Chapter 15
Interfacing with Palliative and End-of-Life Care and Ethical Decisions

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Background

The psychiatric care of youth with serious medical illness involves thoughtful interaction with a wide range of medical specialties, including the relatively young field of pediatric palliative care (PPC). This growing subspecialty is devoted to improving quality of life for children with serious illness and their families through pain and symptom management, skilled communication about priorities, and well-coordinated care throughout the disease trajectory. As in adult palliative care, the focus is on symptom management and achieving goal concordant care rather than the cure of disease (www.capc.org/topics/pediatric-palliative-care/ 2017). The field of palliative care grew out of a British movement spearheaded by Dame Cicely Saunders who founded St. Christopher's Hospice in London in 1967. Trained as a nurse, social worker, and physician, she asserted the importance of dignity, compassion, and respect for dying people. She was known to pay close attention to the narratives of patients and articulated the concept of "total pain" that encompassed physical, emotional, and spiritual distress (Richmond 2005).

PPC has grown since the 1980s to encompass medical, psychosocial, and spiritual care that extends into the early stages of serious and chronic illness for children and that may be offered alongside treatment with curative intent (Temel et al. 2010). PPC has been shown to improve physical symptoms and end-of-life communication for children and their families by helping parents and children to identify and imple-

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ment their care goals, as well as enhance health-related quality of life, strength, and resilience in the face of serious illness (Wolfe et al. 2008; Hays et al. 2006; Himelstein et al. 2004).

PPC is usually practiced in interdisciplinary teams that may include physicians from a range of specialties (e.g., primary care, intensive care, hospitalist medicine, oncology, neonatology, etc.), advanced practice nurses, social workers, and sometimes psychologists, chaplains, art therapists, and child life specialists in primarily inpatient settings. In 2013, 69% of the 162 children's hospitals in the United States had a PPC team; the structure and consultation patterns vary depending on the institution (Feudtner et al. 2013). It is critical for pediatric psychosomatic medicine clinicians to understand the principles underlying PPC and how best to collaborate with palliative care teams in the complex system of care for seriously ill children.

Overlap Between Child Psychiatry and Pediatric Palliative Care

Pediatric consultation-liaison (CL) psychiatry focused on the psychological coping and adaptation of medically ill children from the 1950s through the 1990s and was renamed pediatric psychosomatic medicine in the mid-2000s. General child psychiatry, on the other hand, moved into outpatient settings and emphasized disorders such as attention-deficit/hyperactivity disorder, mood and anxiety disorders, conduct disorder, eating disorders, and other behavioral disorders without comorbid medical illness. During the 1990s, psychotropic medication treatment trials in children advanced rapidly, as did medical technological advances that made many previously life-threatening illnesses become chronic medical conditions. Today, many children survive what once were lethal disorders, but still may experience delayed physical and emotional development in the context of complicated medical procedures and treatments. These youths must engage in complex medical decision-making and may also experience comorbid psychiatric conditions into young adulthood and survivorship. Given their in-depth training in child development, family systems, psychological coping, and risk factors for psychopathology, child psychiatrists have much to contribute to an understanding of youth's experiences of serious illness and death (Buxton 2015, Muriel et al. 2016).

The field of PPC shares many tenets of psychosocial practice with psychiatry, including an emphasis on the importance of doctor-patient communication and the exploration of the values and priorities of young patients and their families (Bartell and Kissane 2005). Figure 15.1 describes both the distinct and overlapping areas of expertise of these two fields (Muriel et al. 2016). PPC clinicians, however, are not mental health providers and have limited training in the assessment and treatment of complex psychopathology, including assessment of suicidal ideation, which does occur in youth with serious illness (Brinkman et al. 2014). Medical teams, including PPC, therefore still rely on psychiatric consultation when faced with comorbid med-

