Supplementary Digital Content

Supplementary Digital Content 1: Phase 1 Interview guides

Family Member Interview Guide Preamble

Thank you for agreeing to participate in this interview. I am [NAME] and will be leading today's call. [NAME] is also on the call. We are part of the team working on this project together with Dr. Jonathan Elmer at the University of Pittsburgh and Dr. Robert Silbergleit at the University of Michigan. This work is paid for by SIREN, an Emergency Care Research Network.

The purpose of this research is to *better understand the experiences of family members and companions after a loved one's severe brain injury or cardiac arrest.* What we learn from you and others will help inform a workshop planned for this fall focusing on improving family member experience and engagement. We are interested in your experiences. Nothing you say will affect the ongoing care your loved one may be receiving.

Before we get started, I'd like to go over a few "housekeeping" guidelines.

- We hope you're comfortable sharing your thoughts and opinions, especially about this difficult experience. There are no right or wrong answers.
- I want to remind you that participation is completely *voluntary.* If you would like to stop at any time, please tell me and we will stop immediately. If there are any questions you do not want to answer, let me know and we can skip them.
- We will be recording today's call. Everything you say will be kept confidential and *not* linked to your name in any report. The recording will be destroyed after we finish the project. If at any time you do not want your comment to be recorded, please let me know and we will turn off the recorder.

Are there any questions before we get started? ***Answer any questions.***

Do you agree to participate in this interview, and do I have your permission to record our discussion? ***Obtain verbal agreement. Turn on recorder.***

Today is [DATE]. Now that the recorder is on, I will ask you again-- do you agree to participate in this interview today, and do I have your permission to record?

Introduction

Thanks again for talking with us today about [your loved one's event]. We understand discussing these experiences may be upsetting and really appreciate your willingness to talk with us.

We want to focus on your experiences early on, specifically in the first 48 hours after [patient's name] arrived to the hospital following [his/her] brain injury/cardiac arrest.

1. **Before we begin, I would like to make sure I understand more about your experience, starting from the beginning.** How did you first find out that something happened to [patient's name]?
    a. Where were you? Were you with anyone else?

Communication Needs

We'll now talk more about the information you received about [loved one] during this time, including conversations you may have had with doctors, nurses, social workers, and other hospital staff.

2. Can you tell me what it was like when you first arrived to the hospital?
    a. Who did you speak to or interact with? What was the nature of the conversation(s)? What did you learn? Where did this take place?
    b. How was this information communicated to you (e.g., written material, verbal communication, meeting, etc.; by doctor, nurse, social worker, etc.)?
    c. What did you think about the information you initially received about [patient's name] and the way it was communicated?
    d. Thinking about what you were told when you first arrived to the hospital, is there any other information that would have been helpful to receive?

3. One thing people in these situations have a hard time with is not knowing what will happen to their loved one. At any point in the first 48 hours, did the health care team tell you that they did not know how [loved one] would recover?
    a. Who shared this information with you? How was this uncertainty communicated to you? When and where? Did anyone else talk with you about the uncertainty of [loved one's] condition?
    b. What did you think about the way [that person] shared this information with you (e.g., communications style, approach)?
    c. During the conversations about the uncertain trajectory of [loved ones'] care or condition, did you feel the [providers] communicated this in a way to you that was easy to understand? Can you say more.
    d. When you had questions about the uncertain nature of [loved ones] care, did you know whom to ask? What sources, other than hospital staff, did you draw on for information during this time?

4. In thinking about the first 48 hours, what aspects of the communication were most important to you? Why?

5. Family and companions may be asked to make decisions about their loved one's care. Prior to this event, had you and [patient's name] discussed his/her wishes if something like this were to happen?
    a. Did the team ask for your input about decisions for [patient's name]? [*IF ANSWER IS NO:* Would you have liked to have been more involved in decisions regarding [patient's name] care? *IF YES*: Tell me more.]
    b. Can you say more about how they involved you in decisions for your loved one when there were options? When and where did this decision making take place (e.g., bedside, waiting room, by phone, etc.)? Who (else) was involved in these decisions?
    c. What helped you make decisions for your loved one?
    d. What did you think of the way [that person/team] discussed different options with you (e.g., communications style, approach)? How did you feel about the level of involvement you had in making decisions about [patient's name] care?

Emotional Needs

Now, we'll transition to discussing the emotions you experienced and the social-emotional support you may have received. Again, I would like you to think back from when you first found out something had happened until about 48 hours after [patient name] arrived to the hospital.

6. Can you tell me how/what you were feeling during this time period? How did you feel when you first found out about [patient name]? How did those feelings change over time?

7. How did you cope during this time?
    a. What, if anything, gave you comfort or reassurance during this early period?
    b. What types of emotional support did you receive?
        i. Who provided this emotional support? When, where, and how?
        ii. What did you think about the emotional support provided by the hospital?
    c. Did you feel that your needs for things like food, rest, and privacy were addressed? Can you say more about that? What support, if any, did hospital staff offer to address these things?
    d. Is there anything else that could have been helpful?

8. Did you ever feel that medical providers or hospital staff treated you differently because of your personal characteristics, like gender, age, religion, race or ethnicity? How so?

9. Based on your experience, how do you feel hospital staff and healthcare providers can best support family members during this difficult time?

Participation in Emergency Research/Clinical Trials

10. Now I would like to learn your thoughts about research study participation following a loved one's cardiac arrest/severe brain injury. Did the topic of [patient's name] being in a research study come up?

IF YES:

   a. How did it come up and how did you feel about it?
   b. Were you asked to make a decision about [patient's name] being in a study? What information was helpful to you to decide whether [patient's name] should participate in the research study or not?

