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Factors affecting stress experienced by surrogate decision-makers for critically ill patients: *implications for nursing practice*

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Abstract

Objectives—This study explores surrogate decision-makers' (SDMs) challenges making decisions related to the care of patients in critical care, to 1) characterize the SDM stress 2) identify personal, social, care-related factors influencing stress and 3) consider implications of findings to improving critical care practice.

Methodology—Semi-structured interviews were conducted with SDMs of critically ill patients receiving care in two tertiary care institutions. Transcripts were analyzed using a grounded theory approach. Domains explored were: stress characteristics, stress mitigators, coping strategies, social networks, SDM decision-making role, decision-making concordance, knowledge of patient's preferences, experience with provider team, SDM-provider communication, patient outcome certainty.

Main Outcomes—We interviewed 34 SDMs. Most were female and described long-term relationships with patients. SDMs described the strain of uncertain outcomes and decision-making without clear, consistent information from providers. Decision-making anxiety was buffered by SDMs' active engagement of social networks, faith and access to clear communication from providers.

Conclusion—Stress is a very real factor influencing SDMs confidence and comfort making decisions. These findings suggest that stress can be minimized by improving communication between SDMs and medical providers. Nurses central role in ICU make them uniquely poised to spearhead interventions to improve provider-SDM communication and reduce SDM decision-making anxiety.

Keywords

Surrogate Decision-maker; Critical Illness; Provider-SDM Communication; Qualitative Data Collection; Social Science Research

INTRODUCTION

There is a growing body of research examining the stress of caring for and making decisions on behalf of patients in a variety of clinical settings (Wendler and Rid, 2011; Goddard,

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2011; Van Rosendaal et al., 1999). Few clinical environments present more challenges to thoughtful and timely decision-making related to patient treatment than critical care. It is often the case that families of patients in intensive care units (ICU) are thrust into the role of decision-maker as a result of conditions that are precipitous, life-threatening and that render patients incapable of making their own care decisions (Luce et al., 2004). Compounding the emotional stress of uncertain outcome, these surrogate decision-makers (SDMs) are called upon to render judgments within a limited amount of time about treatment which is often complex and may be highly technological. These stresses not only impede thoughtful and timely decision-making, but have been found to take a significant psychological toll on SDMs, even when patients survive (Kentish-Barnes et al., 2009). Anxiety, depression and post-traumatic stress disorder (PTSD) are increasingly being linked to families' experiences with critically ill or injured loved ones (Jones et al., 2004; Kross et al., 2011; Corrigan et al., 2007). Female SDMs appear most vulnerable to these psychological sequelae (Paparrigopoulos et al., 2006).

Investigators have identified individual, provider-related, environmental and patient factors that appear to compound stress inherent to the critical care experience. These factors include SDMs' poor comprehension of patients' condition and treatment (Kentish-Barnes et al., 2009) perceptions of insufficiently supportive staff, poor communication with providers (Mitchell et al., 2003; Nelson et al., 2010; Bowman, 2010) and providers' lack of responsiveness to family needs and stresses (Buckley and Andrews, 2011; Gay et al., 2009; Pryzby, 2009). In addition, SDMs appear to experience greater emotional trauma when they perceive that providers are not clear or transparent in discussing prognosis or when they appear to avoid prognostication altogether (Evans et al., 2009; Apatira et al., 2008). Structural factors and policies have been found to contribute to stress and family discomfort, such as limited space to visit, restricted visiting hours, limitations on number and age of visitors, and inadequate waiting areas (Vandijck et al., 2010; Bazuin and Cardon, 2011; Jastremski, 2000).

Many of these studies rely on recall and are conducted after the episode of critical illness has concluded. Few studies have been conducted while SDMs remain actively engaged in the ICU experience. Additionally, while frameworks have emerged helping us understand the broad individual-, provider- and patient- related constructs likely to influence stress in the ICU (Vig et al., 2007), few have examined factors that may exacerbate stress or buffer its impact. Findings reported here are based on individual, in-depth interviews (IDIs) conducted with SDMs of adult ICU patients which explore the challenges of decision-making related to the care of their loved ones. The aims of this analysis were to 1) identify and characterize the stressors SDMs confront, 2) identify personal, social, provider-related and structural factors that appear to ease or exacerbate these stresses and 3) consider the implication of these findings for critical care practice.

