A Story of Illness and Identity:
The Effects of Long-Term Psychotropic Medication Use
in Children

by

Alice Foulkes-Garcia

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A Story of Illness and Identity: The Effects of Long-Term Psychotropic Medication Use in Children

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Abstract
This phenomenological case study was a first-person practitioner account of an in-home therapist working for a case management organization that provides therapeutic counseling services to children. The psychosocial development of this 16-year-old Latina female, a recent immigrant to the United States, occurred in a medicalized environment with biological treatments that led to the development of an illness identity and the need for medication to manage emotions. The case includes a discussion of the side effects of medication, the impact of culture, and role of attachment. The pharmaceutical industry has invested significant financial resources in the treatment of mental illness and emotional/behavioral disorders in children. Little is known, however, about the long-term side effects of psychotropic medication in individuals who initiate use at a young age. This case study argues for a reduction in long-term use of psychotropic medication in children. The author utilized cognitive behavioral therapeutic techniques to teach coping skills and to reintegrate the child into the community after an extended hospitalization and subsequent residential placement.

Mental health professionals agree that a diagnosis of mental illness has an impact on an individual’s identity; however, there has been little research on this topic in adults, and even less in children. Yanos, Roe, and Lysaker (2010) described illness identity as a set of roles and attitudes that individuals develop about themselves in relation to their understanding of their illness, which is affected both by the experience of objective aspects of illness and by how the illness is interpreted. Yanos et al. continued their discussion by identifying that the concept of illness identity is influenced by the sociological concept of identity, which refers to the social categories that an individual uses to describe oneself. They concluded that the meaning of the illness to the individual is the key issue. As illness identity affects self-esteem, there is evidence that transforming identity is an essential part of the process of recovery from mental illness. Recovery involves transforming an undervalued identity associated with internalized stigma and replacing it with more individualized empowered identity. The authors concluded their article with the suggestion that it is important to pay attention to the impact of illness identity in treatment; ignoring it will create barriers to successful treatment. Phenomenological observations suggest that individuals with mental illness are less able to narrate their evolving life story. To illustrate this, I will give the following case history.

In Dr. Smith’s bare-walled psychiatry office, there sat a team of school personnel, a case manager, and myself, an in-home therapist. It had been about eight months into my client Maria’s weekly sessions. I sat tensely with Carmen, Maria’s mother, as we awaited Dr. Smith’s entrance. The walls were white with no diplomas or pictures, and the room was silent. Maria, age 16, had been discharged from a residential program almost one year prior on Clozaril, a very strong antipsychotic medication, which Carmen believed was causing Maria to sleep a lot, to be quite anxious, and to drool during the day. Carmen had increasingly seen her daughter as listless and not present in day-to-day interactions at home with family, and had asked the psychiatrist to take her off the medication. The residential program told Carmen that the medication was to be used on a short-term basis, and Carmen brought her “team” (the case manager and me) to try to convince the psychiatrist to take Maria off the medication.

I had never been asked to go with a family to meet with a psychiatrist, so I was anxious about the situation. I agreed to go because I believed that

*Informed Consent: Informed consent was obtained from the individuals included in the case study.
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Carmen had the right to advocate for her child. Besides being an advocate in this meeting, I was also the translator, as Carmen spoke very little English; the school had been using the lack of direct communication as a way of controlling Maria’s medication regimen. The family was not able to say no to medication changes because they could not understand when changes were being made. The psychiatrist continued to increase Maria’s medication dosage due to the results of monthly blood work, which indicated that the level of Clozaril in Maria’s blood was not in the therapeutic range. The school counselor would leave messages in English on the mother’s answering machine and then send increasingly higher doses of the medication to the home. Carmen’s phone calls to the school went unanswered.

Dr. Smith: I will not take Maria off the medication. The proof that the medication is effective is that she has been out of the hospital for most of the last year.

Case manager: Carmen feels strongly that she would like Maria taken off of Clozaril and placed on a medication that has fewer side effects. Carmen is also very concerned about the long-term side effects of the medication.

Dr. Smith: I will not take her off of the medication. If Carmen stops giving Maria the medication, I will call Child Services and make an allegation of neglect. Maria is doing well, so I don’t know why you would want to risk her being hospitalized again.

Me: I have been working in psychiatric settings for over 20 years and have never seen Clozaril used for anything other than schizophrenia.

Dr. Smith: I am treating Maria for schizophrenia.

Carmen: ¿Qué? [What?] (She continued in Spanish.) Not one psychiatrist in 10 years has even mentioned schizophrenia!

Dr. Smith: Maria has heard voices in the past.

Me: Maria could have major depression with psychotic features. There is a family history of depression and anxiety. Maybe you could try a medication for depression or anxiety.

Silence permeated the room after Dr. Smith’s last statement, and it seemed that he himself could not even believe what he had said. Dr. Smith suddenly agreed to wean Maria off of Clozaril. His closing sentence was directed at Carmen and me.

Dr. Smith: If Maria ends up killing herself, it will be your fault!

Me: But she deserves a chance at a better quality of life than this medication is giving her!

The aim of this case study is to provide a first-person practitioner account of an in-home therapist working for a case management organization that authorizes therapeutic counseling services for children in their own homes. The psychosocial development of this 16-year-old Latina female, a recent immigrant to the United States, occurred in a medicalized environment with biological treatments that led to the development of an illness identity and the need for medication to manage emotions. The side effects of medication, the impact of culture, and attachment will be discussed in this case. The pharmaceutical industry has invested significant financial resources in the treatment of mental illness and emotional/behavioral disorders in children around the world. The long-term side effects of psychotropic medications in individuals who initiate use at a young age remain unclear.

Piecing Together a Child’s Past

One day, about five months into my work, Maria recounted a memory that has haunted her for many years. She was crying, leaning against the wall in a single room house with a dirt floor, in a small town in Puerto Rico. She was wearing large hand-me-down pants—at least one size too big, with holes in the knees—and a stained T-shirt, staring at a man lying on the ground moaning and bleeding. This was her first memory of one of her father’s multiple suicide attempts. This time her father, José, had been drinking, overdosed on pills, and then cut himself with a razor.

Maria was 7 years old and the only one in the home at the time of this incident. She was quite nervous when she was left home alone with her father. This time, she had to wait for her
grandmother to get home to call the ambulance. Generally, Maria accompanied her grandmother on her daily errands, but her grandmother had a doctor's appointment that morning. Although she knew in her heart that her father loved her, she was not sure that she could trust him. His suicide attempts served to reinforce her feelings.

Carmen was 17 years old and unmarried when her second child, Maria, was born into a large extended family; her first daughter, Rebecca, was born 1 year prior. Maria was always very close to Rebecca, but neither she nor her sister were very close to their mother. Carmen saw her daughters frequently as they were growing up, prior to them coming to live with her. Carmen had depression and anxiety after Rebecca and Maria were born, and she described herself as suffering from “ataques de nervios” [attacks of the nerves] (loosely translated as panic attacks), both when the children were young and presently, when her life becomes overwhelming. Carmen married Juan, Maria’s stepfather, when Maria was 10-years-old. Maria and Rebecca went to live with Carmen after she married. Carmen then had two more daughters with her husband Juan—Marissa and Marta. Marissa was diagnosed with leukemia when she was 3-years-old, and spent a lot of time in medical centers and hospitals in Puerto Rico. Marissa’s physical health, along with Maria’s mental health, were constant stresses for Carmen.

Maria spent time in numerous households from birth to age 10. The matriarchal figure in each household took over the primary care of the children. The advantage of the extended family was that there was always someone to watch the children; the disadvantage was that the children may not have developed secure attachments. Maria and Rebecca spent some of their early childhood living with their aunt Gladys, who had three children of her own. Maria spent a lot of time playing outside with her cousins. As she started first grade, her behavior changed suddenly. Gladys became concerned when Maria became increasingly withdrawn and would not interact with her cousins. The once lively little girl often retreated to the corner of the room and watched her family and others, mainly keeping to herself. Teachers reported that Maria began having trouble focusing in school. She was either dozing off in classes because she could not sleep at night, or pacing in the back of the classroom. The teachers believed that she was in a trance at times, not focused on the activity in the classroom. From the ages of 7 to 10, Gladys took Maria to her primary care physician’s office on multiple occasions. Maria was eventually prescribed medication for depression, as this was her doctor’s initial diagnosis. The doctor treated Maria’s non-responsiveness to medication by giving her higher doses and/or other medications. When Maria went to live with her mother at 10 years of age, her mother took her from one doctor to the next, seeking to find out why Maria was withdrawn and anxious, and had trouble communicating.

