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It has been well over half a century since Von Bertalanffy’s *General Systems Theory* was introduced and early family therapy pioneers began to discuss and treat families from a systemic orientation. The assessment and diagnosis of a family system required systemic thinking; it became clear that attempts to address identified problems from a linear modality often created new resultant problems in some other area of the family system. Family systems research, training, and conceptualizations have evolved since the advent of family therapy, yet an important reality remains: Each new generation of helpers must develop as systemic thinkers. *A key question remains: To what degree have today’s clinicians become systemic thinkers?*

For the new clinician in the field, questions about systemic clinical work often take more practical forms. How can I understand and use the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*), from a relational and cultural perspective? What are the current systemic-oriented assessments I can use to help couples and families? How can I avoid ethical dilemmas when counseling couples and families? How do individual diagnoses affect my family treatment planning?

This text arose out of a desire by Drs. Russo, Coker, and King to help systemically oriented clinicians answer critical questions about diagnosis and the *DSM-5* as they counsel families from diverse communities. Although this is an inexhaustible topic, the text demonstrates how to use the *DSM-5* as an aid for assessment, diagnosis, treatment planning, and intervention while dialectically fusing both systemic-focused wellness and pathology considerations. As many clinicians are still shifting from the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (*DSM-IV-TR*) to the *DSM-5*, a focus on clinical applications helps the reader identify and clarify how revisions in the *DSM-5* affect family system views. *DSM-5 and Family Systems* can help clinicians in their goal to develop as systemic thinkers, which, if accomplished to some degree, will help clients in a most natural fashion from their lived experience and context.

Mark D. Stauffer, PhD, NCC
Author: *Foundations of Addictions Counseling; Foundations of Couples, Marriage, and Family Counseling; and Human Development Across the Life Span: Applications for Counselors*
Systemic-oriented clinicians may have an innate aversion to the linear-focused syndrome approach to conceptualizing mental health disorders within individuals. Just as oil and water are two immiscible liquids, systemic-oriented clinicians may struggle with how to properly mix seemingly opposing concepts from the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*, with their circular causality approach to relational problems. Fortunately, this book offers practical strategies for systemic-oriented clinicians to harmonize the perceived mutual incompatibility between an individual’s dysfunction and commonly used systemic theories and techniques.

Users of this book will appreciate the clarification provided on understanding relational problems associated with the onset, progression, and expression of psychiatric symptoms—while incorporating an understanding of parent–child, sibling, extended family, and significant-other relationship issues in overall clinical formulation. This book also advances the discussion about relational and cultural features, family systems assessments, family systems interventions, and ethical and legal implications when working with clients and their family members with identified DSM-5 disorders.

Each chapter in this book focuses on a specific diagnosis or category of diagnoses from the *DSM-5*. Seven sections in each chapter guide the reader to explore how best to integrate DSM-5 diagnoses from a systems perspective:

- **DSM-5 and Family Systems**: Each chapter opens with an overview of the diagnosis from a systemic perspective. Using recent and relevant research from the literature, authors describe the disorders and diagnoses that are the focus of the chapter, and explore how a systemic framework is applied in working with patients with these disorders.
- **Relational and Cultural Features**: Authors share the application of DSM-5 diagnoses, including specific disorders, relevant to understanding the role of relationships and culture in working systemically with the DSM-5. This context addresses the systemic complexities of working with couples and families from a diagnostic framework, and the potential impact of cultural considerations in the treatment of specific disorders.
- **Family Systems Assessments**: In this section, chapter authors describe relevant and empirically validated assessments that can be used when diagnosing clients within a systemic context. Often, assessments designed to aid with diagnosis are designed to assess the individual. Systemically focused counselors also need tools to support working within a systemic framework with diagnoses and treatment planning.
- **Family Systems Interventions**: Once a diagnosis is made, systemically focused counselors need to design treatment plans and interventions that address the disorder within a systemic framework. This section provides specific tools, therapies, and counseling strategies to support clinical work with clients and their families once the DSM-5 diagnosis has been identified.
• Ethical and Legal Implications: In this section, authors present relevant ethical codes and guidelines as well as any legal implications of work with clients and their families when working with particular diagnoses. The ethical codes and guidelines of both the American Counseling Association (ACA) and the American Association for Marriage and Family Therapy (AAMFT) are explored, and relevant legal precedents and implications are presented and discussed in context to the disorder of focus.

• Case Conceptualization: In this section, the authors also present detailed case studies to help bring together the practice of assessment, diagnosis, and systemic interventions to support clients, couples, and families. Additionally, each case conceptualization provides a series of discussion questions for further exploration.

• Summary: Each chapter concludes with a summary of the relevant points, providing a focused understanding of the presented disorder and how to address it systemically.

It is our hope that this textbook will assist the systemic clinician in working from a relational perspective to provide accurate and consistent diagnoses that guide treatment plans to effectively help clients and their families.

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DSM-5® and Family Systems
Neurodevelopmental disorders are broadly defined as disorders that manifest or appear in the developmental period. More specifically, neurodevelopmental disorders can be defined as a series of complex traits that emerge as a result of genetic determinants interacting with various poorly understood environmental components resulting in a diverse clinical presentation (Cristino et al., 2014). This broad category of disorders is a new introduction to the Diagnostic Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association [APA], 2013) and represents significant attention and focus to the area of neurodevelopment. Because neurodevelopmental disorders are generally associated with the developmental period, this group of disorders is associated with infancy, childhood, and adolescence. Most commonly, the onset and diagnosis of a neurodevelopmental disorder occurs in childhood. Despite the onset of neurodevelopmental disorders appearing in childhood, one should note that these disorders rarely experience a remission or relapse and are considered to be a stable set of symptoms over time (World Health Organization, 2014), and thus neurodevelopmental disorders appear throughout the individual’s life span.

DSM-5 AND FAMILY SYSTEMS

Neurodevelopmental disorders impact not only the individual diagnosed with the disorder, but also the family of the individual diagnosed. Because neurodevelopmental disorders are commonly diagnosed in childhood, it is the parent or caregiver of the individual with a neurodevelopmental disorder who seeks assistance through a physician, psychologist, counselor, social worker, or teacher. Parents and family members are often the first to notice differences in their child. Parents are also asked to regularly monitor their children’s development through scheduled pediatric well-child care visits at developmentally critical
periods in a child’s growth and development. See the Periodicity Schedule for a comprehensive schedule of well-child care visits, specifically recommendations for preventative pediatric health care at American Academy of Pediatrics’ (2015) website. The American Academy of Pediatrics’ (2010) recommendation that all pediatricians screen for developmental delays serves to increase awareness about developmental issues and preventative measures that may be taken early in a child’s life to increase the likelihood of developmental milestones being achieved. However, the reality is that few pediatricians use standardized assessments when assessing for developmental delays (Sand et al., 2005). Thus, parents and caregivers need to be able to accurately and regularly communicate with medical providers to ensure care for their child in need and advocate for services to assist their child.

Neurodevelopmental Disorders as Significant Focus of Attention

The *DSM-5* represents a shift in clinical and research focus toward neurodevelopment. Systemic clinicians are now regularly asked questions about the assessment, diagnosis, and treatment of neurodevelopmental disorders, whereas, in the past, neurodevelopmental disorders were treated primarily by medical professionals in neurology or pediatrics or perhaps a psychologist with expertise in neuropsychology. The Children’s Health Care Act of 2000 represented a specific shift in attention by authorizing the Centers for Disease Control and Prevention (CDC) to create the Autism and Developmental Disabilities Monitoring Network. This network, which is funded by the CDC, works to estimate the number of children with Autism Spectrum Disorder (ASD) and other developmental disabilities in the United States. For example, research from tracking estimated prevalence rates from 1991 to 2010 in the Greater Atlanta, Georgia metropolitan area suggests that the incidence of Intellectual Disability and hearing loss among 8-year-old children remained about the same with some minor increase in vision impairment. Similarly, in the same population of 8-year-olds with cerebral palsy in Atlanta, the incidence remained about the same from 1993 to 2010. In sharp contrast, the estimated incidence of ASD among 8-year-olds in Atlanta increased 269% from 1996 to 2010 (CDC, 2015). Even more specifically, the National Institutes of Health (NIH) estimates that in 2012 Autism received approximately $192 million in science, actual research projects funded, and NIH budget, whereas in 2012 Attention Deficit Hyperactivity Disorder (ADHD) received approximately $60 million in science, actual research projects funded, and NIH budget. The trend to fund and research Autism continues with $216 million estimated to be spent in 2017 for science, actual research projects funded, and NIH budget compared to $43 million for ADHD, $33 million for Fetal Alcohol Syndrome, $40 million for Fragile X syndrome, and $5 million for Tourette syndrome. Given the increase in research and treatment attention on neurodevelopmental disorders and neurodevelopment in general, the role of family members is a factor to consider in systemic treatment.

The Role of Neurodevelopment in Families

Parents are impacted by the increased attention on neurodevelopment. Due to research in the area of neurodevelopment and efforts to ensure that children meet developmental milestones, parents are increasingly aware of the importance of healthy and unobstructed neurodevelopment. As the definition of neurodevelopment evolves, emerging research continues to show that neurodevelopment is the interaction between genetic inheritance and the environment. Ultimately, genes and the environment are refereed by nongenetic influences to make up the brain from conception to adulthood (Fine & Sung, 2014). Because of this interaction between genes and the environment, parents have a crucial part to play
in the likelihood of neurodevelopmental disorders whether they are conscious or aware of the part they play or not. For example, a parent with a Specific Learning Disorder, Impairment in Reading (otherwise known as Dyslexia; APA, 2013, p. 67), may be aware that his or her child is at increased likelihood of also having a Specific Language Disorder due to the genetic components of the disorder (Fisher & DeFries, 2002). The biological origination of specific learning disorders according to the APA (2013) is the interaction of genetic, epigenetic, and environmental factors. Dyslexia's behavioral manifestation is difficulty in learning specifically printed words (APA, 2013), and a person would be aware of challenges given school reports and possible educational or psychological assessments. A person with dyslexia may also be aware that a biological relative also struggled in school. Yet, parents with no known neurodevelopmental disorder may be concerned about ASD due to increased media or research attention around this disorder. In addition, there are multiple nonspecific risk factors for ASD. The lack of clear risk factors may lead a parent to wonder about his or her role in ASD. Both parent examples display the role that neurodevelopment and neurodevelopmental disorders, risk factors specifically, play in families.

Families may be curious about how to promote healthy neurodevelopment. Likewise, families may wonder what causes abnormal neurodevelopment. To understand the root cause of the neurodevelopmental disorder or the etiology of the neurodevelopmental disorder is a key element to understanding neurodevelopment as a whole (Thome, Drossos, & Hunter, 2013). Families play a role in the etiology of neurodevelopmental disorders given that most neurodevelopmental disorders have multiple causal sources, including genetics. The etiological contributors include genetic, biological, psychosociological, and environmental (Environmental Protection Agency, 2015). See Table 1.1 for a list of various contributors or causes of neurodevelopmental disorders. Families and counselors have an opportunity to impact these contributors in a positive or negative fashion.

Neurodevelopmental Versus Neurocognitive

Neurodevelopmental disorders can be mistaken for neurocognitive disorders. The important distinction between neurodevelopmental and neurocognitive disorders is that neurodevelopmental disorders emerge in the developmental period of life versus neurocognitive disorders, which are acquired during the life span (APA, 2013). Counselors should make careful assessment of the behaviors associated with the disorder and the age of onset when making a diagnosis. For example, a traumatic brain injury (TBI) can occur at any age with prevalence being high in childhood (Faul, Xu, Wald, & Coronado, 2010), but the associated symptomatology and the fact a TBI is acquired make it a neurocognitive disorder and not a neurodevelopmental disorder. TBI in children may appear as issues in cognition or challenges academically and even meeting developmental milestones. More specifically, a TBI is the direct result of an accident or is an acquired impairment, whereas a neurodevelopmental disorder is not acquired; rather it is part of a person's innate biological and behavioral makeup. Thus, when making a differential diagnosis, an understanding of when the symptoms appeared and if an injury occurred is an important factor in final diagnosis.

Neurodevelopmental Disorders in the DSM-5

The chapter in the DSM-5 on neurodevelopmental disorder categories includes Intellectual Disability (intellectual developmental disorder), Communication Disorder, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Specific Learning Disorder, and Motor Disorders. See Table 1.2 for a list of all the disorders associated with neurodevelopmental category. In the DSM-5, there are notable changes associated with some of the
### TABLE 1.1 Neurodevelopmental Disorder Causes

<table>
<thead>
<tr>
<th>Category</th>
<th>Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic causes</td>
<td>Fragile X syndrome, Down’s syndrome, Rett’s syndrome, ICF syndrome,</td>
</tr>
<tr>
<td></td>
<td>ATR-X syndrome, Angelman syndrome, Other single genetic lesion</td>
</tr>
<tr>
<td></td>
<td>syndromes</td>
</tr>
<tr>
<td>Biological causes</td>
<td>Prenatal disorders, Arrested hydrocephalus, Perinatal disorders, Prematurity,</td>
</tr>
<tr>
<td></td>
<td>Peripartum ischemic encephalopathy, Fetal distress syndrome, Postnatal</td>
</tr>
<tr>
<td></td>
<td>disorders, Anoxemia at birth, Postnatal infection, Primary neoplasm</td>
</tr>
<tr>
<td>Illness or disease</td>
<td></td>
</tr>
<tr>
<td>Nutritional factors</td>
<td></td>
</tr>
<tr>
<td>Psychosocial</td>
<td>Emotional trauma, Neglect abuse, Abuse/maltreatment, Antenatal maternal</td>
</tr>
<tr>
<td></td>
<td>stress</td>
</tr>
<tr>
<td>Environmental</td>
<td>Exposure to toxins known and unknown, Alcohol, tobacco, drugs, Mercury,</td>
</tr>
<tr>
<td></td>
<td>Lead, Polychlorinated biphenyls, Dioxins, Pesticides, Ionizing radiation,</td>
</tr>
<tr>
<td></td>
<td>Aluminum*, Acetaminophen*, In utero exposure to toxins known and unknown,</td>
</tr>
<tr>
<td></td>
<td>Poverty</td>
</tr>
<tr>
<td>Family life</td>
<td>Emotional</td>
</tr>
<tr>
<td></td>
<td>Lack of attachment, Poor family dynamics, Divorce and remarriage</td>
</tr>
<tr>
<td></td>
<td>Foster care</td>
</tr>
</tbody>
</table>

*Causality questioned; empirical evidence may be biased.
**TABLE 1.2 Neurodevelopmental Disorders**

<table>
<thead>
<tr>
<th>Category/Disorder</th>
<th>Subtype/Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>• Intellectual Disability (intellectual developmental disorder)</td>
</tr>
<tr>
<td></td>
<td>▪ Mild</td>
</tr>
<tr>
<td></td>
<td>▪ Moderate</td>
</tr>
<tr>
<td></td>
<td>▪ Severe</td>
</tr>
<tr>
<td></td>
<td>▪ Profound</td>
</tr>
<tr>
<td></td>
<td>• Global Developmental Delay</td>
</tr>
<tr>
<td></td>
<td>• Unspecified Intellectual Disability (intellectual developmental disorder)</td>
</tr>
<tr>
<td>Communication Disorders</td>
<td>• Language Disorder</td>
</tr>
<tr>
<td></td>
<td>• Speech Sound Disorder</td>
</tr>
<tr>
<td></td>
<td>• Childhood-Onset Fluency Disorder (Stuttering)</td>
</tr>
<tr>
<td></td>
<td>• Social (Pragmatic) Communication Disorder</td>
</tr>
<tr>
<td></td>
<td>• Unspecified Communication Disorder</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>• Specify if: associated with medical or genetic condition or environmental factor; associated with neurodevelopmental, mental, or behavioral disorder</td>
</tr>
<tr>
<td></td>
<td>• Specify severity: amount of support required</td>
</tr>
<tr>
<td></td>
<td>• Specify if: with or without intellectual impairment, with or without accompanying language impairment, with catatonia</td>
</tr>
<tr>
<td>Attention-Deficit/Hyperactivity Disorder</td>
<td>• Combined presentation</td>
</tr>
<tr>
<td></td>
<td>• Predominantly inattentive presentation</td>
</tr>
<tr>
<td></td>
<td>• Predominantly hyperactive/impulsive presentation</td>
</tr>
<tr>
<td></td>
<td>▪ Specify: in partial remission</td>
</tr>
<tr>
<td></td>
<td>▪ Specify severity: mild, moderate, severe</td>
</tr>
<tr>
<td></td>
<td>• Other Specified Attention-Deficit/Hyperactivity Disorder</td>
</tr>
<tr>
<td></td>
<td>• Unspecified Attention-Deficit/Hyperactivity Disorder</td>
</tr>
<tr>
<td>Specific Learning Disorder</td>
<td>• Specify if:</td>
</tr>
<tr>
<td></td>
<td>▪ With impairment in reading</td>
</tr>
<tr>
<td></td>
<td>▪ With impairment in written expression</td>
</tr>
<tr>
<td></td>
<td>▪ With impairment in mathematics</td>
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<td></td>
<td>• Specify severity: mild, moderate, severe</td>
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<tr>
<td>Motor Disorder</td>
<td>• Developmental Coordination Disorder</td>
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<td></td>
<td>• Stereotypic Movement Disorder</td>
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<tr>
<td></td>
<td>▪ Specify if: with self-injurious behavior, without self-injurious behavior</td>
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<tr>
<td></td>
<td>▪ Specify if: associated with known medical or genetic condition, neurodevelopmental disorder, or environmental factor</td>
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<td></td>
<td>▪ Specify severity: mild, moderate, severe</td>
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(continued)
disorders within the neurodevelopmental chapter. Specifically, the term *mental retardation* has been replaced with *intellectual disability* (intellectual developmental disorder). The shift to intellectual disability comes as a result of use by persons in the medical community, counselors, educators, and advocacy groups. In addition, the term *intellectual disability* aligns with a federal statue in the United States (Rosa’s Law, 2010). Rosa’s law removed terms such as mental retardation and mentally retarded from educational, federal health, and labor policies. These terms were replaced with the deemed people-first language of “individual with an intellectual disability” and “intellectual disability.” The noted additional terminology (Intellectual Developmental Disorder) is associated with the *ICD-11*, which recognizes disorders.

In addition, the *DSM-5* disorders under the Communication Disorders subsection include Language Disorder (LD), Speech Sound Disorder, Childhood-Onset Fluency Disorder (Stuttering), and the new disorders: Social (Pragmatic) Communication Disorder, and Unspecified Communication Disorder.

In a similar move to combine disorders into overarching and theoretical categories, the specific learning problems from the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; APA, 1994)—reading, math and writing, as well as learning disorder not otherwise specified—were replaced with a category called “Specific Learning Disorder.” One can still acknowledge the more common types of describing reading deficits as dyslexia and specific types of mathematics deficits as dyscalculia. The *DSM-5* continues to recognize motor disorders as Developmental Coordination Disorder, Stereotypical Movement Disorder, Tourette’s Disorder, Persistent (Chronic) Motor or Vocal Tic Disorder, and Other Specified and Unspecified Tic Disorder. The criterion for tic disorders is standardized. Major attention is paid to the description for stereotypical movement disorder. This reflects the importance the motor disorders category has in the diagnosis of self-injurious behavior. Nothing in particular changed from the *DSM-IV* to *DSM-5* regarding motor disorders; the *DSM-5* did add a new Z code of personal history of self-injury. When making this diagnosis of stereotypic movement disorder, the system clinician is required to specify with or without self-injurious behavior and to specify any associated medical or genetic condition, neurodevelopmental disorder (e.g., intellectual disability/intellectual developmental disorder), or associated environmental factors (e.g., intrauterine drug exposure).

In a parallel move to combine and focus the classification, APA (2013) in the *DSM-5* notes ASD as encompassing the previous *DSM-IV* Autistic Disorder (Autism), Asperger’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. ASD is a single condition with severity of symptoms noted in two

<table>
<thead>
<tr>
<th>Category/Disorder</th>
<th>Subtype/Disorder</th>
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<tr>
<td>Tic Disorders</td>
<td>• Tourette’s Disorder</td>
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<td>■ Persistent (Chronic) Motor or Vocal Tic Disorder</td>
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<td>■ Provisional Tic Disorder</td>
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<td></td>
<td>■ Other Specified Tic Disorder</td>
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<td></td>
<td>■ Unspecified Tic Disorder</td>
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<tr>
<td>Other Neurodevelopmental Disorders</td>
<td>• Other Specified Neurodevelopmental Disorder</td>
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<tr>
<td></td>
<td>• Unspecified Neurodevelopmental Disorder</td>
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</tbody>
</table>

TABLE 1.2 Neurodevelopmental Disorders (continued)
core domains. These two domains that are measured for symptom severity are deficits in social communication and social interaction, and restricted, repetitive behaviors, interests, and activities, otherwise known as restrictive, repetitive behaviors (APA, 2013).

ADHD is a neurodevelopmental disorder due to the brain developments associated with ADHD, such as impulse control, attention, planning, and stimulation. Specifically, individuals with ADHD exhibit delays in brain maturation (Sripada, Kessler, & Angstadt, 2014). It appears that the lag in connection development may help to explain the reason for distractibility and behavioral inhibition in persons with ADHD. The previous DSM-IV associated ADHD with disruptive behavior disorders. APA (2013) notes several important distinctions for ADHD in the DSM-5:

- Multiple examples are provided to the criterion items to assist in the diagnosis of ADHD throughout the life span, with examples of symptoms expressed in adults now provided for 15 of the 18 possible symptoms compared to three of the 18 possible symptoms.
- The latest age of onset for ADHD noted in the DSM-5 is symptoms being present prior to the age of 12, instead of age 7 in the DSM-IV.
- There are no longer subtypes of ADHD; instead there are presentation specifics that map to the prior subtypes. These specifics then designate combined, predominately inattentive, and predominately hyperactive/impulsive presentations. The content of the diagnosis has not changed from DSM-IV to DSM-5; this was a semantic change.
- The comorbid diagnosis of Autism Spectrum Disorder is now permitted.
- The symptoms required for diagnosis in persons 17 and older is at least five symptoms, instead of the six symptoms required for persons under the age of 17.

There continues to be the major symptom domains for ADHD: inattention and hyperactivity impulsivity and combined inattention and hyperactivity impulsivity. Similarly, there remain 18 primary symptoms that are possible for ADHD in the DSM-5 as there were in the DSM-IV.

RELATIONAL AND CULTURAL FEATURES

Neurodevelopmental disorders exist in society through the cultural lens, which, in turn, encompasses the relational customs that could play a role on a neurodevelopmental disorder setting. Culture affects how people relate and cope with neurodevelopmental disorders, and defines neurodevelopmental disorders to such an extent that cultural differences among people act as barriers for the proper assessment and treatment of neurodevelopmental disorders throughout the world. Once this is taken into account, it becomes evident that a family systems approach is the most adequate treatment option because, in family systems, the family’s views, goals, relationships, and value systems are the main point of interest for therapy.

Culture and Neurodevelopmental Disorders

Culture is an important denominator in the discussion of neurodevelopmental disorders. Often information about disorders is generalized to individuals in the rest of the world with little consideration on the diverse cultural factors. For example, some studies have shown that Eastern cultures manifest autistic behavioral traits to a greater extent than Western cultures; that Eastern cultures score higher (or lower) on some subscales than Western cultures on the Autistic-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001); and that, furthermore, some Eastern countries differ on scores on
subscales from other Eastern countries (Freeth, Sheppard, Ramachandran, & Milne, 2013). These multicultural studies have inspired thought on whether some of the subscales should be modified or discarded to be able to properly evaluate a more diverse group of people with ASD. Thus, intentional thought and consideration must be paid to culture and family makeup when discussing and treating neurodevelopmental disorders. This is very important for countries with eminent cultural diversity, such as the United States and the United Kingdom (Norbury & Sparks, 2013).

Regarding the diagnosis of LD, there are some important culture-related implications that should be taken in account and that will be discussed further on, such as the nature of the language that a person with LD natively speaks or how a language suffers dialectical modifications in the different communities in which it is spoken. And not only have Western cultures been compared with Eastern cultures, but also Western countries have been compared among themselves, taking in account their culturally diverse population (when applicable). Continuous research with a cultural approach on neurodevelopmental disorders will, as it has already been shown, broaden the understanding on said disorders and will shed greater light on how neurodevelopmental disorders can manifest differently in the innumerable cultural settings throughout the world.

Language Disorder (LD) and Culture

When assessing LD and other neurodevelopmental disorders in developing countries, it is noted that a lack of any formal education or lack of exposure to visual representations of objects (i.e., people who have seen only physically present objects and have never seen a photograph, drawing, or other visual representation of an object) makes applying standardized tests an unreliable way of diagnosing neurodevelopmental disorders (Carter et al., 2005). It is important to explore culture and language of origin when addressing LD. A non-English speaker or English-as-a-second-language speaker may have challenges that can be accounted for by regional, social, and/or cultural variations of language. Considering these factors is important in the diagnosis of LD along with, for example, potential hearing or sensory impairment, intellectual disability, neurological disorders, and language regression associated with ASD.

Most of the LD standardized tests are made by and for White middle-class, English-speaking people (Hirsh-Pasek, Kochanoff, Newcombe, & de Villiers, 2005). It would be understandable that said tests would not correctly evaluate non–English-speaking people. Even if the tests are translated, elemental differences between English and other languages make English-speaking people with LD manifest deficiencies in certain aspects of language where people who speak another language and also have LD do not manifest impediments (Bedore & Leonard, 2005; Leonard, 2009).

Comprehensibly, different ways of diagnosing LD must be developed for people depending on the language they speak—but not only for people who speak different languages but also for people who speak the same language in different countries. The dialectal differences are another border between countries that speak the same language (Norbury & Sparks, 2013). An example of this is British English when compared to American English (e.g., soccer, football; flashlight, torch; French fries, chips).

Language is not only spoken differently in different countries, but it is also spoken differently in different parts of a same country, and, furthermore, by different people in the same place within a country. An example of this can be seen in the differences between “mainstream American English” and native speakers of African American English (Seymour, Roeper, & de Villiers, 2005). The Diagnostic Evaluation of Language Variation is an example of an assessment design that works to evaluate LD in native speakers of African American English. It has been designed to evaluate LD based on similar (noncontrasting)
features instead of utilizing different (contrastive) features of African American English when compared to mainstream American English (Seymour et al., 2005). Assessment designs with this same philosophy are being developed for other dialects in the United States, but many dialects still lack standardized assessments (Norbury & Sparks, 2013).

**Autism Spectrum Disorder (ASD) and Culture**

The AQ (Baron-Cohen et al., 2001) is a widely used test to score the degree of autism in people. It is divided into five subscales: imagination, attention to detail, attention switching, social skill, and communication. The AQ was designed from traits that are relevant to and present in Western cultures. This is evident on the imagination subscale, where people from Eastern cultures tend to score higher than people in Western cultures. Imagination is not cultivated in the same way in Western and Eastern cultures (Freeth et al., 2013), being so that in Eastern cultures, a perceived low imagination may not be an autistic trait, but, in fact, be the outcome of the cultural setting in which the individual develops.

People with ASD tend to be highly aware of details and proficient at identifying patterns. Although this trait may prove to be true in people with ASD around the globe, the items used to score this trait may be biased. One item in which Eastern cultures generally score higher than Western cultures is “I usually notice car number plates or similar strings of information” (Freeth et al., 2013, p. 2577). In some Eastern cultures, some numbers convey a significant meaning, such that people would want certain numbers in their car number plates and avoid others (Pandiyan, 2012; Paul, 2011). Easterners are more prone to notice car number plates than Westerners, and it should not be correlated with the degree of autism, but rather with the beliefs inherent in some Eastern cultures.