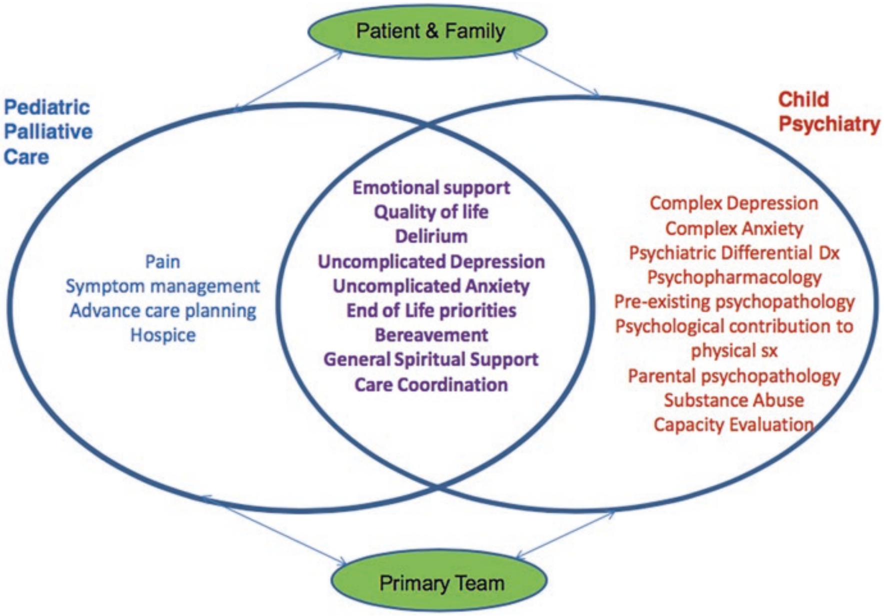

Fig. 15.1 Overlapping and distinct expertise

ical and psychiatric illness or when mental health issues impact ethical dilemmas in the care of seriously ill children. PPC and psychiatry services both serve as consultants to the primary medical team, as well as to the patient and family, and definition of clinical roles and good communication between the services is essential. The specific areas of interaction may vary depending on the availability of each service in an institution. Certain subspecialties such as oncology or solid organ transplant may have embedded child psychiatrists, and palliative care teams may have different capacities to work with children across the trajectory of illness. In addition, both PPC and child psychiatrists may work on multidisciplinary teams alongside social workers, psychologists, chaplains, and child life specialists.

Psychiatric Syndromes in Children at End of Life

The general approaches for consultation psychiatry with medically ill children apply to those with advanced or terminal illness as well, with some specific considerations for children and adolescents closer to the end of life. As addressed in other chapters, the differential diagnosis for depression and anxiety symptoms must take into account physical symptoms such as pain, physical deconditioning, dyspnea, nausea, anorexia, constipation, or malnutrition. At end of life, metabolic and endocrine function may also become dysregulated, further affecting mood and anxiety symptoms. Social withdrawal and energy conservation may occur as part of the dying process, making children look apathetic or depressed. Psychological issues such as anticipatory grief and loss, fear of death, and communication challenges can also contribute to worsening mood and may not be addressed by medication. PPC clinicians may need assistance from psychiatrists in distinguishing depressive syndromes that may respond to antidepressants or stimulants from those that may need to be addressed with therapeutic or communication interventions or simply tolerated as a part of grief and the end-of-life experience.

Children may have been taking psychotropic medications earlier in their illness to manage depression, anxiety, or mood and behavioral dysregulation. Many of these may be continued until the end of a child's life to avoid discontinuation syndromes or return of symptoms. However, tablet formulations may need to be converted to liquid, sublingual, or transdermal preparations as ease of intake by mouth sometimes changes. Compounding pharmacies and hospice programs may be helpful in finding good alternatives. On the other hand, medications for pain or other physical symptoms like dyspnea or hypertension may also address psychiatric symptoms such as anxiety or insomnia, allowing the team to simplify medication regimens and discontinue psychotropic medications. In other cases, potential side effects such as metabolic changes, sedation, or QTc prolongation may be less concerning at end of life, allowing for more liberal use of antipsychotics for delirium or stimulants for fatigue or sedation due to analgesics.

