The Lived Experience Associated with Atypical Antipsychotic Medication Therapy in Children and Adolescents: A Grounded Theory Study

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The Lived Experience Associated with Atypical Antipsychotic Medication Therapy in Children and Adolescents: A Grounded Theory Study

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Signature Page

This thesis for honors recognition has been approved for the Department of Nursing.

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Abstract

In the United States, the prevalence of mental illness has risen significantly: 1 in 10 individuals under age 17 suffer from severe impairment due to mental illness. The rate of atypical antipsychotic medication prescribing for this population continues to climb while lack of an evidence base persists regarding safety and efficacy. The limited research on atypical antipsychotic medications focuses on the short-term effects without examining the long-term safety, tolerability, and effectiveness. The purpose of this study was to examine perceptions and experiences of children and adolescents with mental illness diagnoses treated with atypical antipsychotics. All participants were under the age of 28, under the age of 16 at the time of initial mental illness diagnosis, had mental health co-morbidities, and concurrently were being treated with multiple psychotropic medications. Grounded theory methodology was used to analyze data obtained from the 3 individuals interviewed. The emergent conceptualizations were denoted as categories and their properties rooted in the data obtained through theoretical sampling, leading to the discovery of the core concept *enduring social stigma*. Research needs in child and adolescent mental health care call for broader dissemination of evidence-based practices guiding nurses and other mental health care professionals to promote and utilize holistic mental health care by educating and advocating for change in social attitudes concerning mental illness.
Acknowledgements

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Dedication

This thesis is dedicated to the brave individuals who graciously shared their experiences. This project would not have been possible without them.
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Chapter I

Atypical Antipsychotic Medication Therapy

The prevalence of mental illnesses in children and adolescents is significant and is on the rise. “An estimated 1 in 10 children and adolescents in the U.S. suffers from mental illness severe enough to cause some level of impairment: fewer than 1 in 5 of these mentally ill individuals receives treatment” (Gruttadaro & Miller, 2004, p. 4). In a phenomenology study, DelBello and Greenich revealed the presence of major mental disorders in children is probably more serious than in adults and in fact; childhood onset of several different of these mental illnesses predicts a more severe illness course throughout their lives. Psychiatric disorders with onset in childhood generally have a worse prognosis than those with later onset (as cited in Davis & Rosenbloom, 2006, p. 180). Despite scientific advances in the proper diagnosis and treatment of mental illnesses in children and adolescents, research gaps persist in effective treatment for several serious mental illnesses that impact the lives of children and adolescents (NAMI, 2007). There are a number of effective treatment options available to mental health providers for children and adolescents with mental illnesses. These include cognitive behavioral therapies, home and community-based services, behavioral strategies, family psycho-education and support and psychotropic medications. Remarkably, atypical antipsychotic drugs, which vary widely in efficacy and side effect risks, are being used with a markedly and rapidly increasing frequency for a wide range of psychiatric disorders in children and adolescent individuals (Davis & Rosenbloom, 2006). Children and adolescents in the U.S. treated with antipsychotic drugs are about three to four times as likely to receive atypical antipsychotics rather than the older typical antipsychotics
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(Miller, 2009). The fact remains; there has been a steady increase in the use of atypical antipsychotics in children and adolescent yet the parameters regarding the use of these psychotropic medications for this young population remains unclear. Recently there has been growing research on the use of atypical agents for children and adolescents, yet this very limited research on antipsychotic medications tends to focus on the short-term effects of medication, without examining the long-term safety, tolerability, and effectiveness (NAMI, 2007). At the same time, these medications can be an essential part of the treatment plan for some children and adolescents with mental illness; however, psychotropic medications for young children with mental illnesses should be used only when the anticipated benefits outweigh the risks (Gruttadaro & Miller, 2004).

Background

In the 1950s, antipsychotic medications revolutionized the practice and efficacy of psychiatry, allowing non-institutional care for most individuals with psychosis (Davis & Rosenbloom, 2006). These drugs are referred to as first-generation antipsychotics (FGAs) or typical antipsychotics. The FGAs were effective in treating the positive symptoms of psychosis such as hallucinations but did not alleviate other important features, such as negative symptoms of withdrawal, apathy, cognitive impairment, and affective symptoms. These typical antipsychotics were also associated with high frequency of extrapyramidal side effect reactions: dystonic reactions, drug-induced parkinsonism, akathisia, and tardive dyskinesia (Davis & Rosenbloom, 2006). Then, in 1989, the development of second-generation antipsychotics (SGAs), or atypical antipsychotics, emerged on the psychiatric scene. In comparison to FGAs, these newer drugs were more effective in treating negative, cognitive, and affective symptoms with
few or no extrapyramidal syndromes (EPS) (Davis & Rosenbloom, 2006). These atypical drugs include, in order of U.S Food and Drug Administration (FDA) approval, clozapine (Clozaril®), risperidone (Risperdal®), olanzapine (Zyprexa®), quetiapine (Seroquel®), ziprasidone (Geodone®), and lastly in 2002, aripiprazole (Abilify®) (Davis & Rosenbloom, 2006).

**Purpose**

The primary focus of this study aimed to discover and form conceptualizations within the phenomenological nature of what is described by these young individuals perceived from real-life experience within the complex systems of mental illness diagnoses treatment impact and consequences. There is not yet any compelling evidence establishing a firm and direct link among the risks and benefits associated with mental illness treatment, including atypical antipsychotic drug therapy, and the effects on children’s and adolescents’ daily functioning, quality of life, and subsequent health outcomes. The goal of the research study, through individual interviews and subjective self-report questionnaires, was to use an inductive process through a grounded theory approach to better understand and gain perspective of individuals’ personal experiences. While the long-term safety and effectiveness of atypical antipsychotic drug therapy is clearly an issue impacting mentally ill individuals, much remains unknown of the experiences individuals are actually living. Furthermore, research evidence indicates that the adverse events reach farther than simply adverse physical side effects to personal conflicts (which lead to increased relapse rates) involving; body image, self-harm, decreased quality of life, trust issues, economic difficulties, destructive behavior in opposition to the drugs with poor adherence, family disparities, impaired education and
life opportunities, and high-risk medical co-morbidities with substantially shortened life spans (Haddadd & Sharma, 2007). According to Correll, the current debate regarding the impact of the potentially inappropriate high use of atypical antipsychotics in children and adolescents has shifted from the (a) off-label use of agents with inadequately documented efficacy and with the potential for significant adverse effects in this vulnerable population to the (b) concern about the inadequate diagnoses and alternative treatment approaches of young individuals prescribed these atypical agents (as cited in Leonard, 2008). Correll stated, “There is the possibility that children and adolescents with mental illness symptoms, which are often very impairing and disabling, would also benefit from individual therapy, family intervention or environmental changes, and support” (as cited in Leonard, 2008, p. 3). This grounded theory study aimed to explore the individual perceptions and descriptions of lived experience to promote a new understanding of mental health care needs.

**Treatment Indications**

Currently, (which changed since beginning this study) the FDA has approved the use of four of the six atypical antipsychotic drugs in those individuals under 18 years of age; risperidone, aripiprazole, and newly approved in December of 2009, olanzapine and quetiapine (Waknine, 2009a, 2009b). Specifically, oral risperidone is approved to treat schizophrenia in individuals age 13 years and older, bipolar I disorder with or without mania in ages 10 years and older, and irritability associated with autistic disorder in individuals 5 to 16 years. Aripiprazole (oral only) is approved to treat schizophrenia in individuals’ age 13 to 17 years, bipolar I disorder in ages 10 to 17 years, and in November of 2009, psychomotor agitation associated with autistic disorder in individuals
ages 6 to 17 years old ("Aripiprazole", 2010). Olanzapine (oral only) is approved to treat bipolar I disorder, manic or mixed episodes, and schizophrenia in individuals' age 13 to 17 years ("Olanzapine", 2010). Quetiapine (regular-release tablets only) is approved for the treatment of bipolar disorder maintenance and manic bipolar I disorder in individuals age 10 to 17 years old and treatment of schizophrenia in individuals age 13 to 17 years old ("Quetiapine", 2010). As described above, the mental disorders in children and adolescents indicated for treatment with atypical antipsychotics regulated by the FDA include, schizophrenia, bipolar I disorder (manic or mixed), bipolar disorder maintenance, and psychomotor agitation associated with autistic disorder; however, off-label prescribing often includes drug therapy utilizing all six atypical agents (Davis & Rosenbloom, 2006). Table 1 illustrates a summary of atypical antipsychotic medication therapy indications for those approved by the FDA in the treatment of child and adolescent mental health disorders.

**Context of Etiological Impact**

In the United States, the prevalence of mental illness continues to rise significantly: 1 in 10 individuals under age 17 suffer from severe impairment due to mental illness. These mental illnesses include, but are not limited to early onset bipolar disorder, childhood onset schizophrenia, obsessive-compulsive disorder, major depressive disorder, anxiety disorders, attention-deficit/hyperactivity disorder, Tourette's syndrome, and autism (Gruttadaro & Miller, 2004). The most serious mental illnesses, such as schizophrenia, bipolar disorder, major depression, and schizoaffective disorder are often chronic and can cause serious disability. The rate of atypical antipsychotic medication prescriptions treating mental illness in this young population continue to
climb and lack of an evidence base persists regarding safety and efficacy (NAMI, 2004). The indication for further study of the safety and efficacy of atypical antipsychotic medication use in children and adolescents is important for two main reasons. First, treatment is often continued for long periods, during critical stages of child development, because psychiatric disorders are often chronic (Fleischhaker et al., 2006). Second, exposure of these young individuals to psychotropic medication, even for a short time, may have effects that are long-lasting or that emerge later in life causing further health risks (Fleischhaker et al., 2006). The diagnosis and treatment of mental disorders must be approached with these changes in mind, while some mental problems may be short-lived and may not require treatment, others may be persistent and quite serious, and may require immediate treatment and medications (Gruttadaro & Miller, 2004). When the decision is reached that a child should take medication, active monitoring by all caretakers (parents, teachers, and others who have charge of the child) is essential, children and adolescents should be watched and questioned for side effects because many, especially those who are younger, do not volunteer information (NIMH, 2009).

**Schizophrenia.** This is a chronic disorder associated with deficits in cognition, affect, and social functioning. Schizophrenia and schizophrenia-related disorders are rare in childhood; however, those afflicted generally have more severe symptoms and a worse prognosis than those who develop the disorder in adulthood (Sikich et al., 2008). The onset of illness can rarely occur as early as 5 years of age, but after the age of 13 years, the incidence increases steadily. Early-onset (before 18 years of age) schizophrenia and very early-onset (before 13 years of age) schizophrenia are diagnosed utilizing the same criteria as in adults with the mental illness (Sikich et al., 2008). Schizophrenia strikes
people of all races and both genders and does not discriminate in regards to social or economic class (NAMI, 2008).

**Bipolar disorder.** Bipolar disorder, or manic-depressive illness, is one of the most common, severe, and persistent mental illnesses. Bipolar disorder is characterized by periods of deep, prolonged, and profound depression that alternate with periods of an excessively elevated and/or irritable mood known as mania (Soreff & McInnes, 2009). The bipolar disorder category includes four mood disorders: bipolar I, bipolar II, cyclothymia (oscillating high and low moods), and major depression (Soreff & McInnes, 2009). Bipolar I disorder is also referred to as classic manic-depression, characterized by distinct episodes of major depression contrasting vividly with episodes of mania, which lead to severe impairment and functioning (Soreff & McInnes, 2009). In comparison, bipolar II disorder is a milder disorder consisting of depression alternating with periods of hypomania (Soreff & McInnes, 2009). The exact cause of bipolar disorder has not been determined and no objective biological markers correspond definitively with the disease state; however, first-degree relatives of a person with bipolar disorder are approximately seven times more likely to develop bipolar disorder than the rest of the population (Soreff & McInnes, 2009). The age of onset of bipolar disorder varies greatly. The mean age of onset for both bipolar I and II is approximately 21 years, and most cases commence when individuals are ages 15-19 years (Soreff & McInnes, 2009). Bipolar disorder can occur in children and adolescents and has been investigated by federally funded studies in children as young as 6 years; approximately 7% of children seen at psychiatric facilities fit bipolar disorder using research standards (NAMI, 2004). In children and adolescents, bipolar disease appears more severe and with a much longer
road to recovery when compared with adults; while some adults may have episodes of mania or depression with better functioning between episodes, children and adolescents seem to suffer continuous illness over months and years (NAMI, 2004).

**Autism.** Autistic disorder is a pervasive developmental disorder that starts in early childhood and continues throughout life; core symptoms are problems with social interaction, communication, and rigid or repetitive patterns of behaviors ("Autistic Disorder", 2008). Autism is usually diagnosed by age 3 ("FDA Approves", 2006). In addition to these core symptoms, children may have serious behavioral problems, such as aggression, tantrums, and quickly changing moods. These behaviors can interfere with education, therapy, and socialization ("Autistic Disorder", 2008). In 2006, the FDA approved risperidone for the treatment of irritability associated with autism in children ages 5 to 16 years old; while this atypical antipsychotic does not treat the core symptoms of autistic disorder, it has been shown to be beneficial in treating the associated behavioral disturbances that can interfere with school, learning, and family life ("FDA Approves", 2006).

**Tourette syndrome (TS).** Gilles de la Tourette syndrome is a disorder of the nervous system that causes an individual to make repeated and uncontrolled (involuntary) movements and sounds (vocalizations) called tics. The disorder is commonly called Tourette syndrome. Repetitive, stereotyped, involuntary movements and vocalizations called tics characterize this neurological disorder. The early symptoms of TS are usually noticed first in childhood, with the average onset between the ages of 7 and 10 years (National Institute of Neurological Disorders and Stroke [NINDS], 2005). There is strong evidence that TS is passed down through families, although the gene has not yet been
found. Tourette syndrome occurs in people from all ethnic groups; males are affected about three to four times more often than females (NINDS, 2005). Tics come and go over time, varying in type, frequency, location, and severity; most individuals experience peak tic severity before the mid-teen years, and a majority show improvement by early adulthood (NINDS, 2005).

**Context of Adverse Effects’ Impact**

Adverse side effects related to atypical antipsychotic medication therapy all share a basic risk profile; however, severity and risk level will differ among these drugs. These adverse side effects are usually dose dependent and are influenced by individual characteristics, including age and gender, especially in the pediatric population (Haddad & Sharma, 2007). Importantly, children and adolescents appear to be at greater risk for certain antipsychotic-related adverse events compared to adults including; EPS (except for akathisia), dyskinesia, sedation, prolactin elevation (particularly in post-pubertal females), and developmentally inappropriate weight gain, metabolic abnormalities and potential cardiovascular complications of dyslipidemia, and adverse effects on glucose levels (Correll, 2008b; Leonard, 2008). While children and adolescents appear to be at lower short-term risk for impaired glycemic control and EPS effects, longer atypical antipsychotic exposure or weight gain and the related effects raises concern that these long-term side effects will emerge earlier in their adult lives compared to individuals not exposed to atypical agents at young, vulnerable ages (Leonard, 2008). Consequently, the greater susceptibility of younger individuals to antipsychotic adverse effects highlights the importance of collecting data for this population as the limited research lacks explanation for the mechanisms and the risk and protective factors for the adverse effects
of atypical agents in youth. Furthermore, atypical antipsychotic-related adverse events are a cause for concern as they can lead to the following in young individuals; distress and impaired quality of life, poor medication compliance and illness relapse, unwanted stigmas, physical morbidity, and increased mortality (Haddad & Sharma, 2007). Finally, understanding that atypical antipsychotic treatment in children and adolescents varies in tolerability, safety, and efficacy, is essential for nurses and other mental health professionals to the establishment of standardized monitoring and safe prescribing methods to minimize the burden on these young individuals.

**Metabolic Syndrome.** Excessive weight gain is the leading pathway to this syndrome. This syndrome is defined as “a cluster of metabolic disturbances including abdominal obesity, insulin resistance, hypertension, low levels of HDL cholesterol, and high levels of triglycerides; all of which can pose significant risk for cardiovascular morbidity and mortality” (“Atypical agents-metabolic syndrome”, 2009). The clinical features of this condition include many of the most common adverse side effects related to atypical antipsychotic treatment: abdominal obesity, glucose intolerance, dyslipidemia, and hypertension (Ivanov & Charney, 2008) Ivanov and Charney (2008) noted “The common cause for all features of this syndrome appears to be insulin resistance” (p. 283).

**Obesity and hyperglycemia.** Atypical antipsychotic agents olanzapine, quetiapine, risperidone, and aripiprazole (the four drugs approved by the FDA for mental health treatment in individuals under 17 years) according to new research, are associated with absolute and significantly relative weight gain shifting then to overweight and obesity in children and adolescents (Cassels, 2009). Furthermore, this study highlighted secondary outcomes include increased fat mass, increased waist circumference, lipid abnormalities,
and insulin resistance with glucose intolerance: the leading pathways to metabolic syndrome (Cassels, 2009). “The uniqueness and value of this particular study (Correll) is based on the fact that none of the participants had ever encountered or been treated with these atypicals before, allowing assessment of the effects unconfounded by prior treatment” (as cited in Cassels, 2009, “Unique opportunity”, ¶4). Weiden et al. “identified a linear relationship between weight status and noncompliance, with patients reporting weight gain as the second most predominant life problem” (as cited in Shin, Bregman, Frazier, & Noyes, 2008, p. 70) Likewise, drug induced weight gain and exacerbation may lead to poor compliance, therefore posing a dual risk by increasing symptom relapse by exposing children and adolescents to medical and emotional problems (Shin et al., 2008). Increased weight gain is a major risk factor for diabetes mellitus; however, atypical antipsychotics can also impair glucose control independent of weight gain and significantly raise plasma glucose concentrations, causing loss of glycemic control or insulin resistance (Haddad & Sharma, 2007). Correll and Carlson noted that the development of insulin resistance (increased insulin secretion) is more likely than diabetes in the context of drug induced weight gain (as cited in Correll, 2008b). Overall, treatment with antipsychotic medications can increase the baseline risk of diabetes, associated with a higher risk when using atypical antipsychotic agents.

