

PARTNERSHIP IN ICU COMMUNICATION OUTCOMES REPORT



PROJECT DESCRIPTION

Effective communication is necessary in intensive care units (ICUs), where high-stakes decisions are routinely made. Finding solutions to overcome communication barriers requires collaboration from patients and their families, healthcare providers, and researchers.

The goal of this catalyst project was to leverage the expertise and networks of the partners in the proposal (ICU clinician, expert in patient and family-centered care, and health services researcher) to convene stakeholders from two large healthcare organizations in Southern California (Los Angeles County Department of Health Services and Southern California Kaiser Permanente). By conducting a workshop with these participants to discuss communication dilemmas in the ICU, our objective was to identify practical solutions that improve shared-decision making and promote patient-centered care.

Communication Problem	Improving interpersonal/group communication between intensive care unit (ICU) clinicians, critically-ill patients with advanced medical illnesses, and family caregivers.
Catalytic Activity	Full-day open forum/workshop with key stakeholders in Los Angeles County Department of Health and Kaiser Permanente healthcare systems to explore perspectives on ICU communication and discuss improvement strategies.
Project Output	<ol style="list-style-type: none"> 1. Network of engaged stakeholders for developing strategies to improve ICU communication. 2. Summary report on stakeholder perspectives and priorities for improving ICU communication

PROJECT COLLABORATORS

Dong Chang, MD, MS	Glena Cheng, MD, MS	Libby Hoy
ICU Physician, Harbor-UCLA Medical Center, Associate Professor of Medicine, David Geffen School of Medicine at UCLA, Health services researcher with expertise in ICU communication, Principal investigator in Los Angeles County Department of Health Services (LAC DHS) UCLA Implementation Science Program to improve shared decision-making between clinicians, patients, and families.	ICU Physician, Southern California Kaiser Permanente (KP), Graduate of UCSF Master's Program in Health Policy and Law- Capstone Project explored strategies to reduce non-beneficial ICU treatments.	Founder and CEO; Patient and Family Centered Care (PFCC) Partners; Leads organization that develops partnerships between patients, families, and healthcare organizations to improve quality and experience of healthcare; Advisor for PCORI, American College of Physicians, National Quality Forum, Center for Medicare Medicaid Services and the National Academy of Medicine.

ORIGINAL PROJECT PLAN • Prior to COVID-19 Pandemic

Recruit key stakeholders to participate in an interactive full day in-person stakeholder meeting. Participants were to include patients and family caregivers with lived experience in the ICU setting, ICU clinicians including physicians, nurses, chaplain, palliative care clinicians, and hospital administrators. The key outcome for the multistakeholder meeting was to identify future research priorities to build on earlier efforts by Dr. Chang and his colleagues to improve communication in the ICU, particularly as it relates to discussions of ICU treatments for patients with serious illness and poor prognoses.

TIMELINE

Start Date: September 11, 2019

Project Activities	Months											
	1	2	3	4	5	6	7	8	9	10	11	12-16
Partnership planning meetings	X	X										
Identify and contact stakeholders		X	X	X								
Planning multi-stakeholder workshop		X	X	X	X	X	X	X				
Solicit input on agenda from stakeholders					X	X	X	X				
Multi-stakeholder workshop									X			
Follow-up meetings with select stakeholders										X	X	
Planning meetings for next steps										X	X	X
Summary report on findings from seminar											X	X

IMPACT OF COVID 19 PANDEMIC ON PROJECT PLANNING

When COVID 19 arrived in Los Angeles County in February of 2020 the project was paused to allow the partners involved in day-to-day operations of ICUs in LAC DHS and KP hospital systems to meet the demands of caring for COVID patients and their family caregivers. Among the greatest challenges for front-lines care providers during the pandemic were difficulties in communication with patients and families resulting from restrictions in hospital visitation, uncertainty in prognoses and ICU management, and misunderstandings about the state of the pandemic through mass media and other information sources, among other factors. While the number of deaths surged throughout 2020, the clinicians recognized more than ever the importance of improving communication in the ICU, especially related to discussions of nonbeneficial treatments and end-of-life ICU care. (*See Appendix 1 for further details on the experience of the ICU physician in a pandemic.) Given this, the partners agreed that it was important to move forward with the project despite the strains on all stakeholders and limitations in meeting formats imposed by the pandemic.

