

# The Words Left Unspoken: Stories Surrounding the Hospital Medical Futility Policy

OLIVIA NGUYEN

*olivia.nguyen@sju.edu*

*Biology and Healthcare Ethics Studies, Saint Joseph's University, Philadelphia, Pennsylvania, U.S.A.*

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## INTRODUCTION

Doctors walk a very fine line. They are trained to save lives. They are told to do everything in their power to revive that pulse – to sense the life in a lifeless body. They have toiled relentlessly, sacrificing years of their own livelihood to acquire the knowledge and skill set to uphold their once eagerly proclaimed oath of “Do no harm.” Nevertheless, doctors acknowledge that people are still human beings, subject to the inherent cycle of life: we are born, and we die. There comes a time when a doctor must admit that there are some things that cannot be cured. When it comes to the end of life treatment, there is plenty of gray area when working for the patient’s best interests. Doctors are bound by so many limitations that contradict their own feelings and emotions in their service to their patient. They have been encased in this phenomenon that life is an absolute. But then, when is it enough? Let me tell you the story of how I witnessed this woman’s life being saved.

I walked into a room of fifteen solemn faced people. Most of them fidgeted with their crisply ironed collars or looked down at their legal documents as we all gathered around an elongated table spanning the entire length of the room. The family had already arrived and was patiently waiting at the end of the corridor. I took my seat as members of the clergy, medical staff, and legal department trickled in. There was not much time left until the meeting commenced. Encased by the four beige colored walls of the room, a looming anxiousness came over me. As a result, I decided to follow suit and examine my own notes.

We had been following this case for weeks. Mrs. Katherine Smith was a forty-seven-year old female who was admitted early this August for a chronic obstructive pulmonary disease (COPD) exacerbation.<sup>1</sup> This was her third admittance this year for COPD. However, she had also been diagnosed with lung cancer rendering her incapacitated. We also found from previous visits that she was also diagnosed with HIV/AIDS. And it was killing her. Just like clockwork, she was fading and fading fast. Today marked her twenty-fourth day here at Mercy-Fitzgerald Hospital for this visit. By now she had progressed to end-stage COPD, end-stage lung cancer, and end-stage HIV/AIDS. She was now completely comatose, clinging to her own trachea and PEG tubes. Meanwhile, Mason, as both Katherine’s son and healthcare representative, was begging for everything possible to be done. He wanted her to live to see the next day, so she could hold her newest baby grandchild. The problem was, Mason didn’t know about his mom’s HIV/AIDS, and he was never going to.

<sup>1</sup> Out of consideration for the family and healthcare staff, I have changed the names to protect their confidentiality.

\*Address correspondence to: Olivia Nguyen, Biology and Healthcare Studies, Saint Joseph’s University, 5600 City Ave, Philadelphia, PA 19131, U.S.A. E-mail: *olivia.nguyen@sju.edu*.

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The Pennsylvania Confidentiality of HIV-Related Information Act (Act 148) states that health professionals including clinicians are not permitted to “disclose any confidential HIV-related information they obtain either in the course of providing health or social service or as a result of a written release from a patient.”<sup>2</sup> They are not allowed to speak personally with the patient about his or her condition, but it cannot be extended to either the next of kin or the patient’s healthcare representative. Act 148 falls under the umbrella of the Health Insurance Portability and Accountability Act of 1996 (HIPPA) in which doctors are bound by confidentiality between themselves and the patients in order to establish a means of trust. In sum, the patient decides to disclose his or her condition to another or to keep it to him or herself. On the other hand, doctors cannot. Even if Mason, as both her son and healthcare representative, was to explicitly ask, “Does my mother have HIV/AIDS?” the doctors cannot give any indications to the answer.

Which makes it difficult. Under HIPPA, the doctor’s role is solely to the patient. Anything regarding the patient’s condition cannot be discussed with anyone else unless permitted. Since all medical agents are completely bound by the law of secrecy, with the HIV/AIDS patients in particular, the family is often left in the dark, shrouded by a nebula of mystery and confusion. Mason once expressed to the doctors, “It’s just a minor hiccup. Mom has been fighting lung cancer for years now. She’ll be back up and at it and she’ll come home in no time.” But when her organs were shutting down, her skin caving into her bones, her heart rate struggling to just keep those beeps on the monitor, he began to question what really was going on. *Is this it? Is Mom really leaving me? Why didn’t I see the signs before?* Mason pleaded to the doctors to do everything they could, fighting for that last bit of time that his mother had left.

