Chapter 1

Introduction to Pediatric Psychological Care

1.1 Introduction

Imagine the following presenting concerns when you arrive at your office early Monday morning:

- A child arrives with a diagnosis of functional neurological symptom disorder and no known medical etiology for his apparent inability to use his legs for the past six months.
- An adolescent experiences diabetic ketoacidosis for the eighth time in one year due to nonadherence to his treatment regimen.
- An adolescent has been assessed as being "pre-diabetic" and asks for help in losing weight.
- A child refuses to see the school nurse when she needs medication because she does not want her peers to view her as "different" or "crazy."
- A pediatrician calls asking whether you will assist with a patient who has exhibited a rapid decline in respiratory functioning due to the family's lack of follow-up for specialty medical care.
- A child suffers extensive burns from an accidental house fire and has difficulty returning to the home after discharge from the hospital.
- A sibling has difficulty coping after his brother experiences severe injuries following a motor vehicle accident.
- Parents struggle with setting appropriate boundaries and expectations for their child given the child's history of significant medical trauma.
- A patient has difficulty returning to school following a traumatic brain injury due to his accurate perception that his cognitive abilities and functioning have been adversely impacted since his accident.

What do all of these diverse concerns have in common? Despite the breadth of these concerns, the aforementioned scenarios are all potential referral questions posed to pediatric psychologists. Despite this typically falling within the purview of specially trained pediatric psychologists, many traditionally trained mental health clinicians will be asked to respond to these same concerns due to a lack of access to a pediatric psychologist, an already strong rapport with their current mental health clinician, or other important factors. As such, traditionally trained mental health clinicians, such as master's-level counselors and clinical social workers, are asked to respond to these concerns with the same dedication and expertise they apply to other presenting concerns that they may have more experience with as a result of their previous graduate training or professional clinical experience.

This book was written to help traditionally trained mental health clinicians become familiar with the basic principles and strategies used in pediatric psychology. This book

provides resources to help clinicians enhance their clinical practice as well as providing resources for how to find further resources in specific areas based on the presenting problems of their patients and their own burgeoning clinical interests.

1.2 Foundational Principles of Pediatric Psychological Care

The origins of pediatric psychology have been initially attributed to Lightner Witmer's first discussion in 1896 of a partnership between child psychology and pediatrics (White, 1991). In subsequent years, Logan Wright outlined the profession of pediatric psychology as psychologists working in pediatric settings, with pediatric psychology later being defined by the Society of Pediatric Psychology's Executive Committee in 1974 as "a professionally oriented group of psychologists who deal with children in interdisciplinary settings such as hospitals, pediatric practices, and developmental centers" (Kenny, 1975, p. 8).

When many lay people are first introduced to the concept of pediatric psychology, they may be easily confused with the difference between the work of traditional child psychologists and pediatric psychologists. In contrast to traditional child psychologists who work with children whose concerns are primarily psychiatric in nature, pediatric psychologists' work may span from working with children with typical developmental trajectories to children with developmental disabilities and, in particular, children with medical needs or other concerns that are not primarily psychiatric in nature (Mesibov, 1990). Due to the multidisciplinary nature of the work of pediatric psychologists, it is particularly important for clinicians working within this scope to gain the confidence and competence to interact productively with nurses, educational specialists, medical specialists, pediatricians, medical social workers, and other vital members of multidisciplinary medical teams. Simply put, a pediatric psychologist is severely hampered in their ability to provide effective care without the support of their medical colleagues.

Over the years, pediatric psychology has evolved and redefined its scope and mission from its initial origins. Currently, pediatric psychology has been defined as a "multidisciplinary field of both scientific research and clinical practice which attempts to address the psychological aspects of illness, injury, and the promotion of health behaviors in children, adolescents, and families in a pediatric health setting" (Aylward et al., 2009, p. 3). With this definition, there is great variety in how pediatric psychology is practiced in the real world, with applications ranging from clinicians serving as embedded members of multidisciplinary teams in hospital settings to clinicians in private practice providing outpatient treatment. Despite these variations in settings and other factors, most clinical approaches with children and adolescents with medical concerns typically emphasize briefer interventions that are characteristically behavioral and cognitive-behavioral in approach (Roberts et al., 2014).

