Chapter 20
Addressing Healthcare Disparities

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Introduction

The prevalence of mental disorders varies significantly by race and ethnicity across the lifespan (Breslau et al. 2006; Breslau et al. 2005; Alegría et al. 2007; McGuire and Miranda 2008; Smedley et al. 2002; Williams and Earl 2007; World Health Organization 2014; US Department of Health and Human Services 2001). Minority groups experience greater numbers of risk factors that accrue incrementally over time, with differential effects, contributing to mental health and healthcare disparities (Alegría et al. 2015; Gee and Payne-Sturges 2004). This chapter aims to illustrate the important role that the well-informed and culturally humble pediatric psychosomatic medicine practitioner can play in identifying and addressing mental health disparities in children and adolescents.

Race, Ethnicity, and Culture

Race, ethnicity, and culture are often ill-defined, controversial, and ambiguous. As social concepts, they have many different meanings, and those meanings continue to change over time. Race is often considered a biological category – as a way to divide and label groups by skin pigmentation or other physical characteristics. However, genetic variation within a putative racial group is overwhelmingly greater than genetic variation across putative racial groups. Thus, race is given meaning – albeit non-scientifically – as a social category, especially when certain social groups are separated, treated as inferior or superior, or provided differential access to power

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A. P. S. Guerrero et al. (eds.), *Pediatric Consultation-Liaison Psychiatry*,
https://doi.org/10.1007/978-3-319-89488-1_20

and resources. Ethnicity refers to a common heritage shared by a particular group. Heritage includes similar history, language, rituals, practices, and preferences for music, diet, and foods. Though less common, ethnicity can also include a geographical connection. Culture is a system of shared meanings obtained from a common heritage or set of beliefs, norms, and values. Yet, culture can be experienced uniquely by different members of the same cultural group.

Case Vignette #1

You are a psychiatrist working in a community-based, integrated primary care/behavioral health clinic. During a weekly team meeting to review cases that screen positive for mental health concerns, the primary care provider presents the first case.

A first-generation immigrant Chinese couple with two older daughters gave birth to an infant, now 13 years of age, with ambiguous genitalia. Initially, the physicians wanted to run further tests, and they recommended that the family wait until the test results were completed in order to make a gender assignment. However, the family made the immediate decision to assign the gender of male to this infant and refused any further testing. The child was raised as a boy; however, early on, he exhibited effeminate mannerisms and preferred wearing female clothing and playing with dolls with his sisters. These behaviors led to significant parent-child conflict, which only escalated as he approached adolescence.

The team seeks your advice on how they can best help the family. You begin to organize your thoughts into a matrix to guide further inquiry and assessment, and you highlight for the team the importance of further inquiring into cultural identity issues:

Facts	Hypotheses	Information needed	Learning issues
First-generation Chinese-American parents	Female gender preference	Context of gender selection	Gender identity
Child, now 12 years old, born with ambiguous genitalia	Role of cultural conflict	Context of family conflict	Gender expression
		Child's cultural identity, parents' cultural identity, and expectations for their children	**Cultural identity (discussed further below)**

Cultural Identity

Cultural identity refers to the totality of a person's cultural self-definition, including ethnicity, race, country of origin, language, age, marital status, gender, sexual orientation, religious/spiritual beliefs, acculturation, individualism, and collectivism (Schwartz et al. 2007). Acculturation is the process by which foreign-born individuals and their families learn and adopt the language, values, beliefs, and behaviors of the new sociocultural environment (Sam and Berry 2010). It refers to orientations

toward both heritage and host cultural contexts and practices (Tadmor and Tetlock 2006). Historically, acculturation has been operationalized as a unidimensional continuum ranging from retention of heritage-culture values and practices to acquisition of host-culture values and practices (Flannery et al. 2001). It is increasingly recognized as a bidimensional model in which orientations toward heritage and host values and practices are considered separate dimensions (Ryder et al. 2000). This process takes place over time, and it involves cultural groups with different characteristics.

For many ethnic minority youths, this may entail changes in values, beliefs, and norms such as shifting from a more collectivistic to a more individualistic orientation. This type of emphasis on independence, autonomy, and self-determination is characteristic of Western cultural values. Triandis et al. (1988) explore the concepts of individualism and collectivism as a major dimension of cultural variation in identity formation, providing a list of characteristics related to notions of the self, activities, attitudes, values, and behaviors. Oetting and Beauvais's (1990) cultural identification theory also implies that lower levels of cultural identification are associated with adverse psychosocial characteristics, including lower self-esteem, poor school performance, negative personal adjustment, and fewer personal and social resources. Such characteristics are likely to increase the vulnerability to mental illness among ethnic minority children.

