

End of Life Scenario- Claire: The Documentary

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

I felt very engaged with the video. It's amazing how brave and optimistic Claire remained throughout the time of her disease. She was a very positive and bubbly person, and stayed that way from a very young age, up until she was 21. While watching the video, I wanted to learn more about Claire and learn about her. I began to google her and I became very emotional once I read that she passed a week after her lung transplant, as also told in the documentary. She was an amazing person that inspired so many others. Not only learning about Claire, but the effects of CF.

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

Claire has a condition called Cystic Fibrosis, often referred to as CF. The lungs make overproduction of mucus and blocks and plugs the airways and makes it difficult to breathe causing impaired gas exchange. The genetic disease causes respiratory infections eventually causing damage to other organs in the body. This is a lifelong battle that they have to deal with from the time that they are diagnosed. The treatment is very extensive as Claire explained. She would have treatments throughout the whole day whether it was pills, nebulizers, her vest, and many other things. Most of her life she spent her time in the hospital trying to stay well and trying to stay alive.

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

Some clinical manifestations I observed in Claire were a cough with phlegm, shortness of breath, wheezing was audible, and she seemed to be fatigued. Due to the overproduction of mucus, Claire would try and cough to get up all of the secretions. When she would cough constantly, it would take her a while to catch her breath. When Claire would talk, you could sometimes hear her wheeze, and her voice seemed raspy. On the rougher days, Claire looked fatigued and worn out.

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

I noticed all nurses wore PPE when caring for Claire. Patients with CF are more susceptible to respiratory infections so it is important that they are careful. We don't want to put a patient with CF near a patient with pneumonia or covid. Some patients are recommended to wear gloves and a mask to protect themselves from droplet and contact interactions. Patients with CF are told to stay 6 feet away from those that are sick. They need lots of education on their meds, treatment, condition, procedures, and many other things. We may educate the patient directly, or to the parents depending on their age.

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

Pulmonologist, physical therapist, nutritionist, pediatrician, primary care provider, medical geneticist, respiratory therapist, nurses. These team members are very important to the care of the patient, including many others.

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

Claire stated how sometimes she was alone at the hospital because both of her parents had full time jobs, to keep up with financial expenses. Claire made a Go Fund Me asking for donations so that she could receive a lung transplant. The treatment is not cheap and neither is the cost of receiving a lung transplant. She also helped many others and began a foundation that helped other people that had CF like her.

7. What did you learn from this experience?

I learned to not take life for granted. Claire said how her life is not different from anyone else's because we are all human and we all feel the same emotions. Claire really inspired me to stay positive no matter what happens and to always live life to the fullest everyday with no regrets. Of course Claire's story is her own, so many others do not go through the same things.

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

I would like to be a light to my patients like Claire was to everyone else. I want to show my patients that there is a whole life out there to live, and to not let their health hold them back. I want to inspire them, so that they can inspire others. One thing Claire did not like is when people would pity her. She wanted people to be happy because she was happy and accepted her disease and lived with it and made a positive outcome from it.

9. Are there other significant words that Claire or her mother shared that impacted or inspired you?

I just feel so amazed by how Claire made a negative situation, a positive one throughout her whole life. All of Claire's words inspired me and she talked like a very intelligent person. I loved how she would go out and talk to people, and inspire and motivate them.

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

I really enjoyed this documentary and learning about Claire and her life and journey with CF. She grew up to be an amazing young woman, and I was saddened to learn of her death. She left this world, but left her mark behind and inspired so many.