

# Identifying Information Resources for Patients in the Intensive Care Unit and Their Families

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**BACKGROUND** Providing information to patients in intensive care units and their families is challenging. Patients often are admitted unexpectedly and experience stress and uncertainty. One source of stress has been identified as unclear, uncoordinated, or inconsistent communication and information. Despite the need for information, no centrally located, easily accessible, standardized intensive care unit education content exists.

**OBJECTIVE** To identify educational content for patients in the intensive care unit and their families across 4 different hospitals, develop a general content database, and organize the general content into a framework for education of patients and their families.

**METHODS** Educational content for patients in the intensive care units of 4 participating hospitals was collected and a gap analysis was performed.

**RESULTS** Key content format and categories were identified. Educational content was organized into an information pathway divided into 3 phases: intensive care unit arrival; understanding the intensive care unit and partnering in care; and intensive care unit transitions. The gap analysis revealed substantial variation in content format and categories.

**CONCLUSIONS** Structuring a digital learning center using different stages of the patient's stay in the intensive care unit and placing resources in the context of an information pathway can help coordinate education for these patients and their families, and creates a consistent communication guide for clinicians as well. The optimal digital format should be considered in designing the learning center. (*Critical Care Nurse*. 2017;37[6]:e10-e16)

**CE** 1.0 hour, CERP B

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Explain the importance of patient education among critically ill patients and family members.
2. Describe how the American Association of Critical-Care Nurses Synergy Models supports facilitation of patient and family education.
3. Describe the patient education information pathway according to the patient's experience in the intensive care unit.

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**P**roviding information to families is a crucial task for intensive care unit (ICU) nurses and other clinicians.<sup>1,2</sup> As described by the American Association of Critical-Care Nurses (AACN) Synergy Model,<sup>3</sup> to maximize patient outcomes, nurses need to be proficient in competencies that match the needs and individual characteristics of critically ill patients. These AACN Synergy competencies include caring practices that engage the patient and family, collaboration with patients and families to support the achievement of patient/family goals, systems thinking that leverages system resources for patients and families, and facilitation of learning for patients and families. In addition, the ACCN Synergy Model explains that certain patient characteristics—such as resiliency, vulnerability, stability, and participation in care and decision-making—directly affect the facilitation of learning. Patients admitted to ICUs are often vulnerable and unstable and families may be unfamiliar with ICU routines. Their resiliency is challenged in the face of the stress and uncertainty that is common during critical illness.

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A major source of stress for patients and families is unclear, uncoordinated, or inconsistent communication and information.<sup>4,5</sup> Patients in the ICU and their families have varying abilities and willingness to participate in care and decision-making.<sup>6</sup> Patient education requires a flexible approach, especially with family members who become the main points of contact for decision-making on behalf of the patients.<sup>7,8</sup> Family members of critically ill patients consistently identify the need for information and the need for reassurance as the highest priority needs during an ICU hospitalization, yet the need for information is often unmet.<sup>9-11</sup>

Furthermore, the ICU is a unique setting where patients and family members are coping with stress,<sup>12,13</sup> and they need useful, real-time information adapted to the critically ill patient's anxiety.<sup>2</sup> Delivery of information should be sensitive to the patient and families' current needs, recognizing that some patients report increased anxiety when information is shared before they are ready to receive it.<sup>10</sup> **We organized our education content into a pathway divided into 3 phases: Evidence ICU Arrival, Understanding the ICU and supports Partnering in Care, and ICU Transitions.** that delivery of patient information is most efficient and meaningful when it is presented in small quantities to decrease cognitive load, well timed in response to a patient's readiness to learn, and rich with the use of multimedia images.<sup>14-16</sup>

## Objective

Despite the documented need for information among patients and families, ICU educational content is often not centrally located or organized to make it easily accessible to patients and families within an ICU. To facilitate such communication, it is important to identify a core set of information that is generally applicable to all ICU patients and families. This core information is not intended to replace the essential face-to-face communication updates that occur in clinical practice, or to cover all diseases or conditions affecting individual patients. Therefore, the primary goals of our study were to (1) identify ICU patient/family educational content across different hospitals and develop a general content database and (2) organize the general content into a framework for patient/family education in the ICU. Ultimately, the results of this study will aid in the development of a web-based ICU patient/family

digital learning center. The digital learning center will improve patient outcomes by supporting the nurse in facilitating learning, caring practices, collaboration, and systems thinking, while maximizing patient participation in care and decision-making by providing resources for patients/families that are meaningful within the context of an ICU stay. The digital learning center will also leverage technology to present accessible content on demand.

