




## Trust and conflict in death determination—reflections on the legacy of Taquisha McKitty

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Twenty-seven-year-old Taquisha McKitty lies on her back in a bed of the intensive care unit (ICU) at William Osler Hospital in Brampton, Ontario. Her eyes are closed, and the expression on the young mother's face is peaceful. A plastic tube taped to her cheek guides air into her lungs from the ventilator humming next to the bed, and her chest rises and falls with each regular breath. Chairs for visitors, almost always occupied by a parent, cousin, sibling, or aunt, are positioned under computer monitors, which display in neon green the regular dip and fall of her heart rhythm. Occasionally, Taquisha's toes and feet twitch, and

sometimes she turns to one side, disturbing the otherwise crisp bedsheets. The nurses assigned to care for her diligently rearrange them when they come in to turn her, as they do for all patients in the ICU, to ensure that skin does not decay during periods of prolonged physical immobility.

It is March 2018. According to the hospital administration, Taquisha's treating physicians, and the Superior Court of Ontario, Taquisha is dead and has been dead for more than six months. Two physicians have independently applied nationally accepted guidelines to establish the permanent absence of neurologic function and have already issued a death certificate. Taquisha's family, however, disagrees with this assessment and insists that Taquisha continue to receive ongoing medical support for as long as her heart keeps beating. To support this request, Taquisha's parents, Alyson McKitty and Stanley Stewart, have filed a court case and obtained an injunction to prevent physicians from "pulling the plug." Security guards, cameras, and locked doors have been installed in the ICU to prevent family members from appearing unannounced. As long as the case remains debated in court, healthcare professionals continue to care for Taquisha, maintaining her comfort as best as they can despite the tense environment.

Taquisha McKitty's heart stopped beating on its own at 3 a.m. on 31 December 2018, one year, three months, and ten days after her death certificate was signed. For the better part of that year, Taquisha's family and her healthcare providers interacted at her bedside and faced off regularly in the court room in long sessions in which the medicolegal complexities of death determination were debated from all angles.<sup>1,2</sup>

In public reports, the "McKitty case" as Taquisha's ordeal became known, was a story about the ambiguity of the definition of death in Ontario and whether or not individual values should be permitted to contravene medical authority.<sup>3,4</sup> Similar to other publicized cases in which the concept of death determined by neurologic

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criteria is challenged,<sup>5</sup> the central conflict was positioned as a clash between the medical science community and the perspectives of the patient and family. These types of disagreements over the definition and timing of death often lead to emotional stress for both families and healthcare professionals.<sup>6,7</sup>

Nevertheless, despite a protracted and publicized conflict over whether or not Taquisha had died, there was something about her case that also brought people together. A number of healthcare providers who cared for Taquisha became personally invested, and one of her treating physicians attended her funeral. Weeks later, Stanley Stewart arrived at the department head's office with a gift basket and sat down to discuss and debrief the circumstances surrounding the end of his daughter's life. The fact that a public legal confrontation over the definition and timing of death resulted in a positive and ongoing partnership with Taquisha's family is unusual and warrants further investigation.

While a disagreement about the definition of death was undeniably present as part of the conflict over the end of Taquisha McKitty's life, a more detailed account of family and healthcare provider perspectives reveals a host of other social and relational factors that contributed to the precipitation of conflict and its resolution. Rather than entrenched epistemological or legal opinions about the nature of death, it may be that relationships of trust and styles of communication have a stronger impact on influencing whether and to what degree conflict (and resolution) will emerge. As a result, interventions to improve end of life care for patients who have been determined to have died by neurologic criteria that focus solely on improving understanding or providing additional knowledge about death definitions may be unsuccessful if they are not paired with the ongoing work of building relationships of trust.

