

Family-Based Integrated Care (FBIC) in a Partial Hospital Program for Complex Pediatric Illness



Fostering Shifts in Family Illness Beliefs and Relationships

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KEYWORDS

- Family-based treatment • Integrated care • Patient-centered care
- Patient and family-centered care • Family therapy • Eating disorders
- Chronic illness nonadherence • Somatoform illness

KEY POINTS

- The heuristic model of family-based integrated care (FBIC) grounds case formulation in the context of family beliefs and relationships with a goal of productive joining with families and optimal integration of treatment across illnesses and levels of care.
- The application of the FBIC model is effective in the management of several broadly experienced challenges that occur in the management of complex pediatric illness. Some of these challenges include medical nonadherence, which leads to high morbidity and excessive health care cost, families who struggle with accepting the need for psychological intervention to optimize health outcomes, and the risk of mixed messages across disciplines of health care leading to ineffective care.
- Integrated care is effective in optimizing pediatric health outcomes.
- The HCPHP (day-treatment) model allows for intensive intervention in complex pediatric illness.
- FBIC applied in a partial hospital setting can lead to healthy shifts in family illness beliefs and relationships that support better health outcomes.

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OVERVIEW

Basic Construct of Family-Based Integrated Care

The heuristic model of family-based integrated care (FBIC) was developed over an 18-year period (1998–2016) in the context of the development of the Hasbro Children's Partial Hospital Program¹ (HCPHP) along with the development of a family therapy training program for Brown University child psychiatry and triple board residents.² A description of the heuristic model of FBIC will provide a framework that supports the formulation of treatment needs and coordination of interdisciplinary care across illnesses and levels of care. The FBIC model allows for a meaningful, practical case formulation that is independent of specific illness, presenting symptoms, and context of care. It is also a construct that can be used in all care settings and across disciplines to help organize treatment decisions and interactions in a manner supportive of patient and family empowerment over illness.

The FBIC paradigm encourages providers to join with families around their presenting beliefs about illness and symptoms with an understanding that these beliefs may or may not be divergent from objective medical criteria and provider opinion, and may vary across patient and family members. In addition, the model supports providers in orienting themselves around the relationships between patient and family members, related to specific illness management as well as to overall functioning. With providers grounded in an understanding of patient and family beliefs and relationships in the context and needs of the illness, treatment goal setting becomes connected to the unique needs of each patient. Broadly, the goals include supporting patients and families in having accurate and mobilizing beliefs about their illness and symptoms, and supporting relationships that allow for empathy and effective support around illness needs. The process of aligning providers with these goals across disciplines and levels of care provides a stabilizing construct amidst the crises of pediatric illness while supporting healthy child developmental and family patterns.

The Primacy of Working in the Context of the Family

There is growing evidence supporting the critical impact of the family on children's mental health.^{3–10} This impact is noted in research involving epigenetics, the effects of toxic stress and parental mental illness, as well as in reviews of interventions involving family-based treatment. Evidence-based psychological interventions often focus on the details of the illness or symptoms without considering context. However, these interventions are more impactful when an understanding of family systems concepts is incorporated.

In the heuristic model of FBIC, illness cannot be conceptualized outside of the context of family beliefs and relationships. In the HCPHP, family participation in treatment is central and provides a broader lens on the challenges at hand, which allows for optimization of treatment of all illnesses.

Interdisciplinary Care

The importance of comprehensive, interprofessional care for adults, adolescents, and children has been widely recognized as the ideal way to deliver care. Integrating medical and behavioral health practices leads to lower health care costs, decreased readmission rates, and improved outcomes including greater functioning and quality of life. The literature also supports the concept that mental health and medical conditions are risk factors for each other; the presence of one can complicate the treatment and outcomes of the other. This connection is supported by emerging scientific data that identify shared physiologic pathways connecting mind and body.¹¹

Advantages of Day Treatment

Treating pediatric patients in a day hospital setting has a number of advantages over inpatient and outpatient treatment. This is related to the ability to combine an opportunity for intensive intervention and monitoring with the real-life challenge of illness management at home. Day-treatment models can mitigate the need for inpatient treatment in high-risk patients not responsive to standard outpatient intervention while minimizing repeat hospitalization for others.

Advantages include the following:

- Day treatment provides children at heightened medical risk with daily monitoring outside of an inpatient setting that allows for both cost savings and the comforts of home. Examples might include patients with eating disorders who require periodic nasogastric tube feedings or patients with diabetes with severely poor glycemic control who need frequent monitoring while insulin adjustments occur.
- It also allows daily psychiatric monitoring for children with heightened risk for self-endangering behavior or who are severely impaired in functional ability. This provides a secure base while supporting the process of breaking these self-destructive patterns without the regressive risk that inpatient care can engender.
- The ability of parents and extended family to participate in care in the program and at home with daily support is much expanded in day treatment versus inpatient settings. This provides a safety net that both contains caregiver anxiety and maximizes empowerment over time.
- The presence of real-life challenges in the home environment can help identify skills needed for each patient and family. These may not be as apparent during medical or psychiatric inpatient treatment. Challenges are considered “grist for the mill” in addressing all of the puzzle pieces that lead to outpatient success. Opportunities to practice skills in the home environment also increase families’ self-efficacy for maintaining their goals.

The Family-Based Integrated Care Model

The FBIC heuristic model provides a framework for case conceptualization to organize interdisciplinary treatment by effectively taking into account the unique context of each patient and family. It can be applied across illnesses and patient populations and is useful for all disciplines of health care at all phases of treatment.

The Family-Based Integrated Care Graph

The FBIC graph was developed as a teaching tool that highlights the multidimensional aspects of assessing and treating a patient in the context of a family system.² It allows the therapist to become oriented to “where they are” in the process of joining with the patient and family with an eye toward the big picture arc of treatment. It allows for a concrete “vision” of “where we are” as well as a nonjudgmental path forward that is applicable to all families and illnesses. While providing a visual image, it also respects the complexity and fluidity involved in family dynamics. Of note is that the full range of psychological evidence-based treatment can be “mapped on” to the graph, highlighting where each intervention focuses on patient and family cognitive, behavioral, affective, and relational movement. This meta-view’s consideration can magnify the impact of discrete interventions either through awareness of whether a patient and family are in a starting place that allows them to accept the intervention or by pointing toward barriers that need to be addressed to allow them to. The FBIC graph includes a cognitive dimension (eg, the presence of ongoing beliefs either shared or idiosyncratic

to one family member) as well as an affective/spatial dimension (eg, relationships between family members that generate emotional states and impact the ability to problem solve). Use of this construct to orient joining and treatment efforts is not just for the “evaluation” but rather an effective construct to use throughout treatment (Fig. 1).

Beliefs Axis

Patient and family beliefs are powerful forces shaping behavior and emotional experience overall as well as impacting any illness challenge. Beliefs can be distorted and constraining or accurate and mobilizing. Conflict and immobilization can result when beliefs vary across family members. Beliefs are shaped by a complex set of variables, including individual experience and perception; interactions with peers, family, and social networks; and larger cultural contexts, including religion, ethnicity, and culture. Beliefs are subject to shaping and modification and consequently are a target for many evidence-based psychotherapies (cognitive behavior therapy [CBT], dialectical behavior therapy [DBT], acceptance and commitment therapy [ACT]).

From the perspective of FBIC, establishing a clear understanding of patient and family beliefs about the illness entity and associated symptoms is a key component of joining. Common orienting questions during an initial evaluation of FBIC at HCPHP might include:

- “After everything you have experienced in recent months and all of the input you have received from treatment providers what do you believe about what is causing your _____ (insert symptom)?”
- “After everything you have experienced in recent months and all of your input from treatment providers what do you believe about what is causing your daughter/son’s _____ (insert symptom)?”
- “What is your understanding from input you have had from your treatment team about what is going to help you get your/your child’s illness/symptoms under control?”
- “With all of your efforts with treatment so far are you encouraged, discouraged, or both?”

