

## Letter to the editor: authors' response

Dear editors

We thank Drs Webb and Bryon for their comments<sup>1</sup> on our TIDES paper.<sup>2</sup> We are responding to their critiques of our study. Beyond clarifying the 'devilish details' they highlighted, we want to emphasise the clinical significance of our results<sup>2</sup>—a substantial proportion of our patients reported elevated symptoms of depression (17%) and anxiety (29%) across nine countries. Higher rates were reported by parents: depression (37.3% of mothers, 31.3% of fathers) and anxiety (47.8% of mothers, 35.2% of fathers). Although the 'absolute' number of individuals who have depression or anxiety is difficult to ascertain with *any* screening tool, it is clear that psychological distress is common and has been associated with worse: self-management, pulmonary

function, quality of life, and increased hospitalisations and healthcare costs.<sup>3,4</sup> We can no longer minimise the extent of the problem and its impact on the health of individuals with CF.

Our response to the 'details': First, 6088 participants completed the depression and anxiety screening, with a small minority ( $n=63$ , 1%) failing to provide a birth date or age and were excluded from analyses stratified by age (sample=6025). Second, data from the two screening measures were pooled because each was the 'gold standard' at the time in Europe and USA; participating countries were given the choice. The historical argument in favour of the HADS-D has been its removal of somatic items for those with a chronic illness, but our data on the CES-D showed that *none* of the three most commonly endorsed symptoms related to physical disease. Recent articles also faulted the HADS for its insensitivity, unstable factor structure and lack of correspondence with diagnostic criteria.<sup>5</sup> Thus, rates of depression on the HADS are likely an *underestimate*, and consistent with our results, which found more positive screens on the CES-D versus HADS-D. Third, a conservative strategy was used; a 'case' was identified as an elevation on one or the other measure, essentially 'imputing' a zero for measures not administered. We reported estimates for both measures, but used the combined definition in subsequent analyses and discussion.

TIDES was a 'grassroots' effort growing out of concerns voiced by CF teams in Europe and the USA that patients and parents were experiencing psychological symptoms not systematically identified or treated. Oxley and Webb published a commentary reporting that 63% of referrals to the clinical psychologist at the Manchester Adult CF Centre were for depression and anxiety and called for annual screening of psychopathology.<sup>6</sup>

The editorial challenged us to state how this study is groundbreaking. Let us count the ways. First, these results are robust because they were drawn from the largest sample ever screened in a rare disease across Europe and the USA, increasing their ecological validity and generalisability. Second, no study of this size and cultural diversity has measured depressive and anxious symptoms in parents caring for children with a serious, chronic

disease. We uncovered rates that were both concerning and a call to action. Third, we analysed paired data in over 1100 parent-teen dyads and found an increased probability of psychological distress in adolescents whose parents screened positive, highlighting the link between parent-child mental health. Finally, our results challenge the long-held belief that somatic symptoms (eg, fatigue) drive the commonly reported elevations in depression for individuals with chronic illness and inflate depression scores. Comparisons of the HADS-D and CES-D showed these symptoms were not the most frequently reported. Our inclusion of two screening instruments illustrated the need for standardisation of mental health assessment. If we can agree on a screening measure, this variable can be added to our respective registries and estimate a more accurate point prevalence, evaluate what *precedes* an elevated screen (eg, drop in lung function) and identify health outcomes that *follow* an elevation (eg, worse adherence). A recent survey of CF providers across Europe and the USA indicated that at least 48 different screening measures of psychological distress are in use.<sup>7</sup> Thus, standardisation of this assessment process is needed.

TIDES led to an International Guidelines Committee on Mental Health in CF sponsored by the CF Foundation and ECFS. This multinational, multidisciplinary group of providers and researchers examined recent data on screening measures and set a high bar: the measures had to be free, evidence excellent sensitivity/specification, available in all major languages, and converge with diagnostic criteria. We were not wedded to a particular screening tool. Most important was gathering the evidence—which has led to an innovative, international effort to systematically measure and treat psychological distress. And yes, it is both groundbreaking and an enormous leap forward!

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## REFERENCES

- 1 Webb AK, Bryon M. The International Depression Epidemiological Study (TIDES): unfinished business? *Thorax* 2014;69:1067–8.
- 2 Quittner AL, Goldbeck L, Abbott J, et al. Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. *Thorax* 2014;69:1090–7.
- 3 Smith BA, Modi AC, Quittner AL, et al. Depressive symptoms in children with cystic fibrosis and parents and its effects on adherence to airway clearance. *Pediatr Pulmonol* 2010;45:756–63.
- 4 Snell C, Fernandes S, Bujoreanu IS, et al. Depression, illness severity, and healthcare utilization in cystic fibrosis. *Pediatr Pulmonol* 2014;49:1177–81.
- 5 Cameron IM, Cardy A, Crawford JR, et al. Measuring depression severity in general practice: discriminatory performance of the PHQ-9, HADS-D, and BDI-II. *Br J Gen Pract* 2011;61:e419–26.
- 6 Oxley H, Webb AK. How a clinical psychologist manages the problems of adults with cystic fibrosis. *J Roy Soc Med* 2005;98(Suppl 45):37–46.
- 7 Abbott J, Elborn S, Georgopoulos A, et al. Cystic Fibrosis Foundation and European Cystic Fibrosis Society survey of cystic fibrosis mental health care delivery. *J Cyst Fibros*. Published Online: 12 Jan 2015. doi:10.1016/j.jcf.2014.12.015.