedures that his poor body just didn't want. (SDM13)

When interventions or the patient's condition were judged to be acceptable, treatments were maintained or requested; when highly unacceptable, treatments were stopped or withdrawn. The primary decision judgment of SDMs was impacted by three main psychological dimensions: 1) gist impressions, 2) distressing emotions, and 3) moral intuitions.

Gist impressions—Across all cases, SDMs recalled a number of salient perceptions, or gist impressions, impacting their decision-making process. These impressions emerged from particular events such as family meetings; personal encounters such as with individual members of the health care team (e.g. doctors, nurses), and visually striking experiences such as seeing their loved one connected to machines. Though highly impactful on what SDMs chose to do, the character of these perceptions themselves were often "fuzzy" and "sudden" to SDMs at the time of their actual experience. For example, the details of what was going on physiologically with the patient, the names and purposes of medical procedures, medications, and tests, and what was said by others in conversation often struck SDMs as "vague", "difficult to comprehend", and "coming at you so fast." In this sense, SDMs' perceptions of what they were seeing, hearing, and understanding were more akin to *impressions*. Despite these impressions having a lack of complete clarity in the minds of SDMs, SDMs derived bottom-line understandings, or *gists*, of what was going on from these impressions in their attempts to make sense of what was happening. Three gist impressions that SDMs noted to be highly influential to their decision judgment were: 1) the loss of the patient's normal human presence; 2) the chances of recovery; and 3) the sufficiency of efforts to rescue the patient.

Loss of normal human presence: Most SDMs remarked about patients' changed appearance, and whether the patients appeared emotionally responsive, communicative, or cognitively intact:

She was...becoming less and less aware, more into a coma...the only time she moved...was if the pain was great enough to move her body...very little moaning or anything like that. It was mainly like her body twitching, the last couple of days...She didn't even know I was there. (SDM02)

Many SDMs expressed that as patients neared death, they appeared "cold," "passive," and lacking in emotions and agency. In these cases, several SDMs started to emotionally detach from the patient, sometimes perceiving a dissociation between the patients' corporeal body and their human spirit:

...she lost an extreme amount of weight, and was sort of listless and just was not our mom anymore. (SDM14)

Chances of recovery: Another gist impression reported by every participant was the chances that about the patients' ability to recover to a satisfactory state of health:

...the doctor said "I think I can save her." And I said, "I don't think she's got a chance in hell." She was totally comatose and I knew she'd never come through. (SDM04)

For some, 'satisfactory' recovery meant a return of the person's health to a certain desirable quality of life. For example, several SDMs based their level of acceptable recovery on whether or not the person would be able to become independent or whether their daily existence would be "stuck in a nursing home." Other SDMs believed that biological survival alone was the standard of success upon which to base the patient's chances. No SDMs spoke in terms of precise numeric chances (e.g. 50%, 90%). Rather, SDMs expressed 'chances' or probability in more loose terms about whether they believed patients would or would not "make it":

... I thought she was going to make it and then the reality hit me that she wasn't. (SDM02)

Sufficiency of efforts to rescue: A third gist impression affecting the primary decision judgment was SDMs' perception that all medical tests, interventions, and therapies that could be attempted to rescue the patient, had been attempted:

They tried everything they could to get her off the ventilator, but her body said "no." (SDM23)

And the pulmonary guy was like, "...his oxygen levels are not doing so great today, and there's several things I can do. ...I was like, "Well, do whatever you have to do." (SDM13)

Surrogates gauged whether all possible efforts were being done that could be done to give the patient a chance at survival. Efforts that had yet to be attempted were sometimes specific in people's minds (e.g. MRI, dialysis) while at other times these efforts were more vaguely conceived as "do everything." Across cases it appeared that the more a surrogate believed that sufficient efforts had been attempted to save the patient, the less he or she perceived that further medical treatments or the patient's condition were needed (acceptable):

[THE ICU DOCTOR] was doing everything in his power but he ran out of options...I said to myself, "Now stop the ventilator, stop it now." (SDM04)

Distressing emotions—The second major psychological dimension impacting SDMs' decision-making was distressing emotions, variously alluded to by participants as "feelings" and "moods." At the time of SDMs' experiences, these emotions often had an instigating component (e.g. the site of a loved one in pain) that oftentimes elicited a marked visceral reaction (e.g. "heart pounding," "sobbing," "felt stunned," etc.), which altogether was distressing to SDMs (e.g. "overwhelming," "flooding," and "paralyzing"). The primary

distressing emotions emerging across interviews were 1) anticipatory grieving; 2) empathetic distress; and 3) uncertainty angst.