Key principles to consider when joining around patient and family beliefs include the following:

- It is possible to be empathic around beliefs that may be clearly distorted while also introducing a larger frame to consider.

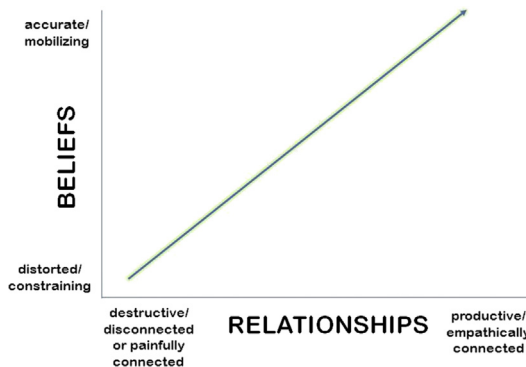


Fig. 1. The FBIC graph.

- For a parent who remains highly anxious about an as-yet undiagnosed rare medical issue that is driving a clinical presentation consistent with conversion disorder: “I hear that you remain very concerned that there is more to figure out medically. The monitoring we will do together daily will help guide our efforts. As we go forward, what is your biggest concern about how this experience has emotionally impacted your child?”
- For a patient with refractory pain who is unwilling to speak in emotional terms: “Is this experience with your headaches the most painful, stressful thing you have ever been through?” ... “I’m glad you are here so we can figure things out. Separate from your headaches, what is the second most painful/stressful thing you are dealing with or have been through?”
- The therapy process of family members sharing existing beliefs often elucidates areas of conflict/discrepancy that are productive for treatment, explain areas of immobility, and set the stage for expanding perspective for all.
 - For parents who are clearly at odds about forces driving symptoms: “Do you mostly agree or disagree day to day on what is going to most help your son/daughter move forward in spite of his/her _____?”
 - For a family with parents more in tune with psychological factors driving physical symptoms than their child is: “Is your son/daughter surprised to hear you say how much you believe his/her anxiety is causing his/her abdominal pain to be worse?”
- Patients and families describing their illness beliefs often point toward areas in which they have received mixed messages across providers, which can serve to hamper mobilization to break symptom cycles.
 - For families in which this might be the case:

“Does your outpatient team mostly agree with each other or do they have different opinions about what is happening for your child?” or “Do you mostly agree or disagree with how the team understands your child’s illness?”

Relationships Axis

Relationships are complex evolving connections with the same range of shaping forces as illness beliefs. Within the constellation of any given family system, there is a complex web of relationships that powerfully impact each member of the family. Significantly, powerful individual variables including temperament, personality, life experience, and the presence of mental and/or physical illness impact how that individual connects with others. From the FBIC perspective, it is important to develop an understanding of the space between people that is impacted by individual, family, and larger network forces, as well as by the force of the illness entity. Interpersonal functioning within relationships is a common area of focus for a range of evidence-based treatments (interpersonal therapy [IPT]; multisystemic therapy [MST]). Expanding the support that can be derived from relationships can impact the ability to cope with illness in powerful ways.

Relationship valences can be markedly positive, significantly negative, and mixed. An overly simplified construct identifies the spatial aspect of the relationship (closeness vs distance in connection and communication) as well as the affective aspect (range from high attunement and empathy to detachment and neglect). Common questions that orient the clinician to family relationships might include the following:

- “Stress like this can pull families together, push them apart, or both. What would your daughter/son/husband/wife/father/mother say is happening with your family? What would you say?”

- “There are so many painful aspects to what you are living with from your illness. Are there some things your mother/father would rather not know, or would she/he rather you tell her what is going on even if it’s really painful to hear?”

Key principles to consider while joining with patients and families around the status of their relationships include the following:

- The presence of illness and the effort required for illness management places a tremendous burden on family relationships in terms of logistics and emotional energy.
- The manner in which an illness complicates a family’s routine is unique to that family.
- The time and energy spent on managing illnesses may take focus away from other significant events that need attention and discussion (“things get pushed under the rug”).
- It is common for parents and children to “protect” each other by avoiding talking about the most painful details of the illness.

A simple way to assess where a family is, includes a review of “Routines, Rugs, and Risky Conversations”:

- “Routines”: “What is the greatest challenge for you in your daily routine related to your managing your/your child’s illness?”
- “Rugs”: “If we weren’t spending so much time talking about diabetes/depression/the eating disorder what else would be most important for your family to spend some time talking about?”
- “Risky Conversations”: “What is the scariest part of living with _____ (insert illness) that may be most difficult for your child/parent to talk about?”

It is also important to become oriented to the status and health of family relationships that existed before the illness challenge:

- We may meet children and families who had a developmentally normal and healthy pattern of relationships that have been profoundly disrupted by the immense pressure of an illness.
- We may meet children and families for whom the illness challenge pales in comparison with other life challenges. Perhaps families have lifelong severe impairment in relationship patterns that long predated the illness.
- Perhaps we meet a family who has had lifelong painful relationship patterns that are now further compromised by the pressure of the illness.

Any of these realities can be conceptualized and intervened with using the FBIC construct with interventions tuned to the family reality. Regardless of the specific illness entity, any pain/distress is eased by the presence of empathic interpersonal connections.

Interdisciplinary Value of the Family-Based Integrated Care Model

The importance of orienting oneself to the context of family beliefs and relationships is not exclusive for mental health professionals. All health care providers can benefit from an awareness of these contextual factors. It is possible to become familiar with common belief and relationship patterns as they impact illness management and to develop a toolkit of responses without formal mental health training. This heuristic model seeks to update the “biopsychosocial model”¹² of patient formulation. Familiarity with this model allows for productive responses to common challenges for

providers in treating complex pediatric illness, including helplessness in the face of severely distorted family illness beliefs and/or severely impaired relationships, frustration in treating families who struggle to incorporate a psychological understanding of their child's challenge, and the risks inherent in becoming entangled in symptom-driven decision making.

The FBIC model can help combat an expectable sense of helplessness for providers, patients, and family members in the face of powerful and life-threatening illness challenges and/or painful family relationship patterns. The meta-view of "acknowledging where the family is," even if it is a very painful, troubled place is a relief, as it naturally implies a path forward. Although the power of any particular illness entity can be overwhelming, providers can shift to feeling empowered by understanding that regardless of illness severity, they can intervene in the family system in a manner that offers relief while the patient and family lives with the illness. Forging a hopeful connection with a health care provider/provider team can often be the first step in breaking a longstanding sense of isolation derived from an illness being out of control. For parents and other family members, the message that "your understanding of your child's illness and your connection to your child are the most powerful forces in their recovery" is a message that allows for a shift from helplessness to empowerment. This helplessness is often magnified by the collateral damage of accommodation patterns already noted. Combatting this sense of helplessness is often particularly critical for therapists in training who often take on a sense of blame around the impact of illnesses on patients and families.¹²

The FBIC model can allow a productive avenue to manage patients and families who struggle to incorporate a psychological line of sight into understanding illness challenges. By assessing the status of family beliefs and relationships as a natural and expected aspect of joining with patients and families in a nonjudgmental way, rather than one that is symptom specific, a framework for the patient and family as people is created. This provides a springboard to normalize the psychological responses to illness that are not specific to a mental health diagnosis but rather inherent to life. Using the FBIC framework in discussing both medical and psychiatric illness in the same framework reinforces the construct that we are always treating the whole person in all cases. Practice with this model of case formulation and treatment discussions for non-mental health professionals allows psychological layers to become naturally embedded in illness conversations without the implication that this is a realm separate from the professional's specialized focus.

