

Community Needs Assessment of Communication in the Pediatric Cardiac Intensive Care Unit

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University of Pittsburgh, 2021

Abstract

Communication is of paramount importance in medicine and varying degrees of proficiency are required for passage of information from patients to providers and for coordination of care between providers. This project explored the quality of communication practices and barriers to communication between families and providers in the pediatric cardiac intensive care unit (CICU) at the Children's Hospital of Pittsburgh (CHP). Nine providers and ten patients/caregivers completed a communication survey and a structured interview. Mixed methods analysis was conducted using quantitative analysis for survey data and qualitative analysis for interview responses. Providers and patients/caregivers identified multiple domains that were important in communication, including Setting goals/expectations, Interpersonal communication skills, Provider roles, Comprehension, Decision making, Challenges, and Areas for improvement. Participants offered several specific recommendations for how to improve communication in the CICU. A few requested family resources were created in response to these suggestions and provided for the CICU staff to consider for use in the CHP CICU. Results of this study will be presented to the CICU staff at a departmental meeting.

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Preface

As a provider I yearn to provide the best care for all my patients and families, a desire shared by my colleagues. Unfortunately, we don't always know exactly how to achieve this goal because we don't always have data to inform our practice.

A needs assessment is the perfect way to engage stakeholders and gather information about what is working well and what needs to be changed. After working as a provider in the critical care units of the Children's Hospital of Pittsburgh, I observed how integral communication is to everything providers do in the intensive care unit. Without meaningful feedback about how well we are communicating with patients and families we are not always aware of what helps families or what we need to change to improve. This project grew out of that observation, with the stated goal of producing a work product that could be used to improve care for all of our patients. The project focused on the cardiac critical care unit because this was a small, self-contained unit with many different providers and teams involved in patient care.

This work would not have been possible without the support of Justin Yeh, MD and the CHP CICU providers. Important contributions were made from my fellowship scholarship oversight committee (Ericka Fink, MD, MS; Elizabeth Miller, MD, PhD; Thuy Bui, MD) and Masters of Public Health Committee (David Finegold, MD; Thistle Elias, DrPH, MPA). The project also would not have been possible without the valuable contributions from the patients and families who participated in this study. Special thanks also goes to the department of Critical Care Medicine and the Pediatric Critical Care Fellowship program for flexibility and support through the process of finishing this MPH degree. I am grateful to all who made this work possible.

1.0 Introduction

Communication is arguably the most important and versatile skill in medicine. It allows for the exchange of information in the hospital but is also necessary for promoting behavioral change in outpatient medicine.¹ Communication allows for coordination of providers, implementation of best practices/new technology and improvement of safety and quality.² People are beginning to recognize how foundational this skill is in medicine because “both *science* and *communication* are essential to promoting and protecting the health of the public.”³ In fact, communication and interpersonal skills are so critical in medicine that the Accreditation Council for Graduate Medical Education (ACGME) and credentialing boards have recognized them as a core competency for medical professionals.⁴⁻⁶ Improvement of Health Communication has also been identified as a target area for the Healthy People 2030 campaign.⁷

The process of communicating is impacted by a host of different factors including the content of the message, the process of communication, non-verbal signals, and the perception of the information.⁸ In medicine, in particular, there may be specific barriers to communication including the deterioration of provider communication skills, reticence to communicate problems to patients, and patient resistance to receiving information.⁹ Additional challenges may occur in pediatrics since most of the information is gathered from the patient and most of the information provided is directed towards caregivers.¹⁰ Communication problems have been associated with an increased risk of preventable adverse events in acute care settings¹¹ and cost billions of dollars each year.¹² Conversely, good communication is associated with increased patient satisfaction¹³ and better health outcomes¹⁴⁻¹⁶.

It is generally accepted that communication is a particularly important part of caring for critically ill patients. Patients in the intensive care unit (ICU) are sicker than other patients in the hospital and may require procedures and interventions that are not needed for other patients. Increasing complexity of treatment and management demands better communication from medical providers. As with any other skillset, medical professionals have varying degrees of proficiency with communication and interpersonal skills. Poor verbal communication between physicians and nursing staff was implicated in 37% of human errors in the ICU in one study.¹⁷ These errors may mediate the preventable complications and increased cost associated with poor communication.

ICU guidelines for family centered care stress the importance of including families in rounds and family meetings, providing empathy, using understandable language, offering communication training for providers, and using structured communication tools to facilitate understanding and improve communication.¹⁸ Despite this recognition of the need for good communication in the ICU, the most effective communication tools remain unknown.¹⁹ Several small studies have explored communication in specific cohorts of ICU patients (like organ donation patients) and demonstrate the importance of things like rapport and attention to the space in which conversations are conducted.²⁰ But to our knowledge there do not exist any studies specifically evaluating communication in the cardiac ICU.

Given the importance of communication for the health and well-being of patients in the ICU, this project seeks to explore the quality of communication practices and barriers to communication between families and providers within the Children's Hospital of Pittsburgh (CHP) Cardiac Intensive Care Unit (CICU).

2.0 Methods

The University of Pittsburgh Medical Center (UPMC) Quality Improvement Review Committee approved this Quality Improvement (QI) project, which was conducted in the UPMC Children's Hospital of Pittsburgh cardiac intensive care unit (CICU). The Pediatric intensive care unit is a distinct unit and was not included. All families admitted to the CICU and all providers who worked primarily in the CICU between January 15 and February 15, 2021 were eligible for participation. Exclusion criteria included non-English speakers and caregiver age less than 18. Families were interviewed within 1-2 days of transferring out of the CICU. Each weekday the primary investigator would ask the CICU staff if any patients were ready for transfer out of the ICU; patients who met this criteria were approached for voluntary participation in this project. Providers were approached throughout the study period in order to maintain an even ratio of providers to families. Enrollment methodology resulted in a convenience sample of both families and providers.

All eligible participants were introduced to the project and given information about the aims/objectives (see Appendix A for information provided to participants). Participation was voluntary. Providers and caregivers who elected to participate first completed the Kalamazoo Essential Elements Communication Checklist, a validated questionnaire for communication within medical settings (KEECC, permission given for use, please see Appendix B for survey).²¹ After completing this questionnaire, participants were interviewed by the primary investigator. Interview questions were developed by induction by the primary investigator after literature review of communication in the medical field (Interview questions can be found in Appendix C). Interviews were recorded using the TASCAM DR-05X handheld recorder with the consent of participants.

The CICU Quality metrics database was used to obtain demographic information, severity of illness metrics and length of stay information for participating patients. Regression analyses were conducted to explore select single variable associations within this sample population. KEECC scores were averaged for providers and patients/families across all domains and as an aggregate score. Pairwise comparisons between provider and patient/family responses were conducted using Wilcoxon Rank Sum Tests.

The audio files were transcribed using the dictation function of Microsoft Word with accuracy ensured by the primary investigator. Speech fillers (including “um,” “uh,” and “like”) were removed when this did not change meaning to improve readability. Interview transcripts were separated into providers and patients/caregivers and then deidentified for each participant. Comments were analyzed individually and then reported on in aggregate for these groups. Qualitative analysis was conducted using a grounded theory approach with an iterative classification schema, coding for themes as they emerged from participant data, with redefinition, addition or collapsing of themes as necessary.²²

Statistical analyses were conducted using Microsoft Excel version 16.43 or STATA 15.1 with significance defined as $p < 0.05$ for all quantitative analyses.

3.0 Results

3.1 Survey Results

Table 1 Demographic and Patient Characteristics

Characteristic	N (%) or Median (IQR)
Gender - Male	7 (70)
Race – Caucasian	10 (100)
Age (yrs)	1.6 (0, 5)
Weight (kg)	4.0 (3.2, 15)
Height (cm)	53 (49.5, 108)
Prenatal diagnosis	4 (40)
Hospital LOS (days)	10 (8, 19)
CICU LOS (days)	6 (3, 17)
CPB Time (mins)	69.5 (0, 118)
PRISM III	9.5 (3, 17)
MV (days)	1.5 (0, 6)
iNO (days)	0 (0, 0)
CVC (days)	6.5 (4, 17)
Foley (days)	2.5 (1, 6)
Open sternum (days)	0 (0, 0)
Complications	1.5 (0.25, 2)
Number of Procedures	3 (2.25,5)

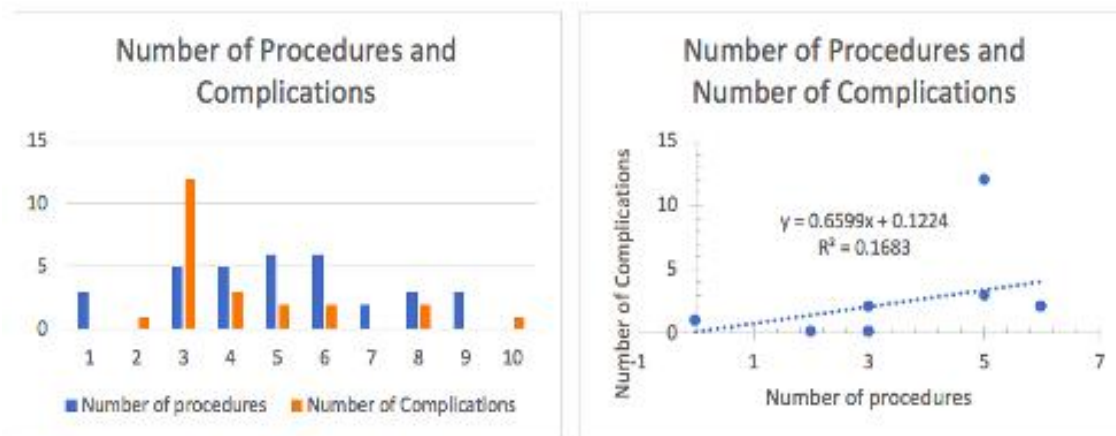


Figure 1 Number of Procedures and Number of Complications

Left: numeric tally of number of procedures and number of complications for each individual patient. Right: scatterplot with linear regression to evaluate relationship between number of complications. $R^2 = 0.1683$

Nine providers and ten families participated in the KEECC survey. Demographic and patient characteristics are included in **Table 1**. The patients whose families participated in this project were exclusively Caucasian and mostly male. Most of the patients were young children (median 1.6 years old). Less than half were prenatally diagnosed (40%). The median length of stay was 6 days in the CICU and 10 days in the hospital. The median number of procedures/surgeries for this group was 3 and the median number of different types of complications was 1.5 per patient.

The number of procedures does not correlate strongly with the number of different types of complications experienced for this sample (**Figure 1**). The PRISM score and cardiopulmonary bypass time (**Figure 2**) do not appear to correlate strongly with the number of different types of complications experienced, either. The absence of significant linear relationships persists even if the suspected outlier (patient 3) is removed.

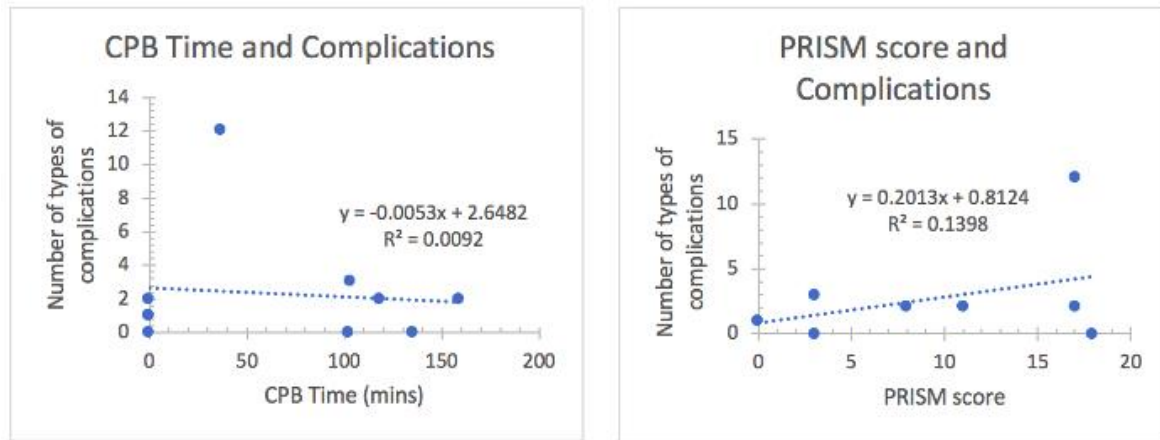


Figure 2 Association of CPB Time and PRISM Score with Complications

Left: Cardiopulmonary bypass (CPB) time and Number of different types of complications for each patient. $R^2 = 0.0092$. Right: PRISM score and Number of different types of complications for each patient. $R^2 = 0.1398$

When surveyed, providers collectively rated their communication skills lower than families rated them (3.98 versus 4.62 out of 5 point Likert scale averaged across all domains). Providers rated communication skills lower in every category than families (values reported in Table 2). The average provider score was highest for providing closure (score of 4.4) and lowest for understanding patient/family perspectives (score of 3.9). The average patient/family score was highest for opening discussions (score of 4.9) and lowest for understanding patient/family perspectives (score of 4.3). The differences between scores in these domains were statistically significantly different for building relationships, opening discussions, gathering information, understanding patient/family perspectives, sharing information and demonstrating empathy (see **Table 2**).

Survey respondents were asked to choose the best communication domains for the CICU and the communication domains in most need of improvement. Respondents were instructed to

pick three domains for each of these questions. Providers had a 100% response rate for these questions; Families had a 96% response rate for choosing the best

Table 2 KEECC Domain scores for providers and patients/families

Comparison between groups done using Wilcoxon Rank Sum Tests. $p < 0.05$ considered significant. Significant values bolded in table

Domain	Provider	Patient/Family	p value
Builds Relationship	4.1	4.7	0.035
Opens Discussion	4.2	4.9	0.032
Gathers Info	3.7	4.7	0.013
Understands patient/family perspective	3.1	4.3	0.006
Shares information	3.9	4.6	0.005
Reaches agreement	4	4.6	0.061
Provides closure	4.4	4.5	0.677
Demonstrates empathy	4.2	4.7	0.043
Communicates accurate information	4.1	4.6	0.079

communication domains in most need of improvement. Many subjectively commented in the free text survey comments that they did not have suggestions for improvement with communication. Of the responses collected, providers selected building relationships and demonstrating empathy as particular areas of strength (**Figure 3**) and understanding patient/family perspectives as the biggest area for improvement (**Figure 4**).

Patients/Families selected building relationships and sharing information as particular areas of strength (Figure 3) and understanding patient/family perspectives as the biggest area for improvement (Figure 4).

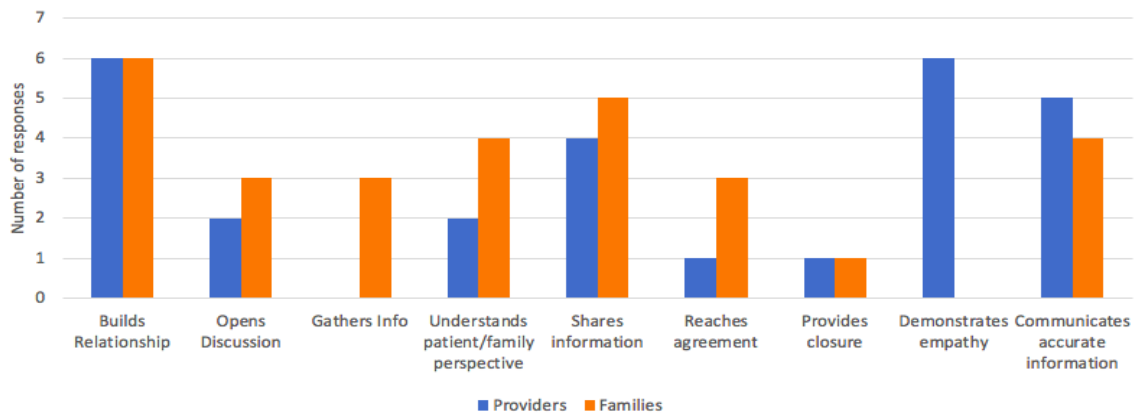


Figure 3 Domains of Communication that are Areas of Strength

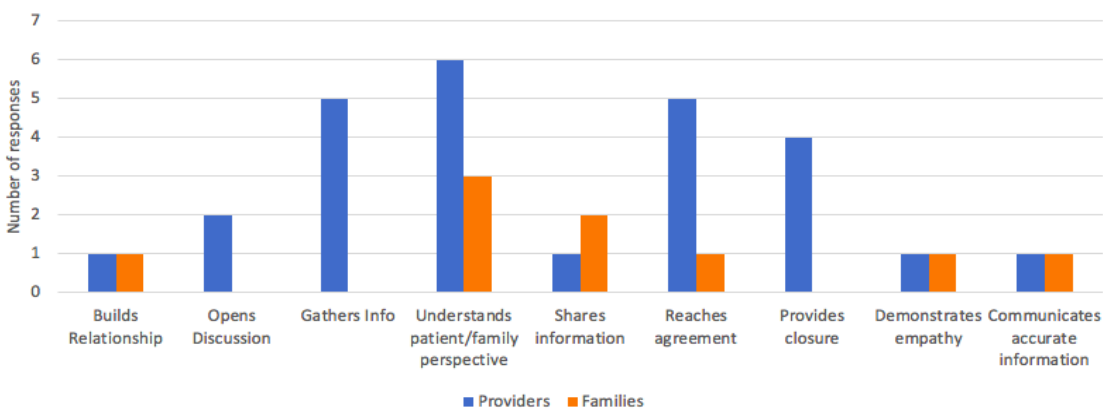


Figure 4 Domains of Communication Needing Improvement

3.2 Interview Results

Nine providers and ten families participated in interviews for this project; one family interview was prematurely ended due to a clinical deterioration of the patient. Participant comments mapped to several communication domains which are noted in **Table 3**. Each of these domains will be examined independently for providers and patients/families.