## Methods

### Context of the Study and Current State of Patient and Family Education in ICUs

The Libretto Consortium, funded by the Gordon and Betty Moore Foundation, was formed among 4 hospitals (Beth Israel Deaconess Medical Center, Boston, Massachusetts; Brigham and Women's Hospital, Boston, Massachusetts; Johns Hopkins Medical Center, Baltimore, Maryland; and University of California San Francisco, San Francisco, California) with the goal of eliminating preventable harm in ICUs and reducing unnecessary health care costs by meaningfully engaging patients and families in a redesigned, supportive health

**Patients and families in ICUs are vulnerable and arrive with varying levels of information to support their participation in care and decision-making.**

care system.<sup>17</sup> As part of the work the Libretto Consortium, a multisite taskforce was formed with the goal of developing a framework for a web-based patient and family digital learning center. Our interdisciplinary study team consisted of ICU nurses and physicians, medical librarians, and patient family advisory council members.

Examination of the current state of patient and family education in ICUs across the 4 institutions revealed a similar pattern. Educational materials were available in various formats such as brochures, pamphlets, printable handouts, and as digital content. Materials were stored in various places, ranging from being openly available and accessible to patients to being stored centrally away from the point of care. None of the sites reported an index or catalog of available patient education materials. Staff were often not aware of the range of materials available. Materials were distributed at the discretion of the clinician as a supplement to direct face-to-face communication. Suitability, in terms of content, literacy demand graphics, layout/typography,

learning stimulation, and cultural appropriateness<sup>18</sup> also varied across sites. We concluded that the current state of providing information and education about an ICU stay was a clinician-driven process, which was used inconsistently and was potentially either inadequate or overwhelming for patients and families.

### Information Sources and Search Strategy

The study members at each hospital worked with nursing directors and educators to gather all patient educational handouts and digital content relevant to their respective ICUs. This material included all available print handouts, "welcome package" material, learning videos, web-based patient portal content, content from the hospital website, and other digital patient education resources. Some of these publications were developed within the hospital while others were purchased as licensed materials from vendors.

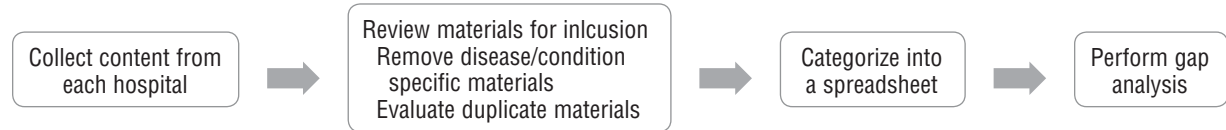
### Data Collection

The study team members collected existing patient educational materials from their respective sites. Various forms of patient educational content, including both paper-based and digital content, were included in our investigation. Three of the 4 hospitals had developed web-based patient portals for patients in the ICU,<sup>19,20</sup> and 1 hospital has an ongoing project to develop an ICU information website with a patient and family advisor.<sup>21</sup> Content from the web-based patient portals were also included in the content collection.

### Data Synthesis

Representatives from each study site met via web conference to review all collected materials. Given our goal to identify a core set of information that is generally applicable for ICU settings, we eliminated content that was disease/condition specific or site specific. If more than 1 material was available for a content area, the study team referred to the patient education materials assessment tool provided by the Agency for Healthcare Research and Quality (AHRQ PEMAT)<sup>22</sup> to inform our choice of the best content for the category.

Content categories were determined by group consensus and the documents were then iteratively organized into a spreadsheet database. Once all of the materials were categorized, the study team performed a gap analysis, which allowed us to identify content categories that



**Figure 1** Process of creating a database of general intensive care unit patient/family educational content database across 4 hospitals.

were common across sites and content categories that were lacking in 1 or more sites. Once we had identified the best materials for each of the categories to include, we organized the content so that it would be the most useful to patients in the ICU, taking into account their shifting needs and priorities during the course of their hospital admission. Lastly, the study team reviewed the entire database and identified missing content areas based on clinical experience. Figure 1 illustrates how the study team aggregated existing patient educational content from each site.

## Results

### Content Format

Results of our study revealed that most (72%) of the educational content was print materials and 28% was digital content. Digital content was web-based materials; no multimedia format (eg, video, interactive learning modules) was found for general ICU-related educational content. The materials varied in reading level, language availability, accessibility features, and use of visual aids.

### Content Categories

The results of the gap analysis of the collected content are shown in the Table. A total of 30 content categories were identified, containing 59 unique materials. The study team identified generally similar content related to ICU care in the 4 hospitals, but the content varied. For example, ICU visitor guides were available in print or digital form in all 4 hospitals, whereas arrival checklists and information about adverse events in ICU, advance directives, and community support were available in only 1 hospital (and not the same hospital for each of these categories).