A focus on symptoms/illness outside the multidimensional context represented by the graph can grant the illness more power over the patient's and family's life rather than less. Because the FBIC model is not symptom or illness specific, it helps mitigate the dangers inherent in symptom-focused decision making. These pitfalls include making treatment decisions that do not use the right balance of medical and psychological focus, including nonproductive decisions about shifts in levels of care. More specifically, the incorporation of a psychological framework naturally leads to professionals conveying the message to families that these dimensions are valuable. With the consequent improved joining that follows, it is expectable that patients and families will be more accepting of interventions in these areas. This acceptance may allow for avoidance of unnecessary and potentially harmful interventions, such as the addition of a medication aimed at a medical etiology of symptom exacerbation that is actually believed to be more related to psychological factors. Decisions about levels of care also need to be context driven to be most productive. A common example relates to decision making around suicidality and level of care. There are situations in which context dictates that, even with intense suicidality, remaining at home with family

support is the most therapeutic option. Conversely, there are other situations in which suicidality is less intense, but family relationships are less nurturing, which may necessitate an inpatient level of care. Similarly, in the realm of physical illness, the family's ability to conceptualize necessary care and mobilize around patient needs should be a critical variable in decision making around the most productive and empowering level of care at any given phase of illness.

Message Magnification Across Providers

The use of the FBIC model across disciplines allows for a productive magnification of messages given to patients and families. The graph orients providers, patients, and families to where the family system is in the treatment and recovery arc, in turn leading to conversations across disciplines around similar themes.

A patient with deeply entrenched cognitive distortions driven by their eating disorder may hear the following from different providers, both of which emphasize externalization of the eating disorder:

- A milieu therapist who encourages them to engage in a skill-building exercise focused on mindfulness might note: "When the eating disorder thoughts get really strong and painful, this is something you can try?"
- A pediatrician may say while doing a physical examination: "Even though the eating disorder is telling you not to eat, we are going to support you fighting back, because nutrition is the medicine that your body needs."

Meanwhile, the parents of the patient may hear the following, which also emphasizes externalization, as well as the importance of parents' relationships with their daughter:

- A pediatric nurse who notes after hearing of a difficult night when the patient was screaming at her parents while refusing dinner might say: "You did a really good job holding the line. Even though she didn't eat everything, the eating disorder didn't win."
- A psychologist doing family therapy with these parents may say: "As powerful as her eating disorder was last night, your relationship with her was stronger and gave the message to the illness that it is not in charge."

When anchored in the FBIC model, medical and psychological messages are integrated instead of divided. The repetition of themes is nonjudgmental, focused on the details of practical needs at hand, and directed at patient and family empowerment even during a period of the illness running rampant.

Case Example 1: Family-Based Integrated Care Case Conceptualization

Brittany is a 14-year-old girl with a restrictive-type eating disorder referred to HCPHP after a 10-day inpatient admission for medical stabilization and refeeding. When Brittany presented to the eating disorder team for an outpatient intake appointment, she was found to be critically bradycardic and symptomatically orthostatic by heart rate and blood pressure, necessitating an inpatient level of care. Brittany reported an 18-month history of restrictive eating, including calorie counting, fat and carbohydrate avoidance, and not eating at all on days that she could not exercise. In addition, she reported compulsive overexercise and water-loading. She denied vomiting, use of laxatives/diuretics/diet pills/herbal weight loss supplements/nonprescribed medications for the purpose of weight loss. Brittany reported 18 months prior she decided to "get healthy and lose a few pounds." Initially she cut out "junk food" and increased her exercise to 3 to 4 times per week. She started using a FITBIT and a weight loss app on

her phone. These changes resulted in modest weight loss, and Brittany began to “feel better about herself.” Approximately 6 months before admission, her parents began to have concerns that she had become extremely rigid in her eating, compulsive and excessive with exercise, and withdrawn from activities that she previously enjoyed. They also noted that Brittany appeared “too thin” and continued to feel the need to lose weight. At that time, her parents brought Brittany to her primary medical doctor who weighed her and felt reassured by a body mass index of 18.5. Over the next 6 months, Brittany became more consumed by a drive to eat “healthfully,” exercise, and lose weight. Her parents remained concerned, and although she would not eat what they prepared, they allowed her to make her own food and eat what she wanted because “at least she was eating.”

In this case example, Brittany’s distorted cognitions about food, body, and health interfered with her ability to make healthy decisions for herself. These cognitions along with her undernourished state contributed to a depressed mood including withdrawal from peers and preferred activities. Her parents’ feeling of helplessness and willingness to inadvertently collude with the eating disorder further reinforced the control it had over Brittany and the family. Despite Brittany developing some insight around the negative impact that her eating disorder had on her and her relationships, her illness remained too powerful to allow a change in her distorted cognitions and behaviors.

Family-Based Integrated Care Case Example 2: Case Conceptualization

Joann is a 14-year-old girl who lives with her parents and 17-year-old sister. She has a 20-year-old sister who attends a prestigious university. She does not have a significant medical history, has friends and plays sports, and is a good student, although she recognizes that academics do not come as easily to her as to her sister. She is currently in the eighth grade and her parents have always encouraged her to do her best, hoping that that would take some pressure off. Joann has interpreted this to mean she should work as hard as possible to achieve. She feared not being able to succeed as her sister did. Unexpectedly, as school was to resume following winter vacation, Joann developed intense abdominal pain and was not able to attend. Her parents were not initially concerned, but when the pain persisted and continued to interfere with school attendance, they began to seek medical advice, first from Joann’s pediatrician and then from a gastrointestinal specialist. Each of these physicians recommended symptom-focused treatment (eg, MiraLAX for mild constipation). Joann continued to experience pain, miss school, and disengage from social activities. Joann’s primary care doctor recommended counseling, but as Joann had always functioned well and did not want to reveal emotional distress to her parents, this recommendation was not followed. Instead, believing in their daughter’s overall competence, they assumed that there must be an underlying medical cause for her pain. They assured Joann they would get to the bottom of her pain and sought several additional opinions from specialists who trialed her on different pain medications. Joann was seen in the emergency department and admitted to the hospital where she underwent several medical tests, all with negative results. Meanwhile, she was home from school, her sleep was disrupted due to lack of a schedule, and she more and more socially isolated.

In this case example, Joann’s parents’ belief that her pain was exclusively driven by an as-yet undiagnosed medical illness led to repeated visits to a variety of medical subspecialists, emergency room (ER) visits, a medical admission, and a variety of medical interventions. At the same time, very little attention had been paid to the psychosocial factors that are likely contributing to Joann’s pain experience as well as to

the psychological impact of her pain experience. Although all family members are worried about Joann, and are confused and frustrated about not being able to find a medical answer, the family's medical focus has made it difficult to talk about important emotional issues. Thus, although the family members share a common belief, this belief is distorted in that it does not include psychological factors. The lack of attention to this dimension has led to distance in family relationships that further escalate Joann's sense of isolation and helplessness.

Family-Based Integrated Care Case Example 3: Case Conceptualization

Caleb is a 15-year-old boy who was diagnosed with type 1 diabetes at age 13. He lives with his mother and father and 2 siblings, ages 11 and 8. He has a long history of excelling socially, academically, and athletically, qualities that his parents have fostered by encouraging his self-reliance. After being diagnosed, Caleb quickly learned to monitor his blood glucose and diet in ways that led to successful HbA1c levels. His parents, who were initially privately devastated that their son would have to manage a chronic illness each day for the rest of his life, began to feel hopeful that this would not interfere as much as they had feared. Because he effectively monitored his illness, they allowed him to manage much of his regimen independently. However, after several months of successful management, Caleb began to find it more difficult to balance his diet, exercise, and insulin, resulting in fluctuating blood glucose levels. This resulted in Caleb feeling frustrated, hopeless, and depressed. His parents, used to their son solving problems effectively on his own, continued to assume he would "figure it out." At the same time, Caleb began to believe that his illness cannot be "figured out" and gave up close monitoring and regular insulin injections, which ultimately led to long periods of very high HbA1c values, as well as an ER visit for an episode of potentially life-threatening diabetic ketoacidosis.