With this variety in how pediatric psychology is practiced, there is also great variability in how training for pediatric psychology occurs. Some pediatric psychologists may have first started as members of clinical child psychology graduate programs and then received specialized training later on in their graduate work through their pre-doctoral internship and postdoctoral fellowship, whereas other clinicians may have trained in other graduate programs with a broader focus (i.e. clinical or counseling psychology) prior to specializing. Whatever the path to training, clinicians should minimally gain clinical expertise in pediatric psychology via traditional coursework, clinical experience, and ongoing clinical consultation and supervision.

With the different training backgrounds of many of its members, the Society of Pediatric Psychology Task Force has worked to identify 12 specific domains recommended for training: (1) lifespan developmental psychology; (2) life span developmental psychopathology; (3) child, adolescent, and family assessment methods; (4) intervention strategies, (5) research methods and systems evaluations; (6) professional, ethical, and legal issues; (7) diversity; (8) the role of multiple disciplines in service delivery systems; (9) prevention, family support, and health promotion; (10) social issues affecting children, adolescents, and families; (11) consultation and liaison roles; and (12) disease process and medical management (Spirito et al., 2003).

With the multifactorial considerations that arise as part of clinical work in pediatric psychology come novel ethical considerations that may not be recognized or typically topical for mental health providers practicing in more traditional mental health roles and settings. For example, ethical considerations that can arise as part of pediatric psychology work can include, but are certainly not limited to, an adolescent's involvement in medical decision-making, the balancing of patient confidentiality and patient safety for adolescents engaging in risky behaviors, and determining when lack of follow through on medical care constitutes grounds for a mandated report regarding abuse/neglect.

When possible, having an adolescent involved in decision-making is preferable in order to help the patient feel some locus of control in an environment that is often well outside their influence. In some states even, an adolescent must consent in order for treatment to occur; for example, an adolescent age 14 and older can refuse outpatient mental health treatment in Wisconsin until there is a court order (Department of Health Services, 2016). It can be difficult to know when an adolescent is able to actively contribute to the medical decision process. As mental health clinicians, it is recommended that an active role is taken in assessing the patient's capacity for decision-making, care is taken to actively solicit their treatment preferences, and clinicians focus on facilitating positive communication between parents, doctors, and child (McCabe, 1995).

Despite this effort to have adolescents involved in medical decision-making, there comes a time when a mental health clinician has to decide whether or not the patient's behavior warrants breaking confidentiality with the patient in order to discuss their health risk behavior with their parents. This is never an easy decision due to the concern the patient may feel betrayed and therefore may not be as forthcoming in the future with the psychotherapist with issues associated with safety. Given this concern, it is not surprising that research indicates that pediatric psychologists tend to not report when a behavior is risky to an adolescent's health when the behavior is perceived to be of low intensity and frequency, such as smoking one cigarette per month (Rae et al., 2002).

Research indicates that pediatric psychologists are typically more likely to break confidentiality when the patient is female and the behavior is smoking or sexual behavior (Rae et al., 2002). Rae and colleagues hypothesize that this increased likelihood to break confidentiality with females may be due to the perception that risky behavior is seen as more normative in males and the possible perception of the increased negative impact of pregnancy and of increased vulnerability to sexually transmitted diseases for female adolescents.

In addition to the above concerns, clinicians working with children and adolescents with medical concerns may run up against the ethical dilemma of when or if to involve state regulatory services due to concerns of medical neglect. Similar to decisions regarding the mandated reporting of suspected child abuse, clinicians must refer to their professional

organization's ethical guidelines when determining whether a patient's lack of medical care or follow-up rises to the level of suspected neglect. This decision can be hard for clinicians due to the fear that mandated reporting will irrevocably alter the therapeutic relationship; however, medical neglect must be viewed through the same lens of other types of mandated reporting that patient safety trumps other concerns.

1.3 Theoretical Underpinnings and Future Directions

In the clinical world of pediatric psychology, there are numerous theories that help guide clinicians in their work. One main theory utilized to help undergird work in health promotion is Bronfenbrenner's ecological systems theory, which recognizes a factor's level of influence based on proximity to the child (Kirschman & Karazsia, 2014). With this theory, the influence of systems and environment on the individual is accounted for rather than relying solely on viewing the individual's behavior one-dimensionally without environmental context. According to Bronfenbrenner's theory, an individual is first impacted by their immediate environment, called the microsystem, which involves the nearest influences (i.e., parents, siblings, and immediate caregivers). It can be an easy mistake for a pediatric psychologist or other mental health provider to assess and monitor the impact of only this easily identifiable microsystem and to lose sight of the larger systems at play, as described below.