Table 3 Communication Domains

Goals/Expectations
Interpersonal Communication
Roles
Communication Tools
Comprehension
Decision Making
Challenges
Changes/Improvements

3.2.1 Providers

3.2.1.1 Goals/Expectations

CICU providers identified setting expectations as a large component of communication in the cardiac ICU. Another indicated that the goal in communication is to “*mak[e] sure that [families] understand what they’re going through and, most of all, at least what to expect.*”

Comments indicated difficulty providing specifics for family in some cases due to the nature of cardiac critical care medicine. One provider commented,

when I set out [a] trajectory for family, I'll say, 'Look this is the usual course or the potential course you could have. Say [a] dTGA baby's born. You may have an atrial septostomy in the first few days. He may go to the OR in the first 7 to 10 days. But you know there's wiggle room in those things – [in] what may happen.

In addition to setting expectations for the family based on the expected clinical course for patients, many providers commented on the need to assess family expectations, preferences and goals related to care. One provider discussed an example where the patient was a teenager and “*had clear thoughts of what he wanted,*” highlighting the need to consider each patient/family in these situations independently. One participant admitted, “*if I don't know what [the family's] expectations are...it's really hard to have a conversation that's productive.*” Another provider stressed the importance of determining how much additional information each individual family wanted, stating it was necessary to “*gauge each family*” for their desire to “*hear more...[or just] know the basics.*” A third provider observed that “*sometimes families make it easy for you and they are pretty vocal and say, 'I want this to happen.' Or, 'I don't want this to happen.'*” These situations may occur because “*families [are often] fixated on things they can control.*” While providers in general seemed to embrace wanting to meet patient/family expectations, there were several comments about the struggle with unrealistic expectations. Unrealistic expectations seemed to be a source of frustration for providers and many discussed specific situations where meeting these expectations was difficult.

Several providers also stressed the need to follow through on any promises that were made to families. The consensus was that “*[w]hen you tell someone you're going to do something [and] you don't do it...[i]t's one of the worst things you can do for a family.*”

Multiple participants also highlighted the need for improvement specifically in managing goals of care in the context of end of life care in the CICU. One participant reflected that in her previous fellowship when families *“had really good primary attending [point person] ... sometimes the families would be able to let go earlier. Or withdraw care. Or have like some sort of like DNR/DNI that they felt so much more comfortable with earlier.”* The CHP CICU does not have a program like this for families. Another participant reflecting on end of life care felt that the *“supportive care [team] does a good job of clarifying [goals of care issues but that] ...it should come from [the ICU physicians] more.”*

Collectively these comments demonstrate several aspects of managing goals and expectations that providers identified as important in the communication process in the CICU.

3.2.1.2 Interpersonal Communication

3.2.1.2.1 Rapport

The relationship that develops between families and providers is just as important as meeting expectations. In general, CICU providers felt that *“families who have been there for awhile you build a rapport with.”* One participant stated that *“if the family’s always here, and they’re involved and they want to know, it’s fairly easy to create a relationship.”*

3.2.1.2.1.1 Provider Approach

Providers have vastly different approaches to building these relationships with patients and families. Multiple participants acknowledged that *“everyone has their own style for how they talk to families.”* One provider observed that a colleague

is just incredible with connecting with families...because she makes a commitment to go in and just check in with everyone. Like, a) fully introduce [herself] b) make sure that they know who she is and when she will be here and how she will be here...[And] she checks in with them every single time that she's here. So she's a familiar face for them.

Another provider described a different approach, saying “*I try, as best as possible, to only get involved personally when I feel that it's something that potentially will require multiple visits and explanations.*” These providers represent the extremes of a very wide spectrum of approaches and illustrate the vastly different approaches patients/families may encounter in the CICU.

3.2.1.2.1.2 Family Approach

By the same token, “*[d]ifferent families have different styles too.*” One provider reflected that “*there's some families that come in and are a little more outgoing, and ask a lot of questions and form relationships with providers pretty quickly. And there's other families that don't do that as much.*” Sometimes providers can help to standardize this process. One provider encourages families “*if something doesn't feel right, if you're worried, if you're stressed, if you're angry about something: I'd rather you just tell me right away than let it build up for like 3 days and then explode. So, I don't care if every day you're complaining about something.*”

3.2.1.2.1.3 Provider-Family Interactions

The personality idiosyncrasies of both providers and families mean that “*on any unit certain people [will] connect [better] with certain families.*” And over time “*[families] learn who they maybe communicate best with, and understand, and just kind of click with better.*” This

suggests that communication will be easier or more difficult for providers depending on their rapport with families.

3.2.1.2.1.4 Provider-Provider Interactions

Interpersonal communication is just as important between team members as it is between the family and providers. One participant reflected that “*the cardiac ICU is a shining example of great communication between providers and nurses*” also saying “*I have worked in very few units of any hospital where the accessibility between the providers and the nursing staff is so great.*” Another noted that “*if a family is asking for reiteration on something we are always usually able to get a fellow or an attending to go and speak with them to clarify.*” While this sentiment was generally echoed by the providers who participated in this project, one nurse reported that if she had “*any questions whatsoever I always just ask*” But she worried that “*there are newer nurses that probably don't. They don't understand what the goal is for the day, [but] they just don't ask [for clarification].*” The complexity of these interactions between providers can significantly impact communication in the CICU, as these comments demonstrate.

Some participants reflected on specific aspects of building relationships with patients, as reviewed in the following sections.

3.2.1.2.2 Introduction

The introduction seems to be particularly important, with one provider stating that “*[all the providers caring for the patient should] introduce themselves and talk to mom and dad. And just kind of establish, 'I'm here. I'm the person that's going to be doing XYZ. Or I'm the person that they will come to for X.'*” This participant suggests that a good introduction provides some

foundation for the relationship, providing parents with the expectation of how the provider will participate in care.

3.2.1.2.3 Trust and Honesty

Trust and honesty between parties was also lauded as important in developing this relationship. One provider commented that *“if someone's really upset, they feel like they've either not been communicated to enough, they haven't been communicated to in a way that they're actually understanding the providers, or they feel like somebody is being dishonest or left something out.”* Another participant provided recommendations for how to address these situations, saying *“[D]on't try to mask things. Be very open and honest with your thoughts and opinions...don't try to spin anything.”* Despite the challenges this poses for communication in the CICU, one provider felt that even though the CICU *“can be a really tough place to be, [she did] think that we generally are able to develop good working friendly trustworthy relationships with the families.”*

3.2.1.2.4 Roles and Proximity

The ease of relationship building may be due in part to the role the provider plays in the CICU. One participant said *“I feel like because our unit is so small I feel like generally the nursing staff has pretty good relationships with their families.”* Another agreed that *“the bedside nurse is the main human being for these families”* and further commented that *“the CICU as faculty and fellows need to establish ourselves more as people for the families. People that the families can rely on. People who are here consistently.”* Nursing staff seemed to agree with this perspective, with one participant noting that

from a nursing perspective, we're in the room all day. So, they see me more than they would probably ever want to see me. Whether I have one patient or two patients, they see me frequently throughout the day and I have lots of conversations. Especially if they're there all day.

3.2.1.2.5 Provider Schedules

Coverage changes can be a challenge to building rapport with patients and families. One provider noted that changing fellows “*really can make the communication suffer. Between both providers and nurses or other, whatever, consulting team members. And also, between providers and families*” She went on to say

I just feel like things get lost in the mix...[If] one fellow goes into one room and is doing things or talking to a family, not all of that's going to be communicated back to the other fellows who are around, or the attending, necessarily. So, I just find it a little more chaotic than it needs to be.

3.2.1.2.6 Difficult Conversations

Difficult conversations may also serve as a barrier to creating rapport with families. One provider noted that during initial conversations the medical team “[is] developing deeper relationships with these families,” also noting that the team can therefore “*be a little bit more softer [sic] with our words.*” Another reflected that “*THE times when I have thought to myself, ‘Wow, that really did not go well,’ are the times when I didn't know that, or didn't perceive that, it was an emotionally challenging issue for the family.*” Conversely, one provider stated, “[Because I do not often have difficult conversations with families], I would say that most of the time I don't have difficulty establishing a professional rapport with the families.” It seems the content of information

communicated by a provider may impact the ability to build a relationship with families in the hospital.

3.2.1.3 Roles

Communication is also impacted by the complementary and overlapping roles played by different providers. Observations noted both the impact of different levels of training as well as different specialties on communication in the cardiac ICU.

3.2.1.3.1 Role of Fellow

Several participants noted that the specific role of fellow in the cardiac ICU presented challenges with communication expectations. Fellows felt like they were “*almost never the first person to talk to a family in the CICU*” and viewed their role in the cardiac ICU to “*act more in the way of...a resident, or an advanced practice provider.*” One fellow went on to say,

It rarely seems to fall to me to have anything more than trivial update conversations with parents. The only times that I, thinking back, have been the one to deliver important news to a family in the cardiac ICU is if an event occurred on my call shift. So, basically if an event or if a diagnosis arises in the evening in the cardiac ICU and it is clinically important and must be disclosed immediately, then I would say it often falls to me. And even then it only often, and not always, falls to me. Because often the cardiac ICU attendings prefer to have that conversation themselves. In the event that such an event occurs during the daytime, my impression is that the conversations are almost always carried out by cardiology and the CICU attendings, with relatively little input from me.

By contrast, one of the attending participants felt like “*oftentimes, it is the fellow or fellows [who function as the front line communicator]. Because they're sitting in the unit all the time. And if—when things happen in real time they'll usually, as you know, go talk to the family, update them with information.*” This perception of the fellow role in the CICU is diametrically opposed to the self-perception of the fellows who participated in this project.

In any case, multiple fellows commented on a desire to have a better defined role regarding communication in the context of their work in the CICU. One participant noted that “*it would be helpful for me to know, as the CICU fellow, what information is or is not my role to disclose. And— or to talk about.*”

3.2.1.3.2 Role of Attending

The specific role of attendings, too, was explored. One provider said, “*I see the attendings who are on for each week take a lot of ownership for the people when they're on for that week. But then they leave.*” One of the attending participants agreed, saying “*I don't try to become the point person for conversation for the surgical plan or cardiac plan, like follow up, and things like that.*” Not everyone seemed content with these roles, with one participant commenting “*that the CICU as faculty and fellows need to establish ourselves more as [support] people for the families.*”

3.2.1.3.3 Role of Cardiology Team

The role of different teams in communication was also discussed by participants. The cardiology team was viewed by many participants as the key communicator with families. One provider reflected, “*I think cardiology becomes a really big group for them as well. Because they're – they have so much of the initial conversations and like education and pictures and things like that.*” Another participant agreed that “*for a new cardiac diagnosis, oftentimes the cardiology*

team sort of takes the lead in talking about the diagnosis and the overarching treatment trajectory. Which to me, makes sense, because they have the most in depth knowledge of what this disease looks like at every stage and not just in the next 24 hours.”

3.2.1.3.4 Role of CICU Team

There was less of a consensus about the role of CICU providers in communicating with the family. Some people felt that *“as ICU providers...we're just there when everything [is] bad and we give all the information and then when everything gets good we sort of take a step back again. I think that's a huge barrier: That people don't often want to hear the things that we have to tell them.”* Other providers felt that

the ICU team tends to communicate with their family more the day-to-day updates of, ‘We're working to get off the ventilator.’ Or, you know, ‘We're—we are coming down on the blood pressure medicine.’ Or, ‘Hopefully tomorrow we'll be able to eat.’ Those kinds of things [rather than big picture things].

3.2.1.3.5 Role of Cardiothoracic Surgery Team

Sometimes the role of different teams was discussed in relationship to the challenge of caring for patients in the cardiac ICU. One provider observed that problems could occur *“if CT surgery is involved and they want a particular thing and our intensive care team doesn't agree with that. I think that's kind of where things get a little bit hairy.”* Another felt that *“[sometimes the CT surgery team does] [n]ot understand any situation, other than what they're immediately looking at.”* These comments highlight the unique challenges that present themselves when different teams collaborate to care for the same patient.

3.2.1.4 Communication Tools

Providers in the CICU have developed and utilized many different tools to help maintain open communication with families. Participant comments addressed communication training as well as different strategies providers employed to communicate with other team members and families.

3.2.1.4.1 Training

Communication training was highly variable. Some providers noted participating in “*practice sessions*,” “*bad news delivery modules*,” and even “*communication course[s]*” Other providers reported that they “*really haven't had [much] formal training when it comes to communication*” even though they recognized resources existed.

Many of the nurse participants referenced AIDET training. One provider said,
We just did the AIDET re-certification as a hospital...[AIDET stands for] 'Acknowledge, Introduce, and then like Determination of the plan, Expectations, and then a Time frame.' So, it's essentially... a way to structure your conversation when you're walking into a room and meeting someone.

While most participants noted that AIDET was helpful training, one participant noted that “*sometimes [AIDET] can get a little bit cumbersome especially if it's ... a family that's been here for a long time and you know – they know who you are. They kind of know what is happening.*”

3.2.1.4.2 Strategies

Beyond the strategies encouraged by these training programs, providers employed a number of different strategies in communicating with families.

3.2.1.4.2.1 Listening

Several providers highlighted the importance of listening to families. One noted the importance of “*just sitting quietly in a room so that a family knows that like a) you're listening to them and being an active listener and b) They're able to say everything that they want to say before jumping in.*” Another participant reflected “*that when you're listening to a complaint or when you're dealing with a family who is upset, the best thing that you can do is just shut up. And let them talk.*”

3.2.1.4.2.2 Nonverbal Communication

Families are not always forthcoming with their thoughts, however, so many providers noted the importance of non-verbal cues like “*direct eye contact*” and “*body language*”. One provider said,

I definitely will look at body language...in some cases that can help me decide whether or not they are processing what I'm saying. Although again, you, I think, can sometimes be thrown off, because sometimes people may just nod, even if they are not fully understanding or following something. But that's one piece of it.

Another agreed, saying “*I try to do a lot with facial cues. So, when I talk to them if they're just blankly staring at me it's a hint to me, they have no idea what I'm saying they're just listening to me talk and they don't know exactly what I'm saying.*”

3.2.1.4.2.3 Questions

Several providers utilized questions in different ways to help them communicate. One provider shared that she uses

[t]he questions [families] ask. [She] use[s] that to help gauge, too, whether the question's appropriate or not. Like, if we're having—telling them that their kid might not survive, but then they say, 'Well, can my kid play baseball when they're older?' Then that might mean they're not understanding.

Another provider asked patients questions to facilitate communication and felt that “[e]very conversation should start with, ‘Tell me what your understanding is in this situation. Tell me how you think things are going right now? Tell me what you think is going on?’”