In this case example, Caleb's belief that his diabetes cannot be controlled has a strong impact on his mood and illness management adherence. His depressed mood likely clouds his judgment about his illness and his efficacy for managing it. Similarly, his parents' distorted beliefs that their son can handle this independently, combined with thoughts that they would not know how to help, further exacerbate the influence diabetes has on Caleb and the family. Family beliefs are constraining Caleb's ability to manage his illness. Meanwhile, Caleb's parents are empathic and concerned, but have been unable to convey support in ways in which Caleb can connect, as he has always been self-reliant. A shift toward increased monitoring in their parent-child relationship has felt like failure to all of them, leading to frustration and distance.

**** Please note that case examples are derived from amalgams of a large sample of patients treated over time rather than being derived from any 1 patient or family.**

THE PARTIAL HOSPITAL PROGRAM MODEL

Program Mission

The HCPHP is a collaboration of the Department of Pediatrics and the Department of Child Psychiatry of Hasbro Children's Hospital, a Lifespan affiliate. The HCPHP has been in operation since June 1998. The mission of HCPHP is to empower children, 6 to 18 years of age, and their families, to face complex pediatric illness challenges, including eating disorders, chronic pediatric illness complicated by nonadherence and/or psychiatric comorbidity, complex pain disorders, and somatoform illness such as conversion disorder. Regardless of illness, the mission is for the team to understand the illness experience and challenges unique to each child and family. In this

context, the goal is to support the development of accurate and mobilizing illness beliefs as well as to support relationships between family members and with providers that are empathic and productive. Sometimes patients and families enter the program with well-delineated diagnoses, whereas in other cases there is clinical uncertainty. When FBIC is applied, the core mission can proceed in either case.

Program Development

The initial unit opened in 1998, in 2 rooms on the medical inpatient floors of Hasbro Children's Hospital with a maximum census of 6 patients ages 12 to 18. The program moved to a renovated space (approximately 5410 square feet) in 2000, along with expanded staffing that allowed for growth into 2 therapeutic milieus (one for 6–12-year-olds and one for 12–18-year-olds). The census target gradually increased from 10 patients in 2000 to 16 patients in 2014. A major expansion of physical space (3900 square feet) and staffing in 2015 increased capacity to 24 patients and allowed for the creation of 3 milieus that are age and developmentally based. All growth was driven by overwhelming need for services within the region and beyond. All renovations and expansions were hospital funded based on fiscal health of the program aside from a philanthropic fund that supported physical space renovation in 2000.

Program Beliefs

The following are HCPHP beliefs that anchor FBIC treatment for complex pediatric illness and provide a framework that encourages family belief shifts that are productive for treatment:

- Any treatment plan or decision that gives the illness less power/control over the child and family's life leads to a sense of empowerment and improved illness management.
 - Accommodation to illness symptoms that leads to avoidance and functional impairment is a feature common to pediatric and psychiatric illnesses, which leads to collateral damage for the child and family.
 - Family understanding of this reality and awareness of their ability to shift this pattern is essential to the effectiveness of many evidence-based treatments.¹³
 - The process of "externalizing the illness"¹⁴ provides a belief shift that takes pressure off of family relationships by allowing blame to shift to empathic mobilization of support.
- Emotional expression is empowering but can be very difficult for a range of reasons.
 - Validation of child and parent emotional experience is essential to effective joining around treatment efforts.
 - It is possible to validate emotional experience without reinforcing distorted beliefs driven by illness cognitions.
- Mind and body are inextricably connected. Treating "the whole child" is essential.
 - Physical pain/distress is connected to emotional pain/distress and vice versa.
 - It is possible to address psychological distress while also attending to physical pain/distress.
- Focusing on functioning is empowering.
 - It is possible to encourage the patient's functioning while at the same time being empathic about how distressing this might be for the patient.
 - Supporting functioning does not mean that pain/distress is not "real."

- The presence of pain/distress, even more pain/distress than was there before intervention, can be an important part of moving toward physical/emotional healing and overall empowerment.
 - It is normal that when there has been longstanding pain/distress that there is fear about “pushing” on the part of patients and parents (“the fear factor”).
 - Although sometimes an increase in pain/distress means that treatment is not working, other times it can mean that it is.
 - It is usual that in the process of supporting change that new “crises” are created in the family.
- Regardless of the specific illness entity, any pain/distress is eased by the presence of empathic interpersonal connections with family and health care providers.
 - Families can learn to communicate about painful things in productive versus destructive ways.

Population Served

Patients admitted to the HCPHP are between 6 and 18 years of age and have combinations of medical diagnoses as well as psychiatric diagnoses. Additional admission criteria include the following:

- Patients must be medically and/or psychiatrically stable enough to not require 24-hour hospitalization.
- If recently discharged from an inpatient medical or psychiatric unit, patients must be at high risk of rehospitalization.
- If currently treated on an outpatient basis, patients have evidence of lack of response to medical and psychiatric treatment to date and/or must be at risk of needing an inpatient level of medical or psychiatric care.
- Patients must have evidence of marked impairment of functioning (eg, inability to attend school or attend to activities of daily living).
- Patients must be able to communicate in English, even if it is not their primary language (the program can accommodate patients if their family members do not speak English).

Criteria that may preclude admission to HCPHP include the following:

- Recent history of severe aggression.
- Developmental delay of a severity that precludes engagement in the therapeutic milieu.
- Inability of the family to transport patient to and from the program and/or inability to participate in family-based aspects of care (minimum of 2 family therapy sessions per week within program hours, as well as daily communication).
- Of note is that on rare occasions HCPHP has served patients living in state custody who are in group or foster homes (in which case, group home staff or foster parents participate in program treatment).

Common *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, diagnoses treated at the HCPHP include the following: anorexia nervosa, bulimia nervosa, avoidant/restrictive food intake disorder, pain disorder with medical and psychological factors, somatic symptom disorder, conversion disorder, major depressive disorder, obsessive compulsive disorder, generalized anxiety disorder, social phobia, and panic disorder. Less frequent psychiatric diagnoses include major depressive disorder with psychotic features, and catatonia. Common pediatric illnesses presenting to HCPHP include type I diabetes mellitus, asthma, inflammatory bowel disorders,

irritable bowel syndrome, encopresis, eczema, celiac disease, pediatric cancer, seizure disorder, refractory headache, failure to thrive, and malnutrition. Less common pediatric diagnoses have included epidermolysis bullosa, lupus, Duchenne's muscular dystrophy, sickle cell disease, and congenital syndromes, such as VACTERL association and congenital heart disease.

The HCPHP preadmission process involves an extensive review of presenting challenges and history with family members and existing providers to ensure that admission is appropriate in terms of clinical criteria as well as timing in the trajectory of treatment. An experienced full-time licensed independent clinical social worker (LICSW) is the intake coordinator with support from a full-time social work assistant (bachelor of arts degree) to coordinate patient flow and triage. The following are notable points based on experience:

- Regardless of how motivated providers may be for a patient to be admitted to the program, unless a parent/guardian makes a direct call to express interest in the program, the referral is not placed on the wait list.
- Substantial effort is used to reduce barriers to participation in the program, including mobilization of extended family or community supports to assist with transportation and support for parents to be granted leniency from employers to participate in schedule of treatment.
- Admission is voluntary, although it is not uncommon for patients to be reluctant or resistant to attend the program, in which case, program staff mobilize support for families to effectively respond to meet their child's needs.
- Rarely, patients and families are mandated by child protective services via family court to participate in the program in spite of parental resistance.

