

A Brief Review of the Research on PCIT for Children with Chronic Illness

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Key Words: chronic medical conditions, chronic illness, diabetes, cancer, traumatic brain injury

Abstract: Compared to their peers, children with chronic illness are more likely to exhibit behavioral problems and experience negative parent-child relationships, which can impair medical treatment and adjustment to chronic illness^{6,11,12,20}. Case studies provide preliminary evidence for Parent-Child Interaction Therapy (PCIT) as an effective intervention to reduce externalizing problems, improve parent-child relationship, and reduce caregiver distress for children with conditions such as cancer, epilepsy, traumatic brain injury, and diabetes^{1,2,5,8,14}.

Emerging evidence for PCIT within this population highlights several factors that may impact treatment and maintenance of treatment gains, including frequent hospitalizations, noncompliance with medical regimens, and parental stress^{5,8}. Coaching parents' modeling/praise of appropriate medical behaviors in play or delivering PCIT in an alternate location (e.g., hospital room) may encourage generalization to medical settings and reduce attendance barriers associated with continued medical care². Introducing motivational interviewing, intensive treatment schedules (e.g., twice per week), or psychoeducation relating positive parenting behaviors to effective illness management may decrease caregiver stress and improve maintenance of treatment gains^{8,15}. Future research should examine multiple-participant studies across illness groups to develop generalizable recommendations for PCIT for children with chronic illness^{15,17}.

Background

Chronic illness during childhood threatens the health and well-being of children across the globe and creates significant burden for their caregivers¹⁵. In contrast to acute (or short-term) illnesses, chronic illnesses are long-term conditions that cause continued impairment and require medical care beyond routine services¹⁵. Prevalence rates of childhood chronic illnesses vary widely across conditions, age ranges, and demographic groups¹³. Some conditions are relatively common, such as food allergies or obesity. Others, such as epilepsy, are less common^{13,23}.

The impact of chronic illnesses during childhood varies according to illness type and severity. Some illnesses may be relatively easy for families to manage (e.g., mild intermittent asthma), while others create a significant burden for children and families (e.g., childhood cancer¹³). In addition, it is important to recognize that while chronic illnesses are, by definition, long-term conditions, they are not necessarily static or permanent. Many illnesses change over the course of a child's lifespan as a function of treatment, environmental conditions, or normal development²³. Accordingly, the associated features of chronic illnesses may wax or wane over time. Thus, clinicians should foster awareness and understanding of the possible effects of childhood chronic illnesses, but must recognize that significant variability exists across persons, illnesses, and time.

Childhood chronic illness can significantly impact children across a number of domains, including emotional and behavioral adjustment, social functioning, and activities of daily living (for brief review, see Morawska et al., 2015). In particular, children with chronic illnesses are more likely to display problem behaviors, such as noncompliance, defiance, or aggression, compared to their peers without chronic illnesses^{10,11,21}. Several factors likely contribute to this, including difficulties adjusting to medical illness, potential for secondary gains, and medication-related side effects (e.g., steroids)¹⁵. Noncompliant behaviors may be especially concerning for this population, as children may need to comply with burdensome or undesirable medical regimens (e.g., injections, pill swallowing) in order to maintain their health.

Caregivers of children with pediatric chronic illness face unique challenges, as well. In many cases, there is a significant financial cost associated with caring for a child with a chronic illness. There may be costs related to doctor's appointments, emergency room and inpatient hospital stays, medication and procedures, as well as lost income from time taken off from work¹³. Beyond the financial burden, caregivers of children with chronic illness often experience a significant amount of stress, which may impact parenting behaviors and the child's adjustment to the illness. Compared to parents of children without chronic illness, caregivers of children with chronic illness tend to have less positive parent-child relationships, characterized by less responsiveness, higher monitoring, and overprotectiveness, as well as higher levels of authoritarian and neglectful parenting²⁰. Caregivers may also have different expectations for behavior or make different attributions as to the causes of the behavior, which can impact the caregivers' strategies for managing behavior^{15,16}. While significant heterogeneity exists across and within illness groups, these findings indicate that parent-based approaches to treating behavior concerns may be especially beneficial, particularly given that caregiver behaviors are highly predictive of children's adjustment to chronic illness and subsequent illness trajectory^{15,19}.

Given the tremendous impact of childhood chronic illness on children and families, researchers have recommended that providers involve both children and their caregivers in treatment, as this may improve outcomes for both groups^{6,15}. Thus, PCIT, an evidence-based treatment for treating behavior problems in young children, may be a particularly useful treatment for behavior problems for children ages 2 to 7 with chronic illnesses. Previous case studies have demonstrated preliminary support for the use of PCIT with medically ill children across a variety of illness groups, including diabetes, traumatic brain injury, and cancer^{2,5,8,14}. By improving both the child's behavior and the parent-child relationship, PCIT has the potential to improve adjustment to medical illness, reduce problematic behaviors, and facilitate positive outcomes for medical treatment.