The doctors were doing everything in their capabilities. They managed to alleviate some of Mrs. Smith’s pain and keep her stable. But as for future plans, they were running out of options. They’ve tried oncology, cardiology, palliative care, pastoral care and even the right of transfer. Five regional hospitals had been contacted: Jefferson, Penn, Christiana, Hershey, and Lancaster General. None of hospitals were willing to take on her case. Katherine didn’t have much time left, but her son couldn’t see why. The remaining option the doctors could offer was hospice care, which Mason adamantly did not want. He didn’t want the doctors giving up on his mom. He just couldn’t come to terms that she was dying. But Katherine’s white cell blood count was four. Without the trachea tube, surviving on eighty percent oxygen, Katherine wouldn’t even be able to breathe on her own. She’s been completely unresponsive for almost the entire three-week admission and was struggling to just stay alive. But Mason wanted more. He wanted everything.

At Mercy-Fitzgerald Hospital, the healthcare staff lives in *cura personalis*, meaning to care for the whole person. They serve as men and women with and for others, especially their patients. The staff believes that everyone has a right to be treated with respect as well as to die with dignity. Therefore, they created a medical futility policy in an effort to resolve the conflicting emotions of the medical staff, whom may believe that the treatments are more aggressive than palliative to the patient, and the family, who still want everything possible done to save their loved one.

The Mercy Health System Guidelines to Resolving Disputes is invoked by the attending physician. After a giving a thorough explanation of the nature of the condition to the patient or healthcare representative, the attending must offer the right of transfer to another hospital. If other hospitals are not willing to accept the transfers, the attending should address with the patient or healthcare representative the option of obtaining an independent opinion concerning medical inappropriateness or medical futility and provide them with a copy of the policy. If the patient or healthcare representative still does not agree, the Chief Medical Officer appoints a second physician to evaluate the patient. The second physician must see the patient within twenty-four hours and sign or counter-sign whether the treatment is medically futile. Within forty-eight hours of obtaining the second opinion, the attending physician must prepare and present the case to the Institutional Ethics Committee (IEC). After receiving the case, the IEC must convene within the next forty-eight hours to hear the case presented by both the doctors and the family and make a recommendation. Throughout the process, Mason remained firm in his decision, which brings us to where we are today.

Mason walked through the door accompanied by his daughter, Jenna. They sat down with the five doctors who have been caring for Mrs. Smith to their right and members of the legal department to their left. In front of them, they faced myself along with the other members of the ethics committee, nursing, clergy, and local community. All eyes laid upon them as they took their seats. Then there was silence. The silence was filled with essences of confusion, compassion, frustration, sadness, respect, grievance, and a sliver of hope from each person’s thoughts as they sat. Shifting their blank stares towards the center of the table, straightening crinkled corners of paper, picking up a pen only to put it back down, each person in the room waited in anticipation for the meeting to commence. The ethics committee chair, Sister Mary Clarence, broke the silence and the battle began.

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<sup>2</sup> Jill Arent and Rhonda B Goldfein, “Comparison of Pennsylvania Confidentiality of HIV-Related Information Act (Act 148) and Federal Health Insurance Portability and Accountability Act,” accessed Dec. 12, 2017, [www.aidslawpa.org/wp-content/uploads/2011/04/comparativechart.pdf](http://www.aidslawpa.org/wp-content/uploads/2011/04/comparativechart.pdf); See also Mercy Health System Guidelines for Resolving Disputes.