   IF NO:

      a. One way that emergency research can happen is by asking next of kin for permission to enroll the patient in a research study. I know it might be difficult to imagine now, but how do you think you would have felt if you had been asked about having [patient name] participate in a research study?

11. Can you tell me more about what information would be important to help you decide whether your loved one should participate in a research study or not? When and how should that information be presented to you?

Closing

Thank you for participating in this discussion today. Before we close, is there anything else you would like to share?

We appreciate that you have taken the time to share your thoughts and personal experience. Should you have any questions about this project, you may contact Dr. Jonathan Elmer at [redacted]

Professional Interview Guide Preamble

Thank you for agreeing to participate in this interview. I am [NAME] and will be leading today's call. [NAME] is also on the call. We are part of the team working on this project together with Dr. Jonathan Elmer at the University of Pittsburgh and Dr. Robert Silbergleit at the University of Michigan. This work is supported by SIREN, an Emergency Care Research Network.

The purpose of this project is to *better understand the experiences of family members and companions after severe brain injury or cardiac arrest.* What we learn from you and others will help inform an NIH workshop planned for this fall.

Before we get started, I'd like to go over a few "housekeeping" guidelines.

- Your participation in this discussion is *voluntary* and you can end the interview or choose *not* to respond to a question at any time. Everything you say will be kept confidential and *not* linked to your name in any report.
- We will be recording today's call. The recording will be destroyed after we finish the project. If at any time you do not want your comment to be recorded, let me know and we will turn off the recorder.

Are there any questions before we get started? ***Answer any questions***

Do you agree to participate in this interview, and do I have your permission to record our discussion? ***Obtain verbal agreement. Turn on recorder.***

Today is [DATE]. Now that the recorder is on, I will ask you again-- do you agree to participate in this interview today, and do I have your permission to record?

Introduction

Thinking about family members' experiences in the first 48 hours after severe brain injury or cardiac arrest, our discussion will explore how you and others' address the communication and emotional needs of family members early in the clinical course during their time in the emergency department and the ICU.

We understand that you will be discussing these topics from your role as [role here], and will be drawing on your experience with many patients and family members over time. We recognize that some questions may not be relevant to your work, and those we can feel free to skip.

I'd like to start with getting a better understanding of how you interact with family members early on in the clinical course following a patients' cardiac arrest or severe brain injury?

Communication Needs

The next questions focus on your approach to communicating with families during the first 48 hours after the patient's arrival to the hospital.

1. What is your typical approach to communicating with families when you first talk with them?
    a. When and where does this take place?
    b. What influences your approach? How do family members' preferences have an influence?
    c. How can you tell if your approach is effective?
    d. What other approaches do you observe [variations]?

2. What about any other times [during the first 48 hours after the patient's arrival] you speak with the family (e.g., communicating updates about the patient's condition, care, treatment)? How does your approach differ at these times, if at all?
    a. In general, how well do you feel family members' communication or information needs are met during this time?

3. I know that prognosis or the anticipated clinical course early after severe brain injury or cardiac arrest is often uncertain. In your experience interacting with families in the first 48 hours following the patient's hospital arrival, how does talking about the uncertainty of the patient's clinical course come up?
    a. When and where is this brought up? By whom? What is your typical approach for communicating uncertainty about the patient's clinical course with families?
    b. What variations do you see? What seems to work? What doesn't seem to work?
    c. What are the challenges? What helps?

4. How do potential long-term implications [prognosis] for the patient come up?
    a. When and where is this brought up? By whom? What is your typical approach for communicating potential long-term implications?
    b. What variations do you see? What seems to work? What doesn't seem to work?
    c. What are the challenges? What helps?

5. Family members seem to fall on a spectrum between wanting to be part of all the decisions and leaving the decision to the doctor. What has been your experience/what have you observed with families wanting to be involved versus leaving decisions with the doctor?

6. Likewise, clinical providers seem to fall on a spectrum between involving the family in most decisions and excluding the family from any decision making by telling them what to do. What is your typical approach/what have you observed with providers involving family members in decisions early in the clinical course?
    a. When and where does this take place? Who is involved?

   b. What variations do you see? What seems to work? What doesn't seem to work?

7. [PHYSICIAN ONLY] When there are different treatment options, how do you handle situations when family members express a preference for an option that differs from your own?
   a. Under what circumstances do you find it most challenging to go along with family preferences, and how do you handle it?

Emotional Needs

Now we are going to focus on the emotional needs of family members during this critical period and how they are addressed.

8. What do you feel are common emotional needs of family members during this time?

9. How are family members' emotional needs typically addressed?
   a. When, where, by whom?
   a. In general, how well do you feel family members' emotional needs are met during this time?
   b. How, if at all, is this influenced by family members' characteristics such as race or ethnicity, age, gender, etc.?
   c. In what way do you feel your own personal identity (e.g., age, gender, cultural affiliation, and minority status) influences your experience with families? Can you share (other) examples where it did?

10. From your perspective, how could the emotional needs of family members during this time period be better identified and addressed?

Participation in Emergency Research Clinical Trials

Now we will briefly cover your experience and views on patient participation in emergency research studies.

11. Can you tell me briefly about your experience with emergency research enrollment [*INTERVIEWER NOTE*: Can probe on "observations". If No experience, go to Demographics]

    a. From your experience, what are families' reactions to the enrollment of their family members (the patients) into a clinical trial?

Demographics

As we wrap up, I have a few questions about you and your background.