METHODS

Findings reported here are based on individual, in-depth interviews with a sub-sample of 34 SDMs randomly selected from the larger study sample of 78 SDMs recruited to participate in focus groups to understand attitudes regarding critical illness research (reported previously) (Iverson et al., 2012; Iverson et al., 2012). The focus groups provided insight into SDM perceptions of several hypothetical scenarios in which they might be asked to provide consent to participate in research on behalf of their loved one currently in critical care. To better understand the emotional and structural context in which SDMs might be asked to make such decisions, the study team designed individual interviews to elicit SDMs' accounts of their experience making decisions for their loved one currently in the ICU and

explore the impact of stress caring for a patient in the ICU on their experience and comfort making decisions.

Setting

Data collection took place from February 2008 to July 2009 in the intensive care units (ICUs) of two tertiary care, urban, university-based hospitals: Barnes Jewish Hospital (BJH), St. Louis, MO and Parkland Hospital (PH), Dallas, TX. Both institutions provide care to ethnically and socio-economically diverse patient populations.

Sample and sample recruitment

SDMs were eligible to participate if the following patient and SDM criteria were met: SDMs play a role in care decisions, the patient was 18 years or older and had been mechanically ventilated or otherwise incapacitated for at least 48 hours. Patients who were pregnant, incarcerated, brain injured or with a poor prognosis were excluded. Two SDMs, randomly selected from each focus group cohort, were invited to participate in an individual interview. Of the 41 invited SDMs, 34 (83%) provided informed consent, completed an interview and received a \$35 honorarium. Commonly reported reasons for non-participation in the individual interview included scheduling conflicts and deterioration in patient condition. The Institutional Review Boards (IRB) from all participating institutions approved this study.

Data collection

Individual interviews were conducted by study team members who had facilitated focus groups with the larger sample. Interviews were approximately 1-1.5 hours in duration and guided by a discussion outline developed by the study team. The discussion guide themes and questions were guided by existing research findings and additional feedback from partner ICU physicians and nursing staff. The guide was piloted in both study sites before data collection began.

Interview topics addressed six broad domains: history of current critical illness, role as decision-maker, communication with providers, experience and challenges related to a reference treatment decision (e.g. surgical or procedural intervention), social support, and other aspects of the ICU experience that influenced decision-making.

Analysis

All interviews were audio recorded and transcribed for analysis. Atlas.ti (Berlin) was used for coding and analysis of relationships between and within text segments. The research team reviewed an initial sample of 10 interviews -- five from each study site and selected to reflect the ethnic profiles of each site -- to identify key themes, forming the basis of the project codebook. The codebook was modified as new themes emerged through review of transcripts. Three members of the research team applied codes to transcript narratives. Inter-coder reliability was assessed through double-coding a sample of approximately 20% of the interview transcripts.

This analysis was driven by two broad aims: 1) to identify the nature and characteristics of stressors SDMs confront and 2) to differentiate factors appearing to mitigate or exacerbate SDM stress. Findings reported here are based on an analysis of narrative segments coded with following codes: decision for medical treatment, coping, provider communication/relationship with providers, role as SDM, faith and values, perception of provider roles, understanding nature of illness, support and access to support.

Initially, six full transcripts chosen at random were reviewed to ensure that the targeted codes provided a full picture of the decision-making experience and factors influencing

decisions as well as to identify broad themes that appeared to influence stress and decision-making. Analysis of all transcripts was organized into ten broad themes emerging from this review: social and information network, decision-making role of SDM and network members, network concordance in decision-making, SDM knowledge of patient's desires/perspectives, positive or negative experience with provider team, communication with providers, certainty about patient outcome, stressors, stress mitigators and coping strategies. For this analysis, the unit of analysis was the patient case. Each interview case was analyzed separately using a matrix (Figure 1) organizing data into these thematic categories and linked to illustrative verbatim quotes.

RESULTS

Respondent Characteristics

The study sites provided socioeconomic and ethnic diversity. As seen in Table 1, nearly a third (32%) of the PH sample was Hispanic/Latino. Both samples were predominately female (79%), reporting long relationships with the patient (mean 34.3 years). Nearly all SDMs were nuclear family members. While spouses represented only 14.7% of SDMs, this percentage increased to 94% when all relatives were considered. The mean age of the two samples was 46.3 years (range: 19 to 75 years); the mean years of education was 12.6 years (range: 8 to 18 years).

