

January 13, 2014

Dear Medical Student:

Thank you for participating in the **Longitudinal Assessment of End-of-Life Decision Making** survey assessing how caregivers use various factors when making decisions about the appropriate level of intensive care intervention to deliver. Please read the attached case scenarios and circle the response that represents the management option and descriptive probability of survival you would most likely choose for the patient in each scenario. When you are done completing both cases and the follow-up questionnaire, please return the survey in the enclosed envelope. Feel free to write any comments in the margins or on the back of the survey explaining your choices, but please select one of the response options offered for each question.

All responses are confidential. A code has been placed on your survey so that those who have not returned the survey can be temporarily identified. This code will be removed at your site after your completed survey is returned. For the results of this survey to be valid, a high response rate is necessary. We will be presenting the results of this study at national conferences and submitting them for publication. If you have strong reservations about participating in this study, please return the survey and explain your reason for declining participation on the back.

Please return the survey within 3 weeks. We will be sending periodic reminders. If you lose the survey, we will provide another copy. This is a longitudinal study; we will be sending additional surveys during the next couple years. Future dates are May 6, 2014 and December 6, 2014.

Thank you for participating,

Dr. David Beyda
Phoenix Children's Hospital

Natasha Sinha
UACOM-Phoenix

CASE 1 – January 2014

A 6-year old girl was admitted to the Pediatric ICU with respiratory failure due to aspiration pneumonia 5 days ago. She is ventilator dependent and on a PEEP of 15 and a FiO₂ of 60% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days. She requires a dobutamine infusion of 10 mcg/kg/min due to myocardial dysfunction from sepsis. She has a coagulopathy from liver dysfunction (total bilirubin 3.7) requiring infusions of fresh frozen plasma to keep her PT less than 16. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 5%.

Three years ago, she underwent successful treatment for Acute Lymphoblastic Leukemia (the chance of recurrence is now 5 - 10%). During an episode of chemotherapy-induced neutropenia she contracted E. coli meningitis. Despite early detection and treatment, this infection resulted in severe permanent neurologic damage. The patient is developmentally delayed and has spastic quadriplegia. She walks with the assistance of devices, has slurred speech but is capable of two word sentences, still requires diapers, and receives nutrition via a gastrostomy tube.

The parents feel that their daughter is suffering and have requested that all measures being used to prevent her death be discontinued. Assume that you are the primary physician making decisions for this patient.

1. After extensive discussion with the parents, they continue to strongly believe that support should be withdrawn. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.
2. In addition to the above, would you obtain an ethics consult? Yes No
3. When making your decision, would the estimated probability of survival of around 5% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
_____ %
4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

CASE 5 – February 2013

A 6 year old girl was admitted to the PICU 5 days ago with respiratory failure due to viral pneumonia. She is ventilator dependent and on a PEEP of 15 and a FiO₂ of 60% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days. She requires a dobutamine infusion of 10 mcg/kg/min due to myocardial dysfunction from sepsis. She has a coagulopathy from liver dysfunction (total bilirubin 3.7) requiring infusions of fresh frozen plasma to keep her PT less than 16. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 5%.

This child underwent a bone marrow transplant for Stage IV Neuroblastoma 6 months ago but neuroblastoma cells were found on her last bone marrow biopsy done 3 weeks ago. She was doing well in school prior to her diagnosis of recurrence and this acute illness. The oncologists have told the parents that at this stage she is incurable and there are no other treatment options for her cancer. They predict her chance of surviving a year to be less than 1%.

Although her poor prognosis has been discussed numerous times with the parents, they state that they are not ready for her to die and request that everything to be done to prolong her life. They believe that if she dies despite full intervention, then they will at least feel that they did everything they could. Assume that you are the primary physician making decisions for this patient.

1. After extensive discussion with the parents, they continue to feel strongly that full support and intervention be continued. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.
2. In addition to the above, would you obtain an ethics consult? Yes No
3. When making your decision, would the estimated probability of survival of around 5% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival? _____%
4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

When you are making decisions about the withdrawal of life-support, please rate the degree to which the following factors influence your decisions (check one of the following from extremely important to completely irrelevant):

Degree of Influence				Decision Factor
Extremely Important	Moderately Important	Minimally Important	Completely Irrelevant	
___	___	___	___	Likelihood of surviving the acute illness
___	___	___	___	Risk of death from the chronic illness
___	___	___	___	The family's wishes
___	___	___	___	The wishes of the patient
___	___	___	___	The ability of the parents to care for the child
___	___	___	___	The threat of a lawsuit
___	___	___	___	The level of chronic neurologic disability
___	___	___	___	The patient's diagnosis
___	___	___	___	Your religious beliefs
___	___	___	___	Previous compliance with medical care