Anticipatory grieving: A number of SDMs expressed feeling sadness in response to having thoughts about their loved one's death and what life would be like without them, even before the person actually died. SDMs talked about their "realization" that the person was dying, reflecting on how they appeared so much different than when they were healthy, and saying good bye and having last moments with the patient. For example, SDM09's husband, who was in his 40s and had been physically healthy and active, died a few days after being admitted to the ICU after experiencing severe head trauma from a sporting injury. Speaking about her thoughts at the time, she related that it struck her that "he was never going to wake up" and that his impending death became more and more apparent to her:

...after they told me about the EEG, I went down to the little sitting room...had a weeping session...then we went and said our final goodbyes. (SDM09)

Empathetic distress: The majority of SDMs talked about some degree of distress they felt by empathizing with the pain and suffering they saw patients going through:

...they took my husband to do another CAT Scan... When he came back he was in agony. ... I freaked out, totally lost it. (SDM22)

...he was in Hell. Simple movement of getting him on and off a bedpan, repositioning him in bed, caused him excruciating pain...was hard to see him like that. (SDM26)

Some cases seemed to suggest that this distress was vicarious to the extent that the feeling fluctuated in intensity based on the degree to which patient was perceived to be in acute discomfort. This distress could also be brought on for the SDM by imagining how the patient would experience future insults to their dignity:

...would it bother her if I changed her diaper?...would it embarrass her if I did it?
...it would bother her if she was aware...Insulting her abilities or what have you.
(SDM02)

This quote also shows that some patients were not necessarily perceived by SDMs to be experiencing bodily pain but rather were perceived to be feeling a loss of dignity.

Uncertainty angst: For the majority of SDMs, there were periods and moments during their experience when they were stressed about the lack of clarity concerning what was going on with patients:

...we really didn't know what was going on...they just kept coming out asking history and saying "He's extremely sick, he's extremely ill." I was like, "That's not saying anything." (SDM09)

In this case and others, this uncertainty was expressed emotionally as anxiety, worry, and fear of the unknown. The specific example alludes to uncertainty angst being triggered by lack of comprehension about the patient's medical situation. Some SDMs sought out or

awaited more information or clarification concerning the state of the patient's health condition in order to move towards a decision:

...the other thing that bothered me was I had asked if they had done an EEG. ...For me I felt like I needed to see the EEG to see if he had any brain activity. (SDM20)

Uncertainty angst was also triggered in several cases by a lack of clarity concerning the patient's past instruction regarding their healthcare wishes:

And I'm like, "He would never talk about it."... Um, "So what does he want us to do?" I said, "I don't know." (SDM18)

In other cases, uncertainty angst also appeared to arouse the notion that there were other healthcare interventions and courses of action that could be taken to help treat the patient's condition:

So I didn't know really what was happening. ...he made it sound like there was still efforts we could take for S---- to survive. (SDM13)

Moral intuitions—The third major psychological dimension identified was moral intuitions. All participants were asked how they went about making the "right" decision and yet few reported undergoing a conscious reasoning process to arrive at their decision. Rather, SDMs appeared to arrive at moral "rightness" and "wrongness" in an intuitive fashion: "It just felt cruel to keep going." When further probed, participants often related very simple maxims they felt were obvious and commonsensical. Four moral intuitions expressed by SDMs emerging from this analysis were: 1) don't do what the person would not have wanted, 2) don't inflict harm if there's no benefit, 3) do X if there is a chance for success, and 4) meet the needs of family.

Don't do what the person would not have wanted: Nearly all SDMs expressed their disapproval of continuing medical treatments or keeping patients in medical conditions that they knew the person previously expressed not wanting. Reference was made in some cases to this being a kind of pact that they were entrusted with by the patient in making decisions on their behalf:

...I basically had to make decisions based on what he had said he would want. Regardless of what my ethical or moral thoughts were on the subject. I had to do what he wanted and I was basically fulfilling what he had expressed to me over the years. (SDM20)

Surrogates commonly framed their thinking about what the patient would *not* want in contrast to what they *would* want, as the following quote makes obvious:

"...they asked me, "What do you think Mom would want?" I said, "I don't know what she would want, but I can tell you what she does not want. .. She did not want to be in an institution." (SDM25)

It was apparent in a number of cases that medical treatments or the patient's condition was increasingly unacceptable to SDMs as they increasingly felt that things ought not be done that the patient would not have wanted.