Ethics, Palliative Care, and Pediatric Consultation-Liaison Psychiatry

Ethics committees in pediatric care were developed in the 1980s and were focused around decisions to withhold or withdraw life-sustaining treatment in newborns with serious medical conditions. This development led the American Academy of Pediatrics to create specific guidelines for infant bioethics committees (1984). As medical progress provides life-prolonging treatment in many situations, the field of bioethics has established widely accepted guidelines for making decisions about end-of-life care. Ethics committees are usually consulted when there is conflict about decisions (1) between the patient and family, (2) between the patient/family and clinicians, (3) among different members of the team, or (4) when there are legal or policy issues. The most common areas of conflict include withholding or withdrawing care, sometimes discussed as redirecting efforts from curative to supportive care and using sedating analgesic medications that may also have the "double effect" of hastening death.

The framework for bioethical consultation may include considerations of medical indication, patient preferences, quality of life, and external factors (Jonsen et al. 2015). Table 15.1 outlines another framework described by McCullough and Ashton

Table 15.1 Framework for ethics consultation (Mccullough and Ashton 1994)

1.	What are the facts of the case?
2.	What are our obligations to the patient?
3.	What are our obligations to third parties?
4.	Do our obligations converge or conflict?
5.	What is the strongest objection that could be made to a convergence of obligations? How can this objection be effectively countered?
6.	Could the ethical conflict have been prevented?

(Mccullough and Ashton 1994). Psychiatry may also be consulted in ethically challenging cases when parental mental health concerns impact medical decision-making or when the child has significant psychiatric or developmental disabilities that affect the assessment of quality of life.

Youth with progressive neurologic illnesses have to address and plan for a shortened lifespan and the balance between quality and quantity of life. Psychiatrists may be called upon to assess for depression or capacity for medical decision-making in the context of progressive symptoms.

Case 15.1

An urgent capacity evaluation is requested for an 18-year-old young man with Duchenne's muscular dystrophy after he reports to his social worker that he is refusing oral or gastrostomy tube nutrition due to a desire to "die faster."

While any licensed medical professional may do a capacity assessment, psychiatric consultation-liaison physicians have unique expertise. Furthermore, hospital staff may consult psychiatry if they do not agree with the results of a capacity assessment from a nonmental health clinician.

Case 15.2

The team is concerned about depression and suicidal ideation as the patient has also told staff he no longer wants a planned tracheostomy to address increasing respiratory failure. His family and team feel conflicted as the patient has Do Not Resuscitate (DNR) (in some states Allow Natural Death "AND") and Medical Orders for Life-Sustaining Treatment (MOLST) forms delineating no cardiopulmonary resuscitation, but they feel at odds around his choice to forego nutrition or the potentially life-extending tracheostomy, to which he previously consented. His palliative care team wonders if he is too depressed to have capacity to make such choices.

Capacity consults for refusal of care in individuals with life-limiting illnesses, even with legal advanced directives to forego treatment, are not uncommon, usually because of systemic issues including staff moral distress, misunderstanding about advance directives, and concerns about change in decision-making due to altered mental states. The reasoning behind capacity consults can often contain explicit and implicit ethical questions in addition to the request for assessment of mental status.

Case 15.3

His family has been giving him hydration through his gastrostomy tube despite his wishes not to receive it, and his weakness makes him unable to resist. His parents feel conflicted about going against his wishes (as does his palliative care team) especially given that he is now legally an adult, but they feel that he is not behaving like himself. He is refusing to speak with his family about his decision.

Family distress may contribute to staff moral distress, and thus it is often social workers and palliative care clinicians who advocate for psychiatric involvement. A history from parents regarding patients as behaving or thinking differently from their baseline warrants a differential diagnosis of delirium, depression, anxiety, traumatic stress, psychosis, and other psychiatric conditions.

Case 15.4

On interview, this young man is frustrated and states people cannot hydrate him against his will. As the psychiatrist explains her role and desire to understand his symptoms and suffering and help him advocate for his needs, he relates how depressed he feels about his situation. He is upset with his family and team's refusal to consider his decisions and continuing to hydrate him against his will.

Psychiatric consultation for capacity in individuals with life-limiting illness requires alliance-building, clear delineation of role, and gradual discussion and questioning around capacity, to ease defensiveness and facilitate shared problem-solving. This patient benefits from the psychiatric presence and approach. Beginning with a discussion of his mood and circumstances, history-taking, dialogue, and patient advocacy follow. Were the patient refusing to talk, he would be informed that the team must assume he does not have capacity to make decisions. Angry or desperate patients may then be motivated to engage in the interview and dialogue regardless of their capacity. In this case, rapport-building and a collaborative approach was sufficient. This style and approach allows for a calm and productive exploration around the reasons for the consult, risk assessment, and solutions.