1. In comparison to my classmates, I think I am _____ to withdraw life support. (please circle only one)

much more likely --- more likely --- as likely --- much less likely

CONGRATULATIONS! THIS IS THE LAST PAGE OF QUESTIONS

(please circle, check, or complete the appropriate response)

1. What is your specialty of interest? Primary Care Surgery Sub-Specialty_____
2. What is your sex? Male Female
3. What is your age group? 18-25 26-35 36-45 >45
4. What is your marital status? Married Single Divorced
5. Do you have children? Yes No #____
6. Number of years of healthcare experience before medical school: _____years
7. a. What is your religious affiliation:
___ Catholic
___ Protestant
___ Jewish
___ None
_____other (please list)
b. If none, are you spiritual? Yes No

This is the end of the survey. Please return the survey in the envelope provided. Thank you for participating. All responses are confidential.

May 6, 2014

Dear Medical Student:

Thank you for participating in the **Longitudinal Assessment of End-of-Life Decision Making** survey assessing how caregivers use various factors when making decisions about the appropriate level of intensive care intervention to deliver. Please read the attached case scenarios and circle the response that represents the management option and descriptive probability of survival you would most likely choose for the patient in each scenario. When you are done completing both cases and the follow-up questionnaire, please return the survey in the enclosed envelope. Feel free to write any comments in the margins or on the back of the survey explaining your choices, but please select one of the response options offered for each question.

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Please return the survey within 3 weeks. We will be sending periodic reminders. If you lose the survey, we will provide another copy. This is a longitudinal study; we will be sending additional surveys during this year. The final date is December 6, 2014.

Thank you for participating,

Dr. David Beyda
Phoenix Children's Hospital

Natasha Sinha
UACOM-Phoenix

CASE 2 – May 2014

A 6-year old girl was admitted to the Pediatric ICU with respiratory failure due to aspiration pneumonia 5 days ago. She no longer requires inotropic support but is ventilator dependent and on a PEEP of 6 and a FiO₂ of 50% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days as a result of her hypotension during her initial few days of admission. She is on a dopamine infusion at 3 mcg/kg/min. All other organ systems are now normal. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 40%.

Three years ago, she underwent successful treatment for Acute Lymphoblastic Leukemia (the chance of recurrence is now 5 - 10%). During an episode of chemotherapy-induced neutropenia she contracted E. coli meningitis. Despite early detection and treatment, this infection resulted in severe permanent neurologic damage. The patient is developmentally delayed and has spastic quadriplegia. She walks with the assistance of devices, has slurred speech but is capable of two word sentences, still requires diapers, and receives nutrition via a gastrostomy tube.

The parents feel that their daughter is suffering and have requested that all measures being used to prevent her death be discontinued. Assume that you are the primary physician making decisions for this patient.

1. After extensive discussion with the parents, they continue to strongly believe that support should be withdrawn. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.
2. In addition to the above, would you obtain an ethics consult? Yes No
3. When making your decision, would the estimated probability of survival of around 40% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
_____ %
4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

CASE 6 – May 2014

A 6 year old girl was admitted to the PICU 5 days ago with respiratory failure due to viral pneumonia. She is ventilator dependent and on a PEEP of 6 and a FiO₂ of 50% with PaO₂s in the mid-80s. She has been in oliguric renal failure for the past 2 days as a result of her hypotension during her initial few days of admission. She is on a dopamine infusion at 3 mcg/kg/min. All other organ systems are now normal. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 40%.

This child underwent a bone marrow transplant for Stage IV Neuroblastoma 6 months ago but neuroblastoma cells were found on her last bone marrow biopsy done 3 weeks ago. She was doing well in school prior to her diagnosis of recurrence and this acute illness. The oncologists have told the parents that at this stage she is incurable and there are no other treatment options for her cancer. They predict her chance of surviving a year to be less than 1%.

Although her poor prognosis has been discussed numerous times with the parents, they state that they are not ready for her to die and request that everything to be done to prolong her life. They believe that if she dies despite full intervention, then they will at least feel that they did everything they could. Assume that you are the primary physician making decisions for this patient.