Narrative Results

SDMs' Characterizations of Stress in the ICU

Stress of Decision Making: The primary focus of these interviews was to gain insight into SDM's experiences making decisions in the ICU on patients' behalf. These narratives contained varied and often detailed descriptions of stress associated with assuming a decision-making role for which most felt unprepared, yet had little choice but to accept. Yeah, so my head was kind of like, 'oh my God, I can't believe all this is on me.' But then you just stop and say, 'OK, this is what you gotta do' (10406, BJH). The emotional burden of decision-making is often protracted, as this respondent describes:

The biggest emotional stress is to know that your child's life is at stake and this isn't an issue about what's the best way to treat...these have been life and death decision everyday now for sixteen days. (10404, BJH)

SDMs describe the strain making intense and time-sensitive decisions. They often feel forced to process information that is highly technological and difficult to understand while making multiple decisions quickly. They describe heightened vulnerability without feeling they have the information they need to make an informed decision:

We don't know what is needed in the ICU. So, we don't know what's goin' on. On the flip side is that they've got to move quick. So when I have an option [to make a decision] about a procedure, me being just a common family member who doesn't know. (21302, PH)

This respondent echoes a common perspective that making treatment decisions while weighing alternatives they do not fully understand feels like a leap of faith:

...because when they give you all the alternatives of what can happen. It just makes the decision even more harder. But, then when it comes to the critical point, you know, it's just something you gotta do and hope for the best. (10301, BJH)

Some were overwhelmed and deeply concerned that they were not making the "right" decision:

Sometimes I get, I don't want to say scared, but it kinda makes me feel like 'Oh my God, here I am and I have to make an important decision like this about grandma... 'Am I making the right decision?...because I don't want to say 'yes' and then it doesn't turn out the way I want it. (10305, BJH)

Uncertainty of Patient Outcome: For most, the shroud of uncertain outcomes appeared to underlie SDM's anxiety, leaving many SDMs feeling vulnerable and helpless. Beyond the broader uncertainty of patient survival, these SDMs faced multiple and changing questions and concerns about patient status and outcome throughout a patient's stay. SDMs whose loved ones had recently been admitted were often struggling to understand key clinical issues underlying patients' illness or injury and whether the patient will survive:

Yeah, I would like to really know what the diagnosis is on this because, I mean, it's really tearing us apart, it's tearing me, it's tearing her mom. (10705, PH)

In cases in which a patient has been unconscious for a protracted period, has suffered head trauma or anoxic brain injury, families' concern focused on how and if patient will be able to function once they regain consciousness or what to expect in terms of patient recovery:

From what they tell me, with his head injury, they say he could get better over time or he could not get better. And that's where I have the difficulty cause you don't know. (21603, PH)

Other Stressors: For many participants, additional stressors included disruption of daily routines, the necessity of traveling long distances, the economic consequences of taking time away from work, conflict within the family, and the physical fatigue resulting from near constant vigilance in the ICU.

Factors Related to the Care Environment That Exacerbate or Mitigate Stress

MD-SDM Communication: Key to buffering stress of decision making was SDM trust in providers and the care patients were receiving and access to clear information about a patient's case. SDMs reflected on their feelings of loss of control and the challenges having to make decisions without adequate expertise or knowledge. SDMs discussed their need to trust that providers are competent and doing their best to care for their loved one, some acknowledging the necessary vulnerability having to trust that providers were making the right decisions: Sometimes, its out of our control, you don't understand it but things happen and you just accept it (10102, BJH).

A few SDMs shared that they were intimidated by physicians and consequently did not feel comfortable asking questions:

I know they're very busy. I mean there's a slew of them and I know they got other things to do, so I don't ask them to take the time to explain things to me (10406, BJH)

However, most were eager to turn to providers for clear, consistent, and honest information about patients' condition when they were asked to make a treatment decision:

I wish I could really just get one of the doctors and pull him to the side and [say] just go ahead and be honest, 'I'm going to give it to you straight... the extent of his brain injury is blah blah.' I really want to know. (10102, BJH)

Multiple Provider-SDM Communication: This respondent describes her frustration with different information coming from multiple sources and from providers with different styles

of communication. This created confusion and led to her perception that the more taciturn providers are intentionally withholding information:

Everybody's speakin' the same thing. If not, then don't speak at all. 'Cause it's confusing to the family. It's like somebody's hiding somethin' or they don't want you to know something. (10301, BJH)

