

My Sarcoidosis. Is it a Curse or Blessing?

ANGELA F. TAYLOR

acantor13@gmail.com

Parish Ministries & Services, Holy Cross Catholic Church, Philadelphia, Pennsylvania, U.S.A.

I am an African American female and a Catholic lay minister suffering from chronic pulmonary sarcoidosis. This is my personal journey on learning about and living with the disease that still seems to have medical professionals stumped. My prayer is that those who know someone or have someone in the family stricken with sarcoidosis may find some answers to many questions they will have.

Sarcoidosis is a chronic inflammatory disease where granulomas, tiny clumps, attack different parts of the body when inflammatory cells appear. The affected regions include virtually all tissues and organs of the body, including heart, skin, liver, kidney, brain, lungs, muscles, and bones. 90 % of those affected by this disease are diagnosed with pulmonary sarcoidosis. In many cases, this disease will be dormant and never develops into a clinical symptom. In others, when activated, it will present for a short time and then go into remission with little to no damage to the immune system or the body. There is a percentage of people for whom sarcoidosis becomes a chronic disease, for these people sarcoidosis can cause permanent damage to the body like organ failure and even death. And for chronic pulmonary sarcoidosis patients, the disease is causing permanent lung damage which may require portable oxygen or even a lung transplant. I, myself, belong to this last category of people.

The causes for sarcoidosis have not known yet; some research suggests that bacteria, viruses, or chemicals might trigger the disease. And once thought to be a rare disease, sarcoidosis is found to be common and affect people worldwide. It affects mostly adults between 20s and 40s, and its severity can vary by race and ethnicity. In the U.S., it is the most common among African Americans and European Americans of Scandinavian descent. But the symptom appears more severe among African Americans than the European Americans with an estimated lifetime risk of developing sarcoidosis as high as two percent among African Americans. Also, the disease is slightly more common in women than in men. Unfortunately, sarcoidosis is often misdiagnosed or not diagnosed at all because highly similar or same symptoms can occur in other diseases. Also, there is no cure for sarcoidosis, so the symptom management is all that patients can do. The patients are advised to maintain good health practices such as regular checkup, eating well-balanced meal, drinking a plenty of fluid each day, getting six to eight hours of sleep, exercising regularly and, of course, not smoking. The other is a drug treatment to relieve the symptoms and reduce the inflammation it may cause.

My diagnosis of sarcoidosis came around 1990 because of surgery on my sinuses, as my doctor found a suspicious clump of cells there. He had the cells tested and found them to be sarcoidosis. At that time there was not much known about this disease, so the doctors were not able to answer my questions about the disease. Thanks, now, to the Foundation for Sarcoidosis Research, I understand better about the disease I acquired.

Over this journey with sarcoidosis the drug therapy has been difficult. I typically start my day with a half-an-hour session coughing to clear mucus and phlegm so that I can take a deep breath. The steroid inhaler that my doctor has recently suggested helped me a little bit. But when the symptom becomes worse, I have to be on the oral steroid, Prednisone, for sometimes 18 months in a row, which makes my face looking like a flat-faced linebacker and my insides feeling trembling all the time. Occasionally I am on antibiotics for upper respiratory infections because my immune system has been so compromised that I could pick up an infection easily. Despite all this, however, I have slowly learned to get back to being me, at least from the outside. The outside world sees me as a hard-working professional, but inside I feel miserable. I am sometimes so out of control that I just want nothing more than to curl up in bed and not

*Address correspondence to: Angela F. Taylor, Parish Ministries & Services, Holy Cross Catholic Church, 140 E Mt Airy Ave, Philadelphia, PA 19119, U.S.A. E-mail: acantor13@gmail.com

+To cite this article: Angela F. Taylor, "My Sarcoidosis. Is it a Curse or Blessing?" *The Journal of Healthcare Ethics & Administration* 4, no. 1 (Spring/Summer 2018): 41-42, <https://doi.org/10.22461/jhea.9.7164>

This work is brought to you for free and open access by the Institute of Clinical Bioethics (ICB) at Saint Joseph's University, Philadelphia, PA, U.S.A. It has been accepted for inclusion in *The Journal of Healthcare Ethics & Administration* by the editorial board and an authorized administrator of the JHEA. For more information, please contact support@jheaonline.org

come out at all. But I know I can't just do that because, like the rest of the world, I have my responsibilities and I need to be out there in the world doing what I can do best.

You may wonder what I do for a living by now. I am Director of Parish Ministries and Services for a Catholic church. One of my primary responsibilities include coordinating funerals. I meet people at the lowest point in their lives. In their trust in me, I hold the privilege to put together a funeral mass that will give them comfort and some closure. I am also a Cantor and a Lector. I sing on three choirs. This is my job, but more importantly a vocation that God has given me. Considering all that is happening with my lungs, you may wonder how I am performing this. All I can tell you is that God has empowered me to use my voice, whether singing or speaking. It is His gift. Therefore, He uses it as He pleases, the truth of which I didn't understand before. But slowly, I was able to see where He was leading me. I was shown where and how my ministry would bring honor and glory to God as well as bring healing to others. It is my joy to sing and deliver a speech for me to see in the faces of the families that they relax and feel comfort from the gift God has given me.

When I was first diagnosed with the disease, I didn't think too much about what it meant. But as I have gotten older and have been hospitalized several times due to the disease, I have had moments when I begged God to take this away from me only to be told like St. Paul that God works in our weakness and that all is for His honor and glory.

Three times I begged the Lord about this, that it might leave me, but he said to me, "My grace is sufficient for you, for power is made perfect in weakness." I will rather boast most gladly of my weaknesses, in order that the power of Christ may dwell with me. Therefore, I am content with weaknesses, insults, hardships, persecutions, and constraints, for the sake of Christ; for when I am weak, then I am strong. (2 Corinthians 12: 8-10 [NAB])

Yes, I begged three times and many more, but I am convinced now that if it were not for sarcoidosis, I could or would not do what I do to bring healing to those in need. I invite them to have hope and gratitude, as they witness my role and capacity in the community. If someone with the terrible lung condition can do all this, they can be glad in where they are and do even more to serve Him.

Another realization I had is that it is a special blessing God has granted upon me that I was able to accept my disabilities in gratitude. It is strange that we humans do not cherish all the blessings and beauty given unless we lose them. We take it for granted that we can physically function every day without medical difficulties. We only learn how valuable they are by losing them. I too was not able to see how blessed I was.

I am not arguing that losing health automatically leads to appreciating the values in a positive way. It does not. Most of the times, when we lost health, we complain and envy healthy people and sometimes blame God and people around us, saying "Why me?" Only in God's grace, we learn how to accept disabilities in gratitude, just as St. Paul accepted his illness and even boast about his weakness that the power of Christ stands out in his own weaknesses. But I admit that I am not Paul. Is sarcoidosis a curse or blessing? On any given day it could feel either. But I am glad that I was given a power to willfully perceive it as a blessing even in my darkest hour of battle. And I know I can fight better as I grow closer to Him. After all, we are all broken vessels and only the Potter can make us whole. I wait in hope until He makes me whole.