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PH In the Time of COVID-19

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Program Description

The mission of *Advances in Pulmonary Hypertension* is to serve as the premiere forum for state-of-the-art information regarding diagnosis, pathophysiology, and treatment of pulmonary hypertension (PH). The 2018 Nice revision of the World Symposium on Pulmonary Hypertension (Simmonneu G, Montani D, Celermajer DS, et al. Haemodynamic definitions and updated clinical classification of pulmonary hypertension. Eur Respir J. 2019;53(1). DOI:10.1183/13993003.01913-2018) serves as a guide to categories of PH addressed in *Advances in Pulmonary Hypertension*. While focusing on Group 1 PH (PAH: pulmonary arterial hypertension), the other categories (Group 2, PH due to left heart disease; Group 3, PH due to lung diseases and/or hypoxia; Group 4, PH due to pulmonary artery obstructions; Group 5, PH with unclear and/or multifactorial mechanisms) are also addressed. This mission is achieved by a combination of invited review articles, roundtable discussions with panels consisting of international experts in PH, and original contributions.

Objectives

- Provide up-to-date information regarding diagnosis, pathophysiology, and treatment of PH.
- Serve as a forum for presentation and discussion of important issues in the field, including new paradigms of disease understanding and investigational trial design.

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Advances in Pulmonary Hypertension is directed to cardiologists, pulmonologists, rheumatologists, pediatricians, internists, and other health care professionals involved in the treatment of patients with PH.

Advances in Pulmonary Hypertension: Official Journal of the Pulmonary Hypertension Association is a quarterly publication directed by an editorial board of renowned pulmonary hypertension (PH) experts with oversight by PHA's Scientific Leadership Council. The mission of *Advances in PH* is to assist physicians in their clinical decision-making by informing them of important trends affecting their practice and providing an analysis of the impact of new findings and current information in peer-reviewed publications. Each article is reviewed and approved by members of the Editorial Board.

While most articles are invited by the Editorial Board, the following submissions will be considered for publication:

- Reviews that summarize and synthesize peer-reviewed literature to date on relevant topics
- Letters to the Editor
- Clinical case studies

Submitted manuscripts are reviewed by the Editorial Board and other experts in the field. Acceptance of manuscripts is determined by factors such as quality, relevance, and perceived value to clinical decision-making.

***Advances in Pulmonary Hypertension*'s Web Platform**

*Advances in Pulmonary Hypertensio*n is available at www.AdvancesinPH.org. This site offers enhanced capabilities including a dedicated DOI and cross-referencing potential, as well as other features valuable to practitioners, researchers, and educators. Registration is recommended to access all site features and benefits.

As we move into 2021, the editorial board, guest editors, and staff of the PHA *Advances in Pulmonary Hypertension* wish you a safe, happy and peaceful new year. The unpredictable challenges that shaped 2020 have transformed much of the way we all care for our patients, promote medical education, and continue important clinical research. We have learned new strategies that have enabled us to continue and even improve our practices in ways that will be important for years to come.

We dedicate this issue of *Advances*, the first of 2021, to all who have been affected in any way by the pandemic. Thank you to Dr. John Ryan, who has graciously created an issue with manuscripts devoted to what we have learned over the last year. Thank you to all who have contributed.

One of the most important issues that has troubled our patients is disparity in our health care systems. Although this topic has been stressed over the last few years, it has been even more apparent in 2020. Dr Jeanna Ryan and her co-authors describe the impact that these obstacles have had on our patients, of which, most important is the impediment to care. The group stresses the call for collaboration with all disciplines in health care to approach this barrier for PH and other patients.

Dr Roham Zamanian and Dr John Ryan discuss how COVID-19 has affected research in PH over the last year and how it will affect us moving forward. They discuss the challenges that have arisen in both clinical trials in basic research. Overcoming barriers with tools like ZOOM meetings, electronic consents, and site initiations helped move the field forward. We are still working on other barriers like onsite visits for patients and monitors.