Don't inflict harm if there's no benefit: Many SDMs reported thinking that keeping someone in an undesirable state, such as in pain or comatose, was wrong when the circumstances of the patient were no longer thought of as 'temporary' but rather indefinite. In these cases, SDMs believed that reaching a future desirable quality of life was unlikely:

...it was cruel to keep going on. It just seemed really cruel...He was never going to get better. (SDM22)

This case as well as others suggested that the more strongly SDMs believed that harm should not be inflicted on the patient without the possibility of long term benefit, the less likely he or she would be accepting of medical treatments or the patient's health condition. Though ultimately intended to be of future benefit to the health of the patient from the healthcare team's perspective, many healthcare interventions in the ICU were perceived by SDMs as "painful," "unpleasant," and invasive (e.g. injections, urinary catheters, central lines, surgery, etc.) or as inducing a comatose state (e.g. sedatives). These were tolerated by SDMs only if there was perceived long term benefit to the patient.

Do X if there is a chance for success: Several participants expressed that if there was some likelihood, however small, that if some treatment, X, could bring about a positive outcome, then that treatment ought to be attempted or continued:

...if there was a chance for him to live, he wanted everything done to do that... (SDM08)

Surrogates often used words like 'miracle' and 'hope' to explain their thinking. Many SDMs reported having points early in their experience where they truly believed that medical treatments had a chance at saving the patient's life and thus they had not yet found the medical treatments or the patient's condition to be unacceptable.

Meet the needs of family: The fourth moral intuition broadened SDMs' decision-making beyond a focus on the patient alone. Nearly all SDMs referred to an obligation they felt to address the grieving needs of family members distressed at the potential loss of the patient, particularly if the person believed that medical treatments or the patient's health condition was highly unacceptable:

...when we had the final meeting to decide about removing life support, we had talked...to everybody prior to that about what course of action to take. So everybody was...informed. (SDM15)

Some SDMs hinted at the role of future regret if certain steps were not taken:

I wouldn't let them take the ventilator out until my brother got there because I did not want him to have guilt that he didn't get up to see her before she died. (SDM19)

It was also apparent across cases that SDMs who were sensitive to meeting the needs of family members were compelled to gain some degree of "consensus" and "agreement" about their decisions before expressing those decisions to the healthcare team.

Discussion

The purpose of this study was to identify the underlying psychological processes of SDMs who had made decisions for adults at EOL in the ICU. Using a CTA interviewing approach allowed us to elicit the moment-to-moment thoughts and feelings underlying the decision-making experiences of 19 recent SDMs. Analysis of these descriptions resulted in a conceptual framework (see Figure 1) wherein an SDM's internal decision judgment was influenced by three psychological dimensions: gist impressions, distressing emotions, and moral intuitions.

The *acceptability of patient's medical treatments or his or her condition* emerged as the primary decision judgment in surrogates' decision-making. Other theoretical models of surrogate decision-making have identified a similar concept that centers on the acceptability of medical treatments (Buckey & Abell, 2010; Caron, Griffith, & Arcand, 2005; Limerick, 2007). Unlike these models, we identified an additional facet of this judgment as often targeting the current or forecasted state of the patient's condition.

We identified three types of *gist impressions* impacting this decision judgment. The first was the *loss of the patient's normal human presence*. To our knowledge, this is the first study to specifically highlight how the physical appearance of the patient played a specific role in surrogate decision-making. It was apparent in many cases that as this gist impression arose in SDMs' thinking, SDMs were more inclined to find patients' medical treatments or conditions unacceptable. This is consistent with the findings of Gao, et al.'s (2013), whose regression analysis of 221 advanced cancer patient-caregiver dyads found that cognitive impairment was associated with less intensive EOL care. The second gist impression was how probable an SDM thought it was that the patient would or would not recover to some satisfactory state of health, or *chances of recovery*. This has been a key concept noted in previous qualitative studies of SDMs (Meeker & Jezewski, 2009) and has been the focus in several studies that have specifically studied the impact of patient prognosis on surrogate decision-making (Apatira et al., 2008; Boyd et al., 2010; Zier et al., 2008; Zier, Sottile, Hong, Weissfeld, & White, 2012). The third gist impression, *sufficiency of efforts to rescue*, is an understudied construct in SDMs' decision-making and should be explored in future research.