12. How many years have you been in your profession?

13. Which gender do you identify with?

14. Are you of Hispanic or Latino origin or descent?

15. What is your race? [INTERVIEWER NOTE: PROBE AS NEEDED USING LIST BELOW]
   - ☐ White
   - ☐ Black or African American
   - ☐ Asian
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ American Indian or Alaska Native
   - ☐ Other

Closing

Thank you for participating. Before we close, do you have any other comments or additional information that you would like to share about *the experiences of family members and companions after severe brain injury or cardiac arrest*?

[INTERVIEWER NOTE: Turn recorder off. Follow-up on family member referrals]

We appreciate that you have taken the time to share your thoughts and personal experience. Should you have any questions about this project, you may contact Dr. Jonathan Elmer at [redacted]

Supplementary Digital Content 2: Workshop Agenda

Family Experience after Cardiac Arrest and Severe Neurotrauma
Virtual Workshop
November 19, 2020, 10:00 am – 4:00 pm ET

AGENDA

I. **Welcome & Objectives (10:00 – 10:15 am ET)**

II. **Housekeeping & Introductions (10:15 – 10:30 am ET)**

III. **Overview of the Field & Findings from Qualitative Interviews (10:30 – 12:05 pm ET)**
   a. **Presentation 1**: Family Involvement in the Early Phase of Cardiac Arrest and Traumatic Brain Injury (TBI)
   b. **Presentation 2:** Preliminary Interviews: A Single Hospital's Experience
   c. **Q&A**
   d. **Reflection Session:** Participant reflections on interview findings

IV. **Breakout Session #1 (12:05 – 1:05 pm ET)**
Topics: Family needs in the first 48 hours; provider training and care team approach

V. **Break (1:05 – 1:40 pm ET)**

VI. **Breakout Session #2 (1:40 – 2:45 pm ET)**
Topics: Uncertainty and information processing

VII. **Break (2:45 – 3:00 pm ET)**

VIII. **Takeaways & Closing (3:00 – 4:00 pm ET)**
   a. **Synthesis/Key Themes**
   b. **Prioritization Activity**
   c. **Next Steps**

Supplementary Digital Content 3: Workshop Discussion Guides

SIREN Subproject #3
Reflection Sessions Guide – Family Member Groups
11/19/2020

Reflection Session Preamble – 5 min

Hi everyone and welcome to the Reflection Session of our workshop. As Jonathan previously mentioned, we're in this breakout room to discuss our reflections on the interview findings. I am [facilitator name], and I will be starting today's discussion, but most of the conversation will come from you all, as we'd like to learn more about your thoughts about the interview findings.

All of you participating in this discussion are family members of a loved one who suffered from a cardiac arrest or traumatic brain injury. There are several others in the breakout room who are either members of the SIREN team or from NIH. They are only observing and will not participate in the discussion.

Jonathan mentioned that one of the limitations of the findings is that the interviews were conducted with care team members that service one hospital in Pittsburgh, PA. These providers then referred family members that had a loved one admitted to this hospital. We'd like to take the time during this session to understand if our findings also resonate with those that are not affiliated with this hospital, or if we are missing any information.

It's important to express yourself openly during our discussion today. There are no right or wrong answers. We simply want to know what you think. I would like everyone to be a part of this conversation. You do not need to wait for me to call on you to talk, but only one person should speak at a time. Also, we ask you to keep what we discuss today within this group and not share what we discussed with others who did not participate in the workshop. This is to make everyone feel comfortable sharing their honest opinions with the group.

As we stated earlier, we are recording the workshop, including this reflection session. What you say will not be linked to your name in any of our reports, and the recording will be destroyed after we have analyzed the discussions.

Lastly, before we begin, I want to note that if you anticipate leaving the session for more than 20 minutes, please send a chat to [backup.] We just want to make sure that we haven't lost or overlooked anyone during the session.

Do you have any questions about what I've said so far? [*Answer any questions.]*

Practice Padlet – 5 min

For this session, we will use Padlet, which is a website that allows several people to collaborate and share ideas in real time. We'll post some initial ideas of our feedback on the interview findings and then discuss further. First, let's walk through a practice Padlet so that we can understand how to use it.

I'm adding a link to Padlet in the breakout room chat. Please click on that link, which will take you to the Padlet website.

Once you are in Padlet, you'll see that there is a question on the top of the page. *[Read the practice Padlet question]* Click on the plus sign to add in your response. Everything is reported anonymously. You can also vote if you agree or disagree on someone's response, and

comment on it as well. *[Allow a few minutes to play around with the features, demonstrate some features, and respond to any questions.]*
Great. Now that we have the hang of Padlet, let's review the findings that Jonathan presented and then hear your thoughts about these findings.

Information Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the need for clear expectations for the progression of illness/injury.
- Family members emphasized the need for logistical information to navigate the hospital environment.
- **From your perspective, what other information would have been helpful to receive during the first 48 hours after your loved one was admitted to the hospital?**

I'm now adding a link to another Padlet in the chat. Please click on that link, which will take you to the Padlet website. Here, you can add your response for additional information under the "Information Needs" column. Click on the plus sign under that column to add in your responses. We're just focusing on information needs at this time.
Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Communication Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the need for effective communication strategies when conveying health information about the loved one.
- Family members emphasized the need for the care team to assist with information processing:
    - Need direct, understandable information
    - Repetition can assist understanding
    - Opportunity to ask questions
    - Receive contact information for care team
- The care team spoke about specific strategies used to assist with information processing:
    - Note taking
    - Use of tools like Google
    - Translation
- **From your perspective, what communication needs are missing from this list?**

Please click on the link to Padlet again, where you can add your response under the "communication needs" column.
Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Emotional Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the importance of:
    - Displaying compassion in all interactions
    - Encouraging support from other family and friends

