

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

I felt sad because I knew where it was going. But also inspired by her words and the way she lived. Too often, we see diseases and handicaps and not the person. Reminds me of the speaker we had that spoke about our bias.

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

Claire has cystic fibrosis, an autosomal disease that produces thick mucus that affects organs and alters how they function.

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

She had thick mucus noticed with the sound of her cough. Multiple breathing treatments and CPT to help loosen and move thicker mucus from lungs. Multiple lung infections due to inability to clear secretions, need for oxygen later in life due to decreased lung function. She briefly mentioned DM which would result from pancreatic fibrosis. She mentioned increased caloric intake for her diet but no mention of other dietary needs and vitamins. She also didn't mention BM state but that omission is completely understandable.

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

Needs for oxygen and possible suction. Need to provide a clean environment free of contaminants that can exacerbate CF. During one interview she stated how allergies affect her disease. Consideration of nursing assignment, keep away from other CF patients. Monitor diet to ensure she is consuming enough vitamins and calories. Monitor weight, BM, signs of infection.

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

MD, RT, nutritionist, social services

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

They had to continuously work to continue to pay bills and provide for their family. Often times, leaving her by herself during hospitalizations.

7. What did you learn from this experience?

Learned more about one's own attitude and self awareness than anything medical. That diseases don't make a person's identity and they are limited by their mental state more so than physical.

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

Learn to see the person over the “patient.” Yes the disease and what comes with it is serious and should be dealt with accordingly. But these people have normal lives, dreams, ambitions, emotions, etc. as “healthy” people.

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

Pretty much the whole video. The death, although sad, was not surprising to me. The understanding and awareness and respect of life and love for life was amazing to see. She didn't let this define her or debilitate her. This thing that had been trying to kill her her whole life is actually what drove her to live more than most ever will. It would have been nice to hear more from the mom and her both their experiences during early years. Too often, kids with such diseases are just beaten down so much by all the negative news and fear from the nurses and doctors that they just give up and give into the diagnosis that it becomes who they are.

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

She was a rarity, a beautiful soul. To pass up on several lung transplants because she understood what a gift those were is something most would not do. She wasn't helpless in any sense of the word, and used her life to better others instead of her own.