3.2.1.4.2.4 Teaching

Multiple providers relied on teaching as a method to facilitate communication. One provider reported that

in some situations, what's really helpful is like if another family member has arrived, or if they've like talk to their mom or their dad on the phone, just understanding what they said to them. Because we talk all the time about how like if you could teach it to someone you understand it. So, I feel like that's a really good gauge of whether or not like they really picked up kind of the finer points of what I was trying to convey to them.

Another reflected that “most of the time it just requires a simple reorientation [to help families understand]. If you have a good explanation or thought process that seems to make sense to the family” then teaching could help.

Teaching is also a method that was used to help keep the provider team on the same page. One participant said, “I think we need to do probably more [bedside] teaching about why we do what we do. So we are sure that everyone is understanding why we're doing things.” Another felt that “[The nurses] just absorb that kind of teaching like a sponge and they take it into the other

family rooms. And I think it improves communication with other patients as well.” Teaching therefore seems to play a role in communication among providers as well as between providers and family members.

3.2.1.4.2.5 Teach Back

Some providers went a step further and used the teach-back method as a way to ensure understanding. One provider said, “*[I will] have the family kind of explain their understanding back to me.*” Another admitted to “*mak[ing] sure that the family can repeat back...what the important next steps are.*” This method was not universally recommended, however, because “*some families sometimes feel like [the teach back method is] almost like a test.*”

3.2.1.4.2.6 Repetition

Many providers commented on the need to repeat conversations, sharing that “*repetition definitely helps*” ensure understanding. One provider felt that “*[i]t usually requires multiple passes, sometimes from different providers repeating the same message, before a lot of the core and important issues resonate with the families.*” Another modified the approach to help ease families into more technical information, sharing that his approach was to “*repea[t] it each time, to layer it...to help the families, again, grab something they understand and [then] build out to understand we’re going to use more technical jargon to be specific*”

3.2.1.4.2.7 Circling Back

Multiple providers not only incorporated repetition, but allowed families time to process information before the follow-up conversation. One provider shared the practice of “*within like 30 to 60 minutes as long as something else doesn't take me [away], I'll come back and lot of times*

what I'll do is sort of reiterate the information that I initially relayed." Some providers used this technique to ensure that goals were being met too, with one provider stating that *"[it's helpful to] circl[e] back and making sure that [our plans] had the effect on a patient that we wanted them to have."* Allowing time and space between conversations seems to have added benefit for communication in the CICU.

3.2.1.4.2.8 Meetings and Conferences

Another strategy that was used was formalized meetings that were set up to help facilitate communication and allow providers and families to convene together. One provider shared the following practice: *"If it gets to the level where the communications has been difficult or discrepant I try to use family meetings to deliver our one message or rectify any misconsiderations by other services or own service and then deliver a solid message."* Another provider noted that *"care conferences can really help [when families are upset]."*

Equally important, however, were meetings among different providers and teams. One participant commented that *"all the different versions of rounds I feel like help [with communication in the CICU] too."* Another said,

I don't think there's anything wrong with meeting to understand everyone's different expectations for the patients and why they are that. And I think that THAT has actually probably improved communication and goal setting in here. I think we're often on the same page more than we were before because everyone's communicating a little bit better with all of the different rounding situations. Or at least like, we know people are thinking about.

These meetings provide structured opportunities for different teams to engage with each other and discuss issues that are important for patient care.

3.2.1.4.3 Individual Tools

Providers referenced many individual tools that were used to help with communication in the CICU. These included “*sign outs*,” “*daily goal sheets*,” and even “*index cards for each patient [containing]...overarching goals*.” These constructs can help prepare and organize providers and help ensure that information is communicated accurately and completely. Some of the tools that were mentioned by multiple providers are discussed in the following sections.

3.2.1.4.3.1 Whiteboard

Each room in the CICU contains a whiteboard that is updated with the date, names of providers, and sometimes plan. This resource was used variably by providers, however. One participant noted that “*[there has been a push to make] sure that we're accurately filling [the whiteboards] out. And ideally the goal is to make sure that they are updated in real time but that doesn't always happen.*”

Another provider explained how she used the whiteboard, saying
sometimes I'll walk into a room and see what's on the whiteboard and be like 'Oh yeah we were going to talk about that. Or we were going to work on that. I wonder if we're really doing a good job with his pain today...' And it will sort of like remind me that that was something that we had really wanted to focus on and that was really important to the families. So, I think that can be kind of like a jolt back for me especially on these long calls. Like, that's the one thing that we really talked about and wanted to focus on. How good of a job am I actually doing with that?

But most providers agreed with the participant who said “*Honestly, I rarely look at the [white]board. Occasionally, I'll look and see that there are goals.*” Others had concerns about whether “*they [were] truly updated every day.*” And some went further still, noting that “*the goals*

of care [written on the whiteboard sometimes] strike me as discordant with what I would think the goals of care should be.”

3.2.1.4.3.2 Inclusion of other people

Some providers used less tangible tools to help communicate, sharing instead their practice of including other teams or individuals in the discussion. One provider stated that she would “*bring in anybody else that could possibly help: clinical leader, the doctors, whoever it may be. Kind of, escalating it past what [she could] do for them.*” Another broadened this idea, stating “[*when we have someone who speaks] a different language we use translators.*” The use of translation tools (people, phones, iPads) allows staff to communicate effectively with non-English speakers.

3.2.1.4.3.3 Family Reference Material

Some reference materials were discussed primarily as a resource for families. One provider shared that she “*print[s] things out a lot. Like, if a family has a question. Some families like to know everything. And [she] feel[s] like the more knowledge, the better for families.*” She also feels that this helps to reduce confusion and miscommunication. Other providers shared that they specifically like to use illustrations. One provider said, “*sometimes I’ll use, if I’m talking about a particular heart lesion or defect using pictures can be really helpful...to get home a point. About...the heart disease itself or what is going to happen to them if they go to the OR, things like that.*” Another provider agreed, saying

I think illustrations oftentimes help [me make sure that families can understand what I’m communicating and are]...something that can remain with them after I leave the room. So, I’ll try to draw something for them -- for example, to show what

the lesion is or what the problems are, or maybe the interventions that might be done to assist.

These tangible adjunct tools can be helpful for patients/families.

3.2.1.5 Comprehension

Comprehension is of paramount importance in communication, but is sometimes difficult to quantify.

3.2.1.5.1 Provider Comprehension

Providers must first work with and understand each other before they can ensure that patients and families comprehend their recommendations. Most participants felt that the comprehension of providers was sufficient. One provider said *“I feel after rounds I have a 98-99% idea of what is happening for that day.”* Some participants were less confident in their own understanding, sharing that if they *“just have that patient for the day and...don't know what happened last week”* that it made it more difficult to answer questions.

The importance of ensuring this understanding was best communicated by another participant who felt that *“everyone who's involved in the care really wants to not just know what the plan is, but truly understand why we've made the choices that we've had.”* Some providers took ownership of this process, sharing that they *“personally ma[de] sure that...[they] understand why we're doing everything that we're doing...[s]o that [it's] not just checking boxes off.”*

3.2.1.5.2 Family Comprehension

Multiple providers commented on the challenges of translating this understanding to families. One participant said, *“I feel like I sometimes struggle with the assumption that families*

that are here have the same basic level of understanding of medical things that...my colleagues have.” Given that “*nursing often time takes down [daily goals] and adapts that for something more truncated for the families on the board*” it is easy to see how these issues can compound and lead to communication problems.

3.2.1.5.2.1 Language

Several providers shared that they were intentional about the language and phraseology they used when communicating with families. One provider reflected, “*I’m pretty cognizant when it comes to using language that families will understand, as opposed to just throwing out medical jargon...[oftentimes] families won’t understand the medical jargon.*” Another shared that her goal was “*making sure that everyone in the room understands what I’m saying and that [she is] speaking on different levels to different people [as necessary].*” Participants embraced using “*similar language [to families],*” echoing the same language as other providers, and providing “*consistency of message*” to help communicate with families in these situations.

Even using these techniques, most providers felt that families usually didn’t understand them. One provider estimated, “*I’d say 50% of the time that [families] completely understand.*” Another said, “*[families are] not medical professionals – it really truly is beyond their scope of understanding.*”

3.2.1.5.3 Why Families Don’t Understand

3.2.1.5.3.1 Complexity

Several reasons were proposed for why families did not understand, including the notion that “*it [is] just the complexity of what we do*” or “*a general medical deficit.*” Some felt that family

concerns preoccupied them to attend to the agenda of the medical team. One participant commented *“You also realize that the thing you're approaching them with is not the most important thing on their minds.”* Another noted that *“It's just hard [for families to understand] in that blast of adrenaline and emotion”*

3.2.1.5.3.2 Misperceptions

Sometimes this emotionally charged environment will lead to misperception. Reflecting on a particular encounter, one provider commented that a family had a *“hopeful, misleading perception that maybe this [surgery] will just be –after this one everything will be fine and we don't need to keep moving forward [with the multi-stage repair].”* Another provider recalled a patient who had

been fetally diagnosed with a very clear diagnosis, like pulmonary atresia” and despite attempts to educate and prepare the family for the necessary surgeries, after the child was born the family said, “Well, maybe they grew back or something like that. Can you check it again and make sure?”

Misperception of foundational information can negatively impact every conversation providers have with families.

Providers used different approaches to address this particular issue. One provider felt that the first thing to do was to *“understan[d] what [the family's] understanding of a situation is”* noting that *“that can be a huge barrier to communication. Because I'm trying to tell you one thing and you don't believe that things are going poorly. Or you don't believe that things are going well.”* Another provider said,

I try to apologize, mostly, if there is a misunderstanding that was delivered to the family. And that tends to – I try to make it very clear from the get go that we're not

perfect and that that messages may be mixed, but ultimately it's one goal, and one team. And try to normalize the process of making mistakes and miscommunications. 'Cause it's inherent to the system.

3.2.1.5.3.3 Family Reactions

Family reactions during these stressful times may further complicate communication. One provider noted that “*sometimes parents just out of courtesy may nod their heads or just understanding is like saying that they understand, but they really...they're just ingesting the full magnitude.*” This means that some of the tools providers use to communicate (like non-verbal cues) may be less effective.

3.2.1.5.3.4 Length of Stay

Providers did feel like the time families had been admitted to the CICU made a difference in their understanding. One provider said,

I feel like a lot of our families, unfortunately, are here for a decent amount of time so they end up getting more familiar with the lingo and what things mean and they pick up a lot of new things very quickly and then they start asking questions – like very specific about their labs or their care that they would have not ever known to ask prior to being here.

3.2.1.5.3.5 Physician Time

Fortunately, most providers felt that understanding could be improved if the “*physicians actually go in and explain it to [the family]*” with the belief that if they “*explain their reasoning...[it u]sually keeps the family calmer.*” One provider reflected on a particular instance

where “[the medical team] didn't explain the why...[noting that the patient] wanted the why.” She went on to say,

I think that that sometimes [is] a disconnect. When there's conversations happening out here. Whether it's life or death, or not even life or death; it's decisions. And then they come here and they just said ‘This is what we decided.’ I think the discussion part is like, ‘Hey we—so a bunch of us discussed it. There's some people that thought this. There's some people that thought this. But this is what we came to and this is why we came to it.’ I think sometimes that would be a better solution than saying, ‘This is the only option’... I think families would be more—less confused in situations like that. Where they would know: OK, they did discuss it. This is why versus just this is the decision

3.2.1.5.4 Do Families Need to Understand?

One provider did say, “I don't know if [families] necessarily need to [understand], either.” Though there were no other providers who clearly articulated this specific idea, many providers discussed the need to tier language or structure discussions to make sure families understand basic concepts before moving on to more complex topics.

3.2.1.6 Decision Making

Decision making is a complex process in the CICU. While parental input is highly valued, often the experience and advice of experts drives care. Providers reflected on many different aspects of decision making while discussing communication in the ICU.

3.2.1.6.1 Parental Preferences

In general providers felt like the CICU staff is “*pretty open to parents’ input.*” One participant went on to say,

I mean if parents express specific wishes we try to go by that. At least in my experience here we haven't really run into any issues with... parents wanting or not wanting one particular thing and then that is really the one thing that they need. I feel like our—we usually can work pretty well with what their specific wishes are

Another felt “*that families wishes or requests are pretty reasonable.*”

Despite the common sentiment that “*everyone want[s to incorporate the family’s wishes]*”, the approach to these conversations and the extent to which families were invited to participate differs depending on individual provider and situation. One provider said, “*I just try to ask that upfront I say, ‘Please tell me your thoughts. Tell me how you think that your child is doing.’*”

Another provider was more subtle, recalling a situation when he told a family

We're considering this. Not necessarily we're going to do this. But how do you feel about that if we do do that? So that they understand that, like, you know, it's not exactly critical right now but we may come to the point where it is. And if we do, now or later, how do you feel about that?

3.2.1.6.2 Patient-Centered Rounds

Many providers indicated that they “*definitely try to make the families a real part of rounds when it comes to, at least certain decisions.*” Some providers described including “*all the family members, you know, mom, dad or whatever partners are preset*” and making sure they “*are all engaged in the conversation.*” One participant provided an explanation for why this is important, saying,

I do notice the families that participate in rounds, they have a little more of an opinion on what goes on. And I think it's because they, at—during rounds, they hear it's a discussion. And then hear we can do this or we can do this. And then they would say, 'Well, maybe my preference would be that' ...I think they feel like they have a little more say when they're standing in rounds listening. And they feel more included in the care team. Instead of just us telling them what we're going to do.

Another provider echoed this sentiment and admitted, *“I often try to incorporate at least some of their wishes into the plan. Because I think it just gives families a little bit more of a sense of control if they feel like they are contributing.”*

3.2.1.6.3 Paternalism and Autonomy

Regardless of the approach used, many providers noted that *“[Encouraging families to offer their preferences] is a little challenging within cardiac critical care.”* Some providers were more paternalistic, with one saying

Yep [I do ask families about their opinion if there are two different options moving forward] ...[but] I only offer their opinion when I feel like there is an opinion...if there's more than one way of doing something, I'll be very honest with it and tell them what my opinion is and what we will enact. I don't offer it as an option a/option b/option c unless it's really they're all bad or they're all good...then it's their preference.

Another provider shared *“[I usually ask the family their opinion, but] if it's a post op day one hypoplast I'm sorry, but I'm not going to be asking the parent's opinion, usually.”* Other providers grappled more with the notion of autonomy, stressing the importance of *“making it very*

clear that that's a choice that [the family] can make so letting them have involvement in that part of the conversation” and “let[ting] the family decide.”

3.2.1.6.4 Reasoning

When families *were* invited to participate in decision making, they seemed to make decisions based on a number of different reasons. Safety was consistently identified by participants as a key driver in medical decision making. No one “*want[s] to put the kid at unneeded risk.*” One patient “*had a traumatic course after the cardiac Cath...[so the family’s] emotions were clearly palpable*” and contributed to the decisions they made. Financial constraints sometimes play a significant role in decision making, too. One provider shared a recollection of a family that

because of financial issues...was basically paying out of pocket for everything. And so, if things were non-essential per se, as non-essential as they can be in a critical patient: working them up for a genetic syndrome to see if they have a diagnosis. The family didn't necessarily want, again, because it's a little bit of a financial constraint.

3.2.1.6.5 Differences Between Provider/Family Opinion

The complexity of decision making ensures that families and providers are not always going to be on the same page. Fortunately, one provider noted that

most of the time, yes [I can find common ground with families even if they're upset]...[It] varies widely [for how long it takes], depending on how severe and how discrepant...and how many mixed messages they've received before, outside forces, and family and community that might provide a different point of view. It all depends. And sometimes [we] never [find common ground].

He went on to say that when the team and family were at an impasse he generally approaches the situation by telling the family “*I’m not here to change your mind. I’m here to just give you what one perspective is and hopefully with time you’ll see that we converge in the same point...[because] we both care about your child.*”

3.2.1.6.6 Provider Schedules

Changes in providers can further complicate the process of medical decision making. One provider noted that “*between physicians there’s some discrepancy in what they’re saying, so families often get confused. And they’re like, ‘Well this physician said this. We agreed on this last week.’ But then a new physician comes on. So, then they get confused again.*”

Another provider echoed this sentiment and said, “*sometimes [new attendings] have different goals or directions that they want to take the care in, which gets kind of frustrating for families.*” This frustration can also arise from the change in providers for night cross coverage. One provider shared

A lot of physicians are very good about being like, ‘We’re not going to change this because this is the plan from daylight.’ Unless something severe is happening. But there are some physicians who I feel like do change things. And then in the morning it’s like, ‘Wait, we didn’t want that...’

