

1. How did you feel throughout the time that you were watching the video?

Throughout the video as Claire was talking about her illness and how she chose to live her life was shocking to me. It is so crazy that someone could view a terminal illness in such a positive light. I was feeling very uplifted by her attitude and began to start thinking about how I take my life for granted every day. Yes, I am going to school so I can help people and serve people, but this video inspired me to look at my day-to-day life and figure out how I can live to make a difference like Claire.

2. Give a description of Claire's condition and identify the main problems that you identified?

Claire had Cystic Fibrosis, which is an illness that affects the cells that produce mucus, digestive juices, and sweat. These fluids are thicker than they should be, which causes passageways to become clogged. The mucus that accumulates in the lungs can become infected and cause serious illness. These secretions are so thick, that mechanical vests and chest physiotherapy may need to be used to help loosen them up so they can be coughed up. The main problem that Claire faced was with her lungs. Her lung function had been gradually decreasing because of the mucous and secretions so she had to be on oxygen and receive therapies like the ones listed above.

3. Based on your observations, what were her clinical manifestations and how would you explain these clinical manifestations?

The main clinical manifestations that I observed were respiratory. She had a cough that sounded gunky due to the mucous accumulation. She stated that she was tired, so fatigue is another one. She had shortness of breath and potentially some wheezing. I would just explain these as symptoms related to mucous accumulation. The cough could be due to her body trying to get rid of the mucous. Any abnormal breath sounds would also be due to the mucous accumulation. With all of the mucous present

in the lungs, they are having to work harder. Her lungs also were not functioning 100%, so that is why she experienced things such as shortness of breath and needed supportive oxygen.

4. What specific nursing interventions would you want to take into consideration to provide for this parent's unique care needs?

I think it could be beneficial to promote exercise as long as the patient is not too tired to do so. I know that this can help loosen up the secretions so that they can cough up the mucous. Before the patient participates in any form of airway clearance therapy, it is important to make sure that they are getting their prescribed bronchodilators in order to open the airway to better get rid of the secretions. It is also important to make sure that patients have a good grasp and understanding on how to use their ACT devices so that it is effective.

5. What other members of the care team should you consider important to achieving good care outcomes?

Respiratory therapy is going to be a great resource to these kids. They can provide great teaching and demonstration of the devices used and establish clear goals. They can let us know what they expect to see so that we can monitor the child's progress. Nutrition is a good resource since there are issues with digestive secretions. There are certain fat-soluble vitamins (A,C,D,E) that they will have to take in the form of water-soluble vitamins so that they can be properly absorbed and used in the body. They can also discuss good food options to make sure they are eating foods that will help them feel better.

6. What financial challenges did this family face because of Claire's condition?

With her condition, she had a lot of hospital stays full of therapies, drugs, and other treatments. These bills surely began to pile up. There were also drugs and treatments that were continued at home that

contributed to financial challenges, as well as the lung transplant that she qualified for in her final days. Luckily, she set up a GoFundMe that helped cover some of the cost for her transplant.

7. What did you learn from this experience?

I learned not to take anything for granted in life. I also learned that sick children may not always want to be pitied. They want to be normal children and enjoy the same activities that other children do. It is important to treat them like human beings and encourage/enable them to do things that their illness allows for them to do.

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

I think it will definitely have an impact on how I treat patients that are dying. Even if they don't have the same outlook on their situation as Claire did, how we act contributes to how they feel. It is important to be sensitive to their feelings, but don't look at patients and treat them differently because they are dying. I would want to have a positive impact on them in their last days.

9. What are your feelings about caring for a child that is actively dying?

I think that our role as a nurse in this situation is as important as ever. Although they are dying, they are not yet gone. It is important to allow them to make the most of their situation by finding activities that they can participate in. We can discuss their level of understanding of what is happening, and maybe even include them in the conversations of what they would want to happen throughout this process. It is important to allow for family bonding during this time and talk about what is happening with parents and siblings and offer support. I feel like it is such a ministry opportunity, and I really think that we can have a positive impact on these families as they go through the unimaginable.

10. Is there anything else that you would like to include in your reflection of this experience?

I would just like to say that we take our health for granted each and every day. It is inspiring that there are people like Claire out there that know that they may have limited time and want to do something impactful with it. It was definitely an eye opening experience and I really enjoyed the documentary.