

Low Incidence and High Profile: Tuberculosis Control in Delaware

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Abstract

Tuberculosis (TB) is an infectious disease of global burden. While Delaware has low incidence of active TB compared to other locales, because of its small size these few cases tend to garner widespread attention. In this article, a study of one such case of active TB is presented. This case serves as a didactic example of the public health response to the complexities of treatment, including institutional, transient settings, and patient refusal. This consequently led to ordered directly observed therapy of the individual. The article concludes with a discussion of the law and legal implications for such cases in Delaware.

Introduction

According to the CDC, one-fourth of the world's population is infected with Tuberculosis.¹ The vast majority of these cases are infected with latent tuberculosis. In 5-15% of cases, latent tuberculosis will become active. In 2017 alone, there were 10 million active Tuberculosis ("TB") cases and 1.3 million deaths.² However, TB cases in the United States have decreased in recent years thanks to the treatment of latent infections and a decrease in TB cases worldwide. In 2017, there were 9,105 cases of active TB in the U.S, a decrease of 2.3% from 2016.³

Tuberculosis infection is caused by bacteria (typically *Mycobacterium tuberculosis*). The bacteria can be anywhere in the body but 90% of TB infection occurs in the lungs.⁴ A person who has TB in the lungs (pulmonary TB), can spread the bacteria through coughing or speaking. Someone close to that person can breathe in the bacteria and become sick and contagious with active TB; alternatively, that person's immune system may be strong enough to contain the bacteria and it becomes dormant (latent TB infection). The person with the dormant bacteria is not contagious or sick, but if their immune system weakens through illness (e.g., from HIV/AIDS) or certain medications (e.g., immunosuppressive therapy), the dormant bacteria may become active and multiply causing the person to become sick with TB disease and, consequently, contagious. According to the CDC, HIV coinfection is the strong indicator that latent TB infection will progress to active TB.⁵ People with HIV are 20 times more likely to fall ill from TB than those who are not living with HIV.⁶

Because of the risk of infection, the Division of Public Health (DPH) encourages people with the latent TB infection to take antibiotics to kill the dormant form of TB to prevent disease in the future. Delaware had 15 active TB cases in 2017, a case rate of 1.5 cases for every 100,000 people, well below the national average of 2.8.⁶ For this reason, Delaware is considered a low incidence TB state.⁷ However, the limited cases of active tuberculosis in Delaware typically garner widespread media attention. In May 2018, the Delaware Division of Public Health notified the public that an active case in a long-term care facility may have exposed more than 600 individuals to TB.⁸ Months later, dozens of students and staff at a Sussex County elementary school were exposed to active TB.⁹ Neither exposure resulted in additional active cases beyond the index case but both made front-page news. In 2014, there were 22 cases of active TB state

wide. One case in particular tested the limits of the law and the resources of the state of Delaware.

Case Study: Daniel

Daniel (a pseudonym) first became known to the Delaware Division of Public Health in early spring of 2014. He was born outside the United States and had been living in Delaware for more than five years. By the end of 2014, he would be hospitalized with cavitary pulmonary tuberculosis after exposing more than 700 people to this contagious disease. When Daniel came to the Division's attention, he had recently been incarcerated in Delaware. He had multiple prior felonies, a history of substance abuse and homelessness, and was HIV positive. During the course of his tuberculosis treatment in Delaware he would be incarcerated two more times.

Daniel was diagnosed with latent tuberculosis earlier in his life but failed to complete his treatment, only completing two months of the required nine months. In the spring of 2014, he had been incarcerated, released and later hospitalized with active pulmonary tuberculosis. Upon examination, cavities (holes) were found in both lungs and he was deemed "highly contagious." Daniel was hospitalized for over one month and was discharged to the community. At the time of his incarceration in early 2014, Daniel exposed a large prison population to tuberculosis. This exposure resulted in the need for 2,000 inmates, former inmates and staff to be tested for tuberculosis. A close contact in the prison subsequently developed active TB from this exposure.¹⁰

Daniel was placed on a nine-month regimen for treatment but was later transitioned to a 12-month regimen due to his immunocompromised status. The treatment consists of directly observed therapy ("DOT") which involves giving the antibiotics for treating TB (isoniazid, rifampin, ethambutol and pyrazinamide) under close observation, three days a week, by a public health nurse. The nurse meets the client for his DOT at a location most convenient for the client. Any doses the client misses are added into the timeline, extending the amount of time the client must receive the medication to complete his treatment. However, missing an extensive amount of doses may cause the individual to "relapse", meaning the disease returns, and could become resistant to some of the medications previously used. A whole new regimen would be needed and the person would need to be re-treated.

