




A Good Death

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Dr. Elizabeth Wickersham




Purpose

- Use surveys of people who had a loved one die at OU to understand how patients and their families experience the dying process
 - Compare experiences of patients who died on a regular hospital floor, in the Emergency Department, in the ICU, while being cared for by the palliative care team, and in the comfort care suites
 - Find areas of improvement in end-of-life care at OU
 - Survey families of both adult and pediatric patients
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Methods

- ▶ Compile next of kin contact information
 - ▶ Handwritten records kept by the OU chaplains' office
 - ▶ Adult: reviewed records of deaths between 90 days and 1 year ago
 - ▶ Pediatric: review records of deaths between 90 days and 2 years ago
 - ▶ Exclude deaths due to prematurity, stillbirth, and accidents
 - ▶ Totals
 - ▶ Adult: 417
 - ▶ Pediatric: 131
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Methods

- Mail out introductory letters to survey groups
 - Prepare family members for receiving survey
 - Test viable addresses

July 5, 2016

Dear Family Member,

We would like to offer our sincerest condolences on the death of your loved one at the University of Oklahoma Medical Center. We recognize that this is a difficult time, and we want to be sensitive to your family's needs.

However, we feel that you have some valuable experience we would like to draw upon as part of our efforts to improve patient care at the end of life. To accomplish this, we would appreciate your feedback on your experience at the University of Oklahoma Medical Center.

Within the next two weeks, we will be sending you a survey about your experiences at OUMC. We respect that this may be a painful time for you and your family, and you are free to decide whether to participate when you receive the survey. Either decision is fine, but, again, we would greatly appreciate your feedback.

Sincerely,

Danny Cavett
Director of Pastoral Care

Elizabeth Wickersham, MD
Assistant Professor, Research Division
Department of Family Medicine

Valerie Kastens, MS-II
Student, OU College of Medicine

July 7, 2016

Dear Family Member,

Please accept our deepest condolences on the death of your young loved one. We recognize that this is a very difficult time. We hope that the Children's Hospital Chaplains and other staff helped to make your time at the hospital more bearable. We continue to be available to assist with your family's needs.

We are always trying to improve patient care here at the Children's Hospital of Oklahoma. We believe that your comments about your experience would help us improve patient care at the end of life, and therefore help others in their time of need. To accomplish this, we would appreciate your feedback on your experience at the Children's Hospital of Oklahoma.

Within the next two weeks, we will be sending you a survey about your time at our hospital. We respect that this may be a very painful time for you and your family. You are free to decide whether or not you want to complete and return the survey. Either decision is fine. We would greatly appreciate your feedback.

Sincerely,

Danny Cavett
Director of Pastoral Care

Elizabeth Wickersham, MD
Assistant Professor, Research Division
Department of Family Medicine

Valerie Kastens, MS-II
OU College of Medicine

A brief note: If you have already received and responded to this survey, there is no need to fill it out again. Please know that we greatly appreciate your comments and willingness to share your thoughts.

Methods

- Mail out surveys, which include a link to the Qualtrics survey

 *The UNIVERSITY of OKLAHOMA*
Health Sciences Center

Q1. How long ago did your loved one die?

Q2. What was the cause of your loved one's death?

Q3. Where was your loved one at the time of his/her death?

In the hospital on a regular floor

In the Intensive Care Unit (ICU)

In the Emergency Department

In the hospital, either on a regular floor/in the ICU, under care of the palliative care team. *The palliative care team is a special team that provides comfort care and looks after the things that improve meaning in life for a patient.*

In the hospital's comfort care suites
These are special rooms that are used for patients who are expected to die within a day or two. These are larger to allow for more family and friends and to feel more like home.

Q4. How long did your loved one stay in the hospital prior to death?

Less than 1 day

1 - 7 days

8 - 21 days

More than 21 days, please specify length of stay

Dear Prospective Participant:

This is a research study. Research studies involve only people who choose to participate. You are being asked to participate in this study because you have a close friend or family member who has died at the University of Oklahoma Medical Center. The purpose of this study is to understand the quality of care that seriously ill patients receive at our hospital so that we can guide healthcare to better serve such patients. While any death is a loss and might never be managed perfectly, family members or friends may have a sense of whether their loved one had a "good death" or one that was not so good.