1. After extensive discussion with the parents, they continue to feel strongly that full support and intervention be continued. At this point, you would most likely (circle only one strategy):
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 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.
2. In addition to the above, would you obtain an ethics consult? Yes No
3. When making your decision, would the estimated probability of survival of around 40% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
_____ %
4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

When you are making decisions about the withdrawal of life-support, please rate the degree to which the following factors influence your decisions (check one of the following from extremely important to completely irrelevant):

Degree of Influence				Decision Factor
Extremely Important	Moderately Important	Minimally Important	Completely Irrelevant	
___	___	___	___	Likelihood of surviving the acute illness
___	___	___	___	Risk of death from the chronic illness
___	___	___	___	The family's wishes
___	___	___	___	The wishes of the patient
___	___	___	___	The ability of the parents to care for the child
___	___	___	___	The threat of a lawsuit
___	___	___	___	The level of chronic neurologic disability
___	___	___	___	The patient's diagnosis
___	___	___	___	Your religious beliefs
___	___	___	___	Previous compliance with medical care

1. In comparison to my classmates, I think I am _____ to withdraw life support. (please circle only one)

much more likely --- more likely --- as likely --- much less likely

December 6, 2014

Dear Medical Student:

Thank you for participating in the **Longitudinal Assessment of End-of-Life Decision Making** survey assessing how caregivers use various factors when making decisions about the appropriate level of intensive care intervention to deliver. Please read the attached case scenarios and circle the response that represents the management option and descriptive probability of survival you would most likely choose for the patient in each scenario. When you are done completing both cases and the follow-up questionnaire, please return the survey in the enclosed envelope. Feel free to write any comments in the margins or on the back of the survey explaining your choices, but please select one of the response options offered for each question.

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Please return the survey within 3 weeks. We will be sending periodic reminders. If you lose the survey, we will provide another copy

Thank you for participating,

Dr. David Beyda
Phoenix Children's Hospital

Natasha Sinha
UACOM-Phoenix

CASE 3 – December 2014

A 6-year old girl was admitted to the Pediatric ICU with respiratory failure due to aspiration pneumonia 5 days ago. She is ventilator dependent and on a PEEP of 15 and a FiO₂ of 60% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days. She requires a dobutamine infusion of 10 mcg/kg/min due to myocardial dysfunction from sepsis. She has a coagulopathy from liver dysfunction (total bilirubin 3.7) requiring infusions of fresh frozen plasma to keep her PT less than 16. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 5%.

Three years ago, she underwent successful treatment for Acute Lymphoblastic Leukemia (the chance of recurrence is now 5 - 10%). During an episode of chemotherapy-induced neutropenia she contracted E. coli meningitis. Despite early detection and treatment, this infection resulted in severe permanent neurologic damage. The patient is developmentally delayed and has spastic quadriplegia. She walks with the assistance of devices, has slurred speech but is capable of two word sentences, still requires diapers, and receives nutrition via a gastrostomy tube.

The parents are very devoted to her. They state that they do not want her to suffer and are trying to decide if it is best to let her go or continue do everything necessary to prolong her life. The parents are looking to you for guidance. Assume that you are the primary physician making decisions for this patient.

1. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.

2. In addition to the above, would you obtain an ethics consult? Yes No

3. When making your decision, would the estimated probability of survival of around 5% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
_____ %

4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

CASE 7 – December 2014

A 6 year old girl was admitted to the PICU 5 days ago with respiratory failure due to viral pneumonia. She is ventilator dependent and on a PEEP of 15 and a FiO₂ of 60% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days. She requires a dobutamine infusion of 10 mcg/kg/min due to myocardial dysfunction from sepsis. She has a coagulopathy from liver dysfunction (total bilirubin 3.7) requiring infusions of fresh frozen plasma to keep her PT less than 16. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 5%.

This child underwent a bone marrow transplant for Stage IV Neuroblastoma 6 months ago but neuroblastoma cells were found on her last bone marrow biopsy done 3 weeks ago. She was doing well in school prior to her diagnosis of recurrence and acute illness. The oncologists have told the parents that at this stage she is incurable and there are no other treatment options for her cancer. They predict her chance of surviving a year to be less than 1%.

The parents are very devoted to her. They state that they do not want her to suffer and are trying to decide if it is best to let her go or continue do everything necessary to prolong her life. The parents have looked to you for guidance. Assume that you are the primary physician making decisions for this patient.

1. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.

2. In addition to the above, would you obtain an ethics consult? Yes No

3. When making your decision, would the estimated probability of survival of around 5% influence your decision (assuming the use of full life-support interventions)?