The next larger system is the mesosystem, which encapsulates several microsystems, and typically involves the child's school, peer group, and religious group (Kirschman & Karazsia, 2014). Within the mesosystem, pediatric psychologists' work is with the extended community of people who have direct contact with the child, such as medical providers and school staff. In the exosystem, which is the larger environment influenced by religious, culture, and social class, pediatric psychologists are not working directly with the individual patient but instead are working with larger programs and communities that indirectly influence the patient, such as injury prevention programs (Kirschman & Karazsia, 2014). Last, the largest system, the macrosystem, involves the broadest level of influence, with the work of pediatric psychologists typically focused on research and legislation.

In addition to Bronfenbrenner's theory, another prevailing theory used in pediatric psychology is social-cognitive theory, which posits that behavior change is associated with one's belief about the outcome and belief in their abilities (Wilson & Lawson, 2009). With this theory, there is an overall emphasis on assisting patients via goal-setting and self-monitoring. According to social-cognitive theory, there are a specific set of determinants, including a patient's awareness and knowledge of health risks, perceived self-efficacy in impacting change in personal health, outcome expectancies regarding costs and benefits of the respective health habits, the goals and strategies for achieving these goals, and the identified barriers and enablers of these changes (Bandura, 2004).

Based on theories such as the aforementioned, the field of pediatric psychology has established a large body of literature with clinical applications. Myriad directions for future research and clinical work have been identified in the years to come for pediatric psychology. Three particular areas that have been noted for further work are the need for the clinical application of empirically supported treatments for diverse populations, the increasing role pediatric psychologists play with regard to genetic counseling and genetic teams, and an increased emphasis on health promotion rather than illness management (Clay, Mordhurst, & Lehn, 2002; Patenaude, 2003; Roberts et al., 2012).

As the US population becomes more diverse with regard to factors including ethnicity and family structures (e.g., single-parent households or multigenerational households), there is a call for culturally sensitive therapies in which therapy is tailored to specific cultures rather than a continuance of "one size fits all" treatment protocols (Clay et al., 2002). This is particularly important given that a large proportion of the current body of research is built on studies with samples consisting of predominantly Caucasian, middle-class participants. As such, there is a lack of data about the influence of empirically supported treatments for diverse populations and a resulting lack of information about the impact of family factors, culture, health beliefs, and other cultural factors on treatment outcomes. In particular, certain groups have been grossly ignored in the research literature, such as specific ethnic populations (i.e., Native American and Middle Eastern populations), as well as a lack of detailed information pertinent to specific subgroups within larger ethnic groups (i.e., Afro-Caribbean) (McQuaid & Barakat, 2012).

In addition to the increasing need for research into the clinical applications of empirically supported treatments for diverse populations, there is also an expanding role for pediatric psychologists in work with genetics teams. In this burgeoning role, pediatric psychologists can play a direct role in patient care by helping patients to understand and cope with the results of genetic testing (Patenaude, 2003). Similarly, pediatric psychologists can help to provide developmentally appropriate explanations for children and families to help them understand the often-complicated science behind genetics testing, as well as advising genetics teams about collaboratively and productively working with patients. Although not currently a role for pediatric psychologists, there will most likely be a future role of pediatric psychologists in the role of psychiatric genetics and risk of psychiatric disorders as the science progresses (Patenaude, 2003).

Last, the field of pediatric psychology has historically demonstrated a strong focus on clinical work geared toward chronic illness management. In the future, there is a call for research that has an emphasis on health promotion, early intervention, and prevention rather than remaining focused largely on chronic illness management, with specific emphasis on intervention in the primary care setting (Roberts et al., 2012). Rather than focusing on the best way to manage chronic diseases such as diabetes mellitus, type 2, there has been a paradigm shift in how we can best prevent these diseases from occurring in the first place. Based on Bronfenbrenner's ecological systems theory, pediatric psychologists are asked to begin placing focus on the exosystem rather than just directly on the micros and mesosystems of each patient.