Welcome. My name is Sister Mary Clarence and I am joined here with my fellow members of the clergy and the Ethics Committee along with the legal department, nursing, social work, and members of the community. We are gathered here today out of love and the bonds that we all share with our beloved Katherine Smith. We are both honored and pleased to welcome Mr. Mason Smith, her son as well as Ms. Jenna Smith, her granddaughter, who have graciously agreed to share their story, thoughts, and concerns regarding the treatment of their loved one. We also welcome Dr. Schueler, Dr. Romano, Dr. Minh, Dr. Brown, and Dr. Gupta who have also devoted their time and undivided attention in their efforts in the care of Katherine. I would like to encourage the fact that this is a safe space and we are all here to listen and share our stories of Mrs. Smith and what we believe is best for her.

First, Dr. Gupta, the attending of record, represented the fellow physicians and residence and presented the case strictly under the diagnoses of Katherine's lung cancer and COPD.

I have actually had the pleasure to get to know Katherine before through her previous visits with us here at Mercy. She was certainly a woman of charisma and vitality. She accepted the treatments with vigor. She responded well at first, but then she got sick...and then she got worse. Her lung got punctured and the whole left side started to collapse. We were able to stabilize the other lung, but there was little hope for the left lung to recuperate. Katherine had also lost a lot of blood at the time, so we gave her a blood transfusion. She improved a little bit, but she would consistently revert to COPD. We re-installed a trachea tube in a slightly different manner than what they did down at the ED. That helped her a little more, but she just kept getting sicker. Her organs were shutting down. She couldn't even eat anymore. At that point we had to place a PEG tube inside her to give her proper nutrients and care. Even then, her body is still failing her. If there was any sign of improvement I would be more than willing to help Mrs. Smith. She is very sick. But I believe that hospice may be a good option for her. Therefore, I leave it up to the Ethics Committee to decide whether it is best to move her to hospice.

The family shared next. Mason kept his head down, fixing his gaze between his hands on his lap and the center of the table. He made minimal eye contact as he spoke. It was as if he had already resigned in his fight against fifteen white-collared professionals. Instead, he had more questions that he simply wanted to address. He asked, "Why wasn't the treatment caught sooner? I thought you were going to do everything you could. Y'all said you were going to do it this way as opposed to the way they did it in the ED?" He pulled out a picture of Katherine on the day she was admitted. In that picture was a woman sitting cross-legged in her wheelchair, leaning toward the side with her elbow perched on the armrest with her hand caressing her own face. Despite having an oxygen tube lacing her face, her eyes gleamed with a fiery passion and her sassy smile stretched across her face from cheekbone to cheekbone. She sat next to the window, surrounded by exotic plants, but nothing stood out more than that proud stature that she had sitting in that wheelchair. Mason implored, "She was full of life. She would take the oxygen tube out and place it on top of her head for fun, as if they were sunglasses. She was a proud and vivacious woman sitting in that wheelchair. Why can't we try and get her back?"

Dr. Ruggiero was an older man who was sitting in as member of the community. He sat next to the family, turning his chair so that he was openly facing them. He leaned slightly forward, one arm resting on the table with the other hand resting on his knee. With a gentle manner, Dr. Ruggiero gave his own opinion on the matter by answering Mason's questions regarding the timing of medical procedures.

The procedure that you have specified happens to be about the intubation procedure. The intubation procedure will only help your Mom in her case. It would not matter if we intubated her now instead of then. The tube is merely a means of helping your Mom breathe. Mason, I have been practicing medicine for many years now. I promise you, if there was even the slightest chance of another option that we could do to successfully help your mother, we would surely be doing it immediately, 100%. I would even be the first to jump in to do the procedure. But right now, we have gathered all the minds possible to evaluate any other options that we could do, but we chose hospice because we believe it would be the best for your mother.

Nurse June tenderly gave her own opinion to Mason and Jenna.

I've been Katherine's nurse for a few months now from her last visits. We would always have our late-night chats of some TV show that we liked, some recipe that we haven't tried, places we've traveled, or stories of our kids when they were little and their mischief drove us crazy. But in the short amount of time I've gotten to know her, I can see that she is a proud woman, certainly with lots of spunk. And I think that Katherine would want to be remembered as that person who was full of life depicted in that picture instead of the person that you've been seeing cling to her dear life on the ventilator and dwindle before your eyes. When you see her day by day, hour by hour, it's easy to remain focused on the present, but it gets harder to remember who she was before she got sick.