Risk and Protective Factors

Alegría et al. (2015) present a model that is useful in examining the risk and protective factors associated with disparities in the prevalence of mental health disorders. Their model focuses on four risk categories as minority children and adolescents transition into adulthood: (i) socioeconomic status, (ii) adverse childhood events, (iii) family structure across development (e.g., single and/or early motherhood, divorce, paternal involvement), and (iv) neighborhood characteristics (e.g., residential composition, stability, and segregation). It also includes individual- and neighborhood-level protective factors (e.g., social support, religiosity, neighborhood stability). These sociocultural factors and the resultant life experiences of youth have a profound impact on their rapidly developing biological systems that also influence their mental health trajectories (Mistry et al. 2012) (Fig. 20.1).

Case Vignette #1 (Conclusion)

You accompany the primary care provider to a follow-up meeting with the family. The primary care provider conducts the interview in both Chinese (a language understood by and primarily spoken by the parents and understood by but not primarily spoken by the child) and English (a language fairly understood by but not primarily spoken by the parents, though primarily spoken by the child). The family describes the various adversities – including poverty and discrimination – they have

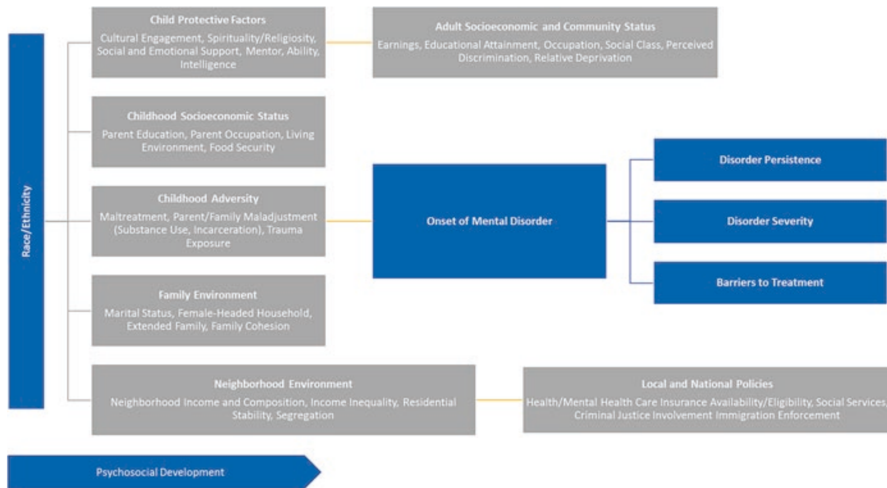

Fig. 20.1 Conceptual model of risk and protective factors for child mental health and mental health service disparities. (Adapted from Alegría et al. 2015)

overcome in raising their children in the USA. The parents work long hours to provide for their children and to send money to various relatives.

In an individual meeting with the child, he conveys that he loves his parents very much but is disappointed with their decision to "raise me as the boy that they always wanted… why can't I be more free like all of my friends are?" Likewise, in a meeting with the parents, they convey that they love their child very much but lament the fact that "he is growing closer to his 'rebel' friends than he is to us… he seems to hate being at home." They admit that the diagnosis of ambiguous genitalia had been a surprise to them, as they had not previously been familiar with such a condition. However, they trust the primary care physician, who has cared for the child since age 2 years, and are open to learning more about how they can best help their child and understand his development.

It has been a while since they have spoken to their child about this condition, and they all agree that establishing a more open and positive line of communication with their child is an important first step, as they plan further follow-up, as recommended, with medical specialists.

This first vignette illustrates the importance, in all consultations, of collaboration with primary care providers and others who may know the patient/family well, who may have the patient/family's trust, who may have skills (e.g., multilingualism) in effectively engaging the patient/family, and who may otherwise have important insights into the patient/family's culture and cultural dynamics. It also illustrates the importance of addressing acculturative stressors and other socioeconomic factors that might adversely health.

