

Autism and Child Psychopathology Series

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Robert D. Friedberg

Jennifer K. Paternostro

Editors

Handbook of Cognitive Behavioral Therapy for Pediatric Medical Conditions

 Springer

Autism and Child Psychopathology Series

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Handbook of Cognitive Behavioral Therapy for Pediatric Medical Conditions

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To my mother, Rachelle Friedberg; my grandparents, Rose and Frank Derewitz; my love of my life, Barbara Friedberg; and my daughter, Rebecca, who always makes me proud, look I made a hat where there never was a hat!!

RDF

I would like to dedicate this project to my parents, Karen and Tony Paternostro; to my brother, Kevin Paternostro; and to my incredible partner, Alex Wiese. I cannot thank them enough for their unconditional love and support.

JKP

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Introduction: Knowledge, Actionable Practices, and Urgency

1

Jennifer K. Paternostro and Robert D. Friedberg

*I have been impressed with the urgency of doing.
Knowing is not enough, we must apply. Being will-
ing is not enough, we must do.*
Leonardo Da Vinci

Delivering Cognitive Behavioral Therapy to young patients challenged by various medical conditions represents an evolving frontier in behavioral health care. In order to traverse this fertile ground, practitioners require state-of-the-science findings and effective clinical practices. The chapters in this handbook provide precisely this type of material. This book reflects the work of 55 contributors from 25 different institutions. The diverse topics are addressed in ways that ideally facilitate the easy transfer from page to practice. In this introductory chapter, we summarize each individual chapter underscoring the salient issues.

Part I of the handbook focuses on broad conceptual issues. The book kicks off by highlighting

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the value of integrated behavioral health care in pediatric medical settings. Friedberg and Paternostro first describe the current state of affairs as it relates to integrated care practices, as well as efforts to pursue the Triple Aim of Health Care—enhanced patient care experience, decreased per capita health expenditures, and improved population health outcomes. Various integrated care models are presented including collaborative and coordinated care options, co-located services, and fully integrated systems. The chapter then delves into common psychological problems and issues that often present in pediatric primary and specialty care clinics. Friedberg and Paternostro argue that pediatric psychologists and behavioral health providers are uniquely skilled in addressing general parenting concerns (e.g., toilet training, discipline, feeding), and developmental, emotional, and behavioral issues that arise in pediatric medical offices. The chapter concludes with a discussion on the value of integrated service delivery models to the patient population served, health care providers, and stakeholders.

By the year 2020, racial/ethnic minority children in the United States will make up the majority of the population. Although this indicates an exciting time of growth in our country, health disparities (e.g., overall health outcomes, oral health, mental

health, increased risk of chronic illness) are far too prevalent among minority youth. Moreover, health disparities are not exclusive to racial and ethnic minorities. Sexual minority youth also experience poorer health outcomes and have higher rates of mental health issues. Valenzuela, Tatum, and Lui provide an insightful overview of evidence-based treatments for diverse pediatric patients and their families. In addition, the authors examine challenges of providing culturally competent care, while emphasizing the importance of adapting to the individual's cultural experience. Specific recommendations for cultural adaptations of evidence-based treatments are provided. Next, the authors identify distinct considerations in working with African-American populations, immigrant youth and their families, and sexual minorities. Historical and systemic barriers to quality care conclude the chapter.

Providing competent, quality, and evidence-based care in pediatric medical settings is associated with unique ethical considerations and challenges. Koocher and Hoffman offer specific knowledge and skills required to deliver ethical care including optimizing treatment manuals while maintaining fidelity, and collaborating with physician colleagues. Moreover, the authors contend that developing a basic understanding of common medical conditions and associated treatment regimens is a basic ethical obligation. Further, attention is explicitly directed to informed consent and assent processes. Since integrated care often requires ongoing collaboration between medical providers and behavioral health clinicians, nuances of confidentiality are reviewed. Potential ethical dilemmas and infractions in pediatric medical settings are explored. Specific examples are provided to further illustrate these concerns.

Parrish, Fajer, and Papadakis' chapter explains the critical role emotion regulation plays in pediatric psychology. When youth are diagnosed with a medical condition, whether acute or chronic, undoubtedly, resources for regulating distress are triggered. The chapter begins with two compelling case vignettes that demonstrate the emotional impact children and families often face when presented with a medical condition or unexpected

medical events. Moreover, adjustment to diagnosis and subsequent adherence to complex medical regimens may provoke significant familial stress and conflict. Emotion regulation is a critical component of psychosocial functioning and adjustment and thus requires tailored intervention. The authors illustrate the relevance of emotional regulation to understanding and treating pediatric patients and their families. Next, Parrish and colleagues provide a comprehensive review of emotion regulation focused interventions and resources for clinicians that aid in the treatment of youth with medical conditions.

Motivational Interviewing (MI) is a patient-centered approach to addressing behavioral change. MI is well equipped to assist patients in successfully managing chronic medical conditions and adherence to complex treatment regimens. Jeter, Gillaspay, and Leffingwell detail essential components of MI as well as necessary modifications for working with pediatric patients diagnosed with medical conditions. Furthermore, the authors review empirical evidence of MI for various referral questions such as adherence and pediatric health behaviors (e.g., asthma, obesity, diabetes). The chapter concludes with an overview of training requirements and resources for MI interventions.

In Chap. 7, Friedberg and Paternostro introduce the foundational elements of traditional Cognitive Behavioral Therapy with youth. The chapter begins with a brief overview of the theoretical underpinnings of learning theory, which prioritizes classical conditioning, operant conditioning, and social learning theory in understanding human behavior. An updated review of the literature is provided with specific attention to the empirical status of CBT for disruptive behavior disorders, depressive disorders, and anxiety spectrum disorders. Next, the authors describe core components of modular CBT, which are well suited to adapt to pediatric settings. The chapter ends with a pertinent case example of a 9-year-old patient with anxiety and functional gastrointestinal and neurological distress, who begins a course of modular CBT.