**Dyslipidemia.** Elevated serum (blood) lipid levels include increased levels of triglycerides and cholesterol. The risk associated with these side effects is their potential to promote further weight gain and cardiovascular problems such as coronary artery disease in obese children and adolescents (Haddad & Sharma, 2007; Shin et al., 2008).
Hypertension is a symptom resulting from the combination and cascade of the other clinical manifestations that comprise metabolic syndrome.

**Sedation.** This side effect is separated into non-specific and specific side effects. Non-specific includes drowsiness and somnolence; specific includes psychomotor inhibition (slowing) and psychic indifference (losing enthusiasm) (Houltram & Scanlan, 2004f). All atypicals cause sedation especially when given at high doses, categorized as high, medium, or low incidence and severity (Houltram & Scanlan, 2004f). Consequently, somnolence is a particularly serious issue in children and adolescents, because they need to pay attention in school to achieve educational milestones and be alert enough to gain knowledge from psychosocial interactions that will allow them to progress developmentally (Correll, 2008a). This side effect tends to be dose dependent, and often individuals become tolerant to the effect resulting in dose limiting and poor compliance to treatment if the individual’s daily life is impaired (Haddad & Sharma, 2007).

**Extrapyramidal syndromes (EPS).** These adverse effects include four main abnormal-involuntary movement syndromes: acute dystonias, akathisia, and parkinsonism are the acute EPS, while tardive dyskinesia occurs late in therapy. Acute dystonias (usually acute and occurring within a few days of treatment or dosage increases), akathisia (occurring within the first few weeks of treatment), parkinsonism symptoms which consist of a triad of bradykinesia, tremor, and rigidity (onset often starts after several weeks of therapy) and tardive dyskinesia (late onset after several months and may be irreversible) (Haddad & Sharma, 2008; “Neuroleptic-induced”, 2009). Acute dystonia consists of the contraction of a voluntary muscle to its maximal degree that is
sustained and thus leads to a postural distortion. The contraction may last from minutes to hours and is highly distressing for individuals. According to Singh and colleagues, it is more common in younger individuals and when higher doses of atypical antipsychotics are used (as cited in Haddad & Dursun, 2008). Furthermore, research by Keepers and colleagues showed a relationship between age and the incidence of EPS such as parkinsonian side effects and dystonia, “children and adolescents are more likely to experience parkinsonian side effects and dystonia than adult patients; however, akathisia was found to increase slightly in the year after adolescence” (as cited in Correll, 2008a, p. 28). Akathisia has both subjective and objective elements. Subjective elements reported by individuals include unease, distress, dysphoria, and inner restlessness (Haddad & Dursun, 2008). Objectively, observation reveals repetitive movements of the legs and feet often manifesting as pacing, rocking from foot to foot, or if sitting in a chair a person may frequently shift his or her body position in the chair or repeatedly sit and stand. An important differential diagnosis of EPS is psychomotor agitation (Haddad & Dursun, 2008). Tardive dyskinesia consists of involuntary movements that usually start orofacially involving the muscles of the tongue, lips, mouth, or face. With continuing antipsychotic treatment, the disorder can increase in severity: any part of body can be affected and there can be a wide range of movements including myoclonic jerks (involuntary twitch), tics, chorea (involuntary writhing of the limbs), and dystonia (Haddad & Dursun, 2008). While the occurrence of EPS has been reduced with the use of atypical antipsychotics, the fact remains that the risk varies among the two classes of antipsychotics (Haddad & Dursun, 2008)

**Hyperprolactinemia.** The effects of elevated plasma (blood) prolactin levels in
children and adolescents can include a wide range of adverse sexual side effects on developing bodies. Females and adolescents are shown to be more vulnerable to developing hyperprolactinemia, with a higher risk associated with risperidone than any other atypical antipsychotics (Haddad & Sharma, 2007). Specifically among female individuals, side effect symptoms include galactorrhea (abnormal milk secretions), amenorrhea (absence of menstrual cycle in a female of reproductive age), oligomenorrhea (infrequent or very light menstruation in a woman with previously normal periods), hirsutism (excessive amounts of coarse and pigmented hair on the body such as face, chest and back), infertility, and acne (Wieck & Haddad, 2002). Correll noted, “Sufficiently elevated prolactin suppresses gonadotropin-releasing hormone resulting in low estrogen and testosterone (hypogonadism)” (2008b, p. 199). Hypogonadism is a reversible state; Kelly reported “sufficiently elevated prolactin levels in adolescence is closely associated with obesity, infertility, and osteoporosis later in life”; “consequently, obesity in adolescence is linked to higher rates of cardiovascular risk disease onset as adults” (as cited in Jerrell & McIntyre, 2008, p. 284).

**Orthostatic hypotension.** This effect occurs through the mechanism of action of atypical antipsychotic drugs which causes a decline in blood pressure when an individual repositions from a lying or sitting to a standing position causing dizziness, tachycardia, syncope (loss of consciousness), and an increased risk for injury. Significant orthostatic change in blood pressure is a persistent drop in systolic blood pressure of at least 20 mmHg or diastolic blood pressure of at least 10 mmHg within 3 minutes of standing up or upright tilt (“Orthostatic hypotension”, 2010). Orthostatic hypotension or dizziness is thought to be a secondary effect and the result of atypical antipsychotic treatment that
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predisposes children and adolescents and thus exacerbates metabolic changes, which subsequently lead to adverse cardiovascular events, such as tachycardia or arrhythmias (McIntyre & Jerrell, 2008).

**Anticholinergic effects.** Atypical antipsychotics block the action of an important neurotransmitter, acetylcholine, which causes a myriad of effects called anticholinergic reactions. These adverse effects can include dry mouth, blurred vision, urinary retention, constipation, cognitive impairment, excessive drooling, increased salivation, and delirium (Haddad & Sharma, 2007). The medical risks associated with these side effects include, but are not limited to, the following: dental decay, falls, injuries, and bowel obstruction (Haddad & Sharma, 2007).

**Neuroleptic malignant syndrome (NMS).** NMS is widely recognized as a rare, potentially lethal, adverse effect of treatment with antipsychotic drugs (Choi-Kain & Pope, 2007). All atypical antipsychotics have the potential to cause NMS, a potentially fatal syndrome marked by hyperthermia, fever, catatonic rigidity, altered mental status, profuse sweating, and occasionally rhabdomyolysis (breakdown of muscle fibers) leading to renal failure, seizures, and death (Haddad & Sharma, 2007). In its classical form, there are four key elements to NMS: muscle rigidity (in generalized or in milder forms it can be localized to the tongue, facial muscles leading to dysarthria or dysphagia); fever (mild to a temperature above 105°F); change in conscious level (mild confusion to coma); and autonomic disturbance (diaphoresis, tachycardia, elevated blood pressure, and hypersalivation) (Haddad & Dursun, 2008). In recent studies, the difficulty ascertaining actual NMS presentation seems to be due to the procedure failing to meet standard diagnostic criteria: this growing literature on NMS suggests that presentations of NMS in
the context of atypical antipsychotic use may be ambiguous and difficult to identify (Choi-Kain & Pope, 2007). In severe NMS, individuals are usually mute and akinetic (no movement); however, diagnosing milder forms of the syndrome can be problematic, particularly as symptoms can fluctuate over hours or days (Haddad & Dursun, 2008). The pharmacological basis is hypothesized to be a sudden drop in dopamine levels which in the hypothalamus affects thermoregulation and in the striatum leads to rigidity, which in turn will cause peripheral heat production and contribute to pyrexia (fever) (Haddad & Dursun, 2008).

**Cardiovascular & Qtc prolongation.** Sudden cardiac death in individuals treated with atypical antipsychotics (specifically ziprasidone) is caused by the increased risk of arrhythmias, which can be identified by prolonged QT intervals as seen on cardiac monitors (Haddad & Sharma, 2007). This increases the risk for adverse side effects including palpitations, dizziness, and cardiac arrest (Haddad & Sharma, 2007). In addition, specifically clozapine therapy is associated with risk for adverse side effects that are serious and can cause sudden death including myocarditis (inflammation of heart muscle), cardiomyopathy, and arrhythmogenesis (such as ventricular tachycardia) (Haddad & Sharma, 2007; Pacher & Kecskemeti, 2004).

**Blood dyscrasias.** The most common dyscrasia seen with atypical antipsychotics is clozapine-induced neutropenia. When the white blood cell count falls below 1000 cells/mm³, the risk of infection significantly rises. Agranulocytosis, an acute disease marked by a deficit or absolute lack of granulocytic white blood cells (neutrophils, basophils, and eosinophils), can be asymptomatic or manifest with symptoms of fever,
headache, sore throat, diarrhea, fatigue, urinary frequency, and generalized body pain (Haddad & Sharma, 2007).

**Seizures.** All antipsychotics can lower the seizure threshold and should therefore be used with caution in individuals with pertinent history of seizures (Haddad & Sharma, 2007). Generally, the more sedating the antipsychotic, the more likely it is to cause seizures (Haddad & Sharma, 2007). According to Haddad and Dursun, “Among the atypical antipsychotics the risk of seizures is highest with clozapine” (2008, p. 22).

Seizures are uncommon in the remaining FDA approved atypical antipsychotics (Haddad & Sharma, 2007). Severe myoclonus or sudden, involuntary jerking of a muscle or group of muscles may be the warning indicator of seizures during clozapine treatment (Haddad & Dursun, 2008).

**Context of Physical and Developmental Impact**

As the rate of atypical antipsychotic treatment rises in children and adolescents, the drugs’ association with behavioral, neurological, metabolic, cardiovascular, and other side effects is emerging as significant adverse effects (Fleischhaker et al., 2006). Weight gain is a serious complication in children and adolescents because it is associated with health and psychosocial issues at a time when self-esteem and sexual functioning develop (Correll, 2008a). Many of the atypical antipsychotic therapies used in children and adolescents result in inappropriate weight gain causing “adverse physical outcomes, which result in psychosocial development consequences such as low self-esteem, social alienation, and lack of self-confidence” (Shin et al, 2008, p. 69). Correll noted, “Weight gain can be associated with the development of eating disorders and depression” (2008a, p. 30). Vitiello and Riddle point out that childhood and adolescence represent “important
developmental periods for growth, motor, emotional, and cognitive development, the use of drugs that affect these systems should be carefully considered and closely monitored” (as cited in Fleischhaker et al., 2006, p. 312). Dietz and Robinson further noted weight gain, obesity, and related metabolic dysfunctions are particularly relevant in children and adolescents as they “occur in the context of important physical and psychological development, a phase of life during which these adverse events may lead to accelerated detrimental cardiovascular effects” later in life and into adulthood (as cited in Correll, 2008b, p. 196).

**Context of Social Impact**

Individuals suffering from mental illness experience social stigma and discrimination. For example, schizophrenia usually presents in late adolescence when individuals are in high school, entering the workforce, or beginning families. Atypical medications used to treat mentally ill children and adolescents cause observable side effects including movement disorders and bodily changes, which cause fear and embarrassment inhibiting social interactions (Houltram & Scanlan, 2004a). Furthermore, social isolation and demoralization (the upset of one’s normal functioning) lead to poor dietary habits and lack of physical activity (Shin et al., 2008). Extrapyramidal symptoms can cause patients distress; impair quality of life, cause stigma and, in severe cases, lead to secondary morbidity and even mortality. For example, even mild parkinsonism can cause muscle aching and weakness. When more severe, parkinsonism can lead to impaired dexterity which may infringe on occupational and social tasks. Akathisia is cited as a common cause of non-compliance with medication and according to Hansen, has been linked anecdotally to suicide attempts (as cited in Haddad & Dursun, 2008).
Adverse physical effects resulting from atypical antipsychotic therapy impact psychological well-being, quality of life, and psychiatric treatment success due to the increased potential for medication non-adherence (Correll, 2008b).

Thus, the greatest challenge for mental health nurses and professionals is to address stigma and discrimination and enable young individuals to feel valued and make informed choices regarding atypical antipsychotic treatment options to decrease the developmental and social burden these children and adolescents face.

**Context of Family and Caregiver Impact**

Mental illness affects the entire family of children and adolescents diagnosed with these diseases. Consequently, the burden impact on caregivers and families of individuals suffering from chronic mental illness includes the following main themes: stigma, systems issues, life lessons learned, and loving and caring for the ill relative (Veltman, Cameron, & Stewart, 2002). In addition, individuals taking psychiatric medications are often unaware of the movements associated with tardive dyskinesia and are usually not distressed by them, but their relatives can find the condition extremely upsetting (Haddad & Dursun, 2008). Furthermore, tardive dyskinesia and dystonias can be very noticeable to onlookers and can set individuals apart socially, adding to the stigma of psychiatric illness.

In the 2008 survey, NAMI polled approximately 1,000 members of the general public, approximately 250 people living with schizophrenia, and 250 caregivers (NAMI, 2008). Caregivers were parents or stepparents of the individuals living with schizophrenia to which they provide care, and the remaining percentage of caregivers was compromised of brothers and sisters, spouses or significant others, and children or grandchildren of the
individual under their care (NAMI, 2008). “The greatest challenge for all these family members is simply finding treatment providers and services for his or her loved ones” (NAMI, 2008, p. 9); these challenges include accessing services in the healthcare system and finding specialized services (NAMI, 2008). In addition, caregivers reported high rates of the following challenges that they face personally while taking care of mentally ill loved ones; (a) strain of providing care for more than ten years, (b) trying to find personal time, (c) trying to manage time effectively, and (d) finding time to take care of his or her own health (NAMI, 2008). The burden of providing care puts strain on family relationships and “half of the caregiver participants reported having felt taken advantage of by loved ones living with schizophrenia” (NAMI, 2008, p. 9).

**Context of Economic Impact**

The survey conducted by NAMI in 2008 was done with the goal to gain an understanding of the real life perception of individuals regarding schizophrenia: 95% of the 250 participants living with mental illness reported that they were currently receiving mental health treatment (NAMI, 2008). These participants reported diminished economic prospects and the use of government aid to receive mental health care: 56% receive social security disability income, 51% Medicare, 45% Medicaid, 40% food stamps, and 34% social security income (NAMI, 2008). Additionally, 63% of people living with schizophrenia have accepted money or financial support from family members or friends, and approximately 50% have depended on family or friends for transportation and housing (NAMI, 2008).

Additionally, bipolar disorder has a clear economic impact on individuals with the disorder, their families, caregivers, and society as a whole; the prevalence of bipolar
disorder is often underestimated leading to treatment that can often be inappropriate (Stimmel, 2004, p. 117). Consequently, inadequate treatment can affect healthcare costs and add to the economic burden on the individual and families as individuals with bipolar disorder often see multiple doctors and seek treatment for many years before receiving proper diagnosis, therapy, or medications, leading to a substantial economic impact (Stimmel, 2004). The ramifications of bipolar disorder include a significant economic toll, as well as family disruption, caregiver stress, and an individual burden encompassing co-morbid illnesses, substance abuse, poor functionality, and high suicide risk (NAMI, n.d.). Bipolar disorder is the most expensive mental health care diagnosis, both for individuals with the illness and for their health insurance plans (NAMI, n.d.), for example, every mental health care dollar spent on outpatient care for patients with bipolar disorder, $1.80 is spent on inpatient care. This suggests that better disease management could decrease the financial burden of bipolar disorder. In 1998, a study showed the average lifetime cost per case ranged from $11,720 for persons with a single manic episode to $624,785 for persons with non-responsive or chronic episodes (NAMI, n.d.)

**Context of Public Health Impact**

Our nation is currently experiencing a public health crisis in the number of youth with mental illnesses that fail to receive any treatment or services. The U. S. Surgeon General has warned that approximately 80% of youth with mental illnesses fail to receive any treatment or services (Gruttadaro & Miller, 2004). We have made major scientific advances in understanding how to properly diagnose and treat mental illnesses in children, but more needs to be done. In addition, drug safety and the potential side effects of atypical antipsychotics are considerable public health issues among children and
adolescents, therefore it is important to identify and establish valid, standardized methods for clinical drug monitoring to detect possible drug-induced adverse events during early as well as prolonged exposure (Fleischhaker et al., 2006). A survey conducted by NAMI further illustrated the public health impact of mental illnesses; treatment and services require public and private sector investment, which depends on public support and ultimately public attitude toward individuals with mental illness (2008). Lack of knowledge, misinformation, misperception, or misunderstanding represents a public health crisis. Individuals living with schizophrenia reported difficulty getting healthcare for physical conditions, disturbingly, 49% of participants said that doctors took their medical problems less seriously once they learned of their mental health diagnosis, and 39% said their mental diagnosis made it difficult to access other physical healthcare (NAMI, 2008). The NAMI survey results illustrate that approximately 90% of those individuals living with a mental illness give precedence to medical support systems and believe that more effective medication and treatment options along with improved, comprehensive private health insurance, would improve their condition (2008). It is important to treat mental illness as an urgent public health concern so that interventions may be implemented as early as possible to give children and adolescents the opportunity to reach their full potential.

Implications

The disorders in children and adolescents indicated for treatment with atypical antipsychotics regulated by the FDA include schizophrenia, bipolar disease, and mania, and irritability associated with autism; however, off-label prescribing is a common practice among general medical physicians and psychiatrists. Off-label use means that a
physician is prescribing a medication for a medical condition or age group that is not recognized on the FDA-approved labeling for that medication, such as in Tourette syndrome (Gruttadaro & Miller, 2004). This occurs largely because of limited research involving these medications and children and adolescents (Gruttadaro & Miller, 2004). Thus, accurate identification, diagnosis, and treatment, (which undoubtedly includes drug implementation) of psychiatric illness are the vital catalyst for holistic-continuing management and individualized mental health care in children and adolescents. Now, more than ever before in the history of mental health care, awareness must be raised and maintained at a vigilant level, especially in the young population of individuals making up a significant portion of those suffering from mental illness. Nurses and other mental health professionals have a duty to recognize individual experiences, perceptions, and needs to provide comprehensive, holistic mental health care.
Chapter II

Review of Literature

The 1990s saw the development of several new drugs for schizophrenia, called atypical antipsychotics. Because they have fewer side effects than the older drugs, they are often used today as a first-line treatment. The first atypical antipsychotic, clozapine (Clozaril®), was introduced in the United States in 1990. Several other atypical antipsychotics have been developed since clozapine was introduced, risperidone (Risperdal®), followed by olanzapine (Zyprexa®), quetiapine (Seroquel®), ziprasidone (Geodone®), and aripiprazole (Abilify®) (Howland, 2005). Children and adolescents are commonly affected by psychiatric disorders, and without treatment, are at risk to experience short- and long-term distress and impairment (Walkup, 2009). Pediatric (under 18 years old) psychiatric disorders typically require a combination of psycho-education, cognitive and behavioral management strategies, and, where appropriate, pharmacological agents. In schizophrenia and bipolar disorder, antipsychotic medication use is the first line of treatment (Jensen, Buitelaar, Pandina, Binder, & Haas, 2007). Medication choice is often driven by side effect profiles in pediatric patients and may influence compliance, development, and educational performance especially if the side effects interfere with the individual's activities of daily living (Jensen et al., 2007).