In this short reflection, we present brief accounts from Taquisha's father (Stanley Stewart), one of Taquisha's physicians (Andrew Healey), and the hospital ethicist (Paula Chidwick) of their experiences with the McKitty case. Juxtaposing these three perspectives offers insight into how conflict surrounding death determined by neurologic criteria developed, and how a positive relationship with Taquisha's family was ultimately formed. It also offers a synthesis of reflections from family, bioethics, and physician perspectives about how similar cases might be approached in the future. Our aim in this paper is not to explore the court case in detail, nor to provide clinical justifications for family experiences. Instead, we aim to describe how factors other than misunderstandings of the concept of death determined by neurologic criteria contribute to family requests for continued organ support after death determination.

## A voice for the voiceless<sup>A</sup>—reflections from Stanley Stewart

Late in the evening of 14 September 2017, Taquisha lost consciousness because of an overdose. When paramedics arrived on scene, Taquisha had a very low pulse. On route to the Brampton Civic Hospital, she lost her pulse and went into cardiac arrest, and paramedics performed cardiopulmonary resuscitation throughout her transport to the emergency department. When she arrived at the hospital, they were finally able to get her heart to restart. In the emergency department, Taquisha was intubated and given a hypothermic blanket to try to control the brain swelling. After a few hours she was moved to the ICU. This is where our true nightmare began.

The attending doctor of the ICU met with us and told us that it was a very serious situation, which we were all aware of. He told us that Taquisha's brain would continue to swell for 72 hr, and after that time he would be in a better position to advise us on her long-term prognosis. We did not know the significance of that statement at the time. We really didn't know what we were waiting for, whether it would be a good outcome or a bad one.

During the first days after her admission to hospital, Taquisha was moving to the sounds of voices of family and friends, and on one occasion squeezed her brother's and her mother's hands for several minutes. One morning she turned her head towards the sound of her name being called. And most important, she was breathing primarily on her own with very minimal support from the ventilator.

Over the first days of Taquisha's stay, we asked the doctors what interventions and medicines they were giving to mitigate the brain swelling. They told us there was "nothing they could do" in her case, which we thought was a strange comment. Another alarming thing we observed was that they were giving Taquisha sedative medications whenever she was moving. We asked why and were told, "It was so her muscles didn't spasm." In retrospect, we felt this assisted in putting her further into a deep coma and shutting down her body.

On 18 September (four days after her overdose), Taquisha stopped breathing because of the brain swelling. At that point, the new attending physician administered a test for the neurologic determination of death, which includes an apnea test. We interpreted this test as, in essence, suffocating the patient and felt that it potentially caused more brain damage because of the build-up of CO<sub>2</sub> and acids released in the brain as a result. Taquisha received three of these tests in a very short period of time and with her compromised condition we felt it did

<sup>A</sup> Excerpts drawn primarily from "A Voice for the Voiceless," personal reflections written by Stanley Stewart in the fall of 2017.

considerable harm to her brain. Taquisha failed the test and was declared brain dead.

Two days later, on 20 September, we were told by the attending doctor that they would be suspending life support, i.e., “pulling the plug.” He told us that we had a few hours to call family in to say our goodbyes. This felt like a lot of pressure. I remember thinking, “Two hours? That’s nothing!” It was insulting, it was condescending, and it put me in a rage. At that time, I informed the doctor that I was not consenting to the plug being pulled and that I wanted Taquisha to have more time. Her movements and sensitivity to touch were signs of life and continued to suggest to us that she had brain function even though she “failed” the test. The doctor informed me that since he had declared Taquisha brain dead, she was technically dead by legal terms and that I did not have the “right” to contest, and my consent was not needed. He also added that, “We were very lucky that he didn’t already pull the plug, because his other colleagues would have already.”

I left the room and contacted a lawyer. I also went to the hospital’s complaints office and warned them I would sue if the plug was pulled without my consent. This bought us 24 hr, which gave us time to get an emergency injunction from the court preventing the hospital from ending Taquisha’s life support and giving us a chance to prove that she was still alive.