Treatment for patients diagnosed with pediatric medical conditions commonly requires modifications

to traditional practice. Accordingly, Catarozoli and colleagues present necessary adaptations to the CBT framework to fit pediatric populations. Pediatric medical settings are replete with comorbid mental health challenges. Budding research supports the use of CBT for pediatric medical conditions, with noted improvement in both mental and physical health outcomes. The nuances of providing CBT for pediatric populations in medical settings are explored. Inclusion of alternative CBT spectrum approaches such as Dialectical Behavior Therapy, Acceptance and Commitment Therapy, and Parent–Child Interaction Therapy to meet the unique needs of this population is emphasized. Additionally, consistent with the patient-centered care model, the authors suggest ongoing collaboration and consultation with other medical providers may be indicated. Next, the chapter provides a comprehensive directory of ways to adjust cognitive and behavioral interventions for pediatric patients presenting with medical complexity.

Dialectical Behavior Therapy (DBT) revolutionized the field of clinical psychology. Originally developed by Marsha Linehan in 1993, DBT has become the first-line treatment for suicidal behavior and Borderline Personality Disorder. Miller and O'Brien provide an overview of the theories, modes, functions, and interventions of DBT as well as its application to adolescents with high-risk behaviors. Next, clinical practices in medical and school-based settings are presented. Empirical evidence of DBT-A for treating multi-problem youth is well supported in the literature for a variety of presenting concerns. The chapter concludes with a clinical vignette of a 17-year-old who presents for a comprehensive DBT-A program with a past mental health history of Major Depressive Disorder, Generalized Anxiety Disorder, Social Anxiety Disorder, and Alcohol Use Disorder.

Building off of the previous chapter, Lois, Corcoran, and Miller explain how to adapt DBT techniques for youth with chronic medical illness (CMI). Living with a CMI can be a difficult and daunting task that requires substantial self-management skills including adhering to complex treatment regimens, attending follow up and routine medical appointments, and following dietary restrictions. This chapter highlights the

specific challenges associated with living with a CMI and the impact chronic illness has on one's mental health. Using a DBT framework, the authors explore various systems-level issues that compound an already complicated situation for patients and their families. Although DBT-CMI research is in its infancy, the authors provide a brief look into the current empirical literature. Throughout the chapter, Lois and colleagues seamlessly interweave "how to" examples into their description of the DBT-CMI protocol and case examples.

The diagnosis and management of an acute or chronic medical condition can be extremely taxing on pediatric patients and their families. Chronic medical conditions are commonly associated with extensive medical intervention, prolonged hospitalizations, changes in daily routines, and complex self-management tasks. Therefore, it is understandable that patients are at higher risks for notable anxiety, post-traumatic stress disorder, depression, and/or disruptive behavior. Jummani and Shatkin provide a comprehensive overview of pharmacological interventions for youth with medical conditions who may be experiencing moderate to severe psychopathology. Along with a basic explanation of specific medications used in pediatric populations, the chapter reviews the empirical evidence supporting the use of psychopharmacological intervention across mental health diagnoses. Moreover, the chapter serves as an excellent resource for clinicians looking for a quick reference on pharmacological interventions in integrated care settings.

Part II addresses clinical work with specific populations. Parrish and Van Eyck begin with a review of CBT interventions in pediatric primary care. Pediatric primary care settings are frequently visited by children and their families. Children are generally seen by their pediatrician at least once per year and often report a trusting and collaborative relationship. Thus, the primary care office is a convenient place to receive behavioral health support and connect with a mental health provider. Parrish and Van Eck argue that integrated primary care settings provide a multitude of benefits for both the patient and medical providers, who are often treating mental health

problems alone and without necessary adjunctive support. The authors then examine the literature on distinct models of integrated care practices and highlight the all too common discrepancy between research and clinical application. The chapter concludes with two case vignettes that demonstrate CBT implementation in a pediatric primary care setting.

The remainder of this section focuses on behavioral health management of acute and chronic medical conditions. Fussner and Lynch-Jordan introduce CBT strategies for patients with widespread musculoskeletal pain. Chronic pain is often associated with substantial declines in daily functioning and can become debilitating if left untreated. Furthermore, chronic pain increases risk for mental health conditions. The chapter nicely illustrates the biopsychosocial model of widespread musculoskeletal by synthesizing the extant literature and clinical case examples. The importance of taking a multidisciplinary team-based approach to treatment is delineated. Next, the authors provide a framework for working with pediatric patients with chronic pain, using CBT components to increase functioning. A sample treatment course is broken down session by session. Additionally, resources for ongoing assessment are recommended. Given the significant impact chronic pain has on the entire family, the authors suggest specific intervention guidelines for caregivers.

Functional gastrointestinal disorders (FGID) and functional abdominal pain include an activation of symptoms within the gastrointestinal tract. FGIDs are very common in pediatric patients. The physical symptoms can be embarrassing to young patients and impact their quality of life. Furthermore, functional disorders are associated with higher rates of anxiety and depressive symptoms. Physical symptoms of FGIDs are akin to the physical manifestations of anxiety and depression. Thus, Baber and Rodriquez present CBT interventions for FGIDs with specific emphasis on functional abdominal pain. Using a clinical case example, the authors highlight the biopsychosocial model as it relates to functional abdominal pain. Evidence for the “brain-gut axis” and the interaction between physiological and psychological factors is outlined and discussed.

Psychoeducation on the brain-gut axis is a foundational element in the treatment of functional disorders. To address worry associated with gastrointestinal symptoms, graded engagement and exposures are key features of treatment with this population. Throughout the chapter, the authors equip readers with tangible scripts and intervention strategies pertinent to addressing functional GI distress.

The next two chapters focus on behavioral interventions for enuresis and encopresis in pediatric patients. First, Christophersen and Kapalu present the assessment and treatment of enuresis. Enuresis is defined as repeated voiding of urine (either voluntary or intentional) in a place other than the toilet. For a diagnosis of enuresis to be warranted, urinary accidents must occur twice per week for at least 3 months or cause clinically significant distress or impairment. The authors provide an overview of the prevalence of enuresis, cultural considerations, and the course and prognosis of the disorder. The chapter is divided into nocturnal enuresis (nighttime wetting) and diurnal enuresis (daytime wetting) sections. For both conditions, a thorough medical and psychosocial assessment of the maintaining factors impacting the youth’s enuresis is discussed, and behavioral interventions for treating this population is explored. The bell-and-pad or urine-alarm training is the first-line treatment intervention for nocturnal enuresis. The urine alarm utilizes both classical and operant conditioning paradigms, which lay the foundation of behavioral interventions. Additional behavioral interventions for enuresis include dry-bed training, cleanliness training, positive practice, nighttime awakening, retention-control training, positive reinforcement, and over-learning. Each of these interventions is illustrated using clinical case examples to highlight the individual treatment components.