Carmen quickly became frustrated with the system, especially because the mental health system in the early 2000s in Puerto Rico consisted of primary care physicians—not mental health experts—who prescribed medication to treat mental health disorders (Dumit, 2012). Jobs were scarce in Puerto Rico, and health care, especially mental health care, was very limited. Doctors and hospitals were places where you went when you were sick; preventative care and outpatient mental health care was almost unheard of in the early 2000s in rural Puerto Rico. Primary care physicians and psychiatric hospitals provided the only mental health care accessible to the majority of the population. The only treatment that Maria had access to was with medical personnel or in a psychiatric hospital.

During this period, the pharmaceutical companies were attempting to market their products to primary care physicians. They understood that general practitioners were busy, had only a cursory knowledge about mental illness, and were generally disinterested in learning about mental health issues; they were therefore more amenable to prescribing psychotropic medication than specialists. In 2007, medical personnel without specific psychiatric training wrote 79% of all prescriptions for antidepressants and 51% of all prescriptions for antipsychotics worldwide. The pharmaceutical companies marketed to nurse practitioners and to physician assistants; these lower-status professions began writing more and more prescriptions after the year 2002. Pharmaceutical companies have described these professionals, along with primary care physicians, as very approachable and very interested in working with the pharmaceutical industry because they had fewer skills to treat mentally ill people. Maria lived in a rural area of Puerto Rico, with no major medical centers or teaching hospitals. She and her family had to travel several hours to reach a larger town where there was a medical center with a psychiatric hospital and specialized mental health treatment.
Maria spent extended periods of her youth hospitalized in psychiatric units, and while on the units, she was prescribed many different medications, including: Prozac, Zoloft, Paxil, Prolixin, Haldol, Effexor, Abilify, Lithium, Vistaril, Adderal, Concerta, and Xanax. Maria’s mother was frustrated by the treatment that Maria received in the hospitals, and by the prescribing medical staff when she was seen on an outpatient-basis in Puerto Rico. Maria received medication treatment with no behavioral treatment or psychotherapy, which frustrated Carmen.

Frustrated with her daughter’s treatment, Carmen moved part of the family from Puerto Rico to New Jersey when Maria was 16-years-old, thinking that Maria would get better care. Maria was hospitalized several days after the family arrived. She continually attempted to kill herself while in the hospital. Maria told me in one of the early sessions that she was very angry that her family immigrated to the United States. She missed her extended family, especially her father, and her older sister, Rebeccca. She stated that she had told her mother that she wanted to stay in Puerto Rico with her aunt, but her mother would not agree.

My first few sessions involved establishing a therapeutic alliance with Maria and the family. Listening to the family and asking questions is a method of establishing a therapeutic alliance. Nancy McWilliams posited that "good therapy involves adapting the treatment to each unique patient rather than trying to adapt each patient to an idealized, ritualized, or non context-sensitive version of treatment" (McWilliams, 2012, p. 2). In the United States, mental health treatment includes many different therapeutic modalities practiced by a variety of professionals; some modalities and therapists are more effective than others. According to McWilliams (2012), the “treatment should be adapted to the unique patient” (p. 2), rather than the therapist molding one modality to fit all clients. McWilliams’s (2012) statement also focused on the “idealized, ritualized, or non context-sensitive version of treatment” (p. 2). McWilliams argued that the context of the therapeutic services and the uniqueness of the patient, including her coping skills and personality, should be considered in the development of a treatment plan.

I began to work with Maria and her family when Maria was 16 years old. She had been admitted to the hospital after the first suicide attempt in New Jersey, just after arriving with her family from Puerto Rico. When the New Jersey residential facility became aware of Carmen’s desire to take Maria home against the advice of the psychiatrist and the hospital staff, the case was referred to the Children’s System of Care and assigned a case manager. The case manager authorized in-home counseling and mentoring services. I was asked to be the in-home therapist—Maria’s first outpatient therapist. Four days prior to our first session, Maria had been released from an 11-month period of in-patient care, during which time she had been transferred back and forth between a psychiatric hospital and residential treatment facility. During our first session, Carmen presented me an intimidating list of medications that Maria had taken over the last 9 years and an equally long list of diagnoses on another separate sheet of paper.

I worked for an agency that was contracted by the New Jersey System of Care to provide in-home therapeutic services to children in their homes. The system-of-care concept was developed in the 1980s and was based on a philosophy that emphasized that services should be community-based, individualized, and culturally competent (Stroul & Friedman, 2011). The system was adopted due to a lack of services for children and adolescents prior to the 1980s. Additionally,
families had difficulty accessing available care due to agency locations, finances, and insurance, as well as single points of admission to particular facilities. The adolescent mental health system relied on outpatient mental health facilities with long waiting lists and only individual treatment for children. By contrast, the system of care is family-driven and youth-guided. Services are provided based on the strengths and needs of the child and family, and they are reflective of the needs of the community. Services are community-based and are provided by culturally and linguistically competent staff. New Jersey received its one and only system of care federal grant in 1999: The grant was not statewide, but rather designated for Burlington County. The implementation of the system of care in New Jersey in all 21 counties was a 6-year process. The first three counties established services in 2001, and the last three counties rolled out services in 2006. New Jersey recruited new providers to expand the counseling base beyond the community mental health centers, and the implementation created the capacity to provide new types of services, including in-home therapy. This is the role that I played with Maria.

My therapeutic approach with Maria had three levels of intervention: (a) utilization of cognitive behavioral therapy with a thorough psychosocial assessment to enhance the child’s coping skills and socialization skills, (b) providing culturally relevant care, and (c) utilizing a strength-based perspective to help Maria develop a sense of self. Initially, it was important to build rapport, both with Maria and her family. Maria, at the age of 16, had never had an outpatient therapist, despite years of mental health treatment; although she had worked with counselors during her hospital stays, she rarely had a particular counselor for more than a few weeks.

Cognitive behavioral therapy is the therapeutic modality that I employed in my work with Maria and Carmen, and the treatment included both individual and family counseling. Key components of cognitive behavioral therapy are modeling, role-play, and psycho-education, all of which I utilized with Maria and Carmen, the primary recipients of the therapeutic intervention (Wenzel, Brown, & Beck, 2009). Treatment was adapted for the suicidal adolescent by addressing confidentiality, engaging the child in treatment, conducting an assessment of the presenting problem, including family members, and developing a safety plan. Cognitive behavioral therapy, developed by Aaron Beck at the University of Pennsylvania, is based on the premise that if you change a person's thinking, his or her behavior will change. In adolescents such as Maria, there is a significant relationship between suicidal and non-suicidal self-injury. My goals with this approach with Maria were to increase her ability to cope with her past and future stressors, decrease her suicidal and self-injurious behavior, improve her communication skills, and to have her feel more connected to her family and her community.

The second component of the intervention was to provide culturally and linguistically relevant treatment. Carmen speaks only Spanish; her family, including Maria, lived in Puerto Rico until a year prior to the commencement of therapy. I speak fluent Spanish and am familiar with Latino culture, having lived in Spain for 6 months and Mexico for 3 years. Just knowing how to speak Spanish does not provide a therapist with the tools to work with recent immigrants, who have lives and family in both countries. The level of poverty in many Latino countries is much more profound than in the United States. While living in Mexico, I spent most of my time in a small town in a rural area, and as such, I am familiar with the struggles of living in poverty in a rural area in a Latin American community. There was a difference, however, and that was that I was just visiting. As an in-home therapist, I focus on my clients’ cultural experience and ask a lot of questions in early sessions—questions about their beliefs, religious practices, and their experiences with family. Despite my experience, I never assume that I understand how an individual sees himself or herself culturally. An important aspect of understanding an individual in counseling is empathy. Carl Rogers believed that empathy was necessary for therapeutic change. Rogers (1980) described empathy as “entering the private perceptual world of the other and becoming thoroughly at home with it” (p. 142). Additionally, he stated:

The process was sensitive, moment by moment, to the changing felt meanings which flow in this other person, to the fear, rage, tenderness, or confusion or whatever he or she is experiencing. This process means temporarily living in the other’s life, moving about in it delicately without making judgment. (p. 142)

Rogers went on to describe cultural empathy, which he stated conveys an attitude of concern for
the cultural aspects of a person's experience (Pedersen, Dragnars, Lonnner, & Trimble, 2002). This understanding comes through communication about a person's values and beliefs. This was the reason for the questions about Maria’s and her family’s experiences in Puerto Rico, and their values and beliefs.