    - Utilizing social/religious support services
    - Engaging in self-care activities (e.g., sleep, eating, walking, etc.)
    - Being with the loved one as much as possible
- Family members expressed the need to:
    - Personally help their loved one (e.g., internet searches, journaling, praying)
    - Receive continued support (after ICU transfer, after death or hospital discharge)
- The care team emphasized the need to address uncertainty in clinical course and outcomes:
    - How to convey; how much to convey
    - Balancing communication of uncertainty with clarity
    - Emotional toll on overwhelmed families
    - Need for time to observe course of illness
    - Effect on shared decision-making
    - Consistency of messaging across teams
    - Perils of using statistics
- **From your perspective, what emotional needs are missing from this list?**

Please click on the link to Padlet again, where you can add your response under the "emotional needs" column.
Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Sociocultural Needs – 10 min

[Present Slide by sharing screen and review bullets]
Now we'll talk about sociocultural needs, or the needs you may have based on you and your family's background including but not limited to your culture, race and ethnicity, religious beliefs, geographic location, and family structure.

- Both family members and care team participants emphasized the need for equitable treatment and socioculturally appropriate communication
- **From your perspective, what other needs based on you and your family's background, are missing?**

If participants don't respond to the above questions, ask: What does equitable treatment and socioculturally appropriate communication mean to you?
Please click on the link to Padlet again, where you can add your response under the "Sociocultural Needs" column.
Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Other Needs – 5 min

[Present Slide by sharing screen and review bullets]

- Thinking about the first 48 hours after your loved one arrived to the hospital, are there any other needs that we haven't already addressed in the interview findings or in this reflection session?

Please click on the link to Padlet again, where you can add your response under the "Other Needs" column.
Discuss common responses, clarify differing responses, and generate discussion

Closing – 5 min

Thanks so much for all of your feedback! Your comments are extremely helpful for us to understand FMs' needs in various types of settings. Do you have any last minute comments to add?
If you have time, summarize main points and reflect back to the group for confirmation.
Now, we'll go back to the main meeting room in a few moments. When you see the prompt that we'll return to the main room in a few seconds, please don't click on it yet, as it will take you immediately to the room.

SIREN Subproject #3
Reflection Sessions Guide – <u>Care Team Groups</u>
11/19/2020

Reflection Session Preamble – 5 min

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All of you participating in this discussion are members of a care team that see patients with cardiac arrest or traumatic brain injury in the ED or ICU. There are several others in the breakout room who are either members of the SIREN team or from NIH. They are only observing and will not participate in the discussion.
Jonathan mentioned that one of the limitations of the findings is that the interviews were conducted with care team members that service one hospital in Pittsburgh, PA. These providers then referred family members that had a loved one admitted to this hospital. We'd like to take the time during this session to understand if our findings also resonate with those that are not affiliated with this hospital, or if we are missing any information.
It's important to express yourself openly during our discussion today. There are no right or wrong answers. We simply want to know what you think. I would like everyone to be a part of this conversation. You do not need to wait for me to call on you to talk, but only one person should speak at a time. Also, we ask you keep what we discuss today within this group and not share what we discussed with others who did not participate in the workshop. This is to make everyone feel comfortable sharing their honest opinions with the group.
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Great. Now that we have the hang of Padlet, let's review the findings that Jonathan presented and then hear your thoughts about these findings.

Information Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the need for clear expectations for the progression of illness/injury.
- Family members emphasized the need for logistical information to navigate the hospital environment.
- **From your perspective, what other information is important to provide to family members in the first 48 hours after their loved one has been admitted to the hospital?**

I'm now adding a link to another Padlet in the chat. Please click on that link, which will take you to the Padlet website. Here, you can add your response for additional information under the "Information Needs" column. Click on the plus sign under that column to add in your responses. We're just focusing on information needs at this time.

Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Communication Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the need for effective communication strategies when conveying health information about the loved one.
- Family members emphasized the need for the care team to assist with information processing:
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  - Opportunity to ask questions
  - Receive contact information for care team

- The care team spoke about specific strategies used to assist with information processing:
    - Note taking
    - Use of tools like Google
    - Translation
- **From your perspective, what communication strategies are missing from this list?**

Please click on the link to Padlet again, where you can add your response under the "communication needs" column.

Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Emotional Needs – 10 min

[Present slide by sharing screen and review bullets]

- Both family members and care team participants expressed the importance of:
    - Displaying compassion in all interactions
    - Encouraging support from other family and friends
    - Utilizing social/religious support services
    - Engaging in self-care activities (e.g., sleep, eating, walking, etc.)
    - Being with the loved one as much as possible
- Family members expressed the need to:
    - Personally help their loved one (e.g., internet searches, journaling, praying)
    - Receive continued support (after ICU transfer, after death or hospital discharge)
- The care team emphasized the need to address uncertainty in clinical course and outcomes:
    - How to convey; how much to convey
    - Balancing communication of uncertainty with clarity
    - Emotional toll on overwhelmed families
    - Need for time to observe course of illness
    - Effect on shared decision-making
    - Consistency of messaging across teams
    - Perils of using statistics
- **From your perspective, what additional strategies are used to address emotional needs?**

Please click on the link to Padlet again, where you can add your response under the "emotional needs" column.

Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Sociocultural Needs – 10 min

[Present Slide by sharing screen and review bullets]

Now we'll talk about sociocultural needs, or the needs family members may have based on their background including but not limited to their culture, race and ethnicity, religious beliefs, geographic location, and family structure.

- Both family members and care team participants emphasized the need for equitable treatment and socioculturally appropriate communication

- **From your perspective, what strategies are used to address the needs families may have based on their background?**

If participants don't respond to the above questions, ask: What does equitable treatment and socioculturally appropriate communication mean to you?