Drs John Ryan, Mark Avdalovic and Jennalyn Mayeux, discussed the trials and tribulations of telehealth and how the creation of these programs began and flourished at their centers.

Elizabeth Colglazier and Anna Brown continued the work on telehealth by describing their experience with the pediatric PH population. Both of these manuscripts help build a road map for any center to start or continue with this process.

Thank you to all of the authors and contributors for this special edition of Advances.

I would also like to give a special thank you and farewell to our Managing Editor, Clarissa Nemeth, for all of her hard work and dedication to getting us through this year. We will miss you but wish you all of the very best in your new adventure. We would also like to welcome Kara Kopchinski, who is now transitioning into this position and we will look forward to working with you!

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GUEST EDITOR'S MEMO

Building Bridges During a Time of Crisis

> *In times of crisis the wise build bridges, while the foolish build barriers.*
> —*T'Challa (Black Panther)*

It has been a hard year. With the ongoing pandemic, a long overdue social justice movement, continuing political conflict, and economic instability, it has been challenging for health care providers to remain focused on providing the highest quality care possible. As societal norms evaporated, health care professionals innovated and adapted, creating new processes for delivering care, and taking on roles and responsibilities far removed from what they were hired or expected to do. In doing so, we had to build bridges, joining the world of technology and health care like never before, integrating assembly line concepts into care models, and involving community members more directly than ever into the practice of medicine. In this issue of *Advances in Pulmonary Hypertension*, we are fortunate to have publications which capture the challenges that were faced in health care during this past year and which demonstrate the agility of health care heroes in responding to crisis.

The article from Jeanna Ryan and colleagues highlights health disparities that play a significant role in quality and outcomes in pulmonary arterial hypertension (PAH). The authors describe social determinants of health and detail the historical and current impact that racism and discrimination have on patients with PAH, as well as the barriers to equitable care. The manner in which the COVID-19 pandemic has exacerbated health inequity is explored, as is the path forward, whereby we can all provide more equitable care by building bridges, creating transdisciplinary collaborations, and addressing the intersectionality of societal risk factors. The message is clear—we need to act and we cannot do this alone.

In the Pulmonary Hypertension (PH) Roundtable, Mark Avdalovic, at the University of California Davis, and Jennalyn Mayeux, of the University of Utah, discuss how their programs have evolved during 2020. Both centers faced challenges which will be familiar to many PH programs around the country,

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and they share how their approaches changed to evaluating patients, adapting diagnostic protocols, and reaching out to the most vulnerable patients in their respective communities. Dr Avdalovic shares best practices on how to identify patients who are most at risk during the pandemic, and Dr Mayeux shares her team's efforts to partner with hospitals and providers in the patients' home communities in order to optimize outcomes and keep patients safe. Again, the theme of building bridges during this time of crisis persists.

So much of the care delivered this year could not have been done without the rapid adoption of telehealth. In this issue of *Advances*, Elizabeth Colglazier and Anna Brown provide an in-depth discussion of the benefits and challenges in providing care to pediatric patients with PH. The paper offers an excellent template on how to structure and deliver telehealth. The authors emphasize the transformative power of technology, stating that "*the barriers that might restrict support group attendance, such as time and distance, may be overcome when telehealth modalities are used*."

Research operations were also dramatically affected by the COVID-19 pandemic. Dr Roham Zamanian describes the broad impact the virus had on basic science and clinical research, as well as the potential long term consequences the pandemic will have on scientific discovery due to barriers to data collection. The need to overcome the challenges presented to us is clear as Dr Zamanian states, "*I feel like since the pandemic…probably because of all the barriers identified, [I] haven't had a chance to make unique conversations with colleagues that I would otherwise have met just out of the blue*."

As I reviewed the themes of the articles in this issue of *Advances in Pulmonary Hypertension*, it was clear that our writers, all clinicians, are imminently concerned about the impact of the COVID-19 pandemic on their patients and their programs. What was missing, however, was a roadmap for how we can take care of ourselves during the pandemic. We must lean on each other and find the best way to practice self-care. The Pulmonary Hypertension Association (PHA) is a unique organization, with the integral role played by patients and community caregivers. The multidisciplinary nature of the PHA can help build the bridges necessary to connect our PH providers with each other, as well as with the resources that they need, so that they too can find healing during this time of crisis.