Case Vignette #2

You are called as a consultant to the emergency department to see a 14-year-old female who is brought by her grandmother, a first-generation immigrant from American Samoa, because the granddaughter has not been behaving like her "normal self." For the last several days, she has been talking to herself, refusing to eat, and only occasionally drinking a few sips of water. The patient's grandmother has been using prayer, massage, and healing herbs without success. The teenager's teacher encouraged this grandmother to bring her to the hospital.

On physical examination, the patient is pale and slightly overweight. She appears her stated age. She is afebrile with a pulse of 105 and blood pressure of 100/68. Her lips appear dry and chapped. Her examination is otherwise unremarkable. Laboratory findings are significant for ketones in her urine. Her urine drug screen is negative, and her blood counts, chemistry profile, and thyroid-stimulating hormone are all within normal limits.

On mental status examination, the patient is mildly disheveled and appears anxious. She can make eye contact and is cooperative with the evaluation. She is noted at times to be responding to internal stimuli and mumbling to herself. Her speech is mostly coherent except for the mumbling. She appears frightened and refuses to elaborate on what she has just said. She admits to believing that her food is being poisoned and that she is being "punished for bad behavior" but refuses to clarify. She describes seeing "a woman in white" at various times throughout the day. She denies suicidal and homicidal ideation. She is oriented to year and month but incorrectly identifies the date and day of the week. She understands that she is in the hospital and desperately wants help. She can register three out of three objects but is only able to recall two of the three after five minutes, and her remote memory is intact. When asked about similarities between a bike and a plane, she responds with "ways to get places." She can provide an abstract interpretation of the saying "don't cry over spilled milk" but does not understand what is meant by "a rolling stone gathers no moss."

The patient is admitted to an acute psychiatric inpatient unit for further evaluation and management. The grandmother initially refuses to allow her granddaughter to be admitted, but when faced with the possibility of the legal system becoming involved, she concedes.

During the hospitalization, additional history is obtained. The patient has never used any substances and does not have any history of sexual or physical abuse. There is no known family psychiatric history. At the age of three, the patient and her father moved to Hawai'i to live with her grandparents. Her mother remained in Samoa with her 5-year-old and 1-year-old brothers. Her father was unable to find employment and returned to Samoa a year later. She has visited her family once since that time. Her grandfather died 6 months ago, and since then, there has been increased financial stress. Up until that time, she had been doing well at home and school. Over the last several months, the patient has become increasingly isolated from friends, and she spends her free time with her grandmother.

Following completion of the diagnostic evaluation, the patient is started on an antipsychotic and an antidepressant. After a few days, she eats again. Her grandmother angrily approaches the medical staff and states that her granddaughter is being treated badly, is "out of balance," and is now constipated. She wants to take her granddaughter out of the hospital, even though the psychiatric symptoms are not yet resolved. In your mind, you quickly review the current facts, your hypotheses, and your working formulation. You reflect on the patient's likely diagnosis of a mood disorder with psychotic features and are worried about what may happen if inpatient care were terminated prematurely. You ask the grandmother to meet with you.

Facts	Hypotheses	Information needed	Learning issues
A 14-year-old Samoan girl presents with psychotic features to ER	Samoan cultural beliefs and practices	Cultural context of child and family including beliefs about illness and traditional healing methods	DSM-5 cultural outline for formulation
Use of Samoan cultural beliefs and practices	Possible alternate view of the etiology of the psychiatric symptoms		
Evidence for mild dehydration and malnutrition	Possible distrust/lack of familiarity with western cultural practices		
Early losses and recent loss of grandfather	Cultural differences between clinician and patient/caregiver may pose barriers		
Grandmother's concern over constipation	Potential compromise of care if trust is lost and treatment is discontinued		

Effect on Help Seeking

Several factors impact whether individuals access or seek care. These factors include perception of illness and its causes, structural components (e.g., lack of transportation and limited access to care), familiarity with services and providers, mental health literacy, mental health stigma, and perceptions of mental healthcare providers (Alegría et al. 2010; Chow et al. 2003; Kilbourne et al. 2006; Raguram et al. 2002; Saravanan et al. 2007).

