

Defining Familial Interactions and Networks: An Exploratory Qualitative Study on Family Networks and Surrogate Decision-Making

OBJECTIVES: To characterize patient preferences for medical surrogate decision-makers in the ICU to capture the complexity of decision-making preferences and highlight potential conflicts between patients' preferences and clinicians' surrogate decision-maker identification in usual clinical practice.

DESIGN: Prospective qualitative cross-sectional study.

SETTING: Two ICUs in a quaternary referral center in the eastern United States.

PATIENTS: Convenience sample of patients admitted to the ICU and their family members.

INTERVENTION: None.

MEASUREMENTS AND MAIN RESULTS: Twenty-six patient-family-clinician units were interviewed. Men were three times more likely than women to have a legally appointed decision-maker that matched their preferred decision-maker as expressed in the interview. Patients who were married or in a long-term relationship were the most consistent group of respondents, with 94% of them selecting their spouse or partner as the preferred decision-maker. The most common reasons for selecting a surrogate decision-maker were intangible themes such as feeling "known" by that person rather than having prior discussions about specific wishes or advance directives.

CONCLUSIONS: Asking about a patient's familial network and qualities they value in a surrogate decision-maker may aid ICU teams in honoring patients' wishes for surrogate decision-making. This may be an important supplement to accepted legal hierarchies for proxy decision-makers and advance directive documents. Further studies with larger sample sizes could be used to shed light on the nuances of familial and relationship networks of a more diverse population of respondents.

KEY WORDS: advance directives; communication; intensive care units; physician-patient relations; proxy; shared decision-making

Modern relationships between patients and the healthcare team have become increasingly focused on patient autonomy and partnership in the medical decision-making process. Adherence to this pillar of medical ethics is challenging in the ICU due to the often unforeseen, catastrophic, rapidly evolving nature of an ICU admission. It is further complicated by the fact that many patients in the ICU lack decision-making capacity (1, 2). Family and close contacts are thus invaluable resources for holistic patient care and shared decision-making (3).

For an ICU team, the initial identification of a surrogate decision-maker (SDM) is a highly variable process that is susceptible to potentially serious errors (4, 5). The legal decision-maker is determined by state-specific hierarchies. In the authors' state of Pennsylvania, the priority is as follows: 1)

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healthcare agent as documented in a healthcare directive, 2) court-appointed guardian, and 3) a person chosen by the patient in signed writing or by informing an attending physician. This is followed by a hierarchy of family relations in descending order: spouse, child, parent, sibling, and grandchild. Few tools are available to today's ICU teams to strategically seek out the patient's preferred SDM, not merely the default decision-maker by law.

We hypothesized that patients' stated preferences for a surrogate decision-maker would sometimes conflict with the legal hierarchy referenced by care teams in our institution. The objectives of this exploratory study were to characterize patient preferences for surrogate decision-making and to compare the patients' stated preferences with responses from one of their family members and one of their clinicians. The goal of this work was to deepen understanding of familial relationships (including kinship and chosen relationships) affecting SDM and to problematize the practice of using legally defined hierarchies without asking about patients' preferences and meaningful relationships.

MATERIALS AND METHODS

This prospective cross-sectional study was reviewed and approved by the University of Pennsylvania institutional review board (number 825573). We performed one-time structured interviews with a convenience sample of patient-family-clinician units drawn from all patients admitted to two mixed surgical ICUs associated with the University of Pennsylvania Health System (Surgical ICU at the Hospital of the University of Pennsylvania and Trauma Surgical ICU at Penn Presbyterian Medical Center) during a 6-month period between October 2016 and April 2017. We used the Consolidated Criteria for Reporting Qualitative Research (6) to guide reporting in this article.

Eligibility Criteria and Target Sample Size

Inclusion criteria for patients and family members included 1) age greater than 18 years, 2) fluency in English, 3) ability to phonate, and 4) ICU admission for at least 24 hours (patients) or having spent at least 24 hours in the ICU with a loved one (family members). Patients were excluded if they were delirious (i.e., positive Confusion Assessment Method for the ICU screen), were unable to speak because of an alteration in consciousness, were

being cared for by the senior author (M.B.L.-F.) at the time of enrollment, or were in police custody. Family members were excluded if the corresponding patient declined participation. Inclusion criteria for clinicians included attending physicians, fellows, resident physicians, advanced practice providers, or nurses who had taken care of the patient over the course of more than one shift or more than 1 calendar day. The sole exclusion criterion for clinicians was patient refusal.