If you agree to participate, you will fill out a questionnaire that asks a series of questions about yourself and your attitudes and perceptions of your loved one's death. This survey should take about 15-25 minutes. You can refuse to answer any of the questions.

There is no benefit or risk to you for participating in this study. Taking part in this study will not cost you anything. In order to keep your answers confidential, your name will not appear on the survey and you will not be identifiable by name in any reports or publications; however, we cannot guarantee absolute confidentiality.

Taking part in this survey is voluntary. You may choose not to take part. There are no consequences to you for choosing not to participate. If you choose to participate, you may return the survey in the enclosed postage-paid envelope or complete the survey online. Your data will be stored anonymously.

If you have questions about this study, please contact the Principal Investigator, Elizabeth Wickersham, MD, at (405) 271-5362. For questions about your rights as a research subject, contact the OUHSC Director of the Human Research Participant Protection Program at (405) 271-2045.


Again, you are under no obligation to participate; however, we would appreciate your opinions so that we may continue to improve the care of seriously ill patients in our hospital.

If you wish, you may complete this survey online at:

<http://tinyurl.com/OUMCSurvey2016>



Main Survey Sections

- Basics of patient's death
 - End of life planning
 - HCAHPS
 - Emotional/physical experiences near time of death
 - Overall quality of dying experience
 - Demographics of respondent and patient
- 




Basics of Patient's Death

- How long ago did your loved one die?
- What was the cause of your loved one's death?
- Where was your loved one at the time of his/her death?
- How long did your loved one stay in the hospital prior to death?




End of Life Planning

- My loved one had advance directives.
 - My loved one had a living will.
 - My loved one had a healthcare proxy.
 - My loved one had a “Do Not Resuscitate” directive.
 - My loved one had a directive for organ donation.
- 




End of Life Planning

- If my loved one had written wishes regarding end of life care, they were followed by the healthcare team.
 - My loved one's wishes regarding life-sustaining treatment were honored in the final weeks of his/her life.
 - My loved one would have been comfortable with the healthcare decisions made by others on his/her behalf near the time of death.
 - Did your loved one have specific religious beliefs about death?
 - The death of my loved one was sudden (accident, heart attack, etc.)
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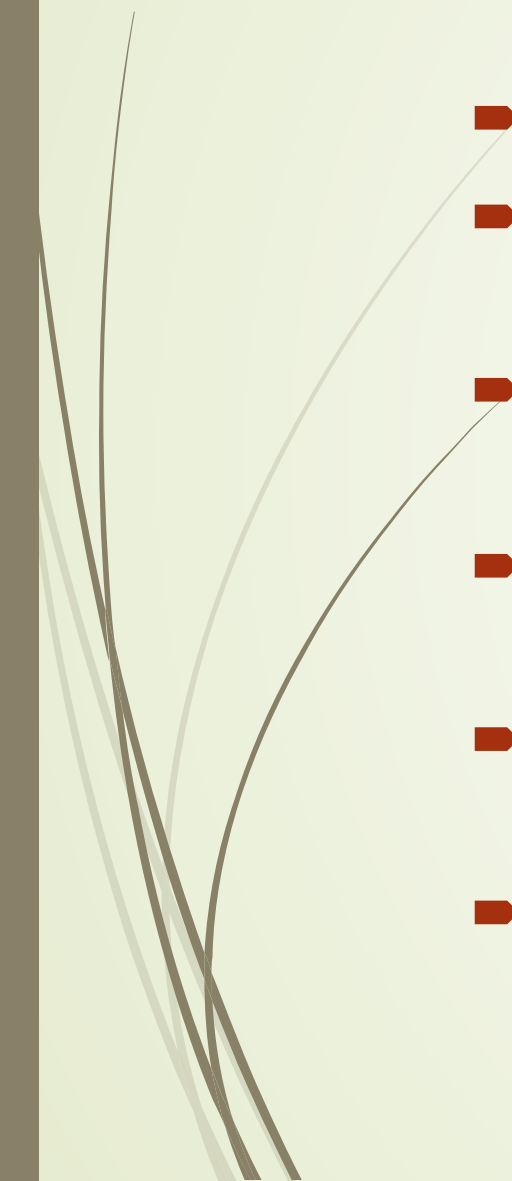