Globally, there is a sizable gap between individuals who need mental healthcare and those receiving them, with the most dramatic differences in lower-income countries and racial/ethnic minority groups (Barnett et al. 2017; McGuire and Miranda 2008). Furthermore, when underserved communities have available mental health services, affective disorders are more likely to be underdiagnosed and undertreated,

while psychotic disorders are overdiagnosed and overtreated (Holden et al. 2014). The Institute of Medicine (2002) identified more than 175 studies documenting racial/ethnic disparities in the diagnosis and treatment of various conditions, even when analyses were controlled for socioeconomic status, insurance status, site of care, stage of disease, comorbidity, age, and other potential confounders. Minorities are also less likely to receive evidence-based, high-quality, newer, and more comprehensive treatment modalities. Making evidence-based treatments and evidence-informed practices accessible in underserved communities has been a major focus of international policies as a strategy to reduce the global burden of mental disorders (Barry and Huskamp 2011; Becker and Kleinman 2013; Dua et al. 2011).

Case Vignette #2 (Conclusion)

You quickly review your notes on the DSM-5 outline for cultural formulation.

You then meet with the grandmother and learn that, in their culture, constipation is a serious condition. The grandmother has always made sure to keep her family members in good health. You ask the grandmother about her methods for relieving constipation. She reports that she makes a paste out of a plant and massages this paste into the umbilicus. The grandmother is encouraged to participate in the treatment of her granddaughter by providing this care. She does so with good results. The patient's mood continues to improve, and her psychosis resolves. Her eating and bowel patterns return to baseline. Her grandmother is very pleased with the outcome and provides the unit with a home-cooked Samoan meal to express her gratitude.

Cultural Humility

As illustrated in the two preceding vignettes, cultural competence is the ability of providers and systems to respond respectfully and effectively to people of all cultures, affirming the worth and preserving the dignity of individuals, families, and communities (Betancourt et al. 2016). Cultural competency implies that better care is provided with a thorough knowledge of the mores and beliefs of another culture. While cultural competency is an ongoing process, more recently the term cultural humility has been taking root. Cultural humility encourages individuals to identify their own biases and to acknowledge that those biases must be recognized. It concedes that it is impossible to be adequately knowledgeable about cultures other than one's own. It also implies an openness to new ideas, advice, and contradictory information. By approaching each encounter with the knowledge that one's perspective may be full of assumptions and prejudices, providers will be more open to the seeking the involvement of the patient.

Case Vignette #3

A 15-year-old Mexican girl is admitted to the pediatric ward for "medical evaluation of possible new onset psychosis." She is "boarding in the children's hospital pending psychiatric bed availability within a drivable radius." The attending

physician requests, from your team, a psychiatric consultation. Her primary language is Spanish. She is reportedly experiencing visual hallucinations and making bizarre statements since being placed in child protective custody after her parents were incarcerated for drug-related charges 6 days prior to admission.

Although you have basic command of the Spanish language, you believe that a psychiatric interview requires a higher fluency level. Therefore, an interview was performed with a native Spanish-speaking interpreter. As she gazes around the room, the patient states, "the angels are protecting me." She reports that she can see these angels: "I sometimes see shadows or movement out of the corners of my eyes, and I know that it is them!" She denies seeing the angels currently but appears to be actively looking for them. She admits to worrying about her and her family's situation, as her father's distant cousin is her only family contact in the USA. The worry has been keeping her awake at night, so she tends to be fatigued during the day. She has cried most of the day since her parents' incarceration. She has always been a picky eater but has not been very hungry at all in the past week. The patient reports that she has always been in good health, and she denies any history of trauma or sexual or physical abuse. The patient and her family arrived in the USA illegally from Mexico a little over a year ago. Prior to arriving in the USA, they lived in a small village and lived a very simple life, helping on a farm. The patient's father became disabled and could no longer engage in manual labor, and the family soon lost their home. Her mother was adopted, and her father was the last alive in his line except for a distant cousin in the USA. The family was assisted in obtaining illegal transportation to the USA; however, upon arrival, they discovered that they were required to engage in drug trafficking to pay off their debt. The patient states that she and her parents did not engage in drug use. She has not attended school in the USA but has been receiving tutoring from a neighbor in exchange for looking after that woman's infant daughter and helping to clean her house. The patient would like to one day "be a teacher, get married, and have children."

Other than the patient's father, who "worries a lot," and a now deceased elderly uncle who became confused and forgetful as he aged, there is no other known family psychiatric history.

Her vital signs and physical exam are unremarkable. Her urine drug screen is negative, and her blood counts, chemistry profile, thyroid-stimulating hormone, and urinalysis are all within normal limits.