There is a lot of evidence that suggests that a person's culture affects her or his illness experience—from the way that one expresses one's illness to the content of one's delusions or the meaning of expressed emotion (Canino & Alegria, 2008). Carmen was raised in an extended family in a village. Addiction was prevalent in her family. Her father was drunk every weekend, and was physically abusive to Carmen, her siblings, and her mother. Carmen's family was very religious, attending Catholic Church every weekend. Carmen spent hours lying in bed at night praying that Maria would not become an addict like her grandfather, her many uncles, and her father. In contrast to this belief, Maria was not concerned about addiction. She felt that because medical personnel were prescribing her medication to manage her feelings, addiction was not an issue for her. Maria did not like experiencing her emotions, as she felt that she would not be able to handle them without losing control. She had no problem taking psychotropic medications, as long as the result was decreased feelings of depression and anxiety.

Maria had become used to being taken care of due to years of being institutionalized in hospitals and outpatient treatment experiences with medical personnel. She was released from her most recent hospitalization in New Jersey on Clozaril, a very strong antipsychotic medication with off-label use for children (Longhofer, Floersch, & Okpych, 2011). Recognizing the potency and potential dangerousness of the medication, the psychiatrist in the residential program told Carmen that Clozaril would only be used short-term to stabilize Maria's moods and improve her impulse control; however, I was still very concerned about such a strong medication being prescribed to a child. Carmen was aware of the multiple side effects of the medication—including sedation, dry mouth, and decrease of white blood cells—but agreed to Maria being placed on it because the hospital and residential program staff were concerned about Maria’s multiple attempts to hurt herself. Carmen knew that Maria continued to have suicidal ideation, even after being released from the hospital. However, Carmen was also quite concerned about her daughter's loss of self. She had no idea who her daughter was or what she was thinking most of the time. Maria’s thoughts came to her impulsively and she also had no firm sense of self. Maria had no idea how to talk about her recreational activities, hobbies, career interests, or strengths. She had not developed imagination or creativity due to lack of continuity in schooling, inconsistent adult figures, multiple hospitalizations, and multiple caregivers. The medical personnel prescribed medications to help Maria with her feelings of discomfort.

**Illness Identity**

Maria was told over and over by mental health professionals that she had a psychotic disorder that required medication. Maria’s sense of self was affected both by her psychiatric illness and her long-term use of medication. The medicalization of Maria’s identity influenced her belief that alternate coping skills would not be successful, and her identity was connected to her having a psychiatric diagnosis and taking medication. Maria had created an illness identity. Elizabeth Carpenter-Song—an anthropology professor at Dartmouth who researches human distress and suffering in the areas of mental and physical health—recognizes that psychiatric diagnoses and pharmaceuticals are constraints to normal development of the self. She discusses how children's sense of self develops in relation to a clinical process (Carpenter-Song, 2009). Although she and her mother felt that none of the medication had helped, Maria had been prescribed medication for 10 years and took it to cope with the normal life stressors. This act became part of her identity. Maria saw herself as having an illness and expected to always be dependent on medications. She was waiting for a medication that would improve her quality of life. Maria was upset by the many side effects of the multiple medications that she had been prescribed over time. She often had rashes on her arms and legs, her speech seemed slurred, and she drooled. Maria and her mother both continued to have hope that Maria’s illness would be cured with a new medication. This belief was influenced by the medicalized culture of both the United States and Puerto Rico, and the respect for the medical profession in Latino culture. Commercials interrupted Carmen’s favorite television programs on the Spanish language networks, and emphatically pronounced that a particular medication would make one happy and less
anxious. Maria and her mother believed that Maria would look like one of the actors in the commercials. They both bought into the messages in commercials and believed that there was a medication that would allow Maria to live the life of a normal young Latina adult in the United States. Carmen found herself telling Maria about medications that she saw advertised on TV, such as Abilify, Zoloft, and Seroquel. Maria listened, but really did not have positive thoughts about most medications. She felt that there might be one that would help her, but was generally skeptical of prescription drugs.

Carmen hoped that there would be a medication that would stop Maria from cutting; none had diminished Maria’s desire to cut. Another psychiatrist who works specifically with adolescents has focused her research on cutting. Lois Platt-Koch is a clinical specialist in adolescent psychiatry at Cook County Hospital in Chicago, a clinical instructor at the University of Illinois College of Nursing, and psychotherapist in private practice. She has worked with adolescents for 30 years and believes that adolescents who feel disconnected from their bodies cut themselves to provide some sense of connection to their physical selves (Platt-Koch, 1983). As Platt-Koch’s (1983) theory posits, Maria had a lack of coping skills to manage her feelings. She lacked the ability to feel connected to her own body and to other individuals. Platt-Koch stated that the cutting counteracts the feeling of being separated from the body because after some time, the individual is able to feel pain. The fact that individuals go to such extremes to feel something demonstrates the panic individuals feel when in a depersonalized state. Maria lacked the ability to calm herself down (self-soothe) and also lacked a personal identity of anything other than being a mental health patient. This was partly due to the lack of a connection to others and also due to dependence on medication. She began to cut herself when she was 8-years-old and had scars up and down her arms by the age of 16 from repeated self-injury; these scars were visible signs of her illness, which allowed the world to identify Maria as a lifelong patient.

Cutting was one of Maria’s maladaptive and destructive coping skills. Physical and emotional relationships were what she sought, and yet they were very elusive. She was unable to trust others, although she very much wanted the connection. She had no emotional ability to build relationships. Platt-Koch (1983) stated that feelings of depersonalization (i.e., a sense of detachment and alienation from one’s body) and derealization (i.e., a lack of a sense of reality about the external world) can occur in children when they cannot identify with themselves or their environment. Maria’s feeling of depersonalization was perhaps due to the excessive use of medications in the past. Maria and other children who depend heavily on medication have separated from their bodies and seek ways to feel connected in the present moment. According to Platt-Koch (1983), “Seeing the blood and feeling the pain . . . reassures them that they really do exist” (p. 1670). Maria stated that she did not feel pain when she cut, but felt emotional relief from the action. Feeling calm, she could continue with her daily activities.

Social situations caused Maria to feel anxious due to a deficit in her ability to communicate with peers. Maria had very poor communication skills, and thus became very anxious when she felt that others expected something from her, even if it was only a response to a question. She had difficulty seeking out and talking to her mother when she was upset, such as in the following dialogue:

Carmen: Maria, how was school today?

(Maria walked away from her mother and did not answer.)

Carmen: Maria, you look upset. What is wrong?

(Maria went into her room and shut the door.)

Carmen: (Following Maria up to her room, speaking from outside her door.). Maria, what happened today?

Maria: (No response.)

Carmen: Maria, open the door! (Maria walked to the door, opened it, and went back to her bed. Carmen was frustrated and clearly Maria knew this.) If you feel like talking, I’ll be downstairs.

As Maria became more comfortable in counseling sessions, she discussed how she had never talked to her mother when she was growing up, and how she continued to feel uncomfortable talking to her. She stated that these feelings were reinforced by recent experiences. She felt that when she had attempted to talk to her mother, it just made family issues worse. Some examples of this include the following: Carmen becoming so upset about Maria’s interpersonal issues in school that she became depressed and anxious herself...
(not able to sleep and losing 10 pounds), requiring her own counseling; and Carmen and Juan fighting a lot about how to manage María’s behavior. Additionally, Carmen experienced a lot of guilt about not raising María from birth to age 10. Carmen’s guilt was manifested in over-protectiveness in the present. Carmen did more than what an average mother would do for her 16-year-old daughter, especially in the Latino community. Girls are expected to begin to help out in the household at a young age in Latino culture; however, Carmen woke up her daughter every morning, made breakfast for her, got her to the bus stop on time, and made sure that she had completed her homework. Despite all of this attention, María had trouble talking to her mother. She had only been able to talk to her sister Rebecca growing up.