Case 15.5

The patient goes on to describe his limited quality of life as he has decreased use of his hands and is disappointed about turning 18 and becoming an adult, but feeling less autonomous. He is not enjoying reading or watching his preferred TV series and has been more isolated from friends on social media. Upon reflection on his mood and thought process, he states he does not feel like his usual self and admits to feeling depressed and hopeless. His sleep has been more disrupted than usual, with early morning awakening and nighttime ruminations.

As in many capacity consults, the psychiatrist can "find out what is really going on" with the patient's mental state and decision-making. Skillful history-taking and consideration of differential diagnosis allow for many vectors of intervention. Most patients with life-limiting illnesses, chronic feelings of helplessness, and loss of agency benefit from being empowered with choices about preferred activities and which ones they are most invested in doing. These may not always be the activities that the medical team or their parents prioritize.

Case 15.6

When given options to improve his mood, he states he would be interested in relief from his negative emotions and consents to a trial of a rapid-acting agent for depression.

Collaborative problem-solving around psychiatric symptoms and interventions is validating to patients whose capacity is being questioned and can lead to further engagement around the initial capacity and medical care concerns. Psychiatrists should gauge how much time is needed before a decision must be made regarding a capacity concern and utilize as much flexibility as possible to come to an agreeable outcome for patients, families, and staff. Staff may be frustrated that the initial consult question is not being immediately answered, but they may not have other options, and hopefully they can come to understand the effectiveness of this patient-centered approach over time.

Case 15.7

The consultant initiates methylphenidate 5 mg once daily and titrates to twice-a-day dosing. The patient can feel a significant improvement in his mood, energy and ability to enjoy things in the first few days of treatment. With increased energy and motivation, he agrees to restart tube feedings. They ultimately settle on 10 mg long-acting methylphenidate every morning.

With successful psychiatric treatment, the tension points for the family, staff, and patient are relieved without having to hydrate or treat against the patient's will. He had some impairment in his decision-making and exhibited maladaptive coping at the time, but it was resolved without a binary, black-or-white capacity determination. There may be a false dichotomy in many capacity consults unless the patient is actively suicidal, delirious, manic, and/or psychotic.

Case 15.8

The patient eventually engages in decision-making about options for more sensitive hand remote controls for his wheelchair and video games. The palliative care team helps to find a technology company that charitably donates equipment to the patient and family. The patient sustains his improved mood with meaning-centered psychotherapy and ultimately decides to undergo the tracheostomy for mechanical ventilation in the next few weeks without any further discussion of his capacity.

The involvement of the psychiatrist does not end at the agreement to restart tube feeds, as many psychiatric issues were identified that impaired the patient's quality of life. The patient, family, and medical team members may find value in the psychiatrist continuing to be involved to provide ongoing mental status assessments and serve as an advocate for the patient's interests once capacity concerns are resolved. Improved agency and engagement in pleasurable activities improve the patient's mood further and result in making life-extending treatment decisions.

The role of depression in impairing quality of life and contributing to patients' foregoing life-sustaining therapies in a passively suicidal way is an important phenomenon that warrants involvement and exploration from psychosomatic medicine and palliative care clinicians.

The assessment and treatment of delirium is a mainstay in the practice of pediatric psychosomatic medicine and may also bring consultants into collaboration with palliative care specialists. There is growing attention to delirium in very young children, with increasing evidence about how to assess the neuropsychiatric functioning of infants and provide effective treatments to enhance their quality of life and capacity for meaningful engagement with caregivers (Traube et al. 2017). As neonatal care advances and more infants with complex conditions survive, psychiatrists may be engaged in assessment and treatment of the very young. Neonatal pediatric palliative care is also a developing field that informs practice in this area.