These and other differences have been noted between Eastern and Western cultures regarding the AQ, but there are some findings that are constant in both cultures. Females have been reported to score lower than males in the AQ. Also, science students score higher than nonscience students (Freeth et al., 2013).

Furthermore, in some Eastern cultures it is deemed rude to look at another’s eyes, so it would be normal for them to perpetuate this conduct upon being examined for ASD. It has been shown that people from Asian cultures usually fixate on the nose area of the face (Blais, Jack, Scheepers, Fiset, & Caldara, 2008; Kelly et al., 2011). This cultural difference is evident from 9 months of age (Liu et al., 2011). Hence, false positives would be common in certain cultures when relying on the area of fixation for assessment.

The overarching differences between people from different cultures (even when residing in the same geographical space) cannot be ignored when diagnosing neurodevelopmental disorders that are so heavily influenced by the social and cultural components of specific populations. Failure to consider these factors will undoubtedly result in false data that will deter progress on the understanding of neurodevelopmental disorders and their undeniable cultural aspects.

**Family Systems**

Systems theories are derived from general systems theory, an interdisciplinary approach that has been conceptualized as a weltanschauung or “unique worldview.” General systems theory proposes that events, situations, and people should be interpreted within their environment rather than in isolation (Von Bertalanffy, 1950). Bearing this in mind, when applying general systems theory, a mental health professional, for example, would treat families coping with ASD together with all the systems and subsystems with which they interact and not as ASD individuals in isolation (Cridland, Jones, Magee, &
Caputi, 2013). Family systems approaches consider families as unique interactive and reactive units that possess a basic social system of rules, values, and goals (Edwards, 2011). Some of the main concepts that are relevant to family-focused ASD research are macroscopic approach, microscopic approach, boundaries, ambiguous loss, and traumatic growth (Cridland et al., 2013).

Macroscopic approaches focus on the way families interact with other systems, such as the community, other families, schools, and social groups. Microscopic approaches examine relationships within the family, such as maternal, marital, and/or sibling subsystems. Both approaches should be taken into consideration when researching ASD families, for they address external and internal family interactions that shape the disorder with which the family lives. Similarly, boundaries encompass the limits to which the roles of a family (as a whole) and the roles of each family member (as individuals) can reach (Seligman & Darling, 2007), and families that are able to do this have high “permeability” of their boundaries (Cridland et al., 2013, p. 215). The most resilient ASD families are able to be flexible in role and responsibility changes as well as communicate with each other about personal needs (Bayat, 2007).

Families coping with ADHD, as expected, present higher levels of stress than families with children who have no neurodevelopmental disorders, but it has also been shown that these families may present higher levels of stress than families with ASD and families with ASD and ADHD comorbidity. Parents of ADHD children presented higher levels of stress than families with ASD and families with ASD and ADHD due to a lack of emotional closeness and affective bonding with their children and a lower capacity to understand their feelings and needs. This can be explained by the parents’ belief that the ADHD child’s behavioral problems are caused by factors that are modifiable by the child, whereas parents with ASD children tend to more easily accept that children may not control their behavior due to the nature of the disorder itself (Miranda, Tarraga, Fernandez, Colomer, & Pastor, 2015).

Parents with children diagnosed with ADHD also manifested a higher degree of stress related to feelings of sadness, unhappiness with oneself, and discontent with one’s life circumstances than parents with ASD. Finally, ADHD parents perceived, to a greater extent than ASD parents, that they were not competent as parents regarding management of the child’s behavior and discipline, and felt a lack of skills and knowledge to appropriately parent their ADHD child (Miranda et al., 2015).

Bearing in mind not only the aforementioned aspects but all the ways that neurodevelopmental disorders affect the family as a whole and its systemic and subsystemic interactions, it is clear that a therapy in which the individual with a neurodevelopmental disorder is treated in isolation would not provide the impact that family systems therapy might attain. Failing to consider the ways families impinge on the family member with a neurodevelopmental disorder, and vice versa, would amount to a partial treatment in which its success would be minimal in comparison to that of a therapy that actively works on goals for the whole family.

Value Systems

An intrinsic part of any family is its value system. Value systems affect the way families see their neurodevelopmental disorder and the goals they have, not only regarding their family member with a neurodevelopmental disorder, but also in other aspects of their lives as a family and as individuals. Some value systems trends have been identified among families with neurodevelopmental disorders (Carona, Silva, Crespo, & Canavarro, 2014). Also, there are studies that show how certain aspects of said value systems affect families.
It is important, as part of an integral treatment for families with a neurodevelopmental disorder, to assess their value systems and to work on them to better improve the family’s quality of life.

It has been shown that parents of children with neurodevelopmental disorders are more likely than parents of children without such disorders to adopt coping strategies that reduce the family’s quality of life (Raina et al., 2005). One of these deleterious coping strategies is disengagement behavior. Disengagement behavior consists of renouncing life goals and other aspects that gave meaning to life (Carona et al., 2014). In this scenario, the caregiving burden experienced by parents was overencumbering (Garner et al., 2011) and led them to feelings of helplessness (Taft, Resick, Panuzio, Vogt, & Mechanic, 2007). Disengagement behavior makes the family’s value system change into an unhealthy state, which makes caregiving not only the number one priority, but also makes any other activity, project, or goal something not worth considering anymore (Carona et al., 2014). Although it may appear congruent that setting everything aside to take care of a child with a neurodevelopmental disorder would render better results, it actually impacts on the child in a negative way (Duffy, 2011). A possible explanation is that, because disengagement behavior diminishes the parents’ quality of life (Guðmundsdóttir, Guðmundsdóttir, & Elklit, 2006), the stress experienced by parents directly impinges in a deleterious manner on the child’s quality of life (Carona et al., 2014). This is an example of why the family’s value systems need to be considered when treating families with a neurodevelopmental disorder. In this case, parents should be refocused on their goals and valued directions in life, by encouraging them to pursue meaningful activities that they have been avoiding or abandoning, while assessing the underlying processes that have led to a maladaptive coping behavior (Veale, 2008). Leaving this aspect of the family untouched could prove to be an impasse in the process of a family successfully coping with a neurodevelopmental disorder.

**FAMILY SYSTEMS ASSESSMENTS**

When it is suggested that an individual has a neurodevelopmental disorder, it is essential to obtain an accurate diagnosis. Many times, the children, teens, and adults dealing with a suspected diagnosis are confused and find themselves confronting time-consuming and costly processes. It is important that family members, especially parents and guardians of children and teens thought to have a neurodevelopmental disorder, locate qualified personnel who are able to determine if their children or teens meet the criteria for a disorder.

Counselors and/or a medical doctor with training and expertise in neurodevelopmental disorders may do an initial assessment for a neurodevelopmental disorder. In many cases, an initial or preliminary diagnosis will require further and more involved assessment and observation. An accurate diagnosis by a clinician is based on specific observable behaviors and characteristics across a variety of environments and situations, in addition to a comprehensive history of early development. Because neurodevelopmental disorders are complex and multifaceted, it is recommended that family members of the person experiencing symptoms be involved in the diagnostic process. Oftentimes, the family must coordinate numerous care providers and clinicians to achieve an accurate diagnosis and/or treatment approach. Specifically, family members of persons with a neurodevelopmental disorder often engage in the assessment process to obtain a diagnosis from not only a mental health professional and a medical doctor, but also assessments from physical and occupational therapists, neurologists, psychiatrists, and speech and language pathologists (SLPs). Similarly, if the individual suspected of having a neurodevelopmental disorder is in a school program, an educator with knowledge of the individual’s academic performance should be involved in the assessment process to determine if educational support is warranted.
Parents of a child with a suspected neurodevelopmental disorder should be encouraged to discuss concerns with their child’s pediatrician and contact individual providers/cents to identify their assessment options. In addition, for infants or toddlers prior to their third birthday, parents can investigate early intervention programs in their locale or a First Steps program via their local health department for early intervention services. If children are ages 3 (children approaching the age of prekindergarten) through 5 (children of kindergarten age) or even up to 21, and in need of assessment, parents can contact their local school district for information. School districts employ psychologists and other trained professionals to assess school-aged children. In order to be eligible for special education and related services, typically a team of qualified professionals must complete an educational assessment to determine suitability. The educational assessments done via the school system are typically at no cost to the family. Parents, guardians, or advocates have a legal right to request that the assigned public school evaluate a child for special education. Federal law, the Individuals with Disabilities Education Act (IDEA) as amended in 2004, gives parents, guardians, and advocates this legal right. States, through local school districts, must “identify, locate, and evaluate every child who may have a disability requiring special education services.” This is called “Child Find.” When there is suspicion that a child has a disability, parents and educators have a responsibility and a right to request a full, individual, comprehensive, multidisciplinary evaluation. However, some families may want a second opinion or second evaluation. In this scenario of second opinion or second evaluation, parents can contact their insurance company to determine how much and what portions of the assessment will be covered by insurance or whether or not they accept Medicaid. Also, if the school district refuses to evaluate the child, the parents may be able to have an evaluation still done at the school’s expense. IDEA requires schools to have procedures in place to ensure evaluation of children in need and resolution of disputed cases.

Because neurodevelopmental disorders appear in the developmental period, associated assessment typically occurs in childhood. For example, in the majority of ASD cases, a diagnosis is possible before or around a child’s second birthday (Chawarska, Klin, Paul, Macari, & Volkmar, 2009). Early and accurate diagnosis of a neurodevelopmental disorder can help families access appropriate services, provide a common treatment objective for professionals working with the client and family, and establish a context for families and caregivers to understand the client’s challenges. Any diagnosis of a neurodevelopmental disorder should be periodically reviewed for changes in the child’s development or revisions to diagnostic categories. Collaboration across an interdisciplinary team of professionals with training and expertise specific to the neurodevelopmental disorder in question and family involvement are essential in assessment and diagnosis of specific neurodevelopmental disorders. More so, it is important that clinicians agree with the assessment results and believe assessment results are consistent with respective diagnostic characteristics of a given disorder.

Assessments Tools or Techniques Commonly Used for Neurodevelopmental Disorders

There are numerous assessments to diagnose a neurodevelopmental disorder. In general, historical information is initially reviewed with the parent(s) and the clinician. There are typically subsequent visits to assess medical, developmental, behavioral, or neurological factors impacting functioning. All of the following might be included in the assessment process:

- Child and parent interviews
- Biopsychosocial assessment with a complete family history
- Genogram
- Parent and teacher self-completed rating scales of child behavior
- Self-reported information from parent or caregivers
- Observation of child behavior at home, school, and in the office
- Psychological tests
- Medical record review
- School record review
- Intelligence testing and achievement testing
- Pediatric examination for medical conditions
- Neurodevelopmental screening
- Vision, hearing, and speech and language assessments

Given the multitude of potential assessments, exams, and tests, the most commonly used measures that are administered by a clinician trained and expert in neurodevelopment are summarized in Table 1.3.

<table>
<thead>
<tr>
<th>Category/Disorder</th>
<th>Assessment</th>
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<tbody>
<tr>
<td>Intellectual Disability</td>
<td>The Wechsler Preschool and Primary Scale of Intelligence—Revised Edition (WPPSI-R; Wechsler, 1989)</td>
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<td>Wechsler Intelligence Scale for Children—Fifth Edition (WISC-V; Wechsler, 2014)</td>
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<td></td>
<td>Differential Ability Scales (DAS; Elliott, 1990)</td>
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<td></td>
<td>Stanford–Binet Intelligence Scale—Fourth Edition (SBIS-IV; Thorndike, Hagen, &amp; Sattler, 1986)</td>
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<td></td>
<td>Wide Range Achievement Test 3 (WRAT3)</td>
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<td></td>
<td>Test of Nonverbal Intelligence—Third Edition (TONI-3; Brown, Sherbenou, &amp; Johnsen, 1997)</td>
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<tr>
<td>Communication Disorders</td>
<td>Sequenced Inventory of Communication Development—Revised Edition (SICD-R; Hedrick, Prather, &amp; Tobin, 1984)</td>
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<td></td>
<td>Nonspeech Test (Huer, 1988)</td>
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<td></td>
<td>Assessing Semantic Skills Through Everyday Themes (ASSET; Barrett, Zachman, &amp; Huisingh, 1988)</td>
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<td></td>
<td>Expressive One-Word Picture Vocabulary Test—Revised Edition (Gardner, 1990)</td>
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<td></td>
<td>Receptive One-Word Picture Vocabulary Test—Revised Edition (Gardner, 1990)</td>
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<td></td>
<td>Clinical Evaluation of Language Fundamentals—Preschool (CELF-P; Wiig, Secord, &amp; Semel, 1992)</td>
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<td></td>
<td>ECOScales Manual (MacDonald, Gillette, &amp; Hutchinson, 1989)</td>
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<td></td>
<td>Peabody Picture Vocabulary Test—III (PPVT-III; Dunn &amp; Dunn, 1997)</td>
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<td>Reynell Developmental Language Scales (Reynell, 1977)</td>
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<th>Category/Disorder</th>
<th>Assessment</th>
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<tr>
<td></td>
<td>Ages and Stages Questionnaire—Third Edition (ASQ-3; Squires &amp; Bricker, 2009)</td>
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<td>Modified-Checklist for Autism in Toddlers—Revised With Follow-Up (M-CHAT-R/F; Robins, Fein, &amp; Barton, 2009)</td>
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<td></td>
<td>Autism Diagnostic Interview—Revised (ADI-R; Lord, Rutter, &amp; Le Couteur, 1994)</td>
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<td></td>
<td>Gilliam Autism Rating Scale (GARS; Gilliam, 1995)</td>
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<td></td>
<td>Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, &amp; Risi, 1999)</td>
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<tr>
<td>Attention-Deficit/Hyperactivity Disorder</td>
<td>Vanderbilt ADHD Teacher Rating Scale (VADTRS) and Vanderbilt ADHD Parent Rating Scale (Wolraich, Feurer, Hannah, Baumgaertel, &amp; Pinnock, 1998)</td>
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<td></td>
<td>Behavior Assessment System for Children—Second Edition (BASC-2; Reynolds &amp; Kamphaus, 2005)</td>
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<td>Child Behavior Checklist/Teach Report Form (CBCL; Achenbach, 1991)</td>
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<td>Conners’ Parent and Teacher Rating Scales</td>
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<td>Gray Oral Reading Test—Fifth Edition (GORT-5)</td>
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<td>Test of Early Reading Ability—Third Edition (TERA-3)</td>
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<td>Test of Mathematical Abilities—Third Edition (TOMA-3)</td>
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<td>Motor Disorders</td>
<td>Beery–Buktenica Developmental Test of Visual Motor Integration</td>
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<td>Peabody Developmental Motor Scales——Second Edition (PDMS-2)</td>
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<td></td>
<td>Pediatric Evaluation of Disability Inventory (PEDI)</td>
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<td></td>
<td>Functional Independence Measure for Children (WeeFIM)</td>
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<td></td>
<td>Vineland Adaptive Behavior Scales (VABS)</td>
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<td></td>
<td>Bayley Scales of Infant Development II (BSID-II)</td>
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<td></td>
<td>Movement Assessment of Infants (MAI)</td>
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FAMILY SYSTEMS INTERVENTIONS

There is a plethora of intervention approaches for individuals and families coping with neurodevelopmental disorders. Ultimately, the intervention approaches differ in the method used to address goals. Interventions can range from behavioral therapies to social–emotional strategies to developmental techniques. Also, the goals of the intervention program can differ from individual treatment of the person with a neurodevelopmental disorder to comprehensive interventions involving parents and caregivers with an interdisciplinary team to address a wide range of skills or behaviors. Since neurodevelopmental disorders are multifaceted and the needs of persons with neurodevelopmental disorders are complex, families often become educators, advocates, and interventionists themselves.

Comprehensive intervention programs work with parents and caregivers to develop effective strategies for the given client and provide feedback for the growth and development of treatment goals and objectives. Clinicians should be aware of the social contexts of home, school, vocation, and community when choosing interventions. In addition, clinicians should incorporate culture, gender, and language when deciding on specific treatment activities. Finally, clinicians should be aware that over time family interactions and relationships will change, and thus the needs of the family for specific interventions will change over time. Ultimately, when planning interventions, careful attention must be paid to family priorities and concerns (Marshall & Mirenda, 2002).

There are a number of different treatment interventions for neurodevelopmental disorders that are systemic in nature. When a clinician is selecting an intervention, the clinician can match the intervention with the treatment goals and objectives for the family and their current functioning around the disorder. The developmental stage and diagnosis of the individual with the neurodevelopmental disorder is always considered. For instance, an intervention that is evidence based for families coping with ASD may not be evidence based for families coping with ADHD. The following is a summary list of family-oriented interventions used for neurodevelopmental disorders.

**Intellectual Disability**

Intellectual Disability is characteristically a deficit in general mental abilities (APA, 2013). Specifically, families may notice minimal-to-slow-motor skills, language skill, and self-help skill development in comparison to peers. Similarly, there may be failure to develop intellectually or problems maintaining expectations in school. Some parents may also notice social challenges, such as difficulty adapting to new situations and difficulty understanding and following common rules. Individuals with an intellectual disability are most commonly served via the educational system via an Individualized Education Plan (IEP). However, prior to school age, family interventions or services for the family and individual may be the best ones. Familial interventions include but are not limited to the following types.

*Individualized Family Service Plan*

An individualized family service plan details the child’s specific needs and the services that will help the child thrive. Early interventions may be numerous and could include speech therapy, occupational therapy, physical therapy, family counseling, or nutritional services. Counselors can assist in the development and coordination of such plans.

*Stress Intervention*

Services associated with intellectual disabilities are often associated with educating parents on how to best promote child development and assist parents in their well-being.
(Blacher, Neece, & Paczkowski, 2005). Because parents of children with intellectual disabilities are at increased risk for stress and other mental health issues, a stress intervention for parents is suggested. Specifically, cognitive behavioral group interventions designed to reduce the stress of mothers show the strongest research evidence for success (Hastings & Beck, 2004).

### Communication Disorders

A communication disorder is a deficit in receiving, sending, processing, and/or comprehending concepts or verbal, nonverbal, and graphic symbols. The specific disorders within the communication disorder domain include LD, speech sound disorder, childhood-onset fluency disorder (stuttering), social (pragmatic) communication disorder, and unspecified communication disorder. Common family interventions may include the following, but are not limited to these interventions.

#### Parent-Mediated Interventions

Parents are encouraged to use individualized intervention approaches at home with their child. Using the learned interventions from a session(s) with an SLP or other trained professional such as teachers, special educators, and/or counselors can increase learning outcomes for the child. Parents can also assist in the coordination of various professionals.

#### Speech Therapy

There are many options for speech therapy. An SLP is able to work with the child and parents to formulate the best treatment approach. Under the umbrella of speech therapy, an SLP may use various modalities or treatment options.

#### Autism Spectrum Disorder (ASD)—Family-Oriented Interventions

There are multiple other interventions for ASD and emerging interventions for ASD. Interventions range from traditional behavioral interventions to social communication interventions. Clinicians are encouraged to do additional research on techniques and treatment approaches that might support the child and family with whom they are working. This is not an exhaustive list.

#### Pivotal Response Treatment (PRT)

Derived from applied behavioral analysis, PRT is play based and child initiated. PRT addresses what are called “pivotal” areas in development, such as motivation, response to various cues, self-management, and social interaction initiation. The result is improvements across a variety of areas and skills (Koegel & Koegel, 2006). Parents and caregivers and everyone involved in the child’s life are encouraged to adopt the skills and techniques used in PRT; more specifically, parents can lead PRT (Minjarez, Williams, Mercier, & Hardan, 2010). PRT is considered one of the most heavily researched and efficacious treatments for ASD (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014).

#### SCERTS® Model

The Social Communication, Emotional Regulation, and Transactional Support (SCERTS) Model involves using various interventions to achieve child-initiated communication and
authentic progress, that is, the ability to learn and apply skills in a spontaneous functional way in a variety of settings (SCERTS, 2016). The SCERTS Model (2016) was derived from empirical and clinical work, and as such is noted to be consistent with evidence-based practice in ASD and other neurodevelopmental disorders commonly related to or diagnosed with ASD (National Research Council, 2001; Prizant & Rubin, 1999).

**Early Start Denver Model**

The Early Start Denver Model (ESDM) is designed to address ASD through child-led, play-based treatment that zones in on the development of social communication skills via individual counseling, peer interactions in a school or care setting, and home-based psychoeducation (Dawson et al., 2010). ESDM is rooted in deep parental involvement and shared engagement in activities. Children engaged in ESDM for a 2-year span showed improvement in cognitive and language abilities and adaptive behavior, in addition to few autism symptoms (Dawson et al., 2010). Clinicians can become certified in ESDM.

**Attention-Deficit/Hyperactivity Disorder—Family-Oriented Interventions**

There are numerous interventions for ADHD. Interventions range from psychopharmacological interventions to school-based interventions. Often parents feel pulled to seek the assistance of medication and can neglect the efficacy of other interventions. Clinicians are encouraged to seek interventions that work with the family and create wellness for the child in all areas of his or her life.

**Parent Behavior Training**

Parent behavior training for ADHD primarily includes four manualized programs of behavior training interventions for parents (of preschoolers). These manualized programs involve assisting parents in managing problem behaviors and developing effective parenting strategies. The programs include the Triple P (Positive Parenting of Preschoolers program), Incredible Years Parenting Program, Parent–Child Interaction Therapy, and the New Forest Parenting Program. All four programs are considered efficacious for treating ADHD (Charach et al., 2011). These programs are also evidence based for disruptive behaviors in general (Charach et al., 2011) and may be beneficial for other neurodevelopmental disorders that present with disruptive behaviors (i.e., intellectual disability and ASD).

**Teacher-Training Programs**

Teacher programs offer teachers the opportunity to learn behavioral strategies to better the classroom environment. Children and Adults With Attention-Deficit/Hyperactivity Disorder is an organization that conducts numerous trainings for teachers interested in improving their interaction with children who have ADHD. Also, the American Academy of Pediatrics offers multiple suggestions of what teachers can do to help students with ADHD.

**Specific Learning Disorder**

In the DSM-5, a specific learning disorder is a single overarching diagnosis with specifiers for deficits in reading, mathematics, and written expression. Characteristics of a specific learning disorder are noted based on a client’s medical, developmental, educational, and
familial history. The broad approach to specific learning disorder diagnosis is an effort to ensure that persons with deficits in learning are provided appropriate services.

**Family Support**
Treatment for learning disorders tends to focus on assisting the child or adolescent in classroom performance, teaching the child how to advocate for him- or herself at school, identifying the learning strengths of the child or adolescent, enhancing self-esteem and general confidence, and finally improving the child’s social and behavioral skill set. There are many mediating factors that can impact the success of a person with learning disorders. Self-esteem may be influenced by what a person with a learning disorder perceives is family support (Nalavany & Carawan, 2011). A supportive parent or family member can make a difference by supporting a child to identify his or her strengths and improve his or her classroom performance. In addition, a supportive parent or family member can help advocate for the child at school, thus modeling appropriate self-advocacy for educational needs.

**School Resource Room**
A child may qualify for part-time or full-time assistance at school depending on what is recommended by his or her IEP. Specialized services can be provided in a resource room for specific academic subjects. Typically, students maintain a “mainstream” schedule for some subjects and activities depending on the specific learning disorder specifier(s).

**Motor Disorders**
Motor disorders are associated with developmental coordination impairment, repetitive movement, or the various tic disorders. With motor disorders, an individual can feel embarrassed. Support groups and psychoeducation around these disorders are often a positive addition to any familial intervention.

**Early Intervention**
Identifying and treating motor developmental concerns early in a child’s life is associated with facilitating developmental gain in motor development (Blauw-Hospers, de Graaf-Peters, Dirks, Bos, & Hadders-Algra, 2007; Blauw-Hospers & Hadders-Algra, 2005). The type of intervention that might be beneficial for a preterm child should be differentiated from a child who was born full term (Blauw-Hospers & Hadders-Algra, 2005). Although the outcomes for early intervention on motor development may not exceed what can be accounted for by maturation, early intervention does assist with cognitive development in at-risk groups (Orton, Spittle, Doyle, Anderson, & Boyd, 2009). In addition, an early enriching environment that stimulates and facilitates cognition, motor, and sensory development is key for successful motor abilities (Morgan, Novak, Dale, Guzzetta, & Badawi, 2014) to develop.

**Occupational Therapy**
Expanding on the idea and importance of early intervention, occupational therapy can be beneficial for children with motor disorders. Occupational therapy is not just for adults with occupations. Children with motor disorders can work with occupational therapists to improve fine-motor and gross-motor development, along with addressing the various social, environmental, and psychological factors that might impact physical functioning and well-being.
ETHICAL AND LEGAL IMPLICATIONS

The legal and ethical issues associated with neurodevelopmental disorders range from informed consent of parents and minors to the legal implications of disorders in childhood. Counselors are called on to service and advocate for children and families in multiple systems from home environments to school classrooms. Thus, it is essential to be aware of the legal and ethical implications of neurodevelopmental disorder diagnosis.

Ethical

In order to receive services, as is often the case with neurodevelopmental disorders, a diagnosis is required. The ethical consideration of treatment needs and current disability may or may not be considered until a diagnosis is reached. This lag in time between assessment and qualifying for services can be critical given the developmental level and need for early intervention as it relates to neurodevelopmental disorders. More specifically, certain programs or services may have restrictive diagnostic criteria for admission or age limitations or geographic catchment areas. Clinicians can assist with the need for service by providing opportunities for intake, referrals for services that are available while waiting for assessment, and advocating for services that are “needs driven.” The aforementioned should be discussed in the informed consent process. The American Counseling Association (ACA) outlines informed consent in the Code of Ethics (2014; Section A.2.a: Informed Consent). Similarly, Section B.2.a of the ACA Code of Ethics outlines the counselor’s responsibility to minors or adults who lack the capacity to give voluntary, informed consent. Also, informed consent, according to the ACA and the American Association for Marriage and Family Therapy (AAMFT) Code of Ethics, is an ongoing process, and as treatment, services, or diagnosis is deemed appropriate, so should the informed consent be reviewed.

Given that neurodevelopmental disorders typically continue throughout the life span, it is important to consider “quality of life” care and services versus curative treatments. Clinicians, parents, family members, and clients can benefit from understanding the lifetime experience of a disorder and what services will look like over time. Similarly, parents and the identified person with a neurodevelopmental disorder can work to share responsibilities of care with various care providers and family members instead of a single parent or the person with the disorder assuming all care responsibilities for a lifetime. Clinicians can assist greatly with diagnosis acceptance and long-term treatment planning.

Clinicians and parents may feel challenged by the overwhelming amount of information about neurodevelopment and what does or does not impact development. Sorting through what is evidence based and is causative for neurodevelopmental disorders may also be a dilemma. Given easy access to the Internet and alternative therapies for neurodevelopmental disorders, parents, caregivers, and clinicians alike may be tempted to pursue untested and biased approaches or even consider explaining disorders via untried causes. However, parents and caregivers should not ignore warnings about the risk factors, precipitating behaviors, and known causes of neurodevelopmental disorders when conceiving and caring for children.

