Introduction

The following guide is meant to provide a brief overview of the film The Journey of Captain Nat, aid a designated facilitator in presenting the film to a group and assist that facilitator in leading a discussion surrounding the topics presented by the film.

Overview and Background

Effective communication is one of the most pressing challenges in healthcare and research arenas. Many factors affect communication. This guide focuses on four of those factors: culture; language; family experience; and provider/presenter biases. These dynamics affect all families as they interact with the medical system.

Culture: Many layers of culture exist, from an individual’s culture to an institution’s, even the notion of a generalized national culture. Culture can also be shaped by social context, such as economic status, education and setting (e.g., rural or urban). Usually, individuals assume that others who look and talk like them share the same culture when in fact they may not. A provider and family may share some aspects of culture and yet hold distinctly different cultural beliefs in relation to healthcare.

Language: Regardless of language ability, navigating a medical and hospital system can be difficult. Even when families and providers share the same native language, medical jargon often obscures meaning. It is critical to make information understandable to the family a provider is engaging.
Families with limited English proficiency (LEP) face similar challenges in the medical environment, but these are made even more complex by a language barrier. According to the 2000 Census, the number of individuals who speak a language other than English at home in the United States has doubled during the past two decades. It is important that those working in the medical field and research arena understand the challenges they will encounter when engaging LEP families.

Working with LEP families also requires the additional element of an interpreter and further assessment of what the family understands. Asking questions is strongly associated with a patient’s or decision-maker’s level of understanding of material presented in a patient-provider interaction (Simon et al). Unsurprisingly, LEP families tend to ask fewer questions further increasing the chance of miscommunication and misunderstanding. Medical staff and research team members have varying levels of experience communicating with LEP families, and institutions have different policies related to the participation of these families in research.

Family Experience: Each family is unique. Past experiences with medicine/research often cause people to form strong beliefs about what the next experience will hold. Everything from the decision-making schema in a particular family to the traffic a family encounters as they make their way to the hospital have the potential to affect communication.

Provider/Researcher Bias: Each of us sees the world through a different lens. Biases are often assumptions we harbor that can greatly inhibit communication and control how we receive information from others. Usually, biases result from firmly held beliefs. Much of controlling for biases is about being able to identify them, and to understand why such a strong belief has been created about an issue or topic.

Working well with all families requires an understanding of issues that accompany the goal of clear, accurate and empathetic communication. Although in the medical environment, LEP families have many of the same challenges as families who are proficient in English, the language barrier further complicates matters. The additional element of an interpreter and cultural differences also complicates communication and hence, exchange of information.

Running time: approximately 15 minutes

**Educational Goals**

- Recognize four aspects of communication (culture, language, family experience, biases) that are integral to improving provider/researcher and family interactions.

- Create an awareness of:
  - Issues when working with interpreters
  - Different policies related to LEP families’ participation in research

- Explore one’s own personal biases and comfort levels.
Film Synopsis

The Journey of Captain Nat asks the audience to take a broader and more holistic perspective when engaging all families and LEP families in particular. County Generic General Hospital provides the background to this mock-umentary that focuses on the experience of a family with limited English proficiency in a hospital setting. Nat is a swarthy, weathered sea captain whose only form of communication is Semaphore — a system for conveying information at a distance by means of visual signals with handheld flags. Nat seeks medical care for his young grandson, Jonah. A documentary film crew, intent on following one of the few remaining Semaphore-speaking sea captains, joins him and his grandson on their hospital journey. Seeing Captain Nat's point of view throughout the film, the audience witnesses the potentially overwhelming situations he, Jonah and his inexperienced Semaphore interpreter find themselves in. The film focuses on communication issues that are applicable to working with all families as they encounter the medical world.

Reading for Facilitator


Facilitating a Discussion

Facilitators should be familiar with the film and overview so that they can set the stage prior to having an audience watch the film. After reviewing the background information and educational goals, the audience should then watch the films. **Facilitators may want to highlight that the results of miscommunication can be tragic and this film in no way intends to make light of that fact. However, the goal of the film is to use humor in an obviously fictitious scenario to bring to light topics that deserve attention.** Suggestions for discussion are listed below.

