

CORRESPONDENCE

Response to: 'On the TIDES study', by Quittner *et al*

Dear editors

In response to the correspondence by Quittner *et al*, we have the following comments. It must be stated that we think your The International Depression Epidemiological Study (TIDES) paper¹ has merit, and we commend any endeavours to highlight the mental health issues of people with cystic fibrosis (CF) and improvements in psychosocial service provision. The editorial has no intention of minimising the extent of the problem, quite the opposite. Your publication (and further correspondence) reports on two different issues: first, the TIDES study, and second, the recommendations of the International Guidelines Committee on Mental Health (IGCMH) in CF. The second is dependent on the findings of the first. So, the TIDES paper has methodological weaknesses and inconsistencies between the various publications that have devolved from the study.^{2 3} The TIDES authors must be conscientious in the conclusions they draw and the level of clinical significance that is truly apparent in the TIDES data as they are likely to have considerable influence. It must be acknowledged that the TIDES study did not in itself indicate accurate levels of anxiety or depression because of inherent difficulties with the measures used and, therefore, most disappointing of all, did not provide guidance on good measures for assessment, though perhaps told us what not to use. We reiterate; it is disingenuous to draw conclusions on rates of depression and anxiety and then decry the measures used to come to those conclusions. That is the basic tenet of the editorial.

Now, does that mean that the IGCMH in CF has nothing to go on? Not at all, we agree that the mental health of people with CF should be given credence and appropriate services provided as part of the package of healthcare required for this group. This is not new information, it has been known for many decades that people with chronic conditions are at risk for developing poor mental health impacting on quality of life and their ability to optimally manage treatment.⁴ As a result, many countries already acknowledge this need by including access to mental health practitioners as part of the health service to people with CF, for example, the UK standards of care have included a clinical psychologist as part of the multidisciplinary team since 2001. So,

although the TIDES study did not give clear evidence for the need for routine measurement of anxiety and depression, never mind which standardised measures to use, there is acceptance and agreement that the emotional needs of people with CF should be met. Nevertheless, the IGCMH in CF has focused just on anxiety and depression and promoted new and unstudied measures (PHQ-9, GAD-7), (though we note in your letter you are now not yet wedded to a particular screening tool). It is important to acknowledge that giving out routine standardised measures is not a no-cost strategy for patients, families, teams and health financiers, it must have infrastructure and so, evidenced need is essential.

Having a chronic health condition like CF does not cause depression; the TIDES study, because of the design, did not robustly provide any clear indicators of risk. More research is required, hence, the title of our editorial that there is unfinished business. Your letter gives a suggestion that your parameters have shifted and agree that more work is required to better understand the nature of the psychological needs of people with CF, and their families as well as the best service provision to ensure needs are met. While it is accepted that not all countries have the capacity to provide clinical psychology as an integral CF team member, we advocate that prevention is better than cure. It has been documented that screening and treating at the point of a diagnosable mental health condition is too late, besides being an ineffective use of resources.⁵ It is much better to aim psychological care at the early stages of adjustment to living with a chronic condition (for the parents at the point of diagnosis), having the opportunity to discuss the emotional impact and use routine psychological coping techniques as part of daily life. This is a model developed and promoted in the USA and adopted internationally.⁵ This is, by far, a better grassroots effort than searching for measures of anxiety and depression. Routine annual psychosocial assessment is a core recommendation of the European Standards of Care.⁶ Routine screening of anxiety and depression is far too narrow, and so we note well in your letter, the significant change of terminology to psychological distress.

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