The gap analysis also revealed disparities in important information frequently provided in ICUs. New categories proposed by the study team included family members in ICU, ICU noises, and hospice care. To support principles

of patient/family-centered care and active engagement in therapy, the role of family members was included to support and encourage their participation in care.

### Information Pathway for ICU Patient Education

In developing a framework for patient/family education in the ICU, we sought to present the materials in a way that would coincide with the patient's experience and information needs rather than in a simple list. Through consultation with our patient stakeholders and work under development at 1 of the participating sites,<sup>21</sup> we developed a pathway structure that would support patient information needs during their time in the ICU. Therefore we organized our education content into a pathway along a continuum divided into 3 phases: ICU Arrival, Understanding the ICU and Partnering in Care, and ICU Transitions (Figure 2).

In the ICU Arrival category, we included information that would assist patients and families in becoming familiar with the ICU environment. The category, Understanding the ICU and Partnering in Care, included information about the ICU room and equipment, patient safety-related information, and condition-specific resources and information about treatments. The ICU Transitions

category addressed the transition from the ICU, ranging from transfer to a rehabilitation setting to a hospice, and included comfort-focused care in the ICU when the patient does not get better.

**Our pathway defines materials that are appropriate based on the patient's experience of an ICU admission and offers opportunities for clinicians to engage patients in their care at these points.**

## Discussion

The Synergy Model supports facilitation of patient and family education<sup>3</sup>; however, our study demonstrated

**Table** Summary of content gap analysis in 4 hospitals

Content categories	Hospital 1	Hospital 2	Hospital 3	Hospital 4	Total
<b>ICU Arrival</b>					
Arrival checklist				D	1
ICU visitor guide	P	P	P	D	4
The care team	P		P	D	3
Family members	NEW				0
Rounding	P	P		D	3
Family meeting	P		P	D	3
<b>Understanding the ICU and Partnering in Care</b>					
ICU room	P	P		D	3
Commonly used equipment	P	P	P	D	4
ICU noises	NEW				0
Pain		P	P		2
Delirium	P		P		2
Restraints	P	P	P		3
Falls	P	P	D		3
Hand hygiene	P		P		2
Central catheters	P			D	2
Peripherally inserted catheters	P				1
Infections (MRSA, VRE, <i>Clostridium difficile</i> , CLABSI)	P	P	P		3
Deep venous thrombosis			D		1
Pressure ulcer			D		1
Early mobilization	P		P		2
Adverse events		P			1
<b>ICU Transitions</b>					
Transfer/discharge information			D	D	2
Health care proxy	P		P		2
Advance directives			P		1
Hospice care	NEW				0
Palliative care	P			D	2
Comfort-focused care	P			D	2
Pastoral	P		P	D	3
Bereavement			P	D	2
Community support	P				1

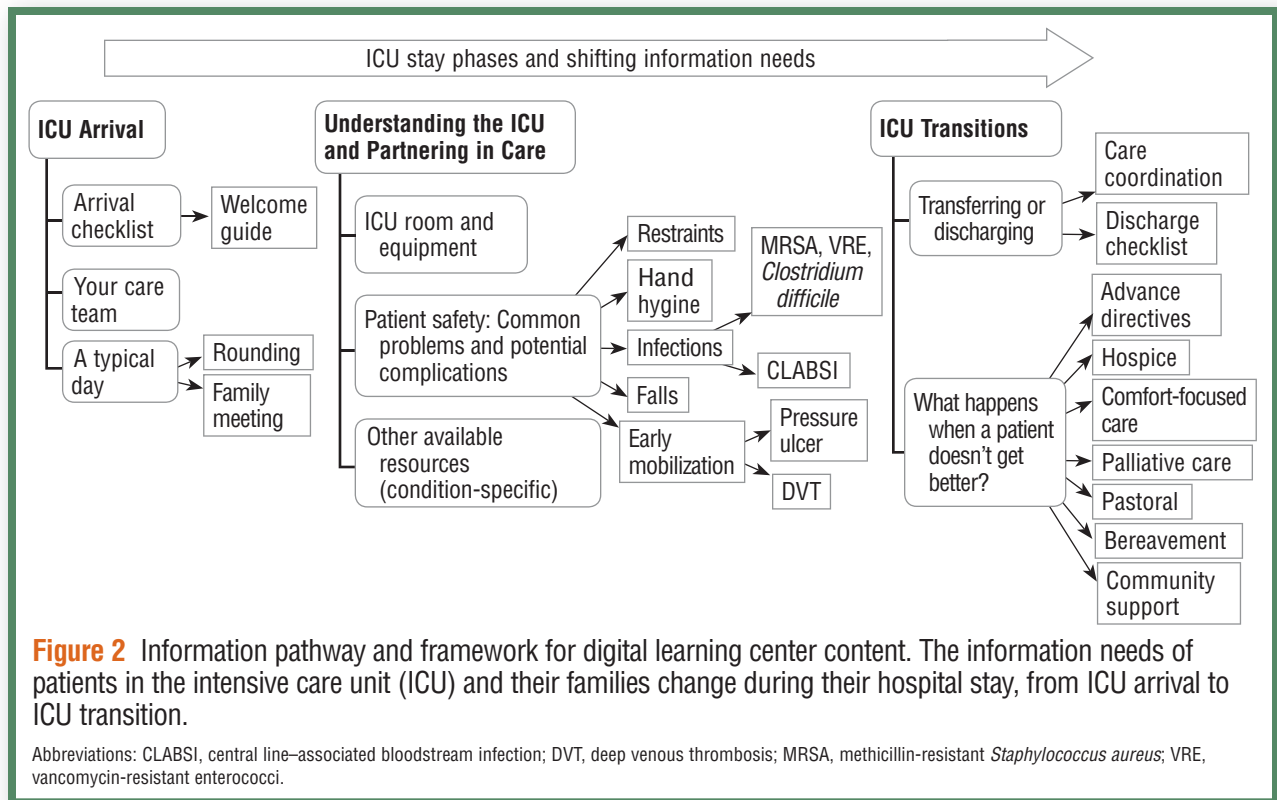
Abbreviations: CLABSI, central line-associated bloodstream infection; D, digital material; ICU, intensive care unit; MRSA, methicillin-resistant *Staphylococcus aureus*; P, print material; VRE, vancomycin-resistant enterococci.

