

# Nurse-Perceived Barriers to Effective Communication Regarding Prognosis and Optimal End-of-Life Care for Surgical ICU Patients: A Qualitative Exploration

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## Abstract

**Background:** Integration of palliative care for intensive care unit (ICU) patients is important but often challenging, especially in surgical ICUs (SICUs), in part because many surgeons equate palliative care with terminal care and failure of restorative care. SICU nurses, who are key front-line clinicians, can provide insights into barriers for delivery of optimal palliative care in their setting.

**Methods:** We developed a focus group guide to identify barriers to two key components of palliative care—optimal communication regarding prognosis and optimal end-of-life care—and used the tool to conduct focus groups of nurses providing bedside care in three SICUs at a tertiary care, academic, inner city hospital. Using content analysis technique, responses were organized into thematic domains that were validated by independent observers and a subset of participating nurses.

**Results:** Four focus groups included a total of 32 SICU nurses. They identified 34 barriers to optimal communication regarding prognosis, which were summarized into four domains: logistics, clinician discomfort with discussing prognosis, inadequate skill and training, and fear of conflict. For optimal end-of-life care, the groups identified 24 barriers in four domains: logistics, inability to acknowledge an end-of-life situation, inadequate skill and training, and cultural differences relating to end-of-life care.

**Conclusions:** Nurses providing bedside care in SICUs identify barriers in several domains that may impede optimal discussions of prognoses and end-of-life care for patients with surgical critical illness. Consideration of these perceived barriers and the underlying SICU culture is relevant for designing interventions to improve palliative care in this setting.

## Introduction

OVER 20% of U.S. deaths occur either in or shortly after admission to an intensive care unit (ICU);<sup>1</sup> and multiple researchers, professional societies, and expert panels advocate for improved palliative care for all ICU patients, regardless of prognosis.<sup>2–4</sup> The public and policy makers emphasize end-of-life care as a key area for improving overall health care quality.<sup>5</sup> Consequently, interventions using both integrative and consultative models<sup>6</sup> to improve delivery of palliative care to ICU patients have been implemented and evaluated.<sup>7–16</sup> However, few of these interventions have been tested specifically in surgical ICUs (SICUs).

For a variety of reasons, patients in SICUs are at risk for receiving inadequate palliative care.<sup>17–21</sup> The time frame of surgical illness is often compressed, which requires patients, families, and clinicians to make difficult decisions in haste, without either clear information on patient prognosis or adequate emotional adjustment.<sup>21</sup> SICUs are more likely to use “open” or “semiclosed” administrative models<sup>18</sup> in which coordination of multiple care teams can be difficult. Surgical culture, with an overemphasis on clinician accountability for patient outcomes,<sup>22</sup> a “rescue credo” amongst surgeons,<sup>23</sup> and pride in technical, as opposed to psychosocial or spiritual aspects of patient care,<sup>24</sup> may also hamper incorporation of palliative care principles. Besides these SICU-specific issues,

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fewer than 10% of all ICU patients participate in decision making;<sup>25</sup> vulnerable surrogates must thus make emotionally laden decisions, often without adequate information about the patient's prior wishes and goals of care.

Previous studies have indicated that ICU nurses have a unique role in the dynamic between surgeons, ICU physicians, and families of critically ill patients. As compared to SICU physicians and surgeons, the nurse spends more time communicating with the patients' family regarding prognosis<sup>26,27</sup> and often acts as "translator"<sup>18</sup> or "information giver"<sup>27</sup> for patients and patient families. If there is conflict between physicians and families or between varying physician groups (such as between surgeons and ICU intensivists), the nurse may serve as a "culture broker"<sup>28</sup> attempting to mitigate conflicts. In end-of-life care, nurses help families "reconnect" with the dying patient to ensure optimal communication and a "peaceful death."<sup>29</sup> Yet, compared to medical ICU nurses, SICU nurses report lower levels of physician-nurse collaboration.<sup>30</sup> They also report fewer opportunities to speak to surgeons about patient prognosis, and often feel their comments to both surgeons and intensivists are undervalued.<sup>17, 26</sup>

A consensus group sponsored by the Robert Wood Johnson Foundation<sup>3</sup> identified seven domains for high-quality end-of-life care in the ICU: patient- and family-centered decision making, communication, continuity of care, emotional and practical support of patients and families, symptom management and comfort care, spiritual support, and emotional and organizational support for ICU clinicians. Based on our experiences as SICU physicians and nurses, we believed the specific domain of "communication" and the general approach to end-of-life care were especially important in our SICU setting. We undertook this qualitative study to explore the barriers to optimal communication and end-of-life care in SICUs as perceived by the bedside nurses.