Case 15.9

An ex-28-week preemie, now 4 months old, with hypoxic-ischemic encephalopathy and seizure disorder on anticonvulsants, short gut after necrotizing enterocolitis, central apnea on caffeine, oxygen-dependent chronic lung disease, and DNR orders, is referred for evaluation of a change in mental status. A psychiatrist on the consultation service has recently given pediatric grand rounds on delirium in infants with multiple risk factors.

Given the variance from “typical” developmental milestones, assessment must be based on changes from the child’s individual baseline status, with an eye toward immediate priorities and goals of care. Bedside nurses can use standardized assessment tools such as the Cornell Assessment of Pediatric Delirium (CAPD) to document mental status over time (Silver et al. 2015).

Case 15.10

The nursing staff reports that the infant previously responded to caregivers by tracking faces, grasping fingers, and reaching for objects. Since having an increase in his oxygen requirement, he responds to physical handling only intermittently and, although awake, does not look at caregivers or have any purposeful movement. His sleep is disrupted, with no regular naps and sleep-wake pattern reversal. Other than tachypnea, he has no vital sign changes or other changes to baseline. On exam, he is a very small infant who appears irritable and unresponsive to soothing. The family and team agree on the goal of improved quality of life, with an understanding that his lung disease is likely to progress further.

Emerging data on the treatment of infant delirium informs a thoughtful multimodal approach that can include antipsychotic medication. In end-of-life care, the potential long-term side effects are less relevant than balancing immediate symptom relief with the immediate safety and side effect profile. Although choice of low-dose antipsychotic use may vary based on regional practices, quetiapine has been used safely and effectively in research populations (Groves et al. 2016; Joyce et al. 2015).

Case 15.11

The psychiatry consultant diagnoses delirium and considers treatment with an antipsychotic medication to improve his mental clarity and ability to interact with his family. After discussion regarding a possible risk of lowering seizure threshold, the team and family agree to a trial of quetiapine (0.5 mg/ kg starting at HS). The infant sleeps at night, but remains irritable and less responsive during the day. Quetiapine *is changed to twice-a-day dosing, resulting in the infant having a calmer demeanor and improved engagement with caregivers. He ultimately dies a few weeks later after a profound apneic episode and is not resuscitated per family's wishes and DNR order. Staff and family are appreciative of more quality time with their child.*

Palliative Sedation

There are times when children with life-threatening illness have severe and refractory physical or emotional suffering that is not relieved with the usual palliative interventions. In these cases with very short life expectancy, palliative sedation may be considered to relieve symptoms that are otherwise not treatable. Examples of such refractory symptoms that may also be the focus of psychiatric consultation include anxiety associated with dyspnea, delirium, or agitation. Psychiatrists may be called upon to consider all possible treatments, including antipsychotics, before the team may consider palliative sedation. While the goal of psychotropic intervention is to relieve symptoms and minimize sedation, this is not always possible. Palliative sedation may therefore be considered and involve higher-dose benzodiazepines or other anesthetics such as pentobarbital, dexmedetomidine, or propofol (Anghelescu et al. 2012). The distinction between palliative sedation and euthanasia is the intent of the clinicians. The aim of palliative sedation is relief of suffering, not shortening of life (de Graeff and Dean 2007). Although euthanasia or assisted death for adults is legal in some states, it is not available for children in the United States.

Advance Care Planning

Childhood cancer affects children and adolescents worldwide and is the second leading cause of death in youth 5–14 years and among the top 10 causes of death among aged 10–24 years (Kochanek et al. 2016). There are 300,000 new cases of childhood cancer diagnosed worldwide each year: 215,000 in children under the age of 14 years and 85,000 in adolescents between the ages of 15 and 19 years (2016) http://www.acco.org/blog/iccd-2017-info-graphics/

While the number of new childhood cancer cases continues to grow, the number of available treatments for childhood cancer globally does not. Survival rates for the most common forms of childhood cancer can range from as low as 10% in low- and middle-income countries to as high as 84% in high-income countries. Cultural differences, access to health care, basic socioeconomic disparities, and these differences in survival impact the practice of advance care planning and palliative care globally.