Legal

Children and adolescents with a neurodevelopmental disorder such as intellectual disability or ASD are covered under the IDEA. IDEA is a law-ensuring service to children with disabilities throughout the nation, including infants, toddlers, children, and youth with disabilities. Infants and toddlers with disabilities (birth to 2 years) and their families receive
early intervention services under IDEA Part C. Children and youth (ages 3–21) receive special education and related services under IDEA Part B (www2.ed.gov/about/offices/list/osep/osep-idea.html, n.d.). There are six pillars under IDEA to which children with disabilities are entitled: an individualized plan, free appropriate public education, least restrictive environment, appropriate evaluation, parent and teacher participation, and procedural safeguards (www2.ed.gov/about/offices/list/osep/osep-idea.html, n.d.). These six pillars are extremely important during the assessment and intervention processes. Parents and families should work closely with schools and care providers around the services provided under IDEA.

Confidentiality and educational records as they relate to the IEP can be confusing for parents and some school personnel. The IEP is considered part of the educational record. The Family Educational Rights and Privacy Act (FERPA; 1974) is a federal law that protects the privacy of student educational records. It is important to note that schools must have written permission from the parent or eligible student to release any information from the student’s educational record. However, FERPA allows schools to disclose those records, without consent, under several different conditions (34 CFR § 99.31); specifically school officials with legitimate educational interest can access the school record. Thus, a teacher working with a child who has an IEP can have access to this record (www2.ed.gov/policy/gen/guid/ferpa/index.html, n.d.). Understanding the legal limits of confidentiality under FERPA is especially important as parents work to coordinate with school personnel, teachers, and care providers the most effective treatment plan for their child.

CASE CONCEPTUALIZATION

In order to further conceptualize working with families impacted by neurodevelopmental disorders, a case example is provided. The following case example discusses Ren and his family as they navigate the various systems associated with the diagnosis and treatment of ASD.

Presenting Concerns

Ren is a biracial (Mexican American) child and his age is 5 years and 3 months. His parents, Anna (26) and Sam (31), report a family history of a learning disorder for the father, Sam. The parents are concerned because Ren is mostly fussy and the mom, Anna, continues to “baby” Ren who does not like the texture of most baby food. He refuses to eat crunchy foods such as pretzels or carrots. Ren is large for his age (reportedly in the 98th percentile for height and weight per his pediatrician). He was slow to walk, starting at 20 months old, but even now he is clumsy and frequently has difficulty running without falling, or manipulating smaller objects with his hands. Ren was also slow to talk, starting at age 18 months, and even now he communicates in simple sentences. Ren does make verbal sounds and will regularly grunt repeatedly when he is frustrated. Ren also is very focused on his large Lego set and does not like other toys. Similarly, Ren will fixate on the ceiling fans in the family home and is soothed to sleep by a spinning night light near his bed.

More specifically, Ren regularly grabs his mom’s hand to do things for him or uses her hand to point at what he wants. Yet, Ren also does initiate conversation and responds to his own name. During time with other children, Ren is reluctant to share and becomes emotional if his preferred toys are not in his possession. Ren’s mom notes that she feels Ren can be “distant” but that he does respond to her kisses and hugs for soothing, even noting that Ren will initiate physical touch from her.
The family lives paycheck to paycheck. Sam, the father, works in construction and regularly gets work. However, his job does not allow for regular time at home. Anna, the mother, is the primary caregiver to Ren and she is now pregnant with her second child. Anna feels strained to care for Ren sometimes due to his size and difficulty communicating. Despite Anna being bilingual (Spanish and English), only English is spoken in the home.

Concurrent Problems (Treatments and Services Received)

Ren regularly sees his pediatrician. Ren is up-to-date on all of his vaccinations. Ren is rarely if ever sick per the mother. The pediatrician referred the family for a developmental assessment due to the lack of emotional reciprocity, deficits in verbal and nonverbal communication, repetitive interest in objects, and sensory hyperactivity to food textures and potentially touches. The pediatrician also referred Ren to a physical therapist for his gross- and fine-motor development to assist him in meeting his milestone of walking.

The parents were aware of this referral after Ren’s 18-month-old developmental screening and routine well-child visit. However, they delayed seeing a counselor because they believed he would grow out of motor challenges and difficulty communicating. But now at his 5-year-old well-child care visit with the pediatrician, he is still experiencing challenges with his development. The pediatrician recommended that the mother and father take the child to a clinician who specializes in child development and consider also following up with an SLP depending on what the clinician recommended.

Background History and Stressors

The mother, Anna, reports that she had a normal pregnancy with Ren and that he was a full-term baby delivered vaginally. The mother reports that there were no complications at birth and that she started taking her prenatal vitamins as soon as she knew she was pregnant around month 2 of the pregnancy. Both mother and father report that they live in a suburban area not far from a large farming community. Anna, who was born in Mexico, grew up on a farm in the United States and regularly helped her parents who were migrant workers. Anna worries that she was exposed to large amounts of pesticides, but is unsure and tries to not think about this impacting her children. Sam grew up in an urban area and reports that he was slow to walk and had difficulty in school, saying that he has dyslexia. Sam believes nothing is wrong with his son and he believes that Anna worries too much and “babies” Ren due to her Mexican heritage. Anna identifies strongly with her Mexican heritage and regularly involves her family in the care of Ren. The family reports that they eat an “all-American” diet and love pizza and pasta and anything that is quick and easy. Anna reports that she knows she should eat healthy for herself and her children but doesn’t know how and feels strained for time to prepare food. Anna feels very concerned about Ren’s development and worries that he might be autistic after looking at the behaviors Ren exhibits online.

Strengths

Both Anna and Sam love their son Ren. They are eager to assist Ren and determine what is “going on” with him. Anna is open to improving her parenting and willing to do things to assist Ren. Both Anna and Sam are self-sufficient and report strong family support from grandparents and siblings. Sam shows resilience from his identified learning disorder and shows empathy for his son not yet walking.
**DSM-5 Impressions and Implications**

Autism Spectrum Disorder—requiring substantial support for restricted repetitive behavior, interests, and activities (level 2-moderate); requiring support for social communication and social interaction (level 1-mild); without accompanying intellectual impairment; with accompanying language impairment, speaks in simple sentences and regularly uses non-verbal sounds to communicate; associated with Developmental Coordination Disorder; without catatonia.

**Relational Problems**

The amount of care that Ren requires and Anna’s pregnancy have resulted in increased verbal arguments between Anna and Sam. Anna feels overwhelmed and stressed. Sam is working extra to pay for recommended physical therapy and assessments with various clinicians, such as a counselor specializing in development and an SLP. It is noted that the family is eating a high gluten and casein diet. And the family may be exposing themselves to unknown environmental toxins.

**Assessments**

The recommended assessments for Ren and his parents could be numerous. Initially, a neurodevelopmental assessment should be completed involving an interview of the parents to gather detailed information about Ren and the family along with an observation of Ren. An Ages and Stages Questionnaire—Third Edition (ASQ-3; Squires & Bricker, 2009) and a Childhood Autism Rating Scale—Second Edition (CARS2; Schopler et al., 2010) are also recommended. Given that Ren is school aged, an assessment from a school psychologist would be requested based on the aforementioned assessments and findings. Depending on the outcome of the assessment from the school psychologist, an IEP would be initiated and followed by school personnel in contact with Ren.

**Interventions**

The suggested intervention would be PRT. Additional interventions are recommended by the physical therapist and SLP to be coordinated by parents via a parent-mediated intervention approach. The adjunctive services of nutrition and environmental wellness counseling are recommended as needed. The parents would also collaborate on the completion of the IEP and follow-up meetings with school personnel to ensure that school interventions are working well for Ren.

**Ethical and Legal Implications**

The required parental informed consent as outlined in Sections A.2.a and A.2.d of the ACA Code of Ethics and Standard 1.2 of the AAMFT Code of Ethics is to be discussed with the parents and child prior to the start of assessment and intervention. Also the counselor should review the limits of confidentiality per Sections B.1.d and B.5.c of the ACA Code of Ethics and Standard 2.1 of the AAMFT Code of Ethics. Given the likely collaboration between multiple clinicians and caregivers, releases of information should be completed to
coordinate services. How to disclose information to third parties is outlined in Section B.6.g of the ACA Code of Ethics and Standard 2.3 of the AAMFT Code of Ethics. It is also important to explain how IDEA and FERPA relate to Ren.

DISCUSSION

As you continue to reflect on the case study and the overall approach, contemplate these questions:

• How might you coordinate with the various service providers in this case, such as the pediatrician, physical therapist, SLP, and potential nutritionist?
• What recommendations would you make for the family as a sibling is born and becomes part of the family system?
• How would you build on the strength of Mexican family heritage in this family?
• What are the identified gender roles of this family and how do they impact the success of interventions chosen? How will you assist in reducing the stress of the parents and building parental wellness?
• What might be some values of this family and how might their value system impact treatment outcomes?

Ren is a 5-year-old male child with ASD. He also has the comorbid diagnosis of a Developmental Coordination Disorder given that he is slow to walk, struggles to run more than a few steps, and he is large with somewhat awkward gross motor movements. At this juncture, it is not believed that Ren has any intellectual deficits to constitute an intellectual disability. Ren’s parents are actively involved in his life. Anna, his mother, is currently pregnant with her second child and still provides constant care and attention for Ren. Sam, his father, is understanding his delay in walking and is working extra to pay for the services Ren is currently in need of. The family is eager to understand what is going on with Ren and how to best assist him.

The family is open and honest in the sharing of all developmental and historical information as it relates to Ren. They are also willing participants in the observation of Ren in the home. Observed behaviors are repetitive vocalization, that is, grunting and fixation on certain toys and home objects. Ren also demonstrates minimal to no flexibility with food and textures of food. He is similarly sensitive to the textures of toys, preferring smooth to rough. Yet, Ren does provide eye contact with his parents and regularly seeks emotional comfort from the mom. His parents are attentive, but noticeably anxious and stressed in their desire to help.

After the completion of assessment, the family is eager to begin interventions to assist Ren and improve the wellness of the family. All persons involved is in agreement that PRT is the intervention to proceed with at this time. The family also agrees to pursue the pediatric recommendations of physical therapy (PT) and speech and language pathology (SLP) as well. The prognosis for this family is overall good, given the early diagnosis, willingness of the parents to participate in treatment, and the additional clinical services being provided.

SUMMARY

Neurodevelopmental disorders can appear throughout the life span, but they are characteristically associated with the developmental period or childhood. The onset of neurodevelopmental disorders is most commonly seen in childhood. Individuals with
neurodevelopmental disorders do not typically experience a remission or relapse, and the disorders are considered to be stable over the course of a lifetime. Given the onset of symptoms occurring in childhood, parents and families are also impacted and involved in the diagnostic and treatment process. Similarly, the value systems and culture of an individual can greatly impact the therapeutic course of neurodevelopmental disorders. Systemic clinicians must be aware of the legal and ethical implications of working with said families while also using evidence-based interventions that are relational in nature. The case illustration of Ren and his family highlights the importance of early intervention and family inclusion in treatment interventions and assessment.

REFERENCES


Success in working effectively with how mental illness manifests itself in individuals is greatly enhanced when clinicians are oriented to how mental illness impacts families. Mental illness does not operate solely in an individual, but appears in relationships with disturbing and often destructive force. This is especially evident in individuals and families impacted by Bipolar and Related Disorders. It is especially important for clinicians to understand the course of Bipolar Disorder (BD) so that they can help promote understanding within a family when one of their members experiences mania and depression as part of their normal way of living. Developing an understanding of the manifestation and the course of BD helps all concerned to approach treatment and management of the disorder more realistically and lessens potential despairing due to unmet expectations. This chapter helps to acquaint clinicians with how BD occurs, its course, and its impact on families and individuals, and to respond with resiliency and effective problem-solving orientations.

**DSM-5 AND FAMILY SYSTEMS**

When individuals are challenged by mental illness, often the challenge is shared by their families in complex ways. Family systems also impact the course and treatment of mental illness by how family members respond to the affected members, how much support is offered, how healthy the family system is at any given time, the stressors the family system sustains and how it responds, and larger support systems that may impact family functioning. BD affects and is affected by the family system and successful treatment is enhanced when family members understand the course and treatment of the illness, respond in supportive ways, and stay patient and empathic within the context of constructive
communication and problem solving. BD is a daunting condition to face alone and even more challenging when a family system is not aligned on some level with a carefully crafted treatment plan. Conversely, as families are supported to learn, accept, and adapt to the needs of the affected member, treatment gains can be multiplied and affected members can find renewed hope for fulfilling and productive lives. Thus, understanding BD from a systems perspective can help clinicians effectively conceptualize how families can be incorporated into treatment, what types of family support to offer, and how the disorder can develop over the life span.

Overview of Bipolar Disorder

BD is a personal and family crisis. As a mental illness, BD takes a significant toll on personal efficacy and self-worth and is often bewildering to family members as they try to manage the symptoms of the illness and support their affected loved ones in the midst of frustrating and competing interpersonal, social, and logistical factors. The emergence of BD as manifested by intense periods of mania, often followed by periods of deep depression, disrupts peace, tests relationships, clouds future dreams and aspirations, and often destroys marriages and family relationships. It is extremely useful to take a family systems approach in conceptualizing BDs, as family relationships are where the fallout of this disorder has the greatest impact.

Primary Features of Bipolar Disorder

The primary feature distinguishing bipolar and related disorders from all other mental disorders is the presence of mania (as manifest in Bipolar I Disorder) or hypomania (as manifest in Bipolar II Disorder; American Psychiatric Association [APA], 2013), which is a state of intense, energized mood, cognition, and behavior, resulting in an increased capacity for creativity and clarity of thought (rational and irrational), rapid ideas and racing thoughts, sometimes irritability and impatience with others, reduced need for sleep, distractibility, an objective-focused activity, and/or energy present most of the time during the episode (APA, 2013; Carr, 2009; Goodwin & Jamison, 1990; Jamison, 2011; Miklowitz, 2008; Rusner, Carlsson, Brunt, & Nystrom, 2009). For example, a young college student who was a blues guitarist had the strong impression during a manic episode that he could create a device that, connected to his guitar, would enhance the resonance from strumming the strings, vibrating through his arm, up the shoulder, through the neck, and up onto the scalp of the person playing to stimulate hair growth; anyone playing the guitar with this device would be positively impacted with a healthy head of hair. He described the concept with passionate clarity and intense emotion because thousands of his friends (friends whom he had not yet met) who struggled with hair loss were all on the verge of financial and social ruin because of their lack of hair. He perseverated on figuring out the mechanism, thinking he was just on the brink of discovery. His invention never materialized and, luckily, he did not have access to the financial resources to make an investment in the venture.

With mania and hypomania, there is a decreased need for sleep, increased sexual desire, and a need for stimulation, which can involve risk-taking behaviors resulting in painful and/or harmful consequences. The subjective experience of mania is also characterized as paradoxical where there is lightning-fast epiphany beyond the vision of all others, which produces a feeling of grandiosity and power. Many who experience mania describe feeling frustrated at their limited capacity to experience and carry forward these creative insights, like drinking water from a fire hose (Rusner et al., 2009). For example, a successful attorney experiencing a manic episode was able to borrow $50,000 against her
retirement when she flew to Las Vegas and walked up and down the strip, cheerfully and enthusiastically distributing hundred-dollar bills to passersby until, within a matter of minutes, the money was gone. She was ecstatic and believed that many were blessed by her efforts and that money would continue to flow to her and she would be the means whereby many more would receive blessings from God, through her. When she came to herself, she realized what she had done and felt deep and pervasive shame. Mania, but not hypomania, is also sometimes accompanied by delusional thinking and psychosis, which mimic symptoms of Schizophrenia (APA, 2013). Hypomania contains similar symptoms manifest in mania, but of a lesser duration and lesser intensity (National Institute of Mental Health [NIMH], 2016a) and is a characteristic of Bipolar II Disorder (APA, 2013).

The most frightening time for those experiencing mania is when it begins to dissipate because for many it signals the descent into depression. Another complex manifestation of depression is Bipolar With Mixed Episodes (see APA, 2013, pp. 149–150). These depressive episodes are characterized by deep sadness, hopelessness, feelings of emptiness, fatigue, lack of energy, loss of appetite, listlessness, dysphoria, and apathy for a minimum of 2 weeks (APA, 2013). Depressive episodes are often attended by shame and embarrassment for the consequence of manic actions, a lack of pleasure in activities once enjoyable, the need to isolate from others, a sense of worthlessness, guilt, somatic aches and pains, troubled sleep, and thoughts of death. Whereas in mania, the risk of death is typically from thrill seeking, in depressed individuals, the primary risk of death is suicide. Many who suffer from bipolar depression describe the subjective feeling of depression as intense as is the feeling of mania (Rusner et al., 2009). Mania is characterized as the “highest of highs,” whereas depression is characterized by the “lowest of lows” (Miklowitz, 2008, p. 23). Suicide is a very real concern for the bipolar client, family, and friends, and those treating bipolar persons. In the course of antidepressant treatment of BD, or depression, the first symptoms that respond to treatment are a lack of energy (i.e., people become more energized) and sleep (i.e., people tend to sleep better when on antidepressants), and one of the last symptoms to clear up is mood. This makes people with BD especially susceptible to suicide because they actually have the energy to kill themselves. States of high energy along with depression increase suicidal risk (Jamison, 2011).

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013) categorizes Bipolar and Related Disorders as: Bipolar I Disorder characterized by a manic episode lasting 7 days or longer; Bipolar II Disorder characterized by a hypomanic episode lasting no more than 4 days; Cyclothymic Disorder characterized by hypomanic symptoms that would not meet the full diagnostic criteria for a hypomanic “episode” and depressive symptoms that would not meet the full symptom criteria for a depressive “episode” (this includes a lower level of intensity of both extremes, a lower level of frequency with symptoms occurring 4 days compared to 7 days for a manic episode, and a subthreshold of symptoms necessary to meet the disorder); Substance/Medication-Induced Bipolar Disorder characterized by symptoms of mania precipitated by a particular medication or substance; and Bipolar Disorder Related to a Medical Condition, in which symptoms of mania can be precipitated by a health-related condition (APA, 2013). Mania becomes the primary symptom distinguishing BD from other depressive disorders and causes significant “impairment in social and occupational functioning” (APA, 2013, p. 124) as well as a disruption to family relationships and functioning, which is the general standard that distinguishes problematic behavior from a mental disorder.

Associated Features of Bipolar Disorder

Prevalence rates for all BDs for adults are 3.9% over the lifetime with 2.6% of the adult population meeting diagnostic criteria in a given year and 2.5% of adolescents over the
lifetime with 2.2% of the population meeting criteria in a given year. Approximately 1.7% of adolescents report having mania alone during the lifetime and 1.3% report having manic symptoms in a given year (APA, 2013; NIMH, 2016a). These data are significant because it appears that adolescent manifestation of BD approaches that of adults and it is important for mental health clinicians to identify, diagnose, and treat BD early in affected individuals. Additionally, 50% to 67% of adults affected reported the onset of BD before the age of 18 and 15% to 28% reported experiencing symptoms before 13 years (Perlis et al., as cited in Miklowitz, 2012). Men and women experience BD equally although there is some evidence suggesting that women experience Bipolar II Disorder at a higher rate (APA, 2013; Miklowitz, 2008; NIMH, 2016a). Women also tend to experience higher “rapid cycling” (i.e., four or more mood episodes within a single year) and more “mixed states” (i.e., mixed symptoms or “features” of mania and depression within a single episode) than men (APA, 2013, p. 130). BD With Mixed Features is especially difficult to treat with psychotropic medications because of the nature of simultaneous manic and depressive symptoms (Miklowitz, 2008). There is a strong hereditary component in BD; “a family history of bipolar disorder is one of the strongest and most consistent risk factors for bipolar disorders” (APA, 2013, p. 130). Goodwin and Jamison (1990) and Jamison (2011) reviewed the research on risk factors and also indicated the strong connection to family members who have had BD and noted that careful assessment as to the course and treatment of the illness is helpful in making predictions to the course of the disorder in newly diagnosed individuals. Over 90% of those experiencing a manic episode eventually have recurring episodes and roughly 60% of individuals having a manic episode also have a depressive episode; so the likelihood is high that mania persists within individuals with multiple episodes, including episodes of depression. The persistence of symptoms within the interepisode phases of the illness indicates that, for many, there is never a break within this chronic condition (Goodwin & Jamison, 1990; Jamison, 2011; Miklowitz, 2008). Miklowitz (2008) noted that depressive episodes in the bipolar cycle are much more difficult to treat and that individuals spend much more time in depressive states than manic ones; research suggests as much as three times more weeks during the year with depressive symptoms versus symptoms of mania (Judd et al., as cited in Miklowitz, 2008). It is clear that BD is a chronic, often debilitating condition that requires a multifaceted treatment approach to manage effectively (Goodwin & Jamison, 1990; Jamison, 2011; Miklowitz, 2007, 2008, 2012).

For both adults and adolescents, symptoms of BD can be comorbid with a wide variety of other disorders including Anxiety Disorders (including specific phobias), Attention-Deficit/Hyperactivity Disorder, Personality Disorders, Substance Use Disorders, serious and often untreated medical conditions, and for adolescents, Disruptive and/or Conduct Disorders, and “disorders with prominent irritability” (APA, 2013, p. 132), which need to be carefully assessed in order not to misdiagnose children as bipolar (Carr, 2009). This vulnerability of comorbidity adds to the complex environmental and family factors that influence treatment outcomes for affected individuals.

Treating Bipolar Disorder Symptoms

The primary treatment of BD is psychopharmacological and typically starts with lithium bicarbonate and other mood stabilizers, antidepressants, and atypical antipsychotics and anxiolytics that are often prescribed in the acute phase of the illness (Goodwin & Jamison, 1990; Miklowitz, 2008, 2012). Because bipolar individuals often have sleep disturbance, sleep medications are often prescribed to regulate circadian rhythms. Good sleep hygiene is one of the easiest and best ways to help prevent triggering mania (Jamison, 2011). The use of electric convulsive therapy is an option for entrenched, severe, and persistent depressive symptoms (NIMH, 2016b). Other treatment modalities are being researched including
deep brain stimulation, the use of optogenetics, and genetic mapping (Detroit Public Television, 2016). A common and frustrating feature of medication treatment for bipolar individuals is medication compliance (Goodwin & Jamison, 1990; Jamison, 2011). Individuals affected with BD often find the effects of drug therapy as blunting the euphoric effects of the experience of mania, and develop abhorrence to the side effects of the medication. They are also often resistant to the idea that they will be taking medications for the rest of their lives in order to maintain a balanced mood, to help them make reasoned choices, maintain their interpersonal relationships and support systems, and lower the incidence of additional and severe episodes. The trade-off of life stability (which is a relative term) with experiencing intense feelings of euphoria, clarity, and power is often a difficult dynamic for individuals to negotiate, and those treated for BD are forced to confront the losses associated with this challenging condition. Approaching assessment, diagnosis, and treatment within a grieving framework can help bipolar individuals cope with the significant changes attendant to their disorder and become more open to living a life with the disorder. Understanding how family systems impact and are impacted by BD provides enhanced insight into developing therapeutic leverage in the treatment of BD.

Family Systems and Bipolar Disorder

The impact of BD on families is hard to fully measure, but the consequences are clearly tragic and often corrosive to close family relationships, friendships, and other support systems. Individuals experiencing manic and depressive symptoms reflect the bewilderment, anger, hopelessness, and existential despair often felt in family members who struggle to support their loved one while at the same time try to make sense of what is difficult to accept: that their loved one has a chronic condition that will persist throughout her or his life and, as family members, they too travel a parallel path.

Practical and Emotional Consequences

There are both tangible and intangible impacts for families of an individual with BD. The tangible consequences include being introduced into the legal system with adolescent or adult family members who may act out during a manic episode and violate the law (Hyde, 2001). Hiring legal counsel for an arrest and interfacing with the legal system become stressful. Other potential, practical consequences include unemployment resulting from inconsistent or poor job performance; impulsive and poor financial decisions resulting in loss of income, savings, or retirement resources; loss of social status within the community; interfacing with mental health agencies and social services, and a wide variety of mental health personnel; and often being marginalized by a mental health system that does not recognize the legitimate burden family members carry and the inability to access important treatment information on behalf of their affected loved one because of right to privacy and confidentiality constraints (Rusner, Carlsson, Brunt, & Nystrom, 2012). Numerous inpatient hospitalizations and intensive outpatient programs, encountering resistance from the affected family member to comply with medication and other forms of treatment, the emergence and persistence of substance use disorders comorbid with BD, dealing with younger family members who may be more vulnerable to the effects of this condition and who may be wondering what is wrong with mommy, daddy, brother, or sister are all lived experiences for family members where BD is prevalent. Sometimes partners of spouses, sons and daughters of parents, and parents of children may cut off and/or leave or divorce the impacted relative because of the stress attendant to this condition. These life disruptions cast a pall on other family and social activities and center the collective energy and family resources on addressing the problem. It is difficult to maintain hope in the future.
Intangible Consequences

The intangible or emotional fallout for the family is a real and felt experience and centers on working to accept the disorder and attendant consequences. Miklowitz (2008) noted that when an affected individual is in a manic state, family members may initially find the observed behavior as interesting or exciting, but soon turn to distress and anxiety as their loved one becomes more impulsive, unpredictable, and erratic; the family member may leave and not return home for days. If the manic episode is new to family members, there is often confusion about how to respond and about the immediate need for perspective. Often, family members seek to discern differences between the illness and the characteristics of the affected loved one in an attempt to make sense of their behaviors. If the affected individual is a parent, children and other family members need reassurance; if a child, parents may seek to discipline or reason with their loved one with little success. Some affected individuals become violent, destructive, and/or manifest delusional and psychotic symptoms that are frightening and family members are faced with having to protect and be protected from the affected family member. If the manic episode is repeated as part of the course of the illness, family members become retraumatized to the episode and may seek equilibrium through a variety of behaviors ranging from acting out themselves (mostly in children) to calmly responding to the situation and following a predetermined plan. Often family members try to reason with the affected member with little success. During episodes of depression, family members seek to motivate and instill hope within their family member and often face their own sense of hopelessness and despair when attempts to support, encourage, and offer solutions are rejected or treated with indifference. Motivating someone who is depressed is extremely challenging and sometimes family members wonder which is worse, the mania or depression. Rusner et al. (2012) summarized the effects of BD on the family:

Being closely related to a person with bipolar disorder means a paradox of both being needed and rejected, (i.e., vitally necessary but simultaneously also excluded), whilst being overshadowed by bipolar disorder. It means living in a state of constant pressure and existential exposure, periodically being exposed to huge distress without means of getting away from it. Life is overshadowed by the illness. One's attention is focused on the well-being of the person with [bipolar disorder] in such a way that one's own needs take second place. In a desperate struggle for survival, the close relatives are stretched to the limits of their ability. Being closely related to someone with bipolar disorder also means simultaneously foreseeing and following the often sudden and unexpected changes of the person with [bipolar disorder]. (p. 202)

This lived experience in family members as well as the affected relative signals clearly that BD is a family illness and the need for family intervention and support cannot be overestimated.

RELATIONAL AND CULTURAL FEATURES

There is little empirical evidence of cultural differences in the incidence and manifestation of BD across cultural groups (APA, 2013; Goodwin & Jamison, 1990; Miklowitz, 2008), but clinicians are best advised to maintain a cultural perspective when diagnosing and treating BD, including uses of assessment instruments, diagnosis, and treatment of individuals diagnosed with bipolar and other disorders. Of particular importance is the recognition that the DSM system is based on a medical model and is inherently limited in validating treatment approaches other than medical (Jacob et al., 2013). However, the DSM-5 does provide an important assessment tool, the Cultural Formulation Interview, which provides
a framework to assist clinicians in assessing the cultural identity of the affected individual, perceptions of the distress (including how the cultural group of the client would view the problem), psychosocial stressors and “cultural features of vulnerability and resilience” (APA, 2013, p. 750), and cultural aspects of both the client and the clinician that might impact treatment (APA, 2013). Viewing culture therapeutically includes a perceptual expansion of cultural groups to include age, gender, sexual orientation, religion, language, occupation, military service, social networks, substance use, migration status, geographical region, relationship status (i.e., married or divorced), and not simply race and ethnicity (American Counseling Association [ACA], 2014; APA, 2013).