Constantly changing plans can make it difficult for families to understand and may impede their ability to participate in decision making. One provider felt that “*communication issues stem from [families questioning]... ‘Well, this person told me this thing, and then you’re telling me this other thing and who am I supposed to believe?’*”

3.2.1.6.7 Provider Agreement

Unfortunately, there are also sometimes disagreements between the different teams involved in caring for a patient and many people felt that “*multiple services [could be a barrier to communication].*” One provider noted,

In the cardiac ICU, in particular, there are always multiple teams rounding on the same organ system for a patient...[O]n a daily basis, they are seeing at least an intensivist and a cardiologist, and often, but not always, a CT surgeon or a member of the CT surgical team.

While some providers felt that there was “*fairly good alignment between the diagnostic impression of all three teams and the treatment plan of all three teams,*” others felt that there was “*a lot of miscommunication between surgeons and families. And intensivists and families.*” Another provider felt that

our biggest problem with communication here, is that we don't always show up as one unified team. Meaning, CI says this, cardiology says this, CT surgery says this. And then, as they each do their own individual rounds, they each tell the family their opinion. Not knowing that the other team had just said something different. I don't think it's malicious in any way. But I think that we could do better at getting on the same page for each patient and being a unified front.

3.2.1.6.8 Consistent Messages for Families

While many potential strategies could be used to ensure consistency between providers, one that was specifically identified by a participant involved including the other care providers, including nursing staff, in care discussions. This provider said,

we need to make more of a point when we have difficult conversations with family to ensure that it's not just the physician and the family in the room. The bedside nurse needs to be there. 'Cause they're the ones who are there at bedside having these conversations, too.

3.2.1.7 Challenges

There are many different challenges that were identified by providers during this project. Some of these challenges are immutable while others are more modifiable.

3.2.1.7.1 Immutable Challenges

3.2.1.7.1.1 Pace

Critical illness and critical care presents its own challenges. The ICU is a “*really high stakes kind of unit.*” One provider noted that the “*pace and the severity of illness [can be barriers to communication]*” Another agreed that “*the busyness of the unit [can be a barrier]. You know, sometimes when a lot of things happen at one time, it's hard to slow down and make sure we're giving everyone the communication they deserve. 'Cause it's just one thing after the other.*”

3.2.1.7.1.2 Critical Illness

The complexity involved in critical care is also unavoidable but can pose challenges in communication. One provider described ICU medicine as “*complicated subject matter that's not easily absorbable or comprehensible.*” This is challenging for providers because “[*t]here's just so much information like that they have to learn to be able to adapt to that environment if they have not already been in a critical care setting and/or a cardiac ICU.*” It is perhaps more challenging

for families, though. Providers try to address this in a variety of ways. One provider said, *“I try [to]...normalize[e] the fact that it’s a complicated topic. And to eliminate some anxiety around listening to something that they anticipate to be complicated.”* Another provider took a slightly different approach after admitting

sometimes I worry that there's so many terms and just so many words used on rounds. But, at least when I'm on service, I try to either have a fellow or myself summarize for the family at the end. To make sure that they've gotten the gist of what's going on and what we're thinking about.

These strategies may help families digest the complex information involved in cardiac critical care.

3.2.1.7.1.3 Uncertainty

Uncertainty is also inherent in both medicine and critical care. Unfortunately, there are never any guarantees and one provider reflected that *“things aren’t [ever] set in stone.”* Another said *“[t]hings can change on a dime. [Families] have one explanation one day and the next explanation it's obsolete or out of date and [providers] have to change [their] plan completely.”* Sometimes having conversations about these uncertainties with families is challenging because *“they probably don’t want to hear it.”* But one provider felt that if these conversations happened earlier then *“if the child would end up great, that's great! But if the child ends up not good, at least that maybe [the family would be] prepared.”*

3.2.1.7.1.4 Time

Participants noted several distinct ways that challenges with time and timing affected communication in the CICU. Time management was recognized by multiple providers as a

particular challenge because they are expected to “*manage multiple meetings and discussions*” every day. One provider lamented the lack of time, saying

if I had all the time in the world I would actually love to circle back and talk with any family who's in the unit. And, I mean, ideally call families who are not. But that doesn't always happen, depending on the acuity of the unit on a certain day, or the volume of patients, etc. So, while we will see good number of families in the morning on rounds, I, as an attending, don't always get back and just check in with families, depending on when I'm in the room versus when they're in the room or in the hospital. And usually this comes down to time.

Another provider admitted that “*when you have only so much time as you go through the day...I guess you kind of have to prioritize.*”

Time management was also noted as a particular issue for fellows because in the CICU “*the fellows have to put in every order, every everything.*” One provider observed that because of this “*it's probably hard for them to get a chunk of time always, if it's busy, to sit down and communicate uninterrupted.*” Another noted that “*[some fellows,] when other things are happening and they're busy—they're not going to come into to just chat with mom and dad.*”

The specific timing of conversations in the CICU may also be more important in certain situations, like when there are complications. One provider said “*I think it's always best to let the family know as soon as possible if something is either not good or suboptimal in terms of care or outcome,*” further reflecting that “*anytime there's a delay in [sharing information with families]...[they] feel it.*” Furthermore, providers recognized the “*need [to spend] more time [with new families]...than others*” to build rapport. Other providers echoed this observation, saying that “*families “like...when you take that time, you know spending extra time with them.*” These

challenges with time and timing can pose significant communication challenges for the provider team.

3.2.1.7.2 Modifiable Challenges

Fortunately, not all challenges are unavoidable; some may be completely preventable. These include challenges related to schedules, care team responses, the presence of families at the bedside, family pressures and external circumstances.

3.2.1.7.2.1 Provider Schedules

Multiple providers identified provider schedules as a barrier to communication. One participant said *“I think the schedule is a huge barrier. Like, how in and out you are all the time. How much rotating of humans there are here [in the CICU].”* One provider said, *“I see the attendings who are on for each week take a lot of ownership for the people when they’re on for that week. But then they leave.”* This seems to be an issue for both attendings and fellows, however. Another provider said that the

[schedule for] the fellows...is bananas. There’s really, just a lack of consistency. And that is not the fault of the fellows. It’s really the fault of the schedule itself. But I find it very hard the way it’s done. Because there’s the on-call fellow who is sort of ultimately responsible for everything once the post call fellow leaves. But there are a bunch of other trainees around as well. But not—with no clear role, exactly. Or people don’t have ownership of a subset of patients.

One of the fellows agreed, saying *“[the fellow] role with the families is not a continuous role...[and that the fellow is] only the primary CICU fellow when [they] are the call person in the CICU.”* This fellow further reflected that he suspected *“that’s one of the reasons why, the*

attendings rather than the fellows are sort of the primary communicators with the family, 'cause they have that opportunity for continuity.”

3.2.1.7.2.2 Care Team Responses

Another challenge in critical care medicine is that acute decompensation can occur at any time. This was identified by multiple participants as a possible barrier to communication. One nurse said, *“If a parent does think something is wrong ...[and a nurse] feels the same way and is escalating then I think the thing not to do is like kind of dismiss it,”* advocating for a more thoughtful approach to investigating these concerns. Fortunately, despite the many challenges posed by schedules, most participants felt that *“everyone [in the unit] kind of knows what's happening with each patient. So that way, if something would need to be escalated or something changes, then there's people that can come in and jump in and help that already kind of have a basic understanding of what's happening.”* Most providers also agreed that *“if there's some sort of acute situation, I think we are pretty good, again, whether or not the family is there, getting in touch with them.”*

3.2.1.7.2.3 Presence of Families

Multiple providers also identified a significant barrier to communication when families were not able to be present in the hospital. One provider said *“families aren't always here. So, you have to make an effort to connect with certain families.”* Another noted that *“unfortunately, those families [with low education] also tend to not be here as often. So, they miss a lot of things. So, when they do come in...[t]hey're just confused. Because they don't understand what's been happening, so to back-explain all of it is a lot of information for them right up front.”* Unfortunately, one provider did not feel the medical team does *“as good a job as we could calling*

[families who are not at the bedside] (on the physician side) and talking to them and updating them.”

3.2.1.7.2.4 Family Pressures

There are a number of other pressures that might be exerted on families, which may be important for providers to understand. These could be quantifiable pressures like “*[a mother who] doesn’t have a car*” or families who “*have different educational levels*.” They could also be less tangible emotional pressures like anxiety or stress. One participant said, “*I know this environment is very stressful for parents. To have a kid in this environment, I can’t even imagine*.” Another provider felt that “*there’s sometimes there’s lot of societal pressure – family pressure ... [that makes them feel like they] have to do all these things*.”

3.2.1.7.2.5 COVID-19

With the recent impact of the COVID-19 pandemic, care in the CICU looks a little different right now than it did before 2019. One provider commented on this, saying “*I do think that since COVID has been around, that the relationships aren’t developing as much, because families are a little more split. They can’t have their family come in here and visit them*.”

3.2.1.8 Changes/Improvements

Many participants noted that the ICU is far from static. One provider admitted that the role of the CICU “*[is] changing a little bit*.” She went on to add, “*I feel like a lot of the attendings are taking a lot more responsibility and the fellows are trying really hard to take responsibility and really connect with their families. So, I think it’s getting better, but I still think there’s a long way to go*.” Other participants seemed to echo this tension between the observed changes and the

distance yet to go. One provider felt that the issues of agreement between care teams “[could] definitely be worked on” while another said, “I feel like, recently, [the consistency between attendings has] been a little bit better.”

3.2.1.8.1 Team Agreement

Participants noted that “It would be easier [to make sure everyone was on the same page] if we could all [sit] in one room.” New rounding initiatives may actually be making this possible. One fellow said

even though it's a little bit of a pain in terms of the timing, I am glad that we're part of the what used to be just cardiology and CT surgery sign out in the morning. Because again, there's just so many people involved in one patient's care that the more you can at least try to be on the same page or have a discussion if something's not going right or going as planned the better. So, I think that's helped a little bit – that we're part of that morning meeting now.

3.2.1.8.2 Consistency of Communication

While the agreement between teams was noted to be improving by providers, one area that was identified by multiple participants as an area for improvement was the consistency of communication with families. One provider felt it would be ideal “if there was some way that we could as a – at least for providers to families—make sure that we have, as providers, touched base with every family every day.” She went on to recognize that it “would [have to] be the medical team or the provider team coming up with a plan for how that's going to happen.” Another provider ventured to explore why this might help, positing that “a more consistent effort to go in and just

talk to mom and dad a little bit, assess the kid, kind of make that precedent...could help just kind of unify everything. Make everything more cohesive.”

Yet another provider noted the need to have “*more of a standardized [process] ...[to] make sure that everyone that’s going to be consistently taking care of those kids— so like the nurse, the respiratory therapist, the clinical leader, the fellow, and the attending that’s on – all have to go in [the patient’s room daily].*” There was less agreement about specifically who this should apply to in the context of the CICU. Attendings were singled out by one participant who said, “*our attendings could stop in more often and see patients. Even if it’s once a day. Or after rounds. Go in and see them on a separate time. Which I know a lot of family is not there at the times physicians are available. But sometimes the family won’t see an attending all day.*” Another provider shared that “*the attending, in my mind, doesn’t need to be the one necessarily talking to every single family every single day. I mean it’s an important skill for all people to have – and trainees, especially, to develop relationships. And learn how to communicate with families as well.*” Another provider commented on the challenge of continuing to do this even when families were not physically present at the bedside, saying “*I do not think we do as good a job as we could calling them (on the physician side) and talking to them and updating them ...I think that we could do a better job talking to them as well by phone, if they can’t be here, and just sort of talking about more of an overarching perspective with the families.*” Even with these slightly different perspectives everyone seems to agree that it would be helpful to have a mechanism by which the team could ensure that all families are updated daily by at least one member of the team.

3.2.1.8.3 Family Support

A few participants commented on the need for providers to be generally more supportive for families. One participant admitted, “*I think we could work on [being more consistent support*

people for the family] as a group.” Another felt that it would help if a single provider could function as a support person for long term patients, envisioning that

whenever there was a really difficult conversation they would at least know about it – or like a difficult situation. And whenever there was a care conference they would be a source of support that was in there. Sort of taking a step back from being the one on service. [Someone w]ho could kind of weigh in and help the family to deal with everything.

She went on to observe, “*We don't do that here. But I actually think it would be really helpful for some of the patients.*”

3.2.1.8.4 Provider Schedules

The need for someone in this role could be related to the challenges presented by complicated schedules and cross-coverage situations. Within this context one provider felt that an easy fix was for fellows to

follow patients consistently while they're on a month or two weeks of service...[so that they] get to know the patients a lot better, ...get to know the families even better, and it's easier for me as an attending to know who to go to in terms of the fellow. And also, to trust little bit more because they're really focused on three or four patients and families.

She recognized that this would require changing from a call structure to a night float system, which would be a major shift in how care is provided in the CHP CICU.

3.2.1.8.5 Roles

Not all comments tackled process issues that large; some comments alluded to a desire just to have better delineation of roles within the CICU. One provider said, *“I do think that we could do a better job, at least on the medical team— between the attending the fellows—sort of, deciding who's going to be the front line communicator.”* Another felt *“it would be helpful for [him] to have clearly defined responsibilities about who talk[s] to the family about what... and when,”* adding that it would be helpful to know *“as the CICU fellow, what information is or is not [his] role to disclose. And—or to talk about. And to have that sort of be laid out in a more clear cut way.”*

3.2.1.8.6 Whiteboard

When asked specifically about how tools like the whiteboard were used, participants felt that the whiteboard might not be used to its full potential. One participant felt that the whiteboard *“could be used better if...[for] afternoon rounds or evening rounds [the team used]...the board and [saw] what was really important in the morning and not just what got signed out to [the night team].”*

3.2.1.8.7 Other Comments

The examples above provide explicit examples of changes to group practice or CICU processes that could improve communication in the CICU. Several participants reflected individually about areas where they could personally improve but these will not be considered here since they do not pertain universally to the unit. It is worth noting that multiple providers recognized that *“we could always do better as providers”* and that *“[t]here’s always a place for progress.”* CICU providers have embraced the dynamic nature of the cardiac critical care, and this

can be leveraged to help address some of the issues that they have identified regarding communication in this unit.

3.2.2 Patients/Families

3.2.2.1 Goals/Expectations

3.2.2.1.1 Family Expectations

Family participants consistently identified management of their expectations as an important part of communication in the CICU. One participant indicated that she was surprised that *“in the middle of the night [the team] removed the catheter,...removed this wire,...removed that wire,”* also commenting that she *“didn’t really realize that they were going to be doing that that quickly.”* When asked to clarify, she said the medical team *“did [set expectations] but they didn’t. When they did, I was more...out there. Like, in outer space.”* This participant identified her own inability to focus and process as the reason she didn’t know what to expect.

Other participants felt that

[sometimes there is not a great] trajectory of what’s about to happen.” This occurred in varying degrees for different participants. One family said “maybe [the nurses] could’ve just said, ‘Oh, he’s out on lunch or something. So, it’ll be an hour.’ Or something like that, so that way we’re not sitting here, like, ‘What’s going on? What’s going on?’

Another caregiver admitted that *“there were some times that, like especially with running some tests and stuff, that [they] weren’t really told timings, all that.”* One family reported that some testing was conducted without them being aware, adding *“I can only imagine if we woulda*

came in Tuesday and they said, 'We swabbed her Monday night and her swab was positive.' We wouldn't have been preparing ourselves for another COVID test at that point." These situations definitely illustrate the importance of family expectations being managed by the care team and the potential for issues if they are not.

