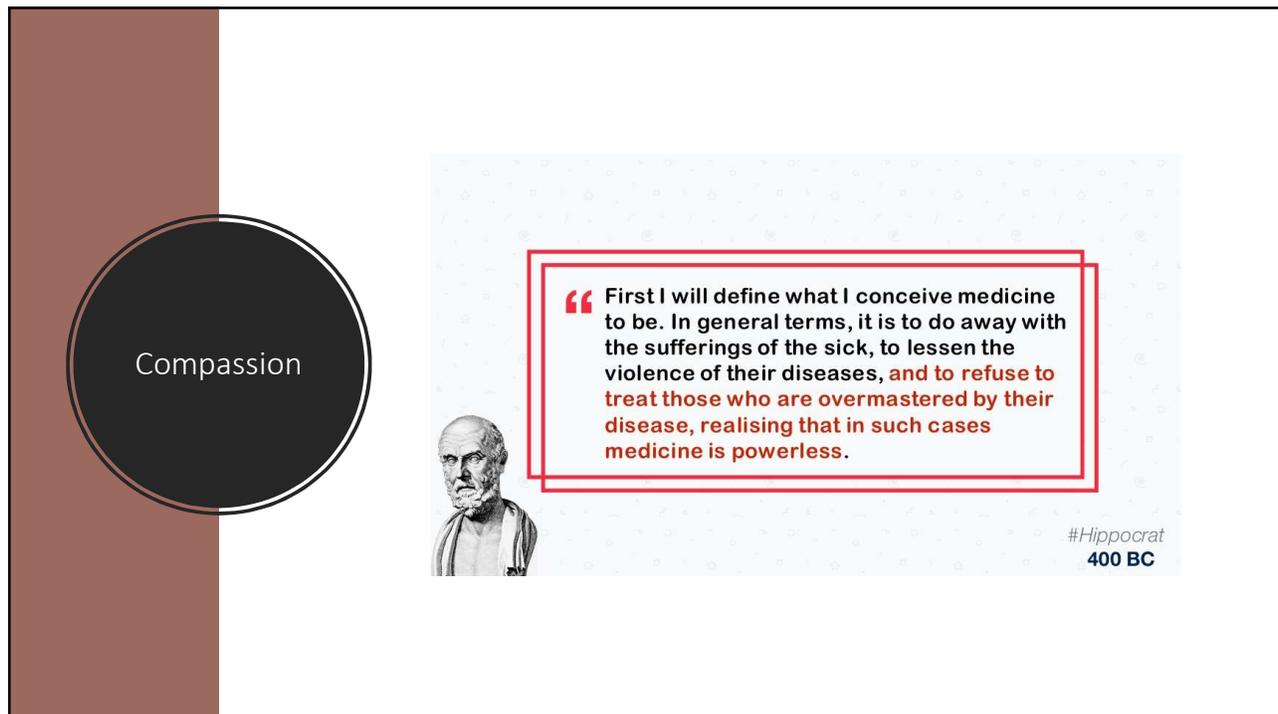


Compassion & Hope: Improving Healthcare Quality at the End of Life

Elizabeth Wickersham, MD, MS, FAFAP
Family Medicine, Hospice and Palliative Care

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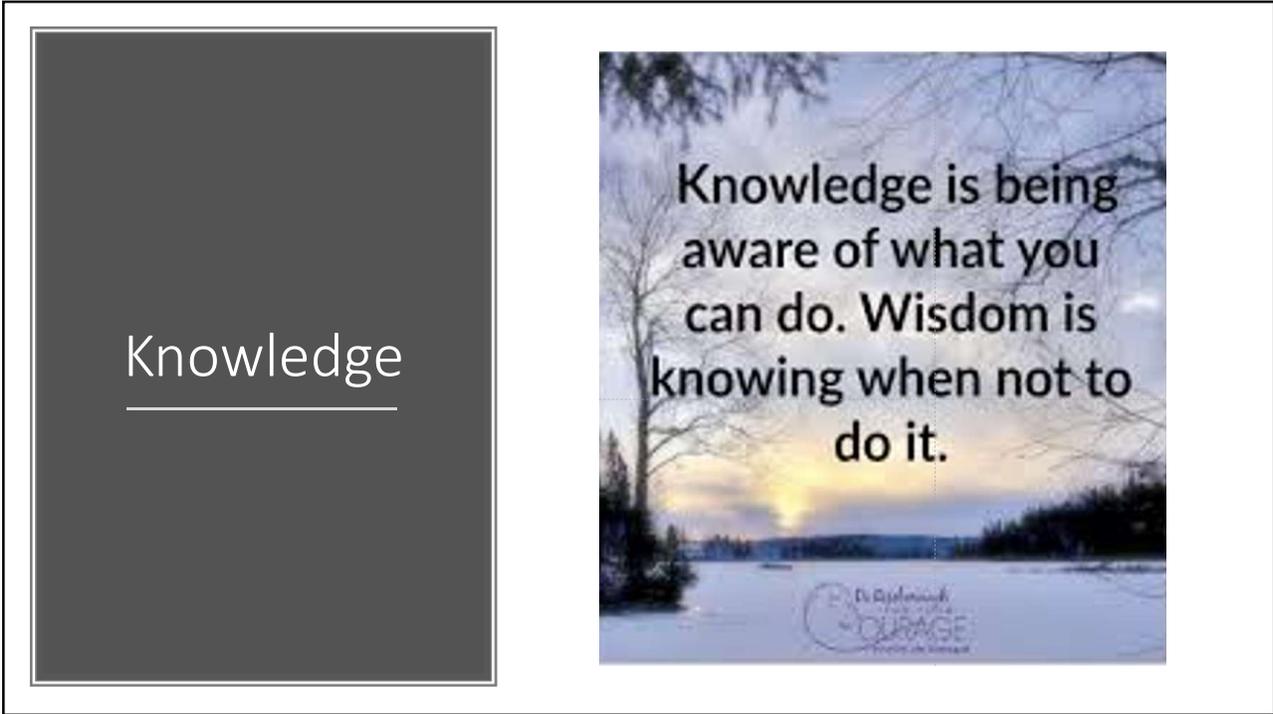