Please click on the link to Padlet again, where you can add your response under the "Sociocultural Needs" column.
Discuss common responses, clarify differing responses, ask if the findings resonated, and generate discussion

Other Needs – 5 min

[Present Slide by sharing screen and review bullets]

- Thinking about the first 48 hours, are there any other family needs or strategies that we haven't addressed in the interview findings or in this reflections session?

Please click on the link to Padlet again, where you can add your response under the "Other Needs" column.
Discuss common responses, clarify differing responses, and generate discussion

Closing – 5 min

Thanks so much for all of your feedback! Your comments are extremely helpful for us to understand FMs' needs in various types of settings. Do you have any last minute comments to add?
If you have time, summarize main points and reflect back to the group for confirmation.
Now, we'll go back to the main meeting room in a few moments. When you see the prompt that we'll return to the main room in a few seconds, please don't click on it yet, as it will take you immediately to the room.

Supplementary Digital Content 4: Representative quotes by analysis domain

Domain	**Representative participant quotes**
Information	● *"I do remember feeling like frustrated or a little just – like the fear of the unknown. Like first they were talking about like on day one they were talking about like being in a coma, and like nobody ever said to me like your [loved one is] in a coma or – I mean, I could see that she wasn't awake, but I don't know, just to hear those words was hard, and then the next day they're talking about a TBI. … but like nobody ever said to me she has a traumatic brain injury. And I'll tell you, that hit me the hardest."* (family member [FM], interview) ● *"I think things should be forthright and the person like me who is waiting for this stuff, especially if they have a major test like that, a CT scan, MRI, when you have those kinds of things, you should be informed on what's going on with them."* (FM, Phase 1) ● *"So much scary info online, so need to direct us to trustworthy sites/sources vs. looking up info on our own..."* (FM, Phase 2 – Padlet). ● *"I don't think everyone does it well, but I can tell you what we try to teach and preach, which is just – In a way embracing uncertainty… So it can be uncomfortable. But I think we do a disservice to our patients when we don't acknowledge uncertainty."* (Professional, Phase 2)
Communication Needs	● *"They'd answer and explain things in, you know, terminology that we could all understand, and never made us feel rushed. We could ask whatever questions we wanted. They gave us their business cards. So, I think they were a source of comfort and you know, just trying to answer our questions and reassure us about things."* (FM, Phase 1) ● *We did not have a social worker greet us. We did not have a single point of contact…never met the neurologist, and I hope I don't offend anybody by saying this, but I felt like they were on two different planets, the cardiologist and the neurologist.* (FM, Phase 2) ● *"One of the principal problems in all of this is that modern medicine is shift work, and so you don't have the same provider from start to finish. And that's true at the nursing level, just as much as that is true at the physician level with very rare exceptions. And that becomes a problem."* (Professional, Phase 2)

Emotional Needs	- *"Just the thought of not knowing, and not know if he's dying, is he going to be okay. You know, I didn't know. So, I just prayed about it, and I didn't know what else to do."* (FM, Phase 1) - *"But I think I'd be disingenuous if I said we just have absolutely no idea, because that's not really discussing and preparing the family for the situation in which – what you're facing...having done this for a very long time, I'm coming from a place where I've been disappointed at the level of certainty that physicians have had when they're wrong over time. And that's been the biggest concern that I've seen over my 25-year career as a neuro intensivist, is that physicians have overestimated their ability to precisely prognosticate poor outcomes early after injury."* (Professional, Phase 2)
Sociocultural Needs	- *"And when I tell you I was treated so nasty, and when I tell you that my son was treated so nasty, (cries) and when I tell you I tried to stay respectful, I didn't say anything out of line to nobody and I just let it pass. And I'm not the one to let nothing pass when somebody's being disrespectful. And you know, I'm glad I'm here to tell my side of the story. I don't know if it's my background, I don't know what it is, but like I said, I have a bunch of professional kids in my family – when we came in there, we were quiet, we kept everything clean. I had to ask for mop buckets for my son's room. I had to ask for – for a sheet, because we had to wash my son up. We had to wipe his butt. We had to suction out his neck and clean his nose out. When I tell you that I was disrespected on every level, I'm honest. I was. But that's okay, though. That's okay. We prevailed.* (FM, Phase 2) - *"Thank you, guys, so much, was so glad to share that, never got to share. kind of suppressed it, was glad to let out because I know there's others that will no doubt go thru"* (FM, Phase 2– Chat). - *"[It is] important [for healthcare professionals] to establish relationships and understand patient values"* (Professional, Phase 2– Padlet).
Physical Needs	- *"I was met at the door by a clergyman who took me into a little room which kind of scared me, because I knew that that meant things were really bad, but it was a space that I could just be isolated from other places. And he stayed with me the whole time. And then there's a whole compassionate care team at the hospital, and the first thing they did (laughs) was give me this blanket that was knitted by Women In Prayer, which I cherish, and I've taken to the hospital any time [name] had to go back."* (FM, Phase 2) - *"So I do think that people get very lost in hospitals. [They] can be very confused about where they're going to go, and unfortunately while providers, physicians, nurses are prioritizing the patient's health, families are often literally lost, and don't know what to do."* (Professional, Phase 2)

Supplementary Digital Content 5: Family Members' Information Needs by Level of Influence

Footnotes: Main themes from interviews and the workshop are presented by level of influence and are in bold text. Subthemes are indicated with bullet points under the main theme. Themes that were endorsed from interviews and/or the workshop are indicated with a checkmark in the designated column in the tables. Gray highlights indicate additional nuances to these themes which emerged from the workshop. Abbreviations: LO, Family member's loved one; FM, Family member; ED, emergency department; ICU, intensive care unit.