Daniel was periodically housed in a motel financed by the state of Delaware, being provided with meals, groceries, hotel vouchers and was compliant with his treatment even though he was re-incarcerated for short periods during the summer of 2014. Then he was released in the late summer of 2014. The Division of Public Health Division informed Daniel that they could no longer finance his motel, and he began missing doses. DPH nurses attempted to work with Daniel, bringing him food they paid for themselves, but he continued to resist treatment and often could not be located. Daniel's DPH case manager attempted to find a place for Daniel to stay, reaching out to shelters and programs but Daniel declined to follow through with offered appointments. Daniel traveled to other parts of the state but refused to meet with nurses from other counties. He traveled out of state and evaded attempts to be located.

In the fall of 2014, Daniel had missed so many doses that the Division of Public Health took the extraordinary step of issuing an emergency order requiring treatment of Daniel. The order included language that authorized local law enforcement to locate Daniel and bring him to a health care provider to receive his medication. Having also violated his parole, Daniel was

picked up by local law enforcement and taken to a prison facility on an outstanding warrant. While in prison, he did not refuse medication. One week after the emergency order, the Division held a hearing to determine if the order for treatment should continue. Daniel was represented by a court-appointed lawyer and was given the opportunity to present evidence and question witnesses. Following the hearing, the Director of the Division of Public Health found that Daniel's noncompliance was a danger to himself and to the general public, that Daniel knew the risks of refusing treatment and that all less restrictive alternatives had been exhausted. The Director of the Division of Public Health ordered that Daniel undergo DOT until he completed his treatment.

Involuntary Treatment, Quarantine and Isolation in Delaware

Daniel's case is unique. He had a history of noncompliance and demonstrated a risk to the general public's health. While he was not contagious at the time of the forced treatment order, he had missed eight of twelve doses in a month and was at imminent risk of becoming contagious again. Isolation and forced treatment are not tools that the Delaware Division of Public Health uses often, and never without great cause. Quarantine and isolation laws are state specific and Delaware's laws are comprehensive. Before an individual can be subjected to testing, treatment, hospitalization or isolation against their will, they must be afforded due process.¹¹

In Delaware, those due process protections are codified in Delaware law.¹² Before any person can be involuntarily examined or treated, hospitalized or isolated in a community setting they must first have a hearing before the Director of the Division of Public Health. At the hearing, the person subject to the potential order has the "right to present evidence, cross-examine witnesses and to be represented by legal counsel." If the individual cannot obtain or afford legal counsel, the Division is required to petition the Superior Court to appoint an attorney for the individual. The individual shall also be "given at least five working days prior written notification of the time and place of hearing, a copy of documentary evidence to be presented, a list of the proposed actions to be taken and the reasons for each said action; and shall be given a verbatim transcript of the hearing on request for appeal purposes." In order for the Director to issue an order of involuntary examination or treatment, hospitalization or isolation, they must find that: "(1) [t]hat there is a danger to the health of the person or that the public health and welfare are substantially endangered by the person; (2) [t]hat the person has been counseled about tuberculosis, the significant threat tuberculosis poses to the public and methods to minimize the risk to the public, and, despite said counseling, indicates an intent by words or action to endanger himself or herself and/or expose the public to infection from tuberculosis; and (3) [t]hat all other reasonable means of achieving voluntary compliance with the treatment have been exhausted and no less restrictive alternative exists." The Director must find that all three factors are met by clear and convincing evidence, meaning that is highly and substantially more likely to be true than untrue that the person has met all three factors.