End of Life Planning

- My loved one's primary care doctor or another healthcare provider referred him/her to hospice care.
 - If hospice services were offered, were they used?
 - My loved one's death was expected (i.e. we knew ahead of time that he/she was in the process of dying).
 - My loved one's primary care doctor or another healthcare provider informed him/her or the family/friends about comfort care options.
- 




HCAHPS

- My loved one had a good relationship with his/her doctor(s).
 - The healthcare providers treated my loved one with courtesy and respect.
 - My loved one had a consistent team of healthcare providers who came to know him/her and the family/friends.
 - The healthcare providers showed compassion for my loved one.
 - My loved one received the appropriate amount of comfort care.
 - The healthcare providers explained things in a way my loved one and I could understand.
- 



HCAHPS

- ▶ During your loved one's hospital stay, after he/she pressed the call button, how often did help come as soon as he/she wanted it?
 - ▶ My loved one was kept clean near the end of his/her life.
 - ▶ How often did your loved one get help in getting to the bathroom or in using a bedpan as soon as he/she wanted?
 - ▶ During your loved one's hospital stay, how often were his/her room and bathroom kept clean?
 - ▶ During your loved one's hospital stay, how often was the area around his/her room quiet at night?
- 

Emotional/Physical Experiences Near End of Life

- My loved one was able to spend as much time with friends, family, and pets as he/she wanted in the hospital prior to death.
- My loved one was worried about problems that he/she would be leaving behind.
- My loved one appeared to regret events in his/her life.
- My loved one knew that his/her dependent(s)/pet(s) would be cared for after his/her death.
- My loved one worried about the costs of his/her medical treatment near the time of his/her death.

Emotional/Physical Experiences Near End of Life


- My loved one was prepared for death.
- My loved one took part in making decisions about his/her end-of-life care.
- My loved one felt like he/she had control regarding treatment decisions.
- My loved one struggled to breathe near the time of his/her death.
- My loved one was in physical pain when he/she died.
- My loved one was in emotional pain when he/she died.
- My loved one felt pain longer than necessary.

Emotional/Physical Experiences Near End of Life

- My loved one's wishes regarding awareness at the time of death were honored.
- My loved one was able to communicate near the end of his/her life.
- It was important for my loved one to have a member of the clergy present when he/she was dying.
- My loved one's religious requests were honored.
- Prayer/sacraments/last rites were said for my loved one just before he/she died.




Overall Quality of Dying Experience

- My loved one's death was not fair (i.e., he/she died before his/her time, or the death could have been prevented).
 - My loved one died peacefully.
 - My loved one experienced a good death.
- 



Demographics of Respondent and Patient

- ▶ Respondent's relationship to patient
 - ▶ Age
 - ▶ Gender
 - ▶ Race
 - ▶ Level of schooling
 - ▶ Urban/suburban/rural
- 



Additional Questions on Pediatric Survey

- I was able to talk with our child about their illness and dying and was able to answer their questions honestly.
- Many parents are comfortable with the decision not to donate organs but there are some who express regret that they did not donate their child's organs. If you did not donate your child's organs, is this a decision you now wish you had made differently?
- I have been able to understand, medically, why my child died.
- I have been able to find meaning in the loss of my child.