Encopresis is the second of the two main elimination disorders that commonly occur in childhood. Also known as fecal incontinence, encopresis is defined as repeatedly passing stool in inappropriate locations such as onto the floor or in underwear/pull-ups. Similar to enuresis, encopresis is considered a biobehavioral or biopsychobehavioral disorder that is treated and

managed with both medical and psychosocial intervention. Kapalu and Christophersen begin the chapter by documenting the prevalence and etiology of encopresis. The role of constipation in the development and maintenance of encopresis is provided. In order to develop pertinent treatment targets, a thorough psychosocial assessment is suggested. Kapalu and Christophersen explain common behavioral interventions including adherence to bowel regimen, reinforcement schedules for appropriate toileting behaviors, toilet training routines, access to preferred activities while completing scheduled toilet sits, and effective parental responses. The chapter concludes with a case example to highlight key components of assessment and treatment of encopresis.

Kaczynski describes the debilitating impact headache disorders have on individuals' daily functioning. With approximately 60% of youth experiencing headaches of varying degrees of intensity and duration, headaches are considered a widespread condition. This chapter dives into the different types of headaches that regularly affect pediatric patients as well as the impact headaches have on a children's functioning and quality of life. Mood disruption, sleep problems, school difficulties, participation in extracurricular activities, family dynamics, and peer relationships can all be affected by chronic headache. Kaczynski then presents the biopsychosocial framework for treating pediatric chronic headache. The emphasis on multidisciplinary treatment is described along with alternative approaches to care. Furthermore, the utility of psychological intervention including relaxation training, CBT, and biofeedback is explored using clinical case examples that highlight treatment targets and techniques.

Pediatric sleep disturbances impact approximately 20–40% of children. Without proper sleep hygiene and adequate sleep per night, children's as well as their families' daily functioning is ruptured. Fehr, Chambers, and Ramasami begin the chapter with a review of the literature on healthy and disrupted sleep. The authors then present the biopsychosocial conceptualization of sleep disturbance using a clinical case example of a 4-year-old with bedtime resistance and sleep

avoidance. Additional sleep disorders are reviewed, including delayed sleep-wake phase disorder, parasomnias, obstructive sleep apnea, and narcolepsy. Next, the authors describe the treatment components recommended for sleep difficulties. More specifically, parental education, sleep hygiene training to increase sleep promoting behaviors, establishing regular bedtime routines, contingency procedures such as reinforcement and extinction, bedtime fading, chronotherapy, scheduled awakenings, and traditional CBT are illustrated. The chapter ends with a case example that embodies individual treatment components to sleep disruption.

Chapter 19 is focused on pediatric epilepsy and is separated into two sections: epilepsy and psychogenic non-epileptic seizures. Consequently, the chapter illustrates the nuances of CBT for each condition. Seizure disorders increase risk for developing mood and behavioral problems in youth and can become a major source of ongoing stress. Therefore, addressing these components is critical for continuous adjustment and improving quality of life. For each section, Fehr, Doss, Hughes-Scalise, and Littles describe treatment components including adjustment to diagnosis, adherence to complex treatment regimens, and psychosocial comorbidities. The goal of treatment for patients with epilepsy is an emphasis on maximizing quality of life and psychosocial functioning. Psychogenic non-epileptic seizures (PNES) is a conversion disorder, as described by the DSM-5. Accordingly, PNES is believed to develop as a response to psychological stress, and biopsychosocial model suggests that unresolved distress produces adverse physiological and emotional responses. A case example is used to illustrate the course of CBT treatment with this population.

It is no surprise that children diagnosed with cancer are at greater risk for developing emotional, behavioral, and social problems than their healthy peers. Invasive treatments, painful surgeries, repeated hospitalizations, and office visits often lead to significant emotional burden and distress. Salley and Catarozoli's chapter focuses on the biopsychosocial assessment and treatment of childhood cancer. Considering

important factors unique to those who are battling cancer, the authors describe flexible adaptations of CBT interventions. Notably, there are distinct modifications for cognitive restructuring. Salley and Catarozoli also provide helpful guidelines for parental involvement, behavior management, emotional regulation, and coping with somatic complaints. A case example of a 12-year-old boy with acute lymphocytic leukemia concludes the chapter.

The impact of psychosocial factors on disease management in pediatric patients with diabetes is well established. In this next chapter, Carpenter and Cammarata augment the biopsychosocial model of diabetes management with special considerations unique to patients with diabetes. Their contribution begins with a brief introduction of insulin-dependent diabetes mellitus as well as biological and psychosocial variables that impact adherence to diabetes self-management. Further, the authors discuss the importance of assessing for executive functioning deficits/delays and diabetes distress. To help illustrate the concept of diabetes distress, a case example of a 14-year-old boy with type 1 diabetes is provided. Evidence-based treatment approaches commonly utilized in the psychosocial treatment of diabetes including behavioral family systems therapy for diabetes (BFST-D), behavioral rewards systems, problem-solving skills training, and traditional components of CBT are explored. In addition, strategies to address diabetes distress, diabetes-related fear or resistance to injections, and fear of hypoglycemia are noted.

Asthma is the most common medical condition among youth. Asthma is characterized by recurrent and intermittent respiratory symptoms and airway obstruction that often include symptoms of wheezing, shortness of breath, coughing, chest tightness, and airway limitation. In Chap. 22, Clawson and colleagues explain the biopsychosocial conceptualization and treatment of anxiety in youth with asthma and describe learning processes that may contribute to increased anxiety in this population. CBT interventions that integrate asthma-related concepts and education are promising and may significantly benefit youth with comorbid asthma and anxiety. Case material augments these salient points.