In 2004, Himelstein delineated four components of advance planning for life-limiting illnesses: (1) identification of the decision-makers; (2) clarification of patient and parents' understanding of the illness and prognosis; (3) establishment of care goals –curative, uncertain, or comfort care; and (4) joint decision-making regarding use or nonuse of life-sustaining medical interventions such as mechanical ventilation, intravenous hydration, or phase I chemotherapy (Himelstein et al. 2004). Over the past decade, as family and medical caregivers recognize that adolescents and young adults (AYA) are capable of and want to be involved in decision-making processes around their illness including at the end of life, advance care planning (ACP) with AYAs has become more acceptable (Sisk et al. 2016; Wiener et al. 2013). In a systematic review on pediatric advance care planning, Lotz et al. (2013) reported on the available empirical research on pediatric ACP for severely ill children and adolescents and found only 13 studies; 5 qualitative and 8 quantitative (Lotz et al. 2013). The use of ACP has been shown, through randomized controlled trials of family-centered advance care planning in youth and their families with HIV/AIDS, to be helpful, to decrease anxiety, and to acknowledge the desires of the AYA, regardless of immediate prognosis (Lyon et al. 2009, 2013). A developmentally appropriate guide has been developed for AYA with additional guidance for clinicians on how to start these difficult conversations with patients and families (Wiener et al. 2012; Zadeh et al. 2015). Clinician readiness in the form of skills and beliefs about the importance of quality communication and the clinical culture around the value of open provider-patient communication may inform whether such conversations can proceed (Brook et al. 2008; Feraco et al. 2016).

Recently, experts in pediatric oncology in the United States established 15 evidence-based consensus standards for the psychosocial care of children with cancer and their families; standard 13 specifically states, “Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary youth and families should receive developmentally appropriate end of life care [which includes bereavement care after the child’s death]” (Wiener et al. 2015; Weaver et al. 2015, 2016).

When available, pediatric psychosomatic medicine psychiatrists as well as the pediatric palliative care teams may be involved in helping physicians provide clear information about what to expect at the end of life, working with physicians on how to convey bad news sensitively, and identifying when to include the patient in the discussion when appropriate. Uncertainty and legal and ethical tensions often complicate end-of-life decision-making and can take time to be resolved. Psychiatrists and ethicists may recognize the appropriateness of a competent adolescent to decline aggressive treatment, for example, but some state laws may forbid it (Mack et al. 2005).

Case 15.12

A 15-year-old girl with cystic fibrosis (CF)*, post lung transplant in acute rejection, presents with dyspnea diagnosed as air hunger by her pulmonary and palliative care teams. Progressive dosing of opiates has not improved her symptoms. Her primary nurse raises the possibility of a psychiatry consult as the patient expresses intense fear and worry that these episodes will not improve.*

Psychiatric consultants have expertise in diagnosing and treating anxiety in the context of medical symptoms. Medical teams may consult for support of anxiety around intense physical symptoms without recognizing that the etiology of primary symptoms may be due to a psychiatric syndrome. Diagnostic clarification and differential diagnosis are the bedrocks of psychosomatic practice and are essential in palliative care and end- of-life patients.

Case 15.13
On mental status exam, the patient is noted to be heavily sedated with complaints of frequent dyspnea. She describes two to three episodes of dyspnea per day. These episodes last 2–10 min and are accompanied by tachycardia, sweating, tremulousness, and thoughts about death. Further history reveals these episodes are brought on by thoughts of her death and possible suffocation. The psychiatrist clarifies that she is experiencing panic attacks and inquires about her medical prognosis.

Panic and other anxiety disorders are often confounding diagnoses for medical clinicians when patients have multiple underlying physical conditions that mimic or exacerbate these symptoms. Linking the symptoms to thoughts and feelings clarifies the diagnosis and broadens opportunities for psychotherapeutic intervention. Diagnostic criteria are helpful in identifying psychotropic options, and knowledge of medical prognosis is important in selecting the most appropriate treatment.