Rebecca was in fact the only peer-aged individual with whom María had been able to talk about her feelings in the past. However, she and Rebecca had become distant over the years due to María’s illness. Physical separation exacerbated the emotional distance as Rebecca had remained in Puerto Rico when the rest of the family moved to New Jersey. Carmen was depressed and anxious after her relationship with the older girls’ father had ended, and spent years trying to be independent and manage her own mental health issues. She always believed that her family had protected her girls from their father’s erratic behavior. María and Carmen’s brief daily conversations focused on family activities.

Carmen wanted María to develop more coping skills, but María felt no need to develop new skills because she was able to manage her environment by using medication. When she did not get the medication she needed, she cut herself. She had difficulty finding the words to explain her feelings, and thus there was always a lot of silence in our sessions. This was not just related to emotional issues, but also due to her lack of communication skills in general. She was a passive observer, watching her family and peers manage their lives.

Me: How was your day? Did you enjoy school today?

María: Yes.

Me: What was good about school?

María: I don’t know. (Silence.)

Me: Did you learn anything new?

María: (Silence.)

Me: Did anything good happen today?

María: (Silence.)

Me: Is there anything that you would like to talk about?

María: (Silence.)

Me: If there is something that you would like to talk about, let me know.

María: (Silence.)

Maria felt no need to break the silence in session, so both of us became comfortable with it. Her communication with her mother also included a lot of silence, and over time, María became aware of the fact that she was angry with her mother for not being a constant force in her life. This led to even more silence because she had no desire to even try to communicate her anger. María realized that she was also angry about leaving Puerto Rico and her extended family. I became more and more comfortable with the silence over time, as I felt that it was important for María to have that time to gather her thoughts and then to make the session hers by initiating conversation. This was a new experience for her. Her limited conversations always included reacting to others, not initiating a conversation.

My efforts focused on assisting María in developing the coping skills to be able to process traumatic memories and cope with future stressors. I started by teaching some relaxation exercises. I taught her deep breathing. By using this technique, I hoped to give her some control and reduce her fear of her thoughts. Following this session, I started helping María to develop a vocabulary to communicate her feelings. This vocabulary was in Spanish because Spanish remained her primary language. María experienced her trauma while thinking, dreaming, and speaking in Spanish. She would not have gotten to the emotional aspects of her trauma by speaking about it in her limited English. I tried to help María understand that her father was sick, and that he had to want to get better in order to change his situation. I focused on the fact that we all make choices in our lives every day and that her father was responsible for the decisions that he had made. María continued to feel throughout the sessions that she should have been able to
stop her father from trying to kill himself. She was continuously anxious because she was afraid that her father would complete suicide while she was in New Jersey, and this was one of the reasons that she was constantly asking her mother for her as-needed (PRN) medication. He had attempted and was hospitalized many times, but his attempts had not been successful. Conflict between Maria and Carmen was common, as Carmen felt that the medications were addictive and not helping Maria to deal with her past.

Another example of a poor coping skill was Maria’s lack of socialization skills. I believe that the uncomfortable feelings that Maria struggled with when interacting with peers were due to years of isolation, which led to low self-esteem, especially during her teenage years. According to Simons and Robertson (1989), “Youth with low self-esteem and high on avoidance are predicted to be at an increased risk of substance use” (p. 275). Maria became very anxious when engaging in interpersonal relationships; she would always seek ways to avoid experiencing anxiety. Her self-esteem was negatively impacted by her inability to feel comfortable with others.

An important part of socializing is communication. Maria was hesitant to talk about her family issues during counseling sessions. I generally start an in-home therapy session by asking about how the week has gone, both at home and in school. Maria generally had very little to talk about during these conversations.

Me: How were things with your mother and stepfather this week?

Maria: (No response.)

Me: Did you do anything nice over the weekend with your mother?

Maria: (No response.)

Me: Did you go to visit any family over the weekend?

Maria: (No response.)

Me: Do you want me to go and ask your mother?

Maria: (Shakes her head yes.)

During Maria’s multiple hospitalizations, she spent her time in treatment focusing on her behavior in the institutions. She had no control over being hospitalized to prevent self-harm, but did have control over her own narrative. Her narrative included being loyal to her family of origin, and she continually neglected to talk about her father. She felt that by talking about him, she was betraying him, and continued to feel that she needed to take care of him. The focus of in-patient treatment became Maria’s safety, as this was an area that Maria felt comfortable talking about. Maria was constantly breaking rules in the hospital and residential treatment center. She was either searching for razors to cut herself with or physically fighting with peers when they offended her. Maria did not start the physical altercations, but had no problem fighting because it allowed her to experience her anger and forget about her anxiety for a short period of time. Maria found it most difficult to talk about her feelings about her father. She was conflicted, both wanting and not wanting to talk, which is culturally appropriate. Pedersen et al. (2002) stated that in the Latino culture, “It is generally accepted that the desirable pattern of behavior is for individuals to handle their problems discreetly, from within the family or other natural support system” (p. 143). Maria did not feel that sharing her experiences or feelings with medical staff would make anything better, and was part of a culture that discouraged sharing personal information outside of the family.

In-Home Therapy

I began individual sessions with Maria in order to build rapport with her. As the counseling progressed, family sessions with Carmen and Maria became more frequent. A focus of the counseling was to strengthen the mother’s role as caregiver. Additionally, the focus was to educate Carmen about the effects of trauma and the importance of Maria being able to manage stress. Thus, psycho-education about addiction and mental illness was the focus of some of these sessions. A stronger mother–daughter relationship will help Maria to cope with stressors after the counseling ends. At the time of the first session, it was hard to believe that Maria was going to be able to remain in the home for any extended period of time. She had very poor communication skills and spent much her youth in institutions.

Although Maria and her family members were recent immigrants, Puerto Ricans have been in the United States for generations. The Puerto Rican migration increased in the 1960s and 1970s.
(Lewis-Fernandez, 1996). According to Lewis-Fernandez (1996), “This immigration was different from those from other Latino populations, as Puerto Ricans are United States citizens” (p. 158). Carmen’s identity was that of a rural Puerto Rican migrant. She spoke Spanish exclusively and planned to live in the continental United States for a limited period of time, resulting in minimal acculturation. Acculturation refers to both individuals and groups, and is not unidirectional, and is affected by the proximity to the homeland and the expense to travel back and forth (Pedersen et al., 2002). The dimensions of acculturation include language proficiency, preference and use, socioeconomic status, culture-specific attitudes, and value orientations. Traditionally, Puerto Rican migration consists of recurrent back-and-forth moves between Puerto Rico and the East Coast of the United States in search of better economic and health care opportunities, and return trips to Puerto Rico in order to reestablish family and cultural links. Carmen was only mildly acculturated given the barriers to integration into the U.S. mainstream society—limited housing options in Latino communities, lack of education, and limited English language skills. Carmen plans to return to Puerto Rico.

Carmen had a hard time communicating with Maria, both in Puerto Rico and also when the family became reestablished in New Jersey. Carmen felt that Maria should have more control over her actions. By contrast, the psychiatric community in both Puerto Rico and New Jersey believed Maria could not control her own behavior at all, even with medications. Maria felt that her mother’s expectations of her were too high and that she did not understand her daily struggles. I spent a lot of time listening to Maria’s view of her life experiences and encouraging Carmen to also listen to how Maria viewed her life and struggles. I believed that Maria witnessing her father trying to kill himself was a trauma that she had not processed, and viewed the fact that Maria did not have a strong bond with her mother from birth as another issue that needed to be addressed in counseling. Carmen did not realize how much her daughter had seen or knew about her father’s mental health issues, and also did not understand the importance of mother–daughter communication because Carmen had not had a strong relationship with her own mother. In this particular session, about eight months into our work together, Maria shared for the first time her memory of witnessing her father try to commit suicide.

Carmen: ¿Qué paso en la escuela hoy? [How was school today?] The nurse called and stated that you had to be removed from class today. She stated that you were banging your head on your desk.