A Good Death Adult Survey 2015

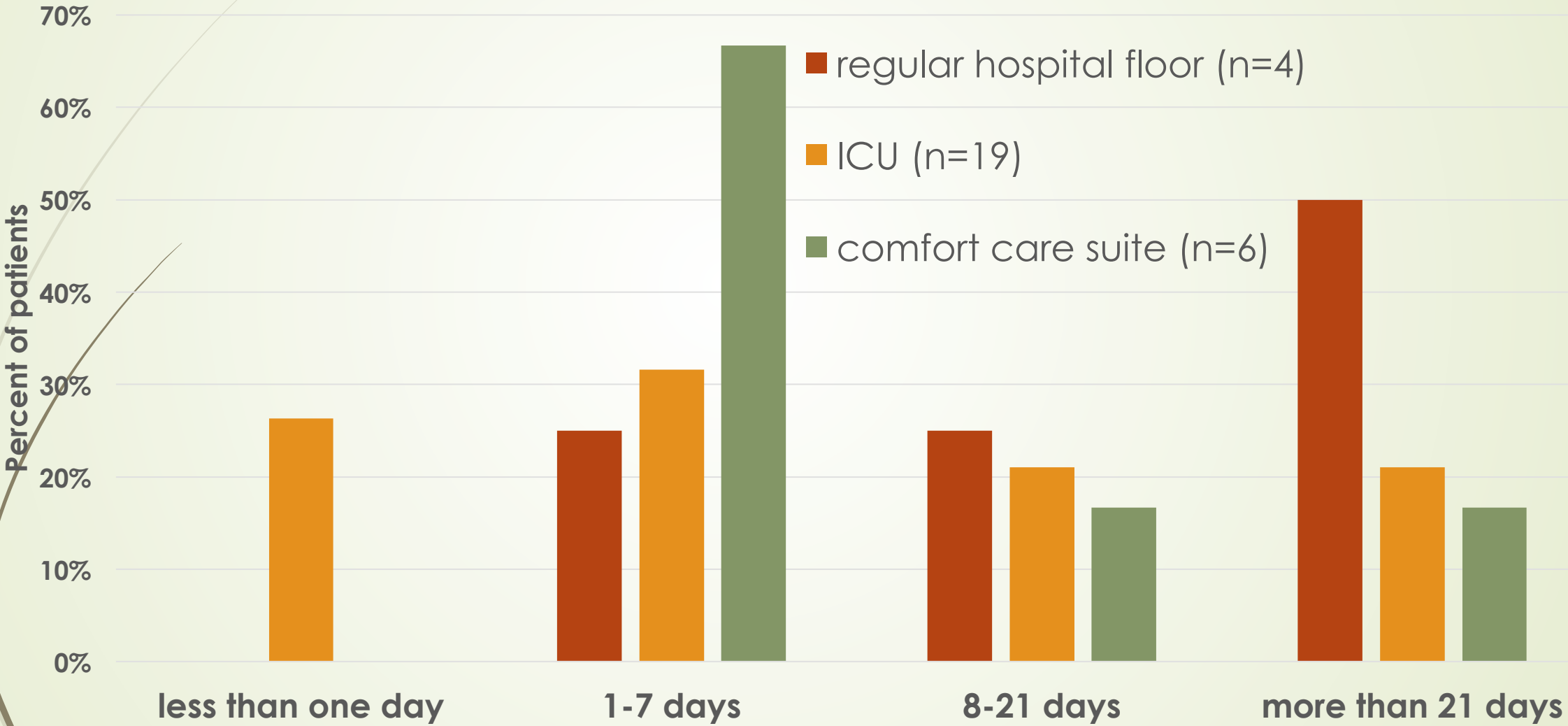
- **Total respondents: 30**
- Where was your loved one at the time of his/her death?
 - In the hospital on a regular floor: **4** (13.3%)
 - In the ICU: **19** (63.3%)
 - Under care of the palliative care team: **1** (3.3%)
 - In the comfort care suites: **6** (20%)