MODIFIED PROJECT PLAN

Key considerations emerged as we pivoted our project plan in the pandemic environment:

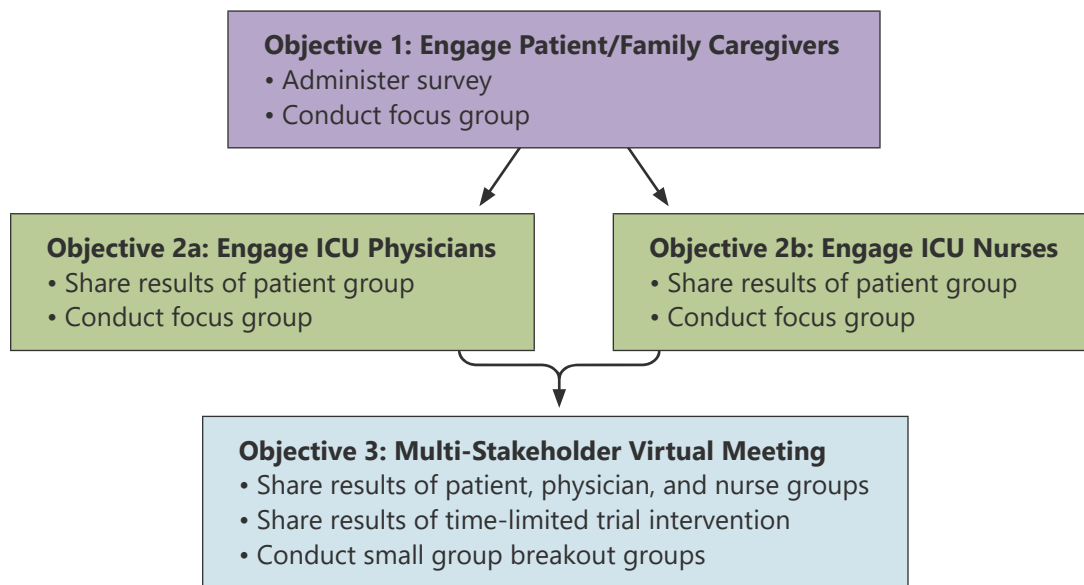
- Transition to virtual meeting
- Reduce burden of participation
- Alternate format to promote multi-stakeholder discussion
- Incorporate experiences in ICU communication during COVID pandemic
- Use of technology

With these considerations in mind, a new project plan emerged in July 2020 which involved holding multiple virtual focus groups with specific stakeholders, culminating in a 75-minute virtual multi-stakeholder meeting (Figure 1).

FIGURE 1 • New Partnership Plan, July 2020

AIMS

1. Document communication patterns in ICU during pandemic
2. Identify opportunities to improve ICU communication
3. Create summary documents to inform efforts to improve ICU communication



FOCUS GROUP WITH PATIENT AND FAMILY STAKEHOLDERS

A preliminary survey was sent to patients and family caregivers to assess past ICU experiences. Survey participants were recruited from the PFAnetwork, LAC DHS Patient Family Advisory (PFA) Program and the Kaiser Permanente Patient Family Advisory Councils (PFAC). Volunteers from this survey then participated in the first focus group in which four topics were discussed.

1. Expectations for communication in the ICU.
2. Experience with informed consent.
3. Influence of patient priorities on care plans in the ICU.
4. Experiences and expectations on how to handle “letting a loved one go.”

The focus group was facilitated by Drs. Dong Chang and Glenna Cheng with Libby Hoy supporting as a patient family representative. The participants appeared to be at ease responding to the topics and supported when sharing deeply personal insights. The tone of the focus group was collaborative, with one participant’s response frequently validating previous comments, suggesting commonalities in described experiences. The participants had fairly high levels of understanding healthcare, and two participants had backgrounds in medically-related fields.

The participants recognized the importance of communication as a key factor in patient and family experiences during ICU hospitalizations. They expressed disappointment in the quality of communication during many of their experiences; they expected to communicate frequently with physicians but found that this was challenging, rushed, or did not occur at all. They identified two important elements of effective communication: content and context. For content, they suggested that healthcare information needed to be comprehensive, easy to understand, and framed in the larger picture of the health issues. For context, they suggested that care providers make greater efforts to humanize and individualize ICU experiences and communication for patients and their families. Examples and solutions offered included small acts of kindness, visual boards highlighting individual characteristics of patients, and paying attention to personal details (names, nicknames, and dietary preferences). When faced with challenging ICU decisions, such as letting loved ones go, participants re-emphasized the importance of clarity and consistency in communication, partnership/shared decision-making between the families and care providers and recognizing that both groups have expertise (in the human and medical sides of ICU care, respectively) that are crucial for such difficult decisions.