Maria: [In Spanish.] I was sick, nada mas!

Me: Maria, do you want to look at me so I know that you are listening to what I want to say? You have been doing well recently. Even the school counselor was surprised by your reaction. Did you have a thought that you did not like? We both want to help you. Your mother really wants to understand how you feel so that she can help you get off the Clorazil.

Maria: I was thinking about my father. I had that memory again. My grandmother left the house. She said that my dad was in his room sleeping. I heard my father opening his door. He fell down. It seemed like such a long time until my grandmother came home. I was really scared.

Carmen: Why didn’t you tell me about this incident at the time? I would have asked your aunt to allow you to stay with her at that time. I had no idea that you had ever been in the house when your father had tried to kill himself (crying).

Maria: You were so angry with my dad. I didn’t want you to tell me that I couldn’t see him. He needed me! He was using drugs because he was sad (crying).

Carmen: I really want to do what I can now so that you don’t have to take extra medication! I don’t want you to start using drugs or to continue taking so much medication. I know that you know the results of the drugs on your father. I also know that taking the medication the way you are could lead to addiction.

The fact that Maria had not talked to her mother about these memories in the past surprised me. After we developed rapport, she was open about her past during some sessions. I was initially surprised that considering all of the hours that she spent with her mother, she had not shared these memories. She did not want to talk
about them now, but felt that she could no longer hide these memories from her mother because Carmen was constantly asking her about why she was upset. Maria felt that she could no longer lie to her mother or shut her out. One of Carmen’s worries was how Maria handled the time she lived in other homes; she always wondered why Maria seemed so worried about her father. Perhaps Carmen did not think much about her children’s father as her girls were growing up because he was physically abusive to her and was not actively involved in parenting.

Initially Carmen felt that it would be helpful for Maria to speak to her father after the family moved to New Jersey. She made contact with Maria’s grandmother (father’s mother) to set up weekly calls. Maria was excited about the chance to talk to her father and spoke to him weekly; however, she found herself unable to tell him how she felt about his suicide attempts or her feelings of preoccupation about his safety. This made the phone calls stressful. Carmen had hoped that the weekly phone calls would encourage Maria to remain out of the hospital. Her conversations with her father were short because she was quite anxious about the interactions and shared very little about herself. She would generally just answer his questions briefly and listen to him talk about his life. Her father was aware of her struggles with mental illness and her frequent hospitalizations. She learned to expect and dread her father’s last sentence: “Behave and take your medications, and don’t try to hurt yourself.” She hated lying to her father, but would always say that she would be good, knowing that the end of some of the calls she was going to cut herself. This weekly interaction made Maria feel very guilty. She feared that if she told her father about her anger regarding his continued suicide attempts, he would reject her. Maria also worried that there would come a day when he would not call, and that she would find out that he had killed himself. She was fearful of him being angry with her. She connected how her anger had led to her own self-mutilation and suicide attempts, and believed that if her father got angry with her that he might kill himself.

Not wanting her daughter to worry so much about her father, Carmen now understood that she needed to let Maria’s father José know that he must support Maria and not tell her about his problems. Because Maria’s father also lacked communication skills (e.g., unable to engage in spontaneous conversation), he discussed his struggles with Maria during their weekly phone calls. He did not know what else to say and thought that his daughter understood him because they both had been in a lot of treatment. José understood after he spoke to Carmen that he should not tell Maria about his struggles. The conversations then became even shorter.

Many of the family sessions focused on Maria’s use of her medication to manage her feelings. During one particular session, I arrived at the home to find Maria pacing back and forth from the front to back door at a very quick pace; she was dressed in very tight pants and a shirt that was too small for her. The shirt showed about three inches of her bare stomach and moved up even further on her body as she paced quickly from one side of the apartment to the other. Maria was sweating and her face was red. Both she and her mother appeared very anxious. We sat down together after I arrived. Maria had been refusing to talk to Carmen about what had happened earlier in the day at school. It had become customary for Carmen to wait for me to come to talk to Maria when she was upset. Carmen, who took a lot of pride in her appearance, was always well-groomed, while Maria generally appeared disheveled. Maria had been a very thin child until she started taking all of the psychiatric medications. She had gained about 20 pounds, which had all settled in her stomach, as evidenced by her T-shirt that was too short and very tight jeans. Her legs and arms remained quite thin. Maria was not focused on either of us as the session began. She gazed at the ceiling and needed conversation to redirect her; her hands were shaking and she was drooling, and repeatedly wiping her face.

Although Carmen and Maria were very different in their appearance, they both had a history of depression and anxiety. Carmen spent a lot of time with Maria because she had been out of work since she came to the United States due to needing to spend so much time in hospitals and residential programs with Maria. Carmen was very concerned about Maria’s use of medication in school to manage uncomfortable feelings. She had been to the school for meetings many times in the past and felt that many of the children appeared to be taking too much medication. Carmen was upset that Maria slept during class and then came home and slept even more.

Maria felt that her mother could not understand her. She knew that her mother had some issues with anxiety and depression, but knew that her mother had never been hospitalized. Maria also felt that she had taken many more
medications than her mother had ever taken. The side effects of medications upset Maria, especially because her body did not tolerate them well. Maria was very anxious when I arrived at the home, and the level of the tension between the mother and daughter was high.

*Me:* I understand that your mother was asking you about how school was today. Your behavior seems to indicate that there was a problem.

*Maria:* School was okay. I just know that my mother will be upset because I was feeling stressed out at school.

*Carmen:* Did you go to see the school nurse today?

*Maria:* Yes, I had to go. Two of the kids in my class were arguing. I did not feel comfortable. I thought that they were going to fight.

*Me:* Did you ask to speak to your social worker in the school to talk about how the arguing caused you to become anxious?

*Maria:* No, I don’t think that she was there, but I didn’t ask.

*Carmen:* Were the kids saying anything to you? Did you feel that they were going to hurt you?

*Maria:* No, I knew that they were not going to do anything to me. I just could not sit in the class. I was walking around in the back of the room and the teacher asked if I needed a break from the class. She sent me to the nurse. The nurse gave me my Vistaril.

Constantly calling Maria’s psychiatrist and school counselor to talk about her daughter’s medication took up a lot of Carmen’s time. Although the psychiatrist continued to tell Carmen that there were no side effects of Clozaril, Carmen knew that Maria had to get blood work weekly because Clozaril can cause death if not monitored. The psychiatrist continued to prescribe Maria Clozaril, even though he knew that Carmen did not approve of this medication. The psychiatrist threatened to call the Division of Child Protection and Permanency (formerly the Division of Youth and Family Services), if Carmen did not agree to continue to sign the consent for medication. The school psychiatrist reasoned that maintenance on Clozaril was necessary because Maria continually asked for PRN Vistaril when she was anxious. Carmen felt that the school was doing what was easiest to manage students’ behavior, and was not focused on what was best for each individual student. She believed that other students were also being given a lot of PRN medications. Miller (2009) wrote about this issue in an article on the use of medication with children in foster care. She discussed the use of medication to manage behavior. In her article, she wrote that some have suggested that medications are used “to help parents, teachers, and other child care workers quiet and manage, rather than treat, children” (Miller, 2009, pg. 1). Carmen felt that the school was not using the medication as part of the therapeutic process; rather, it was being used to quiet students and manage their behavior. The amount and type of medication given to Maria during hospitalizations may have been excessive and/or not indicated; medications were being used to control behaviors, not to treat a specific psychiatric illness with a biological basis. Medication use in children and adolescents is often initiated and continued to manage behaviors, not to manage psychiatric symptoms. An example of this is the use of medications for attention-deficit/hyperactivity disorder among minority youth in large urban schools. Similar to when the family was in Puerto Rico, Carmen was quite angry that the school was not helping Maria to manage her emotions through counseling.