Here, an SDM explains how the lack of coordinated communication among providers can compound the challenges of decision-making:

The reason why it [decision about catheterization] was so difficult for me to make the final, permanent decision was because I have been inundated with four different departments telling me that they're gonna do the same procedure.(21302, PH)

In this case, a respondent makes a clear appeal to take time to ensure that she has and understands the information she needs to make a decision:

I mean the doctors, they explained, but I think they need to have somebody on the side that can explain more. And re-go through it and read it for you to really let you know "Okay, I'm making this decision, I know what it means" and sign it.(21609, PH)

Many described feeling disrespected when they believed their questions and input were being dismissed or ignored:

I feel like they are not asking you for a decision. It's like they're telling you what needs to be done. And, of course you could say, no. But they're telling, not asking. (10105, BJH)

Positive experiences communicating with ICU providers clearly increased SDMs' comfort making decisions. The qualities of communication and interaction that eased SDMs' stress and increased confidence were perceived transparency, inclusivity, availability to answer questions, clarity of information, patience, and responsiveness/empathy to SDMs' concerns and inquiries. A respondent whose son's condition was extremely fragile describes how their physicians' communication helped them remain focused:

Actually they've been good at slowing us down, redirecting us, saying that our focus has to be today or the next three days because we keep wanting to focus on the long term solution or what's next week and there's no reason to do that. We have to focus on the here and now. (10404, BJH)

Many spoke of the importance of the manner of communication and information exchange that is likely to make families feel comfortable and respected:

Whatever information they make available they would make it in a good manner to where the patient's family feels comfortable talking with them...as if you were talking to your family member...the tone of your voice... the way you put it out there. (10105, BJH)

While some SDMs were likely to defer easily to physician's advice, for others, being assertive, demanding answers if their questions weren't adequately addressed helped provide a sense of control, "*being on top of it*" and self-assurance that they were doing everything they could for the patient:

I'm talkin' to the doctors, the nurses, asking questions. Sometimes I feel like they think I'm asking too much questions, but I got to let them know that he got somebody that loves him and cares about how he's treated. (21609, PH)

RN-SDM Communication: Generally, nurses were far more likely to be the preferred nexus for day-to-day communication and information gathering, except when major decisions needed to be made. SDMs often turned to nurses feeling that physicians were too busy, too vague or inconsistently available. Nearly all SDMs perceived nurses to offer more compassionate communication and able to disentangle information that is difficult to understand:

The nurses are more grounded. They can explain it to you like in layman's terms to where you can understand it. The doctors are basically giving you medical terms, which I didn't understand and the nurses were somewhat of an interpreter. (10502, BJH)

...just have the nurses there to tell you what's going on and everything. That makes it easier because you're not in the dark... They're letting you know they're not leaving you in the dark, so that is helping out a lot...Cause if not, I'd be worried. (10701, PH)

Individual and Social Factors That SDMs Use to Cope with Stress

Social Networks: In most cases, access to an extended network of family and/or friends appeared to provide SDMs with emotional, informational, and instrumental support. Many maintained that their social networks offered a significant buffer to the burdens of decision making, communicating with providers and caring for the patient:

And they [family] really gave me a little confidence to know that I'm making the decision, but I'm not making it by myself. 'Cause I have some backup. Somebody that's sayin' "Okay, we all did this together." (21609, PH)

Social networks were often called upon to pass information along to others, relieving the pressure to keep everyone informed:

The one person calls me every night from work and I relay to her what has gone on and then she relates to them and so it makes it really nice that you're not talking to fifty people a day.(10406, BJH)

Additionally, SDMs describe the value of others' perspectives or perceptions:

Yeah, to be able to be here and help with the decisions...they can listen to the doctors, maybe they could pick up on something that I didn't see.(10102, BJH)

SDMs often sought out members in their networks who had some healthcare experience or expertise seeking clarification of information they may not fully understand. It was common to hear of network members assuming different roles in care-giving based on specific knowledge base or character strengths, e.g., assertive, smart, a "solver," "people-person":

What's probably unique about my role is just whatever my personality is and my role in our family...in terms of my knowledge, skill and ability to communicate, especially with medical professionals.(10404, BJH)

A few described the tension and disruption that can occur when network views are not concordant. In cases in which inter-familial tension were described, SDMs may utilize strategies to minimize contact with disruptive relatives:

At first I was bringing her in, you know,...she just started sayin' crazy stuff to me like "I should've had enough knowledge not to let them butcher him up"...after that, I just told her as much as I felt she needs to know. (10301, BJH)

Knowledge of patient's wishes: Most SDMs were unaware of their loved one's wishes related to treatment preferences or advance directives. For some, not knowing patients'

wishes weighed heavily on them as they faced difficult decisions that SDMs knew would have an impact on recovery or survival. Some were concerned that the patient may not have agreed with a decision once they recovered. Several called upon past conversations with patients that provided clues about preferences or beliefs. A handful of SDMs were given “permission” by patients to make decisions on their behalf before they became incapacitated. Generally, when patients’ wishes were known, SDMs felt greater confidence facing difficult decisions:

She always told us; even when I was little, if it comes to a thing where my mind is gone and I'm on a machine, pull the plug. Do not let me suffer. So we, as a whole, we understand that... So we try to basically base our decisions for her on what we know that she would want. (21302, PH)

Faith in God and Spirituality: Many SDMs stated that their faith in God helped them face the uncertainty of patients’ recovery and provided guidance making the often complex and challenging decisions they were called upon to consider:

I had faith and confidence that God wouldn't gonna let him die. I knew that much...Things was happening so fast...All I could do is pray and trust what the doctor said and believe in who's in control over everybody. And that's God. (10301, BJH)

Or, as one SDM reasoned, God was guiding the doctors’ hands:

The hands of God travel by means of the doctors. God is acting. So that God will cure her by means of the doctors.(21404, PH)

Here, a respondent turns to God to bolster her confidence to make decisions without fully understanding the technical aspects of treatment options:

[God said to me], ‘as long as you're connected to me, I'm gonna keep him.’ And, that really boosted my confidence even more once God started speaking to me. (21609, PH)

Additionally, an extended faith community for several respondents represented a significant source of emotional support:

I mean just everybody just say “I'm praying for you.” I mean it's really great...that you've got people praying for you that you don't even know. (10406, BJH)

One respondent who reported that she did not want to assume the role of decision-maker shared that God gave her the strength to do it:

I don't want to have to make a decision for somebody else's life even though it's my child. But now I guess He's [God] given me the strength to do that. (10904, BJH)

DISCUSSION

We undertook this study to examine SDMs’ experience making decisions in the ICU. Using each patient case as the unit of analysis and organizing data into the key domains found to have bearing on stress (as seen in Figure 1) offered a holistic view of how SDMs managed stress and enabled understanding of the constellation and interaction of personal, social and care-related factors influencing this stress.

These narratives provide insight into the nature and intensity of the stresses inherent when making decisions on behalf of loved ones. Not only must SDMs endure the anxiety of uncertainty, they are often called upon to make decisions about patients’ care with little time or few resources to disentangle meaning, options and consequences of each decision. The

ICU is an environment that can be overwhelming; care is often managed by multiple providers, and language and terminology can be unfamiliar or confusing.

Given the nature of critical illness and the environment in which care is provided, facets of communication between providers and SDMs are central to intensifying and/or assuaging the emotional distress associated with serving in the SDM role. Indeed, many participants held the perception that key medical information concerning their loved-one was challenging to obtain or understand. Similarly, participants sometimes felt that treatment options were presented in such a way as to disengage or exclude the family member from the decision-making process. These findings reinforce the need for effective communication between care providers and family members.

Participants were also frustrated by the perceived lack of coordination provided by various practitioners providing care. Enrollment sites in our study were tertiary care medical centers. The ICU teams were large and multi-disciplinary, consisting of attending physicians, sub-specialists, house staff, nurses and ancillary personnel. From the vantage point of SDMs, these various providers created confusion as to hierarchy and conflicting messages and advice.

The identification of the personal and social resources that these SDMs relied upon for support in their role as decision-makers is important because these resources clearly buffer the impact of stress caring for their loved ones. Of particular importance to many was the active engagement of their social networks as sources of advice, emotional support, and validation. Many SDMs sought and found solace and comfort in their faith and faith communities.

