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Specialists in Chronic Respiratory Failure Should Serve More than Just Ventilator-Dependent Patients

To the Editor:

Cao and colleagues have suggested a subspecialty that addresses the needs of people with chronic *ventilatory* failure (1). This is an important and neglected population that deserves focus on research and translation of salient findings into clinical practice and policies.

Most people with chronic *respiratory* insufficiency do not need mechanical ventilation. The population covered by this proposed

subspecialy needs to be broader to realize its full benefits. All people with chronic respiratory insufficiency have long-term physical symptoms (especially pathological breathlessness and fatigue) (2, 3); psychological (depression, anxiety) and social consequences (isolation, fear of being a burden); and existential suffering, which they experience daily and live with most often for years, or even decades (4). The population served by respiratory clinicians today comprise large numbers of such patients whose chronic problems are mostly underrecognized and, even when recognized, are frequently not addressed (5). In the vast field of pulmonology, physicians alone are unable to address all the needs of these patients and their families.

The proposal does not encompass the breadth of this population or the burden of illness experienced. Cao and colleagues speak of "ventilatory failure" rather than "respiratory insufficiency," or just oxygenation failure, whether continuous or just ambulatory (1). The authors understandably advocate for "continuity (of) care," but their proposal neglects the fact that chronic respiratory diseases

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LETTERS

lead to chronic respiratory insufficiency through a long continuum during which people experience increasing symptom burden and appreciable disability long before they may become dependent on a machine. Such disability starts as early as populations reporting Level 1 of the modified Medical Research Council breathlessness scale (6), even when all underlying causes are optimally treated. This definition moves beyond someone having "chronic *ventilatory* insufficiency" because of their imminent or current reliance on a machine.

Even when people are mechanically ventilated, most would be able to describe breathlessness as "the symptom that conveys an upsetting or distressing awareness of breathing" [page 3; (7)]. Sadly, mechanical ventilation is no protection against breathlessness when approximately half of those who receive ventilatory support experience breathlessness (7). Also consider people with ventilatory failure who have periods when they are not mechanically ventilated who often describe periods of catastrophic breathlessness (8). This "pathologic breathlessness" (associated with a fear of dying) cannot be compared in any way with the breathlessness that one experiences when voluntarily exercising beyond one's capacity.

A person who can barely leave his or her armchair (with or without the use of long-term oxygen therapy) would be excluded from the subspecialty advocated by Cao and colleagues because of their restrictive definition. Many people will never qualify for long-term domiciliary oxygen therapy or home mechanical ventilation, yet their chronic respiratory insufficiency profoundly limits them.

As such, the proposal by Cao and colleagues may be strengthened substantially if the definition were broadened to encompass people with chronic respiratory disease. The skill set of the teams providing care would be dictated by the needs of patients and their families and, therefore, move beyond only a technical response (important as that is) to a multidimensional model of care that incorporates the myriad of currently unmet needs experienced by a huge number of people globally in low-, middle-, and high-income countries. So, interprofessional teams are needed, including allied healthcare professionals, social workers, nurses, and palliative care specialists, along with the proposed respiratory subspecialist. Moreover, close collaboration with the person's family physician and community nurse is needed, as well as with healthcare professionals addressing the frequently present comorbidities.

Ultimately, there is an urgent need to create a "chronic *respiratory* insufficiency" subspecialty to care for people—patients and their families. A sub-subspecialty should include the training and technical skills for managing people's mechanical or noninvasive ventilation as part of providing care to people with "chronic respiratory insufficiency."

<u>Author disclosures</u> are available with the text of this letter at www.atsjournals.org.

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Letters 1343