Many of the sessions began with a conversation about medication use. Reaching the school staff by phone was a tedious and time-consuming task for Carmen. She felt that the school staff purposefully ignored her requests for meetings with the psychiatrist. Carmen was upset that the school frequently used medication instead of talking to Maria. She was also very upset that the school psychiatrist was continuing Maria on a medication with very serious side effects. Clozaril upset Maria because she was afraid of getting her blood drawn, and thus she was always very agitated and irritable during the monthly lab work appointments. Although Maria frequently cut her arms and legs using razor blades, metal from pencil erasers, and bottle caps, she had an extreme fear of needles. Carmen worried that because Maria’s father was an addict, Maria might have a genetic predisposition to drug or alcohol addiction; thus, she worried about the long-term effects of medication, especially Clozaril.
The Relationships Among Psychiatric Diagnoses, Prescribed Medications, and Side Effects

Medication use was influenced by the development of the worldwide classification of mental disorders. The first *Diagnostic and Statistical Manual (DSM)* was published in 1952, and this influenced the use of medication for psychiatric disorders. In 1950, approximately 7,500 children in the United States were diagnosed with mental disorders (Weiss, 2008). In the *DSM-I*, there was only one disorder that was specific to children, which was adjustment reaction of childhood/adolescence (Weiss, 2008). In the *DSM-I*, all disorders were thought to be a result of the environment. Karl Menninger, a prominent psychiatrist at the time, believed that all disorders could be reducible to one basic psychosocial process: the failure of the individual to adapt to his or her environment. He believed that the adaptive failure could range from minor (neurotic) to major (psychotic) in severity (Weiss, 2008).

Emil Kraepelin was born the same year as Sigmund Freud, 1856. As Freud developed his theory of psychoanalysis and was concerned with the etiology of mental disorders, Kraepelin attempted to classify, categorize, and describe psychiatric disorders as discrete entities. Kraepelin’s descriptive efforts are the basis for the current approach to the identification of mental disorders, and his work—not Freud’s—has come to dominate modern psychiatry (Kirk & Kutchins, 1992). Psychiatry, which had been on the line between psychology and medicine for a hundred years, abruptly abandoned psychology and aligned itself with medicine. This change was profound for the patients with diagnosed mental illnesses (Weiss, 2008).

In the 1980s and 1990s, the brand of psychiatry changed from a focus on normal behavior and personality disorders to concrete, theoretical treatments for the profoundly disturbed in institutional settings. Individuals seeking treatment were no longer seen as struggling to adapt to their environment. They became referred to as patients and their psychosocial stressors became symptoms of a disease. The patients were not active participants in a collaborative treatment; they were passive recipients of symptom-reducing pharmacological substances. Professionals began to view children as ideal patients because they were compliant when told by a parent to take a pill. Previously, mental illness was believed to be caused by a combination of personality, character, disposition, and upbringing. Now, mental illness is attributed to genetic abnormalities and chemical imbalances. Medical personnel saw Maria as someone with a disease, and thus, she was a passive recipient of a symptom-reducing pharmacological substance.

By 2008, and the publishing of the *DSM-IV*, at least 8 million children were diagnosed with mental illness and most received some form of medication (Weiss, 2008). There were many child disorders described in *DSM-IV*. While the increased use of psychotropic medication in children might, in and of itself, produce alarm, there has been little backlash because of the perception that medically prescribed drugs are safe. Yet, there is evidence that psychoactive drugs have substantial risks. While physical dependence and severe withdrawal symptoms are associated with some of the psychotropic medications prescribed for children, psychological addiction is the most common side effect.

Medical side effects of psychotropic medications include insulin resistance, narcolepsy, tardive dyskinesia (a movement disorder involving uncontrolled facial movements, jerking, or twisting movements affecting 15–20% of patients on antipsychotics), agranulocytosis (reduction in white blood cells), accelerated appetite, vomiting, allergic reactions, uncontrolled blinking, slurred speech, diabetes, balance irregularities, irregular heartbeat, chest pain, sleep disorders, fever, and headaches. Maria had to watch her diet because she had a big appetite, high blood sugar, and high cholesterol. To control these side effects many children take up to eight additional drugs every day. Maria, herself, was often on as many as four different medications each day. Each additional drug produced unwanted side effects. Weiss (2008) writes that an entire generation of young people has been brought up to believe that drug-seeking behavior is rational, and that most psychological problems have a pharmacological solution. With easy access to psychotropic medication, children now have the “means, opportunity, example, and encouragement to develop a lifelong habit of self-medicating” (Weiss, 2008, p. 2). The use of antipsychotic drugs to treat children and adolescents for aggressive behavior and mood changes increased fivefold from 1993 to 2002 (Williams, 2009). Maria was not using illicit drugs, but she was continually asking for additional medication to handle uncomfortable feelings. Her use of as-needed (PRN) medication to manage her
feelings is similar to illicit drug use. Many adolescents who are unable to self-soothe and live with sadness and grief use drugs to numb the body.

**A History of Psychotropic Medication and Its Use With Children**

Maria’s case is an example of how the medical profession prescribes psychotropic medication to treat psychiatric symptoms in children. Dr. Smith was treating Maria’s auditory hallucinations and flashbacks with a medication that was developed for adults with schizophrenia. Based on my experiences, I believe that the psychiatric profession can confuse the reliving of traumatic memories by survivors of abuse with auditory hallucinations associated with psychotic disorders. According to some researchers, hearing voices may have a dissociative origin, and may not indicate a psychotic disorder (Longden, Madill, & Waterman, 2012). Bleuler was a strong advocate for the somatogenic origins of schizophrenia, yet he himself conceded that auditory hallucinations might be rooted in psychological trauma rather than disease (Longden et al., 2012). Longden et al. (2012) argued that many cases of schizophrenia identified by Bleuler would be classified as dissociative disorders by today’s measures; there are aspects of his clinical description that resemble dissociative identity disorder. I believe this to be true in Maria’s case.

Maria was treated for many years with medication, and medication is currently used for both adults and children to manage psychiatric symptoms. In the 1950s, psychiatry in the United States began to use medication on a widespread basis with mentally ill adults. The first drug introduced was Thorazine, which was seen as an antidote to mental disorders. It was an antipsychotic medication and it initiated the psychopharmacology revolution (Whitaker, 2010). Patients who were not able to participate in psychotherapy or recreational therapies began to take medication. Drug therapy allowed hospitals to change from providing custodial care to being therapeutic communities, and it also allowed patients to be cared for outside of psychiatric hospitals (Kline & Davis, 1973). Many group homes were established during this period to house the mentally ill, who no longer needed to be in the hospital for treatment.

When Prozac and other selective serotonin reuptake inhibitors (SSRIs) were introduced to the market, they were referred to as wonder drugs. The prescribing of antidepressants to children increased rapidly. This was the second generation of psychiatric drugs. The percentage of children medicated tripled between 1988 and 1994, and by 2002, one in every 40 children under the age of 19 was taking an antidepressant (Whitaker, 2010). SSRIs had fewer side effects than previous antidepressants and were marketed directly to consumers rather than to physicians. This action represented a change in practice for the industry. Greenberg (2013) argued that medications such as Zoloft and Lexapro are universally recognized, and are part of the daily routine in many homes for both parents and children; however, little is understood about the long-term side effects (Greenberg, 2013). Sales of psychiatric drugs amounted to more than 70 billion dollars in 2010. To put this into perspective, Greenberg stated that 70 billion dollars is what New York City spends yearly to manage the entire city government. Whitaker (2010) believed that if the outcomes with children and teenagers are the same as with adults, then the prescribing of psychiatric drugs to millions of American youth is causing harm on a large scale. My own view is that children are given medication for behavioral and emotional issues because it is easier, but not better, than exploring the reasons for their behavioral responses. My own clinical experience has led me to the belief that children who act out within a family system are often attempting to get help for the family (i.e., they are the identified patients in a system that requires assistance and intervention). The children are often the ones most affected by family systems issues, which include addiction, domestic violence, and poverty. Treating a child with psychotropic medication supports the belief that the child is the problem, when the child may be suffering due to mental health issues of the adults in the family.