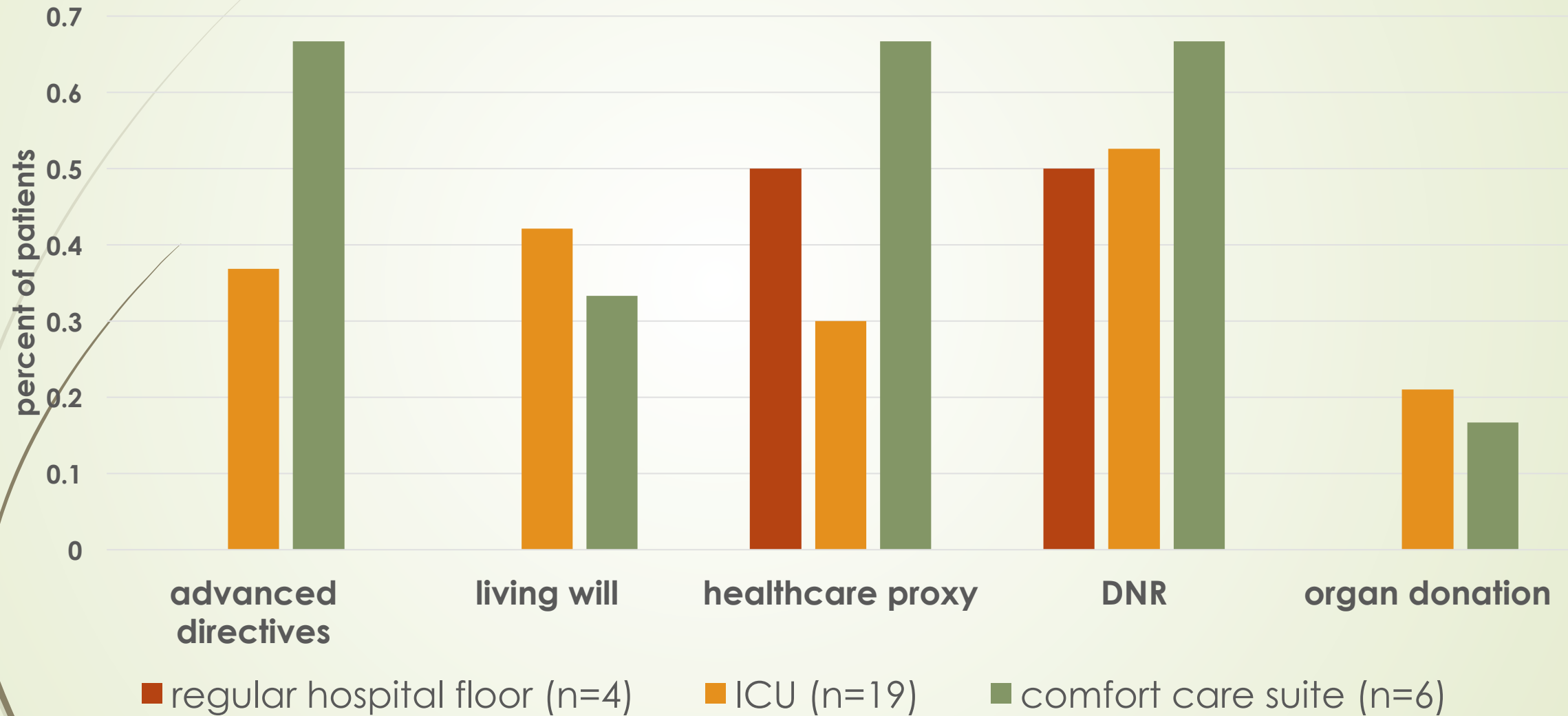
Most Common Causes of Death

- Stroke/intracranial bleed: **7**
 - Cancer: **6**
 - Heart failure/cardiac arrest: **5**