Begin with a general discussion about the film and initial impressions from the audience. It may be helpful to write major themes on a whiteboard and allow the group to comment on what they have seen without much direction.

What were your first impressions?  
What stood out to you as you watched the film?  
What surprised you?  
What bothered you? Why?  
What seemed to work well when clinicians approached the family? Why?  
What issues did you see?  
In your opinion, what would have improved these interactions?

Main Discussion Topics
Following are four topic areas covered by the film, followed by questions to aid in discussing the topic. Beneath each question is relevant information the facilitator may want to ensure is included in the conversation with the audience.

**Topic 1: Families and the Hospital Environment**

“The on my ship I am respected. On land I often get treated like a child. I am not a child.”

~ Captain Nat

1a. What are areas that families could struggle with when entering a hospital environment?

**COMMUNICATION.** While the film scenario is meant to be lighthearted, it points to several key areas related to the interaction between families and medical/research teams. Areas where communication can go awry include culture, language, family experience and biases.
Each hospital has a distinct culture. Pieces of that culture may be shared by other medical institutions (positions of medical hierarchy, for example, such as residents, interns, fellows and attendings, or perhaps views of gender roles), but every hospital has its own culture shaped by its mission, administration, providers and policies. Once a family enters a particular hospital, they may be out of their element or area of expertise. Many families are unfamiliar with Western medical culture even if they are culturally similar to a provider in other aspects of their lives.

The film emphasizes a language barrier. However, even among providers and families that share the same language, cultural backgrounds and personal experiences inform individuals regarding the medical system. Some families are vocal and advocate for their children. Other families respect the authority of the medical team to such an extent that questioning is rarely considered. Still others have a profound mistrust of the medical system itself.

Providers also have personal experiences that create biases and assumptions regarding family choices and behaviors. Exploring and discovering how these biases may affect communication can prevent misunderstandings.

Questions to consider when meeting a family:
- What is the family’s perception of the provider? The hospital?
- What are their expectations?
- Does this family have any beliefs or practices that influence how they perceive or interact with medical care?
- Who makes medical/research decisions in the family? (A way to ask this question, “If we plan a conference to discuss your child’s/family member’s care, who would you like to be there from your family and community?”)
- How is the family’s communication style different from the team’s (teams’)?
- How does the family like to make decisions?

UNDERSTANDING. Family comprehension of a medical or research situation is a primary goal of the communication between provider/researchers and families. Clear presentation of clinical and research information is vital to ensuring family understanding and ultimately, informed decisions. Presenting information well involves solid knowledge of the content area, organization and the use of lay language.

Suggestions include:
- Presenting information that is clear, organized and easy to understand
- Using common terms and clear explanations while avoiding medical jargon and acronyms
- Providing written research information in the language of the family, including but not limited to, the consent and/or assent forms
- Using visual aids, which are often greatly appreciated and beneficial to encouraging understanding
- If research is involved, offering detailed explanations regarding differences between research and standard treatments, alternative options to research participation and treatments that are part of research studies.
- Assessing understanding while presenting information and actively soliciting and answering questions (see the example of the Teach-Back Method below).
- Repeating clinical and research information several times before decisions are made.
- Encouraging a neutral third party to be present during research conversations; this individual could ask questions, take notes and advocate for the family.

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**Teach-Back Method**

*Provider/research team member explains a concept related to the study.*

*Potential participant/family member demonstrates understanding of the concept.*

*Provider/research team member assesses understanding and asks potential participant/family member to demonstrate.*

*Provider/research team member clarifies and tailors the information.*

*Provider/research team member reassesses understanding and asks potential participant/family to demonstrate.*
PATIENT INVOLVEMENT. Families may have varying preferences regarding the sharing of medical information with the patient and other family members. This is especially true of families of different cultural and/or language backgrounds. Medical/research staff should ask the family’s preferences regarding the sharing of sensitive information (such as a diagnosis or treatment options), especially if the patient is a child.