The next day (21 September) we had a meeting with the doctors and the hospital administration. We were given Taquisha’s death certificate, and we served them the court injunction. We also found out that Taquisha had signed up as an organ donor, which gave us further reason to believe that doctors were hastening to declare her dead. After this meeting, we did our own research into death determined by neurologic criteria and found that the concept was conceived to ensure a source of organs for transplant and to save hospitals and the healthcare system money that they would otherwise have to spend on patients in comas.

Over the next weeks and months, we continued to request that Taquisha receive life-saving and potential coma-reversing medications and treatments, all of which were rejected by the hospital and supported by the court in favour of “status quo” maintenance—in other words, they were treating Taquisha as a dead body. We fell into a routine at the hospital, we would do shifts of visiting and sitting with her. We felt like we couldn’t trust the doctors and nurses, we were scared to leave Taquisha there alone.

As time passed, we began to develop a friendly rapport with some of the nurses, and we noticed how they were also following standard routines. I noticed that they weren’t treating Taquisha any differently than other patients, they were just following their procedures. Slowly, over the weeks and months we spent in that ICU while Taquisha’s case made its way through the courts, our daily interactions

with the medical and nursing staff helped to rebuild some level of trust and understanding.

I did not ever believe that Taquisha met the criteria for “NDD,” the neurologic determination of death. I believed that she had severe brain damage but that she still had signs of life that went against the definition. This is the main reason we went through the court process in its entirety. We weren’t ready to stop care while Taquisha was still showing signs of life to us, such as movement of her legs and feet, and reacting to sounds and noises.

After Taquisha’s heart stopped, we had the funeral. When I saw Dr. Healey there, I had a change of view in him. After that day we got to a place where we could talk, and that’s when our relationship of discussion and partnership began.

### **We were focused on the answer. We did not explore the question—reflections from Andrew Healey, intensive care unit physician**

At the outset of this case the clinical team was very focused on clearly defining and explaining the medical facts. On 14 September, Taquisha was admitted to the ICU after an out of hospital cardiac arrest due to drug intoxication. On 17 September, Taquisha was still breathing on her own but her prognosis was not good. We met with her family and let them know that this was the case. Three days later, Taquisha stopped breathing on her own. On 20 September, six days after her admission to the ICU, Taquisha was expertly examined by two staff physicians using nationally accepted guidelines for the determination of death using neurologic criteria and was declared dead.

The determination of death is a medical and scientific act. When a patient meets the standard, death can be declared. We knew Taquisha had met the minimum standard for death, and we knew we did not require consent to stop the machines supporting her body. We assumed that being right was the most important step to helping her family move towards removal of life support. We told Taquisha’s family that we did not need consent to remove the machines. We explained that Taquisha’s movements were not signs of life but spinal cord reflex movements that are possible and even expected after neurologic death determination. What we did not do was provide time and space for her family to absorb the news that she was gone. These choices and actions were not the result of one or two doctors acting. This sequence of events was the typical stance many physicians would have taken at the time.

Unquestionably, Taquisha was loved by her family and friends. That they all wanted what was best for her was clear to us from the beginning; however, our ideas of what

exactly “the best” entailed were different and they changed over time. There was tension among some individuals around the concept of dignity and whether or not Taquisha’s dignity was being disturbed by her continued ventilator support. Some of the medical and nursing staff would ask me, “What are we doing here?” At first, I would answer, “I have no idea.” Later, as the court case progressed, my response changed to, “We are following orders from the court to provide treatment as directed while we wait for a very important process to answer a remarkably important question about death.”

It took us a long while to move our focus away from that question—is she, or is she not dead? I remember at one point, months into the court case, meeting with Stanley and Alyson to explain some events that had taken place in Taquisha’s lungs. I started the meeting with an acknowledgement of the ongoing legal conflict, “Today, the question of whether Taquisha is dead or not is no longer owned by us. It is owned by the process that we are both learning from that is happening outside of here, in the court. Today we are here to talk about Taquisha and where things are with her care.” I explained to Stanley and Alyson the reality that there were going to be physiologic changes happening in Taquisha’s body that were no longer possible to treat. We talked together for a long time. In that meeting, we only focused on what Taquisha would have wanted, what her parents wanted for her, and what I felt that I could do medically. I never compromised my scientific view about what was happening with Taquisha, but it was no longer at the centre of our conversation. Instead, we focused on Stanley and Alyson, their family, and the care we could deliver to the patient who had died.