Closely connected to culture is how relational variables impact and are impacted by BD. These relational factors largely constitute how family and friends interact with their affected loved one(s) and how counselors interact supportively with bipolar individuals and their families and support networks. In the following discussion, we discuss key ways in which counselors can approach bipolar clients constructively to help decrease resistance to treatment and help set the stage for effective treatment. The discussion regarding how families communicate, interact, and create environments that positively or negatively impact affected individuals falls under the section “Vulnerability–Stress Model.”

The importance of developing an empathic, accepting, supportive, and validating therapeutic alliance has been well supported in the research literature (Havens & Ghaemi, 2005; Hersoug, Høgland, Monsen, & Havik, 2001; Horvath, 2001; Jamison, 2011; Kress & Paylo, 2015; Lambert & Barley, 2001; Meyers, 2014; Norcross & Hill, 2004). As it pertains to work with bipolar clients, Havens and Ghaemi (2005) advocated for clinicians to use empathy and authenticity when working with BD clients and to not be afraid of conflict within the process of making therapeutic contact. “The meeting and initial work with manic persons is often complicated. When we meet with them, we collide with them. We have to confirm the collision, not deny it” (p. 142). Demonstrating empathy for paranoid and grandiose thinking is not only critical for a successful therapeutic alliance, but gives the clinician a more accurate assessment as to the extent of the client’s delusions, grandiosity, and paranoia. Counselors modeling for clients a sense of humor and often a playful attitude in their interactions together help clients learn to more realistically view themselves and reality-test relationships. Humor, appropriately and skillfully used, also helps reinforce for clients that their counselors do not view them as a culmination of their manic and depressive episodes, but as people who can be related to, which is empowering to them. Bipolar-affected clients often know that they negatively impact loved ones and others, and as a result, feel deep shame and guilt for what is often irritating and offensive behavior; having a place that is safe for them to explore different ways of seeing themselves is important. Finally, Havens and Ghaemi (2005) noted the corrective therapeutic effect this type of encounter has on the client:

The job of the clinician is twofold initially: first, to seek to existentially be with manic patients and then, to counterprojectively give perspective to those patients about their manic worldview, without completely denying it. This twofold approach then can lead to a healthy therapeutic alliance, which itself has a mood-stabilizing effect. Along with mood-stabilizing medications, this alliance can then lead patients toward full recovery. (p. 146)

Clients experiencing the effects of BD can benefit greatly from the “stabilizing effect” of a strong therapeutic alliance that sets the basis for all other work. The therapeutic relationship provides a place where the bipolar client can experience acceptance and the family can receive real and targeted support. Jamison (1996), herself bipolar, put into perspective the importance of the therapeutic relationship in her own treatment:

Lithium . . . gentles me out, keeping me from ruining my career and relationships, keeps me out of a hospital, alive, and makes psychotherapy possible. But, ineffably,
psychotherapy heals. It makes some sense of the confusion, reigns in the terrifying thoughts and feelings, returns some control and hope and possibility of learning from it all. Pills cannot, do not, ease one back into reality. . . . Psychotherapy is a sanctuary, it is a battleground, it is a place where I have been psychotic, neurotic, elated, confused and despairing beyond belief. But, always, it is where I have believed—or have learned to believe—that I might someday be able to contend with all of this. (Goodwin & Jamison, 1990, p. 725)

Miklowitz (2012) noted the importance of family therapists showing patience and adaptability in working with bipolar patients and their families. Even from a psychoeducational perspective where there are often established protocols toward the goal of educating clients on the disease, its course, and the impacts on individuals and families, being aware of topics that may be highly emotional and aware of the need to address these issues with empathy and sensitivity is paramount for family counselors.

Jamison (2011) noted that an important implication for family treatment is for counselors to involve the family directly in the treatment of the identified bipolar family member. Family members can often provide much more accurate and rich perspectives regarding what happens when the bipolar member is manic and/or severely depressed. Often, the bipolar member is not a completely reliable source of information for these events; she or he can certainly comment on how it feels to be manic or depressed, or how specifically these states manifest herself or himself in daily living, but she or he may not be fully aware of the consequences of her or his actions while in these extreme states. Jamison (2011) also recommended that counselors and therapists can help bipolar clients develop “advanced directives” (p. 31) that may include signed consent from clients about how the illness is to be addressed or treated, including being treated against their will if they are in a full-blown manic or depressed episode. The rationale is that we want bipolar clients to be thinking about the course of their illness and making decisions about treatment when they are balanced, lucid, and making rational judgments rather than when they are manic or depressed. This can best be accomplished within the context of supportive family members who can express understanding and empathy, while at the same time express clearly the consequences of clients’ manic and depressive behaviors and advocate strongly for responsive and responsible action to be taken. Family-focused treatment (FFT) is discussed later as an effective approach within this context of the therapeutic alliance.

Vulnerability–Stress Model

In treating BD and related disorders, it is helpful to conceptualize the condition as comprehensively as possible in order to capture essential facets of the disorder including the associated genetic, biological, and environmental factors and how these manifest in individuals. Miklowitz (2008) noted that these factors do not appear independent of each other but all “interact in bringing about episodes of mood disorder or in protecting against their occurrence” (p. 49). Understanding how these factors mutually impact and are impacted by each other over the course of the disorder can help manage episode occurrence and develop resilience in affected individuals and their families. The Vulnerability–Stress Model (Miklowitz, 2008) is a useful tool in helping clinicians conceptualize the disorder and, in turn, help affected individuals and their families understand the origin, course, and prognosis of the illness. Later in the chapter we discuss how this model provides the foundation for effective treatment approaches.

Genetic and biological vulnerability includes the manifestation of the disorder in members of an affected person’s family (i.e., who in the family has or has had the bipolar or related disorders, including parents, grandparents, siblings, or extended relatives), brain functioning (i.e., to what level may there be structural or brain abnormalities and
quality of functioning and dysfunction in neurotransmitters—this is obviously difficult for counselors to determine without reliance on medical evaluation), and other biological factors (e.g., chemical imbalances, changes in hormonal and immune system functioning, sleep regulation). When vulnerability is high in these areas, the amount of environmental stress needed to trigger a manic or depressive episode tends to be low (e.g., a simple, but unexpected schedule change at work or an unexpected and isolated conflict with a spouse or other family member); those with high vulnerability have a low tolerance for and little protection from events that others without the disorder might manage quite well. Those with low vulnerability to genetic, neurological, and biological factors would likely not be vulnerable to mood episodes unless there were high social stressors at play (e.g., death of a close friend or family member, an eviction from a dwelling, a significant financial event or other crisis, or chronic conflict and stress). Thus, low environmental stress acts as a protective factor from the occurrence and reoccurrence of mood episodes. Because the nature of genetic or biological vulnerability may be hard to detect and determine, managing environmental stress becomes a high priority in treating and managing bipolar episodes and their severity.

One primary manifestation of environmental factors is the quality of interpersonal relationships within the family and the consequent level of stress in the home environment. These factors are referred to as psychosocial provoking agents (Miklowitz, 2008, p. 50) that largely impact vulnerability and the manifestation of manic and depressive states. Because BD impacts individuals and families in often unpredictable and disorienting ways, and because of the real and felt consequences of BD in the family (e.g., loss of employment, social stigma, loss of support systems, financial problems), family members often assume patterns of responding that range from being long-suffering, helpful, and supportive to being critical, blaming, and sometimes uncooperative. These reactions contribute significantly to the emotional climate within the home and impact the perpetuation of continued episodes. Miklowitz (2008) suggested that these “cause and effect relationships between mood disorder symptoms and family environmental factors are bidirectional: Families are affected by bipolar disorder as much as they affect it” (p. 51). Like many family interventions and models of family therapy, the Vulnerability–Stress Model was developed from research on family interactions with patients with schizophrenia. Miklowitz (2008) and his team began researching how this model applied to bipolar-disordered individuals and their families. He built upon the existing research around a fundamental construct related to family functioning: emotional expression (EE). EE is “a measure of emotional attitudes among relatives (usually parents or spouses) of a psychiatric patient” (Miklowitz, 2008, p. 53) and is defined as critical, hostile, or emotional overinvolvement statements and attitudes family members communicate overtly or indirectly to the member(s) affected by the disorder. The DSM-5 has a new Z code that captures this dynamic: High Emotional Expression Level Within Family (Z63.8). Elevated or high EE becomes the primary vehicle for socioenvironmental stressors within the family (Miklowitz, 2007, 2008, 2012). Bipolar-disordered individuals are two to three times more likely to deteriorate into a manic or depressive episode in families where high EE exists and experience prolonged and more severe manic or depressive states. There is no evidence to suggest that high EE families cause BD, but the evidence is clear that high EE causes stress that contributes significantly to the perpetuation of mood episodes (Miklowitz, 2008). Miklowitz (2007) described how EE develops and is perpetuated between the affected child and his or her parents and how the child reinforces high EE reactions within parents, which impacts overall relationship functioning. Children who exhibit behaviors and attitudes consistent with a low tolerance for stress, unstable mood, elevated anxiety, irritability, and problematic cognitive functioning largely meet the criteria for high biological and genetic vulnerability. Miklowitz noted that generational influences within high EE families can significantly impact the vulnerabilities of family members who may be predisposed to BD and vulnerable to criticism toward their condition.
These parent–child dynamics along with the “vulnerabilities” noted create a perfect storm for the development and perpetuation of unstable mood states that often evolve into adulthood and throughout the developmental life span. The Vulnerability–Stress Model helps clinicians assess and further understand not only the relationships between genetic, biological, and socioenvironmental factors, but helps focus attention on the emotional expression and the quality of interpersonal reactions in the home that could be either provoking manic or depressive mood states or protecting affected individuals from their recurrence.

**FAMILY SYSTEMS ASSESSMENTS**

Accurate assessment of BD is essential to the formulation of an accurate and workable diagnosis, which can lead to targeted treatment in areas of need. When conducting formal and informal assessment, it is vital to remember that data generated from assessment can be revelatory (thus opening new areas of inquiry) or confirmatory of a diagnosis. Each assessment acts as an individual data point, like a mosaic of a larger picture. Assessment for BD could be characterized as the individual assessment and diagnosis of the disorder while family assessment addresses essential aspects of the family environment including the quality of family interactions.

**Individual Assessment**

A thorough biopsychosocial assessment should be conducted on the client upon the initial intake (or shortly thereafter) to capture a comprehensive context in which the presenting problems occur. There are numerous models of biopsychosocial assessments, but the primary domains in which they all converge include identifying information, presenting problem, history of the presenting problem including a mental health history, medical history, family history, personal history that includes a developmental timeline, conducting a mental status exam (i.e., appearance, behaviors/psychomotor activity, attitudes, affect and mood, speech and thought, perceptual disturbances, orientation and consciousness, memory and intelligence, and reliability, judgment, and insight (Kress & Paylo, 2015). Other domains of inquiry essential to the biopsychosocial history include legal problems, substance use, spirituality/religion, cultural/ethnic background, suicidal ideation (including ideation, plan, and attempts), financial concerns and socioeconomic status, and resources and resilience factors. Utilizing the Level 1 and Level 2 Cross-Cutting Symptom Measures associated with the DSM-5 can also provide a targeted assessment of symptoms, including the Altman Self-Rating Mania Scale (Altman, Hedeker, Peterson, & Davis, 1997) that was modified for use as a DSM-5, Level 2 Cross-Cutting Symptom Measure for both adults and children. This can be self-administered or administered to a parent or guardian (APA, 2013; see also www.psychiatry.org/psychiatrists/practice/dsm/dsm-5/online-assessment-measures). Another helpful measure that can detect both threshold and subthreshold levels of mania is the Composite International Diagnostic Interview BD Screening Scale (Kessler & Ustun, 2004). This is a clinician-administered assessment that was created and validated as helping to generate conservative diagnoses of BD. For an assessment of general disability, the World Health Organization Disability Assessment Schedule 2.0 is a self-administered (or an informant version) instrument that is also part of the DSM-5 offering (APA, 2013, pp. 745–748). The goal of individual assessment is to obtain a differential diagnosis and it is important to (a) administer formal assessments ethically and according to the protocols specified in specific instruments including being trained in the administration and interpretation of data; (b) gather and make sense of the data and
share the results with clients in a manner that is comprehensible, clearly explaining the limitations of assessment and assessment results; and (c) use the data to confirm existing clinical impressions and/or to generate new clinical directions. The importance of counselors adhering to the diagnostic criteria and being familiar with disorder specifiers (e.g., mixed features, rapid cycling, seasonal pattern) and associated features of each diagnostic category cannot be overstated. Consultation with other professionals including those of a treatment team is essential. Kress and Paylo (2015) reminded clinicians of the importance of understanding clients within the context of their families and social systems, which means that the family can provide important context for the counselor in diagnosis and treatment, which leads to the process of family assessment.

Family Assessment

Family assessment becomes essential in understanding how BP affects and is affected by factors environmental and relational in nature. Previously we discussed areas of assessment related to the Vulnerability–Stress Model including assessing the EE within a family environment. Assessment of EE for research purposes was a matter of extensive training and coding family responses within a 60- to 90-minute interaction between a family or multiple family members and the affected member. Specific benchmarks would distinguish high from low EE. For example, families would be classified as being high EE families when, during the interaction, there were six or more critical comments made (e.g., “If he keeps sleeping in, he is going to lose this job just like he has all the others.”); if there were signs of hostility in the interactions (e.g., “He acts like he can’t control this behavior, but I know he can; he makes me so angry!”); and if there was evidence of emotional over-involvement between a family member (or members) and the bipolar individual (e.g., “I can’t manage to sleep if he doesn’t come home when he says that he will.” or “I’m afraid that if I leave on this trip, she’s going to burn the house down.”; Miklowitz, 2007, 2008, 2012; Miklowitz et al., 2008). These same criteria can be used by counselors in family therapy settings. Miklowitz (2008) recommended that, as part of the protocol of a comprehensive family assessment with all willing family members present, the counselor have the family (or a family member and the affected bipolar member) engage in a conversation regarding their relationships or how they have attempted to solve problems they experience for 5 to 10 minutes and to observe and note the number of EE statements that are generated within the interaction and what the statements are. This not only gives important data about the level of EE, but sensitizes counselors to what family members value, what they may be struggling with, and process and context of their conversations. Developing sensitivity to the quality and types of interactions family members have can give counselors useful information in designing treatment, including areas of interpersonal functioning on which to focus. A very useful family assessment tool is the genogram, which can be used to develop an understanding of where BD (and other mental health problems) has occurred within the family (Watson, Poon, & Walters, 2005). A genogram is a multigenerational family tree that symbolically represents different dynamics related to family and individual functioning that is psychological, cultural, and interpersonal in nature. This comprehensive assessment can include medical issues, symptomatology, treatment, and outcome, as well as family context and patient experience. Genograms have the ability to leverage a clearer understanding of the Vulnerability–Stress Model as applied to individuals affected by BD and their families. Other related areas of family assessment are important in helping counselors understand how family members have been affected by BD and quality of life for the bipolar member. The Mood Disorder Burden Index (Martire et al., 2009) was developed to assess caregiver perceptions and experiences in three core domains: patients’ mood symptoms, caregivers’ worries about the future, and caregivers’
interpersonal difficulties with the patient. This is consistent with supporting caregivers in their experience with BD family members. The Quality of Life in Bipolar Disorder Scale (Michalaka, Murray, & CREST.BD, 2010) is also a self-administered instrument designed as an alternative to psychiatric measures that fail to assess for treatment outcome and recovery and well-being for those afflicted with BD. This instrument can give counselors insight into how the bipolar individual has been impacted by the disorder and indirectly, how the family has been impacted. An important additional source of assessment is in the DSM-5 under “other conditions that may be a focus of clinical attention” or Z codes (APA, 2013, pp. 715–727). Formerly known as V codes, these conditions are accompanied by focused descriptions of individual and family conditions that impact and are impacted by bipolar and other mental disorders. Referencing these conditions helps provide a richer context for assessment and treatment. General headings for these codes include Relational Problems, Abuse and Neglect, Educational and Occupational Problems, Housing and Economic Problems, and Other Problems Related to the Social Environment, among others. Specific Z codes include Parent–Child Relational Problem, Child Physical Abuse Suspected and/or Confirmed, High Emotional Expression Level Within Families, Disruption of Family by Separation and Divorce, Child Neglect Suspected and/or Confirmed, and Social Exclusion or Rejection (APA, 2013).

Just as developing and maintaining the quality of the therapeutic relationship is important in treatment of BD, counselors should always be mindful of being client centered, empathically inquisitive, and validating of the subjective experience of clients and their families as information is gathered during the assessment process. Assessment is not a singular event that occurs upon intake, but a continuous process of measuring symptom reduction, improvement in family communication and problem solving, acceptance, and self-efficacy in living with BD.

FAMILY SYSTEMS INTERVENTIONS

As previously stated, traditional treatments for BD have been grounded primarily in pharmacologic intervention with an integration of individual psychotherapy; in fact, this combination has been found to be more effective than either protocol alone (Carr, 2014; Geddes & Miklowitz, 2013; Miklowitz & Scott, 2009; West et al., 2014). In addition, the goals of treatment for BD have historically focused on symptom reduction and prevention of future episodes (Leboyer & Kupfer, 2010). However, a more contemporary view has recognized the integral role of psychosocial variables—including significant relationships and life stressors—on the exacerbation of bipolar symptomology. In fact, while the biological etiology of BD remains unchallenged, the course and severity of the disorder cannot be separated from the individual’s psychosocial context and influences (Miklowitz, 2008; West & Weinstein, 2012). As was discussed earlier in this chapter, psychosocial stressors can directly contribute to, or even catalyze, the occurrence of a bipolar episode. Similarly, the occurrence of an episode can aggravate psychosocial stressors. For example, marital discord can cause significant stress on individuals with BD, making them more susceptible to a bipolar episode. The occurrence of an episode, in turn, can increase marital discord due to the changes in the individuals’ behaviors and affect regulation. Thus, a cycle can develop of constant challenge and crisis, which may self-perpetuate without the disruption of systemic treatment.

There has been considerable research evaluating the efficacy and outcomes of pharmacological treatment for BD as a stand-alone treatment, compared with both individual and combination (individual and family) psychotherapy. This effort to determine the “optimal” treatment for BD has yielded mixed results (Justo, Soares, & Calil, 2007). Some studies have found a significant impact from the integration of family therapy, while others
found little or no differences in outcomes. Such discrepancies may be accounted for by small sample sizes and variations in study designs. Moreover, it is important for clinicians to remember that BD actually comprises a group of heterogeneous disorders, with significant variations in etiology, manifestation, and severity. In addition, the relative influences of psychosocial factors can vary widely in individuals with BD. It should be considered, then, that the question become not whether family systems treatment is or is not effective for BD, but how and when it can be applied and adapted according to the needs of the client and family. In this section, a selected family systems approach for BD is discussed, including some of the unique considerations and challenges of family treatment for BD.

**Family-Focused Treatment for Bipolar Disorder**

Family-focused treatment (FFT) is an integrative approach to treatment of BD, which combines psychoeducation and family therapy (Miklowitz, 2008). FFT begins with a thorough assessment of individual symptomology and family systems dynamics, and proceeds through a structured and preset treatment, with specific goals throughout the duration. While the detail and depth of family relationships are often not fully understood until well into treatment, it is important for the counselor to gather as much information during intake as possible. For example, a key goal in assessment would be to identify family conflicts that may be contributing to the stress across the system, which in turn can exacerbate BD symptomology in the identified client. Conversely, it is equally vital to understand the strengths and protective factors across the system, which can support the emotional regulation of the individual with BD, as well as the overall health of the family system. This information informs both the psychoeducation and therapy components of treatment, as it guides both specific goals and interventions. Of course, adaptations may need to be made along the way, depending on the observed progress of the client and family.

As part of a thorough assessment, the counselor should have a firm understanding of the cultural beliefs, practices, and influences on the family system. This is important not only to provide a context to the experiences and dynamics of the system, but also to provide the counselor with a perspective on how FFT may need to be adapted somewhat to maximize efficacy. For example, some cultures stress oral over written communication, which would impact the homework and other written assignments that are part of the general FFT protocol (Ozerdem, Oguz, Miklowitz, & Cimilli, 2009). These important elements can be adapted, however, and awareness of this on the front end of treatment can improve the structure and experience for the clients.

Another important element of assessment prior to FFT is the determination of appropriateness of this type of intervention. For example, not all individuals diagnosed with BD have the support of family members willing to participate in treatment. Miklowitz (2008) noted that 46% of adults diagnosed with BD do not have family members participate in treatment. There can be many reasons for this, including geography and access to services; it may also be that the very reasons for family members to not participate in treatment are the reasons they should. That is, often the extremes of bipolar episodes cause significant conflict in family systems, and may make some or all members unwilling to participate. In addition, not all individuals are appropriate for the FFT protocol. Persons who are in acute phases of BD, have developmental disabilities or other biological conditions that impact cognition, refuse to adhere to medication protocols, or have a comorbid active substance use disorder are among those for whom FFT is not recommended (Miklowitz, 2008). Furthermore, counselors will find that the efficacy of FFT is not necessarily predictable across viable treatment groups (Fristad & MacPherson, 2014). Adolescents diagnosed with BD, for example, are positively impacted by FFT, but less so than adults (Miklowitz et al., 2008); further, the degree of efficacy in such cases may differ minimally from psychoeducation
alone (Miklowitz et al., 2014). This could be due a variety of factors, including developmental stage considerations and the differing role of family dynamics in the treatment. Still, the majority of extant research supports the assertion that FFT is an effective adjunct for treatment of BD, and can significantly impact relapse of the disorder (Miklowitz, 2008; Miklowitz, 2012; Reinares et al., 2016).

Another rationale for the use of FFT is its impact on caregivers. Studies have found higher rates of anxiety, depression, and general distress in caregivers of those diagnosed with BD (Goosens, Van Wijngaarden, Knoppe-tr-Van Der Klein, & Van Achterberg, 2008; Martire et al., 2009; Perlick et al., 2016; Steele, Maruyama, & Galynker, 2010). Family-based interventions improve illness outcome and caregiver well-being (Reinares et al., 2016). In fact, FFT has been found to have a positive impact on the mental health of caregivers, even when the diagnosed family member is not participating in the treatment (Perlick et al., 2010).

The course of treatment of FFT for BD is fairly structured, and is based on three distinct treatment stages: (a) psychoeducation, (b) communication enhancement training (CET), and (c) problem solving (Miklowitz, 2008). Each stage builds on the previous one, although counselors may find themselves integrating pieces or reviewing elements of the previous stages as treatment progresses, based on the needs of the family system. Treatment using FFT usually lasts approximately 9 months, and is structured around 21 sessions that generally begin following an acute phase of BD (Miklowitz, 2012). Clinical sessions are conducted weekly for the first 3 months, followed by a step-down to biweekly, then once per month. The underlying philosophy of FFT is that BD is experienced by the family, not just by the diagnosed client. As such, BD episodes are viewed as “disaster” experiences shared by the family system, which in turn cause disequilibrium (Miklowitz, 2008, p. 12). Thus, the treatment focus is on reestablishing balance and harmony to the system, which in turn supports the health and wellness of the diagnosed client.

**General Goals**

Although specific goals depend on the information gathered at intake, and often modified during the course of treatment, FFT for BD has six general goals that outline and guide the overall process (adapted from Miklowitz, 2008, pp. 7–12):

1. **Assist the client and relatives in integrating the experiences associated with episodes of BD.** This goal focuses on understanding the diagnostic features of BD, as well as the experience of it from the perspective of the diagnosed individual. It also helps the family system better understand and accept both the severity and significance of the diagnosis.

2. **Assist the client and relatives in accepting the notion of a vulnerability to future episodes.** The focus of this goal is in the recognition that BD is a chronic, persistent, lifelong diagnosis that requires continual support. The diagnosed individual—as well as the family—may believe that the condition can be “cured” and thus have an unrealistic expectation of treatment. The periods of stability that occur between episodes can often contribute to this assumption.

3. **Assist the client and relatives in accepting a dependency on mood-stabilizing medication for symptom control.** Most clinicians specializing in the treatment of BD can attest to the importance of medication compliance; consistent use of mood-stabilizing medications can minimize the intensity of BD episodes, and prevent future occurrences. While BD cannot be “cured” with a medication regimen, the impact of consistent pharmacotherapy is considerable. Clients diagnosed with BD and their families must understand the importance of this component, which can be especially challenging to convey between episodes when the need for medication is less obvious. Furthermore, the undesirable
side effects of many medications can make the client less willing to maintain this portion of the treatment protocol.

4. **Assist the client and relatives in distinguishing between the client’s personality and his or her BD.** Often with BD, there develops a trend with the diagnosed individual and his or her family system to view the individual’s behaviors solely through the lens of the diagnosis. This can lead to inaccurate assumptions about the meaning and importance of behaviors. For example, if the diagnosed client becomes angry, this is not necessarily “the illness talking” nor is it always a sign of an impending episode; in fact, it may very well be a natural and appropriate reaction to a situation. This goal can be particularly challenging for both the diagnosed individual and the family system, as often BD episodes are marked by intensification of what may otherwise be normal traits and behaviors.

5. **Assist the client and family in recognizing and learning to cope with stressful life events that trigger recurrences of BD.** FFT is based on the Vulnerability–Stress Model discussed previously in this chapter. This model includes both an understanding of preexisting biological conditions that create vulnerability and the environmental stimuli that trigger or catalyze reactions based on this vulnerability. It is essential for the client and family to understand how these two elements interact. While the biological components cannot be altered, clients and families should understand how psychosocial stressors such as conflictual relationships and major life changes can impact the vulnerability of an individual with BD.

6. **Assist the family in reestablishing functional relationships after the episode.** The behavioral extremes associated with BD episodes can be challenging for families to cope with. The before, during, and after phases of BD episodes can be aggravated by the conflicts that arise across family systems in response to the situation. Thus, a key focus for treatment is in enhancing communication patterns and providing families with coping skills. Improving communication across the system is essential, as is helping the family members develop supportive relationship behaviors.

**Psychoeducation**

In the initial stage of treatment using the FFT model, the primary goal is psychoeducation. This stage, in turn, is broken down into phases with focus on different informational needs. In the beginning, the clinician imparts a great deal of vital information to the family system; it is important for this to be done in a warm, interactive manner. Clinicians using FFT must be wary of the potential for this stage to devolve into a solely instructional experience, much like a classroom environment. Continually checking in with family members and encouraging discussion about the material can minimize this risk and enhance rapport with family members. Clinicians may find handouts helpful to illustrate key points (Miklowitz, 2008).