Suggestions include:
- Not assuming a family’s preferences regarding the sharing of sensitive information with the patient or other family members
- Asking the family’s preferences regarding disclosure or discussion of information in the presence of a child
- Offering the option of discussing or presenting information privately, without children or other family members present

• Medical Authority
Different cultures and different individuals endow medical personnel with various levels of authority. Some families may feel as though the doctors are the experts and their recommendations need always be followed. This can be particularly tricky when the treating physician is also a research investigator presenting enrollment in a clinical trial as an option. When a provider assumes a dual role, they can inadvertently influence a family’s decision to participate in research. Because of this, the voluntary component of research and other healthcare options are even more important to explain, highlight and clarify.

Suggestions include:
- Assessing understanding particularly related to treatment and research participation decisions that need to be made
- Encouraging that a neutral third party be present during conversations; this individual could ask questions, take notes and advocate for the family
- Repeating research information several times before a decision about research participation is made
- Allowing a “waiting” period of days or weeks between presentation of a research option and asking for a family’s decision regarding participation solicitation to minimize any sense of obligation and to provide the family with time to discuss, consider and process the information presented
- Continuously emphasizing the voluntary nature of research participation, especially the freedom to withdraw at any time
- Strong reassurance that regardless of what decision is made about research participation, the patient will be given the best medical care possible
1b. In particular, what do LEP families struggle with in the hospital environment, and what are some suggestions for mediating those struggles?

The additional component of a language barrier to what may already be a cultural barrier has the potential to create significant discord and miscommunication. Many books have been written on this topic; however, few address not only cultural and language differences in the medical setting, but how the option of participating in medical research may further complicate matters. Each new factor adds a layer of complexity.

UNDERSTANDING and COMMUNICATION with LEP FAMILIES. Not surprisingly, many LEP families have difficulty understanding diagnoses and treatment plans. In addition, the presentation of research as an option increases the amount and complexity of the information provided.

Suggestions include:
- Providing written information in the family’s language regarding the diagnosis and treatment plans
- Ensuring high quality of interpretation when presenting information to LEP families
- Requiring staff training regarding the role of the interpreter and how to best work with one

INTERPRETERS. LEP families’ satisfaction with their hospital and research experience has much to do with their interactions with interpreter(s). Highly competent and professional interpreters who are aware of their role and responsibilities are needed.

Suggestions include:
- Providing adequate interpreter staff members who meet rigorous tests of competency and professional training
- Discouraging bilingual staff from presenting information to families without the aid of interpreters unless they themselves have been trained and certified as professional medical interpreters
- Instructing staff to avoid asking bilingual patients or family members to act as interpreters
- Training medical staff to assess participant/family understanding as an additional way of verifying interpreter competency
- Training medical staff on how to recognize when interpreter competency is affecting medical care and how to resolve the situation
Topic 2: Working with Interpreters

“It’s just that medical terminology is extremely difficult to semaphore. It’s extremely difficult.”

~ Stephen Whilloughsby, Interpreter

2a. What is the difference between interpreters and translators?

Very often, the words interpreter and translator are used interchangeably. However, the terms denote two very distinct roles.

- **Interpreter**: Mediates spoken or sign communication between two parties
- **Translator**: Converts written text from one language into a text in a second language

A difference also exists between a certified interpreter or translator and one who is not certified. A certified interpreter or translator has taken and passed a written and/or oral examination administered by a knowledgeable authority. When working with interpreters or translators, it is important to find out if they are certified, in what languages they are certified and who has provided the certification.

2b. What is the role of the interpreter?

A certified spoken or sign language interpreter is a trained professional bound by a code of ethics, which includes strict confidentiality. The interpreter’s function is to facilitate communication only, and he/she may not add, delete or modify information. An interpreter has an ethical and professional responsibility to interpret everything that is said. A provider/presenter should never ask an interpreter to refrain from interpreting a phrase or portion of a conversation.

The interpreter’s main function is to interpret spoken communication. Their role is not to read written materials and simultaneously translate them to a second language verbally. This practice is referred to as sight translations. If a medical or research team member wishes to present information written in a language in which the family is not proficient, the team member should read the document aloud allowing the interpreter to interpret as he/she speaks.