1.4 Anecdotal "Golden Nuggets" for Clinical Practice in Pediatric Psychology

For all clinicians, an emphasis on empirical research to guide their clinical practice is paramount. Additionally, hard-earned tips and strategies from experienced clinicians can enhance one's clinical practice and help enhance one's foundational understanding of what it means to work with children and adolescents impacted by a medical event or chronic illness. Anecdotally, the following four themes are suggested for consideration by clinicians working with varying ages and different conditions in a pediatric psychology context: partnership, collaboration, fundamentals, and confidentiality.

Regarding partnership, clinical practice in pediatric psychology requires consistent dedication to forming and developing partnerships with families, medical providers, school

personnel, and other important individuals in each patient's life. In particular, emphasis should be placed on the familial relationship, as almost all aspects of medical and mental health care will be impacted in some way by family members, whether through parenting strategies, sibling communications, or interactions with extended family members.

As such, it is important to **help the patient by helping the family**, as a family in distress (such as a mother experiencing symptoms of an untreated psychiatric illness) leads to a patient in distress. It can feel futile to try to assist a young patient with their mental health or medical concerns when larger familial influences are adversely impacting the course of treatment and the patient's overall prognosis. Despite needing to maintain the boundary of not "treating" anyone other than the identified patient, it is often necessary to ensure that other family members are at the minimum provided with alternative mental health resources if their needs are beyond the scope of the clinician or beyond the parameters of the identified clinical relationship with the patient.

Alongside a relationship with the family, it is vital for mental health clinicians to **develop a working relationship with medical personnel.** Ongoing and collaborative communication is important to ensure that the mental health clinician is up to date with the most current treatment regimen and remains aware of any changes to the patient's functioning and prognosis. The last situation any mental health clinician wants to be in is to be providing clinical recommendations that are not consistent with the recommendations of the patient's medical providers, as this leads to confusion for the patients and family and possibly malpractice by the clinician for operating outside their training and identified scope. It may be helpful for readers to view the sample pediatric psychology intake template in Figure 1.1 to help identify clinical areas to discuss with the medical team, such as discussing patient's treatment adherence and transition to increased patient autonomy in managing their treatment regimen.

With a strong working relationship, a clinician is able to learn the necessary medical information that will allow the provider to provide optimum and holistic care that is individualized to each patient. This leads to the third partnership "nugget" of: **When you don't know, ask!** Even the most veteran and experienced of clinicians will not know all of the medical terminology and information that changes rapidly due to advances in medicine. Clinicians need to be comfortable asking medical team members questions to help better understand their patient's daily journey and expected prognosis, which can often be achieved only by asking clarifying questions and requesting resources to help broaden and deepen their own understanding of the patient's medical status. In turn, this comfort with asking questions can help to support other medical providers in feeling encouraged to reach out to the clinician in the future for recommendations as needed as part of the patient's overall medical care.

Given that the field of medicine and mental health is constantly evolving, one "golden nugget" that is of paramount importance is to **never stop learning**. There are always new and exciting advances in the fields of medicine and psychology that a mental health clinician should remain aware of in order to provide the most competent and evidence-based care for their patients. Memberships on medical and psychology organizations' list servs (Society of Pediatric Psychology, Cystic Fibrosis Foundation, etc.), attending regional and national conferences, auditing graduate classes, pursuing continuing education opportunities, and maintaining both formal and informal consultative relationships are wonderful ways clinicians can stay on top of the ever-evolving research literature. As research expands to become more representative of ever-changing demographics, clinicians must

Sample Pediatric Psychology Intake Template

Referred by:

1) Presenting Problem (how long, when it start, how frequent):

2) Patient Past medical history (broken bones, surgery, illness):

3) Patient Medical:

Diagnosis	Date of Diagnosis	Treatment Regimen/Surgeries

a. Knowledge/Skills related to treatment regimen

b. Adherence concerns

c. Transition to independence with treatment regimen

d. Comfort discussing diagnosis with peers and medical providers

4) Family Medical and Psychiatric History:

Diagnosis	Date of Diagnosis	Treatment Regimen/Surgeries

5) Developmental:

a. Pregnancy/ Complications

b. Temperament

Figure 1.1 Sample pediatric psychology intake template.

c. Developmental milestones

d. Pubertal development

e. Eating/Weight

Current height/weight: BMI:

Recent change in height/weight?