that how this goal is achieved varies widely. We found that materials available were disparate in terms of content coverage and quality. Nurses have a central role in facilitating learning and can do so by engaging and collaborating with the patient and family and helping to create an environment within the ICU that accommodates innovative system resources. We found that no standard educational content for patients in the ICU currently existed among the participating hospitals, compelling clinicians to rely on resources that are often difficult to access. Patients and families in ICUs are vulnerable and arrive with varying levels of information to support their participation in care and decision-making. In addition, informational support to family members of the patients in the ICU equips them with a

better understanding of the stressful situation and decreases their level of anxiety.<sup>23,24</sup>

Our study demonstrated that most learning is clinician driven, and patient agency to control the information received is poorly described. Defining essential content for education of patients and families in ICUs and organizing it into a pathway that mirrors the patient's experience will not only provide consistent direction for clinicians, but will support patients to participate in their care throughout their stay in the ICU.

In practice, the proposed information pathway and content can be used to guide the development unit resources for patient education. Our pathway defines materials that are appropriate based on the patient's experience of an ICU admission and offers opportunities



for clinicians to engage patients in their care at these points. Although web-based patient portals are not yet common in ICUs, providing information in a digital format will allow patients easy access to the materials. Not all patients will favor digital materials; however, digital materials can be printed on demand to provide a written copy to the patient.<sup>25</sup>

## Limitations

Our study was limited by the participation of only 4 hospitals, which were all large university teaching hospitals. The study team attempted to gather all available content; however, some content could have been overlooked. In addition, new content categories were developed through observations from practice by the study team; nevertheless, additional new categories may need to be included.

## Conclusion

An ICU stay involves much decision-making, mostly done by the patient's family or other care partners in a time-pressured and stressful environment. Often their time is extremely limited to learn about ICU-specific information as well as the patient's condition and treatment. In particular, upon ICU arrival, a patient's family may be

overwhelmed by the environment and amount of information received. Our information pathway organizes the general information to be received upon admission to an ICU and throughout the patient's stay.

Further research is needed to validate and expand our proposed content and pathway, as well as to expand development of patient portal and a digital learning library. Additionally, research is needed to understand how the information pathway can promote patient and family communication with their care team members and facilitate their engagement in care, and therefore the potential to improve outcomes of care.

Ideally, information should be easily accessible and adaptable to patients' readiness to learn. A web-based platform would allow patients to access important information on demand according to their readiness and needs. Our study has established a pathway of basic educational content for patients in the ICU and their families and proposes that this information be made available as a web-based platform to fully engage patients in care. **CCN**

### Acknowledgments

The authors thank David W. Bates, MD, MSc, Patricia C. Dykes, RN, PhD, FAAN, FACMI, Anuj Dalal, MD, Omar Badri, MD, and Olivia Dalleur, PharmD, for supporting this study and sharing their insights.

## Financial Disclosures

This study was conducted as part of the Libretto ICU Consortium Taskforce Challenge and funded by Gordon and Betty Moore Foundation in 2015.



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