In an optimal interaction, the interpreter asks about the nature of the assignment and is able to review relevant terminology and written materials before the encounter. When interpreting, the interpreter always speaks in first person. The only exception to this is when he/she asks for clarification.

During an interpreting session, the interpreter manages the flow of communication. Both parties should speak slowly and use short phrases or sentences in order to allow for accurate
interpretation. If either party is speaking too quickly, the interpreter should indicate this (usually with a hand gesture) and request they slow down.

The interpreter also corrects interpretation errors and maintains transparency at all times. Transparency involves asking for explanations of unfamiliar terms or concepts. Throughout the interpreting process, the interpreter should not reveal personal feelings through his or her words, tone or body language.

What does the interpreter, Stephen, do well and what could he improve?

<table>
<thead>
<tr>
<th>Does Well</th>
<th>Needs Improvement</th>
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<tbody>
<tr>
<td>• He clarifies that he is an interpreter and not a translator.</td>
<td>• He fails to interpret the entire conversation.</td>
</tr>
<tr>
<td>• He provides instruction to the presenterprovider to improve the</td>
<td>The introduction should be interpreted.</td>
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<tr>
<td>interaction, such as indicating that the provider should speak</td>
<td>• He does not always use first person when interpreting.</td>
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<tr>
<td>directly to Captain Nat and in the first person.</td>
<td>• He states, “Excuse me, Captain Nat would like to talk with Dr. Peterson…”</td>
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<tr>
<td>• He is very comfortable asking for clarification regarding what the</td>
<td>Perhaps he is trying to be more polite with this phrasing, but he should give</td>
</tr>
<tr>
<td>first physician means and letting her know the pace should be slowed.</td>
<td>an accurate interpretation and should use first person.</td>
</tr>
<tr>
<td></td>
<td>• He does not interpret all communication and is not always transparent in his</td>
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<td></td>
<td>communication either for the family or the physician.</td>
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**Topic 3: Partnering with Families**

“Although it takes more time, it is very important that our families with limited English proficiency hear what our English-speaking families hear.”

~ Dr. Peterson

3a. What are the obligations of a provider/presenter when working with a family?

- **Generalizations**: Provider/presenters should always use caution when making generalizations about any family. Generalizations and labels, while seemingly helpful, can also obscure areas that are unique to the family. While colleagues may attempt to help one another by relaying messages like, “This is a difficult mom,” these labels can skew another provider’s view and make it difficult for the team to see important underlying issues.
Space: In order to facilitate optimal interaction, seating arrangements are important. Therefore, the space selected for the conversation, privacy and sufficient uninterrupted time should be considered.

Timing: It is necessary to plan ahead and schedule the appropriate amount of time and ensure the availability of a meeting place that can be available for the length of time required.

Seating arrangement: The provider/presenter is responsible for creating seating arrangements that allow easy communication between all parties.

3b. What are specific obligations when working with LEP families in particular?

Determining Whether to Use an Interpreter: Team members should be aware of their institution’s policies regarding the use of interpreters and the presentation of information to LEP families in clinical and research settings. Federal regulations regarding medical research require that “information that is given to the subject or the representative shall be in language understandable to the subject or the representative” (Title 45 CFR 46.116). Therefore, particularly in the research setting, if there is any doubt that a family understands information presented in English, the presenter should stop the conference and either seek an interpreter or reschedule the conference at a time when an interpreter can be present. If a family prefers not to have an interpreter and the presenter is concerned about their comprehension, it is wise to assess understanding early on in the encounter and throughout. Again if there is any doubt as to a family’s comprehension, an interpreter should be utilized. Provider/presenters should focus on their need for an interpreter to ensure adequate communication rather than questioning the family’s English-speaking ability.

Space: In order to facilitate optimal interpretation, seating arrangements are important. Therefore, the space selected for the conversation, privacy and sufficient uninterrupted time should be considered.

Timing: Using an interpreter to present information during a conference requires that provider/presenter allot more time, since the conversation will take at least twice as long as a conference held in a single language.