Case 15.14
Given the prospect of months left to live, the psychiatrist starts a selective serotonin reuptake inhibitor. The patient has mild to moderate hepatic failure as part of her CF*, so low-dose citalopram 5 mg once daily is started and titrated to 10 mg once daily over 2 weeks. The psychiatrist also starts concurrent hepatic-adjusted dosing of clonazepam 0.25 mg twice daily, which reduces panic attacks to 2–3 times per week of mild to moderate intensity. The medical team does a gradual taper of opiates without increased dyspnea.*

The psychiatric consultant must gauge risks and benefits along with appropriate timelines for treatment. Given the hepatic impairment of patients with CF, appropriate dose adjustments reduce harm and side effects. Moreover, the consultant must be mindful of using SSRIs such as citalopram and escitalopram, which have the least drug-drug interactions with common CF medication regimens. Planning regarding potential need for agents such as antimicrobials and antibiotics such as linezolid, a weak monoamine oxidase inhibitor, warrants consideration of utilizing serotonergic anxiolytics without long half-lives that would delay treatment of sepsis or make a patient prone to serotonin syndrome (e.g., avoiding fluoxetine). Lastly, appropriate psychotropic treatment can minimize polypharmacy or inappropriate dosing of sedating agents that reduce quality of life.

Case 15.15
There is progressive improvement with follow-up meetings for psychoeducation about panic attacks, relaxation and diaphragmatic breathing, and psychotherapy for existential exploration of death and dying. The patient also engages in legacy leaving and advance care planning using "Voicing My CHOiCES™"(Wiener et al.

2012*). At 4 weeks there is further reduction of panic attacks to 1–2 times weekly; each episode lasts for less than 20–30 seconds and is of mild intensity. Citalopram is increased to 15 mg daily with good control of panic. Clonazepam is reduced as needed, mostly around chest physical therapy or during the nighttime.*

This case illustrates the important roles of diagnostic clarification and appropriate psychopharmacologic management to treat the underlying condition and avoid iatrogenic harm. It also highlights the importance of psychotherapy and meaning-making in improving anxiety and panic in patients facing life-limiting illness.

Youth with advanced illness may present with significant multifactorial symptoms that may be related to primary physical symptoms such as dyspnea or pain, as well as fears about their illness and death. These physical and emotional symptoms interfere with their quality of life and must be addressed directly. Discussion and treatment of these concerns may also allow patients and families to thoughtfully consider ACP. Psychiatric consultation can help clarify the contribution of psychiatric issues to distress and provide both pharmacologic and non-pharmacologic interventions.

Impact of Parental Mental Health on End-Of-Life Care

Pediatric palliative care training emphasizes skilled communication with patients and family members to achieve goal concordant care and quality of life for the most seriously ill children. However, PPC clinicians do not have training in the assessment and treatment of adult mental illness and may face challenges when parental mental health issues interfere with parental coping and medical decision-making. Child psychiatrists may therefore have a role in helping to assess these situations and offer targeted parent guidance and family intervention.

Case 15.16

A 5-year-old boy with relapsed stage 4 neuroblastoma and progressive bulky disease in his abdomen is on a phase I trial, which does not stop the progression. He is admitted with a bowel obstruction and increased abdominal girth and pain. His mother is distressed and at bedside, along with maternal grandmother who lives with them. Parents are separated but have shared custody, and the child's father has been only intermittently involved with his medical care. The oncology team approaches the parents about advance care planning, given the poor prognosis and likelihood of perforation and acute decompensation.

Parental separation and different levels of involvement in a child's medical care may complicate decision-making at end of life. It is important to assess both the legal custody arrangement and the emotional and physical engagement of each parent. Even if there are shared legal custody and official decision-making, the parents may have differing levels of understanding about the illness or different levels of prior engagement in everyday medical care and decisions. They may also have different relationships with members of the medical team. Extended family members (e.g., maternal grandmother) may have participated in the care of the child and are invested in the outcome, but do not automatically have legal decision-making authority. The pediatric psychosomatic medicine service could have a role in assessing the family if decision-making becomes conflicted or complicated. Without any expectation of needing to also provide ongoing treatment – including medication prescriptions – to the adults (who generally would not be registered as patients in a pediatric hospital), any of the team psychiatrists, psychologists, or social workers could fulfill this family assessment role.