FOCUS GROUPS WITH ICU PHYSICIANS AND NURSES

Insights from the focus groups with patients and family caregivers were shared in separate focus groups with ICU physicians and with ICU nurses. The physicians and nurses were asked to reflect on what could be done to better meet these expectations and improve communication in the ICU. Their comments and reflections are summarized in Table 1A and 1B.

TABLE 1A • Individual Focus Group Discussion Points

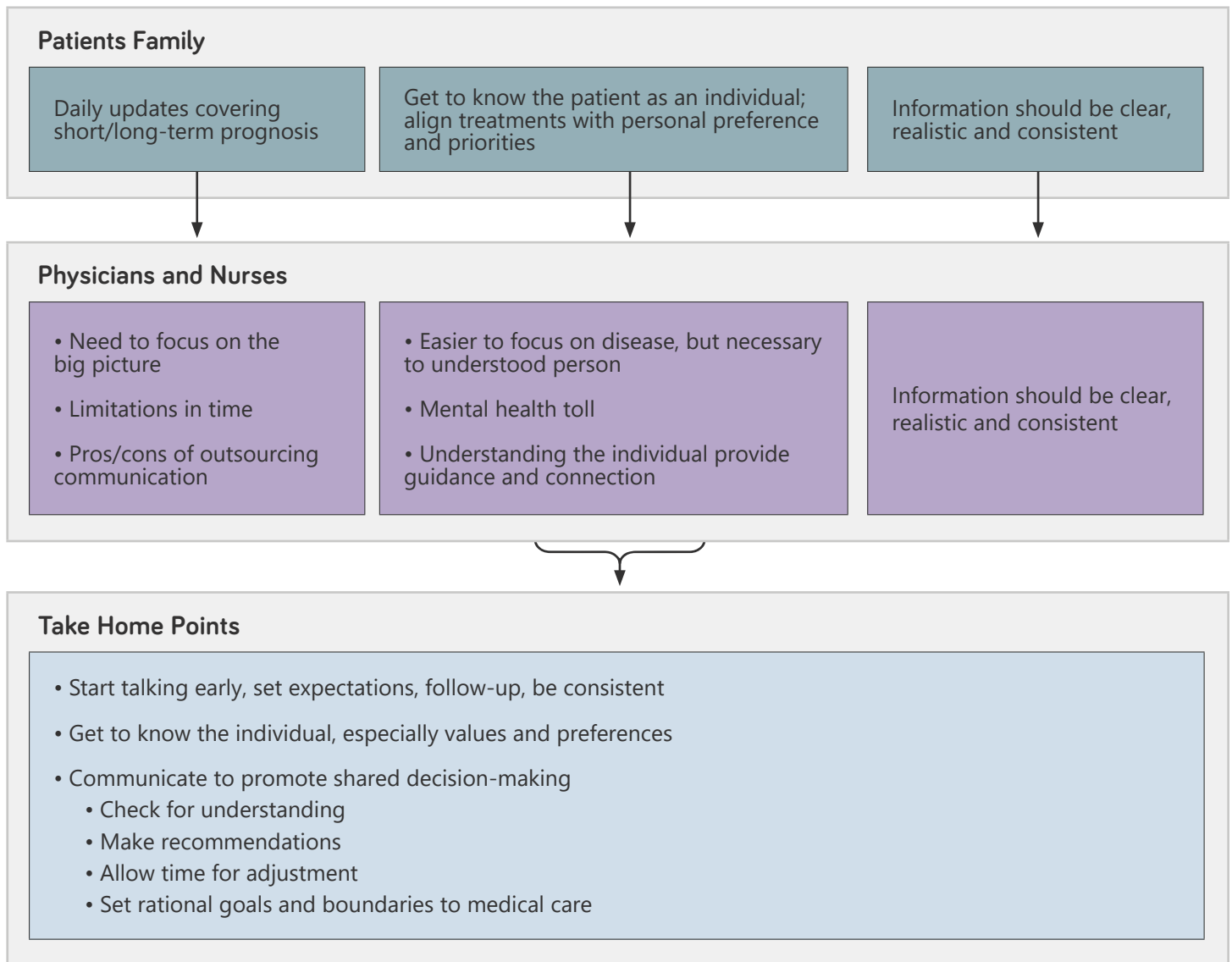
Discussion Topic	Patient/Family Caregiver (PFCG) Insights	ICU Physicians (MD's) Reflections on Patient/Family Caregiver Insights	ICU Nurses (RN's) Reflections on Patient/Family Caregiver Insights
Patient & Family Caregivers (PFCG) expectations for communication in the ICU	<ul style="list-style-type: none"> • Daily communication with a MD is expected • Explanations in plain language is important • Topics covered should include long and short-term prognosis • It is important for PFCGs to have an opportunity to ask questions • Having a designated spokesperson for the patient may help communication 	<ul style="list-style-type: none"> • Daily update by ICU physician is a reasonable expectation • Time is the biggest limitation for updating families • Spending time upfront communicating with PFCGs may minimize future confusion and set realistic expectations • An MD extender/CSW/ RN can supplement information provided by MD • Multidisciplinary rounds allow everyone on the care team to be able to communicate consistent messages 	<ul style="list-style-type: none"> • If care teams outside of the ICU set appropriate expectations re: ICU care/prognosis, this can facilitate communication in the ICU • Giving consistent message to PFCGs about poor prognosis early on is important • Must avoid giving messages that may lead to false hope "The patient is stable/ok." • Strengthening communication between MDs and RNs helps RNs emphasize same points to PFCGs