Despite the recent mental health treatment advances, according to the Surgeon General’s report “the majority of children and adolescents with mental health problem still do not receive appropriate evaluative and treatment services” (Walkup, 2009, p. 962). Over the past few years, atypical antipsychotics are increasingly used to treat children and adolescents, suggesting that prescribers, parents, and patients view
pharmacological treatment as an important intervention (Walkup, 2009). However, it appears that the use of these agents has often surpassed the available evidence specifically with regard to safety, leading to rising “concern that children and adolescents are being over diagnosed with psychiatric disorders and being treated with medications that are not appropriate for them” (Walkup, 2009, p. 962). While some guidelines suggest that atypical antipsychotics may be preferred over typical antipsychotics for selected indications, recent concerns about weight gain, diabetes, and elevated prolactin levels indicate the need to re-examine the evidence on the true risks and benefits of these agents (Jensen et al., 2007). The current national trend in office-based medical practice indicates that atypical antipsychotic drugs are being widely prescribed to children and adolescents, yet the emerging empirical evidence provides a base of support that is limited to short-term safety and efficacy of these medications (Olfson, Blanco, Liu, Moreno, & Laje, 2006). The increase in atypical antipsychotic therapy is coupled with concerns that adverse metabolic effects associated with these drugs are more severe in children and adolescents than in adults (Olfson et al., 2006). However, currently without nationally representative data, it has been impossible to evaluate broad trends in atypical antipsychotic treatment of children and adolescents. Due to the concern about these current treatment patterns and the lack of data to support long-term safety and efficacy, mental health professionals and their patients must work together to find the best medication and dose regimen based on individual needs and medical care (NIMH, 2009).

In the past 20 years, there have been significant advances in our understanding of childhood psychiatric disorders and in developing an evidence base for both psychopharmacological and psychosocial treatments (Walkup, 2009). The current inconsistency
in the reported frequencies of side effects is a major limitation that probably impairs the ability to make a differential decision when prescribing these atypical antipsychotic medications (DelBello, Versavel, Ice, Keller, & Miceli, 2008). As the use of atypical antipsychotics in youth increases, an understanding of dosing, tolerability, efficacy, and safety in children and adolescents becomes essential in mental health treatment.

**Prescription Rates**

In the past two decades, the advances of evidence-based medicine have had a significant influence on pediatric psychiatry leading to the increased acceptance that neuropsychiatric conditions of childhood are in part biologically determined, including schizophrenia and bipolar disorder (Ivanov & Charney, 2008). The use of psychotropic agents, including atypical antipsychotics, for children suffering from these conditions has become increasingly widespread and accepted by both medical professionals and society (Ivanov & Charney, 2008). Results from an analysis conducted by the pharmacy benefit manager Medco Health Solutions, Inc. from 2001 to 2005 showed an 80% increase in antipsychotic prescriptions for children and adolescents, versus a 46% increase among patients age 20 to 40 years. According to the report, in the final year of the study, atypical antipsychotics constituted 97% of the antipsychotic prescriptions for children at a rate of 6 per 1000, only slightly lower than in adults at 10 per 1000 (Ivanov & Charney, 2008). Furthermore, a nationwide survey completed in 2006 documented that 6 million prescriptions for atypical antipsychotics were written for children from 1995 to 2002 (Ivanov & Charney, 2008). A number of factors have contributed to the increased prescription rates including “increased support for the biological basis of childhood psychiatric disorders, a developing evidence base demonstrating efficacy of psychotropic
drug therapy in children and adolescents, advocacy efforts to identify and treat the high number of children with psychiatric disorders, reductions in funding, and changing patterns of reimbursement for mental health care, and the marketing efforts of pharmaceutical companies to prescribers and consumers” (Walkup, 2009, p. 962). The increased use of atypical antipsychotics may also be attributed to the shortage of child and adolescent psychiatrists, limitations in insurance coverage for inpatient and partial hospital programs, and fewer outpatient services by psychiatrists (Walkup, 2009).

The atypical antipsychotics are novel agents that presumably cause fewer acute and chronic neuromotor side effects than the older typical antipsychotics (Ivanov & Charney, 2008). As the prevalence of the use of atypical agents drastically rises, new evidence is emerging that suggests that the previous notion of a safer side effect profile associated with the atypical antipsychotics may need to be re-examined (Ivanov & Charney, 2008). Table 1 illustrates the common adverse side effect profiles for the FDA approved atypical antipsychotic drugs for children and adolescents.

**Off-Label Prescribing**

Much of the current debate surrounding atypical antipsychotic use in children and adolescents focuses on the frequent off-label use of these drugs. Many atypical antipsychotic medications prescribed for children and adolescents with mental illnesses are not FDA-approved for use in children, “but are routinely used off-label, a common practice among general medical physicians and psychiatrists” (NAMI, 2007, p. 34). Off-label use means that a licensed professional is prescribing a medication for a medical condition or age group that is not recognized on the FDA-approved labeling for that medication, which occurs largely because of limited research involving these medications
with children and adolescents (NAMI, 2007). The FDA requires that physicians
prescribing drugs for off-label treatment must be well informed about the product and
base its use on firm scientific rationale and on sound medical evidence, while maintaining
records of use and effectiveness (Ivanov & Charney, 2008). The off-label use of these
drugs in this young population includes the following atypical antipsychotics: clozapine,
risperidone, olanzapine, quetiapine, and ziprasidone. Research conducted by Stafford and
DeVane suggested that 21% of drug use in the U.S. is for off-label indications and that of
these uses, 76% lack strong evidence. Furthermore, the most common conditions
prompting off-label use with limited evidence are psychiatric conditions including
depression and bipolar disorder (as cited in Barclay, 2008). Stafford and DeVane added
“a substantial number of drugs have a high volume of off-label prescribing despite the
absence of adequate evidence, especially for…antipsychotics” (as cited in Barclay, 2008,
p. 2).

In a paper published in the December issue of Pharmacotherapy, a group of
researchers has developed a list of 14 widely prescribed medications most urgently in
need of additional research to determine how effective and safe they are for their off-label
uses. Antidepressants and antipsychotics were the most prominent classes of drugs on the
list, consequently targeting drugs that have high levels of off-label use without adequate
scientific backing. At the top of the list was quetiapine whose most “on-label” uses is
treatment of schizophrenia and lead all drugs with its high rate of off-label uses for
bipolar, maintenance with limited evidence (76% of all uses of the drug), it also had
features that raised additional concerns, including its high cost and heavy marketing with
the presence of a “black-box” warning from the FDA. Risperidone ranked #4 with the
same treatment uses as quetiapine, and olanzapine was #13 on the list treating schizophrenia most commonly on- and depression most commonly off-label. The most common off-label use for six of the 14 drugs on the list was for bipolar disorder. Dr. Stafford, the associate professor of medicine at the Stanford Prevention Research Center who headed the study noted “many of the drugs and the conditions on the list represent situations where inadequate response to treatment is common and where drug side-effects are frequent” (as cited in Ipakchian, 2008, ¶7).

**Clozapine.** The off-label use of this drug in children and adolescents is implemented for the treatment of schizophrenia when the typical antipsychotics have failed to work. Results from studies in children and adolescents show superior alleviation of schizophrenia symptoms, efficacy in treatment of bipolar disorder, and improvement in irritability associated with autism (Stigler, Potenza, & McDougle, 2001).

**Risperidone.** Non-blind prospective trails, case series, and one double-blind, placebo-controlled study in adolescents demonstrate the effectiveness of risperidone for treating pervasive development disorders, tic disorders (Tourette syndrome), disruptive and aggressive behaviors, and as an adjunct in obsessive compulsive disorder (Stigler et al., 2001).

**Olanzapine.** Compared to risperidone, olanzapine has not been well studied in young individuals. According to Cheng-Shannon et al., published reports since 1997 have described olanzapine off-label drug use in young patients 5 years and older with childhood-onset schizophrenia, bipolar disorder, tic disorders, eating disorders, and behavioral problems associated with pervasive development disorders and mental retardation (as cited in Howland, 2005, p. 17). In a most recent development, in June
2009, the FDA gave a positive vote for the approval of olanzapine for treatment of schizophrenia and bipolar I disorder with manic or mixed episodes in age 13 to 17 years. The action was accompanied by revisions to the olanzapine prescribing information highlighting the need for a comprehensive pediatric treatment program than may include psychological, educational, and social interventions; furthermore, the committee advised clinicians that these young individuals should only be treated with medication therapy after a thorough diagnostic evaluation, and careful consideration of potential adverse effects (Waknine, 2009a).

**Quetiapine.** Reports regarding the efficacy and tolerability of this drug vary among children and adolescents. Since 1998, Cheng-Shannon et al. illustrated that reports published have described its off-label use in young patients 5 years and older with childhood-onset schizophrenia, bipolar disorder, tic disorders, and behavioral problems associated with pervasive developmental disorders (as cited in Howland, 2005). Stafford and DeVane stated “quetiapine, which was FDA-approved in 1997 for treating schizophrenia in adults, was found to have the highest rate of off-label uses with limited evidence at a rate of 76% of all uses” (as cited in Barclay, 2008, p. 2). However, (well into the writing of this thesis) in December 2009 the FDA approved treatment of two pediatric indications for quetiapine fumarate (oral tablets): bipolar disorder maintenance and manic bipolar I disorder in age 10 to 17 years and for schizophrenia in age 13 to 17 years. Because of its high-risk profile, the FDA is requiring implementation of a risk evaluation and mitigation strategy for all quetiapine indications; the program requires a medication guide and periodic assessments that include a survey of patients’ understanding regarding the potential adverse effects of treatment (Waknine, 2009b).
Ziprasidone. There are relatively few reports in the literature about the use of ziprasidone in pediatric patients (Howland, 2005). Sallee et al. reported this drug to be effective and well tolerated in children and adolescents ages 7 to 17 years diagnosed with TS (as cited in Stigler et al., 2001). A short-term study reported by DelBello et al. (2008) involved individuals ages 10 to 17 years and showed clinically “meaningful symptomatic improvements in bipolar disorder and schizophrenia” (p. 497). However, adverse effects, including those of a serious nature usually involving cardiovascular events, were higher than observed in adults indicating a greater sensitivity of children and adolescents to certain adverse effects (DelBello et al., 2008).

Common Adverse Side Effects

The most common adverse side effects seen in atypical antipsychotic therapy as described in chapter one include the following: metabolic syndrome (weight gain, obesity, hyperglycemia, dyslipidemia), sedation, EPS, hyperprolactinemia, orthostatic hypotension, anticholinergic, and life-threatening adverse effects. Examined below are the common adverse side effects as they relate specifically to the pediatric population for each atypical antipsychotic drug.

Clozapine. Frequent adverse effects include the following: increased salivation, nasal congestion, hypertension, tachycardia, and orthostatic hypotension (Howland, 2005; Stigler et al., 2001). In addition, the most common side effects that carry significant risks associated with this drug are a high risk and extent of weight gain and a high incidence or severity of sedation, including prolonged drowsiness and decreased motor function (Shin et al., 2008; Stigler et al., 2001). Agranulocytosis is the most serious side effect causing leukopenia and resulting in a significant risk for susceptibility to infection and the need
for close monitoring (Stigler et al., 2001). In addition, documented clinical seizures as well as electroencephalogram (EEG) changes have been significantly demonstrated in clozapine-treated children and adolescents (Stigler et al., 2001). Along with olanzapine, this atypical is associated with the highest risk for weight gain, hyperglycemia, and dyslipidemia (Haddad & Sharma, 2007). Another potentially serious adverse effect is increased liver enzymes (Stigler et al., 2001). Compared to all other atypicals, clozapine is less likely to be associated with EPS, hyperprolactinemia, or NMS (Howland, 2005). However, using this drug is considered treatment of last resort because of the risk of serious side effects and the need for frequent blood monitoring (Howland, 2005).

**Risperidone.** The most common and most pronounced adverse effect is the high risk and extent of weight gain (Stigler et al., 2001). Commonly sedation, somnolence, and drowsiness occur in therapy using this atypical drug (Jensen et al., 2007; Shin et al., 2008). Compared to the other atypicals, risperidone is more likely to be associated with EPS and carries the highest risk for hyperprolactinemia, especially with higher dosages and in female individuals (Haddad & Sharma, 2007; Howland, 2005). Increased salivation, dry mouth, tachycardia, hypertension, and QTc interval prolongation have also been documented with risperidone treatment in children (Stigler et al., 2001). A more serious adverse effect is the risk for increased liver enzyme levels; evidence shows that long-term risperidone treatment is associated with hepatotoxicity in pediatric patients (Howland, 2005; Stigler et al., 2001). Close clinical monitoring for NMS is warranted with risperidone use (“Risperidone”, 2010).

**Olanzapine.** Numerous studies have reported sedation including somnolence, and weight gain as common significant adverse effects (Shin et al., 2008; Stigler et al., 2001).
Other adverse effects include; increased salivation, dry mouth, tachycardia, and increased liver enzymes (Stigler et al., 2001). Along with clozapine, this atypical is associated with the highest risk for weight gain, hyperglycemia, and dyslipidemia (Haddad & Sharma, 2007). Olanzapine is less commonly associated with EPS, hyperprolactinemia, or NMS; however, close clinical monitoring is warranted as olanzapine treatment carries documented risks for these side effects (Howland, 2005; Stigler et al., 2001).

**Quetiapine.** The most common adverse effects are a moderate risk and extent of weight gain and a medium incidence and severity of sedation (Houltram & Scanlan, 2004b, 2004f). Apart from clozapine, quetiapine and olanzapine are most often associated with sedating side effects: this drug is also related to a mild to moderate risk for tachycardia and orthostatic hypotension (Stigler et al., 2001). Quetiapine is not as commonly associated with EPS, hyperprolactinemia, or NMS; however, close monitoring is critical as the risk remains for these adverse events to emerge in treatment (Howland, 2005).

**Ziprasidone.** The most common adverse effect is a low incidence or severity of sedation significantly increased from the baseline (Stigler et al., 2001). This atypical drug is associated with the highest risk for prolongation of heart rate corrected QT interval (Qtc), which causes life threatening arrhythmias and sudden cardiac death (Haddad & Sharma, 2007). Ziprasidone is associated with a low risk and extent of weight gain and compared to other atypicals causes less incidence of EPS, hyperprolactinemia, and NMS; however, close monitoring is indicated as there is an increased risk of these adverse events with this atypical drug use (Shin et al., 2008; Stigler et al., 2001).

**Aripiprazole.** The most common adverse effects include nausea, vomiting,
akathisia (EPS), headaches, and a low incidence and severity of sedation. Haddad and Sharma (2007) “It is the least sedating of the atypicals” (p. 928). This drug is associated with a low risk and extent of weight gain, hyperprolactinemia, and NMS; however, close monitoring must be implemented as with all atypical antipsychotic treatment (Howland, 2005; Shin et al, 2008).

**Side Effect Monitoring**

The tolerability or experience of side effects of a particular antipsychotic medication has been regarded as both one of the key factors predicting continued adherence and crucially the experience of adverse antipsychotic side effects is commonly stated by patients as an important reason for non-adherence (Waddell & Taylor, 2008). Many studies have reported that adherence with prescribed atypical antipsychotic medication is a key determinant of relapse prevention: perhaps because clinicians consistently underestimated the severity and frequency of side effects (Waddell & Taylor, 2008). This consideration highlights the importance of an open and systematic discussion regarding medication-related side effects as an acknowledgment of the risks as well as benefits of atypical antipsychotic treatment. Establishing a collaborative approach between mental health care professionals and the individuals they care for will help maintain compliance and therapeutic relationships (Waddell & Taylor, 2008).

Fleischhaker et al. (2006) reported, “Standardized drug specific questionnaires are preferable to passive surveillance methods” to study side effect profiles among atypical antipsychotic drug therapy in children and adolescents as they “differ from side-effect profiles in adults owing to the maturation process” (p. 315).

Antipsychotic side-effect rating scales have been used over the years to help
identify and quantify the various side effects that can occur on these medications. The Hogan Drug Attitude Inventory 30 item scale is a questionnaire (Appendix A) useful to mental health nurses to gain an understanding of how individuals view their use of and experience with psychiatric medications including atypicals (Mental Health Nurse, 2009). This scale is used to assess medication efficacy, tolerability, and compliance (Gray, Wykes, Edmonds, Leese, & Gournay, 2004). Antipsychotic side-effect rating scales have been implemented for many years to assist in identifying and quantifying the various side effects that may occur with treatment. The traditional observer rated side-effect scales, including the Abnormal Involuntary Movement Scale (AIMS) (Appendix C) and the Simpson-Angus Scale (SAS) (Appendix D) for assessing extrapyramidal symptoms and tolerability, are useful in avoiding over-reporting bias and detecting those adverse effects commonly associated with atypical antipsychotic use (Waddell & Taylor, 2008). Waddell and Taylor (2008) developed a self-rating scale to detect the side effects of atypical antipsychotics “designed to allow a timely, sensitive, and reliable method of assessing individual’s perception” on the number and severity of side effects related to antipsychotic medication use (p. 238). This self-rated tool, called the Glasgow Antipsychotic Side-effect Scale (GASS) (Appendix B), was developed after literature review, discussion with mental health team members, and affected individuals’ feedback (Waddell & Taylor, 2008). Since the routine use of rating scales or systematized evaluation in psychiatry is not widespread, self-report scales such as GASS allow more complete and considered responses, enhancing the therapeutic relationship between the mental health care providers and individuals under their care (Waddell & Taylor, 2008). The GASS is constructed of 22 self-explanatory questions in everyday plain English
while providing a structured systematic method of reviewing antipsychotic side effects. The scale takes approximately five minutes to complete and assesses side effects experienced over the past week by the individual. Questions 1-20 are scored 0,1,2,3 with higher scores reflecting the experience of more frequent side effects. Questions 21 and 22 are scored 0 for “no” and 3 for “yes” relating to the last three months under atypical antipsychotic treatment. Total GASS scores are arbitrarily divided into suggested ranges for categorical severity: 0-21 = absent/mild side effects; 22-42 = moderate side effects and 43-63 = severe side effects. Furthermore, Waddell and Taylor (2008) illustrated that the “experience of a side effect may not necessarily cause distress or functional impairment when present in individuals” (p. 242). Therefore, a separate un-scored column was added to allow individuals completing the GASS to note if the side effect experienced was viewed as distressing. Thus, the GASS “allows a grading not only of the frequency of an experienced side effect but also a subjective judgment of the distress associated with a particular side effect” (Waddell & Taylor, 2008, p. 242). The side effects covered by questions 1-21 include the following: sedation and CNS, cardiovascular, extrapyramidal, anticholinergic, gastrointestinal, genitourinary, hyperprolactinemia, weight gain, and screening for diabetes mellitus (Waddell & Taylor, 2008).