Some SDMs shared their anxiety that they were making the “wrong” decision and the pressure of making decisions on behalf of someone else. The few SDMs participating in this study who were aware of patients’ end-of-life preferences were grateful for guidance, corroborating research suggesting that knowledge of patients’ advance directives can ease the anxiety of making decisions (Majesko et al., 2012). However, most decisions SDMs are called upon to make are day-to-day, moment-to-moment treatment decisions. It is highly unlikely that any SDM would know how their loved one would approach each decision. The cumulative effect of sustained, intense decision-making on SDM stress is understudied, yet, based on these narratives, compound SDM anxiety.

In the past decades, the paradigms of healthcare delivery have shifted toward patient- and family-centered models, integrating patient and family beliefs and preferences into treatment recommendations and decision making (IOM, 2003). These models are especially difficult to implement in the context of critical care, where the need for rapid decision-making and the complexity of treatment creates unique challenges to effective patient-family engagement.

The 2007 Consensus Report of the American College of Critical Care Medicine (ACCM) outlined recommendations for patient- and family-centered approaches to address family stress and improve communication in the ICU. The ACCCM’s report offers a roadmap and recommendations for policy and practice change related to family support in ten areas of focus: shared decision-making, family coping, staff stress related to family interactions, cultural support, spiritual and religious support, family visitation, environment of care, family presence on rounds and resuscitation, and palliative care (Davidson et al., 2007). These recommendations, if implemented, are comprehensive and would certainly address many issues raised among this sample of SDMs.

The report recognizes that stress is exacerbated if family needs are not adequately identified or met and recommends that assessment of family needs be built into patient care plans (Davidson et al., 2007). To date, new models designed to improve family support in the ICU have emerged. Including families in physician rounds and establishing multi-disciplinary team conferences that include family members are practices employed by a growing number of critical care programs (Cypress, 2011; Cypress, 2012). However, there are few models that employ systematic and ongoing assessment of specific SDM needs, sources of anxiety and internal or social assets SDMs may already have in place that could serve to buffer the impact of the stress of care-giving and decision-making.

The findings reported here suggest the important and pivotal role nurses can play as a reliable, compassionate, trusted and understandable source of information and support. As patient and family-centered interventions are considered, nurses represent a natural nexus for intervention and are most likely to accurately identify families' concerns and needs. Indeed, White et al. piloted a nurse-led intervention that integrates a nurse Family Support Specialist who offers daily communication, family needs assessment and coordination of communication throughout the ICU stay (White et al., 2012). However, nurse-led approaches can only be effective if nurses are appropriately trained to assess need and have the necessary information about each case to address SDM questions and offer meaningful guidance. ICU nurses have reported that lack of information about ICU cases can increase stress and represent a significant barrier to nurses playing an effective supportive role (Davidson et al., 2007).

Comparative effectiveness research could offer a useful approach to comparing the impact of multiple models of nurse-driven, family-centered ICU interventions, especially those that address the potentially compounding, cumulative stress of day-to-day decision-making for patients with protracted treatment in critical care.

There are shortcomings to our study that limit extrapolating our findings to the broader ICU community. This study was conducted in large academic medical centers. Patient and SDM demographics as well as organization of services may differ substantially from those encountered in smaller non-academic environments. In addition, individuals agreeing to participate in our study may be self-selecting and their views may not be representative of the broader SDM population. Finally, given its observational nature, we were unable to assess whether specific interventions such as those suggested in the ACCM report might significantly impact the stress that SDMs experience.

CONCLUSION

Stress is a very real factor that influences SDMs in their role as decision-maker for critically ill patients. Although each SDM's personal situation is unique, as are the various conditions that face critically ill patients, these findings suggest that clear communication appears to be challenged in the critical care setting in which care is delivered by multiple providers. Communication is a primary contributor to SDM decision-making anxiety. Emerging changes in care, such as allowing family members to be present on rounds and posting daily goals of care at the bedside may aid in clarifying potentially conflicting information (Davidson et al., 2007). Critical care nurses already play a central role as natural advocates to families in the ICU and, as such, are uniquely poised to spearhead family-centered approaches designed to improve communication and increase SDMs confidence and comfort managing the challenging decisions they are asked to make. Promising nurse-led interventions are emerging (White, 2011; Soury-Lavergne et al., 2012). Hospitals should consider creating and funding a nurse designated to assess family needs and assets and coordinate and interpret vital information for patients' families. However, to become an

effective liaison, it is imperative that this role be endorsed fully by critical care teams, time is carved out from their clinical responsibilities to assume this responsibility systematically and nurses are equipped with training, tools and information needed to effectively assess and address SDM needs. With this assistance, SDMs can become effective as decision-making surrogates and engage as thoughtful partners in the care of their loved ones.

