

End of Life Scenario

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

At the beginning of the video, I really felt a lot of sadness and not to lie, I felt so sorry for her that she only gets to live a couple of years of her life. But then watching the rest of the video made me feel better just watching her outlook on life. She was such a selfless and caring person from a younger age, she dedicated her life and time she had left to devote to helping other with Cystic Fibrosis and she never profited from the donations.

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

Claire had Cystic Fibrosis, Cystic Fibrosis is a genetic condition that affects a protein in the body that affects cells, tissues, and glands that make mucus and sweat. The life expectancy today is 44 years old, but Claire only lived to be 21.

The main problems that I have identified are first the problem with oxygenation, she is always going to depend on oxygen. Her problems with her lungs are due to the accumulation of mucus and secretions that affect the gas exchange and the delivery of oxygen throughout the body. The other problem would be the nutritional needs of a person suffering from Cystic Fibrosis since they need around 5,000 calories per day to maintain the demands of the body. They must be eating constantly to provide the body with the nutrients that it needs due to metabolic demands.

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

The clinical manifestations I observed were a productive cough accompanied by shortness of breath. These clinical manifestations are expected for a person suffering from Cystic Fibrosis, due to the accumulation of mucus and secretions in the lungs.

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

They need specific treatment such as breathing treatments to open the lungs such as bronchodilators, a couple of times per day. They also need to receive antibiotics, due to the infections in the lungs caused by the bacteria *Pseudomonas aeruginosa*. They can receive antibiotics IV or through a port depending on the term (short or long term) of the antibiotic course. I would also consider they need to rest in between treatments or after due to all the energy utilized during the treatments. They fatigue easier and have shortness of breath all the time therefore they need to rest frequently to save energy and to be able to breathe easier. They also need to use a High-frequency chest wall Oscillation (vest) to help with the movement and loosening of mucus and secretions.

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

Other members of the care team would be a primary care doctor, a nurse, a pulmonologist, a respiratory therapist, and a dietitian.

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

Her parents had to work full-time to be able to afford all the treatments and hospitalizations, bills, etc. Due to financial challenges, they were not able to be with Claire all the time or even when she was in the hospital for long periods of time.

7. What did you learn from this experience?

I learned that life is so precious, and we need to do our best to live our lives to the fullest and to help others have a better life in any way possible. This is why I choose this profession to be able to help others have a better quality of life.

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

I have a better understanding of Cystic Fibrosis from the medical perspective and from a person suffering from Cystic Fibrosis and it made me understand so many things I did not fully understand before I watched the video. In my clinical practice, I will remember to understand that they need frequent rest periods, and their nutritional needs are more demanding. Understand that they need their breathing treatments and always monitor for respiratory problems such as lung failure.

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

Yes, I loved her song "Galaxies" in her song one of the lyrics was: "I am broken but I am fixable and that is the worst kind, cause that means the fault is on me" (Claire Wineland, Youtube Documentary, 2020). I think these are such inspirational lyrics because she knows she is sick (broken) and she can get better with a lung transplant, but she knows she is going to die regardless, that was my impression.

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

Yes, I just hope her family is doing well, and I am sorry they had to go through that experience of losing a child at a such young age. Knowing that it was going to happen someday and there is nothing they could do to help her but just be there for her to her last day. I am glad that the foundation helped so many people with Cystic Fibrosis and I hope it continues. Her life was not in vain, she helped others to go through and understand how to help a sick person not to feel pity for them. I wished she could have lived after the transplant, to see what else she could have accomplished and to see if her health would have improved for better.