**American Diabetic Association (ADA) Recommendations**

In November 2003, 14 experts, including specialists in psychiatry, obesity, and diabetes representing the FDA and the drug companies, presented side-effect risks of atypical antipsychotic therapy to an eight-member panel of the American Diabetes Association (ADA) (Davis & Rosenbloom, 2006).
Davis and Rosenbloom (2006) noted the following:

Based on the presentation of many metabolic complications in atypical antipsychotic use, the experts suggested a baseline assessment of the following:

(i) personal and family history of obesity, diabetes, dyslipidemia, hypertension, and cardiovascular risk
(ii) weight, height, BMI
(iii) waist circumference at the level of the umbilicus
(iv) blood pressure
(v) fasting plasma glucose
(vi) fasting lipid panel. (p. 185)

Lifestyle-change counseling should be provided to patients and family, and they should be aware of the symptoms of diabetes, especially those of loss of hyperglycemic control and diabetic ketoacidosis (DKA). The experts further recommended, “Patients who have high risk of diabetes should not be treated with atypical agents that have greater risks for weight gain, such as clozapine or olanzapine” (Davis & Rosenbloom, 2006, p. 185).

Furthermore, Davis and Rosenbloom (2006) illustrated:

In the ADA follow-up assessment recommendations were as follows:

(i) weight checks at 4, 8, and 12 weeks. If the patient has gained more than 5% of his or her body weight, the SGA should be weaned off and switched.

(ii) fasting plasma glucose, lipids, and blood pressure assessment after 3 months.

Thereafter, one should monitor glucose and blood pressure yearly or more frequently in those at higher risk.
(iii) lipid panel repeated after 5 years if the initial study was normal. (p. 185)

Evidence-Based Practice and Nursing Interventions

Currently, people are recognizing the benefit of being well-educated consumers of healthcare and are seeking information about healthcare conditions and treatment options including those families raising children with mental health treatment needs and mental illnesses. Over the past several years, the focus of mental health treatment and support for children and families has increasingly been evidence-based practices (NAMI, 2007). Historically, the mental health community has developed an over-reliance on institutional settings for children and adolescents with mental health treatment needs, but research advances in mental health care of this young population indicate children and adolescents achieve better outcomes when treatment is delivered in their homes and communities (NAMI, 2007, p. 7). Furthermore, while development of evidence-based practice in the mental health care of children and adolescents has increased, these practices are still only available and implemented in a limited number of communities, and many mental health providers lack the training to provide these interventions for children and adolescents (NAMI, 2007). Commonly, “health providers resist change in the way they practice, believing that their clinical judgment, based on years of experience, produces the best outcomes” (NAMI, 2007, p. 8). Currently, there are a number of psychosocial interventions that have shown to be effective for children, adolescents, and their families. There are also medications, often used in combination with psychosocial interventions, which are commonly prescribed for children and adolescents with mental illnesses. Despite scientific advances in the proper diagnosis and treatment of mental illnesses in children and adolescents, much remains to be learned about the long-term safety and
effectiveness of psychotropic medications for children and adolescents. Children are in a state of rapid change and development. The diagnosis and treatment of mental illness must be approached with these changes in mind: while some changes may be short-lived and may not require treatment, others may be persistent and quite serious, and require immediate treatment, which may include antipsychotic medication (NAMI, 2007). Table 4 illustrates the current Evidence-based mental health treatment in children and adolescents.

The discrepancy between the potential benefits of treatments and the realities of practice might have arisen because monitoring and managing adverse reactions are not clearly the responsibly of any one profession (Jordan, 2007). Nurse-led patient monitoring may be one way to minimize the problems attributed to well-known adverse drug reactions. Children and adolescents who are taking psychotropic medications must be closely monitored and frequently evaluated by qualified mental health providers. For some medications, the FDA has required a “black box” warning that alerts families to rare, but serious, side effects associated with the medications (NAMI, 2007, p. 34). Furthermore, with the current rising prescriptions rates of atypical antipsychotics in young individuals, weight control must become a priority in the care and management of child and adolescent psychiatric illness to prevent significant general health consequences over time (Shin et al, 2008). Interventions by mental health nurses can promote physical well-being and health promotion to provide the highest standard of care for young individuals at greater risk because of associated adverse side effects related to atypical antipsychotic drug treatment (Houltram & Scanlan, 2004a).

**Therapeutic role.** Establishing a trusting therapeutic nurse-patient relationship is
vital in mental health care, especially when atypical antipsychotic therapy is used related to the risk of adverse side effects that will impact the lives of these young individuals (Jones & Jones, 2008). One of the major goals of treatment is to get children and adolescents back on track with their lives, returning to the things they enjoy and thrive on most (NAMI, 2007). This essential nursing care approach of holistic high-quality care focuses on the whole person (Houltram & Scanlan, 2004b).

**Baseline and monitoring.** The purpose of routine monitoring is to detect emerging problems early to facilitate steps that can minimize or reverse metabolic and endocrine problems, thereby preventing long-term consequences. Table 2 summarizes the proposed content and frequency of physical health assessments in youths receiving antipsychotics; similar to psychiatric assessment and diagnosis in children and adolescents, physical health monitoring in youths has to consider developmentally appropriate assessments, criteria and thresholds (Correll, 2008b). Metabolic and endocrine monitoring strategies for pediatric patients receiving antipsychotics should include the following; personal and family medical history, lifestyle behaviors, height, weight, BMI, blood pressure and pulse, fasting blood glucose and lipids, sexual/reproductive dysfunction, and prolactin levels (Correll, 2008b); see Table 2 for summary of baseline and routine-follow up recommendations. Atypical antipsychotics can also impair glucose control independent of weight gain and significantly raise plasma glucose concentrations, causing loss of glycemic control or insulin resistance (Haddad & Sharma, 2007). Therefore, if personal and family medical history shows initial high risk for individuals such as: family history of diabetes, non-Caucasian, and BMI ≥95th percentile, measurements that are more frequent may be required (Correll, 2008b). Table 2 shows fasting glucose monitoring
guidelines. Correll and Carlson noted that the development of insulin resistance (increased insulin secretion) is more likely than diabetes in the context of drug induced weight gain (as cited in Correll, 2008b). During these check-ups, individuals should be asked about unintended weight loss, polyuria, and polydipsia to rule out emerging diabetes. In addition, mental health nurses should implement baseline and continued monitoring of lipid levels, especially when the atypical drug is more often associated with metabolic and cardiovascular changes and side effect risks. Fasting serum lipids should be obtained according to the protocol illustrated in Table 2, and more frequently when abnormal levels or significant weight gain has been identified (Correll, 2008b).

According to clinically relevant pediatric parameters, the panel should include total cholesterol, HDL, and triglycerides (Correll, 2008b), as summarized in Table 3.

Ideally, weight change should be monitoring at each clinical visit. Clinically, the most commonly used measures to monitor weight include: absolute weight change, percentage weight change, and change in BMI. BMI measures are only useful for ≤ 3 months in pediatric patients, as they do not account for developmentally appropriate group (Correll, 2008b). Therefore, BMI values need to be adjusted for age and sex-dependent growth factors, using growth charts that are freely available online through the Centers for Disease Control and Prevention’s (CDC) website (Correll, 2008b). Table 3 illustrates clinically relevant thresholds for body weight and metabolic parameters in pediatrics. In addition, with the limited availability of effective means of managing antipsychotic-induced weight gain, prior to initiating atypical drug treatment the risks and benefits should be acknowledged and carefully assessed (Shin et al., 2008).

Since, atypical antipsychotics are expected to produce some degree of postural
ATYPICAL ANTIPSYCHOTIC MEDICATION THERAPY

(orthostatic) hypotension, which is a health issue that produces a number of unpleasant and quite disabling physical effects. The mental health nurse should assess functional ability and monitor blood pressure (sitting, standing, lying down) and pulse before and frequently during initial atypical dose titration. If hypotension occurs, atypical drug dose may need to be decreased (Houltram & Scanlan, 2004e).

Increased prolactin levels cause clinical side effects in up to 30% of individuals being treated with atypical antipsychotics. Sexual side effects related to increased prolactin levels and atypical antipsychotic use in mentally ill individuals is often overlooked because of failure to adequately assess and monitor these adverse events. Sufficiently elevated prolactin suppresses gonadotropin-releasing hormone resulting in low estrogen and testosterone (hypogonadism), which can lead to sexual/reproductive dysfunction, osteoporosis, and increased cardiovascular risk (Correll, 2008b). This is a reversible state, therefore, to identify hyperprolactinemia related hypogonadism, the mental health nurse should inquire at baseline, during drug titration and quarterly about menstruation, nipple discharge, breast enlargement, sexual functioning, and (if appropriate) pubertal development (Correll, 2008b). Subclinical (no recognizable clinical findings) effects of prolactin elevations have not been established; therefore, prolactin levels are only measured in the event of manifestation of clinical symptoms (Correll, 2008b). Thus, management of hyperprolactinemia involves close monitoring and responding to the subsequent side effects that result due to elevated prolactin levels. Mental health nurses should provide other options for these individuals, including dose and drug modification recommendations (Houltram & Scanlan, 2004d).

While the sedative properties of atypical drugs can be perceived as useful for
individuals who are very agitated or aggressive, these effects can also adversely affect well being and functional capability due to the struggle to stay awake during the day (Houltram & Scanlan, 2004f). Sedation as a side effect of atypical drug therapy can often be overlooked, as it may be misinterpreted as a secondary symptom of certain mental diseases or individuals may not complain about it as they consider it natural fatigue or tiredness (Houltram & Scanlan, 2004f). Mental health nurses should obtain a detailed baseline assessment of the individual’s current sleep pattern and history, especially if the prescribed atypicals are associated with high incidence and/or severity of sedation; regularly discuss sleep-related issues, monitor mental status, and implement on-going and thorough medication assessment throughout drug therapy (Houltram & Scanlan, 2004f).

Extrapyramidal side effects are possibly the most difficult of the atypical antipsychotic adverse effects to live with and are a significant factor in noncompliance of medication therapy regimens (Houltram & Scanlan, 2004g). Mental health nurses should implement baseline assessment of risks and presence of extrapyramidal symptoms that the individuals may already have experienced. Continued, close monitoring using self-rated side effect rating tools and observational tools to assess for the development of these adverse physical effects should be implemented and thoroughly documented throughout atypical drug therapy (Houltram & Scanlan, 2004g). This includes observational monitoring for onset of extrapyramidal syndromes by assessing; difficulty speaking or swallowing, loss of balance control, pill-rolling motion of hands, mask-like face, shuffling gait, rigidity, tremors and dystonic muscle spasms, twisting motions, twitching, inability to move eyes, and weakness of arms or legs every 2 months during therapy and 8–12 weeks after therapy has been discontinued. Baseline monitoring should
include the use of side-effect rating scales including: SAS, AIMS, and the Extrapyramidal Symptoms Rating Scale (ESRS). For continued follow-up treatment, the SAS and ESRS should be implemented during titration, at 3 months and then annually. The AIMS should be repeated at 3 months and annually. A review of clinical notes revealed that EPS is frequently not diagnosed or treated, demonstrating that screening for EPS is not routine despite being recommended as drug monitoring and management protocol (Haddad & Dursun, 2008).

Importantly, the role of the nurse is to monitor for symptoms development of NMS (fever, respiratory distress, tachycardia, seizures, diaphoresis, hypertension or hypotension, pallor, tiredness); other important risk factors that the nurse should consider include history of previous episodes of NMS with any drug, young age, male gender, and the presence of specific psychiatric conditions such as affective disorders, delirium, and psychomotor agitation (Choi-Kain & Pope, 2007). If NMS is suspected all antipsychotic medication being used for treatment and ideally other prescribed drugs should be stopped that carry the risk to cause the syndrome. The nurse should closely manage the episode; observation and daily serum creatinine phosphate kinase (CPK) levels should be monitored for renal function level (Choi-Kain & Pope, 2007).

Assessing cardiovascular disease risk factors of individuals treated with atypical antipsychotics should also be implemented to provide safe and effective drug therapy management (Houltram & Scanlan, 2004c). Baseline monitoring for Qtc prolongation is done with and ECG if the patient is taking ziprasidone or clozapine; follow-up monitoring should include ECG during titration and at the maximum dose if the taking ziprasidone. Monitor for signs of myocarditis; unexplained fatigue, dyspnea, tachypnea,
fever, chest pain, palpitations, other signs and symptoms of heart failure, ECG changes (such as ST-T wave abnormalities), arrhythmias, or tachycardia during first month of therapy. If these occur, clozapine should be discontinued and not re-started. Clozapine has an additional monitoring requirement due to the serious risk of agranulocytosis.

Monitor WBC, absolute neutrophil count (ANC), and differential count before initiation of therapy and WBC and ANC weekly for the first 6 months, then biweekly during therapy and weekly for 4 weeks after discontinuation of clozapine. Because of the risk of agranulocytosis, clozapine is available only in a 1-week supply through the Clozaril Patient Management System, which combines WBC testing, patient monitoring, and controlled distribution through participating pharmacies. If WBC is <3000 mm$^3$ or granulocyte count is <1500 mm$^3$, withhold clozapine, increase frequency of WBC monitoring according to management system guidelines, and monitor patient for signs and symptoms of infection. If acceptable WBC and ANC levels were maintained during first 6 months of continuous therapy, monitoring may decrease to every 2 weeks. If levels are maintained for second 6 months, WBC and ANC may be monitored every 4 weeks thereafter (Nursing Central©, 2009). Furthermore, clozapine lowers the seizure threshold; institute seizure precautions for patients with history of seizure disorder. Severe myoclonus or sudden, involuntary jerking of a muscle or group of muscles may be the warning indicator of seizures during clozapine treatment (Haddad & Dursun, 2008).

**Education.** The interventions aimed at enabling individuals to cope more effectively with the adverse side effects associated with atypical antipsychotic medications, their significant associations with weight gain, and metabolic effects, should focus on educating children, adolescents, and their families. According to Correll, “these
adverse effects may be prevented or minimized by educating patients and their families about potential side effects, screening for side effects during treatment, providing nutrition and exercise interventions for patients and families, adjusting medication doses, choosing or switching to a lower-risk medication, initiating a targeted healthy lifestyle program, and adding medications that can alleviate specific adverse effects” (2008a, p. 26). The nurse’s scope of practice includes educating individuals that atypical antipsychotic medications in particular, have been associated with problems controlling blood sugar, cholesterol, and triglycerides. Therefore, the nurse should inform these individuals and their families that these changes can increase the risk of a child or adolescent developing diabetes and heart related problems. The nurse should teach the family that baseline measurements will be obtained at the start of treatment including; their child’s height, weight, BMI (which will be calculated and adjusted for age and gender), and specific laboratory tests will be ordered such blood glucose and lipid profiles. These measurements provide the family and the psychiatrist with baseline information so that changes can be monitored throughout therapy to maintain safety, efficacy, and well-being. The nurse’s role to obtain personal and family medical history is crucial when assessing children and adolescents who may receive atypical drugs; especially history of problems with diabetes, blood sugar, cholesterol, triglycerides, or heart disease. The nurse should let families and individuals know that this information enables the treatment with atypical medications as safe and effective as possible, and that continuing care will include monitoring height, weight, BMI and lifestyle behaviors during each visit. When on these medications, appetite can increase; children and adolescents may also not recognize when they are full. The tips and ideas listed below
can help both prevent and manage medication-related weight gain in children and adolescents and help reduce the risk of serious medical problems (AACAP, 2008).

Dietary guidance:

- Use portion control - all meals and snacks. Important to measure and limit size of portions
- Use more healthy food choices such as fresh fruits and vegetables for snacks
- Limit snacks and junk food
- Substitute low calorie for higher calorie snacks such as pretzels instead of chips or nuts
- Drink several large glasses (or bottles) of water throughout the day
- Limit sugar-containing drinks (sodas, ‘diet’ drinks, and juice). Replace with water or milk
- Have other family members be understanding and supportive; don’t eat high calorie foods, such as fast food, in front of the child or teen

Tips for meals:

- Schedule regular meal times
- Plan menus – limit fast food
- Use meal time for the family to talk – don’t just eat and run
- Sit down to eat – don’t stand and eat
- Chew all food more slowly
- Avoid eating in front of the TV

Tips to increase activity level:

- Limit time spent sitting watching TV, on the computer or playing video games
• Increase walking – walk after each meal
• Use stairs instead of elevators
• Encourage exercise/sports - moderate physical activity for at least 30-60 minutes a day
• Use forms of activities that are fun and interesting for the child or teen

Education as a primary preventative strategy also involves choosing an atypical agent “with the lowest likelihood of adverse effects on body composition and metabolic status” (Correll, 2008b, p. 199). The nurse should provide information to the children and teens regarding the potential for weight gain, encourage healthy eating of low fat and high fiber diets, and discuss the link between sugar drinks and weight gain (McDougall, 2009). Nurses should ensure that these younger individuals have their weight carefully monitored and healthy lifestyle choices should be encouraged (McDougall, 2009). Since EPS, is most frequently seen with risperidone use, nurses should educate and inform patients of this syndrome; what symptoms to look for; the onset associated with dosing and titration, and help weigh the risk and benefits associated with this side effect profile.