By the end of the discussion, Mason had run of options. Dejected, he requested that any decisions made afterward be executed following the weekend so that the entire family can gather and give their final goodbyes.

The family left the room heading to their mother's side in the ICU. Nurse June went with them as a token of support. They were waiting--waiting for us to decide the fate of Mrs. Katherine Smith: a mother, grandmother, sister, aunt, teacher, and believer. Due to the terminal nature of the HIV/AIDS, the members of the committee agreed that to pursue further medical treatment for Katherine was a form of "extraordinary means" that was more aggressive than palliative, meaning the treatment was more harmful to her than helpful. Thus, the committee voted unanimously that Katherine Smith should be moved to hospice. Respecting Mason's wish, the recommendation was not executed until the following Monday, after her family was able to come and meet her for their final goodbyes. The tracheal tube was removed early Monday afternoon and she was transferred to the hospital hospice unit where she passed away peacefully one hour later.

We saved this woman's life. Not necessarily in the sense that she remained breathing and functioning, but her dignity—her person. We saved the person of Katherine Smith, a charismatic, spunky soul who had touched each and every individual she encountered. We preserved her smile, her dazzling eyes, her spirited laughter, and the gentleness of her loving touch. For her family, we saved their memories of a selfless woman loved by all; the hellos and goodbyes, the hugs, the sizzling of food, the late-night snuggles, and the sweet humming that resonated throughout the house as she walked her ways. Most importantly, we liberated a wounded lone soldier, no longer fighting for herself, but striving for her family where it hurt to muster all her strength for a single peak on the monitor. I truly believe we gave her peace—a splendid serenity.

Although, I can only imagine what it must be like on the part of the family--to be in the position of asking questions but never receiving a full answer. Going up against fifteen professionals, it is certainly easy to feel out of place. To have an entire health staff, who you believe are on *your* side, are supposed to openly listen to your thoughts yet already have a predetermined answer before you even walk through the door. It's difficult when your mother is dying. The person who has been there through every moment of your life, from the swaddles to the diploma, the person who raised and molded you into the person you are today. She was that person making all the decisions for you. Now, you are the one making the decision for her—the one to let her go. It must be imprisoning to be stuck between the conflicting emotions of wanting to be able to embrace her more and alleviating her of her suffering but no longer having her present in your life. Death is neither easy nor is it something that you think about until something like this happens. Nevertheless, in your most vulnerable state, you turn to your doctors, trusting in that they will be able to do something to help your loved one. But when they say there is nothing they can do, what else can you possibly do?

By the same token, I can also see the pressure placed upon the doctor as well in having a developed decision from their omniscience of the patient. There is a side of being a doctor that no one ever truly sees. Your patient is in pain, and there is nothing you could do to solve it. The family is grieving, struggling to search for an answer that you are forbidden to provide. I can only imagine the desperation in wanting to tell the family the sole piece that you know will help them understand the methods to your madness—why you think that anything new would just hurt her more than heal her. By one hand, you are chained to the law. And by the other hand are chained by your empathy. You feel those opposing forces steadily ripping you apart as you search for an answer. But there is none. You are forced to resign yourself to the cycle of life and the crushing defeat of being unable to save your patient as a breathing person is maddening. You surrender yourself to your vulnerability and humility when you admit that it would be best to let her go.

There are certainly many components to medicine. To treat, or not to treat. Here, I can see one of the ways being a doctor can be challenging. As a doctor, you are given the knowledge and the skill set to heal. In doing so, because you know more than the average person, the families and the patients place their trust in your abilities to help them get better. In return, the doctor must do their absolute best to help the patient physically, mentally, emotionally, culturally, and morally. Doctors are mandated reporters. They care about the whole person beginning to end from the patient's pre-admittance to discharge. However, there comes a time when doctors recognize there is a limit to being human. Each person has an inherent right to life and therefore each life is intrinsically sacred. The whole essence of medicine is to care, even if it cannot cure. It is essential that we never forget to remain kind, humble, and charitable regarding the comfort of our loved ones—patient or not. There is a time in which each of us must depart from this world but is those we leave behind that truly suffer the most. Living or deceased, our only regrets are the words left unspoken.

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Mercy Health System Guidelines for Resolving Disputes.