Terminal and Chronic Illness Panel Case Studies

Case Study #1 – Terminal Illness

Osteosarcoma is a highly malignant bone cancer with a predilection for spreading to the lungs that primarily affects adolescents. Non-metastatic osteosarcoma has an approximate cure rate of 70%. Patients with osteosarcoma and metastases at the time of diagnosis are cured less than 20% of the time. Treatment consists of surgery and chemotherapy. Many children with cancer are treated according to clinical research trials.

Michael is a 15-year-old who was treated for metastatic osteosarcoma. Michael has not responded to conventional therapy. For almost one year, he was treated on a therapeutic randomized clinical trial, which consisted of standard therapy (up-front chemotherapy, limb salvage surgery, and postsurgical chemotherapy). When his cancer responded poorly to up-front therapy, he was randomized to receive additional "experimental" chemotherapy.

Michael has a very close relationship with his mother, and he has been an active participant in every treatment conference. For the most part, Michael tolerated the treatment; however, he struggled both physically and emotionally with the last 3 months of treatment. Michael’s end-of-therapy scans confirmed that tumor was still present in both the bone and the lungs.

Michael's mother wants to proceed with an (unproven) experimental therapy in an effort to prolong his life. Michael, on the other hand, does not desire this intervention. He asks the physician not to administer the drug and to allow him to die on his "own terms." Michael's mother (emphatically) states that this is her decision to make and not his. She adds that if you are not willing to treat him, she will take him to a doctor who will.

1) What criteria determine a minor's decision / choice as valid?
2) In what situations, if any, should the decisions of a child who lacks legal standing be as authoritative as those of his or her parents?
3) What might a practical decision-making model with appropriate roles for children, parents, and physicians look like?

Case Studies #2 and #3 – HIV/AIDS

#2
The patient, Jessica, is a 19 year old young woman who was perinatally infected. She is cognitively delayed, probably at least in part because of living with HIV for several years before effective medication was available. She has an IEP and is in the 11th grade. She also has been diagnosed with borderline personality disorder. Her mother died when she was seven, her father is ill and living somewhere in Pennsylvania... She is being raised by her maternal grandmother. Her virus is particularly sensitive. She now has a massively resistant virus. She has just been hospitalized for complications resulting from her failure to take anti-retroviral medication consistently.
In discussions with her physician, she says she wants to be healthy and she says she has goals for her life. At the same time, she often fails or refuses to take her medicine. In the hospital, she is again refusing to take meds.

Several questions arise when trying to decide how to treat this patient –

1) Although she is over 18, does she have the capacity to make medical decisions for herself?
2) Is she passively suicidal, i.e., saying one thing and doing something else? What are the legal implications if she is?
3) Can or should her physician consult with her grandmother?

#3
A behaviorally-infected 16 year old, Thomas, has not disclosed the virus to his family. He is presently having a sexual relationship with his 20 year old boyfriend. He has had multiple sexual partners over the past three years. Thomas has not come out to family or to friends at school. He feels certain they will react negatively.

Up until this year, he was doing very well in school. Now he is thinking about dropping out and asking “what’s the point?” He lives with mother and grandmother, but is increasingly spending nights with 20 year old boyfriend. His father is incarcerated and has not communicated with his son for five years. His mother works at nights as a nursing assistant. His grandmother suffers from diabetes, high blood pressure, and depression.

Thomas was tested for HIV about 6 months ago after a partner told him that he should get tested. He has agreed to take anti-retroviral medication after months of education and counseling, but the pharmacy says he is not consistently filling prescriptions.

1) If Thomas refuses to discuss the situation with his family, can and should his medical provider contact the family?
2) What can be disclosed to the family?