The order will continue until "in the opinion of the attending physician or the County Public Health Administrator, the person is cured or said person is no longer a substantial threat to himself or herself or to the general public." The individual subject to the order may also petition the Director for "immediate release and termination of the order." The individual must demonstrate that they are no longer "an imminent and substantial threat to himself or herself or the public's health and welfare; and will voluntarily continue with prescribed medications and treatment, if medically necessary, to reduce the risk of infection to the public." An individual

may also appeal an order directly to the Superior Court. The court reviews the hearing before the Division of Public Health but will also accept new evidence and makes a decision without deference to the Division's previous findings.

The Division of Public Health also has the authority to issue emergency orders, as they did in Daniel's case. An emergency order is issued when: "(1) [t]he person has tuberculosis or is reasonably suspected of having tuberculosis; (2) [t]he person poses an imminent and substantial threat to that person's own self or the public health and welfare" and the person has demonstrated that an order cannot wait for a hearing under section 526. These reasons could include threats to leave the jurisdiction, that the person will not appear for a hearing or the person "will act in such a way as to recklessly disregard the person's own health or the public's health." Before an order for emergency treatment can be entered, the Director of the Division of Public Health must find "the County Public Health Administrator presents clear and convincing evidence that a substantial threat to the person or the public's health and welfare exists unless the emergency treatment order is issued [and there are] no other reasonable alternative means of reducing the threat to the individual or public's health and welfare". The Division must also schedule a hearing under Section 526 when issuing an emergency order. The emergency order will contain a provision directing law enforcement to transport the individual for treatment or isolation. The emergency order cannot be in place for more than five business days.

Responses to Communicable Disease Control

How to isolate, or quarantine, a person in their home or a community setting is a question that many public health professionals struggle with; and when an individual is ordered to be isolated in the home or another community setting the logistics are daunting. States struggle with balancing the public's health with an appropriate response that protects individual liberties. Certainly, no public health lawyer will forget the image of nurse Kaci Hickox going for a bike ride while followed by Maine state police after her return from treating Ebola patients in West Africa.¹³ Or her subsequent lawsuit against the state of New Jersey.¹⁴ Recently, a couple in Wisconsin were criminally charged after violating their measles quarantine orders.¹⁵ Both cases prompt discussion on how states should react to potential public hazards while also ensuring that individual liberties are protected to the greatest extent possible. All states should have plans in place on how to respond with quarantine, isolation and involuntary treatment. These plans should comply with applicable statutes but should also reflect best practices for the treatment and control of communicable diseases.

In the case of Daniel, the process went as smoothly as possible. Because of Daniels' outstanding criminal charges, he was treated while incarcerated. His hearing was conducted at the prison where he was incarcerated and he was given all the resources he and his attorney needed to prepare. While Daniel did not appeal the order, he had the right to do so. Daniel acknowledged the barriers to his compliance were social, informing the Division's responses for future patients with similar needs.

The last time the Division of Public Health forcibly examined, treated, hospitalized or isolated someone was in 2014. Involuntary treatment, examination or isolation is not something that any government agency takes lightly. The legal requirements placed upon the government when it seeks to limit someone's freedom are substantial, and for good reason. For weeks, the process can tie up staff, officials and resources. As in the case of New Jersey, lawsuits can last for years. To avoid the extraordinary step of involuntary treatment or isolation, the Division places

emphasis on education and ease of treatment. In 2017, the Division initiated video directly observed therapy (VDOT) which allows individuals to virtually connect with their public health nurses to ensure treatment compliance. By using the method of VDOT, the individual acquires a confidential app for their phone and can video themselves taking their medications at a time and location which is convenient for them and it is sent to their nurse. VDOT participants demonstrate a higher median fraction of expected doses observed than traditional DOT participants and would recommend VDOT over DOT.¹⁶ A noncompliant patient is counseled by multiple individuals to encourage compliance with treatment. It is only when this counseling and education fails that the Division is forced to begin involuntary treatment, hospitalization or isolation proceedings. Thankfully, the Division has not needed to subject an individual to involuntary treatment, hospitalization or isolation in the past five years. As the incidence of TB cases in Delaware continues to decrease there is hope that the Division may never need to subject an individual to involuntary treatment, hospitalization or isolation again. However, if they do, the law and Daniel's case will guide the administration on how to proceed in a just and respectful manner.

Disclaimer: The views expressed herein do not necessarily reflect the views of the Delaware Department of Justice or the Delaware Division of Public Health.

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