## Methods

In September 2009 we convened four focus group sessions with a goal of discussing barriers to delivery of core elements of palliative care to SICU patients. We interviewed groups of SICU nurses at the Johns Hopkins Hospital who practice in one of three SICUs: a 15-bed cardiac surgical ICU that predominantly admits patients after cardiac surgery; a 13-bed surgical ICU and intermediate care unit (IMC) that predominantly admits patients after trauma, transplant, and vascular surgeries; and a 16-bed general surgical ICU and IMC that predominantly admits patients after thoracic, general abdominal, plastic, gynecologic, and ear/nose/throat surgeries. Each surgical ICU operates under a "mandatory consult" plan; patients are admitted by the primary surgeon with his or her corresponding house staff team, and with a required ICU team consultation.<sup>31</sup> Physician medical decisions are made jointly between the primary surgical and ICU teams. The ICU attending team is interdisciplinary and comprised predominantly of physicians with primary boarding in either surgery or anesthesia and subspecialty certification in critical care. The ICU team is comprised of house staff and of nurse practitioners with responsibilities similar to those of senior house officers.

At the time of this study, the hospital's interdisciplinary palliative care team consulted only on medical-oncologic

and/or medicine patients, not on surgical patients. Questions related to hospice care for a surgical patient were referred to a social worker.

## Item generation and refinement for focus group guide

Our study focused on nurses' perceptions of communication regarding prognosis, specifically, and end-of-life care, more generally. Based on a review of the literature and experience, the study investigators, composed of clinicians in surgical nursing and surgical critical care, generated a list of open-ended questions; the goal of the questions was to facilitate unbiased and unrestricted discussion about these two topics across multiple focus groups. Through successive iterations, the research team reduced and refined this list to include four key questions for each topic (Table 1). For these focus groups, "prognosis" was specifically defined as how a patient's illness and overall health are likely to evolve during the hospitalization or over the next few days to months. Consequently, "prognosis" incorporated both whether or not a patient was likely to die during the hospitalization and what would be the quality of life during the hospitalization and after discharge.

## Focus groups

Nurses were recruited to the focus groups through email messages to full-time nurses employed in any of the three surgical ICUs. We also posted fliers throughout the participating SICUs. SICU nurse participation in the focus groups was voluntary. Meetings were held in the conference room within each ICU.

For each focus group, a moderator (RA) encouraged discussion based on the open-ended questions in the focus group

TABLE 1. ICU NURSE FOCUS GROUP QUESTIONS

In this context I am specifically defining prognosis as how a patient's illness and overall health is likely to evolve during this hospitalization and/or over the next few days to months.

### Communication of prognosis

- Who talks to patients and patient families about prognosis? How do they do it? Good points? Bad points?
- What are the barriers to effective communication about patient prognosis in your ICU?
- Would you like to see a change(s) in the way your unit handles communication about patient prognosis? How?
- In your ICU, who do you think should be involved in discussions about patient prognosis? Practically, who do you think can be involved?

### End-of-life care

- Tell me about end-of-life and/or palliative care for patients in your unit. How do you think it is managed? Good points? Bad points?
- What are the barriers to effective end-of-life care in your ICU?
- What would you like to see change in the way your unit handles end-of-life care?
- Who do you think should be involved in end-of-life care on your unit? Practically, who do you think can be involved?

guide. During the planning phase of the project a large number of SICU nurses expressed reluctance to speak about their views in an audio-recorded session, but nursing staff were willing to participate in sessions led by a specific moderator known to them (RA, who had rotated through each of the surgical ICUs during fellowship training and was transitioning to a faculty position), with note-taking by the moderator and an independent observer (RW, IT, or MZ). Both the moderator and the observer took extensive written notes, including exact key words and phrases used by the participants. Each focus group session lasted an hour and the topic of communication regarding prognosis was discussed first, followed by the discussion about end-of-life care.

