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Administrative Data for Palliative Care Research: Friend or Foe?

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Patients with chronic obstructive pulmonary disease (COPD) receive palliative care far less often than those with cancer, despite having comparable or greater needs (1). Many have called for earlier and more frequent palliative care in COPD, which has strong face validity in clinical practice, yet the evidence base in this population is less robust than that in those with cancer or heart failure (2, 3). Thus, the benefits of palliative care in COPD and other understudied chronic diseases are commonly inferred from the evidence that exists in these other populations (2–4). Although this “one-size-fits-all” approach may enable more rapid progress in increasing palliative care for these

vulnerable populations, it also risks using a scarce resource in an inefficient and potentially ineffective manner.

In this issue of *AnnalsATS*, Maclagan and colleagues (pp. 48–57) report results from the largest study to date examining the effects of palliative care in COPD (5). By using health administrative databases from Ontario, Canada, they examined the association between receipt of palliative care and days alive at home per person-year through at least 1 year or death among patients who had their second or later COPD-related hospitalization between April 2010 and March 2017. Palliative care exposure was defined as receipt of palliative care during the hospitalization or within the subsequent 30 days in any setting. The authors derived a propensity score to estimate a patient’s likelihood of receipt of palliative care and then matched patients who received palliative care 1:1 with those who did not on the basis of their propensity score and sociodemographic and disease characteristics. Secondary outcomes included the place of death and rates of acute care use and mortality.

Among the more than 35,000 patients with advanced COPD included in this cohort study, 1,788 (5%) received palliative care. In the matched sample analysis, patients who received palliative care were followed for a median of 463 days, compared with 664 days in the non-palliative care group. There was no difference in the number of days spent at home between groups. Patients who received palliative care died at a higher rate and were more likely to die at home, although the latter difference disappeared in a sensitivity analysis in which patients who died in nursing homes were included as at-home deaths. Receipt of palliative care was not

associated with a reduction in emergency department or intensive care unit use but was associated with an increased rate of hospitalization among those who received community-based palliative care. Results were similar regardless of the number of prior COPD-related hospitalizations.

We warmly congratulate Maclagan and colleagues (5) on an important contribution to the evidence base for palliative care in COPD. In a recent systematic review of 28 randomized trials of palliative care interventions among more than 13,000 patients with noncancer serious illness (2), only three trials of 441 patients in total focused on COPD as a primary diagnosis, and none demonstrated improvements in patient outcomes (6–8). Although the quality and quantity of serious illness care research has significantly progressed in the past decade (9), clinical trials are not always feasible and often take many years to complete. Thus, researchers may leverage existing data sources and advances in causal inference methods to rapidly generate new evidence toward improving palliative care delivery. This largely negative study engenders important reflection about optimal palliative care delivery for patients with COPD specifically and highlights opportunities and challenges when using administrative data for serious illness research more generally.

Palliative care is fundamentally a heterogeneous intervention and is even more so when one examines it at the population level across different healthcare settings as this study did. However, the vast majority of palliative care in this study was delivered in the community, where the bulk of evidence exists in other populations (2, 3). And yet, no

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benefits were detected in this COPD cohort. Furthermore, the increased hospitalization rate seen among those who received community-based palliative care is inconsistent with findings of previous studies in other noncancer populations (2). In the United States, this finding could be particularly problematic because COPD is a part of Medicare's Hospital Readmission Reduction Program that imposes financial penalties on hospitals for avoidable readmissions (10). Perhaps usual community-based palliative care is not designed to adequately address the unique needs of patients with COPD (11), particularly when initiated earlier in the disease course. The mechanisms behind these findings warrant further investigation to inform novel palliative care delivery models tailored to this population's needs that optimize efficiency and effectiveness.

The absence of a reliable, patient-centered measure from administrative and other existing data sources has limited their utility in serious illness research. An innovative aspect of this study is the primary outcome of days at home, also called "home time," which has recently gained popularity for being simultaneously pragmatic, in that it can be reliably obtained from most existing data sources; patient-centered, in that most patients prefer to spend more days at home; and statistically efficient as a count variable. One potential drawback of this measurement is that days spent in a rehabilitation facility, nursing home, or inpatient hospice are all assigned a value of zero. For many underresourced populations, however, the home may not be a preferable or available option.

Furthermore, as Maclagan and colleagues (5) noted, and we agree, patients residing in nursing homes typically consider it to be home. With 17.4% of patients in the palliative care group residing in nursing homes and that proportion being nearly double that seen in the non-palliative care group, the estimated difference in days at home was likely biased toward the null. Indeed, the positive effect of palliative care on the secondary outcome of the place of death disappeared in a sensitivity analysis in which nursing home deaths were considered to have taken place at home. Future work using the days-at-home measure should include such sensitivity analyses to facilitate interpretation of the study's findings. Alternatively, a related outcome measure, hospital-free days, also called "days alive and outside the hospital," may be more conceptually appealing, as it counts all time spent in non-acute care facilities as days at home (12).

