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Article abstract

Soto's syndrome is a rare form of genetic disorder, which is often non-life threatening. However, this case study will examine the case of a young lady with Soto's syndrome who developed a pediatric cancer. The team and family had opposing goals of care. Ethical dilemmas in surrogate decision-making for mentally challenged individuals can often be resolved through facilitated conversation between the patient's family and healthcare team.

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ÉTUDE DE CAS / CASE STUDY

Facilitated Conversation: A Useful Tool in an Ethicist's Toolbox

Natalie Hardy¹, Nico Nortje²

Résumé

Le syndrome de Soto est une forme rare de maladie génétique, qui ne met souvent pas la vie du patient en danger. Cependant, cette étude de cas examinera le cas d'une jeune femme atteinte du syndrome de Soto qui a développé un cancer pédiatrique. L'équipe et la famille avaient des objectifs de soins opposés. Les dilemmes éthiques liés à la prise de décisions de substitution pour les personnes atteintes de troubles mentaux peuvent souvent être résolus grâce à une conversation facilitée entre la famille du patient et l'équipe de soins.

Mots-clés

Syndrome de Sotos, cancer, leucémie, capacité, conversation facilitée

Abstract

Soto's syndrome is a rare form of genetic disorder, which is often non-life threatening. However, this case study will examine the case of a young lady with Soto's syndrome who developed a pediatric cancer. The team and family had opposing goals of care. Ethical dilemmas in surrogate decision-making for mentally challenged individuals can often be resolved through facilitated conversation between the patient's family and healthcare team.

Keywords

Sotos syndrome, cancer, leukemia, capacity, facilitated conversation

Introduction

Ethics consults are usually requested when there is a clash on goals of care. Often times the ethicist is faced with conflict between the medical teams and patients/families as to whether or not to pursue treatment. The challenge intensifies when the patient is an adult with limited mental abilities.

Case Study

A.B. is a young, non-verbal woman in her late thirties with a known history of Sotos syndrome and the equivalent mental ability of a 3-year-old. The patient has been taken care of by her family, and her mother was her primary caregiver. The patient was brought to an oncology hospital after an initial incorrect diagnosis of otitis externa. At the oncology hospital, she was diagnosed with acute lymphocytic leukemia (ALL), a fast-growing cancer of the lymphoblastic cells usually occurring only in paediatric patients. According to Brown and Shah (1), ALL is one of the most common cancers predominantly diagnosed during childhood and can be treated with intensive chemotherapy, stem cell transplant, CAR T-Cell therapy, and radiation therapy. Most treatments are successful: 98% of cases go into clinical remission (2). In itself, the patient's cancer diagnosis did not present much challenge, however, her accompanied syndrome presented a much greater issue.

Sotos syndrome, also known as cerebral gigantism, is a rare genetic disorder caused by mutations in the NSD1 gene (3). Affected individuals experience excessive growth, intellectual disabilities, and communication limitations which inhibit social development (4). Whereas the average child would learn, develop, and communicate normally, individuals with Sotos have difficulty forming relationships with others and experience delays in walking, speaking, and coordination that carry into adulthood. Given the fact that those with Sotos often cannot fulfill normative societal roles, form meaningful connections, or engage proactively, they experience more anxiety than others. Depending on the severity of their intellectual disability, patients can have difficulty understanding treatment options and voicing their opinion. Treatment for Sotos syndrome is symptomatic, as there is no cure. However, the condition is not life-threatening, and affected individuals often have normal life expectancies (4).

A multi-disciplinary approach is best for individuals with Sotos syndrome (4). Speech, behavioral, physical, psychological, and occupational therapy are often implemented in addition to prescription medications. In everyday life, it is important to communicate in simple terms and present information concretely, as patients can have difficulty understanding abstract concepts. Being mindful of intellectual abilities is crucial to avoiding anxiety, as an individual with Sotos can appear older and more cognitively able than they truly are. Moreover, consistency is wisely implemented; when placed in stressful, unfamiliar situations, anxiety and behavioral difficulties (like tantrums and compulsive behaviour) arise. Although individuals with Sotos syndrome have an increased likelihood of developing cancer, there are currently no protocols on how to approach patients in the oncology setting.

A.B. was seen by the adult leukemia team upon admission. During her initial work-up, A.B. became very anxious and repeatedly voiced to her mother that she wanted to go to her house (about 3 hours away) and play her video games. Nothing gave her more pleasure than being at home and playing video games.