That meeting was a real turning point for me. I remember at the beginning of the meeting Stanley and Alyson talking about how wonderful our staff were. They spoke about the relationships that were forming between some of the staff and physicians and the family. They spoke of many nurses and physicians by name. At that point, we had been to two levels of court battles and they had technically “lost” in the first one. And yet, there they were, talking about the excellent care their daughter was receiving. After that meeting, when the ICU staff would ask me “What are we doing here?” I would explain, “We are caring for people. The family. Taquisha, even though she has died, we can still offer care.”

### **Encountering the shortcomings of standard responses—reflections from Paula Chidwick, ethicist**

Taquisha McKitty was not the first patient I encountered whose family voiced concerns over the concept of death determined by neurologic criteria. Though rare, we do

occasionally encounter families who raise objections. Accordingly, when Taquisha arrived, we had in place a standard medical ethics response to family requests for continued organ support after a declaration of death using neurologic criteria. This involved informing the family about the definition of death determined by neurologic criteria and then asking for their preferences in terms of end-of-life rituals and whether they would attend the disconnection of the ventilator. This routine process was felt to provide space for families to voice their concerns and to make choices at the end of the patient’s life. Nevertheless, it more or less centred the medicolegal reality that death has occurred, and that invasive supports will soon be withdrawn. The underlying message was ultimately, “this is happening, whether we like it or not.” The role of ethics consultation in these types of cases was really to negotiate with families about timing until the agreed-upon outcome—removal from the ventilator—could occur.

In Taquisha’s case, this standard process was interrupted. Our skillful communication of scientific knowledge about the concept of death determined by neurologic criteria and attempts at negotiating the timing of life support withdrawal did not result in increased understanding or any moves towards an agreement on timing. Instead, a breakdown of trust occurred that led to confrontation in the form of a court injunction and formal hearing. With the injunction, Taquisha’s family created an opportunity for us to slow down and revise our usual processes. This waiting time prompted a shift where their perspectives and concerns about Taquisha and her care were centred, moving our medical and legal objectives to the sidelines, which was admittedly uncomfortable at first but nevertheless needed to be done.

As time passed and Taquisha remained supported on a ventilator in the ICU, we began to notice a change in our interactions with her family. Through what Stanley later described to me as, “small incremental acts of kindness and compassion,” trust was slowly rebuilt. With the formal disagreement occurring in the courtroom, the ICU provided a space to slow down and truly listen to Stanley and his family without the need to interject and justify medical or legal positions.

### **Taquisha’s legacy: we can disagree and still trust, respect, and care for one another**

Taquisha leaves behind a multifaceted legacy. The court case surrounding her death led to a number of important legal and medical precedents related to the determination of death using neurologic criteria in Ontario and across Canada. Her case was the first to involve formal legal

recognition of acceptable guidelines for the determination of death using neurologic criteria in Canada. In addition, the McKitty case established an example for how challenges to the determination of death can be approached, and as a result will substantially shape how similar cases occur in the future.

At the level of hospital care, Taquisha's case has prompted a number of ICUs to begin to rethink the focus of end-of-life care for patients who have been declared dead using neurologic criteria and especially in instances where families request continued organ support after a determination of death. While this has certainly been the case for the ICU at William Osler Health System, it is also spreading to other hospitals in Ontario and beyond. Ethicist Paula Chidwick and ICU physician Andrew Healey are often asked for their input on how to build respectful and positive processes when these types of conflicts arise. Their experiences with Taquisha and her family, and the legacy of her case informs their responses.

