Tabitha Torres

Claire

1. How did you feel throughout the time that you were watching the video? This was extremely sad and I really didn't want to watch it. My good friend has a child with cystic fibrosis and it makes me think about his outcome and that no matter what eventually he is going to die from this illness. I loved the attitude of Claire and she really had so much joy and sunshine in her for a child who is literally dying. I thought she as an amazing young girl and so very strong. I tired to tell myself it was good she was finally no longer suffering and that now she could be a normal young girl in Heaven but it didn't help me feel anything but sadness. We lost my nephew of 2 days old from renal failure and to this day I still don't have actual peace when I think about it. Losing him was the hardest thing my sister ever had to face in her entire life and as her big sister I was helpless and had to just stand on the sidelines and watch her endure the worst pain a parent can ever go through. As I watched this video it made me feel helpless and sad because there was nothing anyone could do for Claire. I know we are all going to die but to see young people, children and babies die it just hits me really hard and sometimes makes me question God's reasoning.

2. Give a description of Claire's condition and identify the main problems that you identified? Claire had cystic fibrosis which causes an over production of mucus. Cystic fibrosis is a fatal condition which usually has more respiratory complications along with frequent infections due to being immune compromised.

3. Based on your observations, what were her clinical manifestations and how would you explain these clinical manifestations? Over production of mucus, chronic productive cough, frequent respiratory infections, immune compromised, and at risk for malnutrition due to her body's inability to absorb nutrients adequately.

4. What specific nursing interventions would you want to take into consideration to provide for this patient's unique care needs? Due to the immune system being compromised I would recommend frequent hand washing, wearing a mask when in public or in health care settings. She is going to need nebulizer treatments and CPT treatments round the clock.

5. What other members of the care team should you consider important to achieving good care outcomes? Respiratory Therapy, specialized care from a pulmonologist, possibly home health care nurses, a dietician, and eventually hospice nursing care to help give Claire the best quality of life for as long as possible.

6. What financial challenges did this family face because of Claire's condition? First of all the medical equipment, medications and just the things needed to all Claire to sustain life with cystic fibrosis. The second thing would be the amount of time off work or unable to work because their child has a terminal illness.

7. What did you learn from this experience? I thought it was important to hear how she felt about how people treat her. To give a voice to sick and terminally ill patients beyond a St. Jude's commercial. I made me want to make a

conscious effort to get to know my patients beyond their diagnosis and to focus more on their holistic care and not just their basic medical needs. I think we all get a little lost sometimes and focus on the job at hand without taking into consideration this is not just a job, especially when we are short staffed.

8. How will you apply what you learned by watching this video to your clinical practice?

9. Are there other significant words that Claire or her mother shared that impacted or inspired you?
   “I’ve been sick and dying my entire life” “I just want to go clubbing once, just once” “once you get healthy then you can” those statements hit me the hardest. Claire was just a young girl who had dreams of doing simple things like going out with friends or the chance to go clubbing. She has literally been treated as if she was dying at any minute her entire life and the truth is she was but she wanted to feel something other than just her diagnosis and that hurt my heart for her. Then the once you get healthy comment was sad to me because she was never going to get healthy she was going to continue to be fragile and her illness was going to progress over time not get better.

10. Is there anything else you would like to include in your reflection of this experience? I just am very thankful for healthy children. I forget how blessed I am sometimes and I think we get reminded that sometimes in the medical field as we see patients like Claire and her family. As a mother I just cannot imagine what her mother felt and how hard it was and is to live with a terminally ill child and with the loss of a child. I know God has a plan for each of us and I am thankful we get the chance to love people and be there for them on their most vulnerable days as nurses, it takes a lot of love and empathy to do what we do and I am thankful God gave us the heart of a nurse.