Pediatric obesity has become an epidemic in the United States. Obesity plagues 18.5% of children and adolescents, and these numbers are growing. Children who are obese are at greater risk of developing cardiovascular disease, type 2 diabetes, chronic sleep problems, respiratory distress, poor academic achievement, and mental health issues. Empirically supported interventions for treating pediatric obesity have been found effective in maintaining weight loss up to 1 year post intervention as well as demonstrated improvement in health-related quality of life. Bejarno, Marker, and Cushing explain the biopsychosocial conceptualization of pediatric obesity. Next, initial assessment of obesity is described and includes screening of body mass index (BMI) along with more traditional mental health screening measures. The chapter then delves into specific treatment components to addressing pediatric obesity using rich clinical material.

Historically, transgender and gender expansive youth have been misunderstood and mistreated in both the medical/mental health field and society. In their chapter, Tabuenca and Basile present information aiming to increase clinicians' understanding and treatment of this vulnerable population. They discuss common misconceptions and the lack of social awareness affecting these young people. Further, the authors describe the changes in how clinicians treat transgender and gender expansive youth by providing gender-affirmative care. Empirically supported interventions include a family-based intervention to increase familial support of the patient and trans-affirmative CBT. A detailed case example is provided emphasize treatment components.

Part 2 of the book ends with a chapter that focuses on noncompliance and nonadherence with patients suffering from chronic medical conditions. Medical nonadherence is an ongoing challenge for providers working with pediatric patients and their families. The chapter begins with a clinical case example of an 18-year-old with type 1 diabetes and poor adherence to his medical regimen. Lemanek and Yardley provide the definition and prevalence of nonadherence among pediatric patients. The authors go on to

discuss theoretical models of adherence such as the health belief model, theory of planned behavior, and transtheoretical model. Measures of adherence are provided as a resource for clinicians. Finally, cognitive behavioral intervention components for medical nonadherence conclude the chapter.

The third section of the book focuses on special topics related to delivering cognitive behavioral therapy to pediatric patients diagnosed with medical conditions. In Chap. 26, Landoll, Elmore, Weiss, and Garza explicate the crucial factors central to training issues in pediatric psychology. The authors illustrate the current competency guidelines for working in pediatric primary care and present a brief overview of well-established training programs that emphasize integrated primary care. According to Landoll and colleagues, the Children's Hospital of Philadelphia, Montefiore Medical Center/Albert Einstein School of Medicine, and MetroHealth are leading the way with innovative training initiatives for pediatric psychologists. A helpful review of continuing education and brief training opportunities that utilize modalities such as seminars, workshops, and conferences are also presented.

In Chap. 27, Miller astutely describes the many business and financial considerations associated with working in a pediatric medical set-

ting. Financial issues are paramount in building sustainable clinical practice yet these pivotal concerns are often neglected. The current financial structure of reimbursement for behavioral health services is presented. Obtaining adequate and fair reimbursement is an essential task for the field. One option for demonstrating service necessity in integrated setting is employing outcome measures as well as patient and provider feedback that support value-added benefits. Outcome measures are critical for quantifying the quality of services and creating an argument for behavioral health integration. Miller also explains the financial models that shape the delivery of CBT and various barriers to integration.

Paternostro and Friedberg conclude the text with a brief commentary on common themes and future challenges. These 28 chapters collectively present knowledge guided by contemporary theories and empirical findings. Further, the book offers readers actionable practices that are portable to various settings and populations. If the information rests passively on pages, knowledge is inert. We urge readers to apply the content contained in this text to the vulnerable patients they serve. Carrying around a medical condition accompanied by psychological distress is a weighty burden. These patients deserve the urgent action that impressed Da Vinci. We are proud to introduce this text to readers.

Part I

Broad Conceptual Issues



The Value of Integrated Pediatric Behavioral Health Care

2

Robert D. Friedberg and Jennifer K. Paternostro

Introduction

The health-care system in the United States is in desperate need of a complete overhaul. Despite spending nearly three times as much on health-care expenditures than comparable countries, the United States has one of the lowest life expectancies, highest maternal and infant mortality rates, and highest prevalence of preventable diseases (OECD 2017). The discrepancy between health-care spending and population health outcomes demands critical attention to the development of alternative care models.

Integrated behavioral health care is a forward leaning initiative. Janicke et al. (2015) predicted that integrated services will become a practice exemplar in the coming decade. The confluence of several factors fuel the call for integrated behavioral health-care services (Foy 2015; Hunter et al. 2018; Reiter et al. 2018). The Patient Protection and Affordable Care Act (ACA; Public Law No. 111–148 111th Congress: Patient Protection and

Affordable Care Act 2010) and the Triple Aim of Health Care are major determinants. The Triple Aim advocates for improved patient experience, cost-containment, and a population health focus (Berwick et al. 2008). Behavioral health concerns represent many of the top concerns for consulting a pediatrician (Kazak et al. 2017; Yogman et al. 2018; also see Chap. 12 of this volume). The majority of children with developmental, behavioral, and emotional needs are often first identified and treated in the primary care setting (Committee on Psychosocial Aspects of Child and Family Health and Task Force on Mental Health 2009). Further, pediatric primary care offices are desirable places to market psychosocial treatments (Becker et al. 2018).

Integrated pediatric behavioral health care (IPBHC) seeks to attenuate the isolated nature of stand-alone behavioral health-care clinics and/or mental health-care carve-out services (Freeman et al. 2018). A focus on accountability, accessibility, prevention, and fiscal responsibility drives integration efforts. Asarnow et al. (2015) argued that “effective behavioral health care is particularly critical for pediatric populations, with potentially large benefits over a life-time (p. 930).” Ladd et al. (2017) commented that external referrals for behavioral health problems are challenging due to the lack of trained professionals in most communities. Therefore, treating these patients within the pediatric medical setting is crucial.

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Behavioral health is being integrated in both primary care and pediatric subspecialties. Freeman et al. (2018) claimed “primary care is the front door to the health care system (p. 197).” More specifically, primary care offices are seen as the default mental health clinic (Bray 2010). Tynan and Woods (2013) mentioned that OB-GYN, family medicine, and other specialty clinics (e.g., oncology, endocrine, GI, etc.) are likely to welcome behavioral health specialists. There is a call for behavioral health specialists to be fully integrated throughout the physical health-care system from emergency rooms to primary care to specialty clinics (Bray 2010).

