

Hello [participate name] I am [interviewer name]. Thank you for agreeing to participate. We really appreciate your help. The purpose of this interview is to learn about your experience in the medical ICU. Because you have personal experience, we believe you can help us understand what is most important to ICU patients and their loved ones. There are no right answers. This interview will be recorded but is confidential. This means it will not be linked to you in any identifiable way so please feel free to share your honest opinions. Do you have any questions before we get started?

FREELISTING

We're going to start with an exercise of free association. I'll tell you a word, and then you'll write a list all of the words that you can think of in response to that word. We'll start with an example. Apple. What words come to mind when you think about apples? (*give participant paper and pen, wait approximately 1 minute*)

Good. Now we'll do the same thing with another word and I'll give you a bit more time. Intensive care unit. What words come to mind when you think about the intensive care unit? Please write them down. (*wait 3 minutes or as long as participant needs*)

- *What does the intensive care unit make you think of?*
- *Slow read-back and ask if anything else*

Background

1. Tell me what the experience was like being in the ICU. Are there any memories that really stand out?

[Potential prompts: Tell me about when you first got to the ICU. Tell me about your interactions with the medical team. Tell me about leaving the ICU.]

Decision-making

2. Was there a time when a loved one had to make decisions for you? Tell me about that.
3. Were there times when you had to make decisions about your care? What was the decision about? Tell me what that was like for you.
 - a. *Can probe further:* Did you feel supported in making these decisions?

Regret/Advice to others

4. If you could tell another patient something about the ICU before they were sent there, what would it be? What's the most important thing to know about the ICU?
5. Are there questions you would advise another patient to make sure that they ask the doctors or nurses?

Life after ICU

6. What has your life been like since you were discharged from the ICU? Are there things that you're no longer able to do or that have become more difficult?

[Potential prompts: health, living situation, employment, IADLs, Entertainment/fun, mood]

Expectations

7. How has your recovery been since you left the ICU compared to how you expected it to be?

Outcome measures

8. Imagine that you were to become very sick again, and need to be back in the ICU. Also imagine that once in the ICU, it became clear that in order to get back to your current state of health, you would need to stay in the ICU for an entire year. Would it be worth staying in the ICU for an entire year to get back into your current state of health?

- a. How long would it be worth staying? Why that length of time?
9. Is there a length of stay in the ICU that would be worse than dying in the ICU?
10. Can you think of conditions or results of being in the ICU that might be just as bad or worse than dying in the ICU? What kinds of things?
11. Unfortunately, not everyone can be saved in the ICU. When death is inevitable, what can be done to make the death as good as possible? Are there things that can make the dying process worse?

Research Scenario

Now we're going to do something similar but with a brief scenario. Doctors want to know which of two ICU treatments is better. They are going to give half the people in the intensive care unit one treatment, and half the other treatment. To decide which treatment is better, what should they keep track of? From your perspective, what would make one treatment better than the other?

(Give participant as much time as they need. If he/she gets stuck only on mortality/survival, try to prompt for additional outcomes)

Alternatives:

- 1) Many people want to know if the new treatment saves more lives in the ICU than old treatments. Are there other things you think would be important about the treatment?

Can prompt additionally with: For example, another aspect that some people think is important is how long patients on the treatment stay in the ICU. Does one treatment help people leave the ICU earlier?

- 1) How can we decide whether an ICU stay was successful for patients and their families? Traditionally, we look at whether or not the patient survived the ICU stay – did they live or did they die? Are there other things that are also important?

Patient Centered ICU Outcomes: Semi-Structured Interview – ICU surrogate (survived) 3

Hello [participate name] I am [interviewer name]. Thank you for agreeing to participate. We really appreciate your help. The purpose of this interview is to learn about your experience in the medical ICU. Because you have personal experience, we believe you can help us understand what is most important to ICU patients and their loved ones. There are no right answers. This interview will be recorded but is confidential. This means it will not be linked to you in any identifiable way so please feel free to share your honest opinions. Do you have any questions before we get started?

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Good. Now we'll do the same thing with another word and I'll give you a bit more time. Intensive care unit. What words come to mind when you think about the intensive care unit? Please write them down. (wait 3 minutes or as long as participant needs)

Background

12. Tell me what you remember about your loved one's time in the ICU. Are there any memories that really stand out?

[Potential prompts: mechanical ventilation, dialysis, pain control, interactions with physicians and nurses, interactions with loved ones, physical therapy]

Decision-making

13. Were there times when you had to make decisions about your loved one's care? What was the decision about? Tell me what that was like for you.

- b. *Can probe further:* Did you feel supported in making these decisions? Would you have preferred more guidance or more independence? In what ways?
- c. Are there any decisions that you would have made differently?

Regret/Advice to others

14. If you could tell another patient or family something about the ICU before they were sent there, what would it be? What's the most important thing to know about the ICU?

15. Are there questions you would advise another patient/family to make sure that they ask the doctors or nurses?

Life after ICU

16. What has your loved one's life been like since discharged from the ICU? Are there things that he/she is no longer able to do or that have become more difficult?