Staffing

The range of disciplines within HCPHP include pediatricians, child psychiatrists, psychologists, social workers, pediatric nurses, a psychiatric nurse practitioner, a certified nursing assistant, milieu therapists, certified teachers, unit secretaries, registered dietitians, and a diet technician. Patients also commonly require pediatric rehabilitation consultation and intervention during their stay. The program closely consults with pediatric rehabilitation staff including physical therapists, occupational therapists, and speech therapists. As billing for these services falls under outpatient services rather than the bundled rate for the program, these professionals fall under the budgets of the pediatric rehabilitation department of the hospital. Patients also have access to pediatric subspecialty consultation from hospital-based providers (also via separate billing from the program day rate), such as neuropsychology or neurology. Program staffing has proportionally increased with rising census goals over the years ([Table 1](#)).

Structure of the Day

The program is highly structured with the following goals:

- Having a daily schedule 7:45 AM –3:15 PM that mimics a school day ([Table 2](#));
- Providing educational supports/remediation;
- Providing support for nutritional needs of patients; and
- Providing a range of psychotherapeutic supports on individual, family, and group bases.

Of note is that other services that are worked into the fabric of the daily structure include nursing and pediatric assessment or education sessions as needed, individual

Table 1 Hasbro Children's Partial Hospital Program staffing ratios	
Staff	Total FTE for Average Census Goal- 22.4
Pediatric codirector	1.0
Psychiatric codirector	0.9
Clinical manager (RN)	1.0
Milieu manager (BA)	1.0
Intake coordinator (LICSW)	1.0
Chief psychologist	1.0
Staff pediatrician	1.5
Staff psychiatrist	0.9
Psychiatric nurse practitioner	1.0
Social worker (LICSW)	0.4
Social work assistant (BA)	1.0
Psychology	2.8
Milieu therapist (BA)	6.5
Pediatric nurse	4.0
Certified nursing assistant	0.9
Registered dietician	1.5
Diet technician	1.0
Program teachers	1.5
Unit secretaries	1.9
Per diem staff includes teachers, nurses, and milieu therapists	

Abbreviations: BA, bachelor of arts; FTE, full-time equivalent; LICSW, licensed independent clinical social worker; RN, registered nurse.

therapy 3 times per week, family therapy at minimum of twice per week, pediatric rehabilitation consultations and treatment as needed, and nutrition education sessions as needed. For parents, there are also 2 multifamily support groups per week that they

Table 2 Hasbro Children's Partial Hospital Program schedule	
Time	Activity
7:15–7:45	Staff report (nursing, milieu therapist, certified nursing assistant)
7:45–8:15	Nursing check-in with family
8:30–9:00	Breakfast
9:00–9:30	Community meeting
9:30–10:15	Skills building curriculum (group format, milieu therapist led)
10:15–10:30	Morning snack (for select patients)
10:30–12:00	School for patients/treatment team rounds for the team
12:15–12:45	Lunch
1:00–2:00	Group therapy (clinician led)/1 day per week therapeutic art activity
2:00–2:30	Milieu activity
2:30–2:45	Afternoon snack
2:45–3:15	Nursing check-out with family

may attend. One is an open support group focused on parents' emotional processing of their treatment experience, and the other is parent training on skills that their children are taught in the program. The HCPHP Skill-Building Curriculum is a group curriculum focused on practice with coping skills informed by DBT, CBT, and relaxation training evidence-based treatments.

Admissions

Program admissions are all scheduled and occur 8:30 to 11:30 AM in a team format. When the patient and family arrive at 8:30, they are greeted by a member of the intake team (LICSW or SW Assistant) who meets with them to review the program structure and community rules and have parents sign releases for HCPHP staff to communicate with community health care providers and schools. From 9:15 to 9:30, the program teacher meets with the patient and family to obtain basic understanding of educational status of the entering student and to review the HCPHP school structure. Starting at 9:30, the primary team for the patient (nurse, pediatrician, primary therapist, and psychiatrist) meets the family and spends 60 to 90 minutes in a team admission discussion. The patient is generally present for approximately 75% of the discussion with additional collateral time for parent discussion. The primary therapist serves as the anchor for the admission discussion, which covers presenting illness challenges, medical/psychiatric and family history, psychosocial history and risk assessment, and initial treatment plan. Of note is that the primary team often has access to a significant amount of preadmission history information provided by family and previous/current providers.

Although the complexity of the patients presenting for treatment to HCPHP is high, the goal of the team admission process is not to review all areas in detail, but rather to join with the patient and family around their understanding of presenting challenges and how they are working together and with providers to address these challenges. On completion of the team portion of the admission process, the parents often have some additional conversation with the primary therapist and also spend time completing a clinical admission packet that takes approximately 30 minutes. The admission data collected include the following:

Parent data:

- Pediatric Quality of Life (PedsQL) Core and PedsQL Family Impact^{15,16}
- Illness Beliefs Questionnaire (IBQ) ([Appendix 1](#))
- Family Relationship Index (FRI)^{17–20}
- Health Care Utilization (see [Appendix 1](#))
- Screen for Child Anxiety-Related Disorders (SCARED)²¹
- Children's Depression Inventory (CDI)²²

Patient data:

- PedsQL Core
- IBQ
- Family Relationship Index (FRI)
- Screen for Child Anxiety-Related Disorders (SCARED)
- Children's Depression Inventory (CDI)
- Eating Disorder Evaluation (EDE),²³ when applicable

On leaving the team admission discussion, the patient has a medical examination by the pediatrician and then spends time with a milieu therapist with the goal of getting comfortable before joining the milieu group. During school time of their first day, patients complete a clinical admission packet similar to that completed by parents

(depending on the child's age), to obtain their perspectives as well. The patient is also assessed individually by the psychologist and psychiatrist on the admission day.

Length of Stay

The median length of stay at HCPHP over its years of operation has ranged from 18 to 20 days. Of course within this, is a range with a subpopulation of the highest-need patients being outliers in the distribution. For the subset of patients who may have a history of several lengthy inpatient admissions and multiple diagnoses, the length of stay may be as much as 3 to 4 months. These outlier patients often come from out of the region, having failed multiple intensive levels of care. Common within this subset are patients with comorbid somatoform and eating disorders, a history of complex trauma, and/or a history of alleged or confirmed medical abuse.²⁴

Decisions about timing of discharge occur in collaboration with families and outpatient providers. The standard goals before discharge include the following:

- Clarity about diagnoses and optimal treatment plan
- Establishment of patient safety/stability in medical/psychiatric terms and families
- A sense of confidence that patients can continue progress in the outpatient realm

Although the hope of the team is that both patients and families have significantly moved "forward on the FBIC graph" in terms of having established an accurate and mobilizing perspective regarding their illness and having shifted to a productive relationship pattern around managing their illness, this is not always the case. It is possible that patients have shifted a lot and parents little or vice versa or neither. The reasons that lack of movement by patient and/or family does not always indicate a need for a more prolonged stay include the following:

- It is not unusual given the treatment trajectories required to shift cognitive distortions of eating disorders, depression, anxiety, and somatoform disorders that patients may still be "stuck" in maladaptive beliefs on discharge. However, if their families are understanding of this and mobilized, then moving back into the routines of life with outpatient support serves to "take power away from the illness."
- If parents remain very distorted in their own thinking about their child's illness challenges and/or continue to exhibit destructive patterns of relating to their child even with the intensive support of HCPHP, then the intervention in HCPHP may include parent referral to mental health treatment, mobilization of extended family/community support network around the child's care needs, and/or child protective intervention in collaboration with state child protective services. The key to movement in such cases is not dependent on a lengthier stay for the child at HCPHP, but a stay long enough to clarify the barriers to health with referrals appropriate to meet child and family needs on discharge.

Although uncommon, patients are sometimes discharged within a much shorter timeframe than average. Associated scenarios include the following:

- The family may become aware that they cannot logistically manage the time commitment required by the program due to competing family needs, or they demonstrate with behavior an inability to do so. In these cases, we collaborate with families about maximizing outpatient supports as well as problem-solving about what may mitigate barriers to allow their child to come back when able to participate. We find it more productive to therapeutically discharge a patient than to continue an admission while accommodating to their avoidance patterns.