 - Liver failure: **3**
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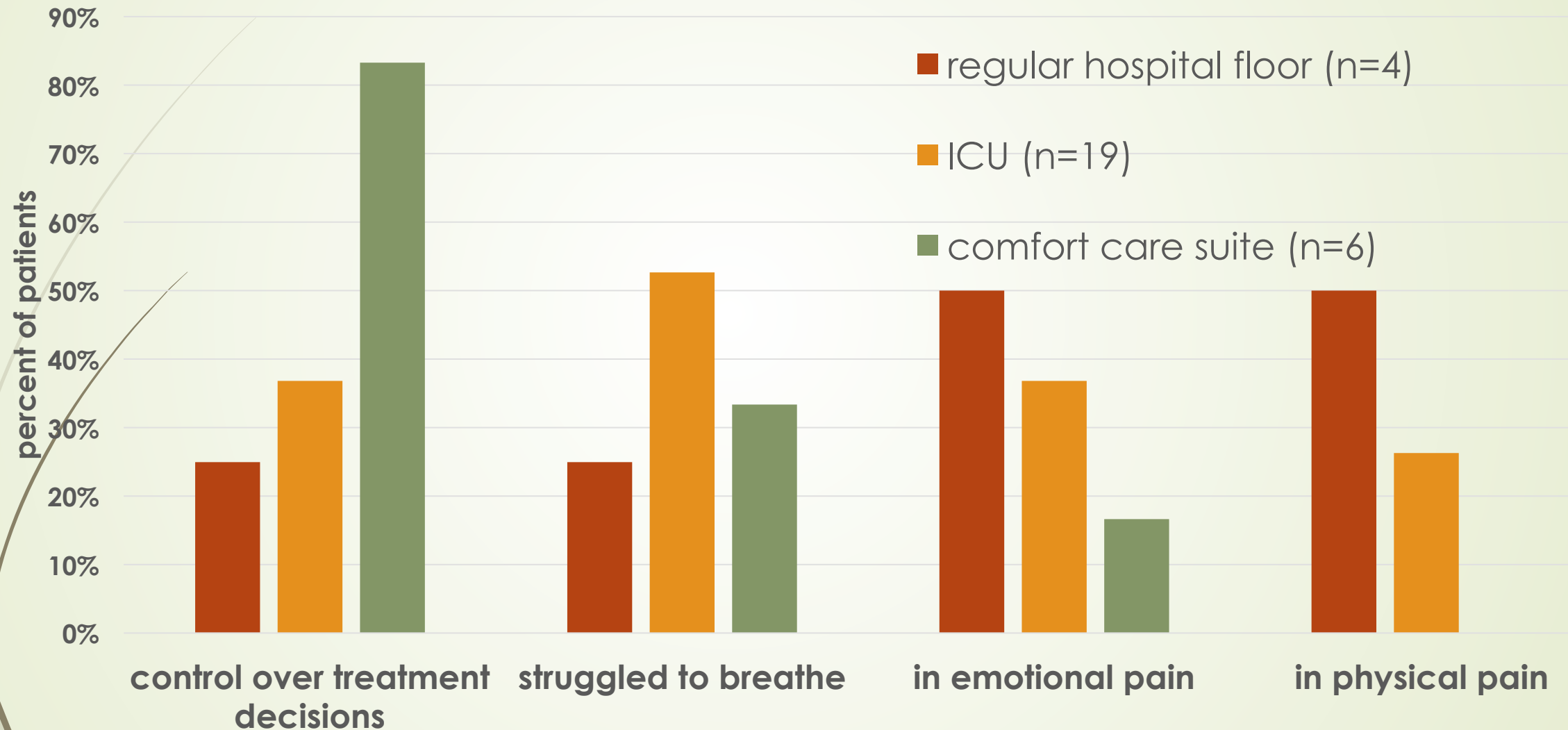
Length of Hospital Stay