Compassion

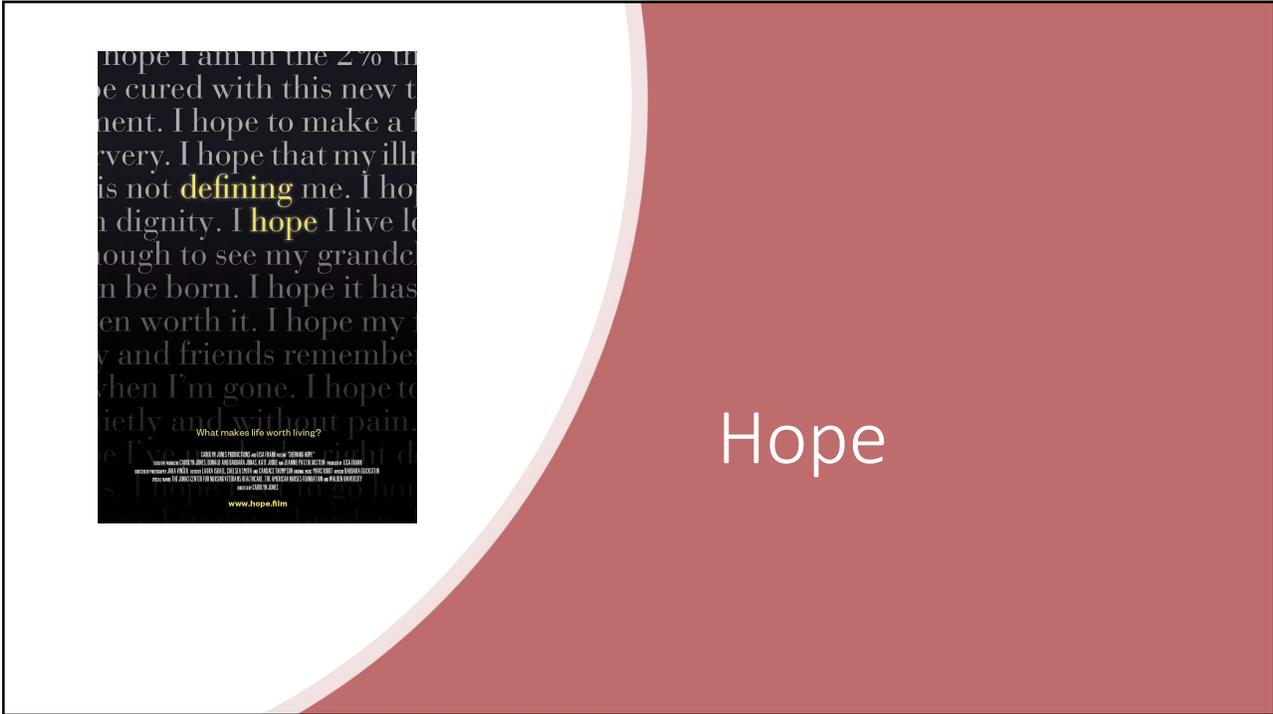
“ First I will define what I conceive medicine to be. In general terms, it is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their disease, realising that in such cases medicine is powerless.

#Hippocrat
400 BC

2



3



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Elizabeth Wickersham, MD, MS

I have no relevant financial relationships or affiliations with commercial interests to disclose.

I just have a **huge debt** of gratitude to those who helped make this study possible, and to the loved ones who shared their stories.

5

Special thanks to...

- Chaplain Danny Cavett and the chaplain's office staff
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- Funding:
 - Family Medicine Student Research Experience
 - Center for Palliative Care
 - OSCTR

6

What percent of people die in the hospital in the United States?

1. 10%
2. 25%
3. 50%
4. 75%
5. 90%

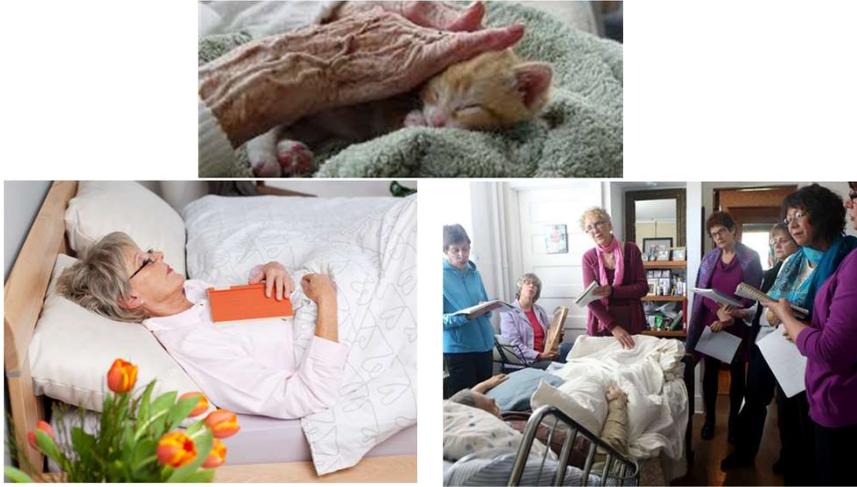
7

Where do most people say they want to die?

1. In a hospital
2. In a hospice
3. In the ICU
4. At home
5. Skydiving

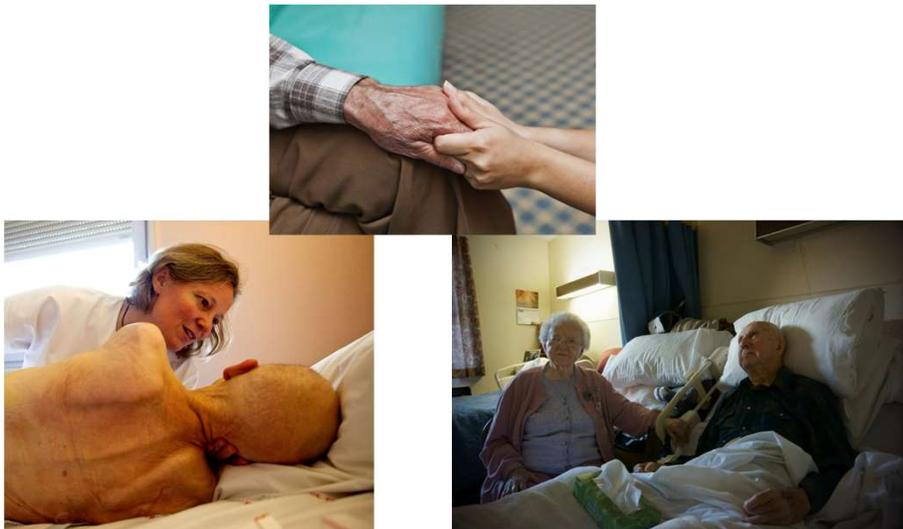
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Death at Home



9

Death in Inpatient Hospice



10

Where does the data show
people **actually** die?