During admission, A.B. developed respiratory distress and was transitioned to the intensive care unit (ICU). While in the ICU, the patient became agitated, "in an uncontrolled way," per the mother. She added, "I have never seen her like this before."

A.B. exhibited further unfamiliar behaviour when she bit her mother's hand. Psychiatry was consulted, and a mood stabilizer was recommended. Five days later, A.B.'s respiratory distress cleared, and she was transitioned to the leukemia floor.

Facilitated Conversation & Ethics

The leukemia team recommended treating A.B.'s cancer through chemotherapy, however her mother voiced that she did not want to inflict more suffering on her daughter. A.B. was clearly distressed and A.B.'s mother was uncertain whether the treatment would improve her daughter's quality of life. The leukemia team requested an ethics consult, and a family goals of care conference was called.

The ethicist applied the process of facilitated conversation to address the issue at hand. According to Bowling Green State University's Office of Equity and Inclusion (5), a facilitated conversation is one that strives to find a resolution between two parties of differing beliefs – in this case, differing beliefs between the patient's mother and the oncology specialists. By creating a respectful, safe, and trusting environment, the ethicist can identify relevant issues and stimulate dialogue between the two parties. Members of each party are expected to actively listen during the discussion. It is the job of the ethicist to establish guidelines and allow all individuals to relay their concerns in a respectful manner; doing so creates a safe space for effective dialogue and problem-solving. Issues are examined holistically with the intent of reaching an agreement at the end of the discussion. Most times, a resolution can be agreed upon (6).

In the case of A.B., the leukemia team was positive that she could get effective chemotherapy. However, the patient ran a high risk of infection and tumor lysis syndrome. The team was also not convinced that A.B.'s cancer had not metastasized to the brain. For there to be a clear understanding of potential metastases, several brain scans would have to be done, which would cause A.B. considerable discomfort and distress.

A.B.'s parents were in a conundrum, most notably her mother, who was also the medical power of attorney and decision maker. They did not want A.B. to suffer but also did not want to lose their daughter. They inquired about the success rate of chemotherapy, should it be given and brain metastasis be found. The parents were informed that the success rate would have been near 50%, however A.B. would need to stay at the oncology hospital for an extended period of time, which posed additional psychosocial challenges.

The ethical issue in the case of A.B. lies in surrogate decision making for adult mentally challenged patients because of the patient's inability to fully understand the consequences of choices. According to the AMA's Code of Ethics (7), if a patient has a mental illness or disability (such as Sotos) that can impede her ability to make appropriate decisions, then the physician must evaluate her capacity. If the physician concludes that the patient does not have appropriate capacity, then the surrogate decision maker must make decisions according to the substituted judgement standard – that is, she should take into account the patient's preferences and values. If the patient's values are unknown, then the surrogate decision maker should act in accordance with the best interest principle and do what is in the best interest of the patient.

Since A.B. did not have decision-making capacity, her mother was her medical power of attorney and decision maker. To facilitate a conversation and identify risks and benefits, A.B.'s family gathered at a meeting (including her mother, father, and siblings). The meeting was intended to empower the family, provide an opportunity for questions to be answered, and facilitate a discussion of what is in the best interest of the patient. After considerable questioning of the medical team, the family was uncomfortable putting A.B. through additional treatment. Hence, the recommendation was made to consider palliative care. The family accepted the recommendation and transitioned A.B. from the leukemia floor to the palliative care floor. The patient's symptoms were managed, and she was eventually made more comfortable. The family was allowed to be in the room at all times, and A.B. happily passed away two days later.

Conclusion

The benefit of facilitated conversation lies in the fact that any power inequality between the parties present can be managed and that the best outcome for all those around the table can be reached. The process allows for the different role players to tell their narrated stories to the other party. This was evident in the case of A.B. Although the team was suggesting more treatment, they got to hear the story of A.B. and her family and came to realise that the family was indeed acting in her best interest.

Questions

1. What other ethical "tools" might work well in conjunction with facilitated conversation in this case and why?
2. Had the mother been adamant on aggressive treatment for A.B., ethically speaking, should the ethicist have done something differently?

Conflicts d'intérêts

Nico Nortje est éditeur de la Revue canadienne de bioéthique.

Conflicts of Interest

Nico Nortje is an editor for the Canadian Journal of Bioethics.

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