There are myriad study design, methodologic, and analytic challenges when using administrative data for serious illness research that can threaten the veracity of results. First, accurate classification of exposure to palliative care is often problematic. In the United States, procedural billing codes for palliative care have been shown to be highly specific but very insensitive (13, 14). The Canadian billing codes used to determine exposure to palliative care have not yet been validated, but the authors hypothesize that they too likely undercapture palliative care, thereby biasing the study results toward the null. Second, most administrative data sets do

not provide sufficiently granular data to account for the "dose" of palliative care (i.e., how often and which services a patient receives) or to enable a precise definition of advanced COPD and those most likely to benefit from palliative care. Third, matching approaches are commonly used to mitigate bias due to the selection effects that plague observational studies in serious illness research. Despite ostensibly successful matching, the higher mortality rate seen in the palliative care group may reflect residual unmeasured confounding or more palliative-focused goals of care in this group (also not captured in administrative data). Finally, although perhaps most importantly, race and ethnicity variables are often of questionable accuracy or unavailable in administrative data, as was the case in this study. Given evidence of existing racial disparities in palliative and end-of-life care (15), it is essential to evaluate palliative care interventions in these subgroups to identify opportunities to improve the access to and the quality of such care.

Despite these challenges, observational studies will continue to play an important role in advancing the science of palliative care delivery. Partnerships with experts in causal inference and adherence to reporting guidelines, including testing the robustness of methodologic and analytic assumptions (16), are needed to ensure a thorough understanding of and trustworthiness in the results that may be used to guide palliative care delivery models, program funding decisions, and performance benchmarks. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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Multidisciplinary Meetings in Interstitial Lung Disease: Polishing the Gold Standard

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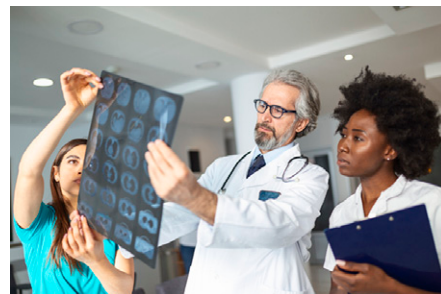
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With many available clinical, radiologic, and pathologic patterns and combinations thereof, diagnosis of interstitial lung disease (ILD) subtypes has been colloquially described as an “alphabet soup.” Despite this confusion, achieving a correct diagnosis early is critical in patients with ILD because treatments can differ depending on underlying etiology. Immunosuppressive agents targeting underlying autoimmune disease, for instance, have proved to be harmful in patients diagnosed with idiopathic pulmonary fibrosis (IPF) (1). Thus, early and accurate diagnosis can lead to early and accurate treatment, thereby ameliorating the disease progression that is so common in these patients.

The ILD multidisciplinary meeting (MDM) is broadly accepted as the gold standard for ILD diagnosis worldwide. Generally, such meetings involve the clinician caring for the individual patient along with other specialists, including pulmonologists, radiologists, pathologists, and/or


rheumatologists, to discuss available clinical data and generate a consensus ILD diagnosis for the patient. The majority of data supporting MDM emphasize its downstream effects on ultimate diagnosis as well as its effect on diagnostic agreement among clinicians. MDM has consistently been shown to change ILD diagnosis in approximately half of patients presented, and these collaborative diagnoses have been found to be more concordant with patient outcomes (2, 3). MDM diagnosis of IPF, considered the ILD subtype with the worst prognosis, is more closely associated with mortality than clinician or radiologist diagnosis of IPF alone (4).

Because of these effects on diagnostic concordance, the international ILD community has embraced MDM as an essential component of ILD care. Indeed, the health systems of some countries, most notably Australia, require MDM diagnosis of IPF before a patient can receive antifibrotic therapy (5). This emphasis on MDM as essential has not, however, resulted in its standardization. The description of these meetings in diagnostic guidelines, whether regarding membership, goals of discussion, or types of cases presented, is variable (Table 1) (6). Accordingly, one survey of expert centers around the world found considerable heterogeneity regarding which experts should participate, what information should be presented, and how a final diagnosis should



be made (7). One area of consensus has been increasingly made clear: standardization of the MDM is needed, including an overall statement of purpose regarding which objectives this meeting must accomplish (8).

In this issue of *AnnalsATS*, Teoh and colleagues (pp. 66–73) begin this important task with a Delphi survey among ILD physicians worldwide regarding essential features of the ILD MDM (9). An initial semistructured interview was conducted with 15 ILD experts, followed by two web-based survey rounds of 102 additional ILD experts. The authors’ definition of consensus was a median score on Likert scale of 4 or 5 with an interquartile range (IQR) of 0. Fifty statements were initially proposed, five of which reached the level of consensus in the first round. Three of these statements involved the use of radiology, and two were exploratory statements regarding the necessity of future benchmarking and

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