Case 15.17

The child's mother and grandmother agree that they would like to redirect care to supportive measures only. The child's father feels that more can be done to address the boy's condition, wants a surgical consultation, and does not agree to a Do Not Resuscitate order. He becomes agitated on the unit and yells and threatens to sue the team. Security escorts him to a consultation room, where he calms down and meets with the oncologist, palliative care team, and psychiatry consultant. He is tearful and overwhelmed. Before engaging in further medical decision-making, he meets alone with the psychiatrist for additional assessment.

Parental behavior under the stress of a child's life-threatening illness may be mediated by several factors. Containing unsafe behavior must occur first and may require the assistance of security personnel. A compassionate, non-threatening stance from staff, demonstrating a willingness to hear perspectives, can ease tension and provide a platform for calm discussions. Along with medical providers, the psychiatry consultant should clarify the parent's understanding of the child's condition and prognosis and seek to understand their priorities for care.

Case 15.18

The psychiatry consultant provides empathy for the father's suffering, seeing his child so ill, and gently inquires about his relationship with his son and his own personal stressors. On further evaluation, the father reveals a history of anxiety and alcohol abuse and reports that he is in the early stages of recovery. He expresses remorse about not being more available to his son and wants an opportunity to be a better father.

It may be valuable to step back, build rapport, and gather additional personal history from the parent to understand their current mental state and internal experience. A history of mental health and substance abuse issues may affect parental coping with their child's end of life and medical decision-making. Parents may need to be assessed for risk of self-harm, suicidality, and aggression to others, as well as risk of substance abuse relapse. Empathic holding in the face of their child's illness may involve engagement of community resources in addition to support in the hospital.

Case 15.19

Additional meetings with oncology, with further explanation of his son's disease, allow the father to better understand the seriousness of his child's illness. The psychiatrist engages the father's Alcoholics Anonymous sponsor for support and the *father's primary care physician in prescribing trazodone for sleep. Over the next week, the father is able to be present at his son's bedside and collaborate with the child's mother to make thoughtful decisions about the child's end-of-life care.*

Pediatric/Palliative Care Clinician Distress

Case 15.20
After the child's death on the floor, the multidisciplinary staff gathers for a debriefing session as they usually do after inpatient deaths. One of the child's primary nurses expresses her distress about the child's death, especially as she observed the father's grief about not being present for his son during his earlier life. As a relatively new oncology nurse, she struggled with how unfair it seemed for this little boy and his family; she looked to her more experienced colleagues to learn how they handle their own feelings and continue to care for other children on the floor.

Children and families with comorbid medical and psychiatric issues may present unique personal challenges to primary care and palliative team clinicians. Regular exposure to childhood suffering and death may contribute to compassion fatigue (Rourke 2007), and high expressed emotion or distorted thinking in the child or caregiver may provoke additional strong reactions in clinicians and further erode their coping and resilience. In caring for a seriously ill child, pediatric teams may find it challenging to establish boundaries between their professional and personal responses. Clinicians of any discipline may become overly involved with patients by extending themselves to meet intense demands, sharing personal stories or resources, having trouble setting limits, or connecting through online social networking. These behaviors can pose ethical and confidentiality concerns and create varying patient and family expectations, which can lead to misunderstandings or resentment about why some staff are more flexible than others. On the other hand, clinicians may be overwhelmed or repelled by a patient's psychiatric issues. They may attempt to avoid caring for the patient or blame and criticize the parents.

By providing an outside perspective, psychiatric consultation can provide reflective strategies to enhance clinicians' awareness about their reactions to patients and reestablish professional boundaries. Careful case discussion or regular debriefings can help clinicians distinguish their own feelings and impulses from what is in the best interest of the patient. Psychiatric consultants may also identify overwhelming staff distress and vicarious traumatization and make a referral to outside mental health providers for clinicians needing ongoing support.

Conclusion

Pediatric consultation-liaison psychiatry can play a significant role in helping children and their families during advanced illness and can create opportunities for collaboration with pediatric palliative care clinicians. In bringing expertise about a child's cognitive, emotional, and physical development in the context of serious medical illness, the psychiatry consultant can play an important role in helping families and other clinicians understand how these impact a particular child at the end of life. In cases of significant psychiatric and medical comorbidity, child psychiatrists can improve the recognition and treatment of mental health conditions and improve quality of life and outcomes for dying youth and their surviving families.

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