Before treatment with atypical antipsychotic medications, nurses should inform individuals of the risk that these medications have the potential to cause sedation and the incidence or severity level associated with the drug being prescribed (Houltram & Scanlan, 2004f). Additionally, nurses should advise against activities that may put the patient in danger if experiencing sedating side effects (Houltram & Scanlan, 2004f). The nurse’s role is to advise individuals that sedation is prominent in the early stages of treatment. Utilizing monitoring and reporting, adverse effects of therapy can be prevented (Houltram & Scanlan, 2004f). The scope of the mental health nurse includes educating
individuals about postural risks and strategies to decrease and prevent injury and physical discomfort related to atypical treatment (Houltram & Scanlan, 2004e). In the event that there is significant weight gain related to atypical medication therapy, nurses should help these young individuals and their families consider the risks and benefits of continuing with the drug or switching to another medication to promote the best options for individualized treatment (Shin et al., 2008). Initially with drug induced weight gain and/or obesity, conservative approaches should be considered for weight control, specifically diet and exercise (Shin et al., 2008). Most importantly, nurses should educate and guide individuals to be knowledgeable about the important questions to ask the mental health providers specifically regarding medications. Empowering children, adolescents, and their families is a vital intervention that will enable informed decision-making and help individualize mental health care in the young population.

Children, adolescents, and family members should be informed to inquire about the following regarding medication therapy: effective combinations of medications, research supporting the use of the recommended medication for young ages and similar needs, the overall treatment plan, other treatment options such as therapy or behavior plans, what changes in behavior may occur, what will changes in symptoms look like, who to contact, potential risks and benefits of the medication, what are the potential side effects, how to monitor progress, behavior changes, symptoms, and safety concerns, stopping medication therapy, and what steps need to be taken before the medication is stopped (NAMI, 2007). Parents should discuss the risks and benefits of specific medications with their child’s physician.

**Advocacy.** Children, adolescents, and their families should be encouraged to ask
questions of their child or adolescent’s mental health provider about recommended
treatment. Nurses should take on the role of encouraging individuals and their families to
share their personal values and preferences with mental health providers. All atypical
antipsychotics are associated with sedation and psychomotor inhibition side effects.
Mental health clinicians and their patients sometimes perceive sedation as a useful side
effect especially if it enables sleep and does not continue to cause sedation during the day
(Houltram & Scanlan, 2004b). In these situations, nurses have an advocacy role to ensure
that sedation is not misused; to use this side effect as a management strategy without the
patient’s informed consent is unethical (Houltram & Scanlan, 2004f). Educated and
informed families are in the best position to advocate for the most effective treatment and
support systems for loved ones, especially younger individuals. The focus and goal of
EBPs in children and adolescents’ mental health care is for family advocacy to lead to an
improved quality of care, increased accountability, and ultimately better outcomes
(NAMI, 2007).
Chapter III
Methodology Design

Definition of Grounded Theory Model

Grounded theory is a qualitative social research methodology in which as the grounded theorist I formulated my own interpretations based on the participants’ understandings of what was occurring in their lives. This research model is complex and systematic, however, through an ongoing-sensitive process of continually reviewing the data, refining questions, and re-evaluating any changes (Glaser & Strauss, 1967). This method is an analytic and inductive journey utilizing the process of constant comparative analysis of data (Glaser, 1978). The purpose of grounded theory, according to Glaser (1978), is “to account for a pattern of behavior which is relevant and problematic for those involved” (p. 93), thus, the researcher’s generation of an integrated, rooted theory of behavior. The researcher is to generate such theory around a core category that emerges from the interview data.

Purpose and Suitability of Grounded Theory

The purpose of this grounded theory study was to obtain the main concerns viewed from the individuals’ own perspectives and develop the core category which encapsulated the substance of behavioral patterns and their relationships extracted from the data; therefore summarizing what was “happening” for these interviewed individuals (Glaser & Strauss, 1967). This researcher moved beyond any preconceptions and towards constructing a fully developed theory that is rooted in and explains the data. Hutchinson explained it is much like nursing inquiry “the goal and advantage of grounded theory is to develop theories describing or explaining particular situations to accurately perceive and
present another’s world” (as cited in Jacelon & O’Dell, 2005, p. 49). The grounded theory is an inductive strategy based on the research method of comparative analysis (Mullen & Reynolds, 1994). The constant comparative method in this research was applied to any kind of qualitative information or data, including observations, interviews, documents, articles, and books (Glaser, 1994).

Specifically in this study, a grounded theory approach was appropriate as the goal of the inductive research was to uncover meaning and processes not found in the existing literature, related to phenomena from multiple perspectives of individuals who have been through similar life experiences. This researcher simultaneously embraced data gathering, analysis, reflection, and conceptual integration, although their mix at any one time differed over the course of this study. Categories or “hunches” and their properties that emerged through the process of interviewing and collection of data were continually compared to the actual emergent data. This step is crucial to understanding the grounded theory approach, especially as a nurse analyzing the world. Glaser (1978) identified several properties that may build a core category and described them as any kind of theoretical code or behavior. Grounded theory method looks at these generated concepts or properties (of the substantive theory) not only as causes, but also as conditions, consequences, dimensions, types, and processes (Glaser, 1994). The properties that occurred again and again and appeared to link other concepts or categories together, is the core category. As discovered in this grounded study, the concepts in turn, lead to an integrated or rooted theory (Glaser, 1994). Theory that can meet these implications must fit the situation being researched, and work then when put into use; the categories must be meaningfully relevant to and be able to explain the behavior under study (Glaser &
Strauss, 1967). Glaser and Strauss suggest that to generate this theory, the best approach in an initial, systematic discovery of theory from the data of social research; and in this researcher’s situation included experience both as a nursing student and a human student of life which developed a detailed sequence for the study, referred to as theoretical sampling (1967).

**Theoretical Sensitivity**

Theoretical sensitivity refers to the researcher’s knowledge, understanding, and skill, which guide the generation of categories. Finding and developing a core category requires theoretical sensitivity (Schreiber & Stern, 2001). Furthermore, theoretical sensitivity was my ability to enter the study and gave me the ability to perceive meaning (inductively) in the data and to distinguish relevant from irrelevant material by moving from particular, possibly preconceived, data to the general or abstract, thereby developing theory from my observations of specifics (Strauss & Corbin, 1990). As was reflecting on my preconceptions, theoretical sensitivity is another way this researcher guarded against potential biases that can be a threat to the rigor of the study. This quality can come from a variety of sources, including personal and professional experience as well as the substantive literature (Strauss & Corbin, 1990). Through the constant comparative method and through asking questions about the data, the research process itself enhances theoretical sensitivity further. Another technique utilized by this researcher to promote theoretical sensitivity was memoing initial, instinctual theories and then setting them aside for later comparison to the data. In this grounded theory study, this researcher essentially entered the lives of the participants knowing personal experience could be removed from the process thereby with intention to bring it into the analysis to see if it
supported the data or not. Consequently, theoretical sensitivity of this research study was significantly enhanced in the course of exposure to the participants’ lives and shared experiences.

**Procedures**

**Confidentiality.** Informed consent was obtained from the participant before starting the interviews (Appendix E). The Institutional Review Board (IRB), given responsibility by Carroll College to review research proposals that involve the use of human participants, approved the study’s research protocol. The researcher’s contact information was on the recruitment flyer so that interested prospective subjects could contact the researcher directly. Contact information between interested participants and the researcher was kept private and secure in a password-locked computer file. The researcher only contacted interested participants through modes that were private and safe in accordance with each individual’s personal preference. The researcher and participants met at a private location of the individual’s choosing which he or she felt was safe and ensured his or her privacy. Before initiating the interview process, the purpose of the research, procedures of data collection including audio taping, coding of identifying data for confidentiality, and dissemination of the results were discussed with potential participants. Participants’ identities and information were coded using random letters and numbers appointed by the primary researcher. Confidentiality of records identifying the participants was maintained by storing data in a password-locked computer file, and no identifying characteristics were used to identify participants in the presentation of the final thesis. Data were transmitted to the faculty director only after it had been coded.

**Sample and setting.** Exclusion of all ages, other than those over 18 yrs old, was
crucial to the discovery process of this grounded theory study associated with atypical antipsychotic drug treatment and history associated with that specific population. The judgment of the primary researcher and faculty director determined the adequacy of the sample size based on the established method approach. Interested participants contacted the researcher or faculty director if they wanted to be part of the research study. The researcher and each individual participant agreed on a time and place to meet for conducting the interviews where the participant felt safe and that her privacy was protected.

**Participants.** The participants were three, English speaking, healthy volunteers between the ages of 18 to 40 years old, living in the Helena area, whose prior treatment included one or more atypical antipsychotic medication within the last five years. If the volunteer participant’s atypical antipsychotic drug treatment regiment changed in type or dose, it was accepted for the subject criteria so long as the individual had been treated with one or more atypical antipsychotic medications within the last five years. Recruitment was facilitated using public flyers posted in a variety of public buildings and locations in Helena, through word of mouth by the primary researcher and the faculty director, and through a trusted contact with a local day program in Helena.

**Data Collection**

**Unstructured interview.** The initial informal interviews began with the explanation of the study to the participant, supplemented with the consent form and study outline. Participants were informed that they could decline to answer any questions and had the right to withdraw from the study at any time during the interview or study process and to abstain from being audio taped. Signed informed consent was obtained before
starting the initial-informal interview process. The informal interview began by asking
the participants to fill out two questionnaires: the Hogan Drug Attitude Inventory
(Appendix A) and the GASS (Appendix B). These assessment tools were chosen because
of their design to gain an understanding of the participants’ personal views, major
concerns, and experience with atypical antipsychotic medication therapy. The
participants were given the choice to discuss the questionnaires as they filled them in,
discuss them after they had finished filling them in, or to refrain from discussing them
with the researcher. Next, the loosely structured informal interview was implemented to
elicit the genuine views and feelings of the participants. This informal data collection
allowed the researcher to listen as the participants recounted their personal stories
allowing for the exploration of the meaning of the participants’ experience, behavior, and
environment. Finally, the researcher used a loosely structured guide composed of
approximately 15 indicators to generate general demographic data of participants. Below
is the summary of the demographic data results.

<table>
<thead>
<tr>
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<th>Participant-1</th>
<th>Participant-2</th>
<th>Participant-3</th>
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<tbody>
<tr>
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</tr>
<tr>
<td>Gender</td>
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<td>Female</td>
</tr>
<tr>
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<td>White non-Hispanic</td>
<td>White non-Hispanic</td>
</tr>
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</tr>
<tr>
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<td>Mood Disorder</td>
<td>Mood Disorder</td>
</tr>
<tr>
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<td>Present</td>
<td>Absent</td>
</tr>
<tr>
<td>co-morbidity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Initial Diagnosis</td>
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<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Other Psychotropic Medications-Current</td>
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<tr>
<td>Included Psychotherapy</td>
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<td>Yes</td>
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<td>Current Treatment</td>
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<td>Other</td>
</tr>
<tr>
<td>Length of Time on Current Medication(s) Therapy</td>
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<td>&lt; or = 1 year</td>
<td>&lt; or = 1 year</td>
</tr>
<tr>
<td>Employment Status</td>
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<tr>
<td>Residence</td>
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<td>Independent</td>
<td>Independent</td>
</tr>
</tbody>
</table>

Table 5 reports the complete demographic data results including indicators and findings.
Semi-structured interview and observation. The second, semi-structured interviews were conducted using open-ended, in-depth, probing questions to elicit participants' views while the researcher maintained personal observation during the dialog. This formal interview was guided by an outline that was standardized for all participants and allowed for probing for what is not known to gain general information and insights relevant to specific properties or categories. Brief observational assessments were conducted to provide information regarding the tolerance and efficacy related to the participants' medication therapy. The plan for observation was controlled by the researcher's questions regarding the participants' experiences with side effects related to his or her drug therapy. Tolerability was assessed using the AIMS and the SAS for extrapyramidal symptoms (Appendix C & D). The SAS is a tool for the evaluation of antipsychotic drug-induced adverse effects and is most often used in clinical trials of antipsychotic drugs to assess extrapyramidal symptoms (Jha, 2009b; Simpson & Angus, 1970). The AIMS is easy to use and widely used as a global assessment for extrapyramidal symptoms (Guy, 1976; Jha, 2009a). The AIMS was implemented as indirect observation for data collection during the interviews and interactions with participants. All interviews lasted between 60 to 90 minutes and unless a participant verbalized that he or she was not willing to be recorded or environmental circumstances prohibited were audio taped for later transcription. The recorded data from these interviews were transcribed and formatted to allow the researcher the ability to revise and reformat questions in order to probe areas where contrast, similarities, and universal themes were noted. Any other observational data, such as verbal and nonverbal behaviors were recorded in descriptive field notes or memos for later use and comparison with
collected data. Upon completing an interview, brief field notes were written describing the circumstances of the interview, the participant's demeanor, and formative ideas pertaining to emerging theoretical categories. Field notes were used to incorporate the data elements of the interview setting and process as well as the emerging ideas of this researcher.

**Data Analysis**

This grounded theory study involved unstructured and semi-structured interviews with personal observation of each participant who met the subject criteria. Self-rated questionnaires were utilized followed by the informal-unstructured interview conducted to elicit the genuine views and feelings of the participants over a broad range of issues related to the participants' personal views and opinions of their individual and unique experience related to mental health treatment. Demographic data was generated through a loosely structured interview guide at the end of the initial interview with each participant. The formal interview was guided by an outline that was standardized for all participants. The structure of this formal interview was more focused and semi-structured so that specific properties of the theory and common trends could be explored in more depth and validated with questions that I developed from the previous data collection during the informal interview. The method of constant comparative analysis of the dialog generated from open-ended, probing questions, allowed this researcher to identify properties of emerging themes and the relationships among categories associated with the participants' shared lived experiences. Finally, when I felt that the properties of the categories were saturated and well developed, I turned to inductive logic to explore similarities, differences, and deviations from what was already known about the research question by
revisiting literature review of data. Research data through interviews were collected in February of 2010. Data collection and analysis occurred concurrently.

**Constant Comparative Method**

Throughout this grounded theory study, data were collected, transcribed, and analyzed using the constant comparative method. The focus initially was unraveling the elements of shared experiences of the participants. This process of discovery of conceptual categories and their properties was developed and rooted in the data, the evidence from which the properties emerged was used to illustrate and integrate these conceptualizations or relevant theoretical abstractions about the unfolding-shared relationships (Glaser, 2002). The constant comparative design allowed vagueness and flexibility to aid this researcher in the creative generation of grounded theory by challenging preconceptions and promoting new questions. Data collection for grounded theory involves an iterative process in which data from one interview is analyzed before conducting the next interview. From this, it is possible to introduce information into subsequent interviews, which is grounded in the information collected from earlier interviews.

**The Core Category and Saturation**

Grounded theory can be presented either as a well coded set of propositions or in a running theoretical discussion, using conceptual categories and their properties (Glaser & Strauss, 1967). Theoretical discussion as means of formulating substantive theory gave an ever-developing feeling to the theory, allowing it to become quite rich, complex, and dense, and made its fit and relevance easy to comprehend. This rephrasing is simply a formal exercise, though, since the concepts are already related in the discussion.
Substantive theory was generated from the use of the comparative analysis method and rooted in the data, which was essential to this study’s sociological inquiry.

**Trust and Authenticity**

The resulting hypothesis and theory do not need to be validated or verified, as these tasks are properties of verification and replications studies (Glaser, 1992). Grounded theory method does not involve obtaining proof or universality of the suggested categories or properties; rather it requires saturation of data (Glaser, 1994). A frequent criticism of all qualitative research is that it lacks rigor and certitude; an element that cannot be assured in the most carefully planned quantitative studies. However, trust in the data and their interpretation is dealt with in grounded theory and other methods of qualitative research in special ways. Glaser and Strauss (1967) explained the effect of their methods, especially the constant comparative method, on credibility of the data. Rigor is a systematic generation of theory using the constant comparative method (Glaser, 1992).

**Study Limitations**

Time and location restraints were possible limitation in this study. This researcher made the decision to remove the AIMS and SAS from the procedure and collection of assessment data as the personal perceptions and testimonies of side effects, gathered through the other questionnaires and general interview results, seemed to be more relevant and powerful in the development of this grounded theory. Furthermore, location restraints decreased their relevance as the themes, categories, and theory emerged throughout the data collection process. Another limitation would be sample size. Finally, an important limitation was compliance of schedule interview appointments.
Summary

As Jacelon and O'Dell (2005) indicated, grounded theory methodology is an excellent tool for gaining a better understanding of the efficacy, safety, and tolerance associated with atypical antipsychotic medication therapy in adolescents as these individuals learn to manage new or chronic mental health conditions. Consequently, the advantage of grounded theory methodology for this study, through a process of constant comparison and reduction, allowed a well-integrated theory to be built from well-defined concepts, which was rooted in the data.
Chapter IV

Findings

Core Concept and Categories

The categories that make up the core concept and grounded theory were conceptualized by the participants' descriptions from their perceived, real-life treatment/experience within the mental health care system. *Enduring social stigma* was conceptualized from the collected testaments and emergent data. This core category arose from the following categories and their properties: (a) facing obstacles to mental health treatment, (b) receiving labels and attitudes from others, (c) developing negative coping skills, (d) struggling with interpersonal relationships, (e) losing autonomy, and (f) enduring medications and side effects. The categories appeared during all stages of mental health care/treatment. Individual life circumstances determined which stage the categories were present. The above categories emerged as common patterns and themes conceptualizing the significant impact of social stigma on individuals with mental illness. The participants' shared experiences were all threaded with the above categories. The subsequent grounded theory, *enduring social stigma*, indicates a social process impacting these individuals' perceived life-experiences and treatment outcomes.

Facing Obstacles to Mental Health Treatment

Each participant perceived stigma and questioned the relevance of treatment, including atypical medication therapy. Each participant verbalized questioning her mental illness diagnosis and/or treatment related to accuracy and relevance, and all noted subsequent stigma experienced from one or more of the following: family, peers, and/or mental health professionals. All participants reported having different initial diagnoses.
and reported multiple subsequent diagnoses throughout their treatment, differing from their current mental illness diagnosis. Only one of the three participants felt that she had arrived at a correct or relevant diagnosis in her treatment course enabled by a “dual diagnosis psychiatrist” that she felt accurately assessed her complicated mental illness struggles and past life experiences.