TABLE 1B • Individual Focus Group Discussion Points

Discussion Topic	Patient/Family Caregiver (PFCG) Insights	ICU Physicians (MD's) Reflections on Patient/Family Caregiver Insights	ICU Nurses (RN's) Reflections on Patient/Family Caregiver Insights
<p>Personal preferences and priorities alignment with care received</p>	<ul style="list-style-type: none"> • Strong desire for healthcare team to know patients as individuals • Desire to have patient preferences acknowledged • High value placed on personalization of care, such as using nicknames, observing previous healthcare experience, and food preferences • Ignoring preferences and priorities result in a perception of dehumanizing care, decreasing confidence in care provided 	<ul style="list-style-type: none"> • Physicians frequently rely on CSW/RN/palliative care to “know the patient” • Knowing patient as individual can lead to better communication and decision-making • Speaking to large families collectively is ideal, but is logistically challenging and time-consuming • There is an emotional toll of getting to know patients personally 	<ul style="list-style-type: none"> • Storyboards with personalized information can help staff get to know patient • Hospitals have limited resources / staff and often rely on social services to know patients’ non-medical situation • Must breakthrough “difficult” barriers with PFCGs before getting to know patient as individual
<p>Making supportive decisions about non-beneficial treatments</p>	<ul style="list-style-type: none"> • Information should be clear and consistent • Communication should be compassionate • Include hospice and palliative care staff when possible • Conflicting recommendations from staff makes decision making more difficult • Ambiguous or unrealistic messages about prognosis increases difficulty in decision making 	<ul style="list-style-type: none"> • Need family members who can understand medical information to be decision makers • Assessing understanding of medical issues with “What have you been told by other MDs?” can be helpful • Have all healthcare team members convey same message to PFCGs • MDs can relieve families’ burden of making decision by only offering treatments options that are medically reasonable; no need to “offer everything” 	<ul style="list-style-type: none"> • RNs feel their role is to corroborate what MD says and focus on patients’ preferences • RNs do not feel they are trained to discuss nonbeneficial treatments • RNs can often tease out what is causing conflicts in decision-making • Communication is more successful if teams are consistent in the information shared with PFCGs.

Some key points from these focus groups that are relevant to improving ICU communication in LAC DHS and KP are summarized in Figure 2. The patients, family caregivers, physicians and nurses felt that communication in the ICU should begin early in the hospitalization, occur daily, and should focus on aligning care with patients' values and preferences. They emphasized the importance of consistent messaging across all healthcare teams and making difficult decisions through shared decision-making. Many of these themes were important elements of a recently completed quality improvement study in LAC DHS that used a communication and care-planning approach called "time-limited trials" of ICU care. The details of the study and time-limited trials are provided in the appendix. Given the alignment of the themes in the focus group with the goals of the time-limited trial project, we used the time-limited trial intervention/tool as a key discussion point in the multi-stakeholder meeting.