11

Medicalized and Mechanized Death



12

Medicalized and Mechanized Death



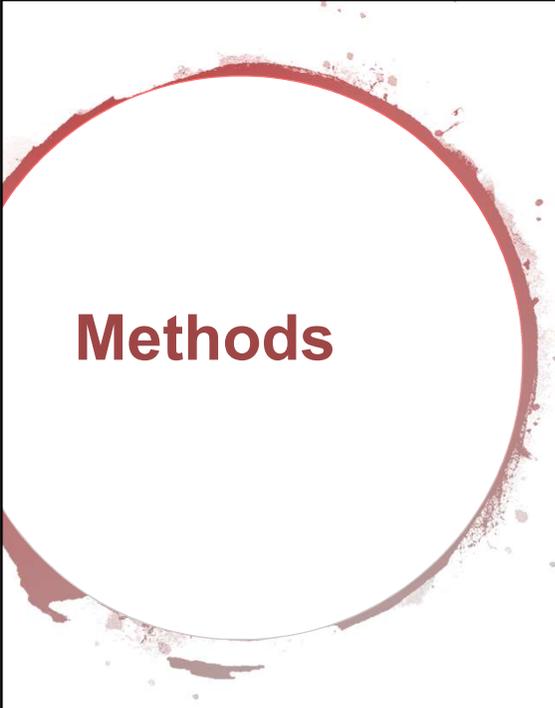
13

Since the hospital is where most people die, we thought it would be helpful to ask about the experiences people have during this final hospitalization.

14

Methods

15



Methods

- Study performed in conjunction with the Chaplain's office at OUMC
- Surveys approved by IRB and Compassionate Friends (for pediatric surveys)
- Survey sent to all those whose loved ones had died within the previous 90-365 days at OUMC, 2013-2017; at TCH 2014-2017

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Sequencing of mailing of surveys and letters

- Presurvey introductory letter sent
- ~2wks later Survey sent with SASE
- ~2wks later, 1st reminder letter sent
- ~2wks later, 2nd reminder letter sent
- ~2wks later, final Survey sent with SASE

17

How did we obtain the addresses?

Office of Resident Affairs Death Log

Patient Name: [REDACTED]

Room: [REDACTED]

Unit: [REDACTED]

DATE OF DEATH: [REDACTED]

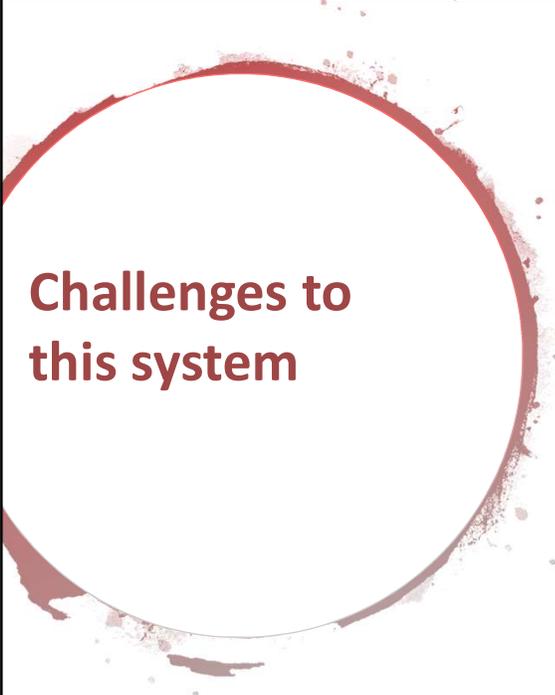
CAUSE OF DEATH: [REDACTED]

DISPOSITION: [REDACTED]

SIGNATURE: [REDACTED]

- Not from the medical record
- From the Chaplain's written death record for each death in hospital system

18

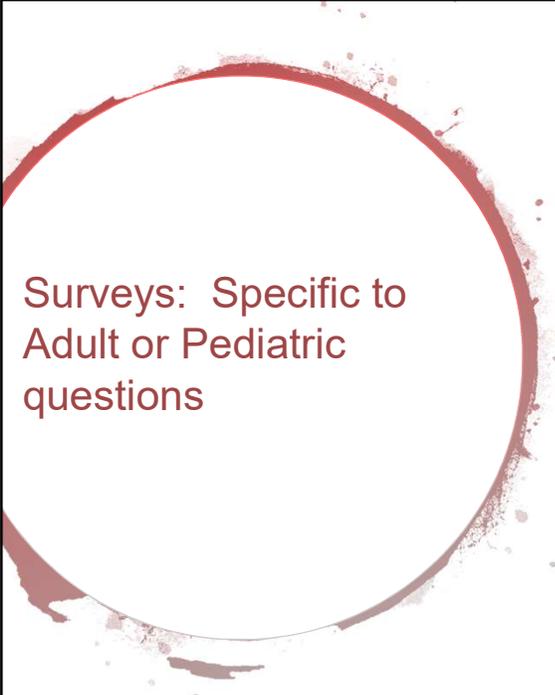


Challenges to this system

- **Records are handwritten**
 - Sometimes challenging to decipher
 - Students cross-referenced with Google Maps when addresses were not clear or complete
- **Frequent returned letters**
 - Address not known
 - Moved w/no forwarding address

Those introductory letters that were returned were culled from future mailings

19



Surveys: Specific to Adult or Pediatric questions

- Basics of patient's death
- End of life planning
- HCAHPS – Hospital Consumer Assessment of Healthcare Providers and Systems
- Emotional/physical experiences near time of death
- Overall quality of life during this time
- Demographics of respondent and patient
- Final Comments

20

Surveys

- Mailings included link or QR code to RedCap online survey form

If you need another copy of the survey, please call the Pastoral Care Department at (405) 271-5758 during regular working hours.

