

Meritt McGehee

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### Clair Reflection

Throughout watching the documentary, I felt like Clair was such an inspirational person. She had fully embraced her illness, and she had taken the initiative to enjoy life fully. She wanted to show that you could live a meaningful life while being sick. She said it was "small everyday decisions to show up is the best way to live your life.

Clair has cystic fibrosis, which is a chronic disease that affects the cells that produce mucous, sweat, and digestive juices. The secretions are thick and sticky, which causes blockage. The main problem I see is her breathing and coughing. She is on oxygen and said that she spent over a quarter of her life in the hospital and at least hours of treatment every day. Based on my observations, I would say her clinical manifestations of cystic fibrosis were dyspnea/breathing trouble; she sometimes would have to stop talking and get control of her breathing before she could continue. She had a chronic cough as well as lung failure. She had to receive a lung transplant, and complications from that resulted in her death. She also had nutritional deficiencies. Clair said she had to eat at least 5000 calories a day. She could possibly have osteoporosis because her bones appeared to be very thin, and osteoporosis can be a complication of cystic fibrosis.

For a patient like Clair with cystic fibrosis, some of the nursing interventions I would implement would be to place the patient in Semi-fowlers to promote lung expansion. I would let the patient do as much of their own care as they wish since this is a chronic condition, and they are very familiar with how to take care of themselves. I would make sure the patient gets adequate rest during the day. I would also make sure the patient is getting enough nutrition and fluid. Some of the other members I would implement into her care would be child life due to such frequent hospital stays, respiratory therapist to help with her breathing, as well as nutrition due to her need for high caloric intake.

Families who have children with chronic conditions usually have financial difficulties due to their child's care cost. Clair's family faced financial challenges of their own. Both of her parents had to work, so they couldn't always be there for her. She said they would sometimes send friends to the hospital to take care of her. She also had to set up a go-fund-me for her lung transplant because it was something her family couldn't afford to do on their own. She never used any money from her foundation on herself.

I think Clair is such an inspiration. She said her primary mission in life is to dignify sick people and continue living their life through their illness. One of the many things Clair said that really stood out to me was, "when you pity people, who are sick, you take away their power." She was dealing with a chronic condition, but she still wanted to constantly help others, and she wanted her life to hold value and purpose. She said she had lived her whole life preparing for death. I think she took what life handed her, and she didn't let it stop her from living. She found a way to make lemonade with the lemon's life gave her.

Some of the things I learned from the video that I want to take into my practice are that it is important to realize people with chronic medical conditions do not want to be constantly treated like a sick person, but simply a person. It is important to uplift them and make sure they have the support they need. Managing a chronic condition is not easy; these patients experience a lot of pain in their life. Something that really touched me was that in the beginning, Claire said that as she was growing up, there was no one she could look up to that was sick like her. And in the end, she said she became the person that "little her" would be inspired by. I think it is important that we could connect these patients with others who are going through the same thing so they do not feel alone.

Taking care of a child that is dying would not be an easy thing to do. But I think it is so important for these children and families to have a nurse who can provide comfort and care for the patient and the family. It broke my heart that she initially did not want a lung transplant because she had already been

through so many painful procedures, and she also did not feel like she could honor the donors gift of lungs when she felt she couldn't properly live a life that would honor them. When she finally decided to get a lung transplant and deal with all the pain that came with it because she believes she will do something worthwhile and help more people, she ended up passing away due to complications from the surgery.