The biopsychosocial model of health and wellness is endemic to IPBHC (Giese and Waugh 2017). When describing the biopsychosocial model, Engel (1977) stated that psychological factors influence the initiation, maintenance, and exacerbation of physical disorders. Physiological, socio-cultural, psychological, and behavioral factors are all causally interactive in a holistic perspective of illness (Williams and Zahka 2017). Yogman et al. (2018) remarked “Integration of care also reframes the behavioral health/physical health dichotomy as a unified concept of whole person health and emphasizes coordination of care between providers so that patients’ receive comprehensive and non-redundant services (p. 461).”

This chapter defines integrated care and speaks to its value. Common psychological complaints that present to primary care and specialty clinics are briefly reviewed. Finally, value-added benefits offered by IPBHC are delineated.

Definition of Integrated Care

Integrated pediatric behavioral health care is traditionally classified into three domains: coordinated, co-located, and fully integrated (Ader et al. 2015; Asarnow et al. 2017). Coordinated care is characterized by physicians and behavioral health-care providers working in separate facilities but communicating about shared patients through various platforms. In co-located practices, physicians and behavioral health clinicians practice in the same location and collaborate on

patient care. Fully integrated services are marked by both behavioral health-care specialists being part of the same treatment team necessitating a variety of systemic changes. Ader et al. (2015) explained, “seamless integration demands a system redesign including the blending of separate practice cultures, introduction of new workflows, an integrated team-based approach to treatment, and consideration of available reimbursement options (p. 910).”

Integrated care models are characterized by several features (Blount 2003; Richardson et al. 2017). Giese and Waugh (2017) stated that integrated care paradigms emphasize patient-centered care, team-based delivery systems, population health, and stepped care models. A common treatment plan incorporating both behavioral health and medical interventions is typical. Sandoval et al. (2018) claimed integrated care creates routine clinical pathways for patients with behavioral health concerns. Multiple providers pool their individual interventions to patients, and outcomes are systematically measured. Further, they asserted that flexibility, tolerance for change, and professional commitment are common values. Finally, a focus on reducing mental health stigma and accountability through measurement-based care defines integrated systems. In sum, Yogman et al. (2018) maintained, “Integration of care also reframes the behavioral health/physical health dichotomy as a unified concept of whole-person health, and emphasizes coordination of care between providers so that patients receive comprehensive and nonredundant services (p. 461).”

One of the most widely established integrated care models is Primary Care Behavioral Health (PCBH; Robinson and Reiter 2016). Reiter et al. (2018) described PCBH as a team-based primary care approach that addresses pediatric health conditions using a biopsychosocial framework. PCBH models incorporate behavioral health consultants (BHC) into the everyday workflow of pediatric primary care clinics. Primary responsibilities include assisting patients with managing their health conditions, providing same-day consultation, sharing clinic space and resources with the primary care team, engaging with the majority

of patients who present to clinic, improving the teams' use of biopsychosocial assessment and intervention, and retaining a routine presence in the biopsychosocial care of patients. Furthermore, BHC are allotted 15- to 30-min consultation and follow-up visits to assist in meeting the behavioral health needs of patients and their families. BHC may also act as a stepped-care triage service for those who need more intensive services.

Since the inception of integrated models of care, innovative behavioral health programs, such as PCBH, have greatly expanded. However, the literature on the effectiveness of these programs remains limited among pediatric populations. In an effort to improve availability and access to quality behavioral health services, the Deepwater Horizon Medical Benefits Class Action Settlement developed the Mental and Behavioral Health Capacity Project (MBHCP) to assess the effectiveness of a variety of integrated care models for underserved populations (Hansel et al. 2017). Results of two different MBHCP programs located in Florida and Louisiana demonstrated statistically significant decreases in child behavior and parenting stress, as well as 87% reporting satisfaction in services provided (Hansel et al. 2017). Albeit limited, an increased number of integrated behavioral health-care programs are being developed and assessed for effectiveness and feasibility in both primary and specialty care settings.

In response to the obstacles facing the sustainability and feasibility of behavioral health integration, several health-care organizations are piloting innovative programs intended to improve integration efforts proposed by the Triple Aim. The Novel Interventions in Children's Healthcare (NICH; Harris et al. 2013) was developed to address the complex psychosocial needs of pediatric patients and their families who are at-risk for avoidable medical complications (Harris et al. 2018). NICH utilizes alternative payment models to promote quality improvement and effective allocation of health-care resources that accentuate intensive behavioral health integration. Additionally, NICH strives to simultaneously address the Triple Aim of enriching patients' care experiences, boosting population health status, and decreasing health-care costs.

The integration of behavioral health services within the context of pediatric primary and specialty care settings is increasingly becoming the gold standard of integrated care. Despite decades of research illustrating the importance of providing holistic care to pediatric patients and their families, a sustainable service delivery model has yet to be identified. However, in order to deliver integrated behavioral health services, payment reform and the development of innovative programming that increase access and quality of care are crucial.

Psychological Problems in Pediatric Primary and Specialty Care

The number of behavioral health concerns that arise in pediatric medical settings has soared over the past several decades (Slomski 2012). Mental health conditions account for the top five disabilities among children in the United States, which are ranked above physical illness and disabilities (Halfon et al. 2012; Yogman et al. 2018). Approximately one in five children are diagnosed with a developmental or behavioral health disorder that greatly impacts the individual patient, family, and community (Halfon et al. 2012; Perou et al. 2013). Common psychological problems that surface in pediatric primary and specialty care settings include general parenting issues, developmental concerns, mental health problems, adjustment to chronic illness, and adherence to treatment regimens (also see Chap. 12 of this volume).

General Parenting Issues and Developmental Concerns

Pediatric primary care settings are designed to provide children and their families with ongoing and routine health care at all stages of development. Frequent contact with pediatricians affords families the opportunity to discuss any physical, emotional, or environmental concerns that may develop throughout childhood. In addition, the American Academy of Pediatrics created

the Bright Future guidelines to bolster health promotion, disease prevention, and optimal growth for all families who present to primary care (Hagan et al. 2017). On average, pediatricians are allotted approximately 18 min of face-to-face time for each well-child visit (Halfon et al. 2011). Thus, the opportunity to fully explore and address behavioral health concerns, physical examinations, and Bright Future guidelines is extremely limited.