Information Needs - Levels of Influence		
Family Members' Needs	**Interviews**	**Workshop**
Expectations for Cardiac Arrest/TBI Progression - Understand the injuries, condition, when the LO will awake, what to expect/treatment plans - Honest appraisals, including impact on quality of life and best and worst case scenarios - To be prepared for LO's physical and mental changes - Understand the nature of the trajectory of illness/injury from a holistic perspective, particularly the realities of non-survival and impact on quality of life - Provide range of expectations to the FMs as early as possible so that they are able to prepare for the eventual outcome	✓	✓
LO's Care and Status - Understand symptoms that could occur/signs to watch for and what to do - Understand the "why" regarding clinical events and progression - To hear results of all tests, changes in health status, as soon as possible - Understand procedures and medical devices - Receive debriefing of LO's condition upon arriving to hospital - Include in daily meetings/rounds, in person or virtual	✓	✓
Information to Navigate Hospital and Support Self-Care Needs - Information on where to go/what to expect when arriving to the hospital, parking, food, place to stay	✓	✓
Informed Decision-making - Clear, direct information from providers - Understand options, including life supporting treatments, testing, devices and new or experimental therapies - Information tailored to the LO's lifestyle, condition, age, etc. - Access to information/second opinions/confirmation from outside sources, including trustworthy web links	✓	✓

Information Needs - Levels of Influence		
Trusted Medical Opinions - Access to a medical resource (e.g., family in the medical field, support groups) to help FMs understand health information, questions to ask, and to inform decision-making - Personal connection/advocates may be more trusted than health care team	✓	✓
Continuity of Care – From Admission Through Post Discharge - Information about the types of support that can be expected post discharge - Understand how staff can support transitions (e.g., information on the roles and responsibilities of support staff, such as social workers) - Information to ease FM and LO transition post ED/ICU, including on disability benefits, what to expect when discharged (e.g., personality changes), whom to call with questions, autopsying	✓	✓
Hospital Staff Strategies	**Interviews**	**Workshop**
Expectations for Cardiac Arrest/TBI Progression - Provide direct and upfront (tailored to the degree of certainty) information about the cardiac arrest/TBI progression - Clearly communicate the seriousness of the situation as early as possible, avoiding false hope	✓	✓
LO's Care and Status - Provide ongoing updates, including results of tests, new directions with treatment, or simply to say nothing has changed - Provide information on what to watch for/expect (signs/symptoms) - Give "pointers" for how to interact with LO and explain what the LO is experiencing - Share care plans - Debrief with FMs after rounding with FM - Answer FMs' questions and concerns or work to get FM in touch with right provider to answer questions - Collect information about LO from FM - Ensure that FMs know who is the care team point-of-contact at all times, including during shift transitions	✓	✓
Information about Uncertainty - Be direct and honest about what is known and unknown during the clinical course - Be clear why there is uncertainty, provide examples if applicable - Keep messaging consistent with others on the care team - Provide continuous reassessments and ongoing communications as things evolve - Use statistics carefully when speaking with FMs - Avoid declarative statements when uncertainty exists - Share best-case and worst-case scenarios - Provide a timeline of the process to help FM manage expectations	✓	✓

Information Needs - Levels of Influence		
Informed Decision-making - Clearly explain options - Provide neurologic and other relevant test results to help decision-making - Encourage advocacy - Identify other individuals for FMs to discuss options if they cannot make decisions - Frame end-of-life questions to avoid bias and relieve FMs of burden and guilt of DNR decisions - Include FM in discussions, even if not legally bound to LO - Include the FM as an essential team member with important clinical and personal information about the LO, including their wishes, values, lifestyle and understand how this information can lead to better outcomes - Understand the context and values of the LO and FM when framing conversations about decisions; align the health care team with these values	✓	✓
Institution (ED and ICU) Strategies	**Interviews**	**Workshop**
Orientation/Arrival at Hospital - Ease FMs into the event and the unknown - Provide details on where to go in the hospital, what to expect	✓	✓
Generic Education Materials for FMs - Provide FMs with education packets, FAQs, questions to ask physicians, fact sheets to provide basic information - Create an app for FMs to download generic information about their LO's condition or who is in their LO's care team - Ensure multiple formats of information to increase accessibility for all ages/preferences, and for all phases of the LO's treatment	✓	✓
Information to Navigate Hospital/Support FMs' Self-Care - Provide information on place to stay overnight, parking, transportation - Create a checklist of what FMs may need - Identify a specific care team member (e.g., chaplain) to provide logistical support and remind FMs to attend to personal needs	✓	✓
Consistent and Coordinated Source of Information - Institute "point person" (e.g., nurse or attending physician) who attends all meetings with family for coordinated and consistent information, and if possible, as family arrives to the hospital - Ensure the same hospital staff person/role has multiple conversations with FMs to provide consistent information and to build trust	✓	✓
Emphasize FMs as Part of the Clinical Team - Include FMs in rounds to the extent possible - Engage through video chats or calls if unavailable to participate in-person during rounds	✓	✓
Continuity of Care – Post Discharge - Provide information and resources for post discharge, including grievance counseling, rehabilitation	✓	✓

<u>Supplementary Digital Content 6:</u> Family Members' Communication Needs by Level of Influence

