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Pediatric Online Simulation:End of Life Scenario

- How did you feel throughout the time that you were watching the video?
 - I experienced many emotions during the time spent reviewing this youtube documentary spanning the life of Claire Wineland. The spotlight emotions identified would have been sadness and gratefulness. Claire is such a bright shining young lady who had a message that everyone should have the opportunity to hear. Her story of strength and gratitude for a life that most would view as depressing is simply wonderful and truly inspiring.
- Give a description of Claire's condition and identify the main problems that you identified?
 - Claire's main problem is that she has a condition called Cystic Fibrosis. Cystic Fibrosis is a degenerative genetic disorder that causes certain cells of the body to produce viscous and sticky mucus that can affect the respiratory and gastrointestinal systems. Most individuals with cystic fibrosis will ultimately require lung transplantation as the disease progresses. Many people with this condition will face co-morbidities like diabetes and pancreatic insufficiency.
- Based on your observations, what were her clinical manifestations and how would you explain these clinical manifestations?
 - Based on observations of this documentary I could conclude that Claire's clinical manifestations would include chronic respiratory failure which requires use of oxygen, inhaled medication, nebulizers, and high frequency chest wall oscillation(Vest) treatments. She also appears to have pancreatic insufficiency based on her use of creon, a medication that supplements pancreatic enzymes to allow for increased digestion of food. Additionally she appears to have an insulin pump which indicates that she has insulin dependent diabetes mellitus.
- What specific nursing interventions would you want to take into consideration to provide for this patient's unique care needs?
 - Nursing interventions for Claire would include maintaining a clean environment as she is prone to infection. If hospitalized she would benefit from being placed on neutropenic precautions. It would be important to frequently monitor the respiratory status as she is at risk for many respiratory complications like atelectasis, hypoxia,

and inability to clear tenacious secretions. Glucose management would be important as her pancreas is unable to maintain stable glucose control.

- What other members of the care team should you consider important to achieving good care outcomes?
 - Dietitian- to maintain adequate calorie consumption
 - Respiratory Therapist-Provide breathing treatments
 - Pulmonologist-Management of Lung Function
 - Endocrinology- Diabetes management
 - Transplant surgeon- to manage care for lung transplant
 - Palliative- If lung transplant is deferred
 - Mental Health professional- For coping skills
- What financial challenges did this family face because of Claire's condition?
 - Claire's parents were faced with many difficult decisions like working to make ends meet or staying with their child while she is hospitalized. They also had the responsibility of covering the cost of medications, home equipment, oxygen, and hospital stays. At one point the price of lung transplant was discussed which was said to be around \$50,000.00.
- What did you learn from this experience?
 - I learned to be grateful for my life through both sickness and health. Additionally, I learned that after a near death experience Claire created a foundation that assists people and their families that also battle cystic fibrosis.
- How will you apply what you learned by watching this video to your clinical practice?
 - I also learned to empower people through their journey with illness rather than pity them. People should be seen as just that; not their illness. In my clinical practice I now know that cystic fibrosis can affect more than the lungs. This disease process requires a holistic approach; including the mental health damage that can be unseen, yet very much felt by the patient.
- Are there other significant words that Claire or her mother shared that impacted or inspired you?
 - "Stop pitying sick people-empower them." This quote resonated with me because we often side with empathy over empowerment. Our brains are hardwired to focus on the negative. Most people will find difficulty finding positivity during tribulation. As a

care team we are gifted with the ability to provide both support and affirmation of positive outcomes.

- Is there anything else you would like to include in your reflection of this experience?
 - During the first few minutes of the documentary, Claire mentions how she believes St. Jude's dehumanizes children. I found this painfully true. Whenever a St. Jude's commercial comes on, you become overwhelmed by fragile, pale, and sickly children filling the screen. The goal of this tactic is to play off of your emotions because these children are being seen as their illness instead of their individuality.