[Potential prompts: health, living situation, employment, IADLs, Entertainment/fun, mood]

17. What has your life been like since your loved one's discharge from the ICU? Do you feel like you have the support that you need to help care for your loved one?

Expectations

18. How does your loved one's recovery since leaving the ICU been compared to how you expected it to be?

19. How has your loved one's experience changed your opinions on health care?
- a. If you were to become critically ill, what would you do and why?

Outcome measures

20. Imagine that your loved one were to become very sick again, and needed to be back in the ICU. Also imagine that once in the ICU, it became clear that in order to get back to his/her current state of health, he/she would need to stay in the ICU for an entire year.

Patient Centered ICU Outcomes: Semi-Structured Interview – ICU surrogate (survived) 4

Would it be worth staying in the ICU for an entire year to get back into his/her current state of health?

- b. How long would it be worth staying? Why that length of time?
- 21. Is there a length of stay in the ICU that would be worse than dying in the ICU?
- 22. Can you think of conditions or results of being in the ICU that might be just as bad or worse than dying in the ICU? What kinds of things?
- 23. Unfortunately, not everyone can be saved in the ICU. When death is inevitable, what can be done to make the death as good as possible? Are there things that can make the dying process worse?

Research Scenario

Now we're going to do something similar but with a brief scenario. Doctors want to know which of two ICU treatments is better. They are going to give half the people in the intensive care unit one treatment, and half the other treatment. To decide which treatment is better, what should they keep track of? From your perspective, what would make one treatment better than the other?

(Give participant as much time as they need. If he/she gets stuck only on mortality/survival, try to prompt for additional outcomes)

Alternatives:

- 2) Many people want to know if the new treatment saves more lives in the ICU than old treatments. Are there other things you think would be important about the treatment?

Can prompt additionally with: For example, another aspect that some people think is important is how long patients on the treatment stay in the ICU. Does one treatment help people leave the ICU earlier?

- 2) How can we decide whether an ICU stay was successful for patients and their families? Traditionally, we look at whether or not the patient survived the ICU stay – did they live or did they die? Are there other things that are also important?

Patient Centered ICU Outcomes: Semi-Structured Interview – MICU surrogate (deceased) 5

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FREELISTING

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Good. Now we'll do the same thing with another word and I'll give you a bit more time. Intensive care unit. What words come to mind when you think about the intensive care unit? Please write them down. *(wait 3 minutes or as long as participant needs)*

Background

24. Tell me what you remember about your loved one's time in the ICU. Are there any memories that really stand out?

[Potential prompts: mechanical ventilation, dialysis, pain control, interactions with physicians and nurses, interactions with loved ones, physical therapy]

Decision-making

25. Were there times when you had to make decisions about your loved one's care? What was the decision about? Tell me what that was like for you.

d. *Can probe further:* Did you feel supported in making these decisions? Would you have preferred more guidance or more independence? In what ways?

Regret/Advice to others

26. If you could tell another patient or family something about the ICU before they were sent there, what would it be? What's the most important thing to know about the ICU?

27. Are there questions you would advise another patient/family to make sure that they ask the doctors or nurses?

Expectations

28. How has your loved one's experience changed your opinions on health care?

Death in the ICU

29. Tell me about your loved one's passing.

30. Was your loved one's passing something you were expecting?

a. At what point did you think/know that he or she was not going to make it? *(hospital admission, ICU admission, family meeting)*

31. What aspects of the experience were positive *(can prompt or lead in with: comfortable, pain control, decision support, dying with dignity/respect)?*

32. Were there aspects you think could have been improved?

Outcome measures

33. Imagine that a loved one were to become very sick, and needed to get to the ICU. Also imagine that once in the ICU, it became clear that in order to get back to his/her current state of health, he/she would need to stay in the ICU for an entire year. Would it be

Patient Centered ICU Outcomes: Semi-Structured Interview – MICU surrogate (deceased) 6

worth staying in the ICU for an entire year to get back into his/her current state of health?

- c. How long would it be worth staying? Why that length of time?
34. Is there a length of stay in the ICU that would be worse than dying in the ICU?
35. Can you think of conditions or results of being in the ICU that might be just as bad as or worse than dying in the ICU? What kinds of things?
 - a. What states of health are important to you?
36. Unfortunately, not everyone can be saved in the ICU. When death is inevitable, what can be done to make the death as good as possible? Are there things that can make the dying process worse?

Research Scenario

Now we're going to do something similar but with a brief scenario. Doctors want to know which of two ICU treatments is better. They are going to give half the people in the intensive care unit one treatment, and half the other treatment. To decide which treatment is better, what should they keep track of? From your perspective, what would make one treatment better than the other?

(Give participant as much time as they need. If he/she gets stuck only on mortality/survival, try to prompt for additional outcomes)

Alternatives:

- 3) Many people want to know if the new treatment saves more lives in the ICU than old treatments. Are there other things you think would be important about the treatment?

Can prompt additionally with: For example, another aspect that some people think is important is how long patients on the treatment stay in the ICU. Does one treatment help people leave the ICU earlier?

- 3) How can we decide whether an ICU stay was successful for patients and their families? Traditionally, we look at whether or not the patient survived the ICU stay – did they live or did they die? Are there other things that are also important?