If you prefer to finish the survey online, please go to:

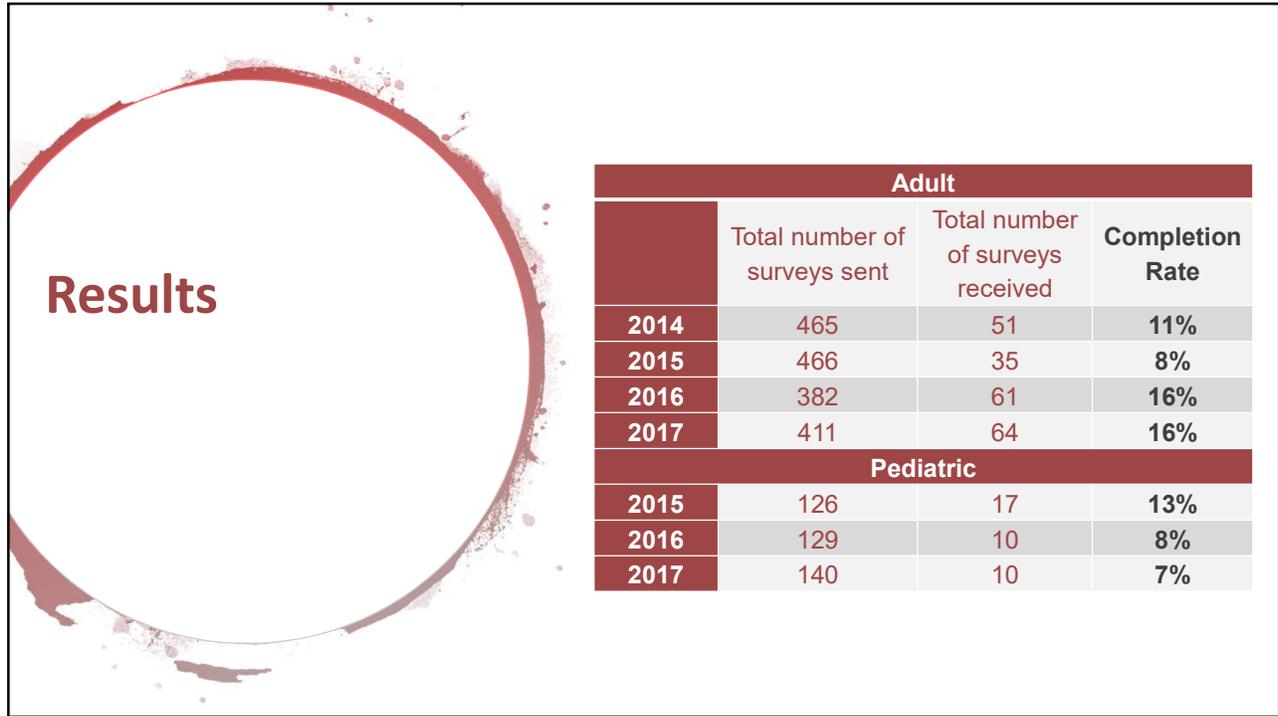
<http://j.mp/2sWcWtb>



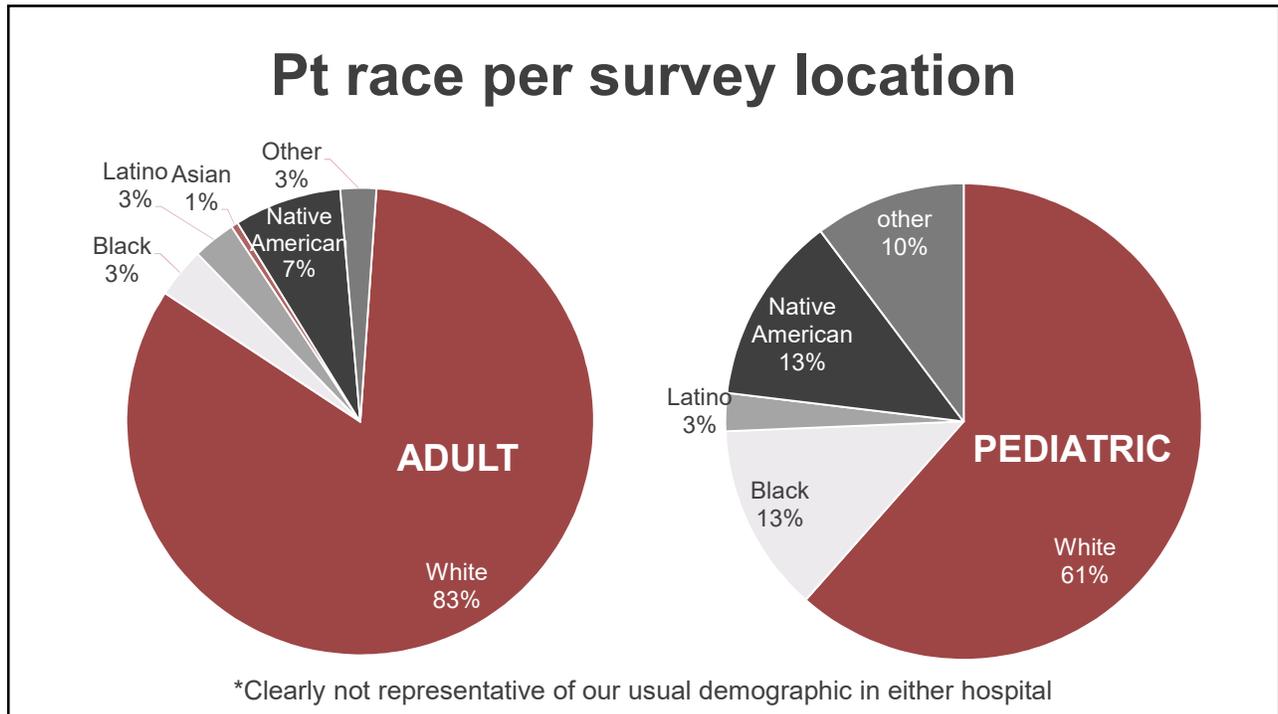
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Results