3.2.2.1.2 Avoiding Speculation

While families want to know what to expect, they do not want to hear projections of what might happen. One father said, *"if I were to give advice on how to handle it again, I would say don't speculate until the whole team has talked about it together. There's just not a lot to be gained by one doctor saying, 'Oh, I think it'll probably be next week' whenever they haven't discussed it with [the full team]"*

3.2.2.1.3 Familiarity

Familiarity with the unit and the staff seemed to help families manage expectations on their own. One family said *"And when you see—when you hear who's coming on the next week, you can see what's coming."* Another participant agreed, saying *"You know what to expect for that week [based on who the attending is]...[You know] what the goals will be."* One of the participants alluded to length of stay as one of the reasons for this, saying it was *"[b]ecause we've been here awhile, you know? So, we kind of [know what to expect]."*

3.2.2.1.4 Family Goals

Goals seem as important as expectations to families, though often the goals of the family are often distinct from the goals being set by the treatment team. Several families indicated that one of their goals was to comfort and care for their child. One participant admitted *"we're not*

doctors. We don't know what we're doing. We just know, as far as feeds and certain things, what he's sensitive to.” Another family shared that because their son “would get really fussy with the ultrasound jelly” that they “just wanted to be able to be there [with him during ultrasounds], to hold his hand and everything.” One participant expressed gratitude that the CICU staff “allowed [their family] to be hands on with some of the things that [they] had [been] robbed of up to this point....changing diapers or swaddling or holding” characterizing them as “all the things you want to experience as soon as your child is born.”

As important as these goals were, many families also indicated that the most important thing was the care for their child. One family reflected on the care from CICU providers and reported “they were focused mainly on him (which they should be).” Another said “Every single attending has been like, ‘This might not be the case, but we're going to check it anyways.’ Which we obviously prefer.” Patients and families recognize the importance of receiving excellent care even if that meant deferring actualization of competing goals/interests.

3.2.2.2 Interpersonal Communication

Families recognized that communication was affected by the relationship built between both parties. This relationship and the rapport that results directly affects the therapeutic alliance as well as the patient/family experience of time in the CICU.

3.2.2.2.1 Rapport

Families generally felt that “it was easy [to have conversations with the team taking care of my child].” Participants said “[i]t was literally like talking to family” and “[e]veryone was so friendly and willing to...get us answers.” One family member noted that providers were gracious even in the face of interruptions, saying “[It was v]ery easy [to talk to the team]. Even if we were

in the halls and needed to stop the attending or anything like that, they were always very willing to just pull in and come and talk to us. Or any of the nurses. Even if they weren't our nurse, they would stop and help at any time.” A parent said,

[A]ll of our nurses have been exceptional as far as treating our child like someone that they are related to. You know, treating us like old friends. Always asking what we need...[O]ne of the nurses came in and was a witness for our baptism. Just all of these things that don't feel like is part of their job...[were] definitely felt and appreciated.

While families were happy with the collective approach of the CICU staff, several comments were made regarding specific individuals. One family noted that “*obviously you have your preferences on dealing with certain attendings or whoever it may be.*” Another reflected that “*A couple of [providers] I think really went above and beyond, to be quite honest with you. In their personability. And I think that that helped us as a family...[and went] very long way.*”

3.2.2.2.2 Accessibility

Not all reflections were complimentary, however. One father noted significant differences in the approach of individual attendings, saying

there are attendings that we see constantly. They come around every hour, or whatever it is. And pop in. Or at least one of the fellows pops in. And then there are times where [another] attending [is] on, and they don't really come around. You know, they don't come around as much. And it just like—again he's been very stable...But even when he's very stable. Things still come up where we have questions or whatever.

Another participant echoed this, noting that “[s]ome of [the attendings] don’t always come back in [to check on him or follow-up with us].”

3.2.2.2.3 Approachability and sincerity

One parent expressed gratitude because she “just felt like [the attendings] were people...Even using their first names and not doctor so-and-so.” Another parent was thankful that even though the team “knew that [she and her husband] knew what was going on [because they are both medical]...[the team] still treated [them] as parents.” This nuanced approach to interacting with families in which they are validated as both partners in care and parents is a difficult balance to strike. The mode of communication may help facilitate this balance. One parent said “I prefe[r] the face to face [communication].” He went on to say, “I never felt rushed on the telephone, but I like to read body language. I like to see how people are interacting with me, their sincerity. And I believe that all of that is better conveyed in a face-to-face conversation as opposed to over the telephone.”

3.2.2.2.4 Open Communication

Open communication was identified by multiple families as important. Some participants felt that “everyone did a really good job of making sure that we knew the plan and what was happening.” One participant felt like “everybody from the surgery to anesthesia to IVs to the ultrasound to the EEG techs, everybody was pretty open with communication.” Another family member said, “if there’s any confusion or anything going on, I feel like they made sure to fill us in and try to answer questions immediately. If anything was going on with him, they were right there when we needed them...[T]hey kept us in the loop, as part of the team.” One participant described

a situation where the medical team and family felt differently, saying when we “*speak up and say, ‘Well, I don’t know.’ They’ll usually...walk/talk through [it] with us.*”

3.2.2.2.5 Family Engagement

It is this environment that allows families to fully engage with the team to help care for their child, however. Multiple participants noted that they had no qualms about actively participating. One mother admitted, “*I’m always someone who definitely voices my concerns. Especially with him.*” Another family said, “*We’ve definitely gotten to the point where we speak up and say, ‘I don’t know if I agree with that.’*” In these situations, the general sentiment was that “*if [families] question[ed the plan] for a second [they didn’t]...ever really [get] any push back.*” The willingness of families to participate demonstrates a trust in the professional role of providers to help them navigate the complexities of critical care medicine.

3.2.2.2.6 Honesty and Trust

Even with difficult situations family members seemed to appreciate honesty from providers. One participant said “*no one’s lying to us. But it was very unclear that that was part of the timeline.*” Honesty even in the face of challenging situations or unforeseen complications allows for trust to develop between families and providers. Describing this trust, one father said “*I know that I could [leave]. I could walk away. And I knew she was fine. And I knew that if she wasn’t, that they would call us.*” Thus, families also recognized the importance of both honesty and trust in building and maintaining the therapeutic alliance.

3.2.2.2.7 Empathy

Empathy was also important to the patients/families who participated in this project. One participant felt that *“Every single time [providers] walked through that door they [we]re empathetic.”* Another family said, *“Honestly, no [there was not anytime where I felt people were not empathetic]...I cannot say enough about everyone here.”* Other families were able to identify specific providers who tangibly demonstrated empathy for them. One family noted that one particular physician *“made things a lot easier. And [they] weren’t afraid to ask her questions. [They] already have a relationship built with her. And so she was instrumental.”* Another family member said,

I can think of one [attending] in particular who really took the time to again explain things out. [It helps to have a g]ood attitude. [It also helps to be f]orward about challenges but not dwelling in them. So, again, just kind of really helping us not get lost in the scary stuff. But also be practically aware of the scary stuff.

And the mother for another patient felt that one of the nurses *“really calmed [her] down. And gave [her] someone to talk to. And made [her] feel better.”* The many examples family members shared highlight the profound impact empathy can have in cementing the therapeutic alliance and building rapport.

Families also felt that the CICU providers did a good job providing emotional support during challenging situations. One family member commented, *“If it’s a really hard day, a lot of times they like leave and then come back and say, ‘We just want to give you time to process it.’ They do a really good job of that.”* Another family member echoed this sentiment, noting that *“from the front of the house, to the back of the house, to the folks that are coming in from an environmental standpoint, everyone’s been super nice, very open, willing to talk to us, also willing*

to give us our space when they felt that we probably needed—or we're projecting that we needed space.” A third family member described a tough situation and then noted that “[t]he nurse did really good job pepping us back up after that moment, as well. As far as, ‘Yes, that was really tough information to hear. But [don’t] forget every milestone that you’ve achieved today.” One father noted that one of the nurses was “constantly making sure [he] was OK [when he was alone because his wife was still in the hospital].” He reflected on how much that meant to him because “[he] wasn’t [okay at that point].” The way providers handled these tough situations directly impacts how family’s experience care in the CICU.

3.2.2.3 Communication Tools

Families discussed the use of communication tools less frequently than providers, but there were several strategies that were specifically recognized.

3.2.2.3.1 Repetition

Several participants noted the use of repetition to help promote understanding. One parent said, “*If I didn't understand, I would ask again.*” Another echoed this practice, saying “*If one of the doctors didn't understand me, I would...just ask somebody else. And then we could get on the same page about things.*” And a third family described intentionally using “*a lot of repetitive questioning,*” going on to say

[W]e would ask different doctors...[we would ask] the same question—sometimes [to] the same doc, sometimes [to a] different doc—just so we could understand it. So, maybe hearing the same thing over and over. Or getting a little bit more information about pieces and parts that an hour or two earlier we couldn’t think of

a question around or still was processing. So, I would say that's probably the biggest thing we did, was kind of this repetitive, let's talk about that again.

From these accounts repetition seems to be helpful for CICU families.

3.2.2.3.2 Circling Back

Providers had identified circling back as a common tool used to facilitate communication. Fewer families discussed this practice, but one family did tout the medical team's propensity to circle back with families, saying *"I do feel that they always took time to come back and reevaluate our understanding of what was discussed."* This sentiment aligned with the comment from another parent that *"if we don't [understand] they can tell... If it's a really hard day, a lot of times [the team] leave[s] and then come[s] back and say[s], 'We just want to give you time to process it.' They do a really good job of that."*

3.2.2.3.3 Active Participation

Active participation was another strategy that families employed to help with communication and to help them feel like they had some control. One family member said *"there wasn't any a point that I was like, 'I feel like I have no control. I feel like I have no information.'"* And went on to say *"I really felt like I was included in everything."*

3.2.2.3.4 Language

One family also reported that *"if there was obviously lingo amongst [the medical team], that they did a good job, at a pause, to come in and [tell us], 'This is what we just now discussed.'"* Another participant reported that *"a couple of the fellows, in particular, really did a good job of that popping in frequently...paus[ing] and turning and saying something to us in a language that*

made sense.” And one parent lamented the difficulty some language posed for understanding, saying, “*maybe if it’s in simple terms we could understand it.*” While no other families specifically commented on the language used, the general sentiment from family interviews was that the medical team took time to explain things in a way that was comprehensible. This will be discussed more in the following section.

3.2.2.3.5 Family Reference Materials

Fewer comments were made about the use of visual aids to facilitate understanding. One participant did insinuate that pictures augmented his understanding, saying “*my only barrier was my lack of knowledge at the beginning...[but everyone took] so much time out of their days to thoroughly explain things and draw us pictures [to help us understand].*” Another participant agreed, saying “*He actually took and he drew an anatomically correct heart and showed us exactly where [the problem was]. And he gave us a couple of pamphlets showing us exactly what was going on. And that really helped us.*”

3.2.2.3.6 Telephone Communication

Most of the participants for this project were family members who were present at the bedside, so fewer offered perspectives about the use of telephone communication in the CICU. One older patient commented that staying informed “*was easy, ‘cause [he] had emails and the myUPMC app. Everything gets sent straight to [his] phone.*” Another family felt that updates were “*also good telephonically*” also saying that if they “*weren’t [there], [the team] would telephone [them][That the nurses were] really good to give [them] a phone call and provide report before [they] got [to the hospital].*” He also said “*from the physician standpoint, I feel the same way.*” Based on the few comments proffered regarding being updated on the telephone by the nurse it

seems that at least some of these families are satisfied with the degree of communication provided when they are unable to be physically present at the bedside.

3.2.2.4 Comprehension

3.2.2.4.1 Provider Comprehension

The majority of participants felt that providers understood them well, though to varying degrees. One family cited a particular instance where the team misunderstood what they heard “*from infection control...[or] whomever they spoke to...misunderstood.*” This caused communication challenges which are discussed more below in the COVID section of Communication Challenges. Most other comments were more complimentary to the medical team. One parent said, “*probably like 75% of the time [the team] knew what I was talking about.*” Another said “*[Our providers understood what we were communicating a]ll the time. It didn't matter what question that they—or I had. They answered them quickly, with knowledge.*” Another participant admitted “*I can't think of any particular moment where we weren't – where we were feeling like we weren't being heard or understood.*”

Families had different responses to situations when they felt the team did not understand them. One of the participants reported that she would “*just ask somebody else...[to] get on the same page about things.*” Another parent said, “*If there was any kind of miscommunication or mis—if I didn't understand, I would ask again and they always answered everything.*”

3.2.2.4.2 Patient/Family Comprehension

Families recognized the importance of their own understanding in helping care for the patient. One mother said, “*Unfortunately, I know way more medical stuff than I ever thought I*

would, out of necessity.” Another parent admitted “*I just wanted to know what was going on with her.*” This desire to know and understand may manifest itself in different ways depending on the specific situation.

Family members employed a variety of strategies to ensure comprehension. Some of these tools, like repetition and active participation in the conversation, are described in the preceding section. No matter what strategies were employed by either the team or the family member, generally participants felt like they understood what was going on. One participant declared, “*I understood it very well.*” Another felt that the medical team “*[was] always keeping [them] in the loop and aware.*” This sentiment was echoed by others, like the participant who said,

I was never really left in the dark. I thought that every time I asked a question and wanted to know what was going on that they were able, even if someone had to get someone else, they got me an answer in a reasonable amount of time. So that I knew what was going on and wasn't confused or anything.

3.2.2.4.3 Questions

Providers recognize this need and desire of families to understand, and often encourage families to ask questions as one way to facilitate understanding. Families perceived this, with one parent saying, “*They just told me and if I have any questions I can ask, and they explain it again to the best of their ability.*” Another commented on the ability to get answers at any time, reporting that “*at any point in the day/night, [somebody] was there to answer any of our questions.*” And one mother noted that if “*[she] had any questions about this, that, or the other thing, [the attending] knew why [the team was] doing what they were doing [and could explain it to her].*”

Fortunately, families not only had the ability to ask questions, but felt that the team “*[did] a pretty good job of answering our questions clearly,*” completely, and with alacrity. One

participant noted that they “*didn’t really have too many concerns throughout everything... [and that] anything that [they] had questions about were answered as fast as they could be.*” Another parent said “[*anytime*] we’ve had a question they’ve explained to the fullest what we’ve asked and what we’ve needed....every time we went to them with a question, they answered it. Either directly or more than what we needed.” And a third parent said, “*Honestly I thought anytime I talked to anyone with the team, that they understood and were receptive and got back to me with whatever question I had.*” This perception of having questions answered completely and directly seems to help families feel heard and understood.

3.2.2.4.4 Challenge of New Information

Families often recognized their own limitations, however. One parent commented on difficulty understanding new information, saying “*I don’t understand [some things] just because maybe it’s the first time I’ve heard of these things...I can’t really picture it.*” Another participant reported “*it’s hard to – for [her], personally, to follow [because there is so much information.]*”

3.2.2.4.5 Complexity of Critical Illness

Sometimes it was not new information that posed problems, but specific details related to CICU care. One participant said,

I feel like [the team] helped me understand everything. But I’m never gonna understand what all of these drugs do. And they’re not going to break down the chemical composition of a drug to explain to me exactly how it affects the flow rate of the heart and everything we’ve got. And that’s completely OK with me, as long as I know that he’s doing better. That’s fine.

3.2.2.4.6 Multiple Care Teams

Still other families commented on the difficulty adjusting to the many different teams and people involved in care in the ICU, noting that people

come in and say things...And [even though] we are familiar with the medical field...we don't know what supportive care is. We don't know what child life is. We don't know what the nurse practitioners or PAs in cardiology or the nurse practitioners in cardiology [are]...there's just all these people [and] a lot of them have the same titles, but they're different.

3.2.2.4.7 Difficult Situations

Some comments demonstrated the challenge that emotionally charged situations presented. One mother said that one physician

did explain to [them] a little more than the first doctor did, as far as 'What measures do you want [the team] to take?'...And [told them], 'This is what it's going to entail.' But...[she doesn't] think [she] understood what [the physician] was saying...[because no one] want[s] to hear that. You don't want to think about that.

These emotionally taxing conversations may pose specific challenges to communication in the CICU.

3.2.2.5 Decision Making

Patients and caregivers recognized the importance and complexity of making decisions in medicine. They identified several aspects of making decisions that were important in the CICU.