In place of a routine that centres "us and our science," Dr. Chidwick now emphasizes the primary importance of building trust and respect with families across all beliefs. She calls this a process of "getting it [the relationship] right, not being right." This approach is based solidly on suggestions shared by Stanley during debriefing meetings after the conclusion of Taquisha's case. "Support families, share information and knowledge, give us time and space because we are people. We need to have some sense of control. Ask us, 'what else do you need?' and most importantly, listen when we tell you" was some of Stanley's advice for healthcare professionals working in the ICU. "The voice of the family is important," he stated. Feelings of being unheard, discounted, and overlooked contributed to Stanley's frustration and grief surrounding Taquisha's case. These feelings began with interactions with healthcare providers and not necessarily from the uncertainties of the medical or court case. "My biggest fear was not that Taquisha had died, but that I did not do enough—I needed to know that I did everything I could so I could be at peace." Interactions with Taquisha's doctors in which Stanley's questions about Taquisha's care seemed to be brushed aside as irrelevant or answered incompletely contributed to his frustration. Stanley acknowledges that families likely have different needs regarding information but that in his case, he wanted to know the clinical plan so that he could have some say in his daughter's care and prepare for what came next. From Stanley's perspective, Taquisha's doctors could have taken more time to respectfully listen to his family's concerns and to explain what was being done (or not done) for Taquisha from the moment of her admission. "Maybe if we had got to that point earlier," notes Stanley, "maybe it would have made a difference in how things proceeded."

Dr. Healey reflects that, "It has been an immense privilege to learn directly from Taquisha and her family about how to do better for families in these difficult circumstances. I've learned from them that because we did not focus on providing time, space, and understanding from the very beginning, we lost their trust." Instead of trust, the approach of repeatedly outlining medical and legal facts inspired fear, doubt, and anger. Now, rather than beginning conversations about the determination of death from a position of scientific and medical authority, Dr. Healey says he tries to, "approach families with real curiosity about the human being that was; to understand where things were before death and how I can support them now." He explains, "I try to give time and space, allow counsel and control, and give the family some predictability around end of life and the determination of death. I no longer try to convince anyone about the definition of death or the concept of determination of death using neurologic criteria. I do provide clear scientific assessments that are based on guidelines and a biological theory of disease, and I explain early my opinions about the brain and the central role of the brain in what we do in critical care. But I remind myself over and over that it is not about convincing. Instead, I look for areas of agreement—we both want what's best for the patient, generally no one wants to increase the patient's suffering, and we don't want to make decisions too early. Sometimes the only point of agreement is that the heart is beating. That is helpful, and true. I am never surprised by a family not being sure about decisions at the end of life. I ask first—not why would someone think that but what are my own assumptions about what should be done?" For Healey, one of the most important lessons learned from the McKitty case was that despite seemingly intractable conflict, it is possible to rebuild a level of trust, mutual respect, and even partnership by spending time, improving communication, and practicing a high degree of empathy with families. He now makes this a priority in all family interactions and encourages other medical staff at William Osler Health System and across Ontario to do the same.

As a result of the McKitty case, Dr. Chidwick has likewise changed her approach to family conflicts in the ICU. "Instead of setting a goal for finding agreement, we set a goal for a family meeting to listen, learn, and respect deeply held values and beliefs of the family and also share our own deeply held beliefs," Chidwick explains. This upstream process of focusing on relationships undoubtedly takes more time than traditional strategies of focusing on communication of scientific knowledge, but, as the McKitty case has shown, this investment is worthwhile if it can help to avoid the immense emotional, physical, and financial strain of a drawn-out legal battle. "You need trust to move forward with a family. So not taking the time to

build trust will not in fact move you forward in decision-making. When you think there is no time to embark on building trust, remember it is the foundation of the path forward and you need it,” notes Chidwick. The question of just how much time and space to provide families struggling with a declaration of death using neurologic criteria is often raised, especially in the contexts of increasing COVID-19-driven resource constraints. Chidwick emphasizes that ethical focus should centre on processes of relationship and trust-building with families, rather than on outcomes. “Once you have that relationship of trust, you’ll know how much time is needed,” she explains. “The starting point needs to be building a space where families feel comfortable enough to share their hopes, fears, and beliefs with the clinical team. We cannot assume that this space already exists or will be created simply because we outline desired clinical outcomes.” Ultimately, Chidwick now feels that disagreement, whether over the course of care or over definitions of death, should not be an impediment to building relationships of trust with families. “When you disagree, acknowledge the disagreement and keep going,” she states.