Alternatively, behavioral health providers could be tasked with providing developmental, behavioral, or psychosocial screening, and parental guidance on typical development (e.g., toilet training, sleep practices, or discipline). In a recent study examining the scope of behavioral health consultation, Talmi et al. (2016) found approximately 20% of behavioral health consultations addressed developmental concerns and anticipatory guidance. Developmental and anticipatory guidance consultations generally attend to common parenting questions such as toilet training, discipline and time out implementation, limit setting, tantrums, noncompliance, aggression, disruptive behavior, obesity, picky eating, homework compliance, school behavior, and sleep problems/bedtime resistance. With expertise in child development and behavior, behavioral health providers are well equipped to further support efforts to provide holistic care in pediatric primary care settings.

Attention Deficit/Hyperactivity Disorder

As the most common neurodevelopmental disorder diagnosed in childhood, attention deficit/hyperactivity disorder (ADHD) is usually first identified in the pediatric primary care office (Perou et al. 2013; Visser et al. 2015; also see Chap. 12 of this volume). In 2016, approximately 5.4 million children in the United States had a current diagnosis of ADHD, and almost two-thirds (62%) were prescribed medication (Danielson et al. 2018). Furthermore, the prevalence rates of ADHD and prescribing practices have increased substantially from 2007 to approximately present day (Visser

et al. 2014). The growing number of children and adolescents diagnosed with ADHD in primary care settings highlights the critical need for improved access to evidence-based intervention.

The literature identified the combination of medication management and behavioral therapy as a well-established treatment for youth with ADHD (Hinshaw and Arnold 2015). However, in pediatric primary care offices that do not provide integrated behavioral health services, medication management becomes the first-line approach to ADHD treatment. With the increasing rates of ADHD in pediatric populations, integrated care is crucial for adequately supporting these patients and their families. In a recent study comparing a fully integrated primary care office to a collocated model of behavioral health care, the results suggested significantly higher rates of standardized assessment guideline adherence, greater collaboration and contact with the patient's school, and improved behavioral observation in the integrated practice setting (Moore et al. 2018). Furthermore, families received more parent/caregiver education on ADHD, behavior management training, and school advocacy, and families attended a greater number of clinical visits and medication management follow-up in the integrated model (Moore et al. 2018). Thus, it is not enough to improve access solely through collocated service models, and greater collaboration and integration among pediatric providers is indicated.

Anxiety/Depression

The average age of onset is approximately 6 years for anxiety disorders and early adolescence, or 13 years, for mood disorders (Merikangas et al. 2010). Bor et al. (2014) postulate that the prevalence of internalizing disorders in adolescent females is rising (also see Chap. 12 of this volume). Although mental health diagnoses can lead to significant problems if left untreated, more than half of individuals do not receive adequate treatment (Merikangas et al. 2010; Stancin and Perrin 2014). Integrated behavioral health in the treatment of targeted mental health problems

demonstrates significant benefit in symptom reduction compared to usual care models (Asarnow et al. 2015). Therefore, there is considerable opportunity for early identification and intervention in integrated pediatric primary care, as youth frequently present to these settings.

Adjustment and Adherence in Specialty Care

When faced with a chronic medical condition, mental health problems can become exacerbated. Youth with chronic medical conditions are often seen more regularly by their specialty care doctor. Thus, integrated behavioral health in specialty care is also recommended. The pediatric diabetes literature (also see Chap. 21 of this volume) is furthest along in capturing the benefit of integrated service delivery models. According to a recent systematic review and meta-analysis, the rates of anxiety and mood disorders in youth with type 1 diabetes are approximately 32% and 30%, respectively (Buchberger et al. 2016). There is a dramatic increase in the prevalence of mental health disorders in the T1D population than in normative samples. However, developing research suggests that addressing diabetes distress and associated burden of living with a chronic medical condition may play a critical role in better understanding and supporting pediatric patients with diabetes.

Diabetes distress is a relatively new concept and describes the negative emotional reactions that emerge as a response to the burden of living with diabetes (Hagger et al. 2016). Diabetes distress is correlated with suboptimal glycemic control, poor adherence to treatment regimen, lower self-efficacy, and reduced self-care (Hagger et al. 2016). Other chronic health conditions are beginning to explore disease distress as a key player in disease management. Pediatric psychologists and/or other behavioral health providers are well suited to provide holistic care for pediatric patients with chronic health conditions. Psychologists can provide short-term intervention aimed at addressing disease distress and burnout of chronic disease management through

intervention strategies including cognitive restructuring, problem-solving barriers to adherence, and goal setting (Hagger et al. 2016; also see Chap. 25 of this volume). Furthermore, early psychological screening and routine monitoring of distress and burnout in specialty care clinics add an additional layer of support and resources to patients and their families.

Value of Integrated Care

IPBHC delivers numerous value-added benefits to patients, providers, and payers. One-stop shopping, decreased stigma, greater access to care, improved clinical efficiency, better outcomes, enhanced patient experience, decreased physician burden, increased focus on prevention/population health, and cost-savings can be realized through integrated care. In the following section, each of these advantages are explained and discussed.

One-stop shopping (Asarnow et al. 2017; Ader et al. 2015; Kelly and Coons 2012; Yogman et al. 2018) is a consumer-friendly and patient-centered way to provide care. Addressing behavioral health issues in a trusted and familiar place where physical ailments are treated is convenient and destigmatizing. IPBHC decreases stigma regarding receiving mental health care (Campo et al. 2015; Hansel et al. 2017; Stancin and Perrin 2014; Tynan 2016; Berkout and Gross 2013). Campo et al. (2015) explained, “Integration challenges stigma by communicating that health is a unitary construct that cannot be parsed into physical health and mental health, and it has the potential to change patient, family, and health care professionals’ attitudes and beliefs as well as address structural barriers to care (p. E1–E2).” A continuum of care where services are simplified and administrative obstacles are avoided facilitates better access (Campo et al. 2015). Since pediatricians are a trusted resource, patients are more likely to follow through with these referrals, which are also located in the same setting (Berkout and Gross 2013; Polaha et al. 2011).