Decision judgments were also impacted by three primary *distressing emotions*. The first was *anticipatory grieving* which is not surprising as a number of qualitative studies on EOL surrogate decision-making have identified and described a similar theme (Meeker & Jezewski, 2009). Some evidence suggests that the more an SDM experiences anticipatory grief, the less likely he or she will be accepting of continued curative medical treatments (Kacel, Gao, & Prigerson, 2011). We observed this association across cases. The second distressing emotion was *empathetic distress*. Psychological research supports the notion that individuals experience somatosensory discomfort when witnessing the pain of others (Morrison, Tipper, Fenton-Adams, & Bach, 2013; Osborn & Derbyshire, 2010). In our study, many SDMs who felt distressed by seeing the patient in discomfort or suffering judged their medical treatments or conditions to be unacceptable. This resonates with Pruchno, et al.'s (2006) study of 291 hemodialysis patients' SDMs who found that SDM

decisions to discontinue dialysis were positively correlated with their perceptions of patients having a negative affect or quality of life. The third distressing emotion was *uncertainty angst*, which is a concept that has been noted in several studies of surrogate decision-making (e.g. Braun, Beyth, Ford, & McCullough, 2008; Chambers-Evans & Carnevale, 2005; Fritsch et al., 2013). Uncertainty is noted to lead to a search for more information and delayed decision-making (Chambers-Evans & Carnevale, 2005; Fritsch, Petronio, Helft, & Torke, 2013), a finding consistent with our study.

Finally, we found decision judgments to be influenced by four *moral intuitions*. The first moral intuition, *don't do what the patient would not have wanted*, is similar to concepts described in other studies of SDMs (Meeker & Jezewski, 2009). However, the findings from this study suggest that this moral intuition is typically expressed as a rejection: SDMs expressed what patients' would *not want* as opposed to what they *would* want. Weighting choices by negative features results in a "rejection" of options in contradistinction to decisions where options are "chosen" based on positive features (Baron, 2008). An SDM may *reject* options on a patient's behalf because the negative features of the situation (e.g. patient's sickly appearance, the patient's unconscious state, perceived pain, etc.) are more salient to the SDM than the beneficial features.

A second moral intuition was *don't inflict harm if there's no benefit*. SDMs exhibited a moral obligation to not harm or continue harming patients if the likelihood of future benefit was low or negligible. The *do no harm* or nonmaleficence heuristic has been recognized and discussed by moral psychologists (Sunstein, 2005) typically in relation to healthcare providers moral imperatives. However, the instance of this moral intuition in this study was unique in that it was used by SDMs and had the added qualifier about future benefit.

The third moral intuition is *do X if there is a chance for success*. In a study by Zier, et al. (2012) of 80 SDMs who were asked to interpret a patient's survival probability based on numeric prognostic statements, the authors found that SDMs tended to greatly overestimate statements that conveyed a low risk of survival. The prognostic statement "a 5% chance of survival" was interpreted on average by participants to mean a 20–25% chance of survival. Zier, et al. attributed SDMs' misinterpretation of dire prognostic information to an optimism bias, which may explain some of the mechanism behind this moral intuition.

The fourth moral intuition was *meet the needs of family*. Corroborating this finding, a number of qualitative studies have reported that SDMs describe an ethical obligation they feel to address the distress or wishes of family members before expressing a decision to the health care team regarding the withdrawing/withholding of life sustaining treatment for patients at EOL (Braun, Beyth, Ford, & McCullough, 2008; Colclough & Young, 2007; Fritsch et al., 2013; Meeker & Jezewski, 2009; Schenker et al., 2012; Wiegand, Deatricks, & Knafl, 2008). A qualitative study of 30 SDMs in the ICU by Schenker et al. (2012) not only identified the need to preserve family wellbeing as a key concern for SDMs, but also found that it often triggered the coping mechanism of sharing decisions with family members. This is consistent with what we observed in our study. Surrogates who strongly believed that he or she ought to meet the needs of family members appeared to regard more highly the

importance of gaining family consensus before feeling comfortable expressing decisions to the healthcare team.

