Telemedicine is an important tool that can advance and enhance access to care for patients with chronic diseases. The coronavirus disease (COVID-19) pandemic caused a catastrophic shift regarding telehealth availability and use across all specialties. With regard to pulmonary medicine practices, whose patients are particularly vulnerable during a respiratory pandemic, access to telehealth became essential for safely advancing patient care. The benefits of telehealth are particularly important for patients with rare diseases, who typically require highly specialized care from experts who may be geographically distant. To meet patients’ needs while maintaining physical distancing, adoption of telemedicine in the United States accelerated dramatically during 2020 because of the COVID-19 pandemic. Patients with alpha-1 antitrypsin deficiency (AATD), a rare multisystem disease affecting the liver and lung, may be particularly vulnerable to COVID-19 infection (1) and therefore need to employ telehealth to protect themselves from potential exposure to COVID-19 related to healthcare use.

Patients with chronic pulmonary diseases stand to benefit from telemedicine in numerous ways, including improved access to and continuity of care, rapid follow-up to address acute needs in complicated pulmonary disease cases, decreased patient wait times (2), minimization of lost work hours (3), and cost savings (4). As an example, Figure 1 highlights the geographic disparities between patients with AATD and locations of alpha-1 clinical resource centers (CRCs). The Alpha-1 Foundation designates CRCs as medical facilities with expertise in specialized care of patients with AATD, including the demonstration of experience in the care of patients with AATD; availability of pulmonology and hepatology services, transplant specialists, and rehabilitation facilities; and the ability to host support groups. Approximately half of U.S. states have one or zero alpha-1 CRCs.

Providers also benefit from telemedicine through increased scheduling flexibility, ability to enhance clinical care with more frequent follow-up, and potential for healthcare cost savings (5). In addition, a telehealth framework provides a means for reimbursement for otherwise uncompensated clinician labor (e.g., follow-up phone calls could be converted to reimbursable telemedicine visits). Nonetheless, challenges exist that hinder wider implementation of telemedicine, including discomfort with technology for some patients, lack of universal high-speed internet access, privacy concerns, high implementation costs, inability to perform physical examinations, challenges of medical licensure across state lines, lack of insurance reimbursement, and difficulties conveying empathy for challenging diagnoses via virtual interactions.

On March 6, 2020, the Coronavirus Preparedness and Response Supplemental Appropriations Act was signed into law, which allowed the Secretary of Health and Human Services to waive or modify Medicare and Medicaid telehealth requirements. As a result, the Centers for Medicare & Medicaid Services issued guidance that dramatically expanded telehealth options available through Medicare and Medicaid for the duration of the public health emergency. The guidance allowed telehealth services to be reimbursed at the same rate as in-person visits, eliminated the requirement that patients and providers have a preexisting relationship.

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before a telehealth visit, and permitted telemedicine services via telephone. In addition, HIPAA (Health Insurance Portability and Accountability Act) regulations regarding secured telemedicine platforms were relaxed to permit telehealth visits via non–HIPAA-compliant applications (e.g., FaceTime or Zoom). Before the public health emergency, telehealth services were available only to patients in designated rural areas and had to be obtained at a local medical facility, but federal policy changes allowed telehealth reimbursement for patients treated in any location, including their homes. Finally, the Drug Enforcement Administration suspended restrictions against prescribing controlled substances via telemedicine.

States also took action to facilitate telehealth expansion. All states and the District of Columbia modified or waived licensing requirements or enacted existing emergency credentialing provisions to permit patient care by out-of-state physicians. In most locations, these changes enabled physicians to practice telemedicine across state lines. Some states implemented additional policies similar to COVID-19 guidance issued by the Centers for Medicare & Medicaid Services at the federal level. Together, these federal and state-level measures facilitated access during the COVID-19 crisis for vulnerable patients such as those with AATD.

Changes to Medicare and Medicaid policy will expire upon termination of the federal public health emergency. Some state-level directives have already ended. As of February 22, 2022, only 24 states had active waivers granting practice privileges to out-of-state physicians (6). Legislation is needed to permanently reform telehealth regulation.

A reintroduced federal bill, the bipartisan Telehealth Modernization Act (S. 368/H.R. 1332), would remove Medicare’s geographic limits on who may receive telehealth and would permit patients to receive telehealth services outside of a provider’s site. At the state level, Arizona’s House Bill 2454, signed into law in May 2021, allows out-of-state physicians to provide telehealth services to Arizona residents and requires payment parity from health insurers for telehealth services, including audio-only interactions (7).

The states of New Hampshire, Washington, and Oregon have also passed legislation mandating payment parity for telehealth (8–10). In addition, South Dakota and Colorado now allow providers to establish patient relationships via telemedicine without an initial in-person visit (11, 12). The Colorado law also provides for payment parity for telehealth received under Medicaid, expands coverage of nonphysician telehealth providers, and prevents insurers from placing limits on the location of telehealth (12). Similar bills are under consideration in state legislatures across the country.

These federal and state-level bills represent a positive start to increase telehealth access in the United States, but more change is needed. One proposal is to expand the Interstate Medical Licensure Compact, an agreement among 29 states, the District of Columbia, and Guam, that simplifies licensing across state lines by implementing uniform eligibility requirements and recognizing the screening processes of physicians’ home states (13). However, the Interstate Medical Licensure Compact does not remove all barriers to
interstate telemedicine, because physicians must hold a separate license for every state in which they practice and must fulfill the renewal obligations for each. Institution of a national physician license or expansion of telehealth-specific medical licenses could further enhance uptake of telemedicine (13). Redefining “place of service” as the location of the physician rather than the patient would ease barriers to practice of telehealth across state lines (13). Finally, enhancing access and affordability of broadband internet and increasing initiatives to expand digital literacy would reduce patient-side technological obstacles to telehealth.

The potential benefits of telehealth for patients with chronic rare diseases are clear, including consistent access to geographically disparate specialist providers. Nonetheless, telemedicine is not suitable for every patient or every context. Telemedicine is most appropriate as a means of consultative follow-up care after initial diagnosis, including for discussion of genetic testing and treatment decisions. Patients with effective local primary care physicians who are willing to work in concert with remote rare disease specialists are best served by telehealth services. Telehealth is least appropriate for patients with a new diagnosis of a potentially life-threatening condition, those experiencing acute illness requiring urgent intervention, situations in which a physical examination is needed, or for individuals with low digital literacy or lack of access to the internet or technological devices.

In the postpandemic era, we recommend establishing a patient relationship via an initial in-person visit, which can be followed up with virtual visits interspersed with occasional face-to-face contact. Both physicians and patients find value in face-to-face visits for relationship building and to allow physical examination. The telemedicine option should not be exercised exclusively for patient convenience when in-person visits are not burdensome but should be used as necessary to facilitate optimal management, in particular when patients require highly specialized care.

There is an urgent need to establish secure and effective telehealth systems for rare disease patients now, in preparation for future pandemics or other emergent situations that could again restrict patient movement.

For patients with chronic pulmonary diseases, telehealth can expand access to specialist providers and allow rapid follow-up for patients with complex management needs. Many regulatory barriers to telehealth have been suspended during the COVID-19 pandemic. An opportunity now exists to enact permanent policy changes to maintain availability of telehealth under appropriate circumstances in the postpandemic era. National organizations have begun to advocate for access to telehealth, and adopting such policies will improve access to specialized care for rare disease patient populations.

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

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