- Sometimes team efforts to “create a crisis” by shifting entrenched maladaptive patient and family patterns leads to an escalation of symptoms (either medical or psychiatric or both) that the family is unable to safely manage at home. In this case, plans are made for inpatient medical or psychiatric admission to our facility with the goal of program return once stable. This is framed not as failure but as indicative of the need for more support during the most challenging phases of transformation.
- Sometimes parent beliefs are so distorted that they cannot be contained within the structure and beliefs of the program. This may be because they believe “more medical intervention is needed” or “not so much psychiatric intervention is needed.” If we are unable to finesse joining within our program containment structure we prepare outpatient teams for the reality of the situation with the goal of allowing for return to intensive treatment when the parent may be more amenable. Of course in extreme cases child protective efforts may need to be mobilized.

Check-In/Check-Out

Program nurses organize check-in and check-out discussions with families. This process serves as the daily bridge between the program and families as we join to support the needs of the patients. Each milieu area has a check-in/check-out room for these conversations. In the morning, nurses meet with patients and families together to review overnight/weekend goals, hear about challenges, and reinforce the treatment process. Themes of these conversations include reminders about externalizing the illness and the importance of family teamwork, as well as support around symptom escalations being expectable while doing the hard work of breaking nonproductive patterns. Although parents often (especially early in the course of treatment) are very symptom focused, nurses always make a point to check on parents' understanding of symptom patterns (eg “What did you make of him having a worse headache last night?”). This provides an important window into where parents are in their illness belief shifts as well as providing an opportunity to reinforce program illness beliefs. Check-ins also provide an opportunity for families to pass on written records (eg, meal plan and diabetic records, program point sheet) and to pass on questions they may have for other members of the team.

Afternoon check-out is generally the nurse and parent and provides an opportunity to review the patient's functioning over the course of the day. Although symptom patterns may be reported (along with details of medical treatment), it is always anchored in the context of how the patient has functioned. This can range from a patient who is highly distressed physically and/or emotionally who struggled to accept staff help to use coping strategies, to a patient who has had great success breaking previously self-destructive and avoidant patterns to function at a higher and more independent level. The language and frame is not one of success or failure based on symptoms, but rather on acceptance of help and active coping with challenges.

Physical Space

The current program space for providing care to 24 patients (annual census goal 22.4) is 9310 square feet ([Table 3](#)).

Other key elements of the space plan include the following:

- Location of program space on the hospital campus for ease of access to emergency department, hospital security, hospital laboratories and imaging, pediatric rehabilitation services, and pediatric subspecialists.

Table 3 Hasbro Children's Partial Hospital Program space breakdown		
Spaces	Number	Function
Lobby	1	Seating for 24 families for check-in and check-out
Front office	1	Secretarial reception window and work area and work space for nutrition team
Milieu area	3	Patient dayrooms
Check-in/out rooms	3	Check-in/out with families, family education meetings and overflow area for patients needing 1:1 interventions
Nursing station	1	Nursing work area and houses medication dispensing machine
Patient bathrooms	5	3 contiguous with milieu; 2 separate (one of which has handicapped access tub and shower)
Examination/treatment rooms	3	Pediatric/nursing examination areas and space for procedures
Family dining room	1	Therapeutic meals, group therapy and family/network meetings
Milieu therapy office	1	Work space and storage for MT team
Teacher's office	1	Shared work space for teachers
Large meeting room	1	Group therapy, network meetings, physical therapy, and admissions
"Quiet room"	1	Physical therapy, milieu overflow for 1:1 intervention and restraint area
Kitchen	2	Storage and food preparation
Team rounds room	1	Rounds, network meetings, and multifamily group
Staff lounge	1	Storage and lunch area
Clinician offices	11	Individual and family therapy

- The entire program area is badge access except for the main entry near reception that remains open during the program day but that has lock-down capability for elopement prevention.
- Multiple milieu overflow areas for when patients need to take space from the group (for treatment tasks or behavioral time-out plans).
- Access to an outdoor courtyard contiguous with the program that allows for outdoor therapeutic activities when weather permits, as well as individualized patient activity/exercise plans.
- The presence of 2 additional bathrooms noncontiguous to milieus given the frequency of toileting plans in the population served (eg, usually 3–6 patients across program who may have some version of nursing-supervised toileting schedule).
- The ability of many rooms to serve multiple functions. Most often, all communal spaces are in constant use throughout the program day (aside from 10:30–12:00 when patients participate in school, and team clinical rounds are happening).

The Milieu

Each of the 3 patient milieus serves as the anchor space for their day where they participate in milieu activities, meals and snacks, and school. Each milieu area is supervised by 2 milieu therapists per group, as well as intermittent presence of nursing staff. Key aspects of the power of the milieu include the following:

- Clear community rules are reviewed with entering patients and reinforced.
- Any newly hired program staff, newly rotating trainees, or volunteers receive an orientation before participating in any activities within the milieu.
- Although there needs to be fluidity throughout the program day for patients to leave for various treatment tasks and therapies, an effort is made for the milieu to feel like an undisrupted space. Team coordination occurs to try to avoid disrupting community meetings once started. Also, for patients on supervised meal plans, an effort is made to avoid removing them during meals and snacks unless the therapist is supervising the meal/snack for therapeutic purposes.
- An important aspect of the program experience embodied by the milieu is the process of patients (many of whom have been hospitalized or have been out of school for extended periods) practicing reintegration into a peer group.
- Having 3 milieus allows for keeping patients grouped by age/developmental ranges that maximize the impact of peer support and allow for appropriately targeted therapeutic activities. Of import is that the older teen milieu (14–18 years old) is usually the largest group (up to 10), whereas the youngest group (6–10 years old) is the smallest (usually 6). That being said, depending on the age range on the program wait list, the “youngest” milieu sometimes includes the tween age bracket. An effort is made to group the youngest patients together (so most commonly the youngest group varies between a 6–9-year-old set and a 9–12-year-old set).

Nutrition

The ability to accommodate 2 meals and 2 snacks per day allows for much-needed calorie support for patients who are the most nutritionally compromised. Although the goal is for patients to succeed with meal plans in the home environment, having the program as an anchor to gradually transition the highest-calorie meal plans to home gradually with use of evenings and weekends as test ground is welcome to families who are acclimating to the details of these intense plans. In addition to the obvious role the nutrition team and structure of HCPHP provide for severely nutritionally compromised patients, there are a range of nutrition needs that the broader population treated by the program presents.

In addition to support for standard-spectrum eating disorders, nutrition issues addressed include the following:

- Support for patients and families managing both type 1 and type 2 diabetes.
- Support for overweight patients with medical comorbidities.
- Support for nutritional repletion of patients with pediatric chronic illness (eg, cystic fibrosis, cancer).
- Management of refractory “picky eaters” with growth delays.
- Management of celiac disease and food allergies.
- Coordination regarding patients who are gastric tube dependent (often patients are referred to move off of tube dependency).

School

The role of school programming at HCPHP is to support patients’ preparation for reintegration into their regular school setting. Although we are not a “school placement,” teachers are certified by state parameters. The teachers work a half-time morning schedule to allow for preparation and home-school collaboration time, as well as receiving report on patient status from clinical staff before school time of 10:30 to 12:00. There is a large range of educational functioning in the patients treated in the

program from highly functional students who have missed school due to health issues to low-functioning students in need of very specialized supports. In addition to the supports provided by program teachers, primary therapists are very involved in communicating with home-school personnel to collaborate about how educational and health needs can best be addressed on reentry. Common educational goals during HCPHP stay include the following:

- Keeping students on track with current work provided by home school.
- Providing remediation support for students who are far behind in school.
- Clarifying at what educational level students are functioning.
- Clarifying issues impeding educational function.
- Advocating and formulating reentry and overall educational accommodations needed for return to home school, which may be in the form of a newly formed or modified 504 plan or individualized education plan.
- Identifying needs for additional evaluation to support educational planning (psychoeducational testing, neuropsychological testing, speech and language/physical therapy/occupational therapy evaluations).