Patients could participate without a family member or clinician. Family members could only participate if the patient they were supporting also consented. Clinicians could only participate if they were caring for a patient who first consented to participate, and they were asked about the preferences for that patient. The target sample size for this study was 20–30 patient-family-clinician triads, based on other studies reporting the number of interviews needed to reach thematic saturation (6, 7).

Screening and Recruitment

One business day prior to the anticipated interview date, the medical records of patients in the ICU were reviewed, and a research team member contacted the attending physician, resident physician, or primary nurse to discuss patient eligibility and ask for permission to complete the interview. If permission was granted, we approached prospective patients, family members, and clinicians in the ICU to inform them of the study objectives and to request their enrollment.

Qualitative Approach

Given the exploratory nature of the study and our desire to “stay close” to the perspectives offered by our participants, we used a qualitative descriptive approach to data collection and analysis (7, 8). We used a structured instrument to elicit patient preferences for surrogate decision-making that could be easily compared across participants while allowing for emic description of familial networks and the factors patients considered in selecting a surrogate.

Interview Instrument

We designed the interview guide for this project based on a review of the literature and our clinical experience with ICU surrogate decision-making (**Supplemental**

Material, <http://links.lww.com/CCX/A742>). We pilot tested the interview guide with five patient-family dyads. The interview instrument focused on the patient's preferences for family members to interact with the care team and to make decisions on their behalf. In addition to decision-making questions, we collected several demographic characteristics for the following reasons:

- “Gender”: There are known gender-related differences in advanced care planning, end-of-life caregiving, and end-of-life interventions (9), all of which are relevant to surrogate decision-making.
- “Race and ethnicity”: There are known racial and ethnic differences in rates of advanced care planning and reported discussions about end-of-life wishes (10).
- “Sexual orientation and marital status”: In the United States, people identifying as lesbian, gay, or bisexual report lower rates of marriage than those identifying as straight (11). As most people with a spouse designate that person as their surrogate (12), the differential rates of marriage for Lesbian, Gay, Bisexual, Transgender, Queer or Questioning persons are relevant to the study of surrogate decision-making.
- “Religion”: Religiosity and spirituality are thought to influence serious illness and advanced care planning (13).

Interviews were conducted by one of five research assistants (A.Y.A. and the data collectors in Acknowledgments; one man and four women clinical trainees) who were not part of the ICU care team. The primary interviewer (A.Y.A.) underwent training by the senior author (M.B.L.-F.) and then trained the additional reviewers. Patients were consented and interviewed at bedside. Family members and clinicians were consented and interviewed in private rooms separate from the patient. Interviews were audio recorded but not transcribed; audio recordings were used to verify correct data capture in Research Electronic Data Capture (14), a HIPAA of 1996 compliant research database. No member checking was performed.

Data Analysis

We used descriptive statistics to characterize demographic categories; measures of central tendency and statistical comparisons between groups were not calculated because we used nonprobability sampling. A “match” in designation of preferred SDM was assigned if the patient and family member or clinician indicated the same individual as the first choice for SDM.

For qualitative data analysis, we used an applied thematic analytic approach (8): records of patient

and family member responses were independently reviewed by two members of the research team and categorized into major themes using an inductive approach. Discrepancies were discussed by the team members until agreement was reached. Themes were not mutually exclusive, meaning one response could be counted for multiple themes. Qualitative data analysis was performed with Microsoft Excel (Microsoft Corporation, Redmond, WA).

RESULTS

Approximately 150 patient charts were screened, and 33 patient-family dyads met inclusion criteria. Of those that met inclusion criteria, 26 patient-family dyads consented to participate in the interviews. Thematic saturation was reached as determined by consensus of the coding team. Patient demographics are summarized in **Table 1**.