### Qualitative analysis

The written notes were de-identified, compared, and pooled. Investigators (RA, PP) used content analysis technique to identify major themes emerging in the discussions. Individual barriers articulated by participating nurses were grouped in domains reflecting these themes. Multiple members of the research team (RA, RW, MZ, IT) met to reach consensus on interpretation of the nurses' responses and on the classification scheme. Ultimately, complete agreement was reached on all domains and classifications of barriers. After internal validation of the domains by the study investigators, these domains were disseminated to a subset of 10 nurses who participated in the focus groups for verification that the domains accurately represented the actual focus group discussions.

### Results

We conducted four focus groups (two in the 13-bed general surgical ICU/IMC, one in the 15-bed cardiac surgical ICU, and one in the 16-bed general surgical ICU/IMC) involving 32 nurses. This sample represented approximately 20% of nurses working in the SICUs. No nurse participated in more than one focus group. Group size ranged from 5-10 nurses per meeting. In general, our cohort consisted of experienced ICU nurses, with a median of 8 (range, 0.5-30) years of ICU experience. Nearly all nurses attending the focus group sessions contributed at least one comment during the meeting.

Nurses in each unit had serious concerns about both the quality and the quantity of communication regarding prognosis and the end-of-life care provided in each respective ICU. They identified four domains of barriers to optimal communication about prognosis (Table 2):

- *Logistics; physical and/or temporal impediments* – “The patient is often intubated and unable to participate in the conversation;” “Surgeons have cases during the day and are not available when families are present;” “The attending is in a hurry [and]...frequently interrupted.”
- *Discomfort with discussing prognosis; health care providers and/or families being uncomfortable with discussions regarding prognosis* – “Some people fear legal ramifications of bad outcomes and do not want to discuss prognosis;” “The goals of care were unclear even before the surgery – for both the surgeon and the patient;” “Updates from the primary [surgeon] are often unrealistic and only portray the ‘small victories’ instead of the overall prognosis;” “No time to talk to patients on rounds – surgeons are rushed;” “Lack of formal family meetings.”

TABLE 2. BARRIERS TO COMMUNICATION REGARDING PROGNOSIS

#### Logistics

Surgical team rounds before the family is present  
 Cannot assemble entire team (ICU doctors, surgeons, nurses)  
 Not all parties (ICU doctors, surgeons, nurses) present when meetings do occur  
 Other support resources not always available (social work, pastoral care, palliative care)  
 Not enough time during meeting  
 Poor availability of doctors or family for a meeting  
 Multiple decision makers in a family  
 Surrogate decision maker not at the meeting  
 Meetings interrupted by health care provider pagers and/or cell phone calls  
 Lack of unbiased person  
 Patient cannot participate in conversations  
 Unclear what prior specialists and consultants have said regarding prognosis

#### Discomfort with discussion

Physician discussions with nurses and families are inconclusive  
 Family members do not want to “hear bad news” and avoid the meeting  
 Prognoses are unrealistic and often portray “small victories” instead of overall prognosis  
 Unclear whose role it is to discuss prognosis and no one ends up doing so  
 Poorly defined goals of care, even prior to surgery – for surgeon and patient

#### Perceived lack of skill or training

Physician discussions are rushed  
 Families are not given adequate time to ask questions  
 Communication is done “last minute,” often before a procedure  
 Families are unaware of a patient’s diagnosis  
 There is no accepted protocol about when and what to communicate  
 If families do not ask for meetings, they will not receive them  
 Physicians both use language that the family do not understand and do not recognize it  
 Families do not remember to ask all their questions  
 Families do not know what resources are available to them  
 Fear of legal ramifications of bad outcomes

#### Fear of conflict

Different opinions about prognosis between care providers  
 Inconsistencies between team members in communicating prognosis to families  
 Surgery and ICU teams rarely discuss prognosis but get angry when nurses discuss it  
 Difficult personalities of some health care providers

- *Inadequate skill and training; care providers not being aware of how best to conduct discussions regarding prognosis, care providers having misconceptions about the consequences of these discussions, and/or family members not being prepared for the discussions* – “Patient and patient families have difficulty forming their questions and asking about their concerns;” “The doctor does not realize when a family

does not understand what is being said;" "Poor bedside manner by surgeons."

- *Fear of conflict; care providers and/or family members avoiding conversations due to anticipated variations in prognosis that could lead to conflict amongst involved parties* – "You don't know how honest a surgeon has been previously in talking with a family, especially if a patient is 'off-pathway;" "Nurses don't know what was discussed with the patient preop and what their expectations are;" "ICU team is sometimes not invited to participate in the family meeting;" "Everyone is not on the same page."