The Point System

Every patient in the program has a “point card” on which to track their participation in all aspects of the day and on which they write down their daily goals during community meeting. Point cards are developmentally modified; for tweens and teens, staff give points on a 0 to 4 graded point system, and for younger patients, a “stamp system” (0, 1, or 2 stamps for effort) is used. There are point cards for home as well, to allow for a common language and set of expectations across settings. Patients “cash in” their points in a multilevel “point store” stocked with a variety of rewards twice daily, in the morning for home earnings and in the afternoon for program earnings. Key elements of this token economy system include the following:

- It provides a concrete representation for the hard work patients are doing on their plans.
- It provides connectivity between program and home for goal setting and tracking. It is a reminder that messages and structuring/coaching from adults matters.
- Family struggles with maintaining/using the point card are reflective of larger family systems issues with communication, messaging, and maintaining limits that need attention.
- A patient’s trajectory of engagement with the system over the course of his or her stay is a barometer for their “owning” aspects of their treatment and health.
- Although patients all begin with standard point cards, there is plenty of leeway to individualize them with specific goals determined by discussion among patients, families, and the treatment team.
- It is important that in collaboration with patients and families expectations/goals are expanded over the course of the stay.

The Process of Collaborative Care

The presence of a colocated interdisciplinary team is necessary but not sufficient for collaborative care. Both within the team at HCPHP and via the team’s collaboration with outpatient providers and schools, there are clear means of collaboration.

Within the HCPHP team structure, a key component of care coordination occurs within the structure of multidisciplinary team rounds. Of note regarding the rounds’ structure and functioning is the following:

- Team rounds occur daily. On Mondays and Fridays, all 24 patients across 3 milieus are discussed (90 minutes). On other days, a single milieu is reviewed (60 minutes). In this way, each milieu group is discussed by the whole team 3 days per week.
- All team members attend rounds on their milieu. Nurses and milieu therapists from each milieu rotate in and out on “all milieu” rounds days, whereas clinical staff (pediatrics, psychology, psychiatry) are present throughout as each member’s patients are spread across milieus. Registered dietitians provide written sign outs for “all milieu days” and attend in entirety on single milieu days. Teachers attend rounds once weekly on single milieu days.
- Each discipline contributes each day in rounds. There is a specific order to stay streamlined: pediatric nurses report on check-in information and their clinical observations, nutrition input, pediatric update, milieu report, psychiatric update, and primary therapist report. Each discipline reports on their perspective to support the coordinated team effort to empower the patient and family moving forward with illness management.
- Many treatment decisions are able to be made in rounds with multidisciplinary input, although it is also common that rounds may signal an area that further discussion across disciplines is needed before a decision.
- When new admissions happen, the team rounds discussion focuses on presenting challenges, brief review of history/family context, and note on “where we are” with family beliefs and relationships. The initial treatment plan also is discussed.

In addition to team rounds, other avenues for team collaboration include the following:

- “Break Outs” are meetings of the pediatrician, psychiatrist, primary therapist, and registered dietitian, as well as representatives from nursing and milieu therapy to have a more detailed discussion of a behavior plan or area of challenge for a given patient. This is also the modality used to process differences of opinion across the treatment team, as well as for complex case management planning. These meetings occur on Tuesday through Thursday after single milieu rounds between 11:30 and 12:00.
- HCPHP Leadership meeting is weekly with focus on coordinating program operations and clinical programming. In attendance are psychiatric and pediatric co-directors, clinical manager (Registered Nurse), intake coordinator (LICSW), milieu supervisor, and chief psychologist.
- A clinician weekly meeting occurs with a purpose of support around challenging cases and coordination of care across disciplines, and includes pediatrics, psychiatry, psychology, psychiatric nurse practitioner, and social work.
- Nursing, milieu therapy, and teachers have subgroup meetings coordinated by collaboration between the clinical manager and milieu supervisor.
- Monthly, all staff meetings rotate among didactic topics, case conferences, and program development collaboration.
- Semiannually all staff retreats occur for a half day and are focused on team building and program development tasks.

With regard to HCPHP team collaboration with outpatient providers and schools, the following are notable:

- Pediatricians coordinate communication with the primary care provider as well as medical subspecialists involved.

- Psychiatrists or psychiatric nurse practitioner coordinates with outpatient psychotropic medication prescriber.
- Primary therapists coordinate with outpatient therapists and schools, as well as parent providers when applicable.
- Communication occurs early in the stay, as well as in preparation for discharge.
- It is not unusual to have a team network meeting (in person and/or by phone), including a range of outpatient providers and school personnel.
- For the most complicated, high-risk patients it is common to have a follow-up network meeting approximately a month after discharge.

Patient Experience

Patients have a wide variety of therapeutic experiences across all program disciplines and the program day. The range of experiences include milieu activities including community meeting, skill-building sessions, therapeutic art experiences, and recreational activities; small amounts of unstructured time in the milieu, which allow for socialization practice under supervision; snack and meal supervision (at times individualized); nursing check-in discussions, assessment, and illness-specific education sessions; nutritional education sessions; one-on-one time with milieu therapists with guided practice for coping strategies; individual therapy with patient-specific focus (CBT, DBT, motivational interviewing, relaxation training, preparation for family therapy); family therapy sessions (may involve one or both parents, siblings, extended family); group therapy with peers; pediatric rehabilitation sessions; and education support from teachers.

Family Experience

It is not uncommon for parents (and other family members) to spend up to several hours per week with a range of program staff. Experiences include check-in and check-out discussion with nursing; nursing education sessions; nutrition education sessions; family therapy sessions, including collateral parent time and conjoint meetings with patients (with extended family network meetings or divorce counseling as indicated); school planning meetings with support from program staff; and multifamily parent groups.

Fiscal Considerations

The HCPHP program has included state and private payers from the outset with bundled rates negotiated with each payer. The proportion of patients covered by state insurance has been approximately 30% to 40% over the life of the program.

Key aspects that allowed for success with the program's initial business plan included the following:

- Establishment of a bundled day rate inclusive of most program billing (not including rehabilitation services, laboratory and other diagnostic tests, subspecialty consultation, and some pediatric billing, dependent on payer).
- Establishment of the need for program services by highlighting excessive costs of high-risk patients with repeated medical admissions (eg, patients with eating disorders requiring supervised refeeding; diabetic patients with frequent trips to the pediatric intensive care unit for diabetic ketoacidosis) who could be more optimally treated in a day hospital setting at lower cost.
- Negotiating for payment across medical and psychiatric side of payers (of note is that for 18 years, one major payer paid for program services out of the medical benefit and other payers covered costs under the psychiatric benefit).

Key aspects that have allowed for ongoing success include the following:

- The ongoing gap in integrated services for this population across the country has led to extremely high demand.
- An expanding mix of payers generated by increasing use of the program by out-of-state and out-of-region patients over time.
- Maintaining the concept of a bundled day rate.
- Effective advocacy in utilization review around these patients “not meeting typical psychiatric day-treatment criteria.”

