

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

Throughout watching the video about Claire, I felt so inspired by her mindset. She truly believed in living her life to the fullest and not letting her condition be the only thing that defined her. Claire's words inspire me to live my life to the fullest and create a life I am proud of.

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

Claire's condition is Cystic Fibrosis. Cystic Fibrosis is a genetic disease that causes an overabundance of mucus. This condition mainly affects the lung and digestive system and makes it very hard for them to breathe and maintain proper growth and nutrition.

The main problem I have identified is ineffective airway clearance, with the thick mucus it must be extremely hard to clear the airway properly. Another problem I have identified is fatigue. Cystic Fibrosis requires a lot of day to day care that takes a lot of time and is very energy consuming. This care cannot be skipped or put on hold so it is very tiring and labor intensive. Lastly, malnutrition is a problem. Claire had to eat 5,000 calories a day just to maintain a sustainable body weight. With fatigue I'm sure making sure you eat at least 5,000 calories a day is exhausting.

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

Claire's clinical manifestations were persistent coughing with phlegm, wheezing, shortness of breath, and poor weight. Claire had persistent coughing with phlegm due to

the overabundance of thick mucus, and the body trying to expel it. Wheezing, and shortness of breath can also be attributed to this and fluid in the lungs. Claire had a poor weight because the over accumulation of mucus causes the pancreas not to be able to release digestive enzymes that help the body break down and absorb nutrients. I'm sure fatigue also played a role in poor weight because with the caloric demands a CF patient needs is very high.

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

I think a specific nursing intervention that I would want to take into consideration to provide for this patient's unique care needs is therapeutic communication. Patients with cystic fibrosis have multiple hospital stays, and I believe taking the time to talk to them and be a listening ear is very important. We should not think of them just as sick people who need medications and other treatments but as a human that wants to be communicated with. I think we should take the time to really get to know our patients and spend time with them. I would also want to provide the patient with adequate rest throughout the day, with minimal night time interruption. Activity not only increases oxygen demand but it also can contribute to fatigue if we are constantly in the room doing something. I think it would be very important to cluster care as best as we can.

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

I believe all of the other members of the care team are important to achieving good care outcomes. Each care team member has a unique role in which we can contribute to one

patient's care. I think the entire team is important for good outcomes because members can all collaborate. We can use each other's strength to come up with the best plan we can for a patient. For example, nurses are educated on respiratory issues and caring for a cystic fibrosis patient but we would and the patient would really benefit with having a respiratory therapist on board. Respiratory therapists would be a great bank of knowledge and help when caring for this patient.

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

Both of Claire's parents had to work full time to stay afloat while Claire was in the hospital. In having to do this her parents were not able to stay with her during many of her hospitalizations which I'm sure was hard on them and Claire. Not only was the hospitalizations expensive, but her medications, and other equipment as well. I think the most important point of this was that they had to miss out of quality time, time that can not be given back. It was very inspirational that Claire created a foundation that would help other families with something she experienced herself.

7. What did you learn from this experience?

What I learned from this experience is that you cannot take life for granted. I also learned the importance of providing compassionate care that motivates our patients to achieve goals. Although they are sick, they are still capable of many things and I believe we have a job to empower these patients. Especially young patients with chronic and terminal diseases. They are not their illness, they have so much to give to the world.

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

I often felt sorry for my patient's that I cared for in the past and this video taught me to empower them. I think it's hard to look at someone who is suffering and not feel bad but, I can still show empathy and be supportive of my patient. I think an important message from the video was that just because you are sick does not mean that you can't live your life.

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

One thing that Claire shared that really impacted me was "Death is inevitable, living a life you are proud of is something you can control." I think we often get caught up with day to day things, and we really need to pay more attention to this life. Looking back, would we be proud of the things we did, how we treated others?

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

I thought it was really amazing that Claire saw the need to help other cystic fibrosis families financially even while dealing with her own struggles. Helping other families financially allowed them to stay with their child during hospitalizations instead of having to leave to work just to be able to make the bills. Not only does Claire's foundation give them financial support, but a community to lean onto. I thought that was astounding and Claire's life will have a lasting impact.