3.2.2.5.1 Inclusion

Participant comments demonstrated the importance of just being included in the conversation. One family said the medical team “*made [them] feel like [they] were part of the decision making process.*” Another admitted, “*I don't know that much about medicine but they still asked my opinion about it.*” Parents valued being “*included...[in] conversations regarding rounds*” or “*[updated by nurses] if [they] missed rounds in the morning.*” One parent even noted that the medical team was “*really good about shift change, letting us be included in the report. And stopping...even if they were mid-sentence and we had a question.*” Another participant noted that their experience at CHP was different from their “*previous experience in [a different] hospital...[where they] weren't really allowed to be a part of the conversation. [They] could just kind of listen. [But here] they involved [them] 100%.*”

3.2.2.5.2 Family Preferences

Parents also recognized that “*each doctor [had] a different plan of care. As far as how we were going to get [to our goals.]*” Inclusion in the conversation does not guarantee agreement between providers and families. One participant said that the medical team “*asked [their] opinion and made [them] feel like [they] were part of the decision making process, too. Even though obviously the medical experts are who [they] trusted with [their son's] care.*” Another family felt like the providers asked for their opinion half the time, noting that “*[s]ome doctors will say, 'What are your thoughts on this plan?' [While o]ther ones are like, 'This is the plan.' ...And if we then speak up and say, 'Well, I don't know.' They'll usually...walk/talk through with us [their plan].*”

One parent reflected on the fact that because of the nature of critical illness, sometimes there are not choices for families. Even in those situations this parent felt included in the discussion, saying

When there was a choice, I definitely feel like we were brought in on it. And if there wasn't a choice, then it was explained to us very matter of fact and we...[they] answered all the questions that we would have had with it. But they definitely let us be a part of the discussion on all of his care.

This experience resonated with other participants and one parent said “*I don't think that we were...presented with any scenarios where there were multiple [possible actions].*” This did not necessarily seem to distress participants; one parent felt like “*There was one route [and they]...were happy to follow the one [the team] put forward.*”

3.2.2.5.3 Provider Agreement

Some participants perceived great consistency and agreement amongst the different providers involved in their care team. One participant said, “*you could just tell, by their demeanor [that the providers were on the same page]... They worked as a team rather than against each other. It wasn't—they weren't running into each other. It was just smooth running.*” Other participants focused more on the consistent message they received from different providers. One parent said, “*We did [get a consistent message when we asked multiple providers]... I wouldn't say we ever got an, ‘Oh my goodness. Wait a second, you said that. And now all of a sudden you're saying this.’ So very consistent, very consistent.*” Another parent agreed that “*the consistency of what they were providing us was important, too...That someone didn't tell us one thing and then the other individual take a completely different approach.*”

The reality of cardiac critical care, however, is that even among the provider team there will not always be complete agreement. Some families were better able to appreciate that “*every attending just has their own style of doing things...Everybody just has their own view.*” Another participant felt that sometimes people would “*contradic[t] themselves...One person would say one thing and then somebody else would say something else.*” One parent demonstrated insight by noting “*It wasn't a lot [that team members didn't agree]. It was just right away, when she was first sent down here...I guess 'cause they were still trying to figure out what exactly was going on.*” Even still, there was one family in particular who seemed more perturbed by this reality than others, noting that

when it comes to the actual ICU team and the non-consensus between—whether it be the fellows and the attendings, or between the attending that's on during the day and the attending that's on during the night—[that's been]...[their] only ongoing frustration...[T]he daytime doctor create[s] a plan. And then something happens overnight that throws the plan out the window.

3.2.2.5.4 Provider Schedules

Other participants felt that despite changes in the provider team, that some effort was made to stick to the established plan. One participant reported,

[The attendings] ask for our input, as well. And we have a give and take there, where we come to an agreement all together. And then, even if we have a new attending the next day and we say, 'You know what, this is what we talked about. This is what our plan [was].' Everyone's like, 'OK. Sounds good.'

Another participant agreed, saying “*we have a give and take there, where we come to an agreement all together...they don't really say, 'Well, I don't like that idea. We're going to change it up.'* So,

if we're in on that discussion and we make an agreement with one attending, they don't just come in and change it the next day."

3.2.2.5.5 Difficult Situations

Participants noted ancillary issues that affected their decision-making. One mother talked about how emotionally charged decisions were difficult to consider because *"you don't want to hear that. You don't want to think about that."* Medical necessity was identified as important for decision making by another mother, who observed that her daughter *"was obviously having some trouble. So, they had to do it."* Another participant focused on trusting herself *"[in situations where she got two different messages from different members of the team and] just [going] with [her] gut. And who [she] thought [was right]."* It is easy to see how many different things influence families as they make medical decisions for their loved ones.

3.2.2.6 Challenges

Families identified a number of additional communication challenges that presented themselves in the CICU. Similar to those identified by providers, some of these were inherent to the nature of ICU medicine and others were more modifiable.

3.2.2.6.1 Immutable Challenges

3.2.2.6.1.1 Critical Illness

While most families endorsed understanding providers, several commented on the challenge presented by the complexity of ICU medicine. One participant said it was difficult because *"so much information is coming to you."* Another noted that she didn't understand things

because it was “*the first time [she had] heard of these things...[and she couldn't] picture it.*” One father observed that “[t]here were a couple of times that they would just rattle off the names of drugs and stuff. And I'd be like, ‘OK, what does this do?’ And they're like, ‘Oh, it's just a heart med.’ And I'm like, ‘Well, what's it do?’” These comments clearly demonstrate how overwhelming the complexity of critical care medicine can be for families.

Some families also commented on the difficulty with the fluidity of decisions in the ICU. Changing clinical situations may dictate changes to the established plan that may be difficult for caregivers to follow and understand. One father described the changing plan as an “*emotional roller coaster*”. Another father shared an example where the team was

talking about putting [his son] through a CT. And then the IV team came in 3 separate times and they were like, ‘All right. I guess we'll put the IV in.’ And then somebody would pop their head in and be like, ‘Oh. We're going to hold off on that for a little bit.’ And then they would go away for like 2 hours. And then come back. Like, ‘All right. Time to put the IV in.’ ‘Oh, we're going to hold off.’ And then they came back a third time. ‘Eh, doc said we don't have the CT anymore.’ I'm like, ‘Well, we were under the assumption that we were still getting the CT. So why...?’ I don't know...When they rounded in the morning [they] said, ‘OK. We're gonna do a CT today.’...[And] probably a little bit after lunchtime they came around and said, ‘Never mind. We don't need it.’

For this family it was difficult to understand how the plan changed within the span of a couple hours.

3.2.2.6.1.2 Pace

In other instances, it is not just the constant clinical changes but the frenetic pace that poses challenges for families. One parent observed that all the “[ICU providers] are all very busy.” Another mother agreed, saying “*when she first came down here...things were kind of crazy...[T]hings just happen fast [in the ICU]. They're hooking this up. They're doing that. And they're telling you a lot of what they're doing. But you don't know why they're doing it.*”

3.2.2.6.1.3 Uncertainty

Several participants commented on the challenge of the uncertainty in critical care medicine. One parent felt that “*what's hard is that a lot of times there's not like a great prognosis. Or trajectory of what's about to happen. So there's a little bit of a mismatch of information at times with that.*” Another mother reflected that the team

told [her] that [her daughter] had an infection but they didn't – wouldn't tell [her] what it was and what cause[d] it. And [she] never, never really got...a clear answer on that. And one of [the team members] said something about RSV. And then somebody else said something about E. coli...[So] it kind of made [her] mad at first that [she] didn't really know exactly what it was.

This participant went on to recognize that “*when they don't know exactly what's going on it's kind of hard for them to give you a straight answer, too.*” Another participant offered a reason for the difficulty in these situations, saying “*It's already like a very stressful situation and when there's so much uncertainty I think that's really hard.*”

3.2.2.6.2 Modifiable Challenges

Participants commented on many different stressors while they were in the ICU. One father noted that “[i]t’s never easy being in the hospital with a sick one.” Another father said “It’s very overwhelming when you walk in for the first time to the ICU.” Other parents agreed describing the experience as “scary” and “stressful.”

3.2.2.6.2.1 New Providers

Some specific elements were identified by multiple participants. Several parents noted the overwhelming number of new people families meet in the CICU. One parent said, “*You have all these people coming in. Your kid is very ill. And you have to figure out who are all these people?*” Another parent agreed, specifying “*I think it’s really difficult to navigate [the cardiac ICU] within the first, especially the first 2 weeks... We were like, ‘Who are all these people?’*” And upon reflecting on her initial impression, another mother said,

on day one when I came in here— I obviously came in a couple days after he was born— supportive care came up to me and was talking to me. And trying to... calm me down and talk through things with me. And I was just like, ‘Who is this person? why are you so close to me? why are you trying to calm me down?’ so, it’s just— yeah, it’s overwhelming.

3.2.2.6.2.2 Lack of knowledge

Lack of knowledge was another stressor multiple participants identified. One participant admitted, “*we’re not doctors. We don’t know what we’re doing.*” Another mother identified her lack of knowledge in the context of being a new parent, but noted that

almost everybody [in the CICU] asked if we were first time parents. Which we are. This is way out of our understanding and knowledge base. So lots of additional little tips/tricks/assistance. Understanding that we're going into this blind, so...[it was helpful] that they took that information and kind of adjusted their approach.

3.2.2.6.2.3 Family Pressures

Parents were also cognizant of emotional stressors they experienced in the context of their ICU stay, though these experiences manifested in different ways. One father noted that some of the visitor policies were particularly challenging, saying “*It was tough to hear [that my wife was not allowed to be here]...especially with what was going on with our daughter.*” Another family noted the additional emotional challenge of caring for a child in the hospital, saying that during previous admissions their daughter would “*beg to go home*” and noting that “*it's very hard to deal with a toddler that wants to go home constantly.*” In another situation a family relayed an experience where they felt dismissed, saying “*we were at his bedside trying to calm [him] down...[and the nurse] was a little rude...she said, 'If he's fussy and you guys are touching him and not calming him down then don't touch him anymore.'*” These situations are good illustrations of some of the emotionally challenging situations families encounter in the CICU.

3.2.2.6.2.4 Provider Schedules

Some modifiable stressors arose more due to policies and processes used to deliver care in the CICU. For example, families identified changes in service providers as a significant challenge in some instances. One father commented that “*the non-consensus between—whether it be the fellows and the attendings, or between the attending that's on during the day and the attending that's on during the night—[was his] only ongoing frustration.*” Another participant noted this

issue particularly with night cross-coverage, saying “we’ll have the daytime doctor create a plan. And then something happens overnight that throws the plan out the window.”

Participants clearly identified two reasons for difficulty with these provider changes. One family observed “there’s so much change with the fellows and everybody. But, there’s so many of them, too. And we just had no idea who they all were.” More importantly, caregivers were concerned that these provider changes were affecting clinical care. Another parent said

there have been like a couple of instances where report from shift to shift has been inaccurate when it comes to what the attendings hear versus what the nurses hear. So, we’ve had that a couple of times. Where the nurse will say, ‘Oh, he had a couple fussy moments overnight.’ But then we get to rounds. And in rounds it sounds like, ‘Oh, we had a horrible night. We had to do this, this, this, and this.’ ...[And] we [just] want to make sure that those two different stories aren’t affecting his care the next day....[And] make sure that we have what exactly happened overnight...[so that we know if we should not be] weaning down his Precedex, or whatever the situation may be.

Parents did note that often attendings were reasonable regarding the changes in plan. For instance, one parent observed

even if we have a new attending the next day and we say, ‘You know what, this is what we talked about. This is what our plan [was].’ Everyone’s like, ‘OK. Sounds good. ...they don’t really say, ‘Well, I don’t like that idea. We’re going to change it up.’ So, if we’re in on that discussion and we make an agreement with one attending, they don’t just come in and change it the next day.’

3.2.2.6.2.5 COVID-19

Families commented more on the effects of COVID on communication in the CICU than providers did. One family in particular described frustration that resulted from several communication failures related to COVID-19. In this situation both parents were exposed to COVID before the birth of their daughter. The father said,

We spoke to three different individuals on Saturday: a social worker, a fellow and a nurse. And all of them confirmed that they had spoken to infection control...[or] infection management, whomever you all use here, and had confirmed that both mom and I could be on site. We get a phone call Sunday, on our way here. Again, from a fellow. Stating that the information that we were told Saturday night was incorrect...even though she had been deemed cleared by our health Department...[the policy here was different and] I found it's nothing in writing. It's almost as though someone just came up with something that fit this situation for them. So, I felt like that communication was extremely poor: that we were told one thing and then told a complete 360 of what we were told on our way up here.

Dad went on to explain that this situation was difficult for them because

[i]t felt like some of the answers that we got were pretty arbitrary. Again, there was no policy and procedure that could be provided. We weren't following CDC guidelines. So, it was—I get we're working with a vulnerable population. But at the same time, we should have something in writing. That should be something we should be able to know ahead of time, look up, research.

This individual expressed surprise when informed by staff members that no official addendums had been added to policies in light of COVID-19.

This same family also described an issue with failure to communicate additional preoperative COVID testing due to uncertainty about whether or not an additional test would be needed. The team ended up sending another test but did not tell the family; reflecting upon this dad said, *“I can only imagine if we woulda came in Tuesday and they said, ‘We swabbed her Monday night and her swab was positive.’ We wouldn’t have been preparing ourselves for another COVID test at that point.”*

This family also reported that

The surgeon insinuated in our conversation after the surgery that her surgery was delayed due to COVID protocols. Through all of our conversations with the attendings that were working with us on a day-to-day basis that was NEVER brought up. That we could be delaying surgery because we’re worried about her possible exposure.

This family went on to say that *“COVID is not going away anytime soon”* and that they *“[didn’t] want this to happen to another family.”*

Other families commented on the difficulty posed by COVID restrictions, too. Some talked about the concerns about the physical layout of the space in the face of COVID while others talked about the difficulty of designated hospital visitors getting tested for COVID. One parent said *“with everything going on, we’re the only ones allowed in here right now. So, nobody else can ask any questions or anything from our families.”*

3.2.2.6.2.6 Other Comments

Notably, some issues identified by providers as significant challenges received only passing remarks from family members. One parent commented *“[There were n]o language*

barriers or anything like that.” Another parent noted that if they weren’t able to be there for report *“the nurse did a good job of taking the valuable information and disseminating that to us.”*

3.2.2.7 Changes/Improvements

The overwhelming sentiment of families who participated in this project was that *“[i]t was [a] really positive [experience being in the CICU].”* Participants commented that the *“nurses [were] phenomenal”* and *“go above and beyond their job,”* and that they *“miss[ed] the nurses down [in the CICU] when [they leave.]”* One participant felt that *“the intensivist team handle[d] things extremely well.”* One family reflected on their stay, admitting *“We’ve been in and out of the hospital for four years now. And this is the best experience we’ve had.”* This family went on to say that they were *“looking forward to coming back...[and that they would have no hesitation to] work with this team again.”*

Even participants who identified specific areas of concern or challenging situations were overall happy with their stay in the CICU. One family said, *“Even though we said a couple of communication things could be better by no means have we ever thought his care hasn’t been perfect. And if anything over the top.”* Another said, *“don’t change a lot. Because our care here has been unbelievable...I have to say we obviously expected the level of medical care. This hospital has a reputation.... But child life...and supportive care...and all these people that have come to help us are, ama—they’re just amazing resources.”*

While many participants communicated that they *“[didn’t] have anything that [they thought] need[ed to be] improved”* some families provided some specific ideas for ways to improve communication in the CICU.

3.2.2.7.1 Medical Team Introduction

One family indicated that there were “so many more people who came to see [them] than what was on the [white]board” and that they “had no idea who [the members on our team] all were.” This family went on to say that for families who “knew [they] were going to be in [this] situation...[it would be helpful to have] a list ahead of time.” Despite being familiar with the medical field they said

we don't know what supportive care is. We don't know what child life is. We don't know what the nurse practitioners or PAs in cardiology or the nurse practitioners in cardiology or in—PAs in intensive care, or...there's just all these people that a lot of them have the same titles, but they're different.

They indicated a desire to know about “*all the people that we're going to see. And...what their role is*” stating that “*that would have been very helpful.*”

3.2.2.7.2 Goals of Care

One mother indicated that she was overwhelmed by the discussion of all of the life saving measures and felt that “[*It might be more helpful and easier*] if they had something in writing that [*the family*] could look at [*for goals of care*]...and then ask questions, maybe.” She also recognized the importance of “[*it being*] in simple terms [*so that families*] could understand it.”