**Participants’ comments.** “[People] need to understand and acknowledge that meds aren’t the only answer and not all medications just ‘fix’ problems.” “Now that I have an accurate diagnosis, my treatment has changed a lot, especially how I am treated, I am more believed now. Before treating providers would say ‘oh she is just borderline and manic.’ “I feel my treatment is taken seriously with the schizoaffective diagnosis and I now have been diagnosed with PTSD as well.” “I would recommend encouraging counseling, especially with family etc., there hasn’t been much of that in my treatment.”

**Receiving Labels and Attitudes From Others**

Experiences that were shared by the participants regarding mental illness and related health issues all involved social stigma and stereotypes, which lead to discrimination and prejudice. Discrimination and prejudice faced by the participants seemed to effect multiple aspects within the experience of mental disorders. The impact that labeling and attitudes from others had on all these individuals compromised health care treatment, their sense of worth, and enabled prejudice towards each of them projected from family members, peers, society, and health care providers.

**Participants’ comments.** “We're people too, we do feel, even if we don't appear to be ‘aware’, we still are there...for example, during times when I was staring off into space [regardless of mental illness stage] at the mental health center people have said
very cruel things to me because they think I can’t hear them...that is just one example.”

“Having a mental disorder does not mean we don’t have feelings.” “A lot of stigma behind mental illness, getting support from a provider is really hard because you get labeled a ‘frequent flyer’... which leads to all people you encounter writing you off because you have that label.”

Developing Negative Coping Skills

The use of non-prescription and/or illegal drugs, alcohol abuse, self-mutilation, avoiding problems/‘checking out’, and denial were reported as methods of self-medication and coping.

Participants’ comments. “Previously I would just take pills, drink alcohol, and cut to feel anything other than what I was feeling [related to mental illness].” “I would binge drink because I felt better than I was feeling on medication”...“I prefer to take a pill for something if it will make me feel better.”

Struggling with Interpersonal Relationships

There was concern about family and close companions because they were worried, helpless, and unsure about what to do. Friends were frightened about their psychiatric status, and both friends and family tried to avoid the person and/or mention of the presence of mental illness. All participants reported being perceived as a threat or danger by someone close to them, and being mentally ill took a toll on relationships, “especially family”; being in-patient was reported as a substantial struggle because “support comes and goes.” There was a general perception that these barriers were due to lack of education and ignorance about the illness. All participants verbalized the need for someone to be there for her not based on her actions, but by who they are as a person.
Participants' comments. “I am viewed as the one who caused all the problems in the family...now there has been no contact for three years.” “...Hard to go back to school after hospitalization.” “Everyone that has even been in my life [during acute psychotic episode and in-patient treatment] has left.” “The impact on family related to medication change issues is ‘what is going to happen now’... very hard for supporter to go through that with her.”

Losing Autonomy

Participants commented that their mental illness, treatment, and related problems led to unwanted behavior, which under other conditions, she would not choose to suffer or tolerate. The following response was chosen on all of the Hogan Drug Attitude Inventory questionnaires ‘I am given medication to control my behavior that other people do not like’.

Participants' comments. “I know that my family wants me to just take a medication so they can feel better about who I am.” “During my psychotic episodes I was very anxious and worried that I might have to return to the hospital as an in-patient.”

Enduring Medications and Side Effects

All participants reported adverse side effects from atypical medication treatment, and results of the GASS questionnaires all scored in the category of moderate side effects in relation to frequency of side effects overall, reported in relevance to the last week of the participants’ lives. The reported daily side effects included feeling sleepy during the day, drugged or zombie like, dizzy upon standing and/or had fainted, irregular or unusually fast heart beat, dry mouth, and had problems enjoying sex. A few times a week participants experienced tense or jerky muscles, shaky hands or arms, restless legs or
could not sit still and uncontrollable movements of face or body. The following side effects were commonly viewed as distressing: feeling sleepy during the day, feeling dizzy upon standing and/or had fainted, dry mouth, problems enjoying sex, and feeling irregular or unusually fast heart beat. Over the last three months, all participants reported a change in menstruation, which was distressing. The Hogan Drug Attitude Inventory questionnaires were utilized to gain some understanding of how individuals view the use of atypical medications and the nature of their experiences on these drugs. The following four negative or non-compliant, responses from these questionnaires were congruent views regarding the nature of the participants’ real-life experience; ‘the bad things about medication outweigh the good things’, ‘the unpleasant effects of medications are always present’, ‘medication(s) makes me feel tired and sluggish’, and ‘I do not get along better with people when I am on medication’. One participant had positive score indicating a compliant view and experience with atypical medication therapy and two participants had overall negative scores indicating non-compliant views and experiences with atypical medication therapy. Participants verbalized many aspects (covering a broad range of factors) toward medications perceived as problematic or impairing. During all interviews, there was acknowledgment of disfavor regarding the way the medication made the participants feel “not like myself.”

Participants’ comments. “I just don’t like taking a pill, I don't like remembering everyday…“oh it's med time, gotta take them again.” “Meds make overall quality of life worse.” “Doctors don’t tell you that's [adverse side effect] going to happen.” “The waiting game is the most difficult for me, waiting for them to take effect and see if they are going to be therapeutic or if I’ll just have to start all over again.”
Chapter V

Discussion

The conceptualized theory *enduring social stigma* and its supporting categories are the summarization of the lived experience findings of the individuals interviewed for the purpose of this study. This researcher began each interview with the self-report, subjective medication questionnaires, which immediately initiated free, honest, and trusting conversations with this researcher. All participants were emphatically focused on this subject, indicating to this researcher the extent of its importance and congruence in the lived experiences of these individuals. The significant reaction from the participants and the urgency to speak freely and openly regarding medications, led to very open discussions about their feelings and experiences with mental illness diagnosis and treatment. One participant accounts her diagnosis history and frustrating experience with inaccurate and misdiagnoses. Initially at 11 years old, it was borderline personality disorder then to bipolar disease at age 16, and finally by age 27 the diagnosis was switched to schizoaffective with PTSD co-morbidity. According to one participant, the significance of this current, and what she feels is “finally an accurate diagnosis, and is actually getting relevant and effective treatment.” She reported that the “borderline personality disorder and bipolar diagnoses were accompanied by stigma and judgment, and therefore ineffective treatment methods were prevalent for most of her life.” Within the participant sample, the overall views seemed to be linked to current age and length of time living with mental illness, diagnoses and treatment, and utilization and/or awareness of available coping skills.

In spite of the existence of effective interventions for the care of children and
adolescents with mental disorders, a huge proportion of those with these disorders do not have adequate access to care due to a series of barriers. These barriers to treatment are several, but reflect a few dominant themes including stigma and lack of resources (World Health Organization [WHO], 2003). Even though progress has been made in developing effective treatments, children and adolescents with mental disorders and their caregivers remain stigmatized; thus priority is given to illnesses labeled as physical without the recognition of the association with mental disorders or of the burden associated with mental illness (WHO, 2003). Consequently, "For child and adolescent mental disorders which progress and sometimes worsen into adulthood, the impact of inattention to treatment on morbidity and mortality later in life is demonstrable" (WHO, 2003, p. 9). In this regard, it is crucial to link overall health with concerns for improving mental health which leads to improved physical health, enhanced productivity, and increased stability (WHO, 2003).

Research shows that early identification and comprehensive, multidisciplinary treatment can improve the long-term prognosis of children and adolescents with mental illnesses; the long-term consequences of under-diagnosed and/or untreated mental illnesses in youth are staggering (Gruttadaro & Miller, 2004). According to the Institute of Medicine Report, evidence strongly suggests that as many as 90% of those young individuals who commit suicide have a diagnosable and treatable mental disorder (as cited in Gruttadaro & Miller, 2004). "In fact, a pressing issue is the number of children [and adolescents] with mental illness that are not being [adequately] diagnosed and treated" (Gruttadaro & Miller, 2004, p. 7). Consequently, children and adolescents with untreated mental disorders leads failure in school, inability to cultivate friendships, and
barriers in the development of social skills. The negative impact on children and adolescents related to the failure and/or lack of adequate mental illness treatment leads to isolation from peers, commonly leads to social isolation, and overall diminished futures and quality of life (Gruttadaro & Miller, 2004).

This research study revealed the subjective experience of stigma was pervasive among the shared experiences of the participants. Stigmatization of people with mental disorders has persisted throughout history, manifested through bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance (Surgeon General of the U.S., 1999a). “A source of stigma lies in the 19th-century separation of the mental health treatment system in the United States from the mainstream of health” and continues to exert an often-immediate impact on perceptions and behaviors in the modern world (Surgeon General of the U.S., 1999a, p. 6). Stigma is a very real problem for people who have a mental illness. Based on stereotypes, stigma is a negative judgment based on a personal trait, in this study, having a mental health condition. Corrigan and Watson theorize that both public- and self-stigma are created by three key components: (1) stereotypes, (2) prejudice, and (3) discrimination (as cited in Kondrat & Teater, 2009). This theory suggests that the negative stereotypes surrounding persons with mental disorders cause society to have negative thoughts about individuals with mental illness (prejudice), and in turn, society reacts negatively towards persons with mental illness (discrimination). Consequently, the stereotypes also affect individuals with mental disorders and are found to decrease their self-esteem and self-efficacy (prejudice) and thus, deny themselves opportunities, services, and a voice to which they are entitled (discrimination) (Kondrat & Teater, 2009). Stigma can be obvious and direct, such as someone making a negative remark
about an individual’s mental health condition or treatment (Mayo Clinic staff, 2009); one participant reported “cruel and demeaning remarks said to her face by others who assumed she was simply not capable of hearing them. “This and other forms of stigma can lead to feelings of anger, frustration, shame, and low self-esteem (Mayo Clinic staff, 2009, ¶2).

Furthermore, individuals may be less willing to offer support and empathy for a person suffering from a mental disorder rather than a physical health problem. “Individuals with a history of mental illness may find that others become uncomfortable or distrustful around them and that they lose contact with family and friends” (“Challenging Stigma”, 2005, ¶2). Likewise, participants in this study reported a common matter impacting social interactions and interpersonal relationships; a lack of trust and a fear of trust being broken. Also, Henderson et al. added that the repelling and undesirable effects of the disclosure of mental disorders could also have negative consequences on relationships with relatives and close friends (as cited in Murphy & Murphy, 2006).

Stigma contributes to loneliness, distress, and discrimination against individuals with a mental illness and their families resulting in individuals that are reluctant to seek help, less likely to cooperate with treatment, and slower to recover self-esteem and confidence (Hocking, 2003). Cresswell et al. commented that a decreased ability to cope with the stresses and demands of everyday life understandably accompanies mental illness and impinge upon necessary social skills to establish and maintain mutually rewarding social interaction with others (as cited in Murphy & Murphy, 2006). In addition, individuals with mental illness may lack opportunities to feel and give affection and be less likely to experience normal social interactions with close friends (Murphy & Murphy, 2006, p.
Henderson et al. added, in long-term mental illness, the individual’s friendship circle tends to be small and relationships will often be unobtrusive, offering few links to other social networks (as cited in Murphy & Murphy, 2006). Historically, mental illness was one size is supposed to fit all, and currently if is not, the mentally ill individual is labeled as resistant, in denial, a ‘frequent flyer’ and is shunned both within and outside the mental health service system (Humphrey & Townsend, 2005). Likewise, it was once a common perception that having a mental illness was due to some kind of personal weakness of behavior, however, it is now understood that mental disorders have a biological basis and treatment can and should be implemented as with any other health condition or disorder (Mayo Clinic Staff, 2009). However, there remains an urgent and overwhelming need to “overcome the many misconceptions, fears and biases society has about mental illness, and the stigma these attitudes and labels create” (Mayo Clinic staff, 2009, 2¹). The combined impact of social stigma on individuals with mental illness suggests that public identification as ‘mentally ill’ can yield significant harm; research suggests that individuals with concealable stigmas, such as mental illness, decide to avoid this harm by hiding their stigma (Corrigan, 2004). Corrigan (2004) notes “alternatively, they may opt to avoid the stigma all together by denying their label and by not seeking the institutions that mark them, ie. mental health care” (p. 616). On that account, individuals avoid being labeled mentally ill and seeking treatment, thereby escaping the negative statements that lessen self-esteem and self-efficacy (Corrigan, 2004).

Consequently, “This kind of label avoidance is perhaps the most significant way in which stigma impedes care seeking” (Corrigan, 2004, p. 616).

William’s et al. “found that patient’s perception of clinician’s support of their
autonomy was a significant predictor of adherence” (as cited in Berk, Berk, & Castle, 2004, p. 506). Berk et al. (2004) noted, “Supporting autonomy and enhancing self-efficacy imply a fundamental change from a treatment alliance that focuses exclusively on the authority and expertise of the physician” (p. 506). As indicated by the finding of this study, participants hold negative and non-compliant views and experiences with atypical medication therapy. Attitudes towards antipsychotic medication may be positive in individuals who recognize therapeutic drug effects; however, other individuals may view medications negatively due to a perceived sense of stigma (Sajatovic & Jenkins, 2007). Results from a grounded theory study indicated that individuals on antipsychotics did not see side effects and symptoms as separate issues, suggestive of the total impact of their treatment (Sajatovic & Jenkins, 2007). Furthermore, research evaluating the predictors of drug attitudes in individuals with mental illness demonstrated that less awareness of current symptoms and presence of deficit symptoms predicted a negative attitude towards antipsychotic medications (Sajatovic & Jenkins, 2007). Antipsychotic medications can be stigmatizing for individuals with serious mental illness, however the roots of stigma are extensive, and efforts to minimize stigma can only be successful when addressed by the individual with the illness, their families and loved ones, treatment providers, and society at large. Thus, it is vital for mental health nurses and other health professionals to appreciate that stigma and its associated prejudice form a very real barrier to mental health treatment and recovery (Hocking, 2003).

**Nursing Implications**

Early assessment and identification of mental health needs does not exist in most of the systems designed to serve children and their families, including but not limited to
primary health care, schools, community centers, and child welfare (Gruttadaro & Miller, 2004). Research increasingly is showing that the failure to intervene and provide early and comprehensive treatment (whether it is medication, psychosocial interventions, or some combination of the two) for many mental illnesses accelerates the course of the illnesses (Gruttadaro & Miller, 2004).

One size does not fit all when it comes to treating mental illnesses. All children and adolescents with mental illnesses must have access to evidence-based assessments and interventions (EBI) and quality care. The EBI system should require mental health nurses and other health care professionals to continually improve care by using the most current evidence and research to make decisions about the most appropriate medication and treatment on an individualized basis. This approach for the diagnosis and treatment of mental illness in children and adolescents should be used by mental health nurses and other professionals, in close consultation with parents, caregivers and youth (when appropriate), when making decisions about whether atypical antipsychotic medications are appropriate for the treatment of a child or adolescent’s mental disorder (NAMI, 2007). In fact, “the younger the child, the less research there is available for the use of psychotropic medications” (NAMI, 2007, p. 33). In these situations, the mental health nurses’ role is to assist young individuals and their families to locate mental health providers who implement current best practices and collaborate to provide the most effective and appropriate mental health interventions. Mental health nurses have more contact with service users than any other professional group; they are well placed to support children and adolescents with mental illness diagnoses during first contact with primary care services, through engagement with specialist mental health services and in
accessing early intervention and crisis services (McDougall, 2009).

The nurse’s role includes implementing a care plan for children and adolescents taking atypical antipsychotic drugs. One of the most important interventions that nurses undertake is in relation to relapse prevention which involves helping young people and their parents or caregivers to recognize early warning signs, and monitoring medication (McDougall, 2009). This includes ensuring that children and adolescents understand their medication, the reasons for taking it, any potential side effects, and the possible implications of stopping their medication (McDougall, 2009, p. 38). Families should be fully informed of all risks and benefits associated with medications and the decision about whether to medicate a child or adolescent should only be made after carefully weighing these factors. The balance between risks and benefits should include consideration of the seriousness of the youth’s symptoms and how they are affecting his or her day-to-day life and functioning (NAMI, 2007). This education and prevention should include ensuring that children and adolescents understand their medication, the reasons for taking it, any potential side effects, and the possible implications of stopping their medication (McDougall, 2009). Antipsychotics can directly and indirectly interfere with and cause physical health abnormalities that can negatively impact the psychiatric well-being of individuals; therefore, healthcare providers need to include appropriate physical health monitoring and management in treatment plans (Correll, 2008b).

Furthermore, patients’ views of medication, notably their experience of side effects, influence prescribing methods with the goal of compliance; “side effects are a key reason for patients stopping their medication” (Barley, Pope, Chilvers, Sipos, & Harrison, 2008, p. 14). Thus, by applying this knowledge, nurses can gain patient trust and compliance by
ensuring that patients’ first experience of antipsychotic medication is a good one through therapeutic nurse-patient relationships and patient education. Nurses’ expanded future role in mental health care includes implementing emerging-standardized monitoring profiles, which will help identify and prevent adverse events and promote compliance (Jordan, 2007). The prescribing process and subsequent treatment of individuals with atypical antipsychotics provides the opportunity for mental health nurses to educate patients and provide them with informed choices about the common potential side effects of these medications (Jones & Jones, 2008). The nurse’s role in monitoring patient safety and tolerability of antipsychotic therapy is an essential part of holistic mental health care and can be achieved through a systematic and collaborative medication management and monitoring plan.

Comprehensive evaluations and assessments are crucial to determine the individual needs of every child, adolescent, and his or her family. When a young individual requires mental health treatment, a range of effective treatment options should be available, and these evaluations should promote choices of effective interventions that support his or her goals, build on strengths, and enhance problem-solving and coping skills. Promoting therapeutic nurse-patient relationships includes the promotion of choice and empowerment in one's care. Choice with medication options is crucial in treatment using atypical antipsychotics, which cause sometimes-intolerable side effects in these young individuals and impair their quality of life. Multidisciplinary teamwork is an integral part in the management of adverse side effects and atypical medications while caring for children and adolescents. Individuals who are enabled to make informed choices regarding medication therapy have improved tolerability and compliance while
taking atypical antipsychotic medications (Jones & Jones, 2008). This suggests a role for
the nurse in providing information and supporting the individual’s autonomy so that
medication adherence, may be truly integrated.