Case Example 1: Family-Based Integrated Care Treatment Course

Treatment in the FBIC model reinforced the notion of food as medicine, and encouraged family and patient to externalize the eating disorder, in turn making it more comfortable to actively fight the eating disorder in an effort to care for and support their teenager. Needing to make decisions about treatment contrary to “Brittany’s wishes” was stressed. The team partnered with parents to prioritize feeding their child adequately for her needs, just as they would ensure she got the exact needed dose of chemotherapy or insulin if she had cancer or diabetes. Activity restriction was also recommended from a medical, nutritional, and psychological perspective. Being clear about expectations of treatment was essential, including communicating that it would not be expected that Brittany’s perspective or motivation for recovery would change over the course of the admission. The impact of the stress of the eating disorder on family was explored, and identifying the need for parents to remain intimately involved in all nutrition-related plans while looking at other areas of a patients’ life in which she could assert some independence and autonomy. Parents engaged in coached family meals, as well as nutrition education, psychoeducation sessions, and multifamily groups. Despite ongoing disagreement about the specifics of the plan, by discharge Brittany had reached her goal weight range, resulting in significant medical improvements (resolution of bradycardia and improvement in orthostasis). Of note, she identified several positive symptomatic shifts as well, including resolution of dizziness with standing; improved energy level, concentration, and attention; and healthier skin and hair. Parents noted that they were “starting to get (their) daughter back.” However, significant shifts in distorted cognitions and unhealthy thinking do not occur in this phase of treatment. Psychoeducation for families about the importance of ongoing intensive, integrated treatment, as well as the persistence of a high level of supervision and support was a critical piece of the work.

Case Example 2: Family-Based Integrated Care Treatment Course

Treatment in the FBIC model in the context of the intradisciplinary day-treatment setting focused on having Joann attend the program daily, even on days when her pain was most severe. Daily contact with the nursing team, as well as frequent contact with the pediatrician who was in close contact with Joann’s outpatient team, helped increase the family’s trust that Joann could attend the program daily although she had been out of school for several months. The entire treatment team acknowledged that Joann’s pain was real and supported the family in helping Joann increase her functioning while medical care was provided. This included participation in milieu activities and also reengaging in previously enjoyed social and recreational activities outside of the program. Attention to pain was decreased and a focus on pain coping skills was increased. Individual and family therapy focused on setting functional goals, supporting Joann in expressing her experience of anxiety and role in the family to her parents, and validating emotional stress associated with parenting a child with chronic

pain. Joann began treatment with a selective serotonin reuptake inhibitor, and toward the end of treatment completed several days of school transition before leaving HCPHP. Together, these interventions positively influenced the family's beliefs about her pain (eg, that Joann could improve her functioning despite pain symptoms) and increased emotional closeness in their relationships as they better understood Joann's anxiety. Joann and her family were referred to outpatient individual and family therapy to support her and the family's progress.

Case Example 3: Family-Based Integrated Care Treatment Course

Treatment in the FBIC model encouraged family members to share unspoken beliefs and empathized with the events that had led to those beliefs (some very healthy, such as the reality of his high level of functioning as a younger child). The impact of the stress of diabetes on family relationships was a focus, as was identifying what Caleb and his parents wanted their relationship to look like at this point in their lives. Caleb's parents were able to share their uncertainty about how to help, given his resistance to their efforts and Caleb was able to share his anxiety and the changing sense of self that he experienced from being "beaten by diabetes." His parents conveyed that they did not see Caleb's struggles as indicating that diabetes had won and therefore controlled his future. Hearing their optimism that he could be healthier, Caleb became more open to support from his parents, and they negotiated acceptable involvement in his regimen. Six months after discharge from a 4-week stay on the day-treatment unit, Caleb's HbA1c showed significant improvement, and his depressive symptoms had largely resolved.

SUMMARY

The FBIC model provides a productive conceptual framework for treating complex pediatric illness. The HCPHP provides an example of operationalizing this model in the treatment of high-intensity illness challenges for patients who have failed less intensive treatment or who have required extensive inpatient medical and psychiatric care without being able to transition their health gains to the home environment.

Important implications of this model and its use in the HCPHP include the following:

- Any painful challenge/symptom/illness is improved with an empowered set of beliefs about illness and an empathic, mobilized set of relationships, which is most effectively accomplished via a family-based treatment model with integrated messages across providers.
- By intensive work with patients and families, illness beliefs and relationship patterns within families can be modified, and targeting these areas can improve treatment outcomes.
- If we are oriented to "where we are" with family relationships and illness beliefs, we will have the ability to most productively join with the patient and family and support their journey toward empowerment over the illness.
- Consistent messages from health care providers and across health care providers matter, are powerful forces influencing successful treatment, and can be effectively be guided by the FBIC model.
- Excellent provider collaboration is a strong force in supporting patient/family efficacy in illness management and securing quality of life.

Current research on treatment outcomes at the HCPHP is focused on assessment of shifts in patient and family quality of life, family illness beliefs, and health care utilization patterns from program admission to discharge, as well as 3-month, 6-month,

and 1-year follow-up. Results of this research will inform continued optimization of the FBIC model as used in a day-treatment setting. Additional research on the application of this model across levels of care is essential as well, with the goal of matching the intensity of treatment intervention to a range in patient and family needs that is illness independent.

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APPENDIX 1: CLINICAL/RESEARCH MEASURES OF HCPHP

1. Pediatric Quality of Life Inventory (PedsQL) Core 4.0.¹⁵ The PedsQL 4.0 is a 23-item measure of health-related quality of life. Versions exist for parent report as well as child and adolescent (8–18 years) self-report. Responses are provided on a 5-point Likert scale.
2. Pediatric Quality of Life Inventory (PedsQL) Family Impact module 2.0.¹⁶ The PedsQL Family Impact module assesses the impact of pediatric chronic conditions on parents and the family. These 36 items measure parent self-reported physical, emotional, social, and cognitive functioning; communication; and worry. The module also measures parent-reported family daily activities and family relationships. It has been shown to be valid and reliable. Only parents will complete this measure.
3. Illness Beliefs Questionnaire (IBQ). The IBQ was developed by the current research team to assess family beliefs about chronic pediatric illness. It consists of 30 items asked on a 5-point Likert scale. The IBQ has been shown to have convergent validity with other measures and be sensitive to treatment (Nassau JH, Development of an Illness Beliefs Questionnaire for chronic pediatric illness, 2010 [Grant number: R03HD061440]). The IBQ is completed by parents and children 13 or older.
4. Family Relationship Index (FRI).¹⁷ The FRI is a 12-item measure derived from the Family Environment Scale.¹⁸ The FRI is composed of 3 subscales measuring expressiveness (how much family members express feelings directly, 4 items), cohesion (the degree of help, commitment, and support family members provide, 4 items), and conflict (open conflict, anger, and aggression within the family, 4 items). Test-retest reliability and construct validity of the FRI are well established,¹⁸ including for use with families of children with chronic illness.^{19,20} The FRI is completed by parents and children 11 years or older.
5. Screen for Child Anxiety-Related Disorders (SCARED).²¹ The SCARED is a 41-item symptom inventory of anxiety disorders for children and adolescents 8 years and older that has been shown to be valid and reliable. Both parent-report and self-report versions exist and will be used in this study.

6. Health Care Utilization (HCU). The HCU was developed for program use to assess the frequency with which patients admitted to HCPHP use health care services, as many families use numerous services in attempts to address the significant health care needs of their children. These parent-report items were adapted from the National Health Interview Survey Child Access to Health Care and Utilization module, which assesses health care services utilization. These collect parent-report information of emergency department visits, days hospitalized (both medical and psychiatric), and outpatient visits (both medical and psychiatric) to gather information regarding services provided outside of the Lifespan medical system (LifeChart record). The HCU is completed by parents only.
7. Children's Depression Inventory 2 (CDI-2)—parent report version.²² The CDI-2 is a 17-item parent-report symptom inventory of children's depressive symptoms for youth ages 7 to 17. The measure has been shown to have strong psychometric properties. Only parents will complete this measure.
8. Eating Disorder Examination—Questionnaire (EDE-Q).²³ The EDE-Q is a self-report measure assessing the features of eating disorders. The psychometric properties of the EDE-Q have been well studied and shown to correspond to clinical interviews for assessment of eating disorders. Only adolescents 13 or older who received the EDE-Q as part of their admission evaluation will complete the EDE-Q as part of their research participation.