In the beginning of the psychoeducation stage, the clinician should provide an overview of the FFT protocol, reasons for family participation, and his or her role as a clinician (Miklowitz, 2008). Treatment goals should also be addressed, both the more broad general goals and specifics for the family system. This is also a good time to provide an overview of BD symptomology, as well as prodromal symptoms and environmental triggers. It is important during such discussions that the clinician take time to explore the unique experiences and perspectives of each family member, as often it is the associated meaning for the system members that impacts the manner in which they cope with and react to a BD episode. Furthermore, discussions around environmental triggers are an important way for families to better understand the blind spots they may have regarding the diagnosed family member’s vulnerabilities. That is—events that may be considered minor, benign, or otherwise simply normal life events to some family members may prove to be substantially more stressful for the family member with BD. For example, starting a new job is
generally an exciting event, marked by optimism and hope. However, it can also be a source of anxiety, as it may trigger fear of failure or insecurities associated with the unknown. For individuals with BD, these emotions are often intensified, and may be difficult to manage. A lack of empathy for the different experience of the family member with BD may also create conflict, as the affected family member may feel unsupported and misunderstood. While such a circumstance may not itself trigger a BD episode, it can contribute to the likelihood of one occurring.

This leads to another important element in the psychoeducation stage of FFT—understanding etiology, course, and prognosis. The reality that almost any life event can contribute to the occurrence of a BD episode may be overwhelming to both the diagnosed client and the family system. As such, it is important for all members to have a basic understanding of the nature of BD, from the genetic foundations to the biological triggers to the environmental influences. As part of this discussion, it is vital for counselors to explain the Vulnerability–Stress Model, as well as how both risk and protective factors impact outcomes. Family members should understand that knowledge is power, and may be their greatest protective factor.

When discussing the genetic and biological influences on BD, it is also crucial for counselors to address “gene guilt” (Miklowitz, 2008, p. 136) and the related topic of inevitability. Conversations around the genetic and biological components of BD may be comforting for some, who are soothed by viewing the disorder as an illness outside their control. Others may focus solely on this piece, raising fears about genetic transmission and the “inevitable” passing of BD genes. It is essential for counselors to tread lightly during these discussions, validating the individual fears and concerns while also educating family members on the multiple influences that impact the development of BD. There is no single etiological pathway, nor one single treatment modality. Family members would benefit most from understanding risk and vulnerability, rather than focusing on responsibility for the existence of the disorder in the family system.

Counselors should wrap up this stage of treatment with a review of topics covered, an opportunity for family members to ask questions they may have about the information, and a plan of support for both the diagnosed individual and the family system. For example, the counselor might suggest a family group activity such as making a plan for how each member can support the success of the individual with BD, as well as steps they can take as a group to improve potential environmental stressors. Such an activity would segue well into the next stage of treatment, which focuses on communication across the system.

Communication Enhancement Training

Following the psychoeducation stage of treatment, family members should have a firm grasp of the basics of BD, as well as recognition of the importance of family dynamics and relationships on the course and severity of BD. The primary goal of this stage is to improve communication strategies, particularly those associated with psychosocial stressors (Miklowitz, 2008). Attention may also need to be given to communication patterns during relatively calm periods, as negative interaction patterns tend to persist during these times as well; however, they are also less obvious, so the clinician may find the focus to be mainly on precrisis, crisis, and postcrisis interactions. There is some degree of psychoeducation to this stage as well, though it is much more interactive with family members, as the clinician uses demonstration and practice to help change communication patterns in the system. The theme throughout this stage is to create supportive communication in which family members become more comfortable with expressing their beliefs and feelings, and more effectively listen to each other.

The CET stage normally begins about 8 weeks into treatment, after psychoeducation has been completed and the diagnosed family member has achieved a degree of stability (Miklowitz, 2008). This is an important consideration, and the time table may need to be
adjusted. While this stage generally positively impacts family dynamics, should tensions still be too high or the diagnosed family member not be stable, efforts to enhance family communication may not only be unsuccessful, they may also be counterproductive. Further, while this stage normally lasts for about seven sessions according to the FFT model, the counselor may find that the emotional traits or developmental stages of family members necessitate a need for some adjustment. For example, families with high emotional expression (EE) in a few or all members may resist the structured communication exercises, and have more difficulty altering their patterns. The counselor will likely be aware of this issue already, however, as a result of the previous 8 weeks of psychoeducation. As such, the counselor should be able to adapt the presentation and practice of CET for the family members.

Four basic communication skills underscore the work of this stage, and provide the foundation for the practice and role-playing demonstrations. It is important to present these in the order listed, as each builds on and supports the next (adapted from Miklowitz, 2008):

1. **Expressing positive feelings.** This is an exercise focused on sharing accolades, kudos, or otherwise positive feedback for the purpose of conveying approval and positive regard. This helps diffuse existing negativity in the system and makes members more amenable to future requests for change. An example of this might be “I was so thankful that you made dinner for me when I had to work late last week.”

2. **Active listening.** This is an essential skill for family members, as it not only supports greater understanding, but can also convey respect and validation. Counselors should demonstrate the components of this skill to help clarify the fundamentals. Examples of active listening include maintaining eye contact with the speaker, nodding head while the other person is speaking, verbalizations such as “uh-huh” or “sure,” and reiterating or paraphrasing pieces of what was said.

3. **Making positive requests for change.** This skill should be introduced as a means of de-escalating tensions as well as fostering growth across the system. Again, this skill is best demonstrated first by the counselor, to include important elements such as making “I” statements and ensuring the request is not a veiled criticism. An example of this might be “I would really appreciate if you would call me and let me know when you are going to work late.”

4. **Expressing negative feelings about specific behaviors.** The goal of this skill is to clearly identify an undesirable behavior, describe the associated feelings, and make a specific request for change. As with the previous skill, it can also foster positive growth across the system. However, it can also be very challenging to implement as it can give rise to defensiveness, or reveal additional conflicts in the system. Counselors should be prepared to intervene and redirect if necessary during practice. An example of effective use of this skill might be “I felt a little disrespected when you came home late last night and never called. I would appreciate it if you would let me know beforehand next time.”

When providing both the instruction and feedback for the CET stage, counselors should remember that these skills may feel forced and unnatural—in many ways, they are. Family members view this stage as learning new “building blocks,” although they ultimately construct their own “house.” The family should also recognize the strengths and skills already in the system, as well as pieces that are less conducive to effective communication. Throughout the practice exercises, the counselor’s encouragement and support, as well as identification of ways CET can improve understanding and dynamics, can go a long way in supporting the efficacy of this stage. Furthermore, it is helpful for the family members to understand that while practice does not make perfect, it can and will improve interactions during times of stress. That is, the more the family members practice these
skills, the more comfortable and natural they will become—which will be especially important during times of stress and conflict.

A secondary benefit of CET can be found in changing patterns of family dynamics (Miklowitz, 2008). That is, training family members to communicate in a more open, positive, and supportive manner can alter existing patterns of interaction that are less beneficial. Whether the family relationships are marked with rapid escalation or avoidance, structured communication can buffer the negative effects of these habits by forcing the individuals to create new patterns of communication. This change often requires a lot of practice, and can be met with resistance; however, the counselor can facilitate this change through consistent practice, and by encouraging family members to raise the more difficult topics in clinical sessions. That way, the counselor can offer feedback and redirection as needed, and more effectively coach the family members toward success in their new communication efforts.

Lastly, a third—and also indirect—benefit of the CET stage is found in its impact on EE. In short, EE is a measure of the emotional attitudes and beliefs conveyed in family dynamics (Miklowitz, 2008). Families that are high in EE often display negative and critical communication, criticisms, hostility, and emotional overinvolvement. These behaviors are observed in response to BD episodes, and can be predictors of future relapse (Fredman, Baucom, Boeding, & Miklowitz, 2015; Fredman, Baucom, Miklowitz, & Stanton, 2008). Thus, it is clear that improved communication patterns can have a positive impact on these behaviors and improve relationships across the system. Furthermore, the resulting improvements in family dynamics observed in this stage help provide a more positive foundation for the next stage of treatment: dealing with problems.

**Problem Solving**

Once family members have a solid understanding of BD and have demonstrated improvement in their communication and dynamics, they are ready to move into more directly addressing issues that persist. Usually introduced at around the 15th session of FFT, this stage focuses on (a) recognizing and discussing problems and (b) developing a plan to address these problems (Miklowitz, 2008). A significant aspect of this stage can also be found in the empowerment of the family system; that is, helping the family learn experientially that they can and will be able to handle issues that arise. The counselor facilitates this through practice in addressing current issues, and by helping the family develop a proactive pattern of addressing these. The success of this stage is directly impacted by the successes of previous stages; thus, the counselor may find the need to go back and review materials or exercises previously covered, depending on the family’s responsiveness to interventions in this stage.

As with the CET stage, the problem-solving stage is best begun with a structured approach, which essentially teaches the integration of previous stage skills while providing a forum for effective family therapy. The approach to problem solving is broken down into five elements (adapted from Miklowitz, 2008):

1. **Define the problem.** It is important for all family members to contribute to the description of the problem, to share perspectives, and to feel heard. This is facilitated by skills acquired in the previous stages.

2. **Identify possible solutions.** Any potential, reasonable solutions should be noted, without any discussion of feasibility. As with problem definition, all family members should contribute with ideas of how the problem might be solved.

3. **Discuss pros and cons of different solutions.** In this step, family members should discuss the benefits and costs of each idea, and select the best solutions. It is possible that more than one solution may be chosen in response to the problem.
4. **Implement selected solution(s).** Based on the selected solution(s), family members carry out efforts to achieve the desired goal.

5. **Evaluate effectiveness.** Family members reflect on the effectiveness of the chosen solutions, give each other recognition for efforts, and discuss ways to improve in the future.

As with the structured approach of the CET stage, family members may be initially resistant to this approach to problem solving. It is important to remember that they are learning new skills, which is most effectively accomplished by breaking pieces down and understanding what does and does not work. Furthermore, the structured nature of this problem-solving approach supports involvement of all family members, which in turn reinforces positive relational dynamics.

It is recommended that families practice problem-solving skills between sessions using this structured format (Miklowitz, 2008). The counselor should consider providing a worksheet to help families follow the steps, and to support their internalization of the related skills. Furthermore, the families should be encouraged to bring their worksheets to sessions, so that the counselor can review the steps and outcomes with them. If additional intervention by the counselor is needed, this is an optimal time for it. However, counselors should also remember that they are essentially trying to work themselves out of a job. That is, their goal is to teach the family skills for solving their own problems, rather than becoming a necessary part of the equation.

### Challenges in Family Systems Treatment of Bipolar Disorder

As with any mental health treatment, there can be challenges and considerations unique to the individual diagnosed with BD, as well as to the family system. For example, there is considerable social stigma attached to the BD diagnosis, which may make both the diagnosed individual and the family less comfortable with participating in treatment. In addition, family systems work necessitates the coordination of multiple family members’ schedules, involves a high degree of openness and vulnerability, and requires them to embrace change. Some individuals and families may feel pressured by the expectations of family treatment, which can present a great challenge to the process. While it is impossible to predict all potential hurdles the counselor may encounter, some common issues are discussed in the following sections.

**Denial**

Denial may be present in the diagnosed member of the family system, the family members, or both. This may be as obvious as complete rejection of the diagnosis, or a more subtle minimization of the severity and significance of the disorder. Regardless, counselors should be sensitive to the reasons behind the denial, and focus treatment on the issues at hand. For example, rather than engaging in what could essentially become an argument as to whether a diagnosis is valid, it is better for interventions to emphasize growth and improvement, and to de-emphasize labels. Although acceptance of the diagnosis is important, the label itself may be contributing to the denial present in the family system—perhaps due to the stigma of mental illness in society as a whole. It is also possible that various members of the family system have differing perceptions about the diagnosis or its severity, making it more likely that there may be some denial regarding the necessity of family treatment. It is helpful for counselors to remember that they treat **people not diagnoses**, and to let that philosophy guide their empathy and validation of the family members’ experiences and beliefs.
Resistance

Resistance is, in many ways, the more active and mobilized form of denial. That is, it is often the presence of denial that drives resistance behaviors. When individuals with BD and their families are mired in denial, it is far more likely that they will be resistant to treatment. Resistance may be as overt as refusing to attend sessions or to comply with medication protocols, or more subtle as observed in chronic tardiness or failure to fully participate in treatment. Resistance may also be present in the form of verbalized blame or defensiveness. Sometimes, family members resent the need to participate in treatment, and may feel as though they are being “punished” for the diagnosis of one family member. As with denial, it is important to focus on the issues at hand rather than the labels, and encourage family members to be open to improving relationships and communication across the family system.

Crises

It would be unfair to assume that crises are inevitable in families with one or more members having BD, but it is essential to plan for them. Even with the most effective treatment, relapse episodes are likely to occur at some point in time, and families should have a plan in place to address these. Planning for crises may be unpleasant and elicit additional resistance, but, if presented properly, it can also empower and calm fears of what may lie ahead. The nature of acute BD episodes, whether mania or depression, can make it difficult for the diagnosed family member to have an objective, realistic view of what is happening for him or her. Therefore, identifying evaluative behaviors and a plan of action to ensure the safety of the individual and family are important aspects of crisis management.

Relapse of acute BD states may be accompanied by additional crises, such as suicidal ideation, substance abuse, aggression/violence, or other self-destructive behaviors. Again, a plan to address these issues, should they arise, is an essential part of minimizing impact and improving outcomes. Discussing the topics before they happen in a nonjudgmental, objective, solution-focused way can help family members better deal with the crises when they do occur.

ETHICAL AND LEGAL IMPLICATIONS

Clinicians working with families in which one or more members is diagnosed with BD must follow, though arguably more complex, ethical, and legal considerations. Basic ethical foundations of beneficence, nonmaleficence, justice, fidelity, and autonomy apply across all clinical fields, including family therapy. In addition, practice standards pertaining to consent, confidentiality, competence, assessment, disclosure, record keeping, and other parameters underpin foundations of practice for family treatment, just as they do in individual work. However, working with multiple members of a family system can make the challenges common to enforcing such standards increase exponentially. That is, the more family members participating in treatment, the more challenging ethical and legal issues can become.

Whether a counselor focuses on individual or family work, it is imperative to have a solid knowledge of ethical and legal requirements and guidelines to which the counselor must adhere. A thorough understanding of local, state, and federal laws can provide an effective foundation. The counselor should also be familiar with ethical decision-making models upon which to rely for more complex circumstances. Still, it is nearly impossible to plan for all potential situations that may present an ethical or legal quandary. Therefore, this section focuses on some of the more common ethical and legal considerations in daily practice as they may specifically pertain to family work with individuals diagnosed with BD.
Informed Consent

The most immediate concern when working with clients diagnosed with BD lies in their capacity for informed consent. For example, common issues with acute mania include impaired judgment and lack of insight (Appelbaum, 2007). It can be argued, then, that clients with BD who are experiencing an acute stage do not have the capacity to ethically and legally consent to treatment (Misra, Rosenstein, Sochermann, & Ganzini, 2008). To complicate matters, assessment of an individual’s manic state may not be immediately reliable, as lower levels of mania are often difficult to detect, and only clearly evident in retrospect. Furthermore, the existence of an acute state does not necessarily equate to inability to consent. Thus, accurate appraisal of competence for consent may be challenging with individuals diagnosed with BD (Borkosky & Smith, 2015).

Another important consideration pertaining to informed consent relates to systems work in which a minor is included. While legally most states allow parents to sign consent on their minor children’s behalf, the family counselor should consider whether ethically this documentation is sufficient. It can be argued that while children rarely choose to participate in treatment on their own accord (Koocher, 2008), if they do participate, they should understand the process and goals of treatment. Furthermore, it may be prudent to have minor children sign informed consent agreements along with parents, even if their signatures are not legally binding. In doing so, the counselor includes the minor child in the process of agreeing to treatment; as such, the minor child may feel empowered and be more engaged.

Confidentiality

As with consent, an immediate concern over confidentiality relates to an individual’s mental state and capacity. Individuals in acute stages of BD may exhibit potentially harmful behaviors that require intervention of external support, such as hospitalization. All family members should understand prior to beginning treatment that safety is first and foremost—and as such, the clinician may need to take steps to ensure safety of one or all members, potentially compromising confidentiality. Such measures should be outlined clearly in the confidentiality disclosure reviewed prior to treatment.

Another common issue in working with family systems lies in the potential for “secrets” to be revealed, compromising the confidentiality of one or more members. This may occur accidentally during a session, or result from the sharing of information outside the clinical environment. For example, stigmatized behaviors such as hypersexuality, gambling, and substance use are common issues with BD; it may be very embarrassing to the client or family members to have such information be shared outside the family system. Counselors and clients should be aware of the potential damage to relationships should such information be revealed, and be clear on the boundaries and practice of treatment.

Counselors should also consider that confidentiality and consent are “parallel and corollary rights” (Borkosky & Smith, 2015, p. 20)—the issues, limitations, and requirements for these considerations are intertwined and interrelated. In other words, ethical and legal concerns that pertain to one of these aspects likely affect the other. As such, it may be in the counselor’s best interest to discuss them concurrently with clients’ families.

Identifying the “Client”

A core philosophy in family systems work is that the family itself is the “client.” The counselor’s focus is on relationships and dynamics, which in turn impact the mental health and
wellness of the individuals in the system. However, because most third-party payers do not reimburse for treatment without an identified client (Kress, Hoffman, Adamson, & Eriksen, 2013), it becomes necessary to select one person in the system as the “client,” with other family members participating in the treatment of that individual. This can present an issue not because this is an unethical decision for the counselor, but because this practice keeps the focus on one individual in the system as the “problem.” This, in turn, can perpetuate some of the very issues the family system seeks to remedy.

Because caregivers and other family members may also be exhibiting mental health issues, counselors might choose to identify more than one client among family members. This practice may “level the playing field” somewhat, but can also be a slippery slope in practice. Diagnoses often become part of an individual’s medical record; as such, family members should be fully informed of the implications of additional diagnoses among family members.

Identifying the “Family”

The “client” in family counseling is the family itself; however, how “family” is defined may vary among participants or even with the attending counselor. Some individuals may consider “family” to mean only legal or biological relatives; others consider meaningful relationships to be the defining aspect of “family.” The individual with the BD diagnosis may wish to include a best friend or intimate partner in family sessions; this may not be acceptable to other participants. Some amount of discussion, or even negotiation, may be needed to maximize the benefit to the individual and to the family system as a whole. It should be agreed upon at the outset of treatment who will participate in the family sessions, whether or not they are legal relatives of the individual with the BD diagnosis.

Counselor Competence

Counselors are bound to practice within the scope of their competence (Sori & Hecker, 2015). It is widely recognized that working with families effectively requires specialized training. Knowledge of family system theory is essential, as is an understanding of the developmental adaptations often necessary for successful family therapy. A counselor working primarily with individuals, even if specializing in the treatment of BD, should not assume that interventions and techniques can be extrapolated to family systems work. Conversely, even the most skilled family therapist should seek consultation and supervision when working with the first clients in which BD is a diagnosis in the family system. Further, it would behoove the family therapist to obtain additional training in empirically supported interventions specific to BD and to have an in-depth understanding of the development, course, and prognosis for the disorder.

Treatment Adherence Versus Coercion

The most prominent issue when considering the topic of treatment adherence versus coercion relates to psychopharmacology. As was noted previously in this chapter, medication is usually an important part of effective treatment of BD. Failure to adhere to a medication regimen can have disastrous effects—not only on the diagnosed individual, but also on the family system. Clients who refuse to take prescribed medications may be deemed “resistant” to treatment; however, counselors should consider the impact of such labels.
Clients with a BD diagnosis may feel coerced into taking medications if they believe failure to do so will cause them to be discharged from treatment. Furthermore, the participation of a caregiver or other family member in medication monitoring (often a recommended part of family treatment) may cause the diagnosed individual to feel pressured to adhere to the medication regimen. It is important for clients with a BD diagnosis to understand that they have the right to refuse medications, but should empower themselves to choose the pharmacological support, as it enhances their treatment outcomes. It is also important to frame the family participation in a positive way, and to minimize the potential perception of coercion.

Legal Issues

It is always important, as an aspect of the confidentiality review with clients, for counselors to address the potential for legal issues and how information might be handled. Clients who are court ordered for treatment may actually be required to share information from treatment, which can result in violation of confidentiality for the participating family members. Furthermore, individuals with a BD diagnosis tend to have higher rates of legal problems than the general population (Frank et al., 2008), which makes conversations about information disclosure in such situations especially imperative. Addressing the topic at the outset of treatment could not only clarify any future questions about legal disclosure, but also foster important conversations between the counselor and participating family members. In fact, it may be wise to include an addendum to the standard consent form that is specific to legal issues (Borkosky & Smith, 2015).

Counselors may also be called to testify or otherwise share information should the family system experience divorce or other legal dissolution of the household. Considering that the divorce rate for individuals with BD is two to three times higher than in the general population (Granek, Danan, Bersudsky, & Osher, 2016), it is important to address this very real possibility at the outset of treatment. Some counselors try to eliminate this involvement by including an agreement in the intake paperwork stating that the clients will not call the counselor to testify in any legal proceedings; however, this rarely holds up in court (Perlman, 2012). It is quite common, in fact, for family counselors to become involved when there are issues of custody of minor children (Borkosky & Smith, 2015; Boumil, Freitas, & Freitas, 2012).

There may also be legal considerations that do not involve the disclosure of information, but rather how the events impact family members. As noted previously, individuals with a BD diagnosis tend to have higher rates of legal involvement. It is important to address the impact of these events not only on the diagnosed individual, but also the rest of the family system. Disclosures of such information—whether preexisting or occurring during treatment—should be agreed upon and limitations made clear prior to the start of treatment.

CASE CONCEPTUALIZATION

Throughout the chapter we have provided some brief examples of how BD manifests in people and impacts families. Practice in working with individuals and families often occurs within training programs, most specifically in internship experiences. The following case of Simon is presented to help you flesh out the concepts we have introduced in the chapter and to prompt you to think carefully about how you would approach working with someone like Simon and members of his immediate and extended family.
Presenting Concerns

Simon was a 46-year-old Caucasian male who was first diagnosed with BD in his early 20s. Simon had been in and out of treatment for BD since age 23. However, he had not experienced a consistent severe onset of symptoms until late into his 20s, which made him believe that his illness could someday be “cured.” Still, he had four prior hospitalizations, two of which had been for depressive episodes so severe that he had been suicidal. Simon had been inconsistent with outpatient psychotherapy, and had only participated in family therapy briefly during hospitalizations. Recently Simon had experienced a relapse, resulting in his needing brief inpatient treatment for stabilization and medication adjustment. Prior to hospitalization, Simon had experienced an acute manic episode that included his withdrawing a significant amount of money from the retirement account he shared with his wife, Bridget (44). Simon had decided that he wanted to pursue his hang-gliding hobby full time, and needed the money for a custom rig and supplies. During this period, Simon was also experiencing reduced sleep, sometimes staying awake for as long as 3 to 4 days at a stretch while he worked on building the motorized component of the rig. Simon had believed he could use the rig to set a world distance hang-gliding record, and dismissed his wife’s disagreement as “not supporting [his] dreams.”

Concurrent Problems

Simon had a history of Bipolar I Disorder, and had experienced multiple inpatient and outpatient treatment episodes, with the most recent being inpatient treatment following an acute manic episode. Simon’s absence from work due to hospitalization, combined with poor work performance and issues about getting along with peers, caused him to be fired from his job. Bridget worked full time as the manager of a small medical practice, but her income was not sufficient to fully support the family. Simon was actively seeking employment at the time he and his family came in for family counseling; the topic of finances remained a source of stress for him and his wife. Bridget shared that they fought about money often, as well as about Simon’s aversion to taking his medications. Although Simon reported he was compliant with medications at the time of intake, Bridget noted that he had a history of stopping his medications because he did not like their side effects, and that he had done so shortly before the onset of the last acute manic episode.

Background History and Stressors

Despite multiple treatment episodes, Simon has been inconsistent with medication management and psychotherapy. He is currently unemployed and experiencing some financial stress. Simon and Bridget had been married for 21 years, and had two teenage children—Danielle (17) and Trevor (15)—who also attended the first family session. The children reported that they loved their father very much, but that he was difficult to live with and that they generally avoided being at home. Danielle also admitted that she was embarrassed by her father’s illness and hospitalizations, and could not wait to go away to college so she could “get away from the craziness” at home. Trevor had a less critical view of his father’s illness, but did admit that “it would be nice to have a peaceful household for once.” Both teenagers reported that their biggest complaint at home was how often and loudly their parents fought. The family did not report any significant religious or cultural affiliations, and had no extended family in the area.
Strengths

Simon expressed a determination to improve and a willingness to adhere to participation in family therapy. The family included his wife and children, all of whom expressed a commitment to participate. At the time of intake, there appeared to be a relatively low emotional expression (EE) in this system, which indicated a more open and supportive communication.

DSM-5 Impressions and Implications

Simon was the identified client in this case. The initial diagnosis was Bipolar I Disorder, most recent episode manic, partial remission. Simon did not present acute symptomology at the time of intake, as he was consistently taking medications to help manage the disorder. At the time of his previous acute manic episode, which resulted in a hospitalization, Simon exhibited abnormally elevated mood, decreased need for sleep, flights of ideas, and excessive spending. The behaviors caused significant impairment at both work and home, and were not due to other factors or influences. Simon reported that in retrospect he could recognize manic symptoms, but at the time of the episode felt incredibly energized and motivated.

Relational Problems

Simon had a history of resisting feedback from his wife regarding her observations of his behaviors, which led to more conflict in the marital and familial dynamics. Bridget had threatened to leave Simon multiple times over the course of their marriage, usually after or during a manic episode. At the time of intake, Bridget expressed that she wanted her marriage to work and still loved Simon very much, but that she had “grown weary” after all the years of conflict and turmoil with Simon. Bridget also noted that the children were almost out of the house, which lessened her motivation to “put up with (Simon’s) antics.” With this in mind, Relationship Distress With Spouse was included in the initial diagnostic impression. In addition, Child Affected by Parental Relationship Distress applied in this case, based on the reported impressions of the two teenage children. Lastly, because Simon was currently unemployed and the family experiencing financial stress, Other Problems Related to Employment and Unspecified Housing or Economic Problem were added.

Assessments

A biopsychosocial assessment was completed during intake; this provided not only a summary of presenting concerns, but the context—both historical and contemporary—needed for effective treatment. In addition, to better understand the interactive systemic influences across the system, a genogram was constructed. This assessment focused on the immediate family system—Simon, Bridget, Danielle, and Trevor—and their relational dynamics. The genogram also included extended family members and their systemic influences. Because Simon’s most recent episode was manic, the Altman Self-Rating Mania Scale (Altman et al., 1997) was chosen both as a starting point for the clinician and as a help to monitor progress during treatment.
Interventions

The recommended systemic approach for this family system was FFT (Miklowitz, 2008). This protocol included interventions focusing first on psychoeducation to help the family members understand the diagnosis, as well as the need to adhere to treatment (including medications). The next step was to address the stressors associated with relational dynamics across the system by improving communication patterns. Although family members exhibited a relatively low EE, they did report conflicts associated with parental arguments and a general avoidance of interaction. The CET component of FFT addressed these issues. Lastly, as the family members moved into the problem-solving phase of FFT, they developed their ability as a system to recognize and address issues, and were able to address these together. This last stage of treatment was particularly essential as it not only reinforced the progress gained from the CET stage, but also empowered the family. This, in turn, supported cohesiveness and wellness across the system.

Ethical and Legal Implications

In accordance with ACA Code of Ethics, informed consent was obtained from all family members, including the minor children. It was vital for all family members to understand the scope and limitations of confidentiality, and that the focus of treatment was on the system as a whole. Furthermore, while there was no reported history of domestic violence in this family system, it was prudent to review this piece carefully, as physical abuse is a common issue with BD. This sensitive topic was approached in a manner that was supportive and nonjudgmental, while also setting clear boundaries regarding family safety and the counselor’s duty to report.