Problem Statement

Childhood chronic illness is associated with increased risk of child behavior problems, poor parent-child relationship, and caregiver stress. Importantly, noncompliant and defiant behavior may be of particular concern for these children, as medical noncompliance may interfere with successful treatment and maintenance of health. PCIT, which is an evidence-based treatment for behavior problems in young children, may be an especially suitable treatment for children ages 2 through 7 with chronic illness. Drawing on the existing literature, this Research in Brief seeks to familiarize readers with best-practice guidelines for treating children with chronic illness and offer suggestions for tailoring and adapting typical PCIT service delivery in order to best serve the needs of children with chronic illness and their families.

Solutions

Case studies provide preliminary evidence for PCIT as an effective intervention to reduce externalizing problems, improve parent-child relationship, and reduce caregiver distress in

families with children with conditions such as cancer, epilepsy, traumatic brain injury, and diabetes^{1,2,5,8,14}. Given this preliminary evidence, we propose that standard PCIT protocol may be well-suited to address behavior problems in young children with chronic illness. Yet, given the needs of this population, clinicians should carefully consider the logistics of service delivery in the context of the child's illness, including the timing and setting for treatment, along with the burden of treatment for families.

First, therapists should consider the appropriate timing to incorporate PCIT as an adjunct to existing medical care¹⁵. Psychosocial treatment must not replace necessary and standard medical care; thus, particular consideration should be given to the family's ability to participate in PCIT without compromising medical care. At times, it may be appropriate to delay PCIT delivery (e.g., if child is in the middle of a rigorous course of chemotherapy). At other times, it may be appropriate to begin treatment as soon as possible (provided the child is medically stable), as providing prompt behavioral intervention may help to reduce long-term stressors and behavior problems, as well as improve parents' behavioral management strategies before they become embedded and resistant to change⁸.

In addition to determining the appropriate timing, clinicians should also consider the proper setting for psychosocial treatment. When possible, psychosocial treatment should be integrated into medical care¹⁵. In some cases, hospitals and medical centers may have PCIT-certified clinicians available who can deliver PCIT services in close collaboration with the child's medical team. Clinics that observe a high incidence of behavioral problems among their young patients may consider having their in-house mental health professionals trained in PCIT or hiring a staff PCIT therapist in order to most efficiently manage care for their families. During the initial intake sessions, PCIT clinicians should coordinate with children's medical providers to assess whether these options are available to families.

Finally, clinicians must also consider the burden of treatment for families. Families with chronically ill children contend with a multitude of stressors, including coordinating medical treatment schedules, time pressures, and financial costs¹⁵. Caregiver stress is often compounded by the presence of children's disruptive and noncompliant behavior. It is recommended to choose a treatment that reduces additional intervention-related burden (e.g., low time commitment and cost) for these families¹⁵. Clinicians should work with families to determine whether the traditional PCIT model (i.e., time-unlimited weekly visits) or alternative models (e.g., one-week intensive treatment) are most feasible or appropriate.

Following appropriate consideration of these areas, PCIT therapists should then determine whether additional tailoring (i.e., changing the focus or delivery of key elements in treatment protocol to meet an individual's needs⁷) or adaptation (i.e., changing the structure or content of treatment protocol⁷) of PCIT protocol is needed. While psychosocial treatments for children with chronic illness should be generalizable across illness groups, it is recommended that clinicians maintain flexibility in service delivery in order to meet the unique needs of each child and family¹⁵. Previous PCIT case studies illustrate creativity and flexibility in treatment delivery, effectively addressing challenges that arise over the course of PCIT due to the child's chronic illness. Drawing on these case studies and our own clinical experience, we suggest several ways in which PCIT could be adjusted to meet the needs of this population:

Targeting medically-related behaviors in treatment: Clinicians should seek to clarify whether adherence to and compliance with medical regimens are goals for treatment¹⁵. PCIT therapists can promote adherence to medical regimens by encouraging parents to pair daily routines with Special Time practice. For instance, a common after-dinner routine for a child with diabetes may

involve checking the child's blood sugar, followed by Special Time. In addition to pairing medical routines with Special Time routines, therapists can coach parents to praise good illness management skills during play^{2,15}. In a previous case study, using a "doctor kit" in Special Time encouraged generalization of appropriate behavior to medical settings². With coaching, parents can model and describe appropriate behavior during pretend medical procedures (e.g. "I need to sit still so the doctor can take my blood") and praise children for using appropriate medical behaviors (e.g., "Thank you for sitting still during your shot!"²). Playing doctor during CDI may have the added benefit of giving a child a sense of control and mastery in medical situations.

In many cases, children may present with comorbid anxiety regarding medical procedures, which can also be addressed in treatment¹⁵. Parents can model brave or relaxed behavior during pretend procedures, which may help to reduce a child's anxiety during real-life situations. For families in which the child's condition is a prevalent topic of conversation or illness management activities constitute the majority of a caregiver-child relationship, keeping illness-related topics out of Special Time may help to build the more positive parent-child relationship and reduce relational anxiety.

