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EDITORIAL

Routine Assessment of Quality of Life: The Next Step in Helping Children With Chronic Medical Conditions Thrive

Survival of children with chronic medical conditions has dramatically improved over the two plus decades of my career because of advances in knowledge and technology. Children who had no options in previous decades now survive, and children who once were expected to die before adolescence survive into adulthood. Because of this, we have shifted from “how to help them survive” to “how to help them thrive.” In this shift, we have implemented aggressive preventative care and screened for and aggressively managed medical morbidity. We have worked with children and families to help them learn to manage their chronic medical condition at home and at school. Yet, with all of this, we see ongoing issues with family and self-management, with school, with peers, with developmentally appropriate activities, and as a result, with quality of life (QOL) across chronic illnesses as diverse as diabetes, congenital heart disease, and cancer. This leads to the question, what else can we do?

In children with renal disease requiring dialysis, the Centers for Medicare and Medicaid Services (2008) now mandates systematic evaluation of psychosocial status testing using standardized tools. Further, pediatric cardiac researchers have called for the routine screening of QOL in clinical encounters with children with heart disease (Uzark et al., 2008). In my team’s research with children after heart transplantation (Green, McSweeney, Ainley, & Bryant, 2007; Green, Meaux, & Huett, 2011), asking two questions yielded in-depth information on QOL and, more importantly, identified areas of potential intervention including procedural pain, difficulties with the medication schedule, and being bullied. For young children, the two questions were “What makes good days for you?” and “What makes bad days for you?” For parents and adolescents, the two

questions were “What things are easy for you?” and “What things are hard for you?” Although we are using these questions in research, we believe that asking the questions routinely in clinical encounters will help clinical teams identify where children and families need assistance in order to maximize their QOL.

As you venture forth, I ask you to reflect on your role in helping children with chronic medical conditions to thrive. Research is needed to evaluate the implementation of routine QOL screening in clinical encounters. Administrative support is needed to incorporate QOL screening into clinical care. Education is needed to help clinicians understand the importance of implementing routine evaluation of QOL. Most importantly, in the clinical setting, plans are needed to integrate systematic evaluation of QOL in children with chronic medical conditions into clinical encounters and to systematically use the results of that evaluation. These are the next steps in our shift from “how to help them survive” to “how to help them thrive.”

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