Tayler Dockray

1. How did you feel throughout the time that you were watching the video?
    a) I love her positive outlook on life. She has been sick and dying her whole life, but she is proud of her life and wants other people to see that. I feel so inspired by Claire's life and her outlook. She realized how important life truly was instead of living in the limitations of her illness. It breaks my heart that such a bubbly girl has had to go through such hardship. Claire does not use CF as an excuse but instead as a method to touch other's lives. I am heartbroken that Claire passed away, but so inspired by her to cherish life like Claire did.
2. Give a description of Claire's condition and identify the main problems that you identified?
    a) Claire was born with cystic fibrosis. Medications, therapy in and out of the hospital, surgeries, hospital stays, nutrition, finances, and supplemental oxygen are some of the main problems that Claire faces. She has spent a quarter of her life in the hospital.
3. Based on your observations, what were her clinical manifestations and how would you explain these clinical manifestations?
    a) Persistent cough, shortness of breath, and wheezing because of the copious amounts of mucus blocking her airway. Her pale skin because of the lack of oxygenation perfusing in her body. Nutrition deficit is a concern because she needs a large number of calories (I believe she said 5,000) a day to keep her from looking like a skeleton. Ineffective airway clearance is a huge manifestation for Claire and that is why you can see her doing breathing treatments, the compression vest, and other therapies to try to break down the viscous mucous.
4. What specific nursing interventions would you want to take into consideration to provide for this patient's unique care needs?

   a) O2 therapy is a constant for Claire, so I would want to make it to where taking oxygen with her was not a burden. She was constantly on the go and did not need to be confined somewhere for oxygen. I noticed in a lot of the videos that she had oxygen tanks and roller backpacks that helped mobilize her oxygen. Skin breakdown with the NC tubing is a concern so finding a way to put a buffer on her ears and keeping her face moisturized where the tubing ran. Lung transplant education and support groups would be helpful because I am sure that is extremely scary. She was very adventurous and outgoing so her at home therapy like compression vests, breathing treatments, and oxygen supplementation so she could avoid hospital stays. I think any support groups that she could get involved in would be good too, for her and her family.

5. What other members of the care team should you consider important to achieving good care outcomes?
   a) Respiratory therapists, support groups, a support system of parents, family, and friends, transplant teams, nurses, pulmonologist, nutritionist/dietician, physical therapists, and others would be members of Claire’s care team. All of these individuals would be important in achieving good care and outcomes for Claire.
6. What financial challenges did this family face because of Claire’s condition?
   a) Claire’s parents could not be in the hospital with her all the time because they would have to work to keep their family afloat. Claire did not get any money from her foundation and with all the medical bill her family already has, she asked for donation on her YouTube channel toward her Go Fund Me account for her lung transplant. Her goal was $50,000 but they raised over $200,000.
7. What did you learn from this experience?
   a) CF is a high maintenance disease. There comes a point where these patients cannot get their health back and their lungs fail on them. There is so much

potential to being alive that we do not even realize. Lung transplants are ridiculously expensive, and these individuals are already burdened with medical expenses.

8. How will you apply what you learned by watching this video to your clinical practice?
    a) The cure to illness does not have anything to do with being healthy but instead having a reason to live. Health does not mean anything unless you are doing something with it. I am going to stop waiting for the right moment to do thing and instead embrace what life has given me and go forward with it. In my medical career I will be mindful to not treat these kids according to illness but rather according to them personally. I do not want to pity or just see the illness; I want to see the wonderful kid/adult fighting so hard behind it. I will not pity, I will empower.
9. Are there other significant words that Claire or her mother shared that impacted or inspired you?
    a) Claire brings up the point that there are no role models that are sick for little kids with illnesses to look up to. Claire asks her mom how she copes with the thought of her daughter dying and I forget that this is a reality for some people. Claire has spent her whole life trying to make her body work and eventually it will give out on her no matter how hard she tries to stop it. Claire says that she feels that everything good in her life has come from her sickness. She became the role model that young her could have looked up to!
10. Is there anything else you would like to include in your reflection of this experience?
    a) Sick kids do not need to feel like pity cases they need to feel like they can live full lives. Sick kids feel like all there is to them is the disease. Stop pitying the illness and empower the person. At her sickest she created a foundation to help others with CF financially. Parents can be with their kids and help them heal instead of

worrying about losing their house and their kid. There was not a selfish bone in that beautiful girl’s body and she spend every last breath she had helping others.