Of the 26 patients, 14 (54%) reported having a legal surrogate decision-maker when asked who their legal surrogate was; no definition was offered for the term “legal surrogate.” Seventy-nine percent of men compared with 25% of women had their preferred decision-maker expressed during the interview also documented as their legal decision-maker. Patients who were married or in a long-term relationship were consistent in their selection of spouse or partner as preferred decision-maker; of the 18 married or long-term relationship patients, 17 (94%) identified their spouse or long-term partner as the preferred SDM. Twelve of those 17 (71%) were also the legally appointed SDM. There were two discrepancies between the person that the patient and the interviewed family member selected as the preferred SDM.

Overall, five of the 26 patients preferred an SDM that would not have been designated the legally appointed SDM by Pennsylvania law. Two married patients indicated that their mother was their preferred surrogate; the law would have named their spouses. Three unmarried individuals preferred that their significant other, father, and friend be their surrogate, respectively. Pennsylvania law would have designated the patients' mother, son, and son as the legally appointed SDMs, respectively.

Several themes emerged about the reasoning that a loved one might be preferred as the SDM. Recurring key words and themes included being “known by”

TABLE 1.
Patient Demographics

Patient Characteristics	<i>n</i>	Percent
Documented sex		
Male	13	50
Female	13	50
Self-identified gender		
Man	13	50
Woman	12	46
Transgender man	1	4
Sexual orientation		
Straight	20	77
Gay or lesbian	1	4
No response	5	19
Race and ethnicity		
White	18	69
Hispanic/Latinx (all races)	1	4
Black	4	15
Multiracial	1	4
Prefer not to answer	2	8
Religion		
Christianity	18	69
Islam	2	8
No organized religion/prefer not to answer	6	23
Marital status		
Married or long-term relationship	18	69
Divorced	4	15
Single/never married	4	15

or “trusting” the loved one, longevity of relationship, proximity and convenience of that particular loved one, expressing confidence in their decision-making skills, or someone with whom they have had prior discussions about their wishes (Table 2). Patients most frequently cited “feeling known” as their reason for choosing a SDM ($n = 11$; 42% of responses). Family members most frequently cited prior discussions and documentation regarding wishes ($n = 8$; 31% of responses) and proximity/convenience of the individual ($n = 8$; 31% of responses) as their reason for why the SDM was chosen.

Of the 26 patient-family dyads, 17 clinicians were available for interview. Fourteen (82%) correctly identified the most important loved one who matched the patient’s preferred decision-maker. There was no apparent correlation between type of provider (primary nurse, resident physician, or fellow physician) or length of time caring for the patient and ability to identify the patient’s preferred SDM.

DISCUSSION

In this single-center exploratory qualitative study, we identified variability in patients’ expressed preferences for surrogate decision-makers, with women patients demonstrating a gap in documentation of their preferred SDM. Although uncommon, there were occasional discrepancies between the patient’s preferred SDM and the person identified by the patient’s family member, which has implications for patients who are incapacitated. Patients expressed “being known” as a key factor in their designation of an SDM.

The ICU is a challenging environment to uphold patient autonomy in decision-making given the severity of illness encountered, often unexpected timing of admission, and high percentage of patients who lack decision-making capacity. More often than not, SDMs are used. Studies have demonstrated that having had prior conversations about treatment preferences is one of the primary determinants of patient confidence in a SDM and of the surrogate’s confidence in their ability to accurately reflect the patient’s wishes (15, 16). Despite this, advance directive checkboxes and the legally predetermined hierarchies for SDMs have failed to produce improvement in care during critical illness (17). In fact, many patients prefer a SDM to use their best judgment as circumstances change, rather than to be bound by the specifics of documents such as living wills (18, 19). The results of this exploratory study seem to similarly reflect the fluidity of patient preferences. Although family members frequently referenced prior conversations about preferences as the reason for choosing a SDM, the patients much more frequently referenced intangible themes such as being “known” or believing a person to have strong decision-making skills as reasons for choosing that particular SDM.