Working with an Interpreter (BEFORE the Conference): In an ideal situation, the provider/presenter provides any written information regarding the topic to be discussed (e.g., consent forms) to the family and the interpreter before the scheduled conference. Immediately before the start of the conference, the provider/presenter meets briefly with the interpreter to explain the goals of the conference, note any special circumstances that the interpreter needs to know about and address any of the interpreter’s questions.

Working with an Interpreter (INTRODUCTIONS): The presenter/provider formally introduces himself/herself to the family, and the interpreter does the same.

Seating Arrangement: The provider/presenter is responsible for creating seating arrangements that allow easy communication between all parties. Usually, this is a seating arrangement that places the interpreter sitting offside the parent/patient and allowing the provider/presenter to face the family (see diagram below).
• **Working with an Interpreter (DURING the conference):** The provider/presenter always speaks directly to the family using first person. For example, he/she says, “How can I help you?” not “Ask him/her how I can help him/her?” Maintaining eye contact with the family rather than with the interpreter is also important. The interpreter’s voice is treated as coming directly from the family. Often, families will focus on the interpreter; however, the provider/presenter should continue to maintain eye contact with the family even when the interpreter is speaking.

The presenter/provider speaks slowly using short phrases or sentences and pausing frequently. He/she allows the interpreter to control the length of each dialogue segment before moving to the next. Spoken language interpretation is NOT a simultaneous process. Neither the presenter/provider nor the family should be speaking at the same time as the interpreter. However, sign language interpreting may be done simultaneously.

The presenter/provider is aware that the length of time it takes to interpret a phrase may vary depending on the family’s language (referred to as the target language). Often, direct word-to-word translations from English to a target language do not exist. Thus, interpreters must often create “word pictures” using words available in the target language to explain English words or concepts. Creating the “word picture” often takes longer than articulating the English word or concept. The same is true in reverse — a word or concept that takes a great deal of time to articulate in one language may take a short time to render in another language.

When presenting information, the speaker avoids humor, as often humor does not translate well. Many jokes have cultural and linguistic components that render them ineffective and sometimes offensive in other languages.

• **Working with an Interpreter (ENDING the conference):** When the discussion is complete, the provider/presenter formally says goodbye and, if possible, briefly reviews the meeting with the interpreter to gain and give feedback in order to improve their skills.
3c. What does the first physician (Dr. Michaels) do well and what could she improve in her interaction with Captain Nat, Jonah and the interpreter?

<table>
<thead>
<tr>
<th>Does Well</th>
<th>Needs Improvement</th>
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<tbody>
<tr>
<td>• She enters and begins introductions.</td>
<td>• She speaks to the interpreter rather than directly to the family.</td>
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<tr>
<td>• She tries to engage with the family and maintain eye contact.</td>
<td>• She does not position herself and the interpreter as to enhance communication.</td>
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<tr>
<td></td>
<td>• She uses medical jargon.</td>
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<tr>
<td></td>
<td>• She interrupts Captain Nat.</td>
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<td></td>
<td>• She does not speak in short phrases.</td>
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<td></td>
<td>• She adjusts her volume with the subconscious assumption that if she talks louder the family might be able to understand.</td>
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<td></td>
<td>• She uses hand gestures that may not be culturally appropriate.</td>
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<td></td>
<td>• She announces she’s leaving and doesn’t wait until the interpreter finishes what she is saying before exiting.</td>
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</tbody>
</table>

3d. What does the second physician (Dr. Peterson) do well and what could he improve in his interaction with Captain Nat, Jonah and the interpreter?

<table>
<thead>
<tr>
<th>Does Well</th>
<th>Needs Improvement</th>
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<tbody>
<tr>
<td>• He engages the family and maintains excellent eye contact throughout conference.</td>
<td>• He does not formally end the encounter and leaves prior to interpretation being complete.</td>
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<tr>
<td>• His body position in the room allows him better access to Captain Nat and Jonah, as well as making it easier to maintain eye contact.</td>
<td></td>
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<tr>
<td>• He speaks in short phrases and pauses to allow the interpreter to keep up with the conversation.</td>
<td></td>
</tr>
<tr>
<td>• He uses lay terminology.</td>
<td></td>
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<tr>
<td>• He provides Captain Nat more opportunities to ask questions.</td>
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</table>
4a. What are the regulations surrounding the involvement of LEP families in research?