Taquisha leaves behind a positive and powerful legacy spanning from personal learning in the healthcare professionals that cared for her to organizational improvements in the ICU to important medicolegal foundations of how death is understood in Canada. These changes at all levels of the healthcare system will have positive ripple effects on countless patients, families, and healthcare providers for years to come. Important work was done in the court, important learning was done in the hospital, and important reflection was done in her treating healthcare providers that changed the way we work and think. Nothing can replace Taquisha’s life and she is deeply missed by her many friends and large family. Her legacy of changes in the courtroom, the hospital, and at the bedside will continue to impact others for years to come.

Though the McKitty case represents just one instance of a family’s request for continued organ support after a determination of death using neurologic criteria, our juxtaposition of family and healthcare provider experiences helps to illuminate how the best intentions of both groups can nevertheless lead to protracted conflict. Both Taquisha’s family and her healthcare providers wanted the best for her, but they disagreed on what this entailed. Initially, instead of taking time to communicate and build a relationship of trust through which options for care could be explored, the implementation of a routine process that involved conveying information about the definition of the determination of death using neurologic criteria and the legal basis for withdrawal of life sustaining therapies caused Taquisha’s family to feel unheard and to seek legal protections. It was only later, through the time

provided by this legal conflict and the ongoing compassionate care for Taquisha, that Taquisha’s family and her healthcare providers were able to slowly build a relationship of trust.

The experiences of this case serve as a counterbalance to recent calls for harmonization and clarity in definitions of death determined using neurologic criteria as a mechanism for strengthening trust between healthcare providers and families.<sup>8</sup> In the McKitty case, the validity of the definition of death using neurologic criteria was not a central concern for Stanley Stewart and his family, despite the space given to this debate in the courtroom. Instead, Stanley reflects that he was primarily distressed with how and why this definition of death was being applied to his daughter in what seemed a sudden and perhaps deliberate change in direction from her otherwise ambiguous admission. Rather than needing conceptual clarity about the concept of death determined using neurologic criteria itself, Stanley describes wanting respect and compassion from Taquisha’s care providers and a clearer explanation of her overall course in hospital. Though harmonization of the focus on the brain, evidence-based guidelines, and legal clarity may be helpful for the scientific community and the general public, these efforts do not address the core issues of a lack of trust and poor communication, which remain central to conflicts over the determination of death and discontinuation of ventilator support. Existing tools for facilitating communication of “bad news” such as the SPIKES approach<sup>9</sup> may help to facilitate clinicians’ skills in informing families of patient death.<sup>10</sup> Nevertheless, in complex cases where families fundamentally disagree about a patient’s condition, outcome-oriented standardized checklists may fail to provide space for processes of fostering the respect and trust necessary for working together despite ongoing disagreement. As part of honouring Taquisha’s legacy and the important work that was done in her case, we suggest that programs to improve definitions and determinations of death should be paired with family-led initiatives to train healthcare providers to facilitate the open and honest relationships of trust and communication needed for helping families to accept that death has occurred.

**Disclosures** Stanley Stewart and Alyson McKitty are Taquisha McKitty’s parents. Dr. Andrew Healey is the Chief Medical Officer for the Trillium Gift of Life Network (Toronto, ON, Canada) and was one of the physicians who cared for Taquisha during her hospital stay. Paula Chidwick is the hospital ethicist who was involved in Taquisha’s case. The authors declare no other conflicts of interest.

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