A higher proportion of men as compared to women had a legally appointed decision-maker that matched

TABLE 2.
Patient and Family Member Reasons for Choosing Surrogate Decision-Makers

Patient's Reason for Choosing Decision-Maker	No. of Times Theme Was Identified in a Patient Response	Percent of Responses, <i>n</i> = 24	Representative Quotes
Feels "known" by this individual	10	42	"The person that knows me best. Knows what you'd best want."
Longevity of relationship	6	25	"We've been together since 47 years...we know what we want."
Most available/closest family member	5	21	"All of the children know what the I would want done. She is the closest and fastest."
Good decision-making skills, critical thinker	5	21	"Because he's the most logical thinker, he's not going to go off of emotion."
Prior discussions/documentation regarding wishes	5	21	"Same values and judgement...have talked extensively about what I would want."
"Trust"	4	17	"She's my spouse and I trust her most."
Family Member's Reason for Why Decision-Maker Was Chosen	No. of Times Theme Was Identified in a Family Member Response	Percent of Responses, <i>n</i> = 10	Representative Quotes
Prior discussions/documentation regarding wishes	5	31	"Has legal documents talking about what he would want in different situations surrounding his health."
Most available/closest family member	5	31	"She is the daughter who lives closest to the patient, lives in town, other two children are out of state."
"Knows" the individual	4	25	"I know and love the patient. Since getting married we have discussed what we would want done in such situations."
Good decision-making skills, critical thinker	2	13	"Level headed, good in crisis, ask questions, researches."
Would act in best interest	2	13	"Parents are in her best interest, working towards getting her cured."
Longevity of relationship	1	6	"I have been with her for almost 50 years and I know what she would want if she were to be in such situations."

their selected SDM during the interview. It is possible that societal or cultural expectations influence men to more frequently appoint a legal decision-maker. In this study, the gender discrepancy is more likely explained by the relatively higher number of men than women in the married or long-term relationship group. This was overall the most predictable demographic group demonstrating 1) consistent selection of spouse or partner as SDM and 2) the highest percentage of legally appointed decision-makers. A patient's spouse is typically the default decision-maker (in the absence of a healthcare agent, court-appointed guardian, or

another individual identified by the patient) and often the first person an ICU clinician will rely on for decision collaboration or consent—a general practice that is supported by the results of this study, other studies (12), and the law.

There were two discrepancies between patient and family member responses for SDM selections. The first instance was a patient who identified her unmarried significant other as the preferred decision-maker. The patient's mother as the interviewed family member identified herself as the individual who her child would want to make decisions on

her behalf. The second instance was a patient who identified a sibling as the preferred decision-maker, whereas the patient's daughter as the interviewed family member identified herself as the patient's preferred decision-maker. These discrepancies are both examples of the patient's preferred decision-maker falling out of order with the legal hierarchy of family relations for the state of Pennsylvania where this study was conducted and would have been missed had their preference not been elucidated by the ICU team. With two examples in a sample size of 26, it is not unreasonable to presume an ICU clinician could encounter this scenario over the course of an attending week or month-long rotation, thus should be vigilant in confirming patient preferences when given the opportunity and taking measures to help align the preferred and legally appointed SDMs. Therefore, in addition to asking "Who is your legal decision-maker?" ICU clinicians should consider asking "Who do you feel knows you best?"

This study has limitations. First, the study was purposefully exploratory, using thematic saturation to determine sample size. For this reason, we are not able to make population-level inferences about patterns in surrogate decision-making. Our findings may however be useful in the design of larger studies to characterize patient perspectives about SDMs. Specifically, larger studies could provide a more nuanced analysis of how patient preferences for SDMs vary within a diverse patient population with different races, ethnicities, religions, sexual orientations, and other identities. Second, laws about surrogate decision-making in the United States vary greatly by state (20, 21), limiting the transferability of our findings. Despite this, the concept of eliciting and documenting patient preferences is broadly relevant. Third, we did not distinguish between patients' self-report of having a legal surrogate and the presence of a legal surrogate in the medical record. The high rate we reported (> 50%) likely represents over-reporting of surrogate documentation.

CONCLUSIONS

Patients value both conventional kinship relationships and being known by potential surrogate decision-makers. Legal hierarchies that are often referenced in critical care practice may conflict with patients' elicited preferences for surrogate decision-making.

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