



Angela and Paolo

"I just don't know what to do!" Angela said, "I feel so guilty, but sometimes I just have no energy, I can barely get out of bed."

Angela is a single mother of Paolo, a 3 year old boy with bronchopulmonary dysplasia (BPD), and an adolescent daughter with autism. Angela and Paolo live alone in an inner city apartment, and Angela's daughter lives in state-funded program for people with disabilities. Angela has been married three times, twice to men who were abusive. Her third husband married her to get his green card, and left her after it was obtained.

Angela had a difficult childhood, abandoned by a mother with mental illness and raised by an abusive father. A single mother on welfare, she utilized a welfare-to-work program to obtain her Registered Nursing credentials. She was able to find jobs, but has been unable to keep them. In one instance she lost her job when she was unable to stay on for a second shift when a co-worker did not show up, as she needed to return home to oversee Paolo's care. Angela was proud when she got a job that provided health insurance. When the job became difficult, she questioned whether it was better to quit or keep working to maintain health insurance.

Angela suffers from bouts of depression related to childhood memories of abuse. During these periods, she is unable fulfill basic tasks, including managing Paolo's medical care.

Paolo was born at 26 weeks/3 days gestation. His birth weight was 585 grams with a length of 28cm and HC 22cm. Paolo remained in the NICU for 4 months due to multiple complications related to his prematurity. His newborn screens were normal. His discharge plan included oxygen, saturation monitor, infant formula, and multivitamins with iron. His weight was 2803 grams, length 44 cm, and HC 35 cm. Follow up plans included visits to the pediatrician in 1 week, and visits to the Newborn Follow Up Clinic, BPD clinic, and Eye clinic in 4 months.

A home visit was made to deliver holiday gifts to Angela and 3 year old Paolo. The BPD Social Worker and Nurse Practitioner went to Angela's apartment. Present in the home were Paolo, Angela, Angela's nephew's girlfriend (the nephew was out), the girlfriend's toddler son, and Angela's two school-age nieces. Angela reported to the Social Worker that the nieces had been staying with her "for a couple of days" and that she did not know where her sister was. The home was a 2 bedroom apartment with a kitchen, living room, and one bathroom. The house was somewhat cluttered and dusty. The kitchen was somewhat dirty; there were several bottles sitting near the sink that contained small amounts of clabbered formula. There was no kitchen table. During the visit Angela fed Paolo Spaghetti-Os and applesauce while sitting on her lap in the living room.

Over the next several years, Angela missed many of Paolo's clinic visits. She brought Paolo to clinic

intermittently and Paolo had several hospitalizations for respiratory issues and pneumonias. The PPC healthcare team had concerns about the intermittent adherence to Paolo's treatment regimen and questioned his mother's interest in overseeing his care. The team described Angela as someone who had initially appeared scattered but had recently seemed more "together." Other than this, they had no real sense of the family or their life outside of clinic.

ADDITIONAL QUESTIONS TO CONSIDER:

1. What additional information would you like to have?
2. Where and how would you get this information?
3. What knowledge base/skills do you need to effectively assess and respond to this situation?
4. What impedes and maximizes effective interaction with the family?
5. How would you communicate your recommendations/actions to the other team members?
6. How will the team arrive at "team" recommendations and how will they be communicated to the family?
7. What outcomes would you like to see for Paolo and Angela?
8. Is there anything else that you feel needs to be said or done?