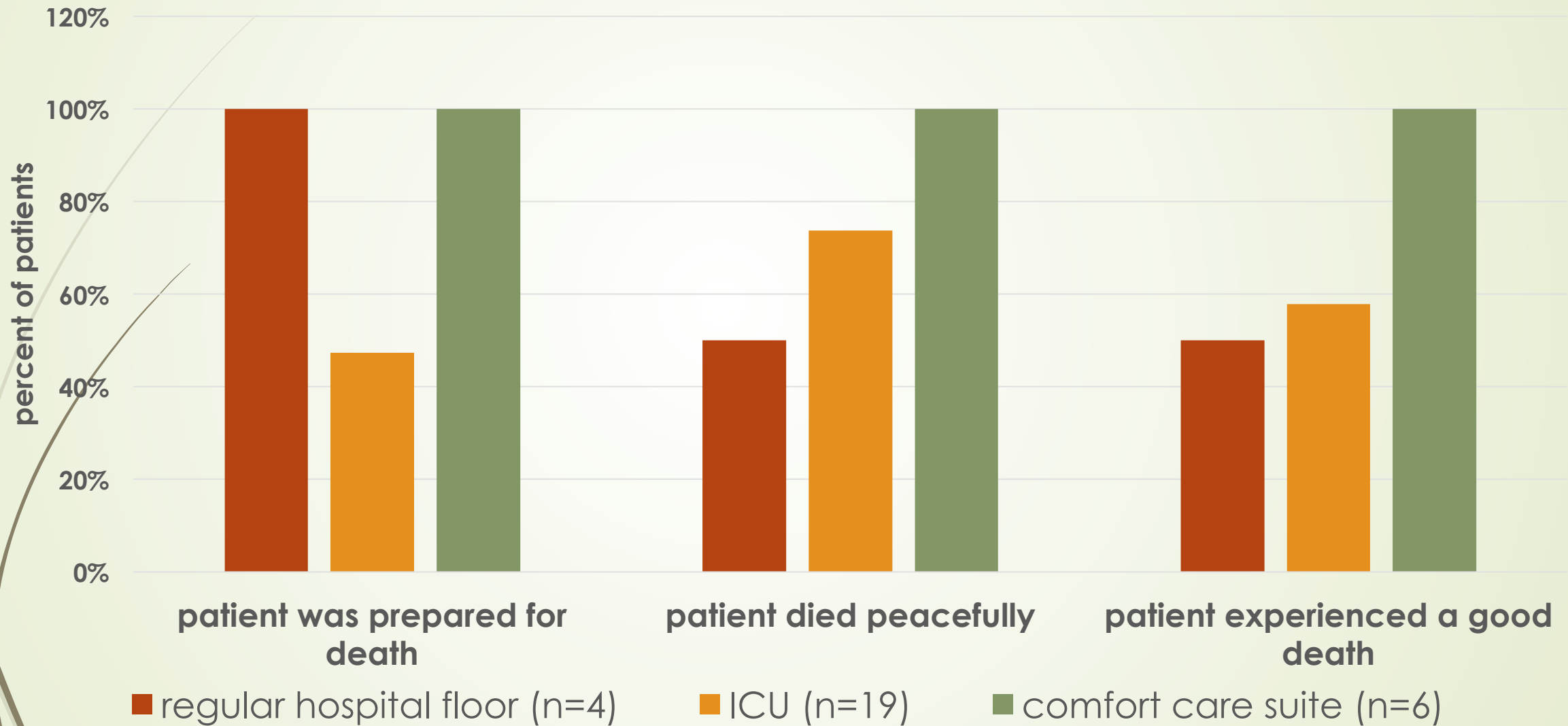
End of Life Care Planning



Emotional/Physical Experiences Near End of Life



Overall Quality of Dying Experience





Overall Trends

- ▶ Patients who passed away in the hospital's comfort care suites seemed to generally have the best outcomes, as reported by their family members
 - ▶ more likely to have had advanced directives, a designated healthcare proxy, and a DNR order
 - ▶ more likely to have felt they had control over treatment decisions




Overall Trends

- Comfort care suite patients are also:
 - less likely to have struggled to breathe or experienced emotional/physical pain at the time of death
 - family members are more likely to report their loved one was prepared for death, that their loved one died peacefully, and that their loved one experienced a good death



A Good Death Adult Survey 2016

- ▶ 12 responses so far
 - ▶ The majority of patients passed away in the ICU
 - ▶ Top causes of death are stroke, cancer, and pneumonia
- 



Selected Excerpts from 2016 Responses

- “I feel everyone was very supportive during all his hospital stays. He was in & out of hospital several times during his last 6 months of life. I appreciate all the care & support he & I were given.”
- “Pastoral Care was extremely helpful with donating his body (brain) to be studied. Also, were very helpful signing important documents during his awake/aware first week in ICU.”



Selected Excerpts from 2016 Responses

- “They did a great job, even cheered a little when they thought they might have a chance to save him. I had spent time in U.S.M.C, seen death many times, knew life support was no use and they allowed me to make a decision.”
- “I felt the ICU was too noisy at times. Lots of laughing by nurses. I know it is very stressful working there but it was hard for me to hear the laughing when [my husband] was dying.”



Selected Excerpts from 2016 Responses

- “I alone was proud to have [my brother] taken off life support, he would have done the same for me.”
- “He had several strokes the week before death, so he was not with it mentally to know he was dying. He was aware that family was always by his side.”



Questions?