FIGURE 2 • Summary of Findings of Individual and Multi-Stakeholder Focus Groups



MULTI-STAKEHOLDER MEETING OUTCOMES

The 23 participants in the multi-stakeholder meeting included patients and family caregivers, physicians and nurses from the previous focus groups and hospital administrators in the KP and DHS healthcare systems (Figure 3). Prior to convening, participants were asked to review a recent publication by Chang et al which evaluated if timed-limited trials reduced nonbeneficial treatments in the ICU, both in its original form and as described in an editorial (Appendix B). The group was divided into three discussion groups (with mixed stakeholders in each group) to discuss the following questions:

1. How does the time-limited trial tool help improve communication in the ICU?
2. How can we implement this type of intervention more effectively (improve) and broadly (scale-up) in healthcare systems?
3. What does this tool not address?

Responses from the multi-stakeholder break-out groups are summarized in Table 2A and 2B.

FIGURE 3 • Make-up of participants in the Multi-Stakeholder Focus Group

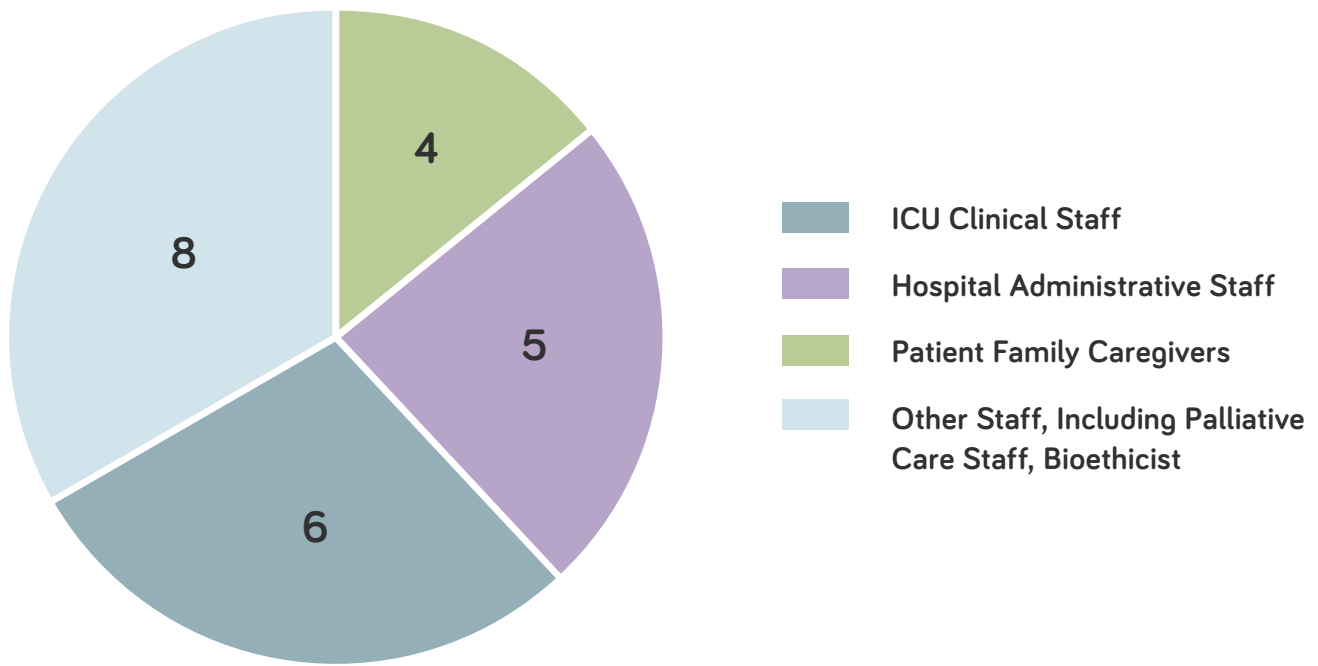


TABLE 2A • Multi-Stakeholder Group Discussion Points

TLT Discussion	Multi-Stakeholder Focus Group Insights
How does this tool support improvement in ICU communication?	<ul style="list-style-type: none"> • Provides a framework for physicians that encourages early communication with patient and family caregivers regarding prognosis and decision-making • Allows physicians to set expectations early and avoid giving false hope • Requires clear, transparent communication and exchange of information • Outlines important clinical milestones and benchmarks for decision-making • Must avoid giving messages that may lead to false hope "The patient is stable/ok." • Strengthening communication between MDs and RNs helps RNs emphasize same points to PFCGs