How feel about weight/body size?

Any restricting/purging/binging/compensatory behaviors?

6) Patient Past/Current Psychiatric:
   a. Medications
   b. Outpatient care
   c. Hospitalizations
   d. Self-harm/violence/suicide
   e. History of abuse/trauma

7) Heath Promotion:
   a. Typical exercise pattern
   b. Cigarettes/e-cigarettes/smoking
   c. Alcohol use
   d. Illicit drugs
   e. Reckless driving, wearing seat belt
   f. Vaccinations
   g. Sexual activity/contraception

8) Social:
   a. People in household

Figure 1.1 (*cont.*)

b. Relationships with people in household

c. Stress in household/family environment (marital conflict/financial difficulties)

9) Hobbies/Extracurricular Activities:

10) Education:
a. School: Grade:

b. Current grades/academic performance

c. IEP/504

d. Special services at school

e. Behavior problems/suspension

f. Current academic performance

g. Prior academic performance

h. Relationship to teacher

i. Relationship with peers

11) Legal Issues/Interaction with Child Protective Services

Current Psych:

a. Appetite
b. Sleep
c. Crying
d. Mood (happy, sad, angry, okay)
e. Self-esteem/self-concept
f. Fatigue
g. Anhedonia
h. Feel lonely
i. Motivation
j. Anxiety
k. SI/HI
l. Hallucinations/Paranoia
m. OCD

Describe Typical Day:

Goals for Treatment

Figure 1.1 (*cont.*)

make reading the research literature a priority in order to ensure that their patients are accessing the most evidence-based care.

Partnering with families, medical organizations, and other medical providers are not the only critical partnerships that must be developed and maintained by mental health clinicians working with children and adolescents with medical issues. An important partnership is forming relationships with individuals "in the know" in order to **have an awareness of community resources**. There are numerous resources available for children with medical conditions that can help serve the psychosocial needs of patients and families. Children's hospitals and pediatric specialty medical clinics tend to have a wide swath of resources available for members of the community, including resources such as information about college scholarships, disease-specific summer camps, and parent support groups. In particular, it may be helpful to reach out to social workers embedded in specialist clinics given their knowledge of local resources and to help enhance future collaboration between providers. Grassroots medical organizations are also superb ways to learn more about community resources that may be pertinent to providing overall family support that goes beyond just the provision of therapeutic support for the pediatric patient.

Based on this writer's experiences, the second theme of "normalization" appears to arise at some point during at least one clinical interaction with most patients. Clinicians should be mindful that most children and adolescents with a medical (and/or a psychiatric) condition will at some point feel "different" or "not normal" in comparison to their peers without their particular condition. The implicit, and even explicit, message that should undergird these clinical interactions is the message that "**You are unique and different, as is everyone**." This message can be further strengthened by being mindful of using language that conveys that the patient is seen for who they are as a person, rather than as their illness.

The **power of language** can be identified by the following change in a description of the same patient as "Katie, a volleyball player with epilepsy" as opposed to "Katie, the epileptic." This nuance not only is important for the patient hearing the description, but also helps to prevent the clinician from becoming clinically detached and unmindful of the uniqueness of each patient, regardless of similar symptomology with other patients. This emphasis on the uniqueness of each patient rather than their diagnosis can help to serve as an important model for how medical providers can actively develop rapport and convey respect during interactions with or about patients.

As part of the awareness of the theme of "normalization," it is also important to be aware of typical developmental challenges that can occur within a medical context. In particular, adolescents are developmentally tasked with learning to individuate and gain autonomy from their parents. As such, "typical" adolescent behavior can include some growing pains related to difficulty with being "adult enough" to manage their treatment regimen consistently when responsibility is first transferred to the adolescent. This "treatment nonadherence" can be determined by clinicians as being either **pathological or developmentally appropriate** given that clinician's understanding of the child's developmental stage and chronological age and, thus, will require different interventions or strategies for assistance. Most parents will wonder at some point or another whether their child's behavior is "typical," and it is good clinical practice for a clinician to be strongly grounded in developmental theory in order to answer accurately whether that child's behavior is developmentally appropriate.