The nurses also identified four domains of barriers to optimal end-of-life care (Table 3):

- *Logistics; temporal factors, such as the short time when end-of-life care might be provided, as well as practical factors,*

TABLE 3. BARRIERS TO OPTIMAL END-OF-LIFE CARE IN THE SICU

<i>Logistics</i>
Often only a small window when can offer end-of-life care
Prognosis is often uncertain
Patient often cannot be involved in discussions
Lack of palliative care service for surgical patients
Unclear patient advance directives
Unclear surrogate decision maker for patient
Few other care resources beyond an ICU for patients on advanced life support
<i>Inability to acknowledge an end-of-life situation</i>
Families are often given "false hope"
Care providers often have "false hope"
Differences in opinions amongst care providers regarding prognosis
<i>Education</i>
Poor communication between care providers
Care providers uncomfortable discussing end-of-life care
Poor knowledge concerning available resources (chaplaincy, palliative care, hospice)
Not all care options are understood and/or presented
Poor care provider training in providing end-of-life care
Families do not understand the technologies used in ICU to keep patient "alive"
<i>Cultural barriers</i>
Care providers and families uncomfortable discussing end-of-life care
Prognosis is often uncertain—patient death is seen as a defeat by care providers and/or families
Hospice is rarely discussed as a care option
End-of-life situations are particularly difficult when the patient is younger
Disagreements about whether the patient should be involved in the discussion
Patient cultural beliefs that contrast with those of the care providers
Unclear as to what is a "natural death" or what are "extreme measures" or "futile measures," particularly when a patient is already on life support in an ICU

*such as the lack of a palliative care consultation service for surgery patients* – "No palliative care service for surgical patients"; "No standardized order set for end-of-life care;" "Current drug infusion limits, such as max doses for pressor doses, are already not followed;" "There are no other care resources for patients beyond this ICU, especially for VAD [ventricular assist device] patients."

- *Inability to acknowledge an end-of-life situation; care providers not acknowledging that the patient might die* – "Doctors have different standards for what end-of-life care means;" "Physicians are slow to acknowledge that it is end-of-life care;" "False hope given;" "It is unclear as to what is a 'natural death', especially in this ICU with patients on VAD."
- *Inadequate skill and training; care providers not aware of how best to provide end-of-life care* – "Nurses don't know what resources are available;" "No [nurse] training in end-of-life care;" "[Doctors] prolong [end-of-life care] and miss the window to address leaving with dignity;" "[Poor] doctor training in communication;" "Nurses don't know what to say to a family after [a patient has been] told that [a tumor] is unresectable;" "Don't know what the next steps are after the ICU;" "What is hospice?" "Families do not understand the implications of technologies used in the ICU."
- *Different cultures concerning end-of-life care; care providers and/or family members not feeling comfortable with end-of-life care due to the culture of the patient and patient family and/or the culture of the SICU* – "Disagreements exist about whether the patient should be involved in the discussion;" "Family choosing not to be honest with patient about diagnosis;" "Unclear what constitutes 'extreme measures' or 'futile measures,' especially when a patient already [is] with a VAD;" "Some of what we already do and do successfully is on the barrier of what is possible;" "Differences in what patients, patient families, and health care providers consider to be good 'quality of life.'"

Some other quotations highlight key nurse concerns and illustrate their discomfort with discussing these issues. "You're cornered as a nurse...it's not the nurse's place to prognose [*sic*] but to give possibilities" and still "a lot of conversations get dumped on the nurse." "Talking about prognosis is not always well received by the surgical attendings, PAs (physician assistants), or NPs (nurse practitioners)." Patients are "not told the truth about being in an end-of-life scenario" and "We have the sickest patients in this unit."

## Discussion

In this qualitative study, bedside nurses from three SICUs identified barriers for delivery of high-quality palliative care, with barriers addressing key domains such as inadequate education or skill in palliative care, logistical difficulties, and patient and SICU cultural differences and difficulties discussing end-of-life care. Some barriers are unique to ICUs, such as "few other care resources beyond an ICU for patients on advanced life support;" other barriers are more universal for dying patients, such as "unclear patient advance directives." Many barriers applied to both communication regarding prognosis and optimal end-of-life care. This cross-over could be due to conversations being convened with the



same groups of nurses at the same time. However, it also could be because, in SICU culture, communication regarding prognosis implies potential end-of-life discussions and decisions.