TABLE 2B • Multi-Stakeholder Group Discussion Points

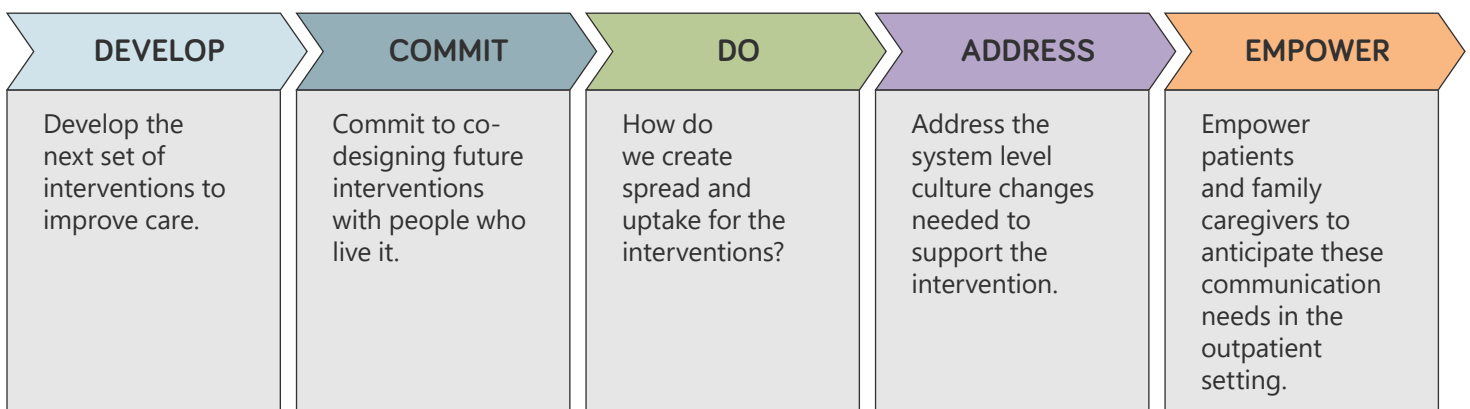
TLT Discussion	Multi-Stakeholder Focus Group Insights
<p>What does this tool not address to improve communication in the ICU?</p>	<ul style="list-style-type: none"> • Does not address educational and cultural differences which affect communication and health equity • Does not address how to assure that all providers are communicating consistent messages to family caregivers, ie, that “everyone is rowing in the same direction.” • May be less useful when physicians do not have good communication skills • Does not incorporate non-physician ICU staff and extenders (nurse practitioners, physicians’ assistants), palliative care, social, and chaplain services • Does not incorporate discussions in outpatient/pre-hospitalization settings which are helpful for decision-making during inpatient settings • Does not address how to select the most appropriate surrogate decision maker

SUMMARY

In the initial focus group session, we were able to learn from patients and family caregivers what they needed from the healthcare team to enhance communication in the ICU, particularly with regards to care in the setting of severe illnesses. The two subsequent focus groups allowed frontline ICU physicians and nurses to reflect on the thoughts of the patients and family caregivers and to suggest ways how communication can be done better at an individual- and systems-levels to better meet the expectations of patients and family caregivers.

Ultimately, the multistakeholder meeting allowed discussion about ICU communication among participants from all the prior focus groups, palliative care and other staff, and hospital administrators. The discussion focused on exploring the use of the time-limited trial for patients with advanced diseases to allow delivery of more concordant care while avoiding the harm of nonbeneficial treatments. The strengths and weaknesses of this communication tool were reviewed in order to determine how this tool could possible be used to as an initial step to improve communication in the ICU.

FUTURE IMPLICATIONS



The next steps for our partnership are to improve ICU communications in LAC DHS and KP healthcare systems by leveraging the ideas and collaborations we have developed during this project. We will adapt and improve the time-limited trial intervention using a community-partnered approach. This will include adapting and co-designing the intervention tool with clinicians, patients and family caregivers, and creating system-level strategies with administrative leadership to implement the intervention effectively in the healthcare systems.