Recommendations for Future Research and Needs

In the U.S., according to Murray and Lopez, “mental disorders collectively
account for more than 15% of the overall burden of disease from all causes and slightly
more than the burden associated with all forms of cancer” (Surgeon General Of the U.S.,
1999b, p. 3). These data underscore the importance and urgency of treating and
preventing mental disorders and of promoting mental health in our society by tearing
down the most formidable obstacle to future progress in the arena of mental illness and
health: “That obstacle is stigma” (Surgeon General Of the U.S, 1999b, p. 3). The
challenge is also to develop strategies to bring about systemic change so that the rights of
people with mental illness are respected (Hocking, 2003). Therefore, public policy
addressing the treatment of mental illnesses in children and adolescents must be shaped
by research and evidence-based practice, not stigma and discrimination that persist
against mental illnesses which will only harm the public health and build up the barriers
to mental health treatment (Gruttadaro & Miller, 2004). Current trends in recognition of
child and adolescent mental disorders and advances in the care of these young individuals
with mental disorders identify issues for future exploration, and consider appropriate
policies with the following areas of primary concern; (a) magnitude of the burden of child
and adolescent mental disorders, (b) advances made in treatment and diagnosis, (c)
barriers to treatment, and (d) trends in care for children and adolescents with mental
disorders (WHO, 2003).
Recovery is the aim of pharmacological and psychosocial treatment in individuals with mental illness, however, evidence based clinical strategies are not sufficient to address the barriers to recovery (Corrigan & Wassell, 2008). The stigma of mental illness may also impair achievement of personal aspirations; therefore, evidence-based practices need to be examined in terms of their effect on stigma (Corrigan & Wassell, 2008, p. 48). Furthermore, future research should incorporate measures of actual behavior, including direct observation, to find out whether stigma attitudes impede individuals with mental illness from seeking care and to determine how preexisting attitudes influence care seeking as the individual needs mental health services (Corrigan, 2004). Research on understanding and changing label avoidance is not well developed; knowledge development and thus education on anti-stigma strategies for the public is projected to have positive effects on individuals participating in treatment. “Clearly, label avoidance is a phenomenon that needs to be part of future research on stigma change: education may also challenge myths about mental illness that may be interfering with care seeking or participation in treatment” (Corrigan & Wassell, 2008, p. 47). The ongoing development of strategies to help reduce stigma by dispelling myths about mental illness should include dissemination of accurate knowledge to ensure more informed mental health consumers, and encouragement towards treatment seeking of individuals experiencing mental health problems. As nurses, we must be charged with the task of education aimed at challenging stigma and replacing it with hope, recovery, and empowerment.

**Conclusion**

This grounded theory study developed a detailed sequence that depended on the
data available, the interpretations of the researcher, and the contingencies that influenced and guided the research, both personally and professionally. The work in this phenomenological, grounded tradition is especially important in pressing the question of what it is to understand or explain mental illness, and how this can lead to better evidence-based and clinically applied practices. Finally, the final step and focus of this chapter was to compare the emerged theory with the current literature and examine what is similar, what is different, and why. As discovered, the literature was considerably congruent with the conceptualized grounded theory. Overall, tying the emergent theory to existing literature enhances the internal validity and theoretical level of the theory building from case study research because the finding often rest on a very limited number of cases, as in this study with three participants.
References


http://www.cnsforum.com/clinicalresources/ratingscales/ratingpsychiatry/side_effects/


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ATYPICAL ANTIPSYCHOTIC MEDICATION THERAPY


Appendix A

Hogan Drug Attitude Inventory

<table>
<thead>
<tr>
<th></th>
<th>I don't need to take medication once I feel better</th>
<th>T</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>For me, the good things about medication outweigh the bad</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>3.</td>
<td>I feel strange, &quot;doped up&quot;, on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>4.</td>
<td>Even when I am not in hospital I need medication regularly</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>5.</td>
<td>If I take medication, it's only because of pressure from other people</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>6.</td>
<td>I am more aware of what I am doing, of what is going on around me, when I am on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>7.</td>
<td>Taking medications will do me no harm</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>8.</td>
<td>I take medications of my own free choice</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>9.</td>
<td>Medications make me feel more relaxed</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>10.</td>
<td>I am no different on or off medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>11.</td>
<td>The unpleasant effects of medication are always present</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>12.</td>
<td>Medication makes me feel tired and sluggish</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>13.</td>
<td>I take medication only when I feel ill</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>14.</td>
<td>Medications are slow-acting poisons</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>15.</td>
<td>I get along better with people when I am on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>16.</td>
<td>I can't concentrate on anything when I am taking medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>17.</td>
<td>I know better than the doctors when to stop taking medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>18.</td>
<td>I feel more normal on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>19.</td>
<td>I would rather be ill then taking medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>20.</td>
<td>It is unnatural for my mind and body to be controlled by medications</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>21.</td>
<td>My thoughts are clearer on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>22.</td>
<td>I should keep taking medication even if I feel well</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>23.</td>
<td>Taking medication will prevent me from having a breakdown</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>24.</td>
<td>It is up to the doctor to decide when I should stop taking medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>25.</td>
<td>Things that I could do easily are much more difficult when I am on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>26.</td>
<td>I am happier and feel better when I am taking medications</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>27.</td>
<td>I am given medication to control behavior that other people (not myself) don't like</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>28.</td>
<td>I can't relax on medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>29.</td>
<td>I am in better control of myself when taking medication</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>30.</td>
<td>By staying on medications I can prevent myself getting sick</td>
<td>T</td>
<td>F</td>
</tr>
</tbody>
</table>

If you have any further comments about medication or this questionnaire, please write them below.

Appendix A (continued)

Hogan Drug Attitude Inventory Scoring Criteria

The scale has 15 items that will be scored at true (T) and 15 items that will be scored as false (F) in the case of a fully compliant response.

A correct answer to these item will be scored as "plus 1". An incorrect answer will be scored as "minus 1". The total score is the sum of pluses and minuses. A positive total score means a compliant response. A negative total score means a non-compliant response.

Below is the standard of a completely compliant response profile:

1. F
2. T
3. F
4. T
5. F
6. T
7. T
8. T
9. T
10. F
11. F
12. F
13. F
14. F
15. T
16. F
17. F
18. T
19. F
20. F
21. T
22. T
23. T
24. T
25. F
26. T
27. F
28. F
29. T
30. T

Appendix A (continued)

Hogan Drug Attitude Inventory Instructions

The purpose of this questionnaire is to gain some understanding of how individuals view the use of psychiatric medications and the nature of their experience of these drugs. Your replies will be used for the research purposes of this study only, are strictly confidential, and will in no way affect your treatment.

Please answer every question. If a statement is worded not quite the way you would express it yourself, decide whether it is mostly true or mostly false. Remember to give your own opinion; there are no right or wrong answers. Do not spend too much time on any one item.

For the purpose of this study, the medications referred to in the statements are atypical antipsychotic medications only.

How to fill in this questionnaire:

➢ Read each statement and decide whether it is true as applied to you or false as applied to you.
➢ If a statement is TRUE or MOSTLY TRUE to you, circle the T at the end of the line.
➢ If a statement is FALSE or MOSTLY FALSE to you, circle the F at the end of the line.
➢ If you want to change an answer, mark an X over the incorrect answer and circle the correct answer.

Appendix B

Glasgow Antipsychotic Side-effect Scale (GASS)

Please list current your medication(s) and total daily doses below.

This questionnaire is about how you have been recently. It is being used to determine if you are suffering from excessive side effects from your antipsychotic medication. **Please place an X** in the column that best indicates the degree to which you have experienced the following side effects.

*Also check the end or last box if you found that the side effect was distressing for you.*

<table>
<thead>
<tr>
<th>Over the past week:</th>
<th>Never</th>
<th>Once</th>
<th>A few times</th>
<th>Everyday</th>
<th>Check this box if distressing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt sleepy during the day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I felt drugged or like a zombie</td>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>3. I felt dizzy when I stood up and/or have fainted</td>
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<td></td>
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<tr>
<td>4. I have felt my heart beating irregularly or unusually fast</td>
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<tr>
<td>5. My muscles have been tense or jerky</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. My hands or arms have been shaky</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. My legs have felt restless and/or I couldn’t sit still</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8. I have been drooling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. My movements or walking have been slower than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I have had uncontrollable movements of my face or body</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. My vision has been blurry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. My mouth has been dry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I have had difficulty passing urine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I have felt like I am going to be sick or have vomited</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>15. I have wet the bed</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>16. I have been very thirsty and/or passing urine frequently</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. The areas around my nipples have been sore and swollen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I have noticed fluid coming from my nipples</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I have had problems enjoying sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. <strong>Males only:</strong> I have had problems getting an erection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Check yes or no for the last three months**

<table>
<thead>
<tr>
<th>Check this box if distressing</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>21. <strong>Females only:</strong> I have noticed a change in my periods</td>
</tr>
<tr>
<td>22. <strong>Females &amp; Males:</strong> I have been gaining weight</td>
</tr>
</tbody>
</table>
1. Allow the participant to fill in the questionnaire themselves. All questions relate to the previous week.

2. Scoring
For questions 1-20:
1 point for the answer “once”
2 points for the answer “a few times”
3 points for the answer “everyday”
0 points for an answer of “never”

For questions 21 and 22:
3 points for a “yes” answer
0 points for a “no” answer

Total for all questions =

3. For male and female patients a score of:
0-21 absent/mild side effects
22-42 moderate side effects
43-63 severe side effects

4. Side effects covered per questions include:
1-2 sedation and CNS side effects
3-4 cardiovascular side effects
5-10 extra pyramidal side effects
11-13 anticholinergic side effects
14 gastro-intestinal side effects
15 genitourinary side effects
16 screening question for diabetes mellitus
17-21 elevated prolactin level side effects
22 weight gain

5. The column relating to the distress experienced with a particular side effect is not scored, but is intended to inform the investigator of the participant’s personal views and condition.

Appendix C

Abnormal Involuntary Movement Scale (AIMS)

### Facial and Oral Movements

<table>
<thead>
<tr>
<th>1. Muscles of facial expression</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g., movements of forehead, eyebrows, outer orbital area, cheeks. Include frowning, blinking, grimacing of upper face</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Lips and perioral area</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g., puckering, pouting, smacking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Jaw</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g., biting, clenching, chewing, mouth opening, lateral movement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Tongue</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate only increase in movement both in and out of mouth, not inability to sustain movement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Extremity Movements

<table>
<thead>
<tr>
<th>5. Upper (arms, wrists, hands, fingers)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include movements that are choreic (rapid, objectively purposeless, irregular, spontaneous) or athetoid (slow, irregular, complex, serpentine)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do not include tremor (repetitive, regular, rhythmic movements)

<table>
<thead>
<tr>
<th>6. Lower (legs, knees, ankles, toes)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g., lateral knee movement, foot tapping, heel dropping, foot squirming, inversion and eversion of foot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Trunk Movements

<table>
<thead>
<tr>
<th>7. Neck, shoulders, hips</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g., rocking, twisting, squirming, pelvic gyrations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Include diaphragmatic movements

### Global Judgments

<table>
<thead>
<tr>
<th>8. Severity of abnormal movements.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on the highest single score on the above items.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. Incapacitation due to abnormal movements.</th>
<th>none, normal minimal mild moderate severe</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>10. Patient’s awareness of abnormal movements</th>
<th>no awareness aware, no distress awareness aware, mild distress awareness aware, mod. distress awareness aware, severe distress</th>
</tr>
</thead>
</table>

### Dental Status

<table>
<thead>
<tr>
<th>11. Current problems with teeth and/or dentures</th>
<th>Yes / No</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>12. Does patient usually wear dentures?</th>
<th>Yes / No</th>
</tr>
</thead>
</table>

AIMS Examination Procedure

To be completed before entering the ratings on the AIMS form by unobtrusively or indirectly observing the individual at rest (during interview).

The chair to be used in this examination should be a hard, firm one without arms.

1: Ask individual whether there is anything in his/her mouth (i.e., gum, candy, etc.) and if there is, ask to remove it.

2: Ask individual about the current condition of his/her teeth (pain, discomfort, etc.).

3: Ask individual whether he/she notices any movements in mouth, face, hands, or feet. If yes, ask to describe and to what extent they currently bother the individual or interfere with his/her activities.

4: Ask individual to sit in chair with hands on knees, legs slightly apart, and feet flat on floor. (Look at entire body for movements while in this position).

5: Ask individual to sit with hands hanging unsupported. If male, between legs, if female, and wearing a dress, hanging over knees. (Observe hands and other body areas).

6: Ask individual to open mouth. (Observe tongue at rest within mouth). Do this twice.

7: Ask individual to protrude tongue. (Observe abnormalities of tongue movement).

8: Ask individual to tap thumb, with each finger, as rapidly as possible for 10-15 seconds: separately with right hand, then with left hand. (Observe facial and leg movements).

9: Flex and extend individual’s left and right arms, one at a time.

10: Ask the patient to stand up. (Observe the patient in profile. Observe all body areas again, hips included).

11: Ask individual to extend both arms outstretched in front with palms down. (Observe trunk, legs & mouth).

12: Have individual walk a few paces, turn, and walk back to chair. (Observe hands and gait). Do this twice. Indirect observation of this can be done throughout interview or interaction with participant.

Appendix D

Simpson-Angus Scale (SAS)

**Item 1: Gait**
The participant is examined as he or she enters a room. Observation of gait, swing of arms, & general posture. These form the basis for an overall score for this item. This is rated as follows:
- 0 normal
- 1 diminution in swing while the patient is walking
- 2 marked diminution in swing with obvious rigidity in the arm
- 3 stiff gait with arms held rigidly before the abdomen
- 4 stooped shuffling gait with propulsion and retropulsion

**Item 2: Arm Dropping**
The participant and the observer both raise their arms to shoulder height and let them fall to their sides. In a normal subject, a stout slap is heard as the arms hit the sides. In the individual with extreme Parkinson’s syndrome, the arms fall very slowly. The scoring is as follows:
- 0 normal, free fall with loud slap and rebound
- 1 fall slowed slightly with less audible contact and little rebound
- 2 fall slowed, no rebound
- 3 marked slowing, no slap at all
- 4 arms fall as though against resistance, as though through glue

**Item 3: Shoulder Shaking**
The participant’s arms are bent at a right angle at the elbow and are taken one at a time by the examiner who grasps one hand and clasps the other around the patient’s elbow. The participant’s upper arm is pushed to and fro and the humerus is externally rotated. The degree of resistance from normal to extreme rigidity is scored as follows:
- 0 normal
- 1 slight stiffness and resistance
- 2 moderate stiffness and resistance
- 3 marked rigidity with difficulty in passive movement
- 4 extreme stiffness and rigidity with almost a frozen shoulder

**Item 4: Elbow Rigidity**
The elbow joints are separately bent at right angles and passively extended and flexed, with the participant’s biceps observed and simultaneously palpated. The resistance to this procedure is rated. (The presence of cogwheel rigidity is noted separately). Scoring of shoulder shaking is as follows:
- 0 normal
- 1 slight stiffness and resistance
- 2 moderate stiffness and resistance
- 3 marked rigidity with difficulty in passive movement
- 4 extreme stiffness and rigidity with almost a frozen elbow

**Item 5: Wrist Rigidity**
The wrist is held in one hand and the fingers held by the examiner’s other hand, with the wrist moved to extension, flexion and both ulnar and radial deviation. Scoring of resistance is as follows:
- 0 normal
- 1 slight stiffness and resistance
- 2 moderate stiffness and resistance
- 3 marked rigidity with difficulty in passive movement
- 4 extreme stiffness and rigidity with almost a frozen wrist
Appendix D (continued)

Item 6: Leg Pendulousness
The individual sits on a table with his legs hanging down and swinging free. The ankle is grasped by the examiner and raised until the knee is partially extended. It is then allowed to fall. The resistance to falling and the lack of swinging form the basis for the score on this item:
0 □the legs swing freely
1 □slight diminution in the swing of the legs
2 □moderate resistance to swing
3 □marked resistance and damping of swing
4 □complete absence of swing

Item 7: Head Dropping
The individual lies on a well-padded flat area and his or her head is raised by the examiner’s hand. The hand is then withdrawn and the head allowed to drop. Normally, the head will fall upon the table. The movement is delayed in extrapyramidal system disorder. In extreme parkinsonism the neck muscles are rigid and the head does not reach the examining table. Scoring is as follows:
0 □the head falls completely with a good thump as it hits the table
1 □slight slowing in fall, mainly noted by lack of slap as head meets the table
2 □moderate slowing in the fall quite noticeable to the eye
3 □head falls stiffly and slowly
4 □head does not reach examining table

Item 8: Glabellar Tap
While seated or lying, the individual is told to open his or her eyes wide and not to blink. The glabella region (area between eyebrows, 1 cm above bridge of nose) is tapped at a steady rapid speed (1 second intervals) while standing out of direct view from the individual’s eye-line. Taps should be applied until the blink reflex has stopped (but no more than 21 is required) The number of times the individual blinks in succession is noted:
0 □0 - 5 blinks
1 □6 - 10 blinks
2 □11 - 15 blinks
3 □16 - 20 blinks
4 □21 and more blinks

Item 9: Tremor
Patient is observed walking into examining room and then is re-examined or observed throughout interaction for this item:
0 □normal
1 □mild finger tremor, obvious to sight and touch
2 □tremor of hand or arms occurring spasmodically
3 □persistent tremor of one or more limbs
4 □whole body tremor

Item 10: Salivation
Individual is observed while talking and then may be asked to open his or her mouth and elevate the tongue. The following ratings are given:
0 □normal
1 □excess salivation to the extent that pooling takes place if the mouth is open and the tongue raised
2 □when excess salivation is present and might occasionally result in difficulty in speaking
3 □speaking with difficulty because of excess salivation
4 □frank drooling

Order of items

The ten items do not have to be performed in the order set out in the scale. The observers may modify the order of the items according to personal preference and the convenience of the participant, including interview environment.