Technical or logistical concerns pose significant barriers to palliative care in SICUs. Because most SICU patients cannot communicate, clinicians may have difficulty understanding their goals of care, obtaining advanced directives, and identifying surrogate decision makers. Improved preoperative "advance care planning," such as preoperative discussions to clarify patient goals, fears, and choice of surrogate, could possibly circumvent some of these barriers. Other technical barriers could be mitigated by clarifying which SICU patients require a formal family meeting, when this meeting should occur, and who should attend.

Even after technical barriers are addressed, multiple educational barriers remain. Nurses noted that they lacked training in communication regarding prognosis and optimal end-of-life care and that they thought that physicians also lacked these skills. Indeed, the nurses thought that communication by physicians, particularly in the form of family meetings and end-of-life care was often done quickly, inadequately, and ineffectively. Moreover, nurses believed that families were not being educated in what to expect for communication and how to communicate effectively with health care providers. These are multiple potential targets for future interventions.

The barriers to palliative care offered by the SICU nurses are consistent with previous observations about SICU and surgical culture as well as consistent with our hypotheses about why palliative care in a surgical culture is often challenging. In providing palliative care, each group of key SICU clinicians – the surgeon, the SICU intensivist, and the SICU nurse – is hampered for different reasons. "Total care" or "ownership" of the surgical patient, including control over key decisions, has been documented as an integral part of surgical culture.<sup>19, 22</sup> This "total care" yields great benefit to many surgical patients and has, without a doubt, advanced the field of surgery in numerous ways. However, with palliative care and specifically with end-of-life care, such "total care" can be counterproductive, particularly if the participating surgeon sees a transition to end-of-life care as a "failure."<sup>22</sup> Furthermore, optimal palliative care requires multiple, frequent, unhurried conversations about goals-of-care, symptom-management, and prognosis; many surgeons, who already balance time-intensive operating room, clinic, and inpatient rounding schedules, do not have the time for these meetings. ICU physicians are hampered in that they frequently rotate on and off service; even assuming a semi-open or closed administrative model,<sup>18</sup> they frequently direct a patient's care for only a few days to a week – an often inadequate duration of time to build sufficient rapport with a patient and family. SICU nurses could direct palliative care discussions; however, previous studies note that patients want prognostic information from physicians<sup>32</sup> and even cite physicians to have an obligation to convey this information.<sup>33</sup> Moreover, each of the above scenarios presumes that the surgeon, intensivist, and/or SICU nurse have the desire and skill set to adequately conduct palliative care related meetings – a presumption that some experts question.<sup>20,22</sup>

There are multiple limitations to this study. First, we studied staff from surgical ICUs in one academic medical

center; our findings may not be representative of the views of nurses working in other settings. Second, it is possible that the views of our participating SICU nurses did not represent those of others who did not participate in the focus groups. Third, although we provided a working definition of "prognosis" for purposes of the discussion, clinicians may have understood the term differently based on their prior experience. Fourth, perhaps some of the identified barriers would not be valid if there was a palliative care team available to consult on SICU patients. Fifth, the participation of an investigator/clinician as moderator could have influenced both which nurses participated in the study and what they said during the focus groups; this potential problem was unavoidable given the nurses' selection of the investigator as their favored moderator. Finally, because we used written note taking rather than audio recording with verbatim transcription, we could not accurately count the frequency with which specific themes were identified. Like all qualitative work, however, this study is hypothesis-generating. Future studies including projects involving larger cohorts and quantitative methods must be designed and evaluated to further test hypotheses suggested by this work.

Nurses providing bedside care identified several specific barriers to delivering optimal palliative care to SICU patients. To overcome technical barriers, changes to policies, procedures, staffing, or training may be effective. Other barriers, such as belief in the need for the surgeon to provide "total care" to the patient or that palliative care implies "failure," relate to the culture of the SICU and will likely need further discussion. Practitioners and policy makers seeking to improve palliative care should address these barriers in design and implementation of interventions.

This study suggests multiple potential intervention targets for improving palliative care in the SICU. Such culture change requires both transparency concerning rationale and goals as well as closely coordinated teamwork between clinician groups. All potentially affected clinicians – nurses, surgeons, intensivists, palliative care specialists – are passionate patient advocates who individualize care and desire the best for their patients. By working together they may better ensure that patient goals are met, particularly regarding provision of optimal palliative care in the SICU.

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### Author Disclosure Statement

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