Case Study: A Normal Life

Caleb Williams was a 10-year-old boy who was referred to a pediatric psychologist at a large children's hospital. Caleb was diagnosed with sickle cell disease shortly after birth and has an extensive medical history related to this condition.

Caleb's disorder, hemoglobin SS disease, is a recessive genetic disorder. Both his mother and father were carriers of the disease and Caleb was unlucky enough to inherit the recessive gene from each parent. The disease is especially prevalent among African American children, like Caleb. The disorder causes red blood cells to have a sickle shape, rather than the round shape shown by healthy children. The sickle shape limits the amount of oxygen the blood cells can carry and can cause occlusion (blockages) in children's blood stream. Sickle cells also have a much shorter lifespan (10-20 days) than healthy red blood cells (120 days) causing children with the disease to experience anemia, that is, a low red blood cell count.

Caleb had experienced the most common effects of sickle cell disease. First, because of his anemia, he was frequently tired and often experienced weakness and fatigue. These symptoms often reduced the amount of time that he could play with other children and limited his participation in certain high-intensity sports, like basketball and football -- two sports that he enjoyed.

Second, Caleb experienced frequent, intense episodes of pain associated with occlusions. Usually, these painful crises occurred in his chest, arms, and legs and lasted for several hours or days. Sometimes, the pain was severe and caused him to miss school and other daily activities. Painful crises often occurred when he was dehydrated (e.g., after running or playing), when he experienced a sudden change in temperature (e.g., playing in the snow, swimming in a cold pool), or when he was under stress (e.g., listening to his parents argue).

Third, Caleb has a history of infections and hospitalizations associated with his disorder. As a toddler, he was diagnosed with acute chest syndrome, a condition characterized by occlusions of vesicles in the lungs, resulting in severe chest pain, coughing, and breathing problems. In preschool, he experienced splenic sequestration syndrome, a serious condition in which his sickle-shaped cells became trapped (i.e., sequestered) in his spleen, causing severe anemia and abdominal pain. He has also been hospitalized on several other occasions because of recurrent fevers. Currently, Caleb takes a medication called hydroxyurea (Droxia) that increases hemoglobin and reduces the frequency and intensity of his pain.

During the initial interview with the pediatric psychologist, Caleb's parents reported that Caleb appears irritable and moody. Over the past 6 months, Caleb has shown an increase in lethargy

and feelings of hopelessness, associated with his sickle cell symptoms. On one occasion, during a painful episode, he commented that "he wished he had never been born." He has also grown angry at being limited in his ability to play sports, run and swim, and do many other physical activities because of chronic fatigue and recurrent pain. Although many of his friends and classmates are sympathetic to his medical problems, his parents have noticed that Caleb is less often invited to others' homes to play.

Caleb's medical condition has also taken its toll on the Williams family more generally. His parents reported very high levels of stress associated with caring for a child with a chronic medical problem. Stressors include (1) making sure that Caleb takes his medication regularly; (2) coordinating Caleb's medical care with his schooling; (3) working with teachers to help Caleb make up missed schoolwork; (4) transportation to and from medical appointments; (5) medical bills; and (6) missed work. Mr. and Mrs. Williams are also concerned that they may be neglecting Caleb's two younger brothers. These stressors have led to increased marital conflict that, in turn, exacerbates Caleb's symptoms.

When interviewed alone, Caleb denied suicidal ideation, but readily admitted to feelings of hopelessness and helplessness regarding his illness. "No one understands what it's like…" he repeatedly said. "I can't do all the things that I want to do, all the things even my little brothers can do. I can't be a normal kid."

Questions

1. What is a pediatric psychologist and what are their three main professional activities?

2. What mental health problem(s) might Caleb experience?

3. If you were Caleb's therapist, how might you address adherence in therapy?

4. In what way might behavioral factors (besides adherence) exacerbate Caleb's sickle cell symptoms? How might a therapist address these factors?

5. In what way might emotional factors exacerbate Caleb's sickle cell symptoms? How might a therapist address these factors?

This case study accompanies the textbook: Weis, R. (2025). *Introduction to children's mental health: Integrating science and practice, 5th edition.* Thousand Oaks, CA: Sage. Answers appear in a separate instructor's manual available through the publisher.