22



23



24

Gender statistics, by percent

	Patient M	Patient F	Patient other
Adult (n=200)	55	45	
Pediatric (n=35)	43	51	2

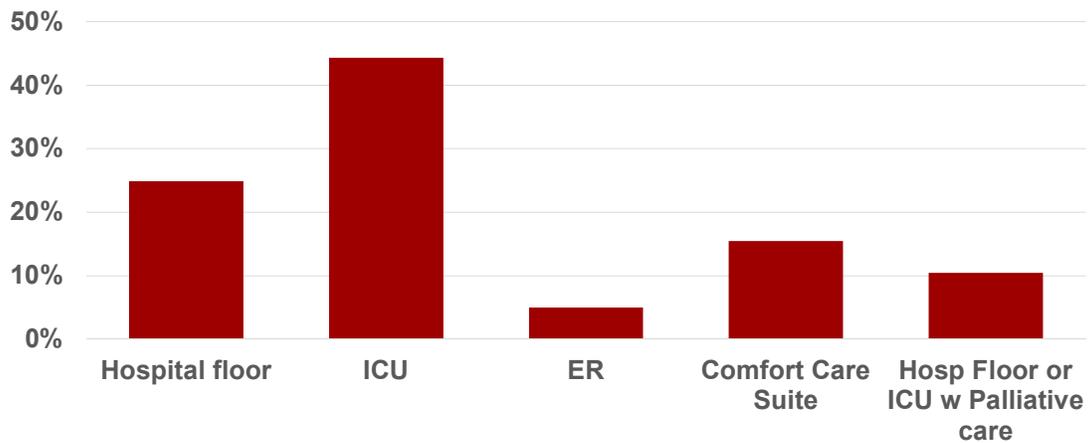
Pt gender fairly evenly distributed

	Respondent M	Respondent F
Adult	33	67
Pediatric	8	92

Majority of respondents were female

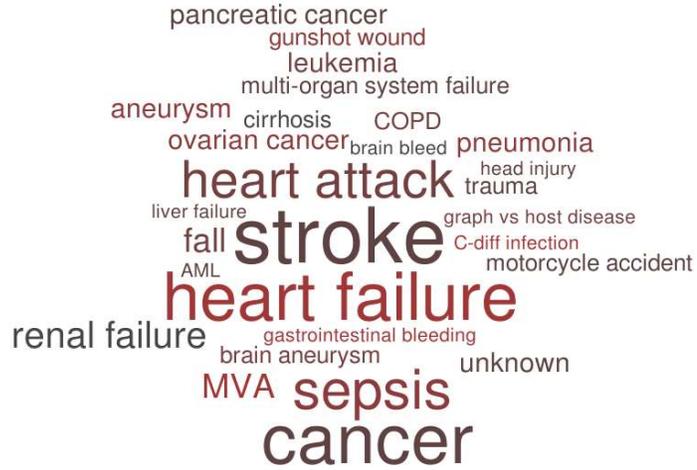
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Hospital Location at Time of Death Adult, 2014-2017



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Adult Causes of Death, 2014-2017

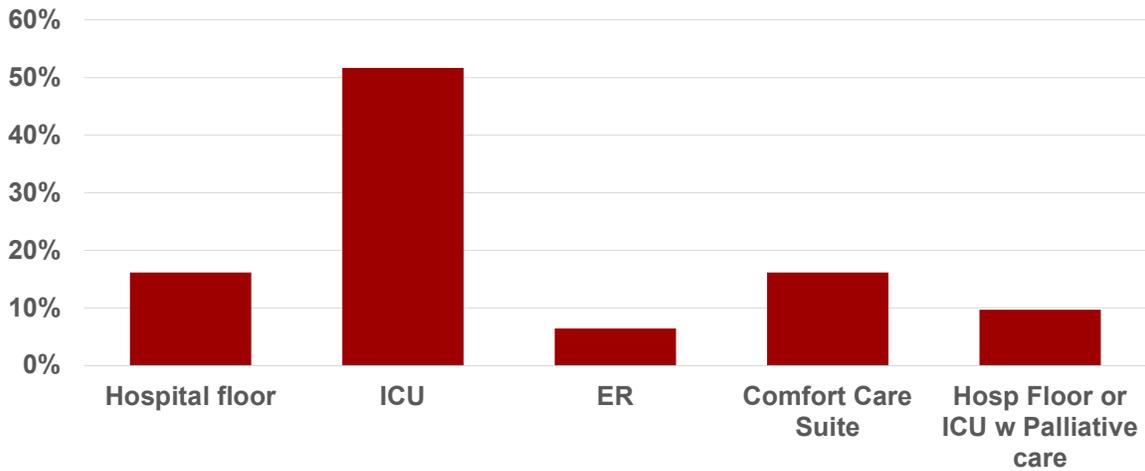


WordItOut

*Only causes of death mentioned 2 or more times included

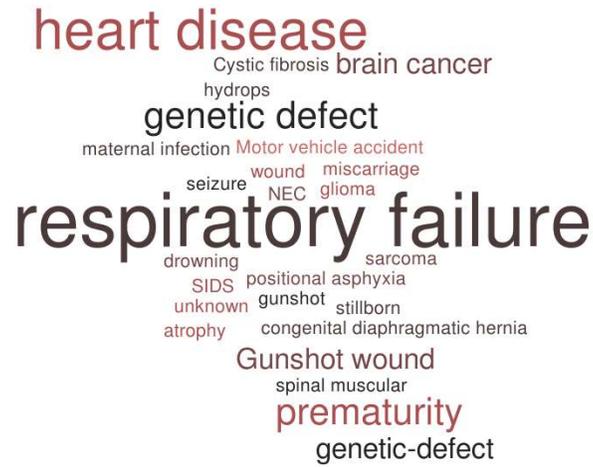
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Hospital Location at Time of Death Pediatric, 2015-2017



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Pediatric Causes of Death, 2015-2017



WordItOut

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Adult Cases: In their own words

Exploring themes of selected cases for opportunities for improvement

30

Wife, 60-69 yo m, complications from surgery, ICU, 6 weeks:
communication, recognizing EOL

- “In the end they refused to respond to questions were not on the same page as far as prognosis + plan very frustrating.”
- “Could have let him go sooner”
- “I had to throw a fit to get them to turn off the life support.” unrealistic hopes about his prognosis. Feel they were using him to experiment
- “The ICU is not a great place to die- too loud not private, I felt like I had to fight the doctors for my wishes to be honored, I got so angry with them I could not focus on saying goodbye. I called my son to come make them do something. One nurse helped me, hospital administrator never came despite my asking to see one, I am a nurse myself (RN) they acted like I was an idiot. When the chaplain got there I had to wait around to sign papers and just wanted to go home.”