 Yes No If no, what would be your best guess estimated probability of survival?
 _____ %

4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

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Extremely Important	Moderately Important	Minimally Important	Completely Irrelevant	
___	___	___	___	Likelihood of surviving the acute illness
___	___	___	___	Risk of death from the chronic illness
___	___	___	___	The family's wishes
___	___	___	___	The wishes of the patient
___	___	___	___	The ability of the parents to care for the child
___	___	___	___	The threat of a lawsuit
___	___	___	___	The level of chronic neurologic disability
___	___	___	___	The patient's diagnosis
___	___	___	___	Your religious beliefs
___	___	___	___	Previous compliance with medical care

1. In comparison to my classmates, I think I am _____ to withdraw life support. (please circle only one)

much more likely --- more likely --- as likely --- much less likely

September 7, 2014

Dear Medical Student:

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Thank you for participating,

Dr. David Beyda
Phoenix Children's Hospital

Natasha Sinha
UACOM-Phoenix

CASE 4 – September 2014

A 6-year old girl was admitted to the Pediatric ICU with respiratory failure due to aspiration pneumonia 5 days ago. She no longer requires inotropic support but is ventilator dependent and on a PEEP of 6 and a FiO₂ of 50% with PaO₂s in the mid-60s. She has been in oliguric renal failure for the past 2 days as a result of her hypotension during her initial few days of admission. She is on a dopamine infusion at 3 mcg/kg/min. All other organ systems are now normal. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 40%.

Three years ago, she underwent successful treatment for Acute Lymphoblastic Leukemia (the chance of recurrence is now 5 - 10%). During an episode of chemotherapy-induced neutropenia she contracted E. coli meningitis. Despite early detection and treatment, this infection resulted in severe permanent neurologic damage. The patient is developmentally delayed and has spastic quadriplegia. She walks with the assistance of devices, has slurred speech but is capable of two word sentences, still requires diapers, and receives nutrition via a gastrostomy tube.

The parents are very devoted to her. They state that they do not want her to suffer and are trying to decide if it is best to let her go or continue to do everything necessary to prolong her life. The parents are looking to you for guidance. Assume that you are the primary physician making decisions for this patient.

1. At this point, you would most likely (circle only one strategy):
 - a. Discontinue inotropes and mechanical ventilation but continue comfort measures.
 - b. Discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures.
 - c. Continue with current management but add no new therapeutic intervention.
 - d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
 - e. Continue with full aggressive management and plan for dialysis if necessary.
2. In addition to the above, would you obtain an ethics consult? Yes No
3. When making your decision, would the estimated probability of survival of around 40% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
_____ %
4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

Almost Zero Very Low Low Moderate High

CASE 8 September 2014

A 6 year old girl was admitted to the PICU 5 days ago with respiratory failure due to viral pneumonia. She is ventilator dependent and on a PEEP of 6 and a FiO2 of 50% with PaO2s in the mid-80s. She has been in oliguric renal failure for the past 2 days as a result of her hypotension during her initial few days of admission. She is on a dopamine infusion at 3 mcg/kg/min. All other organ systems are now normal. Although it is difficult to estimate this child's probability of survival with accuracy, the best estimate (based upon the admission PRISM score, the patient's current status, and the consensus of the involved ICU attendings) is approximately 40%.

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1. At this point, you would most likely (circle only one strategy):

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- c. Continue with current management but add no new therapeutic intervention.
- d. Continue with current management, add further inotropes, change antibiotics, and the like as needed, but do not start dialysis.
- e. Continue with full aggressive management and plan for dialysis if necessary.

2. In addition to the above, would you obtain an ethics consult? Yes No

3. When making your decision, would the estimated probability of survival of around 40% influence your decision (assuming the use of full life-support interventions)?

Yes No If no, what would be your best guess estimated probability of survival?
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4. When talking with the parents, I would describe this patient's probability of surviving to ICU discharge (despite full life-support interventions) as (circle only one estimate):

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___	___	___	___	The family's wishes
___	___	___	___	The wishes of the patient
___	___	___	___	The ability of the parents to care for the child
___	___	___	___	The threat of a lawsuit
___	___	___	___	The level of chronic neurologic disability
___	___	___	___	The patient's diagnosis
___	___	___	___	Your religious beliefs
___	___	___	___	Previous compliance with medical care

1. In comparison to my classmates, I think I am _____ to withdraw life support. (please circle only one)

much more likely --- more likely --- as likely --- much less likely

CONGRATULATIONS! THIS IS THE LAST PAGE OF QUESTIONS

(please circle, check, or complete the appropriate response)

1. What is your specialty of interest? Primary Care Surgery Sub-Specialty_____
2. What is your sex? Male Female
3. What is your age group? 18-25 26-35 36-45 >45
4. What is your marital status? Married Single Divorced
5. Do you have children? Yes No #_____
6. Number of years of healthcare experience before medical school: _____years
7. a. What is your religious affiliation: ___ Catholic
 ___ Protestant
 ___ Jewish
 ___ None
 _____other (please list)
- b. If none, are you spiritual? Yes No

This is the end of the survey. Please return the survey in the envelope provided. Thank you for participating. All responses are confidential.