According to Koupernik (1972), the first documented instance of drug therapy for children in the United States was in the 1970s. In the early 1980s, the path to providing adolescents with stimulants for ADHD was initiated. In the late 1980s, adolescents began to be treated with Prozac for depression, and in the mid-1990s, the drug companies started claiming that ADHD adolescents actually had bipolar disorder. This coincided with the marketing of epilepsy drugs as mood stabilizers as well as the arrival of the new atypical antipsychotic medications. Prescriptions for psychiatric drugs increased 50% for children in the United States between 1996 and 2006 (Pringle, 2009). The use of medication with
children remains very controversial. Gwen Olsen, a pharmaceutical sales representative for over a decade, and author of the book *Confessions of an Rx Drug Pusher* (2009), writes that children are forced to take medications by their doctors, parents, and school personnel, and thus are ideal patients because they have a higher rate of compliance than those with less support, though, as Olsen points out, also make them lifelong patients and repeat customers of the pharmaceutical industry. Olsen reports that every manager who she worked for told her that children are their biggest and most profitable expansion market. The introduction of psychotropic medication as a form of treatment for children with emotional and behavioral difficulties—with no psychotherapy to assist in understanding oneself and learning new coping skills—guarantees the continued need for medication. Maria was given medication at a young age and both she and her mother felt that she could not live without it.

Few studies have looked at the effects of psychotropic medication on children and adolescents in their communities. Many studies have been clinical trials with controlled environments. Jowers and Lichenstein utilized data from the National Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families program to study the effects of psychotropic medication use on children and adolescents between 6 and 18 years of age (Drilea et al., 2013). They found that more severe mental illness was associated with fewer recoveries, longer periods of illness, and increased recurrence; further, it was a better predictor of post-treatment functioning than the type of medication treatment received (Molina et al., 2009). Additionally, the study found that no particular medication was more effective than another. Medications had some effect on clinical symptoms, but not a sufficient effect to normalize symptoms. Carmen expressed a similar belief when discussing the long list of medications. Carmen did not feel that any of the medications allowed Maria to fully participate in activities with the family or peers, or to develop an identity. She felt that some of the medications reduced Maria’s anxiety and depression, but not to the extent that Maria could interact with peers or family in a relaxed manner. The medical profession often does not refer families on public insurance to counseling due to lack of resources and inability to pay for services. Maria was on Medicaid both in Puerto Rico and in New Jersey, where there is a limited number of counselors in the mental health system that accept Medicaid.

The use of medication in lieu of psychotherapy as first-line treatment has had some unanticipated consequences. Children that start on strong antipsychotic medications at a very young age have difficulty coping with stressful situations. This is similar to an addict who starts using illicit drugs at a young age and stops growing emotionally at that time (American Society of Addiction Medicine, 2013). The developmental process changes when a child starts using drugs. Addiction professionals assert that use of illicit drugs in adolescence is a way of coping with problems, anxieties, and the uncertainties of growing up (Lee & Goddard, 1989). Olsson, Crystal, Huang, and Gerhard (2010) pointed out that even with privately insured young children, the annual rate of antipsychotic medication treatment doubled between 1999 and 2007. The study also found that most of the young children had little or no psychosocial services, such as mental health assessments, psychotherapy visits, or psychiatric care. One wonders if children on strong psychiatric medications from a young age are coping with stress in the same manner. The use of psychotropic medication to treat children has increased over the last 20 years, even though many of the psychotropic medications are not recommended for use with children (Longhofer et al., 2011). Maria was given medications beginning at the age of 7, and although she had been prescribed many different medications, none appeared to help her; neither she nor her mother could name one that really made a significant difference on her mood or behavior. Maria had been treated for depression, anxiety, psychosis, cutting, suicidal ideation, and suicide attempts, yet her symptoms increased rather than decreased. Maria felt that she needed the medication, yet could not put into words what it did for her.

Maria’s father was also treated with medication for many years for what the psychiatric community had labeled as a co-occurring disorder. In his early 20s, he received a diagnosis of depression and alcohol, cocaine, and heroin dependence after multiple suicide attempts and hospitalizations. While Maria’s earliest memories began at the age of 5, her most vivid memories began at the age of 7 when her father’s illness became more pronounced. She continues to wake up at night with bad dreams, dreaming that her father is an intoxicated state and in danger. She seeks extra medication (Vistaril on an as-needed basis) when she has memories of her
childhood that cause her to become anxious or depressed.

Maria was being treated on Clozaril after being released from the psychiatric hospital at the age of 16. Clozaril is an atypical antipsychotic drug that helps to control impulses believed to be the basis of thought disorders (Cirulli, 2005). The drug was first used in New Jersey in the early 1990s. When first introduced, it was believed that the medication would allow many individuals with schizophrenia to lead healthy and active lives. The side effects, as well as the need for compliance with regular blood work, were obstacles to its widespread use with adults, and it has not yet been recommended for use with children or adolescents.

**Conclusion: The Story Never Ends**

Counseling occurred over an 11-month period and focused on teaching Maria healthy coping skills to deal with her anxiety and depression, initially a difficult concept for Maria to grasp, as her father had modeled for her only two coping skills to deal with unhappy events: self-medication and suicide attempts. Prior to our sessions, Maria only used medication or cutting to manage her stress.

As Maria was slowly weaned off of Clozaril, she needed other coping mechanisms to manage life stressors. She was able to identify music as something that helped her to relax when under stress. Carmen and Juan gave her an iPod for her birthday, and Maria found music that helped her to feel more relaxed. There was initially some concern about the type of music that Maria listening to; for example, at one point she was listening to songs by Spanish artists about depression and suicide. After Maria received the iPod, she had it with her at all times. She increasingly chose popular music with more positive messages, and began to feel better as she was able to identify music that helped her to relax.

I suggested that Maria use a ponytail holder on her wrist as an alternative to cutting. Maria could snap the ponytail holder on her skin if she felt that she had the urge to cut. She used this quite often, and started to wear it all times. At school, she occasionally asked for her Vistaril, but was using it less. Maria found some bracelets made of rubber, and typically wore four to six of them at any given time to cover up the scars on her arms, which caused her significant embarrassment. Maria loved collecting different colored bracelets with slogans on them, and though sometimes she did not know what the words meant, the rubber bracelets became a fashion statement for her.

I encouraged Maria to write about her feelings in a journal. As she did not like to write, she began to draw in a notebook. She used pictures to represent her feelings, which significantly diminished her desire to hurt herself. In the past, Maria quickly acted on thoughts of hurting herself, but soon found that she had less desire to cut if she focused on an activity she enjoyed. Fascinated by the Twilight series—she became interested in the series as it was a topic of conversation with peers—Maria spoke often of the roses in scenes from the books, how they inspired her, and she began to draw beautiful pictures of roses. During this period of time, she was using her Vistaril less to manage her anxiety.

In the second summer of our work together, the Clozaril was discontinued. Maria was listening to music and talking to her school counselors; she had not tried to hurt herself for months. She responded to others in social situations and even willingly showed me her forearm at the beginning of each session. She was proud that she was not cutting. She had very few new incidents of cutting, as she wanted to avoid being hospitalized. During one particular session during those summer months, Maria and I went to the mall. She wanted to do what “normal” teenagers enjoyed, but her life experience had been so different; her ability to enjoy what other teenagers enjoyed was limited. Maria brought a CD that she had made and we put it on in the car. Sunroof open, windows down, we both sang loudly to “Diamonds in the Sky” by Rihanna. That became our song, and after that session, sometimes we would just sit in the car in her apartment parking lot, put on the CD, and sing. The lyrics “Shine bright like a diamond. Shine bright like a diamond.” could be heard by passersby while we sat in the car on warm summer evenings:

*Shine bright like a diamond.*
*Shine bright like a diamond.*
*Shine bright like a diamond.*
*Find light in the beautiful sea.*
*I choose to be happy.*
*You and I, You and I*
*We are like diamonds in the sky.*
*You’re a shooting star I see.*
*A vision of ecstasy.*
*When you hold me, I’m alive*
*We’re like diamonds in the sky.*
*(Rihanna, 2012)*
Maria’s favorite lines were “Find light in the beautiful sea. I choose to be happy. You and I, you and I.” On those nights, she seemed happier and more expressive than I had ever seen her. Although neither of us could sing without the CD playing, the sound coming from the car was beautiful and Maria was relaxed during those moments; however, she never smiled or showed it physically. When Maria sang, she accentuated the word “happy.” She had no concept of the word. She was beginning to be able to identify sadness, anger, and loneliness. She had watched movies when she was young in which the characters lived happily ever after. She wanted happiness for herself, but had no idea what it would look or feel like, or how to go about finding it. Through the music, however, she had learned to sing about happiness, and thus, to desire the feeling. Maria knew some things about Rihanna’s past, and could identify with some of Rihanna’s struggles; she saw Rihanna as a role model. She shared that Rihanna was from Barbados, another island in the Caribbean. Her father was a drug addict and her parents separated when Rihanna was 14 years old. Rihanna’s family was poor and she worked as a young child selling clothes with her father in a stall. After some sessions, Maria seemed to want to hug me goodbye, but it was so awkward for her. She would come close when I left the home, but would not stretch her arms out. Maria always saw her family members hug and kiss others as they came or left the house—this behavior was culturally appropriate. Carmen hugged me from the first day that I came to the home. During those moments, I felt the pain that Maria must feel every day. I felt empathy for Maria. I entered “the private perceptual world of the other and was becoming thoroughly at home with it” (Rogers, 1980, p. 142). I experienced Maria’s world as cold, distant from others, untrusting, and fearful. I wanted Carmen to understand this world as well.

