Patient Important Bleeding Online Interview Guide

Introduction:

Ask everyone present to briefly introduce themselves.

Thank you for taking the time to participate in an interview that we are conducting as part of the REVISE study.

Before we begin the interview, I am going to review a few things:

Logistics:

• Today’s interview will take approximately 1 hour

• If you need to take a break to use the bathroom or take a call, please let me know and we can pause the interview – please remember to use the mute function

• Please ensure that you are in a quiet space with minimal distractions so that I can hear you clearly.

• As was described in the consent form, we will be audio recording today’s discussion, and all information shared today will be anonymized—that is, you will not be identified in association with anything you say.

• You can choose to have your video on or off during the discussion. Having your video turned on is preferable as it will help facilitate discussion and allow for a more natural flow of discussion. However, if you are not comfortable, you may turn off this function. We will not be recording any video.

About the Interview

• I would like to remind you that your participation in this study is voluntary and you can end your participation in the interview at any time.

• YOU ARE THE EXPERT! There are no right or wrong answers to the questions we have for you. We are interested in learning about your experiences and your perspectives.

Consent

• As I mentioned over email, we do not need to collect your signed consent for this interview. Before we start the interview I do want to check if you had a chance to read the consent form I sent you? (If no, review consent form). If yes – do you have any questions before we begin?
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Introduction to Study:

We'd like to share some slides on-screen with you to introduce you to the REVISE Study and provide you with some background information on why we are conducting this study to prevent gastrointestinal bleeding.

[share screen – presentation]

[After presenting GI bleed information (and before the information on tests and treatments), stop the presentation at a slide with a picture of a ventilated ICU patient.]

[Ask people to unmute and click “show small active speaker” in top right-hand corner]

Ask the following questions:

1. What do you think of, and what do you feel when you hear the term “GI bleed”?

2. I’d like to ask you to think of this scenario: You or your family member is critically ill in the ICU on a machine which is helping them to breathe called a ventilator. One day, the doctor says that an upper GI bleed has just started a few hours ago. Some blood is seen in the tube placed in the stomach, but it is not clear exactly where the bleeding is coming from, and so far, no particular treatment is needed.

3. What are your concerns about the GI bleed?

Probes: the amount of bleeding; location of the bleeding; seeing the bleeding; short-term impacts and long-term impacts of the bleeding; reason for the bleeding; how the patient experiences the bleeding (e.g., discomfort, pain); how serious is the bleeding (in the context of the primary reason for admission).

Thank you for discussing your feelings and concerns about GI bleeds. We are going to return to the presentation to learn about the different tests and treatments that are used to find and stop GI bleed.

[return to presentation]

Do you have any questions about the information in the presentation?

- Before we begin the interview questions, I just wanted to describe the context for this research study. As you may know: In the ICU patients are often sedated and not able to take part in discussions about their medical tests and treatment options. This is why we are doing this study - it is important to hear from patients and family members about what things are important when considering different tests and treatments for upper GI bleeding.
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As we move into the interview questions, I am going to begin recording the audio component of our discussion.

[start the recording function on Zoom]

[Moderator to share the slide with the spectrum of tests and treatments on the screen]

I am going to share my screen again and put up the slide showing the different tests and treatments that might be used for upper GI bleeding.

[share screen with online handout]

Some of these are more invasive than others. It is possible that a blood transfusion may be required or new drugs might be started to increase low blood pressure that develops due to bleeding. In addition, procedures to find out where the bleeding is coming from may be necessary, which might also involve treating the bleed. There are potential risks and benefits to each of these, which we reviewed earlier.

4. Has anyone had personal experience with a GI bleed? If yes, please describe your experience.
5. Do you have experience with any of these tests or treatments for a GI bleed or for another medical condition? If yes, please describe your experience.
6. The clinical team works with patients and families to make a management plan. Thinking about the scenario whereby you or your family member is on a breathing machine in the ICU and has developed a GI bleed:
   1. Which of the tests and treatments are you most comfortable with? Why?
   2. Which of the tests and treatments concern you the most? Why?

Probes: We're interested to know what tests and treatments are most preferred and which are least preferred (how and why they made the decision). For example, if participants list drugs first, ask about drugs and ask if all drugs are viewed the same way and then ask explicitly about the different drugs (i.e. antacids and medications to increase blood pressure). Perceptions of level of invasiveness of the test or treatment, level of discomfort for the patient, effectiveness of the test to locate the bleeding, effectiveness of the treatment to stop the bleeding, balancing possible discomfort or risk (e.g., infection) and possible benefit, drug interactions, location where test or treatment is done (i.e., in another part of the hospital vs. just done in their room), if any chronic health conditions or personal experience influence views on the test or treatment, short-term effects, long-term effects, perception of recovery time, if the test or treatment includes the patient being sedated again or put under anesthetic?

7. Thinking about the scenario where your family member is critically ill, on a breathing machine in the ICU and has developed a GI bleed. Is there anything the care team could do that would make you more comfortable with these tests and treatments?

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Probes: Would the clinical condition of the patient change the information they would want to receive or extent to which they are involved (e.g., if GI bleed is not primary concern or the size of the GI bleed), trust in doctor, relationship with doctor, understanding the different options (doctor took the time to explain them and answer questions), hearing the same things about the options from everyone on the medical team, knowing the treatment is commonly used, treatment is a familiar experience (i.e. IV medications), level of emotion experiencing when making the decision, gut feeling/perceptions, not feeling pressured to make a decision, knowing the numbers about the success of the intervention (i.e. % of patients whose response to this treatment is successful).

8. What do you want to avoid with these tests and treatments?
9. If you found out if any of these tests or treatments were considered life support (i.e., needed to keep the patient alive or save the patient’s life), would that change your concerns? Would it change your comfort level? If so, how?

Wrap Up Discussion

10. Does anyone have any final thoughts they would like to share with us? (Is there a “take home” message they would like the research team to capture?)

Conclusion:

Thank you everyone for your comments. Once again, your participation today is helping us advance the care of patients in the ICU. I can't stress it enough, that we cannot do this research without you! These are all of the questions I have for you.

Do you have any questions for us? (e.g., length/format of focus group, what worked well/didn’t work well for the virtual format)

As a thank you for your input and your participation in this focus group, we would also like to give you a gift card. This will be emailed to you. We appreciate that you took the time to talk to us!

11. I just have a few demographic questions to ask you now

[complete PIB Interview Tracking Requirements Document]