3.2.2.7.3 COVID-19 Policies

The family who experienced several communication errors related to COVID policies indicated a desire to make the situation better, stating that they “[*didn't*] want this thing...to happen to other families.” Several comments alluded to the desire to have more transparency

regarding policies. They commented that *“there was no policy and procedure that could be provided”* and *“that [it] would have been really nice to know [the policy] ahead of time.”*

3.2.2.7.4 Consistency of Communication

One family reflected on navigating uncertainty with families and said,

I would say if I were to give advice on how to handle it again, I would say don't speculate until the whole team has talked about it together. There's just not a lot to be gained by one doctor saying, 'Oh, I think it'll probably be next week' whenever they haven't discussed it with namely CT surgery.

They went on to recommend that the team tell the family *“Well, here's what we discussed on Wednesday. We'll discuss with the team again as a group [and come up with the plan]”* also saying they *“really didn't need to know anything until it was discussed with [the CT surgery team].”* This family did recognize that these uncertain situations can be extremely challenging for providers, noting that they themselves had contributed to their frustrations because they *“kept pushing [the team for answers].”*

3.2.2.7.5 Provider Agreement

Provider agreement was noted by many participants but one participant felt strongly that *“there needs to be a little bit of work done to try and align a little bit on the styles...from attending to attending.”* This was identified as the biggest *“ongoing frustration”* for this participant and seemed to augment the difficulty this family experienced due to constantly changing plans from the medical team.

3.2.2.7.6 Other Comments

Of note, all of the participants were happy to contribute to this project and seemed to have a favorable view of research in the CICU. One participant recommended that the ICU providers “*just try to push more studies so [they] can learn even more.*” .

4.0 Discussion

This project offers an incisive look into the views of both providers and families on communication within the CHP CICU. The small group of caregiver and provider participants (N=10 and 9 respectively) shared in-depth perceptions of a number of different aspects of communication in the CICU. Caregiver survey results were more forgiving than provider self-rated surveys, but both groups identified Understanding Families/Patients as an area for improvement. Also notable, providers perceived empathy as an area of strength, though this was not recognized as an area of strength by any of the participating families. Even though providing closure did not have statistically significantly different average scores it is notable that providers rated this area as one of the highest domains while families rated this area as one of the lowest domains. Collectively, these data suggest that provider perception of communication skills and strengths may not be accurate. This discrepancy may be in part that providers do not reflect on these skills often enough. Perhaps more consistent self-assessment of communication would help remedy the gaps noted here. Self-assessments are frequently used in medicine^{23,24} but some studies now question the validity of using these measures to evaluate the efficacy of communication.²⁵ Given these observations, providers may need to consider employing alternative evaluations to address these discrepancies.

Participant comments identified many different important aspects of communication in the CHP CICU; Overall, comments mapped to eight distinct areas including Setting goals/expectations, Interpersonal communication skills, Provider roles, Comprehension, Decision making, Challenges and Areas for improvement. Similar themes were identified by both providers and patients/caregivers, though often different perspectives were offered on these issues. These

categories are similar to those identified by Street *et al.*,¹⁴ though this article specifically explored communication pathways rather than evaluating communication within a specific unit. The difference in how themes were organized between these two evaluations is therefore unsurprising. There were two conspicuous differences in identified themes, however. Our data suggest an important role of specific communication tools/strategies and the significant impact of provider roles within communication in the CICU. Neither of these themes were explicitly addressed in the model crafted by Street *et al.*¹⁴ This analysis offers new insight into this established model and deepens the concept of what some of these categories mean in the context of cardiac critical care medicine.

4.1 Goals/Expectations

Managing expectations for families can be challenging. While some families expressed a reasonable desire to know the trajectory and anticipated clinical course for their loved one, providers also indicated that sometimes familial expectations were unreasonable. Families may fixate on things that they perceive they can control because so much that happens in the ICU is out of their control. Nevertheless, unrealistic expectations come sometimes impede patient care and drive a wedge between the family and medical team. Helping to manage and temper these expectations may result in a more positive experience for everyone involved. This is consistent with prior research which demonstrates improved communication is associated with improved patient satisfaction.²⁶ Of note, some provider participants commented on the ability to address these situations with clear, open, honest communication.

4.2 Interpersonal Communication Skills

The therapeutic alliance is significantly impacted by complex interpersonal interactions between providers and caregivers. The strength of a therapeutic alliance will always be variable depending on the specific provider and caregiver. Some elements like trust and honesty were identified as important by both providers and families. Providers commented on how rapport was specifically affected by the provider role; roles like bedside nursing, which allow for greater proximity to the patient/family, may allow for easier relationship building. This was observed by both nursing and physician CICU staff. Providers also identified length of stay and continuity as important variables. By contrast families highlighted the importance of provider accessibility, approachability, empathy, and open communication. The differences in the priorities for each of these groups may proffer an explanation of why sometimes building rapport can be difficult.

The approach different providers choose to take and personality idiosyncrasies can lead to vastly different experiences for patients/families. Both provider and caregiver participants identified provider agreement and consistency in communication as particular areas for improvement. Families were frustrated by changes to the plan that were perceived as arbitrary or related only to attending preference.

4.3 Provider Roles

Some participants struggled with the delineation of what their own role in the CICU entailed. In particular, there was a difference in perception about the role of fellows in communication in the CICU. Fellows themselves felt they did not always play a major role in

communication and reported a desire to have better guidelines about which team/team member was the primary communicator in different situations. Attendings, on the other hand, felt like fellows played a major role in communicating with families in the CICU. These results are consistent with a study evaluating communication challenges between pediatric hospitalists and primary care physicians, in which the authors concluded that these groups had little understanding of each other's roles with resultant impacts on communication between these parties.²⁷ The difference in perceptions about fellow role identified in this project is thought provoking and begs the question about whether these perspectives are shared by other members of these groups or whether they are views held only by the participants of this study. In any case, clearly defined roles could allow providers to function better individually in the CICU and maximize the impact of the collective team.

4.4 Communication Tools

The use of communication tools varied significantly from participant to participant. Providers reported significant variability in communication training, with some having virtually no formal training. Both groups identified repetition, circling back, including families in the conversation, and family reference materials as useful to help with communication. Providers also specifically commented on the utility of listening, non-verbal communication, questions, teaching, using the teach-back method, and using meetings/conferences. Novel joint rounding initiatives were identified as a possible contributor to the noted recent improvements in communication. Perhaps unsurprisingly, medical providers seemed to have a more studied approach to these conversations and could enumerate more strategies they would employ to help communicate in

different situations. Communication tools are felt to be effective and based on these data, are used frequently by providers and caregivers alike. Current research is being conducted to explore the benefit of providing resources like websites, brochures and posters to relatives of ICU patients.²⁸

Several suggested improvements from both providers and caregivers were new communication tools. Providers requested the implementation of a concerted and structured way to ensure that the medical team touches base with every patient/family every day. Families requested two specific family resources, too. Families were overwhelmed by the number of new people they met and had difficulty identifying what team people belonged to or what role they played. Families who are unable to identify their provider because of the inundation of new people and constantly switching coverage may feel more adrift and less in control in the ICU. They felt a medical team introduction sheet (see **Appendix D**) would be helpful and would allow them to familiarize themselves with the medical providers involved in their care. Alternatively, the videos that are used for prenatal diagnoses could be made available to all CICU families to help orient them to the unit. Another family reported feeling overwhelmed by being asked to make a goals of care decision without knowing what all the options were and not being able to picture what providers were describing. This family requested a goals of care reference sheet (see **Appendix E**) so they could read about goals of care issues at their own pace.

4.5 Comprehension

Based on the interview results, both families and providers felt like providers were usually (according to some participants at least 75% of the time) able to understand patients/families. This is interesting given the survey results collected from the same group of people. “Understand” is a

non-specific term that could refer to cognitive processing in some situations and acceptance in others – and perhaps the application of these different definitions leads to a different patient/family perception in the CICU.

Providers did identify several strategies to help patients/families understand, including paying particular attention to diction and avoiding use of medical jargon. Many providers also cited using non-verbal cues to help them know if patients and families were understanding. The utility of this latter strategy is tempered by the realization that some caregivers nod out of courtesy rather than understanding, meaning that this may be a less useful indicator of patient/caregiver comprehension in some situations.

Patients/families felt that they understood the medical team nearly all of the time. By contrast, providers felt that up to half the time families had difficulty understanding, for one reason or another. One provider suggested that a patient advocate system could help address concerns regarding patient/family comprehension. The proposed system would allow families who are admitted for a long time to develop a relationship with a continuity provider who could serve both as a sounding board for the family and a patient advocate.

As the field of critical care medicine moves forward and becomes more complex, the risk of families not understanding the plan of care will likely only become more pronounced. Because cardiac critical care is such complicated subject matter, it is not surprising that there are things that caregivers do not understand. One provider went as far as to question whether families need to understand some things. There is an argument to be made that there might be a hierarchy of knowledge or a demarcation between things that patients/families should understand and things they do not need to bother learning.

4.6 Decision Making

Numerous factors affect medical decision-making in medicine. Family preferences, emotions, provider agreement (both with the family and other providers) and provider schedules were identified by both provider and caregiver groups as decisive factors. Providers also noted the importance of the provider approach to decision making (autonomy versus paternalism), family financial constraints, patient safety, and the consistency of message in medical decision making. Families and providers do not always agree on decisions because they prioritize and value different things.

Disagreement between providers is also common, and was noted to sometimes be frustrating for families. This was noted for both disagreement between providers from the same team (as a result of cross coverage or on-service providers) as well as disagreement between different teams. One family recommended that providers not provide any speculation regarding plan. Instead, they recommended waiting until after the multidisciplinary surgical conference and then communicating the consensus decision.

This project suggests that when emotionally difficult decisions must be made, patients/families will require more time to process and understand before a decision can be made. Providers need to understand this and adjust their communication style in order to support families in this need. This is consistent with prior research, which demonstrates that the satisfaction of anxious parents is positively correlated with interpersonal sensitivity and provider support.²⁹

4.7 Challenges

Many challenges to communication in the CICU were identified. Both providers and patients commented on the challenge of critical illness, busyness of the unit/pace, uncertainty, provider schedules, family pressures, and COVID-19 with respect to communication. Of these, perhaps the most commonly discussed challenge by all comers was related to provider schedules. Changes in service providers, cross coverage and the fellow call schedule were all identified as specific challenges for participants. Several participants lobbied for changes in the service structure to try and minimize these issues, but recognized that the medical team would have to be involved in any attempts to restructure the schedule.

Providers also identified time, the response to acute decompensation, and the presence of families at bedside as challenges. Different providers had different perspectives on the best way to mitigate the challenge posed by families not being present at the bedside. Some advocated for structured efforts to ensure that everyone received at least a phone call daily. Regardless of how these situations are handled in a particular unit, providers will need to find other ways to effectively communicate with these families.

Families also commented on the challenges of the overwhelming number of providers and requested a medical team introduction reference (see Appendix D) to help manage the overwhelming feeling of being in the CICU. Families also felt that lack of knowledge could be challenging, though they often felt that with open communication and repetition this challenge could be overcome.

4.8 Changes/Improvements

While specific areas for improvement in communication were identified by both providers and caregivers, participants were generally optimistic about the CICU. Multiple parents indicated that they were pleased with the care and attention they had received. Providers, too, observed that the communication and culture of safety in the CHP CICU was laudable. It should be noted that this culture is maintained through the on-going commitment of all the CICU providers. If nurses are afraid to ask for clarification or explanation either because of the hierarchy in medical training or fear of being seen as unknowledgeable, then this culture of safety disappears.

Consistent communication and better agreement between providers was identified by both participant groups as areas for potential improvement. While agreement between providers was cited as an issue by several participants, it should be noted that the different styles/approaches used by different providers might result in different ways to explain the same thing and inadvertently contribute to the perception of disagreement. Providers also felt that better delineation of specific provider roles, alterations to provider schedules and development of mechanisms to better support patients/families could be helpful for communication in the CICU. Families requested some specific reference materials (Appendix D and Appendix E) and development of specific COVID-19 policies could enhance communication in the CICU. These are described in more detail in relevant sections above.

4.9 Strengths

Interview questions for this project were developed by induction of communication literature and were crafted as open-ended questions. The free response format of interviews and structured interview method allowed for adequate data to be collected to achieve salient thematic saturation.^{30,31} Rigorous qualitative methods were employed to evaluate the content from 19 interviews and identify thematic elements related to communication in the CICU. Additionally, the resulting analysis provides information from both provider and patient perspectives and allows for comparison between the two groups. Several actionable interventions were identified by participants and can be used to improve and enhance patient care in the CHP CICU.

4.10 Limitations

This project had several limitations as well. First and foremost, the limited sample size resulted in a homogeneous study population. Our findings may therefore not be generalizable to other cardiac critical care units or more diverse patient populations. This structured interview method offered no mechanism for internal validity redundancy or test-retest reliability. Another significant limitation of this study methodology was that caregiver participants were enrolled had to be present at the patient's bedside. The recorder used to capture interviews could not be used to conduct telephone interviews. This methodology could have led to sampling bias with the exclusion of families without a caregiver present at the bedside. Two families were not approached during the study period because a caregiver was not present at the bedside. Given that this was one communication barrier identified by providers, this bears consideration for future projects.

5.0 Conclusions

Providers are more stringent with self-assessment of their communication skills, but both providers and patients/families identified understanding patients as an area for improvement in communication in the CHP CICU.

Providers and patients/caregivers identified multiple domains that were important in communication, including Setting goals/expectations, Interpersonal communication skills, Provider roles, Comprehension, Decision making, Challenges and Areas for improvement.

Participants also identified several specific suggestions for improving communication including improvement in provider agreement, consistency of messages between providers, provider schedule changes, better delineation of provider roles in communicating with families and provision of some additional family reference materials.

Additional research is needed to expand the impact of this work to challenging situations like when families cannot be present at the bedside. Collection of additional perspectives from a more diverse patient population could offer additional insights as well. Further exploration of the specific areas noted by participants to be communication domains needing improvement (understanding patients/families, providing closure, empathy) could also be helpful. Ultimately, this information can be applied in the CHP CICU to improve communication between providers and families for all patients.

Appendix A Information Provided to Participants

Children's Hospital of Pittsburgh Cardiac Intensive Care Unit Communication study

Title of the Study: Community Needs Assessment of Communication in the Cardiac Intensive Care Unit

Project Coordinator Name(s): Stephanie La Count, MD and Ericka Fink, MD MS

The general purpose of this project is to examine how well providers and families are able to communicate with each other. Participants in this study will be asked to fill out a survey about communication and then answer questions about their experience with communication in the cardiac ICU. Findings from this study will be used to complete a needs assessment of communication within the cardiac intensive care unit, with the goal of helping improve communication.

I hereby give my consent to participate in this project. I acknowledge that I have been provided with:

- A. An explanation of the project's general purpose and procedure.
- B. Answers to any questions I have asked about the project procedure.

I understand that:

- A. My participation in this project will take approximately 45 minutes
- B. The probability and magnitude of harm/discomfort anticipated as a result of participating in this project are not greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
- C. There are no expected benefits associated with my participation.
- D. I will not be compensated for participating in this project.
- E. My participation is voluntary, and I may discontinue participation in the project at any time. My refusal to participate will not result in any penalty or disadvantage.
- F. My responses will be kept confidential, to the extent permitted by law. The data will be stored in a secure location on the hospital network with access limited to password protected computers, will be available to Dr. La Count and her collaborators. Aggregate data will be used to create a needs assessment report and will be presented to the cardiac ICU team without any personally identifiable information.

Children's Hospital of Pittsburgh Cardiac Intensive Care Unit Communication study

Title of the Study: Community Needs Assessment of Communication in the Cardiac Intensive Care Unit

Project Coordinator Name(s): Stephanie La Count, MD and Ericka Fink, MD MS

Thank you for participating in this project. We are conducting this project to examine communication within the cardiac intensive ICU. Past work has demonstrated that communication is an important part of caring for patients and their families. We hope to identify things we are doing well in the cardiac ICU as well as any areas where we can improve.