Some progress had been made between mother and daughter, but Maria continued to feel that her mother did not understand that she could not always control her impulses to cut in order to relieve stress. She knew that her mother did not approve of her cutting, and Maria even became upset with herself after she cut. She continued to wish for her mother to understand her. Maria knew that her mother had experienced anxiety, and could not understand why she did not want to cut herself when anxious.

Carmen encouraged Maria to join a teen center with a gym. I went to the gym with her for several weeks. She began to work out as a means of decreasing anxiety and depression; however, because she did not trust her peers at the center, the visits were stressful. Maria asked for Vistaril at school to manage her anxiety on the days that she was going to go to the gym; with the medication, the visits became somewhat less stressful over time. A young man at the gym always approached her as she arrived, but her response to the attention was very awkward. Maria also attended art classes and visited an art museum as “normalizing” activities. She stated that she would like to continue to take art classes because she felt better when drawing. Her mother was looking for art schools in the area.

When the sessions ended, Maria was taking only a low dose of Buspar and had been prescribed Vistaril as a PRN medication. She had been off of the Clozaril completely for 8 weeks. Dr. Smith let Carmen know every time they communicated (using a translator) that Maria needed Clozaril. He told her that if Maria ended up back in the hospital, he would start her on Clozaril again. Would returning to the hospital indicate that Maria should not have been taken off Clozaril? Although Maria continued to have some thoughts of wanting to hurt herself, she was able to talk to her mother and a family friend. She was coping better with her anxiety due to an improved ability to experience her feelings. Maria expressed a desire to improve her relationship with her mother and wanted to learn to trust others.

When Maria turns 18-years-old she will be responsible for signing her own consents for medication. Carmen fears that Maria will decide that it is easier to avoid feeling her emotions, and will continually seek out stronger medication to manage stress. Maria has been out of the hospital for over a year, and her self-esteem has improved. She is able to manage stress without returning to an institution, but stress related to daily activities remains very difficult for her.

Maria wanted to go to a vocational school to study cosmetology because she likes doing hair and makeup, and thought she would like to do it for a living. Career preparation is a reality for most adolescents, but was not part of her plan a little over a year ago. The school that Maria was attending had very little related to vocational skills training. The expectation for many of the students at her school was that they would be on social security and that someone would take care of them. Maria was beginning to develop a sense of self. She was focusing on her strengths and setting goals for the future. However, Maria could not imagine living in any other household other
than her mother’s, and she also couldn’t imagine a life without medication to cope with anxiety. Maria’s use of psychotropic medication over a span of 10 years has created significant struggles in dealing with the stress of everyday life. Because of the therapeutic relationship and her new coping skills, Maria has been able to rely less on her medication to handle her emotions.

About two weeks prior to our last session, however, Maria started to rely more on medication again. She seemed more distant in her interactions with me, as evidenced by increased anxiety and an inability to sit still. She was no longer interested in music and had trouble transitioning to an outpatient therapist at the community mental health center. Her referral was changed to a partial care program, which she had attended once in the past. I was surprised by her quick decompensation and could see Dr. Smith saying, “I told you so,” because Maria was becoming increasingly more anxious and depressed. Contrary to Dr. Smith, I don’t believe that the reason Maria decompensated had anything to do with Clozaril being discontinued.

I believe that Maria still continued to have difficulty experiencing emotions. Though she tried to be comfortable with who she was, she could not get to a place of feeling calm without medication. I am fearful that Maria will become more dependent on medications, or illicit drugs if she cannot get the medication that she wants as she grows older. Maria had ready access to alcohol and marijuana from peers at school; however, she did not use because she had easy access to medication to manage her feelings. If she were not able to get the medications, she would likely seek out illicit drugs. She has smoked marijuana and consumed alcohol in the past, but had no need to do that with easy access to medication. I did not anticipate the rapid return of her intense need for medication. Although the use of psychiatric medication may be appropriate for some children, I believe that psychiatrists and medical doctors ought to be cautious about prescribing it for long periods of time and at high dosages. Maria is no longer just dealing with her emotional issues; she is also dealing with the need for medication and her loss of identity, which she will struggle with for the rest of her life. She has become a lifelong patient—the target of pharmaceutical companies—due to her use of medication to manage her emotions.

As I prepared to terminate with the family, Maria was more aware of her ability to have relationships with and care about others. Carmen stated that Maria was sad that I would no longer be coming to the home, but Maria was not able to say this out loud. However, her behavior seemed to indicate that she had an attachment to me and would miss the weekly visits. Despite all of her accomplishments, she never considered the possibility of being able to live without medication. Carmen continued to feel that Maria would have had a very different course of illness if she had received therapeutic services without medication at the onset of her emotional problems. The psychiatric profession, which is often dismissive of the benefits of counseling and therapy, had influenced Maria and Carmen. Did Dr. Smith and other psychiatrists feel helpless in the face of serious mental illness?

Terminating with the family was difficult for Carmen and Maria, and was not my recommendation, nor was it the case manager’s; rather, it was the recommendation of the care management organization. Neither Maria nor I had any control over this. Eleven months of in-home counseling within the context of the Children’s System of Care is actually a very long time, and Maria had been making progress.

Maria’s psychiatric symptoms began after witnessing a traumatic event. They continued due to feeling a lack of control over the circumstances of that event and similar events. Maria experienced the loss of her identity due to years on medication. For many years she was an observer of her life, not an active participant. Family therapy to address trauma when Maria was young could have led to a very different life trajectory. Culturally competent services in Spanish were the key to improving family communication. In the future, such services should be continued with a culturally competent therapist. They should be provided on an outpatient basis, and should focus on communication. Maria and her mother listened to the medical professionals, and felt that medication was the answer to her emotional and behavioral disorders. After years of medication, however, Maria continues to have psychiatric symptoms and has lost a sense of self in the process.

The United States has significant disparities in educational and medical services. Services appear to be divided into two categories: (a) services for the educated and insured, and (b) services for poor minorities and immigrants. Immigrants like Carmen come to this country seeking the American dream for themselves and better lives for their children, yet in some instances, live in more dangerous neighborhoods and in the same
poverty as in their country of origin. They continue to contact their family members in their countries of origin. Carmen continues to contact her family in Puerto Rico weekly via Skype, and thus maintains her connection with her family.

Care management organizations have provided in-home services to children in New Jersey since 1999. In-home therapy has been a key component to meeting the needs of this population. Being an in-home therapist means providing services to more than just the identified child. It includes multiple roles: advocacy, providing services to the family, and intervening with the systems that serve the child.

There are many Marias in the world—children who have not been provided with psychological services to help them cope with early childhood trauma. American inner city minority and immigrant youth do not receive adequate education, medical care, or mental health care. Race and class influence who receives psychotherapy and who receives medication only. As Maria’s family was from a poor rural area in Puerto Rico, she received the worst care available from the mental health system. Maria’s case supports a reduction in the use of long-term psychotropic medication with children. It also demonstrates the importance of medication as secondary to psychotherapy. Psychotherapy facilitates the development of coping skills and self-esteem. Maria developed an illness identity due to years of medication use, which included a belief that she will need medication for the rest of her life to manage her emotions. Her illness identity will have a constant effect on her self-esteem and self-efficacy—one of the hallmark messages of our medicalized society. Is this the message we want to transmit to the next generation?

References


A Story of Illness and Identity


