On the surface, the Scott family seems like a typical American family: three kids, a dog, a nice house in a suburban neighborhood. And, it is typically hectic in their home. In the mornings, making sure everyone is dressed, has his or her lunch packed, and gets out the door on time is reminiscent of any family with kids in school. In the afternoon, juggling Andrew's soccer practice, Millie's piano lessons and Claire's ballet sometimes leaves the Scotts feeling overwhelmed. In addition, Mr. Scott runs his own business and Mrs. Scott works part time at the children's school. All pretty typical.

Add to all of this activity planned trips to the hospital every three weeks, constant hand-washing to avoid bacterial infections and frequent doctor visits for anything that resembles a potential illness. Still sound pretty typical?

Yes, if, like the Scotts, you have a child with an immune deficiency disorder. And, to complicate the scenario, a new research study on the psychosocial functioning of children with immune deficiency diseases indicates that these children may have elevated behavioral and emotional difficulties.

This research study was initiated when Dr. Carrie Piazza-Waggoner was working with children with asthma at Ruby Memorial Hospital in West Virginia. A physician on staff noticed that children with immune deficiency disorders often displayed an array of psychological difficulties and suggested Piazza-Waggoner investigate their increased risk of behavioral and emotional problems.

The recognition that children with chronic illness are at an increased risk for both behavioral and emotional difficulties is not new. But, children with immune deficiencies and their families had yet to be the focus of research. Piazza-Waggoner's research attempted to determine if children with immune deficiency diseases and their caregivers have altered psychological function and if the severity of the disorder is related to psychological functioning.

Piazza-Waggoner and her colleagues collected data from 40 children and their caregivers. Twenty of the children had a diagnosis of pediatric immune deficiency disorder, and 20 had asthma, serving as a comparison group. The children and their caregivers completed a variety of psychological questionnaire forms.

The findings from Piazza-Waggoner's study seem to confirm many perceptions parents of children with pediatric immune deficiency disorders express: The caregivers of immune deficient children reported more behavioral problems in their children than did caregivers of children with asthma. The caregivers also reported their own elevated psychological distress.

Furthermore, the severity of the immune deficiency disorder was significantly associated with several behavioral adjustment issues. More specifically, results from this study show that children who received intravenous immune globulin or immunomodulatory treatments were reported to have more problems than children not receiving them, i.e., children with very severe immune deficiencies were more likely to have a psychiatric diagnosis and receive special education services.

Piazza-Waggoner had hypothesized that illness severity may impact the degree of psychological functioning. She clarified the study's results, "It's not necessarily the [disorder], but perhaps it's all the complications of the medical issues of having multiple diagnoses—there's a lot to manage.

"There is absolutely a need for more research," she continued. Additional research on the psychological functioning of pediatric patients with immune deficiencies could help identify interventions that promote the children's overall adjustment.

In the meantime, what can families like the Scotts, their teachers and doctors glean from the study's findings? The research should heighten awareness that psychological distress may be elevated in individuals with immune deficiency disorders. If doctors are not aware of this, caregivers can raise the issue and request referrals. If families notice that their children display increased sadness, fear, worry or withdrawal; high levels of social distress; interpersonal difficulties; low self-esteem or other distress, they should consider seeking such assistance.

Another important point to remember: Parents and other caregivers should recognize their own distress as well. The heavy burden of disease can take its toll on the entire family, even in families as typical as the Scotts.

References