Cystic Fibrosis and the Depressed Parent
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In a study released this month in Pediatrics, Drs. David Barker and Alexandra Quittner (10.1542/peds.2015-2296) present a powerful and convincing prospective trial that examines the relationship between depression among parents of children with cystic fibrosis, adherence to (child) pancreatic enzyme replacement, and 3-month weight outcomes.1

The authors demonstrate that parental depression had an indirect, but significant, impact on child weight gain, via enzyme adherence. Pancreatic enzyme replacement is essential for absorption of needed calories for most children with cystic fibrosis, yet adherence as documented in well done studies can be less than optimal, as the authors note and reference. Given the critical impact of good nutrition and weight gain on lung function and hence survival among those with cystic fibrosis, this window of insight into a potentially treatable cause of poor adherence is very welcome. Publication of this study comes on the heels of an important consensus statement from the Cystic Fibrosis Foundation and the European Cystic Fibrosis Society addressing the broader topic of depression and anxiety in children and adults with cystic fibrosis, and their caregivers.2

Now that this issue is being discussed widely, it seems obvious and intuitive that depression may play a critical role among parents of children with cystic fibrosis, and child outcomes. One almost wonders how this could possibly be news to the attending and trainee physicians who care for patients with cystic fibrosis, to the parents who shoulder endless treatment regimens from childhood well into adulthood, and to those individuals who have cystic fibrosis themselves. Have we physicians been functioning with virtual falcon hoods over our heads all these years? (A falcon hood is apparently the most important piece of equipment for training birds of prey - it covers the bird's head so it cannot see and hence remains calm). It will likely be a great relief to all to acknowledge the importance of a parent or child's inner feelings, including depression, as they relate to both having cystic fibrosis, as well as to caring for those afflicted by this devastating chronic illness.

Recent work shows that rates of depression among parents of children with cystic fibrosis range from 20-37%, and are thus easily 2-3 times higher than rates of depression in broad community samples. 3,4 Rates of depression among children and teens who have cystic fibrosis range from 8-29%, and among adults with cystic fibrosis range from 13-33%.5,6 Additionally, elevated rates of depression have been found to be co-morbid with elevated rates of anxiety among both parents of children with cystic fibrosis and children with cystic fibrosis themselves.4 These high rates of depression, and anxiety, are alarming, and serve to frame and underline the critical importance of the work by Barker and Quittner, and others.1,2

The tipping point here is the recognition that parental depression impacts, albeit indirectly, aspects of medical care that are linked directly to survival. As part of a new body of evidence connecting parental and patient depression in cystic fibrosis with measures of adherence, disease progression, quality of life and survival, new avenues for treatment may become possible.5,7 New Guidelines (in the Consensus Statement referenced above) lay out a pathway to promote high quality mental health care for persons with cystic fibrosis and their caregivers.

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The pathway includes 1) primary prevention including development of coping skills, 2) active annual screening for symptoms of depression and anxiety, 3) clinical assessment by a trained healthcare provider, and 4) active intervention for individuals with symptoms of anxiety and/or depression. The opportunity for transformative research that directly and positively impacts patients and families is immense, and should not be limited to cystic fibrosis only: this approach is a potential model for treatment for many other chronic diseases of childhood.

1. Barker and Quittner in Pediatr this month reference.

Further Reading
- Comparison of the US and Australian Cystic Fibrosis Registries: The Impact of Newborn Screening
- Inconclusive Diagnosis of Cystic Fibrosis After Newborn Screening
- Pediatrics on Facebook
- AAP Journals on Twitter