31

Husband, 50-59yo f, GVH dz, hospital reg floor, 84d:
communication among physicians and agreement on plan, pain management

- ACP w/in last hospitalization
- Hospice offered, not used
 - “One doctor wanted us to stop treatment. Another said to continue. I chose to continue.”
- Strongly agree: Struggled to breathe; Agree: Physical pain.
 - Didn’t feel there was anything the hospital team could do to make better
- “She experienced a lot of pain during her last few months”
- “Hated food and had trouble finding things she could eat”

32

Wife, 50-59yo m, fall/broken neck, ED, <1d:
process of notifying family, communication

- “Next time a family comes in and they are sent to a private room with the clergy, make sure they have the "BALLS" to be upfront with the family. This woman beat around the bush, trying to make conversation so finally I asked, "Did my husband not make it?" She looked down and finally said, no ma'am, I'm sorry he didn't! I shouldn't of had to ask that question!”

33

Wife, 60-69 yo m, complications from cancer surgery,
 ICU, 65d:
communication, serious medical error

- “My loved one, [name] spent 65 days in the hospital at OU Medical. His health was up and down after his cancer surgery. We had more than one experience with the crash cart. He never left the ICU but there were many days that were good. Many days that we got good news from the doctors and truly thought that with Gods help their efforts would pull him through. There was talk about sending him to an LTAC facility closer to home. I had had some dealings with these facilities previously, so I thought this was a very viable option.
- I was spending less than 40 hours a week away from the hospital when his son would come and stay. I usually left sometime late on Wednesday and would return early Friday morning. This was our routine on the good days. There were a few times when I got a call and had to rush back. We lived 3 hours away.

(cont on next page)

34

Wife, 60-69 yo m, complications from cancer surgery,
ICU, 65d (cont):

communication, serious medical error

- Late Wednesday evening [date] they did a [xxx]scopy. I was not there, but Thursday [date] I got a call from Dr. [name] explaining that they had done the [xxx]scopy with a dirty scope that had been used on another patient and had not been cleaned before they used it on [name]. We discussed how it could have happened, we talked about the other patient being healthy and about how he didn't think this mishap would do [name] any harm. And also that he just wanted to be forthcoming about it. I told him hopefully this would be a learning experience for the hospital, that it wouldn't cause any health issues for [name] and that maybe there could be new protocol setup so that this situation could not possibly happen again. I assumed that maybe there would be discussions in person, but it was never spoken of again.
- By Thursday [date, 1 week later] we were told that [name] had an infection. He was throwing up and they put the NG tube back. By Monday [date, <1wk] they suggested that we talk to palliative care. He passed on [date, 2 days later].
- There are many many details left out of this story. Dr. [name] and staff worked very very hard for us to have a good outcome. However, I do believe that the mistake that was made with the [xxx]scope mitigated a lot of their hard work and played a huge roll in [name]'s death."
- Signed name, address, date

35

Sibling, 60-69 yo m, renal failure, comfort care suite, 2 mo:
cleanliness of room, communication

- "Social security sent papers stating the Dr's said his condition was not severe enough for the benefits and denied it even though he was in renal failure and had cirrhosis of the liver"
- "Other than the room not being cleaned at times the nurses and aides took very good care of my brother the medical team was awesome event too one Dr holding his hand in comfort and compassion"
- "Better housekeeping, Better communication between dietary and nursing to avoid waste"
- "Chaplain's office also showed us compassion and care after the death of our loved one an made themselves available to us"
- "Thank you from our hearts"

36

Mother, 40-49 yo f, cancer, comfort care suite, 8-21d
EOL/palliative care discussion, communication

- ACP: Yes, no DNR
- Expected death, not referred to hospice
- Agreed: Worried re problems leaving behind → more emotional support
- Agreed: Not prepared for death → more emotional support during last year
- Agreed: emotional pain at death, Strongly agreed: suffered pain longer than necessary

(cont on next slide)

37

Mother, 40-49 yo f, cancer, 8-21d, comfort care suite, *(cont)*:
EOL/palliative care discussion, communication

- “The healthcare is excellent, but the communication is terrible. Patient was in a clinical trial, which meant guinea pig. I felt that they kept her alive beyond what was humane. We've extended quantity of life, but not quality.”
- “During her last 10 days, I don't think she was in pain, but during her last year I believe she should have been offered palliative care rather than medically prolonging her life.”
- “The OU chaplains were awful! They need training on how to talk about what's happening + how to deal with it. The chaplain who visited us wasn't compassionate, look us in the eye, etc. He seemed completely out of his element.
- *No one ever spoke to my daughter about dying well, only living.”

38

Daughter, 60-69yo f, cancer, 1-7d, ICU

Continuity of care, communication

- “I felt like more time was spent trying to determine the primary cancer (which we never found out) than was spent explaining treatment options and managing the issues that were happening in the hospital (i.e. elevated ammonia levels, not using the restroom, etc.)”
- “My mom was moved around a lot. Just when I felt we would get to know a nurse and feel comfortable that the nurse knew what was going on, we would move again and we were only there a week! The nurses are clearly understaffed. To me it seems hard to diagnose changes in a patient when they're moving around that much. I feel like nothing was being done to help my mom until they knew the exact primary cancer and they didn't move fast enough to determine it before her organs began shutting down. I think the team of doctors knew my mom was dying but never fully told me. Maybe they tried and I didn't want to hear it. I can't be certain. If given the choice, I probably would not choose to take another loved one to OU Medical Center. I know it's supposed to be the best around but that has not been my experience.”

39

Son, 50-59yo f, renal failure, cardiac arrest, ~3 mo ICU

Prognosis, communication, listening

- “We understood ICU rules, however, they did not allow as much time as we wanted with her.”
- “We were always told things were looking better, then all of the sudden cardiac arrest we weren't expecting that.”
- “Dr. [name] was great. We asked nursing staff to call for him multiple times and they failed to do so. We felt he knew her better, and did great with her before her sudden death.”
- “Communication. I feel we may have been lied to a few times. If we ask for something, just help us instead of making us wait. Bigger ICU rooms, they could be better too. Communication...communication.”

40

Husband, 85+yo f, stroke, 1-7d, hospital floor Honoring pt/family requests, listening

- “The PA that saw him while we were in hospital, I asked her if he could get on urologist to check on him when we thought all the pain was from kidney stone. She said "don't you have a urologist at [home town] I said yes but he is in hospital now. She said well he can just go see his when he gets home. He had the septic poisoning at that time but we thought it was kidney stones. He died two days later.”
- Was there something you felt the hospital team could have done to help?
“Maybe a little bit. He really thought the feeding tube might help him gain weight and would be able to have chemo and maybe beat it again.”
- “I wish they had called in a urologist and maybe done X-rays to find the septic poisoning so we could have know why. He was in so much pain.”