Interpretation of scores

After adding the total of all items the sum was divided by ten, thus, the scale has a range from 0 to 4 points per item. In the majority of research reports, scores are reported in this way. However, for clinical purposes it is equally reasonable to report scale values as simply the sum of item scores and the range of values is then 0 - 40. The method for scoring needs to be documented in the final report. Simpson and Angus originally reported that scores below 0.3 (raw score of 3) are considered normal. Raw scores greater than or equal to 6 represent a clinically significant degree of movement disorder such that some elective revision of therapy should be considered. Raw scores greater than or equal to 12 should attract decisive attention, while a raw score of greater than or equal to 18 almost certainly dictates a modification of the pharmacotherapy on an expeditious basis.

Appendix E
Subject Consent Form for Participation in Human Research

Part A:
Description of Project

Title of Study: A grounded theory study of the lived experience associated with atypical antipsychotic medication therapy in adolescents.

You are being asked to participate in a research study about your lived experience associated with atypical antipsychotic medication therapy in mental health care. From this study, the investigator(s) hopes to gain knowledge that may help assist nurses and other health care providers obtain a better understanding of the efficacy, safety, and tolerance associated with atypical antipsychotic drug therapy and mental health care in adolescents.

You have been selected to participate in this study because you meet the voluntary subject criteria for this grounded theory study. If you agree to participate, you will be asked to meet with the primary investigator at a private location of your choice for one informal interview and one formal interview with observational data collection. During the informal interview process, you will be asked to fill out two questionnaires designed to gain and understanding of your personal view of your experience with atypical antipsychotic medication therapy. During the formal interview (which is standardized for all participants) the investigator will perform two, very brief observational assessments that will provide information regarding the tolerance and effects related to your medication therapy. The two interview meetings will last no longer than 90 minutes each, and will be audio-taped so that the investigator can capture your responses “word-for-word” to best understand your individual experience. If you agree to participate, you can decline to answer any questions and have the right to withdraw from the study at any time during the interview or study process and the right to refuse audio-taping of the interviews. The study is expected to involve three to five volunteer participants and will be conducted over the summer of 2009 through March 2010.

Participation in this study involves minimal or no risks. A potential risk of the interview processes is emotional distress; however, research concludes that the nature of interviews being used in this study pose no greater risk than everyday life. The investigator will conduct the interviews guided by ethics and with sensitivity.

The study is of no benefit to you.

There is no funding for this study. If you choose to participate, there will be no cost to you, only time commitment for interviews and study related correspondence with the primary investigator.

Your privacy is important to us. As a participant, your identity and information will be coded using random letters or numbers appointed by the investigator, or you may choose your own code for the investigator to use. Confidentiality of records identifying you will be maintained by storing data in a password-locked computer file, and no identifying characteristics will be used to identify you in the presentation of the final thesis. After the study is completed and no longer than 30 days after, all identifying data and audio tapes will be destroyed and disposed of.

Carroll College cannot be held responsible for injury, accidents, or expenses that may occur because of your participation in this project. In addition, Carroll College cannot be held responsible for injury, accidents, or expenses that may occur because of traveling to and from your appointments at the site of data collection. Further information about this research study may be obtained by calling Meghann Moran at (503) 810-5930 or via email at mgm.moran@gmail.com. The Chairman of the Institutional Review Board, John Scharf (406) 447-4457, can answer additional questions about the rights of human subjects.
Part B: Authorization Statement

1. For one's own participation:

I, __________________________ (name of subject), agree to participate in this research. The investigator has thoroughly explained the nature and process of this research to me. I have read the above and understand the discomforts, inconvenience, and risk of this study. I understand that I have the right to refuse to participate in this study and that refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled. I also understand that I may withdraw from the study at any time without penalty or loss of benefits to which I am otherwise entitled. To the best of my knowledge, I have no physical or mental condition that would be adversely affected by my participation. I have received a copy of this consent form for my own records.

Signature of Participant
Date

Printed Name of Participant

* 

Signature of Witness
Date

Printed Name of Witness
*(Optional)

2. For the participation of a minor (under 18 years of age):

I, __________________________ (name of parent or legal guardian), related to the subject as __________________________ (relationship), agree to the participation of __________________________ (name of subject) in this research. The investigator has thoroughly explained the nature and process of this research to me. I have read the above and understand the discomforts, inconveniences, and risks of this study. I understand that the subject or I may later refuse participation in this research and that the subject, through his/her own action or mine, may withdraw from the research at any time without penalty or loss of benefits to which the subject is otherwise entitled. To the best of my knowledge, the subject has no physical or mental condition that would be adversely affected by his/her participation. I have received a copy of this consent form for my own records.

Signature of Participant’s Parent or Legal Guardian
Date

Printed Name of Participant’s Parent or Legal Guardian

* 

Signature of Witness
Date

Printed Name of Witness
*(Optional)
Table 1

Atypical Antipsychotics - FDA Approved Indications and Warned Side Effects

<table>
<thead>
<tr>
<th>Atypical Antipsychotic</th>
<th>Clozaril® clozapine</th>
<th>Risperdal® risperidone</th>
<th>Zyprexa® olanzapine</th>
<th>Seroquel® quetiapine</th>
<th>Geodone® ziprasidone</th>
<th>Abilify® aripiprazole</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pediatric FDA-approved indications with atypical antipsychotic drugs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Safety and efficacy has not been established</td>
<td>Schizophrenia: 13 yrs and older</td>
<td>Bipolar disorder/Mania: 10 yrs and older</td>
<td>Autistic disorder with irritability: 5 to 16 years</td>
<td>Bipolar disorder maintenance: 10 to 17 years</td>
<td>Schizophrenia: 13 to 17 years</td>
<td>Schizophrenia: 13 yrs and older</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bipolar I disorder, manic or mixed episodes: 10 yrs and older</td>
</tr>
<tr>
<td><strong>Metabolic Syndrome</strong></td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
</tr>
<tr>
<td><strong>Weight gain</strong></td>
<td>+++ ***</td>
<td>+++</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++ ***</td>
</tr>
<tr>
<td><strong>Sedation-Somnolence</strong></td>
<td>+++ ***</td>
<td>+++</td>
<td>+++</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++</td>
</tr>
<tr>
<td><strong>EPS</strong></td>
<td>++</td>
<td>+++ ***</td>
<td>++</td>
<td>++</td>
<td>+++ ***</td>
<td>++</td>
</tr>
<tr>
<td><strong>Hyperprolactinema</strong></td>
<td>+++</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>+++</td>
<td>+++ ***</td>
<td>+++ ***</td>
</tr>
<tr>
<td><strong>Orthostatic Hypotension</strong></td>
<td>+++ ***</td>
<td>+++</td>
<td>+++ ***</td>
<td>+++ ***</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td><strong>Anticholingeric</strong></td>
<td>+++ ***</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td><strong>Upper respiratory infection</strong></td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>+++</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td><strong>GI disturbances</strong></td>
<td>+++</td>
<td>++</td>
<td>++</td>
<td>+++</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td><strong>Liver function abnormalities</strong></td>
<td>++</td>
<td>+++</td>
<td>+++ ***</td>
<td>++</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td><strong>Headache</strong></td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>+++</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td><strong>Insomnia</strong></td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td><strong>NMS</strong></td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++</td>
<td>++++</td>
</tr>
<tr>
<td><strong>Prolonged Qtc interval/Sudden Cardiac Death</strong></td>
<td>++++, ***</td>
<td>++++, ++</td>
<td>++++, ++</td>
<td>++++, ++</td>
<td>++++, ***</td>
<td>++++, ++</td>
</tr>
<tr>
<td><strong>Blood Dyscrasias</strong></td>
<td>++++ ***</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
</tr>
<tr>
<td><strong>Seizures</strong></td>
<td>++++ ***</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
<td>++++</td>
</tr>
</tbody>
</table>


**Key.** Risk for ++, Very common +++; Very common and high risk for that specific drug ***; Life threatening ++++.
Table 2

Monitoring Strategies for Metabolic and Endocrine Abnormalities in Pediatric Patients Receiving Antipsychotics

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Baseline</th>
<th>Routine follow-up&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal and family medical history&lt;sup&gt;b&lt;/sup&gt;</td>
<td>✓</td>
<td>Annually</td>
</tr>
<tr>
<td>Lifestyle behaviors&lt;sup&gt;c&lt;/sup&gt;</td>
<td>✓</td>
<td>Each visit</td>
</tr>
<tr>
<td>Height, weight, BMI</td>
<td>✓</td>
<td>Each visit</td>
</tr>
<tr>
<td>Blood pressure and pulse</td>
<td>✓</td>
<td>At 3 months, then every 6 months</td>
</tr>
<tr>
<td>Fasting blood glucose and lipids</td>
<td>✓</td>
<td>At 3 months, then every 6 months</td>
</tr>
<tr>
<td>Sexual/reproductive dysfunction</td>
<td>✓</td>
<td>During titration, then every 3 months</td>
</tr>
<tr>
<td>Prolactin</td>
<td>Only if symptomatic</td>
<td>Only if symptomatic</td>
</tr>
<tr>
<td>Thyroid stimulating hormone (TSH)</td>
<td>✓</td>
<td>Annually</td>
</tr>
</tbody>
</table>


<sup>a</sup>More frequent assessments in the presence of abnormalities risk factors for specific adverse events by personal or family history.

<sup>b</sup>Including metabolic syndrome components (obesity, hypertension, diabetes, dyslipidemia), past medical history for coronary heart disease (CHD) or equivalent disorders (diabetes, peripheral arterial disease, abdominal aortic aneurysm, symptomatic carotid artery disease); history of premature CHD in first-degree relatives (males <55 years and females <65 years), and past personal or family history of efficacy/adverse effects.

<sup>c</sup>Lifestyle behaviors: diet, exercise, smoking, substance use, sleep hygiene.

Summary of the proposed content and frequency of physical health assessments in youth receiving antipsychotics.
Table 3

**Clinically Relevant Thresholds for Body Weight and Metabolic Parameters in Pediatric Patients**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Clinically relevant thresholds</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body weight</strong></td>
<td></td>
</tr>
<tr>
<td>Underweight</td>
<td>BMI &lt;5&lt;sup&gt;th&lt;/sup&gt; percentile for sex &amp; age&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Normal</td>
<td>BMI 5&lt;sup&gt;th&lt;/sup&gt;-&lt;85&lt;sup&gt;th&lt;/sup&gt; percentile for sex &amp; age&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Overweight</td>
<td>BMI 85&lt;sup&gt;th&lt;/sup&gt;-95&lt;sup&gt;th&lt;/sup&gt; percentile for sex &amp; age&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Obese</td>
<td>BMI ≥ 95&lt;sup&gt;th&lt;/sup&gt; percentile for sex &amp; age&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Blood lipids</strong></td>
<td></td>
</tr>
<tr>
<td>Total cholesterol</td>
<td>≥ 70 mg/dL</td>
</tr>
<tr>
<td>LDL cholesterol</td>
<td>≥130 mg/dL</td>
</tr>
<tr>
<td>HDL cholesterol</td>
<td>&lt;40 mg/dL</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>≥110 mg/dL</td>
</tr>
<tr>
<td>Blood glucose</td>
<td></td>
</tr>
<tr>
<td>Fasting hyperglycemia</td>
<td>100–125 mg/dL</td>
</tr>
<tr>
<td>2-hour post-glucose load hyperglycemia</td>
<td>140–199 mg/dL</td>
</tr>
<tr>
<td>Fasting diabetes (on 2 occasions)</td>
<td>≥126 mg/dL</td>
</tr>
<tr>
<td>2-hour post-glucose load diabetes</td>
<td>≥200 mg/dL</td>
</tr>
<tr>
<td>Blood insulin and insulin resistance</td>
<td></td>
</tr>
<tr>
<td>Fasting hypersulininemia</td>
<td>&gt;20 umol/L</td>
</tr>
<tr>
<td><strong>Homeostatic model assessment (HOMA)&lt;sup&gt;b&lt;/sup&gt;</strong></td>
<td>≥4.4</td>
</tr>
<tr>
<td>Triglycerides: HDL-cholesterol ratio</td>
<td></td>
</tr>
<tr>
<td>Metabolic syndrome</td>
<td>≥3 out of 5 criteria</td>
</tr>
<tr>
<td>Abdominal obesity</td>
<td>BMI ≥95&lt;sup&gt;th&lt;/sup&gt; percentile for sex &amp; age or waist circumference ≥90&lt;sup&gt;th&lt;/sup&gt; percentile&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Fasting hypertriglyceridemia</td>
<td>≥110 mg/dL</td>
</tr>
<tr>
<td>Low fasting HDL cholesterol</td>
<td>&lt;40 mg/dL in males and females</td>
</tr>
<tr>
<td>Arterial hypertension</td>
<td>≥90&lt;sup&gt;th&lt;/sup&gt; percentile for sex and age&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Fasting hyperglycemia</td>
<td>≥110 mg/dL</td>
</tr>
<tr>
<td>Revised fasting hyperglycemia&lt;sup&gt;e&lt;/sup&gt;</td>
<td>≥100 mg/dL</td>
</tr>
</tbody>
</table>


Italicized variables have specific thresholds for pediatric patients. BMI, body mass index (weight (kg)/height (m)<sup>2</sup>; or weight (lbs) x 703/height (inches)).

<sup>a</sup>Sex- and age-adjusted BMI expressed in percentile (population mean: 50th percentile) or z-scores (population mean: 0), obtained from growth charts (www.cdc.gov/growthcharts/) or calculators (http://www.kidsnutrition.org/bodycomp/bmiz2.html, http://www.gcrc.uci.edu/utilities/bmi2.cfm).

<sup>b</sup>HOMA, Homeostatic model assessment (HOMA)=fasting insulin (μmol/L) x glucose (mmol/L)/22.5; glucose mmol/L=glucose m/dL/17.979797.

<sup>c</sup>Sex- and age-adjusted waist circumference percentile tables (Fernandez, Redden, Pietrobelli, & Allison, 2004).

<sup>d</sup>Sex- and age-adjusted blood pressure percentiles tables (National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents, 2004).

<sup>e</sup>Revised fasting hyperglycemia criterion (Grundy et al., 2005).
# ATYPICAL ANTIPSYCHOTIC MEDICATION THERAPY

Table 4

**Child & Adolescent Evidence-Based Mental Health Treatment**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Evidence-Based Psychological Interventions</th>
<th>*Psychopharmacology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>Ages 3–13 • Behavior Therapy &lt;br&gt;Ages 3–13 • Individual and family therapies that target communication skills, interaction skills, and behavior modification.</td>
<td>Antipsychotic medication has been shown to reduce aggression.</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>No controlled studies of psychosocial interventions for youth with bipolar disorder have been done. However, behavior therapy, family education, and support benefit youth and families and improve relationships, communication, and coping skills.</td>
<td>Mood stabilizers (Lithium and Valproate); Atypical antipsychotic medication; and other medications may be appropriate.</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>No controlled studies of psychosocial interventions for youth with schizophrenia have been done. However, behavior therapy, family education, and support benefit youth and families and improve relationships, communication, and coping skills.</td>
<td>Antipsychotic medication</td>
</tr>
</tbody>
</table>

*Note. Adapted from “Choosing the right treatment: What families need to know about evidence-based practices©,” by NAMI, 2008, p. 15, retrieved from http://www.nami.org/Template.cfm?Section=Child_and_Teen_Support&template=/ContentManagement/ContentDisplay.cfm&ContentID=47656. Information in the chart is based on reviews by Burns, Chorpita, Chambless and Halloran, Hoagwood, Jensen, Weisz, and the authors of the Guide. *Generally, there is limited research on children’s medication use.*
Table 5

Demographic Data from Sample

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Age</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>28</td>
</tr>
<tr>
<td>Gender</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>F</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White Non-Hispanic ++</td>
</tr>
<tr>
<td></td>
<td>Other ++</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>Public ++</td>
</tr>
<tr>
<td></td>
<td>Private +</td>
</tr>
<tr>
<td></td>
<td>Other +</td>
</tr>
<tr>
<td>Mental Health Diagnosis</td>
<td>Psychotic disorder +</td>
</tr>
<tr>
<td></td>
<td>Disruptive behavior disorder +</td>
</tr>
<tr>
<td></td>
<td>Mood disorder +++</td>
</tr>
<tr>
<td></td>
<td>Tic disorder +</td>
</tr>
<tr>
<td></td>
<td>Pervasive development disorder +</td>
</tr>
<tr>
<td></td>
<td>Mental retardation +</td>
</tr>
<tr>
<td></td>
<td>Other +</td>
</tr>
<tr>
<td>Mental disorder comorbidity</td>
<td>Present +++</td>
</tr>
<tr>
<td></td>
<td>Absent +</td>
</tr>
<tr>
<td>Age of initial diagnosis</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>16</td>
</tr>
<tr>
<td>Other psychotropic medications</td>
<td>Stimulants +++</td>
</tr>
<tr>
<td></td>
<td>Antidepressants +++</td>
</tr>
<tr>
<td></td>
<td>Anxiolytic and Hypnotics +++</td>
</tr>
<tr>
<td></td>
<td>Mood stabilizers +++</td>
</tr>
<tr>
<td>Included psychotherapy</td>
<td>Yes ++</td>
</tr>
<tr>
<td></td>
<td>No +</td>
</tr>
<tr>
<td>Current treatment</td>
<td>Psychiatrist +</td>
</tr>
<tr>
<td></td>
<td>Other ++</td>
</tr>
<tr>
<td>Length of time on current</td>
<td>&lt;=1 year +++</td>
</tr>
<tr>
<td>medications</td>
<td>&gt;1 year</td>
</tr>
<tr>
<td></td>
<td>&gt;2 years</td>
</tr>
<tr>
<td></td>
<td>&gt;3 years</td>
</tr>
<tr>
<td>Employment status</td>
<td>Full-time (&gt;20/week) ++</td>
</tr>
<tr>
<td></td>
<td>Part-time ++</td>
</tr>
<tr>
<td></td>
<td>Other +</td>
</tr>
<tr>
<td>Residence</td>
<td>Independent ++</td>
</tr>
<tr>
<td></td>
<td>With parents ++</td>
</tr>
<tr>
<td></td>
<td>Other +</td>
</tr>
<tr>
<td>Education level</td>
<td>High School Diploma +</td>
</tr>
<tr>
<td></td>
<td>GED +</td>
</tr>
<tr>
<td></td>
<td>College +</td>
</tr>
</tbody>
</table>