On mental status examination, the patient is a slender female with good hygiene and grooming. She constantly frowns and wrings her hands. She is cooperative and has good eye contact. Her mood is anxious and dysphoric with a congruent affect. She speaks in a rapid but non-pressured manner, with low volume. Her thought process is goal directed. She denies any suicidal or homicidal ideations. She is abstract in her interpretation of similarities and a Spanish proverb that roughly translates to "the shrimp that sleeps gets carried by the current." She is alert and oriented to person, place, and time.

She points toward a glass of water and asks if you and the interpreter understand the importance of that glass of water. When the provider asks the patient to explain what she thinks is the importance, the patient expresses her disappointment and refuses to elaborate. She becomes tearful and insists, “no one understands.” She then terminates the interview.

You apologize and reflect on what may have happened.

Facts	Hypotheses	Information needed	Learning issues
A 15-year-old Mexican girl with “visual hallucinations” and “bizarre statements”	Bipolar disorder with psychosis?	Patient’s perception of problem/fears for future	DSM-5 cultural concepts of distress
	Substance-induced psychosis?		
	Major depressive disorder with psychosis?		
	Anxiety disorder? Adjustment disorder?		
Immigrated within last year from a small rural environment to an urban city with different language and culture	Inadequate support system?	Timeline of symptoms	**DSM-5 cultural formulation interview**
		Cultural context	
Parents incarcerated less than 1 week ago, and now the patient is in temporary custody of CPS	Culture or language barrier with current foster family	Information about foster family’s language and culture	Effective/appropriate use of interpreters/translators
Language barrier		Contact with case manager to obtain information on options/support available	

Case Vignette #3 (Conclusion)

Following the interview, the interpreter informed that provider that in the Mexican culture, it is believed that placing a glass of water over the refrigerator or some other conspicuous area helps to absorb any bad spirits and prevents harm or evil to the family there. The patient feels validated when this issue was later discussed with her, as she reported previously feeling isolated and misunderstood when she attempted to discuss her beliefs with her foster family, who spoke only a little Spanish and had limited knowledge of the Mexican culture and traditional belief systems. They also regarded her “seeing angels” as visual hallucinations. In the context of her anxiety, tearfulness, lack of sleep, poor appetite, and fatigue, they were worried about her mental health.

You observe her over the next couple of days, and you conclude that the likely diagnosis is an anxiety disorder, exacerbated by significant social stress, rather than a psychotic disorder or mood disorder with psychotic features.

Cultural Formulation Interview

The cultural formulation interview (CFI) can guide providers to explore four areas in which culture can impact the assessment of the clinical presentation. These include (1) cultural definition of the problem; (2) cultural perceptions of cause, context, and support (including cultural identity); (3) cultural factors that affect self-coping and past help seeking; and (4) cultural factors that affect current help seeking (American Psychiatric Association 2013). There are 12 modules that supplement the core CFI, aiding clinicians in conducting a more comprehensive cultural assessment (American Psychiatric Association 2013). Eight of the supplementary modules explore the CFI in greater depth including (1) explanatory model; (2) level of functioning; (3) social network; (4) psychosocial stressors; (5) spirituality, religion, and moral traditions; (6) cultural identity; (7) coping and help seeking; and (8) clinician-patient relationship. Three modules focus on specific populations, including children and adolescents, older adults, and immigrants and refugees. The last module explores the caregiver experiences and views in order to clarify the nature and cultural context of support they provide.

Such an interview allows the patient and family to provide their own illness narrative and information about the community context, and it encourages the patient and family to engage in the treatment process. The CFI can be used by all clinicians and with all patients, not just in clinical encounters with cultural minorities or in situations where there are obvious cultural differences between clinicians and patients. In all clinical encounters, providers bring their own cultures, values, and expectations, which influence how specific aspects of care are approached.

Conclusion

Advancing our understanding of cultural issues is critical for good patient care, particularly as we practice in a shortage specialty and work in settings where there may only be a small window of opportunity to engage a patient and family. A focus on culture clarifies that one cannot consider cultural influences separate from the influence of other social factors including cultural identity, gender ideologies, generational experience, racial discrimination, and socioeconomic status. As we continue to understand how culture influences mental illness, health, and well-being, we enhance our ability to reduce stigma, optimize screening, and design more effective interventions for all groups.

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