There are no federal regulations specific to LEP individuals or families and their involvement in medical research. Most institutions have policies and/or guidelines with regard to the approach and recruitment of LEP families. However, federal regulations require that “information that is given to the subject or the representative shall be in language understandable to the subject or the representative” (Title 45 CFR 46.116). Institutions must meet this requirement and often do so via their policies in a variety of ways.

4b. What are specific issues presenters should take into account, and what strategies can medical teams and research staff employ when working with families with LEP?

Before approaching an LEP family or potential participant regarding possible participation in research, presenters must ensure they are operating within the parameters set by the institutional review board-approved application and are complying with any applicable institutional policies. At times, policies regarding LEP participants are complex and require a high level of familiarity in order to ensure compliance.

It is important that LEP families hear the same information that English-speaking families hear. This may seem obvious, but as previously discussed, this requires additional personnel (i.e., the interpreter), resources (translation of research materials such as the consent and/or assent form), coordination and time. Occasionally, presenters unconsciously simplify research study information so that it will fit into the allotted timeframe for a conference with a family and presenter not proficient in the same language. As indicated, on average, twice the time allotted for a conference with an English-speaking family will be needed.

LEP families are faced with the same difficult issues that English-proficient families encounter. However, these issues are compounded by language and possible cultural barriers. Important areas to note when dealing with language barriers include voluntariness, asking questions and assessment of understanding. Due to their culture and their experiences in the medical realm, LEP families may find it difficult to understand that participation is indeed their choice and/or may be frustrated that the medical team does not make the decision for them. Cultures that place a high value on the advice of clinicians may require extra time and effort to set the stage for research and how it fits in the Western medical paradigm.
LEP families tend to ask fewer questions than their English-proficient counterparts. The number of questions a person asks may be a good indicator as to their level of understanding. It is important for presenters to engage LEP families and encourage questions and take the time to provide clear, complete and accurate answers.

To ensure that information that is given to the family and/or patient is in language that is understandable to them, it is critical for presenters to assess understanding. Assessing understanding can also give the presenter a sense of their own presentation skills and the interpreter’s competency. A presenter may encounter an interpreter who is less experienced or is simply a poor interpreter. The family may also give a presenter clues. They may not ask questions or appear to shut down if they feel the conduit of communication is ineffective. The presenter “owns the encounter” and is therefore responsible for how well it is carried out. It is always within the presenter’s purview to request a different interpreter and he or she should do so as soon as they realize communication is ineffective.

In the film, Dr. Peterson is explicit regarding the practical aspects of what participation will entail. The scientific facts are critical, but it is important that families are aware of how study participation will affect their daily lives. In the film scenario, Captain Nat would need to keep a daily journal if Jonah participates in the study, and this is not a responsibility he is willing to take on. Another interesting aspect of this exchange is the availability of study tools in the language of the participant. Research participation extends beyond enrollment. Therefore, research studies should provide study materials and tools in the language of the participant/family. Only then can researchers ensure that all participants can benefit fully from their participation.
Conclusion

Learning how to work well with families, regardless of their background or language, can be challenging. Provider/presenters are responsible for numerous factors, such as space, timing and seating arrangements when engaging with families. When working with LEP populations, further considerations include understanding the role of interpreters and working with them to facilitate optimal communication. It is important that LEP families hear what English-speaking families hear. Communication is a multifaceted process affected by a variety of factors, including culture, language, family experience and provider biases. There are many areas of potential struggle for families when they enter a hospital environment, and these struggles can be exacerbated by a language barrier. Hence, assessing understanding of patients, participants and decision-makers, as well as utilizing effective communication strategies, becomes crucial. Effective communication is critical to successful interactions between healthcare/research staff and families.

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