DISCUSSION

As you continue to reflect on the case study and the overall approach, contemplate these questions:

- A genogram is a vital assessment tool for family work. How can you integrate the Vulnerability–Stress Model into this assessment, and why is it such an essential component for this family?
- Z codes identify other conditions that may be the focus of clinical attention. Based on the information in the section “Case Conceptualization”, what additional possible Z codes may apply to this case? What more do you need to know to determine the accuracy of these, and how can you integrate these into treatment?
- How do the psychosocial stressors in Simon’s life impact his level of functioning at this time?
- An important aspect of psychoeducation would be to ensure that Simon and his family accept and commit to a consistent medication regimen. How can you approach this with the family system without coercion?
- How does the low EE of this family system impact the CET and problem-solving stages of treatment? How might these, in turn, support Simon’s recovery and the overall wellness of the family system?
SUMMARY

BD affects individuals and families in profound and important ways. It is important to understand that primary treatments for bipolar symptoms also include a family systems perspective in putting into context how manic and depressive symptoms occur, including how the therapeutic relationship impacts affected individuals and families. Family-focused treatment (FFT) provides an effective, evidence-based model of supporting families. It is also vital to maintain a strong ethical stance when incorporating treatment options to ensure that ethical principles (e.g., beneficence, fidelity, autonomy, etc.) are preserved. The meaningful inculcation of these concepts and practices is an individualized process where counselors are faced with practicing effectively and being mindful and intentional about how they personalize effective interventions. We encourage counselors to be thoughtful, intentional, and intelligent in their consumption and integration of the treatment research. Counselors have as much potential to learn about themselves, their values, biases, and how they contextualize their own personal life experiences from working with clients and families as they have to learn about the clients and families they seek to help. This awareness is essential in gaining a true and empathic understanding of how people deal with BD as a challenging, life-disrupting condition. Clients and their families can easily become resilient heroes instead of ineffective victims through the challenging and often uncertain process of treatment.

REFERENCES


The word paraphilia is derived from the Greek language. The term para means “around or beside,” and philia means “love.” In literal terms, paraphilia means love that is outside the norm or it can be translated as “abnormal or unnatural affection” (Morrison, 2014, p. 565). Paraphilias specifically refer to sexual arousal and satisfaction other than through behaviors associated with human courtship and genitalia (American Psychiatric Association [APA], 2013b). The term first appeared in reference to early 20th-century ethnographic anthropological research that called for a less medicalized view of sexuality (Janssen, 2014).

We can thank Dr. John Money for popularizing paraphilias as he spent much of his career categorizing paraphilias in the 1970s. Before that, the term paraphilia was largely unfamiliar. In 1980, paraphilias made it into the Diagnostic and Statistical Manual of Mental Disorders (3rd ed.; DSM-III; APA, 1980) as official diagnoses and there have been changes along the way to these categorizations. For instance, is an atypical sexual behavior always a Paraphilic Disorder? Or can a paraphilia be a sexual orientation, like “kink” or “fetish” communities, for example? We discuss the answers to these questions in great detail throughout the chapter.

Let us first be clear that fetishes and kink are not the same as paraphilias or Paraphilic Disorders, as they are now termed, even though they are often used interchangeably. We differentiate among these terms in great detail later in the chapter along with giving readers guidelines for distinctive treatment approaches. Since we cite research and other literature written prior to a change in terminology, we refer to “paraphilias” and “Paraphilic Disorders” interchangeably in this chapter. However, clinicians should make the distinction in their practice with clients and refer to the current revised term Paraphilic Disorder when a diagnosis is indicated.
Systems theory allows us to understand the connections that either reinforce or add to the disintegration of ourselves and our relationships. By assessing and addressing the client’s family, social, and moral influences, we are able to increase our understanding of how best to move forward with a client diagnosed with a Paraphilic Disorder. There is a common thought that systems theory can be used only when working with families, and this thinking has led many counselors to put the systems approach on a shelf, in favor of individually focused theoretical counseling approaches (Smith-Acuña, 2011). Using a systems approach to diagnosing a Paraphilic Disorder, however, allows for less linear thinking and more contextual reasoning, which aids in lowering the number of false positive diagnoses for the paraphilias. Connectivity and attachment style within the family generate distinctive emotional patterns that are greater than what one person could accomplish alone (Chibucos & Leite, 2005; White & Klein, 2008; Whitechurch & Constantine, 2009). It is our belief, therefore, that addressing treatment within a family systems approach is one of the most effective ways to treat Paraphilic Disorders. Currently, we are in the age of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013a), where the term Paraphilia is changed to Paraphilic Disorder. Someone with a Paraphilic Disorder experiences significant distress and impaired functioning from personal sexual interests and sexual arousal outside of the cultural norms established by the family of origin system, current relationship system, ethnicity, or legal system. Just being embarrassed about certain sexual urges or feeling shame does not elicit a Paraphilic Disorder diagnosis. And although the DSM-5 has opened the door for women to be diagnosed with paraphilic behaviors other than Pedophilic Disorder, almost all people diagnosed and treated for a Paraphilic Disorder are male (Garcia & Thibaut, 2011; Morrison, 2014).

Paraphilic Disorders are defined in the DSM-5 as emotional disorders caused by sexually arousing fantasies, urges, or behaviors that are recurrent, intense, occurring over a period of at least 6 months. Such disorders cause significant distress individually or across a variety of systems, often having a negative impact on the sufferer’s work, social, and/or familial system. The legal system is sometimes involved as well, causing additional problems and monetary costs.

The definition of the disorder, aforementioned, stands in contrast to the definition of sexual variants, which are nonpathological, atypical, consensual sexual behaviors, not diagnosable as mental illness. This means that although someone may engage in sexual practices outside the norm, he or she may not have a Paraphilic Disorder at all. For example, for many years all fetishistic and kinky behaviors were categorized as disorders. In the DSM-III, there was no differentiation made between pathology and orientation, meaning if someone practiced atypical sexual behavior, that person was diagnosable as mentally ill. This changed a bit with the Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV; APA, 1994) revisions that stated a paraphilia was a pathology only if it caused distress to the targeted person or sexual interest. This interpretation was still pretty faulty, however. Why? If a person acted horrified at the idea of kink play suggested by his or her partner (e.g., “Hey, let’s role play—I’ll dress up in your underwear and maybe you can tie me up with this scarf then slap me until I say stop. What do you think?”), the partner suggesting atypical sex play could be diagnosed with a mental illness, and worse. During contentious custody hearings, a spouse could report such atypical sexual behaviors as perverse and deviant acts, causing loss of child custody due to editions of the DSM that predated the current fifth edition (Wright, 2014).

Still, there is work to do in future DSM revisions with regard to the paraphilias. Research has historically used samples drawn from forensic populations, which is viewed by some as sampling bias (Krueger, 2010; Wollert & Cramer, 2011). Others believe that bias was not overcome during the most recent DSM revision of Paraphilic Disorders, citing a
lack of diagnostic specifier uniformity and omission of key research in support of new diagnostic categories for sexual and gender identity disorders, as well as significant conflict regarding validity of the paraphilias included in the fifth edition (Balon, 2013; Welch, Klassen, Borisova, & Clothier, 2013). Currently, due to exclusion of a remission specifier for pedophilia, a person with this diagnosis has no hope of full recovery and experiences perpetual legal entanglements (Balon, 2014).

Those diagnosed with a Paraphilic Disorder of one type are often comorbid with another type, meaning that they often exhibit symptoms from two or more Paraphilic Disorders. It is not uncommon to have multiple paraphilic behaviors present even if they are not all diagnosable per DSM-5 criteria (APA, 2013a; Morrison, 2014). Polyamory is also common among certain nonpathological paraphilic behaviors, with one or more identified primary partners and multiple “play” partners. In family systems parlance, such polyamorous relationships may exhibit a high level of differentiation from family of origin practices while also presenting a level of emotional fusion with multiple partners.

Gender is currently not used as a DSM-5 diagnostic criterion for the Paraphilic Disorders; however, transvestic disorder no longer restricts the diagnosis to heterosexual men. This shift may see an increase in the number of people diagnosed with transvestic disorder as heterosexual and homosexual men and women who experience significant impairment and/or distress across life domains due to such behaviors can now be diagnosed (APA, 2013b).

Currently, with the DSM-5 revisions, no paraphilias or kinky behaviors are now regarded as mental disorders in themselves, prompting the question, “Are we missing a large group of people who need treatment but who fear seeking treatment due to perceived or real counselor bias and stigmatization?” This question is addressed in more detail in the subsection on ethics and assessing for bias.

Historically, sexuality has been both demonized and glorified, depending on the cultural context. There has been a fluid shift between viewing uncommon, fringe, or otherwise “abnormal” sexuality as resulting from a disease state or from a place of biological variations on a theme. Viewing sexuality and sexual expression from the lens of pathology is the work of the DSM, and it is our work as counselors to change the lens toward normative, albeit atypical variations of sexual expression, if specific parameters for diagnosis are missing (De Block & Adriaens, 2013).

Moving from this broad overview, what, specifically, are the diagnosable Paraphilic Disorders? Are they merely a culturally defined combination of sexual preferences that are frowned upon due to social mores and norms? Is there no longer a clear-cut way of assessing for sexually deviant behaviors? Must counselors have specialized training to work with clients diagnosed with a Paraphilic Disorder? Are all paraphilias pathological? These questions are very much at the forefront of counselor education on diagnosis using the DSM-5.

In this chapter, we provide information on the specifics of each paraphilia listed in the DSM-5, with a discussion on cultural and family systems implications, assessment and intervention strategies, and legal and ethical guidelines for working with Paraphilic Disorders. We end with a case study for clinical practice in diagnostics and interventions.

### Exhibitionistic Disorder

People with Exhibitionistic Disorder get sexually aroused by exposing their genitals to unsuspecting strangers. In other cases, people with this disorder have a strong desire to be observed by others during a sexual activity. Urges are acted on with nonconsenting others and people who suffer from this disorder experience significant distress and have impaired function because of their urges and impulses. In order to meet diagnostic criteria,
a person must be distressed or impaired by exhibitionistic behaviors, fantasies, or urges for 6 months or more or cause harm to others. Because of these strict guidelines, many people who engage in exhibitionistic behaviors do not meet criteria for Exhibitionistic Disorder. In fact, the definition for exhibitionistic disorder differs from the definition for the general pattern of behavior of exhibitionism (Zucker, 2013).

Many people with exhibitionistic disorder may masturbate during their exposures or may fantasize about exposing themselves while masturbating. Most of these are men. They may be aware they need to shock or surprise nonconsenting observers in order for them to be sexually aroused. In most cases, the victim of exhibitionistic behavior is an adult female or a child. Exhibitionistic behaviors are often viewed as nuisance behaviors since physical harm is rare and actual sexual contact with a victim is hardly ever pursued.

People who suffer from this disorder usually start exhibiting symptoms during adolescence, but the first exhibitionistic act could occur as early as preadolescence and as late as middle age. Although most people with this disorder are married, they often have troubles in their marriage due to social problems or sexual problems.

More men than women are diagnosed with Exhibitionistic Disorder, and this may be a cultural factor. Western society, along with other cultures, accepts and encourages female exhibitionism. Hence, distress and impaired function may not be factors for many women with exhibitionistic behaviors and tendencies.

Some people with exhibitionistic tendencies want others to watch them perform sexual acts, and they prefer a consenting audience rather than surprising an unsuspecting stranger. Many people with these urges end up in the pornography industry or may make amateur pornographic videos of themselves. They do not usually have distress over their desires and so are not candidates for diagnosis.

Most exhibitionists (diagnosable or not) are married. However, their marriages are often negatively affected by poor social and sexual issues, including frequent sexual dysfunction. Couples working from a systemic perspective are encouraged to jointly take responsibility for the problems in their relationship, which decreases some of the shame associated with treating this disorder.

Frotteuristic Disorder

People who suffer from this disorder have an intense sexual arousal when they touch or rub against nonconsenting people. They may also fantasize about touching or rubbing up against others who are nonconsenting. Usually, people with frotteuristic behaviors rub against others in public settings, such as crowded places like subway systems or buses. In order for people to be diagnosed with frotteuristic disorder, they must experience significant distress or functional impairment over their urges, fantasies, or behaviors for 6 months or more.

People with this disorder are diagnosed when they rub against or touch nonconsenting individuals on three separate occasions or more. They must also exhibit distress, and they could also be diagnosed with this disorder even if they never had any physical contact with others but feel significant distress over their desires and impulses.

People with frotteuristic disorder can exhibit symptoms as early as late adolescence. They might initially rub against their friends, family members, or teachers and feel pleasurable feelings without feeling sexual arousal. This will later progress to sexual arousal, but frotteurism is often pleasurable but nonsexual in the earliest phases of this disorder.

Because the nature of this disorder is engaging with nonconsenting others, legal consequences can occur. Although many people with the disorder are breaking the law, many of these behaviors are seen as nuisance behaviors since they rarely end in physical harm or pursue more invasive sexual acts. Because frotteuristic behaviors are usually conducted
in public, crowded places, nonconsenting individuals may just interpret these behaviors as accidental or annoying but not intentional. One can see how many frotteuristic acts may go unreported (Fileborn, 2013) and statistics for people with these behaviors may be grossly distorted. In addition, families and spouses may not be aware of a family member or spouse who suffers from this disorder since people engage in frotteuristic behaviors outside of the home.

**Pedophilic Disorder**

Pedophilic Disorder is characterized by recurring sexually arousing fantasies, urges, or behaviors that involve prepubescent children or young adolescents (usually younger than 13 years). These urges must persist for 6 months or more and are often understood as biological sexual drives (Berlin, 2011). A person with pedophilia does not have to have acted on these urges to be diagnosed. Pedophilic urges and fantasies must be impairing to the individual or greatly distressing for diagnosis to occur.

This disorder is diagnosed in people who are at least 16 years of age or older and when the child who is the target is 5 years younger than the person diagnosed. Older adolescents (e.g., ages 17 and 18) may not meet diagnostic criteria if they are involved with younger adolescents (around ages 12 or 13). That is not to say that legal issues would not arise from such a relationship.

It is important to note that legal and diagnostic criteria differ substantially with this disorder. Although a person may not meet diagnostic criteria for Pedophilic Disorder, he or she may break laws when involved with younger adolescents (i.e., statutory rape cases) and suffer legal consequences due to those behaviors. It is also important to note that the age ranges under this diagnosis are Western cultural ranges. In other cultures, sexual activity, childbearing, and even marriage are allowed and accepted at younger ages.

Most people who suffer from pedophilic disorder are males. They will be attracted to either young boys or young girls, or even both. Preference is more often toward the opposite sex than the other way around. In most cases when there is an attraction toward a child or offense toward a child, the offending person with pedophilic disorder is usually known to the child. He or she may be a teacher, family member, family friend, and so forth.

Some people with pedophilic disorder or pedophilic urges can be attracted to both children and adults at the same time, whereas others are exclusively attracted to children and have no attraction toward adults. People with pedophilia who have victimized a child are often in denial that an offense happened. In many ways, they think that they are helping the children they victimize by being close to them. Many people with pedophilia choose children whose parents seem unfit or absent in their eyes. In this way, an offending adult feels as if he or she is taking care of the victimized child. Hence, you can see how most offenders are known to the child. They are usually close to the parents as well.

Some people with pedophilic disorder may threaten their victims with violence if they disclose the abuse. Others may detach completely if the child seems as if he or she will disclose the abuse to others. Many offenders feel betrayed by this disclosure when this “special relationship” that developed between the offender and the victimized child is dissolved.

Many people with pedophilia suffer from substance use as well as depression, posttraumatic stress disorder, and anxiety. Most people diagnosed with this disorder have a history of sexual abuse themselves and may feel stuck within a certain age range, often choosing victims in the age range within which they were abused as children. The course of pedophilic disorder is chronic, and perpetrators often have or develop substance abuse or dependence and depression.

This disorder is not easily treated since legal barriers prohibit most diagnosed people who have offended from seeking treatment. Imagine if you knew that you would be
arrested if you told your therapist about your problems. Would you seek help? This legal dynamic makes it particularly difficult to seek treatment within a family systems perspective. Offenders and family members may deny child sexual abuse within the home even if there is evidence to substantiate it for fear of legal repercussions. In these situations of not reporting or seeking help for the family, marriages often become toxic and children are even more traumatized.

There may be an association between viewing child pornography and hands-on sexual offenses (Bourke & Hernandez, 2009), but studies differ on this relationship between offenses (Endrass et al., 2009; Kaufman, 2014; Seto, Hanson, & Babchishin, 2011). In any case, viewing child pornography is often a reliable indicator of sexual attraction toward children, but it is also illegal. If a client disclosed this information in therapy, it would have to be reported to legal authorities since therapists are mandated reporters.

### Sexual Sadism Disorder

Sexual sadism was listed under the heading of Sociopathic Personality Disturbance, sub-section OOO-x63 Sexual Deviation in the *Diagnostic and Statistical Manual of Mental Disorders* (1st ed.; DSM-I; APA, 1952). Rape, sexual mutilation, and sexual assault were given as examples of sadistic sexuality and clinicians were encouraged to explore any underlying issues that might suggest a primary personality disorder before giving a diagnosis of sexual sadism. Revisions of the *DSM* through the fifth edition published in 2013 echo the call to consider what else may be underlying the sexually sadistic behaviors presenting in the client. The *DSM-5* goes the furthest in this consideration by suggesting that under certain consensual situations, sexual sadism is not pathological nor diagnosable.

Sexual Sadism Disorder in the *DSM-5* involves a nonconsenting other or others and/or provokes significant distress or impairment for the person who has such desires. The disorder is distinguished from atypical sexual behavior that falls under the banner of *safe, sane, and consensual* sexual kink (Connan, 2010). An important part of this distinction is the level of psychosocial and psychological distress and impairment experienced by those who admit interest and participation in sexually sadistic behaviors. If someone has the interest yet only fantasizes about such desires, and the assessment reveals no history of legal problems associated with victimization, nor intense feelings of regret and shame, Sexual Sadism Disorder is not diagnosable.

The recurrent nature (over a period of 6 months or more) and intensity of sexual arousal based on inflicting physical or psychological suffering on a nonconsenting other and causes distress of impairment warrants diagnosis of Sexual Sadism Disorder. The diagnosis can be given if there is no identified victim when such types of sexually related fantasies or urges are accompanied by clinically recognizable impairment across the domains of social, occupational, and relational functioning (APA, 2013b).

Diagnosis can include the specifier of *In a controlled environment*, wherein the person is residing in a restricted environment, such as a correctional or a residential facility. *In full remission* is also a specifier if there is no acted upon nonconsensual urges nor impairment across social and work systems, nor in other areas of functioning for a period of 5 years or more in a nonrestricted setting. It is noted in the *DSM-5* (APA, 2013a) that consensual sexually sadistic behaviors are not diagnosable per se, so attention to level of dysfunction and intensity of disturbance across system domains is important for the counselor to consider.

Differential diagnoses include other Paraphilic Disorders, certain personality disorders, substance use disorders, and bipolar and related disorders. Comorbidity is linked to those who have been convicted of criminal acts against a nonconsenting other or others and to other mental health diagnoses. Nearly all of the published research papers on sexual
sadism using DSM criteria for diagnosis were conducted on adult incarcerated males, which may be an indicator of sampling bias for comorbidity (Krueger, 2010). The disorder is differentiated from sexual sadism orientation, which is seen in both males and females and first appears in mid to late adolescence.

Use of sexually explicit, sadistic pornographic literature or media may be an indicator to support the diagnosis of sexual sadism disorder, especially if the use of such materials provokes feelings of shame, guilt, or other psychological impairment for the participant.

Sexual Masochism Disorder

Sexual masochism first appeared in the 1968 edition of the Diagnostic and Statistical Manual of Mental Disorders (2nd ed.; DSM-II; APA, 1968) and was listed as a sexual deviation indicating “coitus performed under bizarre circumstances” (APA, 1968, p. 44). In the DSM-5, Sexual Masochism Disorder has diagnostic criteria similar to Sexual Sadism Disorder in that it is a recurrent pattern of intense sexual arousal from behaviors, fantasies, and urges lasting 6 months or longer that cause significant, clinical distress across the domains of work, social relationships, and/or other domains of importance. Although the duration of 6 months or more is typical, the diagnosis can be made if the period of time is less than 6 months if the activities are sustained during a specific period of time. Specifiers include restriction of breathing (asphyxiophilia), controlled environment (correctional, residential, or other restricted setting), and full remission if the client experiences no distress nor impairment across social and work systems, nor in other areas of functioning for a period of 5 years or more in a noninstitutional setting (APA, 2013b).

Sexual Masochism Disorder can also be diagnosed if the behaviors are self-inflicted, and a feature of the disorder is loss of control (Morrison, 2014). Loss of control results in self-inflicted injury and possibly accidental death, as is some cases of autoerotic asphyxiation. Loss of control helps differentiate the disorder from the orientation in that consensual sadomasochism makes use of words or a word that signals the activity must stop, thereby allowing for control of the duration and intensity of pain received by establishing clearly defined and respected limits (Connan, 2010; Gross, 2006).

The person with sexual masochism disorder achieves arousal from receiving physical and/or psychological practices such as bondage, pain infliction, suffocation, and humiliation rather than inflicting pain, as is the case for sexual sadism disorder. Through the circular process of inflicting or receiving pain, sadism and masochism form a symbiotic role relationship, calling to mind a structural system of behavior wherein one person’s behavior directly affects and is grounded in another’s behavior so that the system’s task is accomplished. It is noted that not all sexually masochistic behaviors are diagnosable so attention to intensity of impairment across system domains is critical for consideration.

Differential diagnoses include other Paraphilic Disorders, substance abuse disorders, and personality disorders, which may also appear as comorbid diagnoses. Age of onset of problematic symptoms is late adolescence. Use of explicit pornographic literature or media portraying acts of humiliation and suffering supports the diagnosis of sexual masochism disorder.

Transvestic Disorder

Transvestism, also referred to as “cross-dressing,” has a long history of representation by both men and women across time. Think Joan of Arc. Think Shakespearian actors. Today, transvestism is more or less accepted, depending on geographical location, religious persuasion, and cultural norms, and it may or may not be used for sexual arousal purposes.
Cross-dressing is distinguished from transvestic disorder by way of the disorder’s focus on cross-dressing for sexual arousal and by the level of clinically significant impairment and distress across social, occupational, and relationship systems as a result of the behavior. Recurrent, intense sexual arousal that is driven by cross-dressing behaviors, urges, and/or fantasies occurring over the course of 6 months or more is diagnosable as transvestic disorder.

Specifiers include sexual arousal due to certain fabrics or clothing type, such as silk or women’s lingerie (with fetishism) and sexual arousal at the thought of oneself as female (with autogynephilia). A further specifier, In a Controlled Environment, can be used when cross-dressing occurs while residing in a restricted setting (i.e., correctional facility, psychiatric hospital, or residential clinic). Systemic clinicians may also use the specifier In full remission if symptoms and distress abate for 5 or more years (APA, 2013a).

Heterosexual males are more likely to be diagnosed with transvestic disorder, although a change in wording in the DSM-5 opens the door of diagnosis to homosexual men and heterosexual and lesbian women (APA, 2013a). Significant distress can result especially for heterosexual married men who often experience marital problems due to the partner’s expressed fears, shame, confusion, and judgment of the behavior. A 2011 case study of the personal stories of cross-dressers and their spouses revealed a poignant aspect to the secrecy, relationship impact, and spousal tolerance that surrounds this socially questionable behavior (Hill, 2011).

Often, cross-dressing appears first in childhood, and by puberty males may ejaculate while wearing or fantasizing about wearing women’s clothing. Adolescent males and young adults are more likely to present with sexual experiences when cross-dressing, through masturbation or other penile stimulation. Conflict ensues when socially normative heterosexual experiences, such as a desire for marriage, interferes with the ability or willingness to cross-dress. Increased distress is the result and it is at this time that a counselor may first encounter transvestic males. Abatement in cross-dressing behaviors usually proves temporary and is likely to return with time, coupled with secrecy and the likelihood of shame. Intensity of distress surrounding the behavior increases, with noticeable, recurrent patterns of throwing away and then repurchasing women’s clothing. Such buy and purge behaviors indicate a potential diagnosis (APA, 2013b).

With age, males experience less or no sexual release as a result of cross-dressing while at the same time experiencing an increase in feelings of well-being while cross-dressing, and lowered levels of distress and impairment across domains. When the level of distress or impairment at cross-dressing is lowered to this degree for a period of 5 or more years, in a noninstitutional environment, full remission is the diagnostic specifier.

Differential diagnosis includes fetishistic disorder and gender dysphoria, and comorbidity is high for other paraphilic behaviors, and especially so for masochistic disorder and fetishistic disorder.

Fetishistic Disorder

In the original Portuguese, fetish referred to a magical charm or idol and its use today refers to sexual activity involving an inanimate object or objects for the purpose of sexual arousal (Morrison, 2014). Normative sexual objects, such as dildos and vibrators, are not considered fetish items, but body parts (or missing body parts in some cases) can be. Ears, feet, toes, hair, and arousal at the thought of sex with an amputee all qualify as fetish activity, as well as all other nongenital body parts and the plethora of fetish objects used for sexual arousal and stimulation: shoes, dirty socks, leather, rubber, and silk items, to name a few.

A preference for fetish objects during sexual arousal does not constitute a disorder, however. Similar to all other Paraphilic Disorders, Fetishistic Disorder is present only when,
over a period of 6 months or more, a client experiences intense sexual arousal from behaviors, fantasies, and urges due to the use or thoughts of use of fetish items not normative to genital sexual activity, and such thoughts and behaviors cause clinically identifiable distress across the domains of social, work, and relationship functioning, and the fetish items are not related to cross-dressing or a comorbid diagnosis of transvestism (ACA, 2013).

Research suggests use of fetish items is a way to control sexual behaviors and alleviate internalized anxiety, in that there is predictability in responsiveness to an object, which is questionable with a living sexual partner (Bhugra, Popelyuk, & McMullen, 2010).

Specifiers include body parts (Partialism), nonliving objects, and “other” objects. Environment is also a specifier if the behaviors are absent due to an institutional, controlled environment (e.g., jail, rehab). Full remission is the specifier if, over the period of 5 years or more, the client experiences no distress across domains while living in an uncontrolled environment (home). Comorbidity is high for all other paraphilic behaviors, and males far outnumber women when meeting diagnostic criteria.

Support for a diagnosis can include sexual arousal due to touching, holding, tasting, inserting, smelling or otherwise interacting with the fetish item while masturbating and such activity is persistent across time, often staring in puberty. It is not unusual for those with a fetishistic disorder to have vast collections of items used for sexual arousal and stimulation, other than those typically associated with sadism or masochistic sexual behaviors (e.g., belts, whips, blindfolds) and assessment for such a collection supports the diagnosis. As with all of the Paraphilic Disorders, cultural considerations of the client must be considered during the diagnostic process.

In addition, consideration of how the relationship system is affected by fetishism is important, especially with regard to where, when, and with whom such behaviors are practiced. If the couple is in a polyamorous relationship, for example, rules for engaging in fetishism are likely spelled out and a part of the poly agreement. If, however, fetishism is practiced outside of a monogamous relationship without the knowledge of the spouse or partner, such behaviors are likely to cause significant disruptions to the relationship system, with the possible outcome of divorce, separation, or loss of child custody.