41

Wife, 60-69yo m, cancer and septic shock, 8-21d, ICU Cleanliness of room, billing

- “We were there 8 days. I changed his sheets twice myself. They brought in one of those breathing exercise things to prevent pneumonia it was never used but I'm sure we were charged for it. The PA noticed the things on his legs to prevent blood clots was not turned on. I said they never plugged them in since he come out of surgery 7 days ago.”
- “I think a patient should be bathed and gown changed every day. I did the best I could, but had to go to nurses desk and ask for towels + gown when I did clean him up. I would love to see some better sleeping chairs in the rooms for the person staying with the patient. The RN's were very nice and came to give medicine. I personally in our case felt like they (the Dr's) thought he is terminal and not much we can do but was upset when it took him almost dying and they did cpr and got him back to decide to do a pet scan to see what was happening and found the septic poisoning after two days of me asking if they could do something for his severe pain. And then I called accounting when I got the bill and told them I will have to make monthly payments for the bill. After I paid three payments with none being late or missed I receive a letter from a collection agency where I was turned into them. So I called and hopefully have that fixed but my nerves are shot and therefore I continue with pain and suffering over his death. I do hope none of my family members have to use O.U. Hospital again. Sorry but I did not have a good experience with them.”

42

Wife, 60-69yo m, lymphoma, heart attack, 8-21d, ICU
Communication among physicians, agreement on prognosis and plan

- “My husband was in and out of OU Med for 8 months prior to death. Much of care was on the 6th floor receiving chemo and also many days receiving treatment for complications. We also received care in ER -- 'step down' room and ultimately coronary ICU + regular ICU. He received excellent care in all the areas he was treated. Nurse on 6 were excellent. My only complaint would be: toward the end he had many specialists in numerous areas and their didn't appear to be enough communication between them, leading to some confusion about chances of survival.”

43

Son, 70-84 yo m, hit by truck, 8-21 d, ICU
Pt worry: family burden of cost of hospitalization

- In hospital 8-21 days, pedestrian MVA collision.
- My loved one was worried about problems or responsibilities that he/she would be leaving behind. “\$450,000 Bill”

44

Pediatric Cases: In their own words

Exploring themes of selected cases for opportunities for improvement

45

<1yo, Trisomy 18 w/extreme prematurity,
mother, reg floor, <1d:
struggled to breathe, EOL photographer

- Strongly agree: struggled to breathe at time of death

“They tried to intubate him and were unsuccessful. I feel like they did everything they could prior to handing him over to me so I could hold him before/while he passed.”

“I would highly recommend that you get in touch with photographers like "Now I Lay Me Down to Sleep" in order to provide photography for those parents who wish to have their babies photos taken. A nurse offered to take pictures with our son, but was unable to because she didn't have her camera there.”

46

<1y, SIDS, mother, ED, <1d:

ED communication, concern for family

“The Dr's in the E.R. gave up & stop trying to save my daughter before my husband & I had a chance to get to the hospital. We left our home right after the ambulance took her. We just wish the Dr's did more to keep her alive until we could get there.”

“My family are Christians & have/ live by strong beliefs/ faith. Of course God's presence was there, but my daughter did not have us, her parents, there to hold, hug, kiss or just love her before she slipped away & no clergy was in the room either.”

(cont on next slide)

47

<1y, SIDS, mother, ED, <1d, *(cont)*

ED communication, concern for family

“The Dr. had poor bedside manners & was not sympathetic @ all. He told us very coldly that they "tried everything they could but they couldn't get her back," so they "stopped all measures. He had already called the M.E./ coroner so we were only allowed a few minutes w/ our deceased baby girl. Then we were removed by staff to be bombarded by social services, while we were in the worst pain ever.”

“My daughter was still alive when the ambulance took her & while she was in the ambulance. But the one place & the "top children's hospital" didn't & couldn't save my baby & just gave up on her. My/our daughter was everything to us & our horrible experience is still extremely traumatizing. If anything (God forbid) ever happens to my 9 yr. old son or the child I am pregnant w/ now...we will never come to or allow our child to come to OU Children's Hospital, ever. Billing Dept. also made a huge mistake by sending us a huge bill about 2 wks. after her death when she was fully covered by insurance. Our ins. company & us informed the billing dept. of this & the next mth. they sent us another full bill. Ridiculous!”

48

<1y, female, hydrops, mother, reg floor, <1d:
Post-mortem care

- “It would be nice if pastor was there to baptize baby [name]. My own pastor blessed her though”
- “Hospital did the best they could. only suggestion is no parent should have to see their child bagged like trash. That’s an image that hurts badly. Cooling cots for babies need to be available for families to spend time with their babies.”
- “For babies there needs to be cooling cots to allow family much needed time and ability to have deceased baby kept in room at all times. It really hurt that my child was bagged like trash and put in a cooler. And education about the choice parents have to transport their baby to funeral home. And when doing so child should be swaddled and then covered with respect to be taken out, not bagged. But I loved how the nurses helped bathe and dressed my baby girl and care for her with love as if she was alive.”

49

<1y, unknown, mother, ?, <1d:
communication, responsive to pt needs

- Strongly Disagree: Hospital team good at communication among team members to me and my family about my child’s condition.
 “I wanted them to tell me what went wrong with my baby they never did”
- Agree: HCT treated my child with dignity and respect; compassion
 “I kept calling the doctor to come in there to give me pain meds didn't come in until time to deliver I was in pain”
- Agree: I have been able to find meaning in the death of my child.
 “The staff members there need to come when needed. I was in so much pain and kept calling them it was the shift after 7 pm night”

50

Miscarriages:

1. Clear communication/handoff: “Make sure all staff that talk to the patient is aware of what is going on. I had to go to labor and delivery and a nurse asked if I was excited?? She was unaware of the situation & made it extremely awkward. Also some people aren't religious and don't want to talk to a chaplain? Maybe offer just a counselor?”
2. Maternal guilt/opportunity for counseling: “My child died of a miscarriage from myself contracting hepatitis E. My hospital stay was good & I have no complaints.”

51

Discussion

52

“Thank you”

- “I would like to give a very special thanks to the OU Medical team. Very respectful + kind. Never once did I feel uncared for.”
- “Thank you to your hospital and staff for their skill and compassion and for offering us the opportunity to have this [comfort care] suite.”
- “They let me in there to see my son cleaned him up and everyone let me see him in time to say goodbye and be there. I appreciate that no matter hard it was.”
- “The doctors, nursing staff and support personnel were wonderful.”
- “The doctors, nurses, and aids were very caring and supportive.”