It may be appropriate to incorporate a brief psychoeducation component that is tailored to the child's specific illness¹⁵. This may include information regarding best practice in illness management and treatment, as well as information regarding the link between childhood illness and behavioral and emotional adjustment^{3,9,15,22}. To this end, clinicians should communicate with the child's medical team to ensure they have appropriate knowledge of the child's condition and treatment and are the appropriate clinician to provide this psychoeducation.

Accommodating hospitalizations: During a child's hospitalization, continuing with Special Time is encouraged, as this can provide families with a much-needed respite from the stress of the hospitalizations. Clinicians should assist families in problem-solving barriers to implementing Special Time, particularly during long-term hospital stays.

Furthermore, a previous case study illustrated how it is still possible to conduct either a CDI or PDI session during a hospitalization with the therapist present. Bagner and colleagues (2004) suggest placing toys on the bedside food tray while the child sits in his/her bed. They also suggest moving a hospital chair into the corner of the room as the Time Out chair². For the Time Out room, most patient rooms have an in-room bathroom that could act as the Time Out room or, depending on the child's mobility, a Swoop-and-Go procedure may be more appropriate. In this case study, the PDI session conducted within the hospital room was a particularly positive experience, as it encouraged generalization of CDI and PDI skills to the medical setting, an environment in which the child had frequent behavioral outbursts².

Despite this initial evidence, few studies have examined the implementation of PCIT sessions within an inpatient hospital setting, as well as the extent to which families benefit from such sessions. The feasibility and appropriateness of conducting a PCIT session during a hospitalization should be determined on a case-by-case basis. In order to tailor PCIT sessions to a hospital setting, medical providers must be informed about the rationale and implementation of specific techniques (i.e., time-out) that will be implemented. We also recommend that clinicians carefully consider session logistics, as the single-room hospital setting varies considerably from the traditional PCIT session set-up. For example, clinicians should approach the session with a plan of how to carry out DPICS coding observations, coach the parent's use of CDI/PDI skills, and provide the parent with feedback.

Adjusting for potential physical limitations of the child: Children may present with physical limitations, which should be thoroughly assessed prior to beginning treatment in order to anticipate fitting accommodations. For instance, a child who is experiencing a flare of inflammatory bowel disease (IBD) will likely need to use the bathroom frequently. Thus, clinicians should consider the appropriateness of conducting PDI sessions with a child who is undergoing an IBD flare due to concerns for compromising Time Out sequence follow-through. Similarly, we recommend that PCIT clinicians assess whether children with chronic illness are immunosuppressed due to their medical treatment. Clinicians must be frank with families and the children's medical team regarding their cleaning routines for PCIT toys and rooms in order to ensure proper awareness of children's possible exposure to germs.

Addressing maintenance of treatment gains: While case studies of PCIT for this population have illustrated immediate improvements in behavior, some have raised concerns for the maintenance of treatment gains over time⁸. Integrating motivational interviewing into PCIT may increase retention, motivation for change, homework adherence, and parenting self-efficacy^{4,18}, all of which may improve long-term treatment gains. Another adaptation that may improve long-term outcomes for higher risk families include increasing sessions to 2 to 3 times a week⁸; however, the feasibility of this option would depend on the family's availability, caregiver stress levels, and overall family functioning.

Conclusions and Recommendations

The existing literature offers preliminary evidence for the efficacy of PCIT for children with chronic illnesses. Based on case studies and best practice guidelines, we encourage PCIT practitioners to maintain the core features of PCIT, including observation and coding of the parent-child dyad and coaching the parent towards more positive parenting behaviors⁷. At the same time, we encourage clinicians to consider ways in which the typical delivery of PCIT could be adjusted to best serve this population, including integrating PCIT with medical care, minimizing treatment burden for families, and employing flexible service delivery models. Clinicians can draw upon several strategies in order to tailor or adapt service delivery to meet families' needs, such as targeting coaching to address medically-related behavior problems and anxiety, including a psychoeducation component to facilitate parents' understanding of the link between physical health and emotional/behavioral problems, accommodating frequent hospitalizations, and considering the impact of children's physical limitations on treatment delivery. Clinicians should also consider alternative ways to encourage maintenance of treatment gains, as this has been identified as a concern for this population.

We caution providers that it may not be necessary, or even appropriate, to incorporate each of the aforementioned adaptations into treatment for a specific child with chronic illness. If "standard" PCIT without tailoring or adaptation is feasible for a family, this approach should be attempted first. We therefore encourage providers to consult with the child's family and medical team, as well as exercise good clinical judgment in determining the necessary tailoring or adaptations for each child's treatment, considering the child's unique illness features, family background, and medical regimen.

Although the current literature provides a strong case for the use of parent-based treatments for children with chronic illness, additional work is needed to solidify the efficacy of PCIT for this population. The existing literature examining PCIT for this population is limited by its reliance upon case study methodology. Future research should examine multi-participant studies across illness groups in order to ascertain the efficacy of PCIT for children with chronic illness. In addition, researchers should seek to establish the incremental validity of the recommended tailoring and adaptation for PCIT with this population⁷.

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