Voyeuristic Disorder

People who suffer from voyeuristic disorder have a desire to spy on nonconsenting people during their private activities. Their urges, fantasies, and behaviors bring them significant distress or impaired functioning for a period of 6 months or more. Usually, voyeuristic individuals get sexually aroused by looking at people undressing or being naked as well as watching them during sexual acts. In most cases, people with this disorder are aware that they are looking at a nonconsenting individual and will not ask for consent to spy on the targeted individual.

Since people with voyeuristic disorder engage in behaviors that are essentially anonymous, diagnosis can be difficult in terms of assessment. Self-report is typically the mode of diagnosis, and the most common symptoms of this disorder are experiencing strong sexual urges or fantasies from watching another person naked with or without consent. Just like in other paraphilias, tendencies do not equal diagnosis. People with this disorder must suffer from significant distress or hindrance to normal functioning because of their voyeuristic tendencies (for 6 months or more), and this is not the case for all people who engage in voyeurism.

People who do not disclose their voyeuristic behavior after being caught spying on nonconsenting individuals usually say that those engagements are accidental or not sexual in nature. According to DSM-5, these people (who fail to disclose behaviors and deny having sexual fantasies or continual sexual interest in voyeuristic behaviors) deny feeling of stress and/or social impairment. Interestingly enough, because of this denial, they can be diagnosed with having voyeuristic disorder.
Having a desire to watch others engaging in sexual situations can actually be quite common and not abnormal (Rye & Meaney, 2007). Voyeurism usually starts during the adolescent years or even in early adulthood. When adolescents are caught for voyeuristic behaviors, they are not often arrested since the legal system is pretty lenient with adolescent voyeurs.

Voyeurism becomes pathological when individuals spend a great amount of their time seeking opportunities to spy on nonconsenting individuals involved in private acts. Impairment is evident within voyeuristic disorder since many diagnosable individuals will neglect their responsibilities to seek out voyeuristic opportunities. On many occasions, voyeuristic individuals will masturbate to orgasm during a spy session. However, in most cases, people with voyeuristic disorder will not seek sexual contact with the people they observe. Families and spouses are often not aware of a person’s voyeuristic tendencies when someone has a voyeuristic disorder since behaviors are often engaged in outside of the home.

**Other Specified Paraphilic Disorder**

Clinically recognizable distress across social, work, and relationship system domains due to sexual fantasies, urges, and/or behaviors that are not addressed in the identified diagnostic categories for Paraphilic Disorders fit this diagnostic code. This code includes specifiers for sexual arousal and behaviors that cause significant distress due to thoughts, urges, and sexual activities with animals (zoophilia), corpses (necrophilia), anonymous sexual phone calls (telephone scatologia), body fluids (urophilia, known collectively as “water sports”), enemas (klimaphilia), rape scenarios (paraphilic coercive disorder), feces (urophilia), and sexual satisfaction from dressing in diapers or being treated as a baby (infantilism; ACA, 2013). This list is not exhaustive, since sexual expression comes in various culturally and socially adaptive forms. Such behaviors have high comorbidity with all other Paraphilic Disorders. Include specifiers for environment (institutional settings) and remission (5 or more years of nonsymptomatic sexual behaviors while out of an institutional setting).

**Unspecified Paraphilic Disorder**

Because of the complexities of human sexual behaviors, it is sometimes difficult to diagnosis a Paraphilia Disorder. Systemic clinicians may encounter clients who present with atypical sexuality and sexual behaviors that are causing significant distress across the domains of social, work, and/or relationship functioning, yet the behaviors do not meet the specifications for diagnosis as outlined in the *DSM-5*. When a counselor is unable to determine if a specific Paraphilic Disorder exists, yet the client is experiencing clinically significant impairment due to atypical sexual fantasies, urges, and/or behaviors, a diagnostic code of F65.9 is applicable.

When in doubt about diagnosing a paraphilia, consider a session wherein the behaviors can be openly discussed with the spouse, partner, or the sexually invested other so that collateral information can be collected for a more specific qualifier, and to rule out differential diagnoses as primary. A discussion of each partner’s understanding of what it means to be sexually intimate may reveal differences in perceptions and definitions that can then be worked on during ongoing couple’s sessions. A shared perception of what defines sexual intimacy and the recognition that “sexual intimacy is consensual,” (Birnie-Porter & Lydon, 2013), may lead to renewed investment in the relationship and clarity for the system.
Remember that the family or relationship system that functions in or around paraphilic behaviors can be a supportive base for treatment options or may serve as a contributing factor in paraphilic behavior morphing into a Paraphilic Disorder (see case study example at the end of this chapter for distinguishing differences). Because all family members bear responsibility for systems dynamics, it is important to consider how each person contributes to maintaining the status quo, whether through silence, denial, or full awareness of ongoing paraphilic behaviors and what this means to systemic function and dysfunction (Hentsch-Cowles & Brock, 2013).

RELATIONAL AND CULTURAL FEATURES

Turning from the particulars of diagnostic criteria for the Paraphilic Disorders, we now draw your attention to relational and cultural factors that have an impact on the etiology of the disorder. We start with a brief discussion of the research on neurological and biological factors of interest.

Etiological understanding of the paraphilias is still limited and continued research is needed on nonforensic populations and women, who present with paraphilic behavior significantly less than men (Garcia & Thibaut, 2011). There is commonality in the neurological responses of those with chemical addiction and in those with intense sexual arousal: the involvement of the pleasure–reward pathway (mesolimbic dopamine system corridor; Keane, 2004). Once the pleasure pathway becomes involved in a behavior, the likelihood of a person returning to that behavior is increased and, over time, pleasure-seeking behaviors are escalated, amped up so to speak, to compensate for a decrease in the release of dopamine that results over time. Repetitive paraphilic behaviors usually start in adolescence and histories of paraphilic clients bear out the idea that the search for increasingly more intense sexual arousal and release is part of the dynamic of such behaviors. This progression is led by a simple concept: the anticipatory incentive of a pleasure payoff (Berner & Briken, 2012).

Rahman and Symeonides (2008) looked at the impact of fraternal birth order and non-right handedness on the likelihood of paraphilic behavior choices. Although these factors seem somewhat disparate with regard to paraphilias, the researchers demonstrated statistical significance between non-right handedness, number of older male siblings, and increased paraphilic sexual interests in their sample of 200 nonincarcerated males.

What does such seemingly disconnected research mean for counselors diagnosing Paraphilic Disorders using a systems approach? Simply that the paraphilias are, indeed, complex diagnostic categories, rich with potential for misunderstanding if we look only at biological and neurological factors in the etiology of the conditions. Hence, our next focus is the impact of relationships and culture on the development of paraphilic behaviors. You will quickly find that questions arise that call for an introspective counseling stance.

Although family upbringing, attachment style, and historical context all have an impact on the way sexuality is expressed, culture is by far one of the most influential factors in determining whether a certain behavior is pathological. Human sexuality is, in all cases, a part of social life, and all social life is governed by norms, inferred rules of behavior, and status quo. The rules in societies differ in terms of sexuality. What is consent? What is homosexuality? What are gender roles? What is premarital sex? All of these questions can be answered differently depending on the culture of the group you might be asking. Dictated laws about sexual behaviors also differ across cultures. Age of consent is one particular law that grossly differs depending on the country one might visit and can even differ within a country. In the United States, for example, the age of consent ranges from 16 to 18, depending on which state or district (Washington, DC’s age of consent is 16 years old). This is important information when determining whether a behavior is problematic (i.e., pathological) or merely a preference.
The Role of Family

Children learn about sexuality through observation of sex roles and by direct teaching from their primary caregivers, media, and peer relationships. The family system, however, has the largest impact on how individuals express their sexuality and sexual behaviors as they grow through adolescence and into adulthood. Families differ tremendously in terms of how they express and deal with sexuality and sexuality is especially affected by religious views, geography, and historical context. Think about your own family and upbringing. Were you raised in an era known for its sexually liberal views or sexually conservative views (e.g., 1950s America versus 1970s America)? Were sexual messages based on religious beliefs as normed by the state or world region where your parents lived or where you were raised? What were your family’s views on homosexuality? What about birth control? What did your family think about premarital sex? What about cohabitation or polyamory? Was nudity acceptable in your household? What did your family teach you about the purpose of sex? Was this an acceptable practice in your family’s value system? Were there instances when males/females or older/younger children were treated differently? How do you think your experiences have shaped you today? If you interviewed three other people and asked them the same questions, you would most likely get completely different answers. In this way, you might be better able to see how differently “normal” is viewed in terms of sexual behavior just from family upbringing.

Assessing a client’s family of origin views on sexuality is not a routine practice for many counselors, but it should be. When family background and systemic contexts are ignored, problems due to family upbringing (e.g., parent–child problems, sibling rivalry, other parent–child problems, other specified problems related to upbringing) can often be missed by counselors. Therein, counselors can quickly also miss opportunities to fully understand their clients.

The Role of Culture

Let us now expand our conversation of differing sexual norms to social cultures, niche group cultures, religious cultures, county, state, country cultures, and so forth. A sexual behavior that is accepted in one group may be shunned in another. From microculture to macroculture, sexual norms change along with laws and ethical guidelines. Is exhibitionism pathological? It can be, as it is dependent on gender and context in our Western culture. Exhibitionistic women do not often have problems in our culture when they sexually expose various body parts in dance clubs. Men might be arrested if they acted in similar exhibitionistic ways. What about pedophilia? Isn’t that always pathological? Not necessarily, since cultural context greatly influences such things as age of consent. Remember that the age of sexual consent ranges from 16 to 18 in the United States, and it is as low as 12 in India and Mexico (Anagol, 2016; UNICEF, 2016).

Transvestism is also a matter of cultural and historical interpretation. Women dress in men’s clothing routinely in Western culture without a problem and cross-dressing “lady-boys” are common in Tokyo, taking on various roles in society such as entertainers, tribe leaders, shamans, and models. Many traditional Native American societies respected and valued androgynous cross-dressers, referred to as Two-Spirits. They were viewed as spiritual members of the society, often interchanging male and female roles, sexual practices, and clothing. Early European settlers and religious orders were quick to condemn, demonize, and “convert” Two-Spirits, who often resorted to suicide as a result (Williams, 2016). Whether accepted, revered, outcast, or feared, it is clear that geography and culture played a large part in shaping historical and current views on transvestism.

With all of the varying cultural factors contributing to our understanding, one can easily get confused on how to assess for pathology in an effective way. Although some countries...
may have clearly defined cultural parameters, helping clients in our Western culture presents more challenges. The United States has long been known as the “melting pot,” accepting a wide range of people from various cultural backgrounds, races, and religions, and counselors are ethically mandated to consider cultural and relational norms when determining if a client has a problem with a paraphilic behavior. Although some rules about sexual problematic behavior are clear in our society, like laws surrounding child endangerment, others are a bit more murky. Hence, assessment of a paraphilic “disorder” is often complicated, changing from one situation to the next, requiring careful consideration of multiple factors and systems.

FAMILY SYSTEMS ASSESSMENTS

Since its first appearance in 1952, the DSM has shifted to meet changes in cultural normative behaviors that are now considered preferential rather than pathological. The removal of homosexuality as a mental disorder from the DSM in 1973 is the best example of this shift toward acceptance of a new cultural norm for sexuality. Such a shift has allowed for increased family understanding and support of a behavior that was, until very recently, considered a sexually deviant perversion. Moral, social, and familial definitions of sexuality continue to evolve, and use of a systemic approach creating a connective thread throughout the various systems involved in the diagnosis of a Paraphilic Disorder is helpful (see Figure 19.1).

It is clear that the initial assessment is of utmost importance in establishing the level of social functioning and emotional distress of clients who present with paraphilic behaviors. The overriding rule of thumb in defining whether pathology is present is “hostility and the incapacity for consensual sexuality” (Berner & Briken, 2012, p. 130).

Assessing whether an individual has a Paraphilic Disorder versus a sexual lifestyle or orientation can present some challenges for counselors. Yes, guidelines in the DSM-5 tell us that impairment and distress are key factors, but how can a counselor identify “distress” for a client? What about a client denying having a problem? Many people who suffer from Paraphilic Disorders will not seek help, and if they do, they are often referred for treatment involuntarily. They may be referred through the legal system, through the school system, or because of a troubled marriage on the brink of divorce or custody disputes. When such individuals enter treatment, they may try to present their sexual behaviors as

**FIGURE 19.1 Systemic view of paraphilias and diagnosis potential.**

*Source: Figure created by Emily Meyer-Stewart.*
acceptable and orthodox for various reasons—denial, shame, ignorance, and fear of stigmatization or legal repercussions are just a few reasons for a client’s inaccurate testimonials. Even when counselors get the entire truth from clients, there are still some significant challenges in making a diagnosis. Some questions for the counselor to keep in mind during assessments are: Is what I’m hearing a Paraphilic Disorder or a paraphilic lifestyle choice since the client is accepting of the sexual behavior? Is the client’s relationship or marriage in trouble because of paraphilic sexual behaviors? Have I taken a look at how the client’s personal values, culture, and religious beliefs are at play (Kleinplatz & Moser, 2004)?

One very clear-cut diagnostic red flag for diagnosis is victimization of self and/or others. If, for example, a client with an attraction toward children is arrested for child pornography, the diagnosis is clearly made (pedophilic disorder) due to the illegal nature of the behavior, and treatment can begin with a well-defined treatment plan: avoid any sexual behaviors involving children.

Now consider sexual sadism and sexual masochism as diagnoses. If a client routinely engages in consensual sexual bondage behaviors with his or her spouse, is it pathological? What about if that client widens and later marries a spouse who does not want to engage in bondage sexual play? Does the client’s need or desire to engage in bondage become pathological? What if the marriage suffers because of the client’s sexual preferences? Does a paraphilia then become pathological? As a counselor, you can see how “distress” can change as life dynamics change, and it can be very confusing to pinpoint problematic behavior. After all, who has the problem in such a scenario, the client who wants to engage in bondage sexual play or the spouse who may have rigid sexual boundaries? Either spouse might have the problem depending on relational and cultural norms.

In addition to having confusion over who might have the problem, a counselor may wonder what the best treatment intervention might be. Should the client work on ceasing bondage behaviors or should the spouse work on incorporating bondage into their sex life? What does the couple want, and what if they want different things? How does a counselor decide where to draw the line between what is acceptable sexual behavior and pathological conduct? In our experience of working with clients who engage in paraphilic activities, determination of pathology is made by asking two simple questions: “Is there consent?” and “Is there a victim?”

Is There Consent?

Consent is defined as permission for something to happen or agreement to do something (Merriam-Webster, 2016). When counselors work with clients who are engaging in paraphilic activities, the first thing that should be asked when determining if behaviors are pathological is whether the sexual target has given consent. If no consent was given by the person who is the sexual interest, the client’s sexual behavior can be assessed as problematic and opens the door to diagnosis. Age of consent, of course, is also a factor here. In Western society, a child cannot give consent under a certain age.

Is There a Victim?

A victim is someone who is harmed, injured, or killed as a result of a crime, accident, or other event or action (Merriam-Webster, 2014). Is there a victim of a client’s sexual behaviors? If there is, the paraphilia is pathological. Just to be clear, “victim” can also include the person with the paraphilia. If a person is in great distress because of having a paraphilia and cannot perform basic duties at work and/or if the sexual activity caused significant personal harm to the person, then he or she is a victim of the Paraphilic Disorder. Significant harm can result, for example, during autoerotic asphyxiation or when objects...
inserted into or used upon one’s own sexual organs cause physical damage needing medical attention and/or repair. As a result, the emergency room may be the first place that a spouse or invested sexual partner discovers his or her partner is practicing paraphilic behaviors since use of certain fetish and sadomasochistic sexual practices can lead to physical harm or even death due to asphyxiation. Hospital staff assigned to such admissions would do well to consider referring these patients to a practitioner familiar with family systems assessments and cognitive behavioral treatment modalities that can identify and modify sexual practices that are harmful physically and psychologically (Gladding, 2015).

Assessment Tools

A variety of assessment tools are available in helping the counselor understand a client’s attitudes regarding sexuality and sexual expression. When determining if a paraphilic behavior is a disorder or merely atypical sexual behavior, such assessments can provide additional insight and treatment direction for the counselor. Use of the Adult Attachment Interview (George, Kaplan, & Main, 1996) provides an excellent starting point in assessing family constellations and will identify attachment style. This information will help the counselor support the client through transformative change, as the counselor becomes the secure base from which the client can explore experiences and learn how to tolerate, assess, and communicate difficult feelings related to those experiences (Wallin, 2007).

An additional tool is the BARE: the Brief Accessibility, Responsiveness, and Engagement Scale (Sandberg, Busby, Johnson, & Yoshida, 2012) that measures attachment behaviors in couples, focusing on “a systemic perspective on relationship functioning” (2012, p. 524). Knowing how each individual in the relationship perceives partner accessibility, responsiveness, and engagement can allow for increased communication and understanding about these and other attachment issues that are reflected in the family or relationship system. In addition to the Adult Attachment Interview, we suggest the following assessment tools that deal specifically with sexuality. This is by no means an exhaustive list of all psychosexual assessment tools, but a few we selected to give you an overview of what is possible to assess with an instrument. Use of these individual assessments for increased understanding of relationship and systemic functioning is helpful for the individual seeking treatment, for treatment planning, and as aides to rule out or corroborate differential diagnosis.

Attitudes to Sex Questionnaire

A Likert-scaled tool to measure such items as personal willpower, belief in God, intelligence, and a general belief in ability to overcoming problems related to fetishism, pedophilia, sexual sadism, and voyeurism (Twohig & Furnham, 1998). Couples can gain insight and understanding into the sexual wants and desires of their partner, based on a broad range of predecessors, such as moral beliefs and upbringing. Sharing the results in an emotionally safe couple’s counseling session can be beneficial.

Multiple Paraphilic Interests Scale

A rating scale tool to measure paraphilic interest and criminality. This is a lengthy multi-itemed scale entailing 96 pages, capturing specific behavioral information across various domains and time (Smallbone & Wortley, 2004). This scale is best used with an individual since the information may cause the counselor to take on the role of mandated reporter, in the case of known and identified victims who may be revealed. This assessment tool is an aide in understanding the generational attitudes and family of origin–learned patterns of dysfunction, since it works back through time to childhood and considers trauma, violence, and sexual abuse to which the client may have been exposed or have been a victim.
Paraphilias Scale
A Likert-scaled tool to measure sexual arousal, attitude, and occasion of thoughts involving paraphilic behaviors (Seto, Lalumiere, Harris, & Chivers, 2012). Because the disclosure of thoughts about sexual violence can be disruptive to the couple’s relationship, and since the thoughts are not determinate of behavior, it is best to use this tool with the identified client and for the purpose of gaining clinical insight and awareness into the level of dysfunction resulting from the paraphilic behavior.

Sexual Behaviors and Desires Measure
A scaled measurement tool for assessing willingness to participate in various sexual activities, including paraphilic behaviors (Reese-Weber & McBride, 2015). Couples who may be searching for ways to develop sexual intimacy through atypical sexual behaviors would benefit from taking this assessment and sharing the results in a counseling session. This is also a way to assess if the relationship system can tolerate atypical sexual behaviors or if the behaviors are considered too disruptive to the system.

Assessing the Impact of Paraphilic Disorders on the Family
Now that we have determined how to assess whether a paraphilia is a problem, let us move forward in assessing Paraphilic Disorders through a family systems perspective. Many characteristics must be considered within the family systems lens to assess a pathology: (a) Assessing Paraphilia as a Pathology or a Lifestyle; (b) Assessing How Behavior Has an Impact on the Sexual Relationship; and (c) Assessing How Family Is Affected by Paraphilic Behaviors. In using a systems lens for diagnosis and in treatment, the entire family system is reviewed so that the influence of and emotional problems generated in partners and spouses are addressed (Hentsch-Cowles & Brock, 2013).

We address each of these general assessment guidelines in detail so that we can highlight the family systems assessment approach. It is assumed that a clinician would also complete a detailed formal assessment of the family, including a detailed sexual history of all sexual behaviors from childhood to present day.

Assessing Paraphilic Disorders as a Pathology or a Lifestyle
When a person is distressed over his or her partner because he or she likes to engage in sexual paraphilic behavior, it can be difficult to assess whether the paraphilic urges of said partner are pathological. How can a clinician assess this within a family systems lens? After all, we are taking the entire family into account so what is a pathology and what is lifestyle that might need to be worked out?

Previously, we addressed the two questions a counselor needs to ask in order to determine whether he or she is dealing with a pathology or a lifestyle choice: “Is there a victim?” and “Is there consent?” Although these two questions are the core of determining pathology, it is important to note that they may not always determine a specific paraphilia. For example, a father who molests his young daughter absolutely qualifies for a pathological label, needs treatment, and can suffer legal consequences. However, he may not meet criteria for pedophilic disorder since he may not have recurring sexually arousing fantasies, urges, or behaviors involving prepubescent children for 6 months or more. Regardless, family treatment needs to occur for all family members because of the molestation that occurred. Treatment may vary depending on whether a person has molested a child or if a person has pedophilic disorder and has molested a child, but pathology exists in either situation.
For the sake of the rest of this discussion, we assume that a paraphilia exists within a family dynamic in order to illustrate how to assess appropriately. What a clinician needs to correctly determine is whether a paraphilia is a disorder (i.e., pathology) or an orientation (or lifestyle choice). To that end, use of a narrative approach to collecting information from each person in the system is beneficial for the clinician as well to those present in session as it allows for increased understanding and insight about family of origin influences on sexuality and current levels of function and dysfunction due to these factors (Smith-Acuña, 2011).

Assessing Consent
Assessing whether there is consent involved with a Paraphilic Disorder is straightforward. If a sexual interest or target did not give consent to the sexual behavior being exhibited, pathology exists. This rule applies to all nonconsensual sexual behaviors, from coercive behaviors such as sexually violating children to nuisance behaviors such as rubbing up against people in subway systems. If a husband acts on a sexual urge with his wife in the bedroom, and the wife does not consent to the behavior, but the husband sexually acts out anyway, it is a confirmation that the husband has a pathology.

Assessing Victimization
Determining a victim can be more difficult at times, but a simple way of assessing victimization is to determine whether anyone is harmed by the sexual behavior, including the person with the paraphilia. For example, if a person is downloading bondage images at work because he or she has a compulsion to do this and cannot wait to go online within more appropriate environments, like home, there are plenty of victims. The person with the paraphilia may lose a job. The family may suffer financially because of the job loss. One can even argue that the person's boss is victimized, paying an employee for a job not done. Another victim scenario is if a person with a paraphilia cannot enjoy sex with another person in any other way except engaging in a certain paraphilic activity. In such a scenario, there are victims—the person with the paraphilia and the sexual partner if one exists at that time.

If both questions of consent and victimhood are met with a resounding “no,” a clinician can, in most cases, safely assume that the paraphilia is not a pathology. Many people who are into kink or fetishistic behaviors enjoy these behaviors within a functional sexual relationship and utilize these behaviors as a way of connecting with their sexual partners. For many people, kinky sexual play is just another form of intimacy and enjoyed with no problem to the relationship. But what if a paraphilia is not pathological but is definitely a problem in a sexual relationship? Now that is a common problem that necessitates further discussion. Let us move forward to that.

Assessing How Behavior Has an Impact on the Sexual Relationship
After asking the two pathology questions of consent and victimization, a clinician will know whether a paraphilia is a disorder or a lifestyle choice. Depending on the assessment, treatment will differ drastically. If a paraphilia is assessed as a disorder, a client should meet the criteria within the DSM-5 guidelines and treatment can begin helping the client change or avoid destructive patterns. If any sexual behavior involving a child is discovered, a clinician, of course, needs to report that information to the proper authorities under mandated reporter requirements. In most cases, the state will take over the treatment process with state-approved clinicians to treat individuals who have sexually offended against a child or have been involved with any sexual activity involving children.
But what if a clinician has determined that the paraphilia is *not* a disorder but a lifestyle choice *and* the sexual partner is distressed by that lifestyle choice? In essence, the marriage suffers because the sex life suffers. Partner A wants to get a little kinky in the bedroom to spice things up after a few years in marriage and Partner B is disgusted by Partner A’s sexual desires. Partner B says “no way, no how.” Partner A feels rejected, frustrated, and resentful. The marriage suffers because of the emotional backlash from the sexual decision Partner B made for both partners. In such a situation, it is safe to conclude that Partner A’s paraphilia is not pathological, but the sexual relationship is certainly suffering because of the paraphilia. To complicate things even more, once sexual preferences are acquired, they are really challenging to alter. In essence, after some time of repeating certain behaviors, individuals solidify their preferences into a sexual template of sorts (Carnes, 2010). This can create a big problem when a couple cannot or will not work together to merge differing sexual preferences. In certain terms, the couple is suffering from sexual incompatibility, and a family systems lens is most effective for assessing this problematic situation.

In systems theory, family members are understood to relate to one another through interdependence patterns and those relations affect other members (Chibucos & Leite, 2005). Hence, one person influences the other person and as one person acts, another person is affected by those actions (Whitechurch & Constantine, 2009). In marriage, one partner’s decision about the relationship is always a decision for both. For example, if a wife does not want to have sex with her husband, she is making the decision for both of them to not have sex. By looking at this undeniable series of actions and reactions, one can see why family systems approaches are so effective in assessing paraphilias.

Although many problems with paraphilic tendencies start in the bedroom, they most often stem out to other parts of the family system. In the example stated previously, Partner A and B’s sexual incompatibility did not only affect their sex life. Resentment developed in Partner A because of Partner B’s rigid stance against engaging in any kinky sexual play. Now the problem is emotional, and that touches everything in Partner A’s and B’s lives, including the family system.

**Assessing How Family Is affected by Paraphilic Behaviors**

In family systems theory, it is understood that all members of a family take full responsibility for what is going on in the relationship (Collins & Collins, 2012), which is very different from the victim-perpetrator model that restricts recovery when dealing with sexual issues (Shursen, Brock, & Jennings, 2008). In a recent study, researchers used genograms to map paraphilias, and their selected families contained clusters of paraphilias within their family systems. Many individuals carry unresolved issues from their childhoods, and therefore, problematic sexual behaviors and patterns are commonly traced across generations of families (Brown, 2001). This demonstrates that families do, in fact, share symptoms, confirming that a family systems lens is most appropriate for assessing paraphilias.

All family members learn to cope with problematic sexual problems in their own ways as they come up. Unfortunately, their coping mechanisms are often dysfunctional (Carnes, 1989.) Many families have periods of time when they may be dysfunctional because of stressful circumstances or traumas. For example, a death in the family may elicit some dysfunctional coping mechanisms. However, after a time, healthy families usually return to a functional state after the trauma or crisis passes.

Dysfunctional families have problems that are ongoing and chronic. Children do not get their needs met appropriately, and negative parental patterns are common. When assessing the impact of paraphilic behaviors on the family, a counselor needs to understand the difference between function and dysfunction in a family unit. After all, many families
are unique and not all family units have the same messages around sexual norms. Although a family may be more open sexually, it may function in a healthy way. Another family that is more rigid may function healthfully as well. Therefore, it is not productive to focus solely on sexual behaviors when assessing the impact paraphilic behavior may have on the family. The focus needs to be more global. The question to be answered is, “Is this a healthy and functional family unit?”

**Function Versus Dysfunction**

Attachment theory, first understood through the 40-year collaborative work of John Bowlby and Mary Ainsworth, plays an important role in understanding how family connectedness or disconnectedness affects relationship and intimacy function or dysfunction across the life span. Researchers have considered this impact and the conclusions drawn are not surprising: attachment style is related to psychological adjustment in all areas of functioning, including sexual behaviors (Bogaert & Sadava, 2002; Conde, Figueiredo, & Bifulco, 2011; Péloquin, Bigras, Brassard, & Godbout, 2014).