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ID: Patient X	Site: XX	Ethnicity: XX	Relationship to pt: Father
Brief case summary: 22 year old son, after many weeks at local hospital and ED being treated for pneumonia (fluid in lungs), transferred to Barnes and diagnosed as heart problem (virus); heart at 10% function; lungs below 90% O2; many treatments can't use (e.g., tx of clot) because is so fragile; not diagnosed for long time; much regret from father that was not aggressive enough and depended on local providers; while at hospital, 2 minutes without heart and lung function; uncertain outcome; father hoping that will not need transplant and can ultimately survive on meds; reconciled to future in rehab and long road to recovery; its one day at time			
Network Description (#, relationship to R and pt)	Role of R and network members in care and decision-making	Concordance/discordance/conflict resolution	Knowledge of patient desires/perspective
Wife – sister (nurse) – daughter Very extensive network of friends, family, community, work (1)	He and wife co-DM; I lived with him for 22 years (10); on same page or provide new, different perspective; role determined by personality, knowledge, communication style (8); sister can provide medical knowledge	Sometimes on the same page, sometimes provide different perspective which is good (2)	No
Experience (positive/negative)	Communication provider team	Nature of trust in provider	Certain/uncertain outcome?
Negative experiences with local MDs/ED; did not look to alternative diagnoses, treated with same meds/dx; finally transferred to current hospital At current hospital, generally very good, thorough, trusted; trusts expertise Transplant surgeon – bad communication; conflicts with how long trach should be in	Local teams: would acknowledge they didn't know; he beats himself up that he was not aggressive enough Current hospital: now asking, talking, discussing every decision, status, with every provider type (9); glad that MDs are slowing him down and urging him to focus on heart and immediate issues, not future; Transplant surgeon – in 15 min interview said son not candidate (3)	Low trust of local providers (4) who did not diagnose correctly or question themselves Trust in current hospital providers very high (7)	High degree of uncertainty, stress; son's status fragile; still don't know what is causing heart issue, but is functioning at 10-20%
Stress (describe/characterize degree): Son's condition very fragile (16); don't know what is causing problem (6); will need rehab and long recovery (19); seems high stress beating himself up about not moving more quickly and be more aggressive (5)(15)(18)		Stress mitigators: Extended social network (1); need some rest, have to be healthy for him (20); Ambien, Xanax; Talking to all the doctors (12); Doctors communicating everything and "slowing him down" (14)(17); talking to others in waiting room (13); connecting with ordinary, day to day processes and routine (21)	

Illustrative quotes (samples):

- 1) I keep talking with my principals, my, our office staff and my board representative, my board president and they're giving me information about what's going on there and I'm giving them information for people more on a personal level and just to keep them informed.
- 2) I think just as any two individuals possibly our thought processes are most often in line but occasionally they diverge and she might think of a question, comment, concern that I wouldn't. So it's just, just the value of having two people as opposed to me being by myself making all of the decisions for my son

Figure 1.

IDI Analysis Template (footnote and list illustrative and supportive quotes below the table)

Table 1

Surrogate Decision Maker (SDM) Characteristics

Characteristic	Barnes-Jewish (n=18)	Parkland (n=16)	Combined (n=34)
Age (mean ($\pm$ SE) years)	52.8 ($\pm$ 13)	41.2 ($\pm$ 16)	46.3 ($\pm$ 14.5)
Gender (% female)	80.0	78.9	79.4
Ethnicity (%)			
African American	60.0	36.8	47.1
Caucasian	40.0	31.6	35.3
Latino/ Hispanic	0	31.6	17.6
SDM Relationship to Patient (%)			
Spouse	26.7	1.7	14.7
Child	20.0	36.8	29.4
Parent	33.3	15.8	23.5
Other *	20.1	42.1	32.2
Relationship with Patient (mean ($\pm$ SE) years)	37.0 ($\pm$ 12.1)	32.02($\pm$ 16.5)	34.3 ($\pm$ 14.7)
Formal Education (mean ($\pm$ SE) years)	13.7 ($\pm$ 2.5)	11.7 ($\pm$ 4.5)	12.6 ($\pm$ 3.5)

* Grandchild, Grandparent, Sibling, Domestic Partner