Communication Needs - Levels of Influence		
Family Members' Needs	**Interviews**	**Workshop**
Assistance with Processing Information - Need to receive information, repetition - Ability to have several FMs to also listen/process information - Need information to be provided in an easy to understand way - Require opportunities to ask questions - Directness in the face of uncertainty - Receive communication in a calm manner - Be mindful of timing, as well as volume of information, so as not to overwhelm FM	✓	✓
Sensitivity in Delivering Bad News - Appreciate when devastating news or expectations are communicated with empathy	✓	
Connection with Health Care Team - Receive contact information from care team so they can stay connected, particularly if there is a change in care team members - Receive information on when care team members will make rounds, or when consultants visit the LO so that the FM can form a connection with the care team; include FMs in rounds - Consistent access to a trusted care team member - Use social media and networking apps (e.g., Facebook, Caring Bridge) to keep family updated	✓	✓
Consistent Information from Care Team - Receive consistent information from care team members - Care team members are in close communication with each other, should operate as a holistic team		✓
Care Team Responsibilities - To understand the roles and responsibilities of care team members - A single point-of-contact to avoid confusion and to receive updates, particularly if LO has transferred to another facility - Staff that prioritizes communicating with FMs rather than medical students in teaching hospital environments	✓	✓
Hospital Staff Strategies	**Interviews**	**Workshop**
Assistance with Processing Information - Repeat information to FMs - Encourage questions - Assess FM's understanding of information; listen and observe - Utilize active listening approaches - Use language level that is appropriate for FM's medical literacy - Encourage tools to help process information (e.g., provide keywords to Google) - Prioritize information to FMs (i.e., what is most important for the FM to know and think about right now)	✓	✓

Communication Needs - Levels of Influence		
- Take time and pause when delivering information - Use language interpretation services when needed - Encourage FMs to take notes or record (with consent) conversations with physicians - Allow FMs to conference other FMs during discussions with physicians so several people will have the same information		
Outreach to Family ASAP and Provide Timely Updates - Meet with family ASAP, face-to-face - Ensure all appropriate family receive news/updates - Ensure family that are traveling are kept informed early/often	✓	✓
Communicate with Compassion - Spend time with FMs to build trust, assess communication needs, engage with FMs - Deliver news in a human and empathetic way, with sincerity and authenticity - Be patient, pause, be comfortable with providing silent breaks when speaking with FMs - Recognize that FMs have different styles and communication needs - Pay attention to how FMs respond and how body language and communication style affects people; modify communication style if needed	✓	✓
Institution (ED and ICU) Strategies	**Interviews**	**Workshop**
Specialized Roles - Utilize specific staff to assist with communication between family and medical team, such as a nurse “point person” or “mediator” - Dedicated staff are able to spend time needed with FMs, allowing physicians to focus on the LO, particularly during the early, acute, intense stages of care	✓	✓
Diverse Team Approach - Employ a care team of diverse disciplines (e.g., social workers, nurses, attending physicians) to address communication needs - Utilize a diverse team ensures that FM will find a connection with a team member	✓	
Consistency of Care Team - Create a dedicated, consistent care team to ensure continuity of care and to build trust with FMs - Ensure that care team members are in constant communication with each other and provide consistent information to FMs; consultants and attending physician function as a team - Designate a consistent communication point person	✓	✓
Communication Training and Observation - Require physicians to do training or palliative care rotations to learn how to have proper family discussions, how to address uncertainty - Provide providers with tools and opportunities to improve communication competency (e.g., audio recording and feedback; implementing family meeting debriefs)	✓	✓

Communication Needs - Levels of Influence		
- Train providers on good communication “models” and strategies - Provide training for religious staff and others to serve as family support facilitators		
Organizational Culture that Prioritizes Communication and Communication Training - Support for continuous learning and quality improvement - Setting expectations around communication competency - Buy-in and investment from leadership - Culture should support physicians’ accountability for their communication errors; set the expectation for physicians to acknowledge erroneous prognostications - Organizational changes to manage time constraints so that physicians are able to spend time communicating with FMs, include FMs in rounds		✓

<u>Supplementary Digital Content 7:</u> Family Members’ Emotional Needs by Level of Influence

Emotional Needs - Levels of Influence		
Family Members’ Needs	**Interviews**	**Workshop**
Compassion from Health Care Team (Builds Trust) - Feel the health care team genuinely cares for the LO, doing all they can, part of the “family” - Appreciates empathy, compassion towards family (e.g., checking in, eye contact, asking FMs questions about the LO, listening to FM’s concerns and responding to questions)	✓	✓
Sense of Control - Strategies to gain sense of control and make sense of information (e.g., internet searches, discussions with family/friends in the healthcare field) - Self-care strategies to gain sense of control and grounding (e.g., journaling, walking, praying, cleaning) - Empowered to request a new provider if there is not a “good fit”	✓	✓
Family/Friends Support - Ability to have family/friends visit FM	✓	✓
Support Services - A dedicated care team member (e.g., nurse, social worker, peer from support group) to serve as a liaison with the care team and provide emotional support - Should be available and offered early in the course of treatment	✓	✓
Continuity of Care – Post Discharge/Death - Bereavement resources, counseling and other sources of emotional support	✓	✓
Closure with Care Team - Desire to revisit the care team members post-discharge to express gratitude; part of the healing process for the FMs, LO, and care team		✓
Hospital Staff Strategies	**Interviews**	**Workshop**
Compassion from Health Care Team - Waiting for and greeting FM at the door of hospital upon arrival - Providing reassurance to FM - Provide time and space for FM to process information - Encouraging FM to stay in the present - Giving FM simple tasks in the very early period - Helping FM acknowledge and name their emotions - Provide FMs with emotional support, including religious services - Spend time with FMs and ask questions about the FM and LO to build trust - Show empathy; express that devastating news about LO also affects the care team	✓	✓
Addressing Uncertainty - Recognize that FMs are overwhelmed and emotional	✓	✓