APPENDIX A • Reflections on a pandemic by the Project Collaborators

Libby Hoy, Patient Family Advisor

2020 was an extraordinary year to be exploring communication in the ICU. Meeting the challenges of communicating potentially non-beneficial treatment to loving family members is difficult enough, but the complexity the pandemic brought to these discussions was difficult on everyone. Though hospital staff may have initially thought not having family caregivers at the bedside would make their work easier, we learned that they quickly realized that the presence of family caregivers actually reduced the burden on their communications. The quick transition to technology supported communications coupled with the volume of seriously ill patients and the novelty of the virus left ICU clinicians and family caregivers without the usual tools for supportive, compassionate and clear communication.

Meeting with Drs Chang and Cheng gave me unique insights into the pandemic response inside two Los Angeles County ICUs. The pandemic started with fear, panic and a human experience that united communities. As the months wore on, I witnessed the fatigue of our clinical staff and the grief of our family members. When the vaccine came on scene, I saw the relief reflected in the eyes of our clinicians and a sense that they could finally take a breath. Amidst the early days of clamoring for a turn to get the vaccine, we saw people finally getting some glimpse of a new normal. So the question now is, what have we learned? What will future conversations with family caregivers include? What will the role of technology be? What elements of communication will be considered essential? What did we gain during the pandemic and what did we lose?

As a patient family advisor, I am often asked to share our family's journey through the health system. However, at this point, I think it's imperative that we hear the stories of Dr. Chang and Dr. Cheng and their colleagues to understand the realities of the ICU as it exists today in order to build a compassionate environment together.

Dong Chang, MD MS

Our project was developed before the world became familiar with COVID-19, masks, and social-distancing. This was because even before these unprecedented times, improving communication about non-beneficial ICU treatments was an important healthcare priority. In the Winter of 2020, when Southern California became the epicenter of the COVID pandemic, I was apprehensive about moving forward with our project. Given the challenges in communication (i.e. no family visitors) and the tremendous amount of suffering and death we all witnessed, I wondered if discussions about improving ICU communication and reducing non-beneficial treatments would expose memories and frustrations that were simply too raw. What I noticed among the participants, however, was a conviction that this issue was too important to ignore, and even if it was difficult to reflect on these tragic times, the best way to honor our collective experience was to improve the way we deliver medical care. I was truly inspired by this attitude of resilience.

As a critical care physician, this past year has been difficult. I feel drained both physically and emotionally. However, the philosophy that sustains me was exemplified by our stakeholders during the focus groups and meetings: that the difficulties we faced will not simply be historical artifacts. Instead, the lessons we learned during the pandemic, while tragically heavy in price, will be transformational: that we understand with greater clarity than ever that communicating effectively and empathizing with each other are the foundations for effective medical care.

Glena Cheng, MD MS

Working on this project taught me how both subtle and overt aspects of ones' communication style can make a tremendous impact on care in the ICU.

Since 2020, the pandemic has altered usual communication patterns in the ICU, in great part due to the limitation on face-to-face interactions. I previously could glean information about a patient by observing interactions between patients and their visitors. When people were no longer allowed to visit hospitalized patients, I had to directly elicit details about patients and their prior lives from their family caregivers. Although the deadly nature of the pandemic magnified the usual tension and anxiety in the ICU, I was touched by stories shared by family members, reminding me of the unique characteristics and preferences of each individual patient.

Updating people through daily phone calls alone does not feel as complete as updating a family member at a patient's bedside. However, most caregivers were grateful for these calls, despite not being able to see their loved ones or the staff caring for their loved ones. The appreciation did not diminish, even when I delivered news that patients were dying and would not benefit from further aggressive care. The silver lining is that if we can improve ICU communication under duress that leads to increased trust, we should be able to build on necessary skills and systems during less tragic times.

APPENDIX B

Chang DW; Neville TH, Parrish J, Ewing L, Rico C, Jara L, Sim D, Tseng C; Van Zyl C, Storms A, Kamangar N, Liebler J, Lee MM, Yee H. **Evaluation of Time-Limited Trials Among Critically Ill Patients With Advanced Medical Illnesses and Reduction of Nonbeneficial ICU Treatments.** JAMA Intern Med. 2021;181(6):786-794. <https://doi.org/10.1001/jamainternmed.2021.1000>

Span P. "The New Old Age 'I Need to Know I Tried' Time-limited trials offer I.C.U. patients and their families a sense of empowerment in the face of low odds." New York Times, 11 May 2021, <https://www.nytimes.com/2021/05/10/health/elderly-hospitals-palliative-care.html>