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“Thank you”

- “Everyone was wonderful, kind, and respectful to our unique situation. Nobody acted as if we were "just another" family in a difficult situation. Everyone was kind, considerate, and respectful of my special needs brother. Thank you. Priest after his passing was helpful in explaining next steps in the process of funeral. Much appreciated.”
- “She knew some of her choices contributed to some of her medical problems. The staff helped to keep us all away from those thought processes. Your staff used knowledge and skill that was amazing to watch - They gave us a few good days with her before she passed.”

54

“Thank you”

- “Your staff is an amazing team who strives to learn, teach and grow with skill and compassion. The only area I felt could improve was post death care of immediate family. I have never been so filled with grief. For a week or more I was totally hopeless + helpless. I would like to see help for those family members. Thank you for your doctors, nurses + students-you are all wonderful. Keep learning and teaching always.”
- “Did a great job.”
- “We (the family) felt OU Med provided him quickly and very professionally with a Dr. and staff qualified to perform in the only way possible to help him. So sorry that professionally was not quite enough to save him, but at least the Dr. really tried. Thank you OU Medical!”

55

“Thank you”

- “She was DOA for all intents + purpose they simply kept her breathing with the vent until I got there. They were awesome.”
- “ICU staff made the whole experience the best it could possible be. I appreciate them immensely.”
- “I thought it was very kind of the nurses that had cared for him the years came to say goodbye. Very touching!! The quality of care was excellent! The doctors and all the nurse were educated, kind, compassionate and always informed us of his status.”

56

“Thank you”

- “I feel at the time of my mom stayed everything went accordingly. The nurses and doctors were all good to my mom and our family. They understood our need. Thank you from her oldest daughter and her family.”
- Do you have any comments about the way your loved one's religious beliefs were handled? “excellent and helpful, thoughtful”
- “The nurses on duty were very thoughtful and comforting. The chaplain on duty was great. He helped me in fulfilling my loved one's request (to donate his body for medical training). Bless him!”

57

“Thank you”

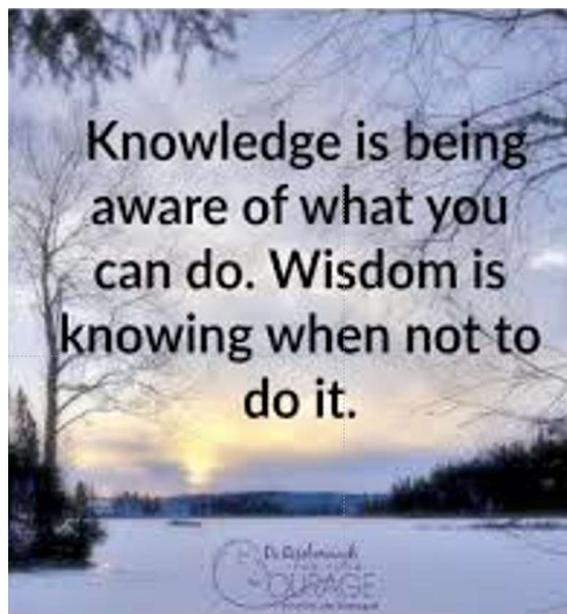
- “For 22 days, the doctors treating [name] provided me daily status reports on her condition + treatment. The ICU nurses are the best in the business, outstanding people. OU Med can be extremely proud of ICU team.”
- “The whole staff from people in admissions, to the ER doctors and ICU doctors, the nurses and respiratory therapists were attentive to my dad's needs and kind to my sisters and me. They even didn't give me the "look" when I sang to him.”

58

“Thank you”

- “You did all you could. Wish we could have come while the cancer was treatable. Really appreciated the comfort care suites. Provided a quiet; private place for me and family to say good-bye.”
- “The clergy provided was very much appreciated.”
- “The staff was wonderful. It was a terrible time for our family and they made the situation bearable.”
- “Except for 1 nurses everyone was very caring and pleasant to dad and our family. Thank you!”
- “Thank you for asking”

59



60

Compassion

“ First I will define what I conceive medicine to be. In general terms, it is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their disease, realising that in such cases medicine is powerless.

#Hippocrat
400 BC

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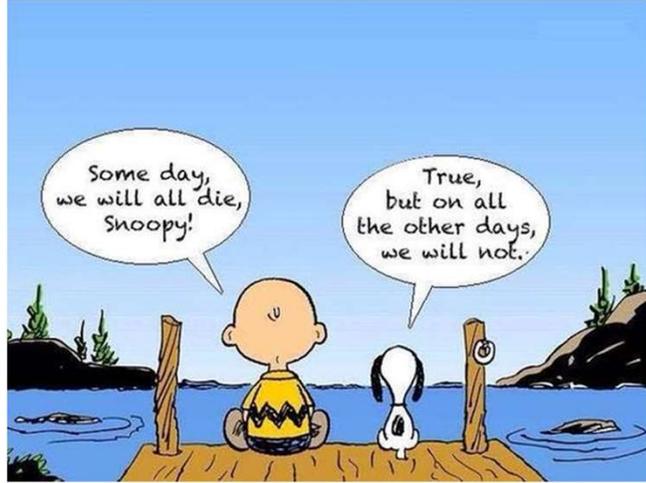
I hope I am in the 2% that will be cured with this new treatment. I hope to make a difference. I hope that my illness is not defining me. I hope to live with dignity. I hope I live long enough to see my grandchildren be born. I hope it has been worth it. I hope my family and friends remember me when I'm gone. I hope to die quietly and without pain.

What makes life worth living?

www.hops.film

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Questions?



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Questions

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40-49yo m, MVA, spouse, ED, <1d:

- “The chaplain that came to the ER room where they told me + my family that [name] had passed in ambulance on the way there from the accident kept pulling me away from my family to ask questions like how we met, our song etc. Very inappropriate. My family + I were talking + comforting each other. She was asked to leave. I don't remember her name. She was replaced by a very nice gentleman. The accident was the evening of [date]. It angered all of us that she kept pulling me out of conversations to ask pointless things. Very touchy too.”
- Healthcare team showed compassion, treated pt with dignity and respect, explained things in a way loved ones/pt could understand