McMillan et al. (2016) noted, “The American Academy of Child and Adolescent Psychiatry (AACAP) is well aware that the 8700 child and adolescent psychiatrists in the United States, many of whom do not engage in full-time practice, are not able to meet all the mental health needs of America’s children (p. 5).” Orwat et al. (2018) concluded that due to shortages of child psychiatrists and other mental health professionals, a high number of uninsured youths, and poor reimbursement policies, led to approximately 64% of young people experiencing depressive symptoms not receiving care. There is wide agreement that IPBHC increases access and promotes greater service utilization (Ader et al. 2015; Davis et al. 2015; Hansel et al. 2017; Tynan and Woods 2013). Simply, greater access is realized when more patients are served in an efficient and effective manner (Campo et al. 2015; Hansel et al. 2017; Ward-Zimmerman and Cannata 2012). Further, racially and ethnically diverse youth may be well served by integrated pediatric behavioral health-care clinics (Arora et al. 2017). Improved access will attenuate health disparities. In their review, Arora et al. (2017) noted that marginalized populations may prefer integrated services due to decreased stigma and financial barriers.

IPBHC facilitates workflow by curbside/hallway consultations and warm handoffs (Davis et al. 2015; Freeman et al. 2018). Warm handoffs refer to in-person referrals that occur in the presence of patients. In general, the physician typically introduces patients to the behavioral health specialist, explains the reason for referral, communicates the clinician’s competence, and declares how they can be helpful (Ader et al. 2015). Warm handoffs propel increased access (Davis et al. 2015; Reiter et al. 2018). Reiter et al. (2018) claimed that warm handoffs facilitate same-day appointments, eliminate frequency of no-show appointments, and reinforce team-based care. Moreover, stigma is reduced by warm handoffs (Ader et al. 2015).

The focus on value-based payment models calls for an increased attention on tractionable outcomes (Freeman et al. 2018). Examples of compelling outcome metrics include cost-savings, lowered

medication dosages, decreased lengths of hospital stays, reduced emergency room visits, fewer missed school days, and less unnecessary utilization of specialty medical services (Janicke et al. 2015). Better patient care outcomes are realized by IPBHC (Herbst et al. 2018; Bucholz et al. 2018; Cohen et al. 2015; Davis et al. 2015; Gomez et al. 2014; Kazak et al. 2017). In their meta-analysis, Asarnow et al. (2015) found that young patients receiving integrated care had a 66% greater probability of obtaining a more favorable outcome than youth in treatment-as-usual settings. Patient satisfaction and experience with care also increased in IPBHC settings (Yogman et al. 2018). Integrated care settings were associated with greater clinical efficiency (Aupont et al. 2012; Ward-Zimmerman and Cannata 2012). Finally, both patients and physicians appear to favor IBHC services over other more siloed delivery systems (Asarnow et al. 2005; Kolko et al. 2014; Polaha et al. 2011; Rozenman and Piacentini 2016). Sixty-three percent of parents sought help from pediatricians for behavioral health problems compared to only 24% who consulted mental health specialists (Polaha et al. 2011).

IPBHC decreases the workload burden for pediatricians. McMillan et al. (2018) lamented that pediatricians are ill-equipped to care for patients with behavioral health concerns. Treating behavioral health problems imposes significant time demands on pediatricians (Meadows et al. 2011). Meadows et al. (2011) found that when patients present with behavioral health-care concerns, appointments last 2.5 times longer than appointments addressing medical complaints. Furthermore, pediatric residents are more comfortable assessing behavioral health problems than treating them (Ladd et al. 2017). Increased collaboration between pediatricians and behavioral health clinicians in integrated settings can decrease physician burden (McMillan et al. 2018; Tynan 2016; Yogman et al. 2018). IPBHC settings facilitate closer collaboration between providers. Additionally, co-locating pediatric and behavioral health training programs expand skill sets in all the trainees (McMillan et al. 2018). Further, they also discovered that reimbursement for pediatricians’ treatment of behavioral complaints was offered at a far lower rate (e.g., approximately 119

dollars for a medical visit compared to approximately 79 dollars for a behavioral health visit). Kelly and Coons (2012) learned that 92% of pediatric staff reported less burden due to IPBHC. Cummings et al. (2011) called these benefits “physician leveraging,” which is defined as “releasing them to perform procedures more in keeping with their medical training (p. 44).”

Preventative care is intimately tied to a population health focus. Giese and Waugh (2017) maintained that an emphasis on population health “shifts the health care system from a diagnose-and-treat-disease model to a whole health continuum (p. 7).” Janicke et al. (2015) rightly lauded the previous clinical child and pediatric psychology efforts at preventing substance abuse, conduct disorders, bullying, and depression in youth. Hunter et al. (2017) listed anxiety chronic pain, diabetes, insomnia, and tobacco use as additional targets for early intervention and prevention projects.

Although the research is in its infancy, IPBHC can yield cost-savings (Cohen et al. 2015; Tynan 2016; Yogman et al. 2018). For example, integrated care practices reduced spending for patients by over 50% (Yogman et al. 2018). Additionally, Yogman et al. (2018) noted there was a decrease in emergency room spending for patients receiving integrated care. Despite potential cost benefits, funding issues for integrated behavioral health care are cumbersome and complicated.

New business models are necessary to implement and sustain IPBHC practices (Robinson et al. 2018; also see Chap. 27 of this volume). Tynan (2016) argued that public and private financing options should be developed to support IPBHC. They identified restrictions on same-day billing for mental health and physical health care as well as lack of reimbursement for health collaborative care, nonphysician delivered services, prevention and treatment for mental health diagnoses. Tynan (2016) offered several recommendations for mitigating problems including unbundling service, finding Common Procedural Terminology Codes (CPT) that are reimbursable for psychologists and negotiating with Medicaid to ensure parity with Medicare. Hansel et al.

(2017) advocated for training integrated clinic staff in the ICD-10. They explained, “Direct billing and contracts would not be possible without training practitioners in the ICD-10 system, as reimbursement is often contingent on a diagnosable condition that falls under the category of an F code (p. s22).” The use of Health and Behavior Assessment and Intervention Codes for payment is essential (Freeman et al. 2018).

Miller et al. (2017) proposed the adoption of a global or capitated payment system to fund IPBHC services. Perrin (2017) explained that capitation is “payment based on the number of patients attributed to the provider(s) potentially adjusted for risk (p. S86).” Capitation rates are derived from actuarial claims data and are paid out on a per member per month (PMPM) basis (Freeman et al. 2018). Global payment structures allow a health-care organization to determine the appropriate integrated care team, and subsequent services, for each individual patient using a fixed prepayment arrangement. Freeman et al. (2018) noted that information technology, population risk adjustments, and patient engagement/management processes must be in place for capitation to be successful.

