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Children with Hepatitis C: The Impact of Disease and Treatment on Patients, Caregivers and Families

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Purpose Previous research on children with HCV has examined patient psychosocial outcomes but little is known about the impact of HCV and its prolonged treatment, which includes weekly injections and oral medications for 6–12 months, on caregivers and families. The present study aimed to address this gap.
Design and Methods: Using a case series design (N = 10), baseline distress levels of individuals and families as well as changes during HCV treatment were examined. A brief patient, caregiver, and family assessment packet was given before and immediately after treatment, but before the final outcome of treatment was known. During the study period, 10 families at our site began treatment for HCV. Each family was given a battery assessing patient quality of life, (the Pediatric Quality of Life Inventory; PedsQL), caregiver distress related to their child's illness (Impact of Events Scale; IES), and overall family functioning (Family Assessment Device; FAD).
Results: At baseline, patients displayed poorer quality of life than population norms, caregiver distress was elevated and family functioning was also in the "stressed" range. After treatment, all parameters worsened.
Conclusions: In conclusion, in this case series of patients in treatment for HCV, significant psychosocial distress was noted for individuals and families and this was exacerbated over the course of treatment.
Practice Implications: Caregivers may benefit from additional support given the implications of HCV and grueling nature of its treatment. Broadly, the impact of continuous intensive treatments on families perhaps should be monitored.

Background

Pediatric Hepatitis C virus (HCV) although rare, confers a tremendous challenge for affected families as they must decide whether to begin treatment or wait and monitor disease progression. Pegylated Interferon (subcutaneous weekly injections by a caregiver) and Ribavirin orally is the current treatment for HCV infected-pediatric patients (Mack et al., 2012). Treatment is delivered for either 24 weeks (HCV genotypes 2 or 3) or 48 weeks (HCV genotypes 1 or 4). Yet, this treatment is effective only 45–85% of the time, depending on the HCV genotype, and patients are often asymptomatic when it is being considered (Mack et al., 2012). Therefore caregivers face the difficult decision of whether to initiate an invasive, lengthy treatment that may not work at a time when their child is showing no signs of sickness while waiting it out may be appropriate given slow disease progression. Conversely, the hope to stave off sickness is salient for parents and it may be that

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childhood treatment is ideal given familial support and more predictable lifestyles. Monitoring patients for the development of depression has been incorporated into treatment guidelines (Mack et al., 2012) but little is known about the psychosocial impact of HCV and this prolonged treatment on caregivers and families. The present study sought to uncover more data on the psychosocial effects of treatment in order to better inform families and perhaps help with their decision making.

The Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress (PMTS) offers a theoretical framework for understanding how children and families may be impacted by illness or injury (Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2015). Because PMTS is prevalent across pediatric populations, one of the cornerstones of this model is that there are common precipitants shared by different types of illnesses. For example, as is quite relevant to HCV, the intensity and duration of treatment as well as the threat of long-term consequences and uncertainly may increase risk for PMTS. Indeed, in pediatric hepatology, it is known that rates of PMTS may be high (Supelana et al., 2015). The PMTS model extends its scope beyond patients but also to family members. Consistent with this lens, a large study of HCV positive children enrolled in a placebo-controlled treatment trial found that based on parent-report, rates of depression were low and psychosocial functioning appeared stable in most domains for patients (Rodrigue et al., 2009). However, it was observed that in contrast, parents appeared distressed when reporting on their children and formal assessment of caregiver adjustment was recommended (Rodrigue et al., 2009).

In addition to examining caregiver distress in the wake of their children's diagnosis and treatment regimens, it is important to consider family coping as well. HCV treatment may be especially taxing on families due to mode of transmission (i.e., vertically passed from biological mother to child) and accompanying feelings of guilt, concerns about stigma, the nature of treatment (e.g., weekly injections delivered by family members), possible side effects, and fears about unsuccessful remission. Although there is no scholarly evidence regarding these particular considerations in pediatric HCV, parallels can be drawn from other pediatric populations. A recent study found that family functioning may mediate the relationship between neurocognitive late effects and quality of life among pediatric survivors of brain cancer (Hocking, Hobbie, Deatrick, Hardie, & Barakat, 2015) suggesting that family response to illness can ameliorate negative effects. Previous work has displayed the critical role of caregiver and family functioning among pediatric patients who face difficult treatment protocols as well. For example, caregiver symptoms or family processes have been shown to influence adherence among different types of pediatric patients (Cohen, Lumley, Naar-King, Patridge, & Cakan, 2004; Horsch & McManus, 2014; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004). A study of children with Type 1 diabetes, who face a similarly demanding treatment regimen as HCV, found that family variables, such as higher levels of cohesion, predicted better adherence (Cohen et al., 2004). Therefore, given the toll that HCV treatment can take on families, like diabetes, it is important to examine similar constructs in this population.

To date, little is known about how pediatric HCV impacts patients and families beyond recognition of depression as a possible treatment side effect. The purpose of the present study was two-fold. First, within the context of the Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress, we aimed to learn if caregivers and families experience distress before and after their child's treatment for HCV. Given the characteristics of pediatric HCV and its treatment, we hypothesized that caregivers and families would experience elevated levels of distress, as measured by the Impact of Events Scale and the Family Assessment Device respectively, in the face of this illness and during the course of treatment. As a secondary aim, because patient quality of life (QoL) has yet to be explored during HCV treatment, we incorporated this assessment, using the Pediatric Quality of Life Inventory, to offer families guidance on how their children's QoL might be impacted by this treatment or analogous ones. Broadly, such findings may apply to other pediatric populations facing challenging treatment regimens, an area that has received little recent attention in the literature.

Design and Methods

Participants and Procedure

Initially, treatment for HCV was only offered via research trials at our site but once it became integrated into clinical care, we developed this psychosocial research protocol. Given the low prevalence of the disease, we anticipated that a small pool of families would be eligible for and choose to begin HCV treatment, and therefore we decided to employ a case series design with a goal of obtaining 10 patients. As described by Drotar (2009), case series methodology offers a unique opportunity to address the needs and challenges of an underrepresented topic area/clinical population.

Children, ages 3–17, diagnosed with HCV, and their caregivers initially attended at least one appointment with an attending physician and a nurse coordinator to review treatment options. The age range of prospective study participants was in accordance with treatment recommendations and clinic parameters; Pegylated Interferon and Ribavirin is indicated for children age 3 and above and patients age 18 or above were not treated in our pediatric service. If families elected to begin treatment, one or more teaching visits with a nurse coordinator was held before commencement to instruct caregivers on how to administer the weekly injections and to comprehensively explain possible side effects. At this point the present study was introduced.

Informed consent and assent procedures for the present study were administered during a teaching visit. As a part of this process, confidentiality and privacy were discussed in depth with caregivers given the implications of vertical HCV transmission. A brief patient, caregiver, and family assessment packet consisting of validated measures was given before and immediately after treatment, but before the final outcome of treatment was known. In the event that more than one caregiver