Pediatric Intake Report (Pediatric Caregiver Report)

Report on: Ms. Martha C (real names not used), caregiver for/parent of Rudy, age 6

Construct: Pediatric Caregiver Report

Ms. C. is the mother of Rudy, a 6-year old diagnosed with acute lymphoblastic leukemia age 4. He was treated with chemotherapy, but relapsed and in fall of 2009, he underwent a stem cell transplant. He and his mom are seen today in clinic for a follow-up appointment. Rudy is doing well, although he has had some graft-versus-host disease, especially skin problems and mouth sores, making eating difficult. As a result, he has not yet returned to school, though his mother is hoping that he will improve sufficiently for this to happen in fall of 2010.

Ms. C is a single parent who has 2 other children, Larissa who is 8 and Jackson, who is 4. Before Rudy's diagnosis, Mrs. C. was working part-time as a postal worker and the children were cared for by her mother. Since Rudy's diagnosis, Ms. C. has not worked. Her mother continues to help her with babysitting for clinic appointments, but she has not been able to rely on her mother as much for this since Ms. C's father suffered a minor stroke last spring, necessitating more care from her mother.

Ms. C reports that she has been very anxious since her dad had his stroke and has had difficulty sleeping. She says she often gets little sleep, since there is much to do to take care of the children. Rudy needs special care and food and she is still wary of his being around children who may have contagious or infectious diseases. This is especially true when one of her other children gets a cold or a fever. She feels very torn between the children's needs. She also feels very worried about money and insurance. She had good insurance when she was working, but her benefits will run out soon and she wants very much to be able to go back to work soon to be able to take care of her children without so much worry about money. If Rudy can go to school this fall, it would make it possible for her to go back to work. But she worries also that when Rudy goes to school, he will encounter more ill children and she is very scared because he still is quite vulnerable. Ms. C and Rudy have become particularly close over the period of his illness and she worries a great deal about his health and safety going forward.

Ms. C is also worried about Larissa. She had more trouble academically in school last year and has seemed withdrawn and sad over the summer. Ms. C. tries to make time to spend with Larissa alone, but several times she has had to postpone their time together because of other demands.

Ms. C also reports feeling depressed at the long recovery period. She is so grateful that Rudy seems well generally, but she feels worn down by the many months of his hospitalization and recovery. There has been no respite for her; she is never away from her children. Ms. C often skips meals herself or she feels, at other times, she overeats out of frustration. She is disappointed that, even though she is home, she has little energy to cook for her children and to make healthy meals. She also feels badly that she cannot be more help to her mother and father at this time in their lives, but she knows this is not possible. Ms. C has one sister but she lives in another state. She is supportive by phone, but is not able to help either Ms. C or their parents very much.

Impression: Ms. C appears depressed. She has eating and sleeping problems, periods of sadness (though she says it is difficult for her to cry) but has no suicidal ideation. She says she often feels inadequate to care for her children, something she previously prided herself on being able to do. She was also a hard worker on her job and was often praised for her performance. The necessary changes in her family's life due to Rudy's illness have been very difficult. She also misses the support of the hospital staff which she drew on extensively when Rudy was undergoing his transplant.

Ms. C is a very appealing, conscientious person who has found it increasingly difficult to balance the emotional and physical needs of her family members over the long period of illness which her son Rudy has experienced. She feels guilty even thinking about her own needs, when she is so grateful that her son is alive and doing well, but, like many parents, she worries a great deal about whether he will retain his good health going forward. As a single parent, Ms. C carries the sole burden of her family's financial and emotional well-being. Her strongest supporter is her mother,

who is close to Ms. C and her children and babysits when she can, but this support has been compromised over the past few months because her mother is also caring for her husband who had a stroke last spring. Since that time, Ms. C has felt increasingly anxious and depressed, finding it difficult to sleep, waking and not being able to return to sleep, and alternately overeating and forgetting to eat. Her 8-year old daughter also appears strained by the family illness experiences and appears withdrawn and unhappy to Ms. C, which further worries Ms. C.

Recommendations: We arranged that for the next month at least, I would call Ms. C. weekly at a pre-appointed time to talk about how she is feeling and what the current stressors are. It was felt that this was preferable to a referral to a local mental health provider for therapy because Ms. C. has little childcare available and would not be likely to get to appointments regularly. Also, I am most familiar with Rudy's and Ms. C.'s experiences here at the medical center.

I will also consider utilizing a web-based, evidence-based problem-solving intervention (http://www.medscape.com/viewarticle/565021_4) for parents of children with cancer to support Ms. C. I spoke with her briefly about his today and will talk with her more at length in our calls over the next few weeks.

It was suggested that we would talk today with Rudy's pediatric oncologist about the likelihood of his being able to return to school in September. Assuming that he agreed, we will set us a conference with the school liaison team here to have them schedule a time to go out to Rudy's classroom to help prepare his teacher and classmates for his return to school.

It was recommended that if Ms. C's problems do not resolve somewhat over the next few weeks, that on her next visit to clinic, she could see the clinic psychiatric consultant to determine if medication for sleep and anxiety would be likely to be helpful.

Ms. C. was referred to the financial office to discuss her concerns about insurance.

Ms. C. was encouraged to access the SuperSibs website (http://www.supersibs.org/) and to sign Larissa up. This site offers support and peer contact for children who have an ill brother or sister. We also discussed that it might be helpful for her to let the school officials know when Larissa goes back to school about her behavior and to ask for their help in evaluating whether referral is needed for Larissa.