In addition, anxiously or avoidantly attached adults are negatively affected in the areas of dysfunctional relationship beliefs (Kilmann, Finch, Parnell, & Downer, 2013), commitment struggles (Coy & Miller, 2014), and couple bonding (Sandberg et al., 2012). As may be expected when one thinks about the implications of avoidant attachment styles, each of these studies supported a related hypothesis around negative intimacy outcomes and avoidant attachment. Insecurely attached individuals are more likely to identify with risky sexual practices and are less choosy when it comes to sexual partnering. Since both risky sexuality and less discrimination when seeking a sexual partner are attributes of certain paraphilic behaviors, it seems important to consider a client’s attachment style during the assessment process. (For additional reading and understanding of attachment theory and its use and effectiveness in the counseling room, we recommend Wallin’s 2007 *Attachment in Psychotherapy* as a starting point.)

Functional, securely attached families are certainly not perfect, however, and may exhibit dysfunctional behaviors from time to time, yet they carry the trait of being what Winnicott (1953), in his work on attachment, referred to as “good enough.” They may yell, misunderstand one another, there may be tension and anger, and triangulation, but these unproductive behaviors are not chronic in functional family systems. Rules are clear and consistent yet flexible when appropriate. Messages from parents are explicit. Family members feel free to interact and ask for attention when needed. Family members are allowed to be individuals and encouraged to pursue their individual needs. Boundaries are respected. There is no emotional, physical, verbal, or sexual abuse among any family members, and parents are dependable. Children and parents all function within their appropriate roles. Children are not expected to be parents, and parents do not act like children. Mistakes are expected and dealt with appropriately, whereas perfection is viewed as unattainable.

Although many families may miss the mark on some of the functional family criteria from time to time, they meet all functional expectations on a consistent basis. Dysfunctional families do not. Some parents may not do enough for their children, leaving them to parent themselves. For example, a couple that attends swingers’ clubs together while their children are left alone night after night by themselves may have a harmony in their sexual lives, but are sorely suffering as parental units and breeding dysfunction in their family system. Other parents may overcompensate with the raising of their children, never allowing their children to be autonomous and learn on their own. For example, a father may have a great deal of shame about his desire to dress in female clothing, and, due to that, he forbids his son to engage in any activities that may seem “girly.”

Abusive parents always cause dysfunction in a family system, and abuse can be emotional, verbal, physical, sexual, or a combination. Verbal abusive parents can be super critical or insulting, and might criticize their children’s intellect, abilities, looks, or basic conditions. Although some verbally and emotionally abusive parents are direct, others might be more
passive-aggressive and may disguise put-downs with humor. Physically abusive parents create dysfunction since they create an environment of fear, leaving a child with feelings of anger, sadness, distrust, and feeling unsafe. Sexual abuse may be the most blatant example of family dysfunction, leaving children with tremendous emotional consequences.

Questionnaire for Use in Family Assessment

Once a counselor can identify the differences between function and dysfunction within a family unit, assessment of how a paraphilia affects the family is more easily evaluated. The following simple questionnaire can be used as a guide when assessing the effects of paraphilic tendencies on a family. Asking these questions as part of the family assessment can reveal the origins and current levels of family functioning:

- What are the family rules?
- Can rules be changed if needed?
- How do parents communicate what is expected to children?
- How do family members ask for attention when they need it?
- How do family members express individuality?
- How does the family view mistakes?
- Do parents operate within parental roles? How?
- How do children operate within the family? What are their responsibilities?
- Is there any abuse (emotional, verbal, physical, or sexual)?
- What are the messages about sex and how are they communicated in the family?

Mallory conducted a study to “examine how parent-child sexual communication (frequency, quality and type of messages) influences the development of sexual attitudes (idealistic and pessimistic) and in turn couples sexual communication” (Mallory, 2016, p. 2) and his appendix section includes various scales to use when assessing what was communicated about sexuality via the family of origin.

FAMILY SYSTEMS INTERVENTIONS

When using family systems interventions, family members are understood to all contribute to the problem at hand. Each family member works through individual issues with a focus on showing how his or her behaviors have an effect on the rest of the family unit. All members of the family are seen as being connected to each other through their network of interwoven relationships. When all family members begin to work together, they see how their individual roles have an effect on the roles of others within their family system. Once family members recognize how their actions affect one another, they can then begin to make more positive changes that are beneficial to the family as a whole (Bowen, 1978).

Incorporating medications as part of family systems treatment may or may not be appropriate depending on the situations and symptomatology of the person with paraphilic tendencies. For some with a Paraphilic Disorder, medication may be a requirement of family members, especially if the Paraphilic Disorder is diagnosed in an adolescent family member. Counselors must work collaboratively with a referral to a psychiatrist for medication need assessment and follow-up medication checks, on a case-by-case basis. Selective serotonin reuptake inhibitors and tricyclic antidepressants as well as hormone treatment with estrogen and/or progesterone are part of a pharmacological approach to treatment. However, these types of treatments are considered to be a “minefield of ethical issues” (Garcia & Thibaut, 2011, p. 784) and should be used only under the care and direction of a psychiatrist trained in ethical pharmacological treatment delivery for Paraphilic Disorders.
Guidry and Saleh (2004) offer 10 nonmedication interventions for counselors working with paraphilic sex offenders who present with comorbid psychiatric diagnoses. Although we must be clear that not everyone with a Paraphilic Disorder is a sexual offender, the incidence of psychiatric comorbidity is high for all of the paraphilias and therefore, a somewhat reworked overview of the Guidry–Saleh interventions is appropriate and useful when considering how best to help clients and their families or invested others. The following suggestions, based on the clinical interventions of Guidry and Saleh, can be used in an individual session or in a small group of the client’s family members or significant others:

- Provide psychoeducation on how to manage symptoms of the co-occurring psychiatric disorder (e.g., depression, anxiety) if any are present.
- Encourage the client’s acceptance of personal responsibility for paraphilic behaviors. We would add that an aid to this is use of in-session language and goals for out-of-session behaviors that reflect personal responsibility for overall mental and physical health as they relate to the paraphilic behavior (I chose . . . I decided . . . , etc., rather than blaming language and shame-based behaviors).
- Invite family or supportive others into session, keeping the group small (3–4 at most), and only when appropriate and helpful for the identified client’s treatment.
- Using a dialogical, collaborative stance, increase insight and awareness into the repetitive cycle of paraphilic sexual behaviors as in a “chain of events” determination.
- Identify and actively address feelings of shame and social stigmatization of a Paraphilic Disorder that may accompany the family and the identified client.
- Be aware of the cultural, intellectual, and developmental issues that may be present for the client and the client’s family. Create a list of client and family strengths, weaknesses, and learning styles so that these can be considered when planning innovative or creative in-session activities and out-of-session coping skills strategies.
- Review the initial assessment for clues on the client’s socialization in childhood and adolescence (was he or she in foster care, a runaway?). Use this information to increase understanding and potential negative life schemas and cognitive distortions so that these can be addressed in session with psychoeducation and evidence-based cognitive behavioral interventions.
- If a limited capacity for empathy is identified in the client due to a psychological diagnosis (e.g., depression, anxiety, or narcissism), work on increasing an appreciation for and understanding of the identified victim (self, other, family) using various creative and cognitive approaches.
- Cast a wide net in addressing all potential areas for increased self-efficacy, personal responsibility, coping techniques, and awareness of self and other, and use these to cultivate overall improvement in functioning across social, family, and occupational domains.
- Develop a plan to prevent relapse that identifies triggers and skills for relapse avoidance.

Education

Educating family members is one of the most important first steps of treating problems attributed to paraphilic tendencies. After a counselor has determined whether a paraphilia is a disorder or a lifestyle choice, educating the family should be the very next step. Families may need to learn about the symptoms of a Paraphilic Disorder and how to best support a family member trying to decrease or eliminate paraphilic behaviors. If families are dealing with a lifestyle choice or orientation, they may need to be educated about sexual norms and how they can work together to incorporate a new but not necessarily understood paraphilic behavior into their lives. As families are educated, they can learn how to support each other through some difficult changes and work together to overcome challenges.
Educating yourself as a clinician is also important. Several organizations such as the National Coalition for Sexual Freedom in the United States, and Pink Therapy in the United Kingdom have a goal to educate clinicians with specific training in awareness, knowledge, and skills when working with clients with paraphilic behavior.

ETHICAL AND LEGAL IMPLICATIONS

By this point in our discussion, you are likely realizing that even though diagnosing a Paraphilic Disorder can be challenging, there are skills worth learning and tools worth using to help you in using a holistic, contextual systems approach to working with clients. Although we have already mentioned a few ethical and legal areas that surface with the Paraphilic Disorders prior to this section, we delineate the major ethical and legal implications here.

One specific area of ethics to which we now turn our attention is most important when beginning a counseling relationship with someone with paraphilic tendencies: counselor awareness of personal beliefs, assumptions, and biases toward those who have paraphilic urges or engage in paraphilic behaviors.

Addressing Personal Biases

As a profession, we are called to the practice of self-awareness via various ethical codes that govern our education and licensing. “Know Thyself” is a call to personal understanding of how our own background, religious views, cultural heritage, attachment style, and attitudes have an impact on our ability to be effective, empathic counselors. When personal beliefs and biases go unaddressed, a counseling relationship can quickly become ineffective or, even worse, destructive. We strongly suggest that counselors complete a self-assessment on their own biases when beginning to work with this population. Otherwise, bias can turn into stigmatization and pathologizing of atypical sexual behaviors in clients (Ford & Hendrick, 2003; Hoff & Sprott, 2009; Kelsey, Stiles, Spiller, & Diekhoff, 2013; Laska, 2013; Lawrence & Love-Crowell, 2008; Yost, 2010).

Mandated Reporting

Every counselor is a mandated reporter and must know the reporting laws of the state in which he or she practices. This is particularly important when working with Paraphilic Disorders. Since sexual trauma or abuse, past or present, is somewhat of a staple conversation when working with this population, counselors may confront some murky scenarios that may or may not mandate reporting. First and foremost, counselors must assess whether there is a violation at all. (See sections on “Assessing Consent” and “Assessing Victimization” for guidance.) If a violation has occurred, counselors would then assess whether the offense required a report to legal authorities or if it should be addressed confidentially with the client through counseling.

Although suspected child abuse or any sexual activity involving a child is always reportable, it is not always clear. What about a case that is 20 years old and was never reported? Suppose your client told you that he experienced sexual abuse as a child that he never reported. Now he still sees his abuser and is retraumatized every time. What are the legal and ethical implications of such a scenario?

Many states are not clear on child abuse reporting and how far in the past their legal mandates extend. Although there may be clear child abuse in a client’s past that was never
reported, a legal report may not be mandated depending on a state's statutes of limitations (if those are clear in the first place). Furthermore, in the age of online therapy, abuse might have happened across state lines, further confusing the responsibilities of a mandated reporter.

When legal guidelines fail to clearly communicate responsibilities to counselors, they must depend even harder on the ethical principles of *fidelity* (Am I being trustworthy?), *beneficence* (Am I doing what is best?), and *nonmaleficence* (Am I not causing harm?). Even more so, it is important to find out what the client needs during these times. In most cases, a client will want to process the abuse and talk about the large range of emotions attached to such a trauma. After all, that was probably the biggest reason the subject was highlighted in the first place.

Because bringing up such sensitive information was probably a difficult thing, a counselor needs to be respectful, reassuring, and have control over any personal reactions to hearing difficult and, perhaps, shocking information. Based on the session (or sessions) of disclosure, counselors should let their clients guide them as they express their wishes and needs. Only then can counselors make better decisions about what the next steps should be, in collaboration with their clients.

Counselors do not need to investigate or substantiate their clients’ claims. Their job should be only to help clients clarify issues on their own as they come to terms with what is going on with them interpersonally. If a client should ask a counselor to seek legal remediation for any scenario that does not require legal action, clinical supervision should be the first step in the process. Although a clinician can document a client’s reported distress and discuss future treatment goals, it is often recommended that counselors avoid requests to participate in advocate situations within the legal system or help clients confront perpetrators.

Finally, counselors must respect their clients’ wishes when legal guidelines are unclear. If they do not, they can put their clients at risk across a wide range of circumstances. When in doubt, counselors should seek supervision, and always focus their attentions on their client’s well-being. The ACA is clear about its focus on client well-being, stating that “[t]he primary responsibility of counselors is to respect the dignity and promote the welfare of clients” (ACA, 2014, Section A.1.a) while always making use of an ethical decision-making model (Section I.1.b). Both of these concepts are reiterated in the 2015 American Association for Marriage and Family Therapy (2015) *Code of Ethics*.

**CASE CONCEPTUALIZATION**

In this case conceptualization, we introduce you to James, a man who is struggling with his paraphilic behaviors and tendencies. As you read over this case, you will have an opportunity to see how spouses are so closely affected and how people with paraphilias may not consistently be diagnosed with Paraphilic Disorders even though they may cause them significant problems. Lastly, we will challenge you with some questions about this case and ask what you would do in a situation such as this if you were James’s clinician. Use the information you have learned in this chapter to guide you in your decision-making process.

**Presenting Concerns**

James is a 65-year-old married White male who is seeking treatment for relationship dys-function he is facing in his second marriage. James is currently working a recovery program for alcohol use disorder, now in full-remission (he has been sober for 6 years). His first wife died from breast cancer, and 3 years later he met Anna. Five years ago, James and
Anna were married, and he considered his marriage to be happy and stable. James and Anna hit their first marriage crisis 2 weeks ago when Anna discovered James’s subscription to a hard-core Bondage and Submission, Sadism, and Masochism (BDSM) site on their credit card bill. When Anna looked up the site, she saw various disturbing sexually explicit images of women being bound and gagged. She was horrified and told James that she wanted a divorce. She was not going to be married to a “pervert and abuser of women.” When James pleaded for her to forgive him and told her that he would get counseling for his problem, Anna agreed on the condition that he would never bring “this smut into the house again.” James agreed to Anna’s terms, cancelled his subscription, and called a counselor to help “fix him.”

Concurrent Problems

Prior to requesting treatment now, James had never thought he had a problem with his BDSM urges. Although he had some shame about seeking pleasure through pain as an adolescent, he attributed it to his family’s sexual rigidity and not that there was anything wrong with him. James had previous treatment for his alcohol abuse and admitted that he was an “alcoholic” but never felt he needed treatment for his paraphilic urges.

Background History and Stressors

James filled out a detailed background history on his childhood upbringing, family environment, and sexual experiences at the start of his counseling session. He described having a “sexually rigid” family environment. James’s parents were staunch Catholics, and sex was not something that was thought about as pleasurable or recreational. At the age of 7, James’s father walked in on him playing with his penis in his bedroom as he was getting dressed for church. He immediately yelled at James to “Stop that sinful behavior!” and made an appointment with their family doctor so that James could be treated for his perversions. At the doctor’s office, James was “treated” with “shocking devices” to his penis in an effort to dull the urge to seek pleasure “down there.” James remembers being really frightened at the time, but after a few days, he started intentionally hurting his genital area to produce pain “because it felt good in some weird way.” He started with mild pressure of his hand on his penis and later started to use tools like clothes pins and some of his father’s tools to intensify the pain and pleasure that he felt. By the time he was a late teen, he often included alcohol in the mix of pleasure and pain.

As James became an adult, his fondness of creating pain to seek pleasure became more sexualized. He participated in rough sexual play with girlfriends, and masturbation usually had a pain element associated with it. He enjoyed having sex without any pain associations, but he got the most pleasure when he was able to feel some kind of pain or pressure to his genitals or anus.

James met his wife Julie when he was 33, and they married a year later. He and Julie were able to enjoy the use of alcohol for relaxation and prior to sexual activities. James and Julie both enjoyed rough sexual play, and through their years of marriage, they engaged in many BDSM activities together including, tying up, whipping, gagging, orgasm control, psychological games, anal play, and other impact play. James said they got “really rough” from time to time, but they always used a “safe word.” He described fantasies of their kinky sexual experiences in which he refused to stop despite her use of a safe word, but these thoughts were never acted upon, nor did it cause him any internal conflict. Overall, they enjoyed their sex life together immensely.

After James’s wife passed away from cancer, his use of alcohol increased to the point of his recognition that he needed to enter a 28-day inpatient rehabilitation program for
recovery. His grief and use of alcohol as a coping tool were addressed in rehab and he reports no relapse after entering a recovery program 5 years ago. He met Anna at a recovery meeting, and they fell in love very quickly. James said that his sex life with Anna was fulfilling but very “vanilla” (i.e., no kinky activities were present in their sexual activities). He remembers wondering if a few drinks would help them both relax so that kink could be introduced into their sexual relationship, but he never discussed this thought with Anna and he did not relapse with alcohol despite the urge to use.

After 2 years of marriage, James started to have stronger urges for feeling pain during his intimate time with Anna. When he asked Anna to smack his butt “really hard” during sex, Anna became very angry with James, telling him “no way!” and ending the sex session immediately saying he better go to Sex Addicts Anonymous meetings. James was embarrassed by Anna's disdain and suggestion to attend a new kind of recovery program, as he did not view himself as a sex addict nor to have inappropriate sexual desires. He never suggested any kind of rough sex play with her again, nor did he attend the suggested recovery program. Instead, he started looking online at “lighter bondage sites” until he progressed to “hard-core BDSM sites” in a matter of 3 years. He usually imagined himself receiving pain from a willing partner, but he was also sexually excited by images of women being bound and gagged.

Strengths

James did not feel any guilt or shame over his sexual urges or behaviors nor did he relapse into alcohol use. His continued abstinence from using alcohol as a coping mechanism showed that he responded to treatment directives well to manage current stressors in his life. James also showed that he had an awareness of his destructive behaviors in his relationship with Anna since he felt badly about hiding his sexual activities from Anna. He was aware that he was hiding sexual behaviors that Anna probably would not agree with and that his “mild BDSM habit” had increased to “something disgusting,” as Anna put it. James never cheated on his first wife, and stated that he certainly did not plan on cheating on Anna, showing his ability to commit to a long-term partner despite significant stressors.

DSM-5 Impressions and Implications

James showed many masochistic tendencies as he was sexually aroused by behaviors, fantasies, and urges of bondage and pain infliction, and he enjoyed being the receiver of pain rather than the giver. He did meet criteria for a comorbid diagnosis of alcohol use disorder, sustained remission. However, James did not meet criteria for Sexual Masochism Disorder since his behaviors, fantasies, or urges did not cause him any significant, clinical distress across the domains of work, social relationships, and/or in other domains of importance. His marriage was distressed because of Anna’s difficulties with James’s behaviors and urges and not due to James’s paraphilic tendencies alone. Also, since James was able to engage in a functional sexual relationship with Anna without the need to engage in masochistic activities, he did not meet any criteria for loss of control.

Relational Problems

Due to his marriage to Anna, someone who did not engage in any BDSM activities and did not approve of such sexual behaviors, James experienced significant problems in his marriage (problems in relationship with spouse or partner). Although James did not feel
guilt or shame about his sexual urges, he did feel like he was the problem in the relationship. Anna thought he was “disgusting” and did not understand why James had these urges or how they could be pleasurable. Her disdain for James paraphilic urges became the primary problem in their marriage. When James was married to his first wife, they shared the same sexual desires and engaged in paraphilic behaviors together in a way that worked well for their marriage. After he married Anna, those sexual behaviors stopped for a few years but James’s sexual urges reignited after some time. When he tried to incorporate some masochistic behaviors into his sex life with Anna, he felt embarrassed for the first time after being rejected. Instead of discussing this incident with Anna to try to come to some resolution, James started engaging in secretive sexual behavior that satisfied his masochistic urges. This hiding behavior quickly turned into a “dirty little secret” and left Anna feeling betrayed, confused, and angry when she found out about James’s “underground life.” Although James did not meet criteria for Sexual Masochism Disorder, he certainly created a problem because of his masochistic tendencies and behaviors.

Assessments

Three assessment tools that might be helpful for gaining more information about James’s condition and situation are the Attitudes to Sex Questionaire (Twohig & Furnham, 1998), the Paraphilias Scale (Seto et al., 2012), and the Sexual Behaviors and Desires Measure (Reese-Weber & McBride, 2015). Although James does not meet criteria for any Paraphilic Disorder, these assessments would be helpful tools in helping James identify problematic areas in his life that he may not have identified through his background history. Assessment tools should always be used in conjunction with a therapeutic conversation and in the context of what is going on in the client’s life at that time.

Assessing Consent and Victimization

In James’s case, there was no evidence of either lack of consent or victimization. Throughout his history and in his current position, James did not engage in any sexual behavior without consent from his sexual partner. His first wife engaged consensually with James during BDSM activities, and they designated a “safe word” to stop any sexual activity if either of them felt uncomfortable at any time, and he did not act upon his sexual fantasy of ignoring her safe word. James disclosed this information privately, and stated he did not share this information with his current wife. James’s current wife, Anna, stated that she never felt coerced or violated at any point during their sexual time together.

No victim was identified in James’s case. Although Anna was hurt and felt betrayed over the discovery that James subscribed to a BDSM site, James stopped the behavior immediately after he found out about Anna’s distress and sought help. He did not continue the behavior despite Anna’s disapproval. James was able to enjoy sex with Anna without engaging in paraphilic behaviors, therefore further demonstrating the lack of victims in his case.

Assessing How Behavior Has an Impact on the Sexual Relationship

It was determined that James’s paraphilia is not a disorder but a lifestyle choice or atypical sexual orientation. However, the complexity of James’s case lies in the fact that his wife Anna is distressed over his tendencies and their marriage is suffering. James and Anna, in some areas of their sexual relationship, are incompatible. James likes kink and Anna refuses such activities. Furthermore, Anna has decided for both partners that they will not be engaging in any BDSM activities. Although James came in to see the counselor with
hopes of squelching his sexual tendencies, he will quickly find out that this request is often improbable as he has engaged in sexually masochistic activities for most of his life. After some time, his feelings of panic, guilt, and remorse may turn to resentment and anger toward Anna.

Assessing How Family Is Affected by Paraphilic Behaviors

James and Anna had a very functional marriage for the first few years of their relationship together. After James was sexually rejected by Anna, some dysfunction started to creep in. James felt like he could not express himself to Anna and felt “shamed” by Anna’s abrupt rejection to his sexual suggestion. In order to cope, he created a secret sexual life where he engaged in secretive sexual behaviors in the online environment. Just like he learned in his family to hide his sexual masochistic urges, James hid from Anna and engaged in masochistic behaviors in secret. The family rule seemed to be: “Don’t talk about kinky sex and certainly don’t engage in it.” James did not feel like the rule could be changed, but he never approached this subject with Anna so no discussion was ever had about how they might come to a working agreement in their sexual life. James did not feel like he could slip or make a mistake after he was found out. His initial request to “be fixed” was from the fear that Anna would leave him if he acted on his masochistic urges in any way.

Interventions

After James met with his counselor for a number of sessions to discuss his background, assess for Paraphilic Disorder, and talk about treatment goals, he was encouraged to bring Anna in for sessions on an ongoing basis. Anna agreed to come consistently, and marriage counseling began.

James and Anna both met with the counselor together to discuss their concerns and their goals in marriage counseling. They talked about what they both wanted in their marriage and the problems they needed to overcome. Initially, Anna just wanted James to “get fixed” and stop engaging in any masochistic sexual behaviors. After some education about Paraphilic Disorders versus paraphilic orientations, Anna felt less anxiety about James’s desires but did not have any interest in engaging in “hard-core” BDSM activities at any point.

Anna and James realized how their behaviors affected one another and that any sexual decision one partner made was a decision for both of them. They learned how to communicate more openly about their sexual wants and needs as well as their relationship engagements in general.

James did not have any symptoms that required medication treatment, but both were informed that if they felt that medication was needed for any reason that they should discuss this in counseling and an appropriate referral would be made to assess that need at that time.

James was encouraged to take personal responsibility for his secretive behavior, whereas Anna was able to discuss how she had been hurt by James’s actions. James, in turn, had the opportunity to tell Anna about his past and how masochistic tendencies had been a large part of most of his life. Although he knew that Anna did not want to engage in any hard-core BDSM activities, the couple was able to take small steps toward a compromise. Anna was nervous about trying new sexual behaviors with James, but she told him what she might be comfortable with to begin. Anna was also able to talk about the sexual messages she received growing up and how they had an impact on her sexual “rigidity” today. She was also honest about her own feelings of loss of control with chemical addiction prior to her own recovery 10 years ago and her fears of feeling out of control in sexual situations.
James and Anna continued to address their sexual issues and relationship issues in counseling week to week and eventually moved to every other week and then monthly. Although they had many areas to address and a lot of work to do together to become “sexually compatible,” they were off to a good start. Regularly scheduled sessions kept them on task with treatment goals and allowed them to address challenging areas as they surfaced.

Ethical and Legal Implications

First and foremost, the counselor must have an understanding of his or her own sexual bias, preferences, and attitudes so that the client’s best interests are not lost in a personal agenda. Suggested assessments designed to increase counselor self-awareness are the Comfort and Willingness Scale to Address Client Sexuality Scale, developed by Harris and Hays (2008), and the Attitudes about Sadomasochism Scale (Yost, 2010). Each can be used to address the ACA Code of Ethics, Sections A.4.a and A.4.b (2014).

Based on the guidelines given previously, there is no evidence of either lack of consent or victimization with regard to James’s atypical sexual orientation toward BDSM. No child or under-aged adolescent was involved in any of James’s activities and, therefore, there is no ethical mandate to report his activities.

DISCUSSION

As you continue to reflect on the case study and the overall approach, contemplate these questions:

- Since James’s marriage is suffering due to James’s paraphilic tendencies and behaviors, why would James’s condition meet criteria for significant distress in the DSM-5?
- If Anna stated that James violated her consent at one time during sexual play, would James’s masochistic “orientation” or “lifestyle choice” become a “disorder”? Why or why not?
- Since James, by self-report, has an identified diagnosis of alcoholism (in remission for 5 years), what is the counselor’s responsibility in establishing if a current substance use disorder is also having an impact on his marriage with Anna?
- At what point should the counselor refer Anna for individual counselor sessions, if at all?
- Since James experienced sexual arousal when fantasizing about not listening to his first wife’s “safe word,” what is the appropriate counseling response? Is it a good idea to bring this information into the couple's work? Why or why not?

SUMMARY

Paraphilias are conditions that can be exhibited as disorders or orientations, and it takes a skilled and open-minded clinician to differentiate between the two. Although many people will have significant distress due to their paraphilic tendencies, there are many others that embrace paraphilic urges and behaviors and create lifestyles that work for them and their sexual partners. It is vitally important for counselors to listen to their clients about their situations, assess their wants and needs, identify whether there are significant stressors, and find out if there are any victims associated with paraphilic behaviors before giving Paraphilic Disorder diagnoses or identifying pathologies or dysfunctions. Although
many families may experience dysfunction in their lifetimes, not all families are dysfunctional, so completing a full family assessment is essential for properly working with this population. Cultural norms are also incredibly important to take into account when working with paraphilias since norms can range drastically from one culture to the next. Although many therapeutic approaches exist in the treatment of Paraphilic Disorders, a family systems approach is most recommended because it focuses on personal responsibility in relation to others within a family dynamic. Although one person may have paraphilic urges, all family members are affected and contribute to the problems within the family. Finally, ethical and legal issues can occur regularly when treating this population, especially within the realm of personal biases and mandated reporting so that counselors should regularly assess their value systems and keep their clients central in their decision-making practices.

REFERENCES