Emotional Needs - Levels of Influence		
- Communicate the importance of ongoing critical care, allowing time for the clinical situation to “declare itself” - Provide information on what signs to watch for, expect - Be honest about not having all the answers immediately, emphasizing the need for more time for clinical signs to emerge - Reassure FMs that health care team is working effectively - Emphasize that FMs must be patient, comfortable with waiting, continue ongoing care - Focus on describing processes (e.g., next steps for testing, observations) and what they mean for LO’s course of treatment - Find balance of presenting range of what is known and what are possible outcomes while acknowledging level of uncertainty - Be careful not to overestimate ability to prognosticate, but provide enough information for the family to prepare for decisions that align with the LO’s values - Introduce the possibility of uncertainty; losing the person they knew before the event (“ambiguous loss”)		
Management of FMs’ Emotions and Distress - Offer support services (e.g., social workers, counselors, pastoral care) early in the process - Recognize that FMs are overwhelmed and anxious; attempt to make them as comfortable as possible so that they can accept and process information - Reassure/validate FMs’ care for LO, alleviating guilt, emphasize patient autonomy (FM cannot control patient’s decisions) - Encourage FMs to reach out to other FMs, friends (self-care) - Suggest ways to “normalize” the situation to handle emotions (e.g., tending to children, crafts, note-taking) - Explain when/under what circumstances FM can be with their LO	✓	✓
Tailored Approaches - Consider FM’s individual needs, context, tailored approaches, listening, responding (not one size fits all) - Meeting FM “where they are;” adapting delivery of bad news based on where the family is emotionally with understanding the life-threatening condition - Observing FM reactions and body language to tailor fit of communication	✓	
Encourage Family/Friends Support - Provide suggestions for communicating with others (e.g., Caring Bridge) so FM on-site not overwhelmed	✓	✓
Institution (ED and ICU) Strategies	**Interviews**	**Workshop**
Provide Support Services - Provide support services, social workers, counselors, pastoral care - Offer a dedicated care team staff, such as social workers, early in the course of treatment	✓	✓
Allow FMs to Spend Time with LOs		✓

Emotional Needs - Levels of Influence		
- Offer FMs to spend quiet time with LOs (e.g., bathing, holding LO), including to prepare for LO’s end-of-life		

Supplementary Digital Content 8: Family Members' Sociocultural Needs by Level of Influence

Sociocultural Needs - Levels of Influence		
Family Members' Needs	**Interviews**	**Workshop**
Sociocultural Background and Influence - To feel that FMs are not treated differently due to sociocultural background - To be included in conversations, treated with respect, treated as part of the health care team and not belittled or disregarded	✓	✓
Religious Support Services - Ability to receive religious support, such as receiving blessings, last rites, prayers for a variety of religions - Allowing members of one's faith community be present for support	✓	✓
Hospital Staff Strategies	**Interviews**	**Workshop**
Awareness of Sociocultural Background and Influence - Understand how cultural background and beliefs may influence level of trust with providers, communication and how they ask for assistance and support - Understand how cultural and religious beliefs may impact how FMs cope and grieve - Be aware of how racial disparities, systemic racism and historical mistreatment of Black, Indigenous, and People of Color communities in the US health care system affect health decisions, trust in providers - Understand how sociocultural background and social network (e.g., personal relationships with health care providers) affect concepts of quality of life, health care decisions - Understand how social networks (e.g., personal relationships with health care providers) affect health care decisions - Respect FMs' decisions that are based on cultural beliefs that may contradict providers' assessment	✓	✓
Assessing Sociocultural Preferences and Social Support - Assessing the patient's/FM's cultural and religious preferences - Assessing the patient's/FM's social network and support early in the first 48 hours		✓
Addressing Language Barriers - Use language interpretation services when needed	✓	
Religion and End-of-Life Decisions - Understand FMs' religious beliefs that make end-of-life decisions difficult, provide reassurance that the FM is making the right choice for the LO's quality of life - Provide religious support services to discuss end-of-life decisions - Be aware of FMs' religious beliefs and reliance on faith to heal LO - Clearly communicate LO's condition, treatment and end-of-life options, quality of life	✓	

Sociocultural Needs - Levels of Influence		
- Respect FMs’ decisions that are based on religious beliefs that may contradict providers’ assessment		
Institution (ED and ICU) Strategies	**Interviews**	**Workshop**
Financial Support Services - Offer discounted parking, affordable housing options, subsidized meals	✓	✓
Religious Support Services - Offer support services for a variety of religions	✓	✓
Addressing Language Barriers - Offer language interpretation services when needed	✓	

Supplementary Digital Content 9: Family Members' Physical Needs by Level of Influence

Physical Needs - Levels of Influence		
Family Members' Needs	**Interviews**	**Workshop**
Adequate Space for FMs - Comfortable space where FMs can stay long periods of time to ensure they are available to communicate and build relationships with care teams - Hospital rooms designed so that FMs are able to comfortably spend the night, take notes, research medical topics, provide support to their LO	✓	✓
Private Conference Rooms - Private conference rooms for sensitive conversations		✓
Visitations Rules - To be able to visit LOs 24 hours/day to provide support, as well as to be available for early morning rounds and visits from care team members - Allowing visitors to grieve and say goodbyes is imperative for FMs		✓
Personal Items when Traveling - Basic items when away from home (e.g., phone charger, toothbrush, change of clothes)		✓
Hospital Staff Strategies	**Interviews**	**Workshop**
Offer Privacy - Offer quiet location for conversations, private conference rooms	✓	✓
Institution (ED and ICU) Strategies	**Interviews**	**Workshop**
Offer Privacy - Ensure an adequate number of waiting rooms (near ED and the ICU) so that FM can have privacy for themselves and also for discussions with providers	✓	
Waiting Areas and Hospital Rooms - Create comfortable areas for FMs, especially when FMs may need to wait many hours or spend the night	✓	