Limitations

There were several limitations in this study. First, the findings of this study were derived from a purposive sample of Caucasian, educated adults from Northern New England, which potentially limits transferability to other more diverse locales. Future testing of the constructs in our framework will need to be done with a more racially and ethnically (or culturally) heterogeneous sample of SDMs. Second, the data collected to describe SDMs' moment by moment decision-making processes was based on participants' recall of that experience. It has been noted that recollections of past experiences can be highly inaccurate due to the biasing effects of reflection and selective recounting (Baron, 2008). The design of this study attempted to compensate for this limitation by interviewing SDMs as soon as possible after the death of patients; by explicitly prompting participants repeatedly during the interview to describe what *actually* happened at various time points in their experience; and by using non-judgmental probes and non-leading questions in order to minimize socially desirable responses. Regardless, the findings should be interpreted in light of this possibility.

Conclusion

The findings from our study highlight several implications for nursing practice and research. Nurses can best help SDMs in their decision-making by encouraging their physical presence at the bedside; urging SDMs to quickly involve other family members who might be impacted by the potential loss of the patient; repeating information to SDMs often in easy-to-understand language about what's happening with the patient; prompting SDMs to think about what the patient would *not* want in particular situations; and frequently reminding SDMs that everything is being done that can be done to help the patient. Our study showed that SDMs with critically ill, decisionally incapacitated loved ones in an ICU are typically under high emotional duress and are thus extremely challenged to make decisions that they feel are thoroughly considered. Thus, decision support for SDMs that fosters respect for patient preferences and values and helps reduce guilt about decisions after the patient's death would likely be most beneficial if introduced upstream long before patients were sick enough to be in the ICU. Finally, the degree to which the different dimensions and elements in our conceptual framework are present needs validation in future research. However, our conceptual framework identifies multiple potential targets for future development of decision support strategies.

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Research Highlights

- We identified the psychological processes of end of life surrogate decision-making in the ICU
- We used a cognitive task analysis interviewing approach
- The emergent framework consists of gist impressions, distressing emotions and moral intuitions
- Further research is needed to test the framework

Figure 1.
Framework of Psychological Dimensions of Surrogate Decision-Making at Adult EOL in the ICU

Table 1

Aspects of decision-making and cognitive task analysis interview probes (Crandall, Klein, & Hoffman, 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?”

Reprinted with permission from *Working Minds: A Practitioner's Guide to Cognitive Task Analysis*, by Beth Crandall, Gary Klein, and Robert R. Hoffman, published by The MIT Press.

Table 2

Demographic and Background Characteristics of Surrogates

Characteristic	Value
Surrogates (n=19)	
Age, <i>mean (SD), yr</i>	59 (11)
Female, <i>n (%)</i>	10 (52.6)
Race, <i>n (%)</i>	
White	19 (100)
Marital Status, <i>n (%)</i>	
Married	4 (21)
Living with a partner	3 (15.7)
Separated or divorced	2 (10.5)
Widowed	10 (52.6)
Education, <i>n (%)</i>	
Grammar school	1 (5)
Some high school	2 (10.5)
High school graduate	5 (26.3)
Vocational or technical school (2 year)	1 (5)
Some college	3 (15.8)
College graduate (4 year)	4 (21.1)
Masters degree (MS)	2 (10.5)
Professional degree (MD, JD, etc)	1 (5)
Religious affiliation, <i>n (%)</i>	
Protestant	6 (32)
No religious affiliation	6 (32)
Catholic	4 (21)
Other	2 (10)
Buddhist	1 (5)
Relationship (The patient was a...), <i>n (%)</i>	
Spouse	10 (52.6)
Parent	6 (31.6)
Sibling	1 (5.3)
Friend	1 (5.3)
Cousin	1 (5.3)

Table 3

Demographic and Background Characteristics of Decedents

Variable	Raw Value (%)
Decedents (<i>n</i> =19)	
Age, <i>mean (SD)</i> , yr	67 (12.9)
Female, <i>n (%)</i>	9 (47)
Race, <i>n (%)</i>	
White	19 (100)
Durable Power of Attorney for Healthcare designated, <i>n (%)</i>	11 (58)
Living will present, <i>n (%)</i>	11 (58)