While participating in this project, you filled out a questionnaire about your experience with communication in the cardiac ICU. You also answered a series of questions about your experience communicating with different members of the team. The responses from all the people who participate in this project will be compiled to help identify things that we can do better. The findings will be communicated in a written report and reported to the cardiac ICU at the monthly Quality Assessment and Performance Improvement meeting.

Thank you again for participating

Appendix B Kalamazoo Essential Elements Communication Checklist (KEECC)²¹

Gag-Kalamazoo Communication Skills Assessment Form*					
Parent/Family Assessment:					
How well did you/your family member's clinician do at...					
	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
A. Builds a Relationship:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor was really interested in my family. The doctor's words showed that he/she cared for my child. The doctor seemed to care about our feeling and what we wanted. The doctor's body language showed that he/she cared for my child. 					
B. Opens the Discussion:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor let us finish things we had to say without interrupting. The doctor asked us about other things that might be worrying us. The doctor clearly explained why we were meeting. 					
C. Gathers Information:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor didn't try to force the conversation with his/her questions. The doctor asked us for more detail about things that we said. The doctor would occasionally repeat back what we had said as a summary. The doctor did not seem to interrupt us as he/she asked his/her own questions. 					
D. Understands the Patient's and Family's Perspective:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor asked about parts of our lives and personal histories that would affect health. The doctor showed interest in our personal beliefs and concerns. The doctor asked what we thought about the treatment and team being done. 					
E. Shares Information:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor asked what we understood about our child's illness. We understood the words the doctor used to describe our child's illness. The doctor would check to see if we had any questions after each explanation. The doctor gave us enough time to think about what he/she had said before moving on. 					
F. Reaches Agreement:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor included us in all the decisions that were being made. The doctor made sure that we understood what the next step would involve. The doctor asked what our feelings were about those plans before making any decisions. The doctor brought in outside help when we needed it. (Client Work, Partner) 					
G. Provides Closure:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<ul style="list-style-type: none"> The doctor made sure that we had no more questions before leaving. The doctor gave a summary at the end of what we had talked about. The doctor set a time to meet again. The doctor told us who to call if we had more questions. The doctor showed a real interest in our family as people as he/she ended the meeting. 					

H. Demonstrates Empathy:

- The doctor showed compassion for our family
- The doctor seemed to understand how we were feeling.
- The doctor responded to how we felt in a way that made sense to us.

1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I. Communicates Accurate Information:

- The doctor clearly explained our child's condition.
- The doctor clearly explained what our options were.
- The explanations our doctor gave were good enough for us to make important decisions.

1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What did this doctor do the best at? (Please pick three choices)

<input type="checkbox"/> Builds a Relationship
<input type="checkbox"/> Opens the Discussion
<input type="checkbox"/> Gathers Information
<input type="checkbox"/> Understands the Patient's and Family's Perspective
<input type="checkbox"/> Shares Information
<input type="checkbox"/> Reaches Agreement
<input type="checkbox"/> Provides Closure
<input type="checkbox"/> Demonstrates Empathy
<input type="checkbox"/> Communicates Accurate Information

Why did you choose those particular answers?

What could this doctor improve on? (Please pick three choices)

<input type="checkbox"/> Builds a Relationship
<input type="checkbox"/> Opens the Discussion
<input type="checkbox"/> Gathers Information
<input type="checkbox"/> Understands the Patient's and Family's Perspective
<input type="checkbox"/> Shares Information
<input type="checkbox"/> Reaches Agreement
<input type="checkbox"/> Provides Closure
<input type="checkbox"/> Demonstrates Empathy
<input type="checkbox"/> Communicates Accurate Information

What could they have done better?

*Adapted from: Essential Elements: The Communication Checklist, ©Boyer-Fetzer Group on Physician-Patient Communication in Medical Education, May 2001, and from: The Boyer-Fetzer Conference on Physician-Patient Communication in Medical Education, Elizabeth Fiske, MD, MD-Elizabeth, and from: The Kahnman Consensus Statement, *Academic Medicine* 2001; 76:390-393. Contacts: Ellen Eisen, MSW, MD-Elizabeth, elise@jhmi.harvard.edu (member, Kahnman Consensus Statement Group) and Aaron Calhoun, MD - aaron.calhoun@jhu.edu (PERCS Program).

Appendix Figure 1 Kalamazoo Communication Skills Assessment Form for Patients/Family Members

Kalamazoo Communication Skills Assessment Form*
Self Assessment

How well do you feel you did the following:

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
A. Build a Relationship (includes the following):					
<ul style="list-style-type: none"> Greet and show interest in the patient and patient's family Use words that show care and concern throughout the interview Use tone, pace, eye contact, and posture that show care and concern Respond empathically to patient and family statements about ideas and feelings 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Open the Discussion (includes the following):					
<ul style="list-style-type: none"> Allow patient and family to complete opening statement without interruption Ask "Is there anything else?" to elicit full set of concerns Explicate major statements as agenda for the visit 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. Gather Information (includes the following):					
<ul style="list-style-type: none"> Address patient and family statements using open-ended questions Clarify details as necessary with more specific or "you" questions Summarize and give family opportunity to correct or add information Transition effectively to additional questions 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D. Understands the Patient's and Family's Perspective (includes the following):					
<ul style="list-style-type: none"> Ask about life events, circumstances, other people that might affect health Elicit patient's and family's beliefs, concerns, and expectations about illness and treatment 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E. Share Information (includes the following):					
<ul style="list-style-type: none"> Assess patient's and family's understanding of problems and desire for more information Explicate using words that family can understand Ask if family has any questions 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F. Reach Agreement (If new/changed plan) (includes the following):					
<ul style="list-style-type: none"> Include family in choices and decisions to the extent they desire Check for mutual understanding of diagnostic and/or treatment plan Ask about acceptability of diagnostic and/or treatment plan Identify additional resources as appropriate 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G. Provide Closure (includes the following):					
<ul style="list-style-type: none"> Ask if patient and family have questions, concerns or other issues Summarize Clarify future time when progress will again be discussed Provide appropriate contact information if serious questions arise Acknowledge patient and family, and close interview 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
H. Demonstrate Empathy (includes the following):					
<ul style="list-style-type: none"> Clinician's demeanor is appropriate to the nature of the conversation Shows compassion and concern Identifies/validates patient's and family's emotional responses Responds appropriately to patient and family's emotional cues 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I. Communicate Accurate Information (includes the following):					
<ul style="list-style-type: none"> Accurately conveys the relative seriousness of patient's condition Took other participating clinician's input into account Clearly conveys expected disease course Clearly presents and explains options for future care Gives enough clear information to support decision making 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What did this clinician do the best at? (Please pick three choices)

- ☐ Build a Relationship
- ☐ Open the Discussion
- ☐ Gather Information
- ☐ Understand the Patient's and Family's Perspective
- ☐ Share Information
- ☐ Reach Agreement
- ☐ Provide Closure
- ☐ Demonstrate Empathy
- ☐ Communicate Accurate Information

Why did you choose these particular answers?

What could this clinician improve on? (Please pick three choices)

- ☐ Build a Relationship
- ☐ Open the Discussion
- ☐ Gather Information
- ☐ Understand the Patient's and Family's Perspective
- ☐ Share Information
- ☐ Reach Agreement
- ☐ Provide Closure
- ☐ Demonstrate Empathy
- ☐ Communicate Accurate Information

What could they have done better?

*Adapted from: Everett E. Everett, The Communication Checklist, UK: Royal Free Group on Physician-Patient Communication in Medical Education, May 2003, and from: The Bayne-Peterson Conference on Physician-Patient Communication in Medical Education, Everett's Elements of Communication in Medical Encounters, The Kalamazoo Consensus Statement, *Academic Medicine* 2003; 78:390-393. Comments: Elizabeth R. Fink, MD - elizabeth_r_fink@umich.edu (speaker, Kalamazoo Consensus Statement Group) and Aaron Colburn, MD - aaron.colburn@utoronto.ca (PERLOS Program)

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Appendix Figure 2 Kalamazoo Communication Skills Assessment Form for Providers

Appendix C Interview Questions

Patient Questionnaire

Informativeness (What is Communicated)

1. How often did the providers understand what you say/ask?
2. How often were your questions answered so that you can understand?
3. How did the team ensure your understanding?
4. What suggestions do you have for improving communication in the ICU?

Interpersonal Sensitivity (How it is Communicated)

1. How would you grade the ease of the doctor-patient/family conversation?
2. Give an example of when your team was empathetic. An example of when they weren't.
3. How did providers keep you informed about care your child was receiving?
4. What barriers have you experienced in communicating with the team?

Partnership Building (Thoughts/Feelings Evoked)

1. How did the team encourage open communication about treatment preferences?
2. Did clinicians ask you about your ideas/opinions when planning care?
3. How were decisions made collaboratively with you?
4. How did the team address your complaints/concerns?

Any additional thoughts about how the team has communicated with you during your time in the cardiac ICU?

Provider Questionnaire

Informativeness (What is Communicated)

1. How often did the patients/families understand what you say/ask?
2. How often do you know and understand daily patient goals?
3. How do you try to ensure that the patient/families understand you?
4. What suggestions do you have for improving communication in the ICU?

Interpersonal Sensitivity (How it is Communicated)

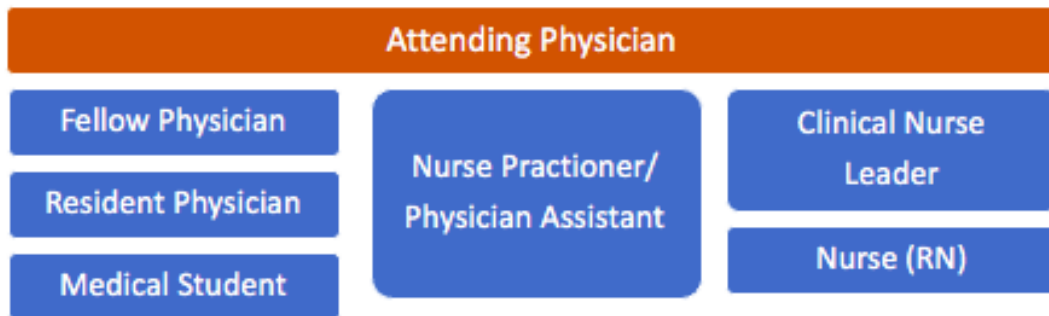
1. How would you grade the ease of the doctor-patient/family conversation?
2. What are the biggest barriers to communicating with families/patients?
3. What training have you had regarding communication?
4. What communication tools are helpful (daily goals sheet, whiteboard, CAP rounds, etc)?

Partnership Building (Thoughts/Feelings Evoked)

1. How do you encourage open communication from the family about treatment preferences?
2. Do you ask families about their ideas/opinions when planning care?
3. How are families encouraged to make decisions collaboratively with you?
4. How do you address complaints/concerns from family members?

Any additional thoughts about how the team communicates with patients/caregivers in the cardiac ICU?.

Appendix D Medical Team Introduction Sheet



An **Attending Physician (Attending)** is the supervisor of the team. He/She has completed their medical training including completing fellowship. Some cardiac intensive care unit (CICU) physicians have completed both cardiology and intensive care fellowships. The attending oversees everyone else on the team.

A **Fellow Physician (Fellow)** is a doctor who is doing extra training in a given specialty under the direction of an attending physician. In the CICU we have fellows who are completing Cardiac Critical Care, Pediatric Critical Care, and Cardiology fellowships. Some of these fellows may have already completed a different fellowship. Our fellows will help lead the team, coordinate care, evaluate patients, do procedures, write prescriptions and answer your questions.

A **Nurse Practitioner (NP)** is a nurse who completed extra training to help care for patients under the direction of an attending physician. Our NPs will help coordinate care, evaluate patients, do procedures, write prescriptions and answer your questions.

A **Physician's Assistant (PA)** is a mid-level provider who has completed their medical training to help care for patients under the direction of an attending physician. PAs may work with some of the specialty teams who will see you in the CICU. Our PAs will help coordinate care, evaluate patients, do procedures, write prescriptions and answer your questions.

A **Resident Physician (Resident)** is a doctor who is completing his/her specialty training. An **Intern** is in his/her first year of residency. During your time in the ICU you may meet residents from Pediatrics, Surgery, Anesthesia and/or Interventional Radiology. Residents help coordinate care, evaluate patients and write prescriptions.

A **Medical Student** is a physician in training. He/She has not finished medical school yet but is learning how to be a doctor. During your time in the ICU medical students may evaluate patients, ask you questions, and present patients on rounds.

A **Clinical Nurse Leader** is the charge nurse for the unit. He/She helps to coordinate nursing care and provide extra assistance for patients who require additional care. He/She can also answer any questions you have about unit policies or hospital policies.

Appendix Figure 3 Level of Training

Pictorial representation and description for different providers in the medical training hierarchy

Specific Teams/Groups You Might Work With During Your Admission

Cardiac Critical Care Medicine: The primary team managing all patients admitted to the cardiac intensive care unit. These providers help care for sick patients with heart and lung problems. They help coordinate care between different teams. They can also do procedures that might be needed including placement of central lines, arterial lines and breathing tubes (also called intubation). This team will round with you each day that you are in the CICU. There are always two people from the CICU team at the hospital in case of emergencies (usually an attending and a fellow).

Cardiology: This team specializes in care for the heart. They will help obtain ultrasounds of the heart (echocardiograms) and may help with other specialized procedures like heart catheterizations for your child, if necessary. They also help with long-term monitoring and follow-up for patients with heart problems.

Cardiothoracic Surgery (CT Surgery): This team specializes in surgeries for the heart and lungs. They will help to evaluate each patient and in concert with the ICU and cardiology teams determine the next best steps for patients based on their specific heart problem. This team will perform all surgeries and some bedside procedures for patients in the CICU.

Anesthesiology: This team specializes in keeping people comfortable and helps keep patients stable during surgeries and procedures. They can also do procedures that might be needed including placement of central lines, arterial lines and breathing tubes (also called intubation).

Supportive Care: This team specializes in making sure that any symptoms the patient is having are optimally controlled. They may help with pain control and sedation. They may also help figure out ways that we can support you and your child during the admission. They may help organize family meetings so that providers from different teams can sit down with you together to discuss what has been going on as well as next steps.

Nutrition: This team provides recommendations for the best way to make sure children are getting the nutrition they need. They provide recommendations both for children who are able to use their gut (special diets, tube feeds) as well as those who are not able to use their gut (TPN/lipids).

Our Therapy teams help to make sure that children admitted to the ICU are moving and rehabilitating as much as possible. **Physical Therapy** works with gross motor movements that are needed for standing, walking, and sitting. They also help with range of motion for joints. **Occupational Therapy** works with fine motor movements of the hands. **Speech Language Pathology** works on speech and feeding/swallowing. These teams may be involved to help get your child stronger or work on specific tasks.

Care Coordination: This team helps get things ready for you to leave the CICU. They help to coordinate home equipment and home nursing you may need, help to coordinate transfers back to long term care facilities and rehab units (which are sometimes needed before children can go home so they can get stronger).

Social Work: This team helps support our patients and families with issues they may be dealing with outside of medicine. Our social workers can help provide resources that may be available to help support you with any other problems you may be having.

Appendix Figure 4 Different Teams in the CICU

Description of different teams that patients admitted to the CICU might encounter in the CICU

Appendix E Goals of Care Sheet

Goals of Care Information

When patients are very sick your medical team may ask you about the goals of care. This question is appropriate for anyone who is sick enough to be in an intensive care unit. The purpose of this question is to make sure that in an emergency situation the medical team knows if there are any procedures or interventions that should not be attempted.

Specific Questions That Might be Asked:

1. If his/her breathing worsens to the point where he/she cannot breathe on his/her own then would you want us to put in a breathing tube to help her to breathe (this procedure is also known as intubation)?
2. If his/her heart stopped beating would you want us to try and do everything to try and restart it?
 - a. This often includes chest compressions (CPR), medications, and electrical shocks
 - b. Sometimes it includes a procedure called Extracorporeal Membrane Oxygenation (ECMO) – This is a procedure in which two big catheters are placed in the blood vessels and the patient's blood is pulled out and run through a heart/lung machine.

Please ask your team if you have specific questions about goals of care or any of the interventions mentioned above.

Appendix Figure 5 Goals of Care Information Sheet

Explanation of goals of care information for families.

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