Conclusion

The next decade will likely see a rise in integrated pediatric behavioral health-care services (IPBHC). Continued theory-building, empirical research, innovative practices, and robust training programs are necessary to sustain growth. In order to make good on promises, IPBHC will need to be subject to both more randomized clinical trials and cost-effectiveness studies. Additionally, the emerging workforce must receive more specialized training. Doctoral, predoctoral, and postdoctoral programs will need to modify their pedagogical practices to develop new competencies in trainees (also see Chap. 26 of this volume). As Jonas Salk noted, “the reward for work done well is the opportunity to do more.” Ideally, the future will yield greater opportunities for work in integrated care settings due to the hard work completed by academicians and clinicians.

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Diversity Issues in Pediatric Behavioral Health Care

3

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Impact of Minority Status in Pediatric Health

Existing US population trends and a significant relationship between minority status (both racial/ethnic and sexual) and health outcome suggest the importance of competence in working with diverse pediatric populations. In the USA, racial/ethnic minority children will be a “minority majority” by 2020. The US Census projects that by 2020, less than one-half of children will be non-Hispanic, White, with the racial/ethnic composition of children changing more quickly than that of older cohorts (Vespa et al. 2018). Immigration is likely to become the primary driver of population growth in the USA. In fact, the proportion of the US population that is foreign born is projected to be higher by 2030 than at any time in the last century (2018). This is likely to be costly for our health systems given that, in just a 3-year period (between 2003 and 2006), the Joint Center for Economic and Political Studies estimates that existing health

inequalities for racial/ethnic minorities cost more than one trillion dollars (LaVeist et al. 2009).

Decades of data across disciplines point to significant differences in racial/ethnic minority youths’ overall health, health behavior, oral health, mental health, and risk for chronic illness (e.g., diabetes and cardiovascular disease). Some examples of disparities in key national indicators of well-being include increased risk of low birth weight and infant mortality experienced by African-American mothers, increased risk of obesity in African-American and Mexican-American youth, and increased risk of asthma in African-American and Puerto Rican youth, especially those living in poverty (Federal Interagency Forum on Child & Family Studies 2017). In addition, the 2017 Youth Risk Behavior Surveillance (YRBS; Kann et al. 2018) demonstrates higher rates of depressed mood in Hispanic youth and higher rates of suicide attempts in Black females. Disparities are also alarming among sexual minority youth who identify as lesbian, gay, or bisexual. In fact, there is consistent evidence indicating that sexual minority youth experience poor health outcomes including increased odds of asthma, sexually transmitted infections, and multiple behavioral and mental health concerns including attempted suicide, depression, substance use, and eating disorders (Coker et al. 2010; Marshal et al. 2011; Strutz et al. 2015).

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In addition to increased risk in the general population, health disparities exist in the outcomes of minority youth who receive care for chronic conditions. African-American children with asthma have lower quality of life and higher rates of emergency room visits, hospitalizations, and mortality, and many of these disparities remain after adjusting for disease severity (Harper et al. 2015; Haselkorn et al. 2008). Similarly, racial/ethnic minority youth with type 1 diabetes have higher rates of poor glycemic control across a variety of ethnic groups (Naranjo et al. 2015). In particular, African-American youth with diabetes experience more frequent life-threatening complications like diabetic ketoacidosis and severe hypoglycemia and have a twofold increased risk for diabetes death compared to non-Hispanic, White youth (Saydah et al. 2017).

Pediatric psychologists provide evidence-based clinical care in health settings as part of multidisciplinary teams. They play an important role in “address(ing) the psychological aspects of illness, injury, and the promotion of health behaviors in children, adolescents, and families” (Aylward et al. 2009, p. 3). As such, psychologists in pediatric primary and specialty care have a role in addressing health disparities affecting youth and families, a critical public health concern. The literature reviewed below suggests that both evidence-based clinical practice at the individual and family level, as well as participation in systems-level changes within health settings and communities (discussed briefly at the end of the chapter) may meaningfully improve the outcomes of youth from diverse, minority backgrounds.

Evidence-Based Treatment for Diverse Pediatric Patients and Families

Evidence-based treatments (EBTs) provided by psychologists in pediatric health settings frequently target improving a patient and family’s adjustment to injury or chronic condition, treatment adherence, lifestyle behavior change, and/

or comorbid behavioral health issues. A wealth of research on common behavioral concerns such as depression, anxiety, and disruptive behavior problems has pointed to a higher risk of these diagnoses among youth with chronic health conditions (Pinquart and Shen 2011). EBTs for these presenting concerns have been largely designed and tested in non-Hispanic, White youth and families. However, there is growing evidence that available EBTs also hold promise for diverse, minority youth. EBTs have been shown to have meaningful benefit for racial/ethnic minority youth, and a growing literature suggests potential benefit for sexual minority youth as well (Huey et al. 2014; Safren et al. 2001).

Huey and Polo (2017) systematically reviewed the literature and found that current EBTs targeting a variety of concerns ranging from depression and suicidal behavior to ADHD benefited racial/ethnic minority youth (note that existing research primarily included African-American and Latino youth). The authors reported on 45 interventions, examining them based on revised criteria for “well-established” treatment that included a requirement for the treatment to be tested in a largely racial/ethnic minority sample (at least 75%) and for the effectiveness of the treatment in minority youth to be specifically examined. Among the interventions reviewed, only motivational interviewing was classified as “well established.” However, 22 additional treatments were categorized as “probably efficacious” for racial/ethnic minority youth. The authors note that “cognitive-behavioral psychotherapies predominated, accounting for more than 53%” of the EBTs that were effective in racial/ethnic minority populations (Huey and Polo 2017, p. 362). The authors further synthesized 18 meta-analyses evaluating treatment outcomes in racial/ethnic minority youth and found a majority of studies demonstrating “few ethnic differences in youth treatment outcomes.” Their review provides strong evidence that existing EBTs for common behavioral concerns are largely effective in racial/ethnic minority youth.

Beyond traditional mood and behavioral concerns, there is also a need for EBTs to address disease management (e.g., medication