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Health Disparities in Pulmonary Arterial Hypertension and the Impact of the COVID-19 Pandemic

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INTRODUCTION

The COVID-19 pandemic and coinciding events of 2020 involving political and social instability have put additional strain on the United States (US) population, highlighting and widening health disparities experienced by minoritized and marginalized patients.[1] The disproportionate effects of COVID-19 on vulnerable populations may represent deeper systemic challenges of interrelated known and unknown variables contributing to health inequities. To date, the research addressing health disparities in pulmonary arterial hypertension (PAH) has been limited.[2,3] In this article, we will explore potential contributing factors to health disparities in PAH. We hope to shed some light on areas of influence or intervention that may need further investigation to improve quality of care and outcomes in PAH.

Pulmonary hypertension (PH) is characterized by increased pulmonary arterial pressures.[4] The World Health Organization (WHO) categorizes etiologies of PH into 5 groups. WHO Groups 2–5 PH are common and serious.[4–6] WHO Group 1 PAH remains classified as an orphan disease associated with many underlying causes[5,6] and has an estimated 2.8-year median survival if left untreated.[7,8] Since 1980, hospitalization and death rates from PAH have increased because of increased diagnosis and improved reporting patterns, but the total number of cases remains underestimated due to difficulties in disease detection.[9–11] PAH remains underrecognized, with many patients being diagnosed more than 2 years after symptom onset, thereby contributing to worse outcomes and missed opportunities to intervene before the occurrence of irreversible life-threatening disease progression.[2,12,13] With advances in PAH therapies, treatment is becoming more complex, requiring a more individualized approach.[6] By disproportionately impacting vulnerable patients, the delay to diagnosis and the barriers to introducing therapies have the potential to worsen health disparities in PAH, especially when compounded by the challenges facing patients and families during the COVID-19 pandemic.

Discrepancies in health outcomes in people with PAH based on race, ethnicity, gender, age, and socioeconomic status (SES) have been demonstrated.[11,14–20] Researchers have shown that women have better survival than men with PAH, possibly due to different etiologies, hormonal differences, and other unknown reasons.[14,21,22] However, because the risk and prevalence of PAH is higher in women, the overall death rate secondary to PAH remains higher in women.[2] The data regarding the impact of race have been conflicting. Authors of some studies have shown that African American or Asian patients with PAH have an increased risk of death.[16,18] However, analysis of the REVEAL Registry found no significant association between race or ethnicity and survival in PAH after correcting for variables of prognostic impact.[23] A review of vital statistics data from 1994–1998 revealed that African Americans with PAH exhibited substantially higher mortality rates compared to White populations, and African-American women had the highest mortality rates across all ages.[15] Underlying causes for these differences are unknown but could be related to social determinants of health (SDHs) and health inequities.[3]

HEALTH DISPARITIES AND DETERMINANTS OF HEALTH

There is some disagreement surrounding the definition and use of the term “disparity.”[24,25] For this article, we use the definition provided by Healthy People 2020, which defines health disparity as:

> “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. . . [that] adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial

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Key Words—pulmonary hypertension, health inequity, inequality, discrimination, social determinants of health
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> or ethnic group; religion; SES; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion."[26,27]

SDHs and how they intersect as well as other determinants of health are important to consider, as they influence health outcomes and, when overlooked, could negatively impact the health of some populations more than others.[28] The difficulty in categorizing these factors and the likelihood of disagreement with a preconceived classification demonstrate how complicated these factors and their interrelationships are (Figure 1). Many studies suggest links between inequities in psychosocial, economic, environmental, lifestyle, behavioral, experiential, technological, and biological factors and health that may contribute to health disparities.[2,3,26–31] We have designated the information into the following groupings for organizational purposes, but a great deal of overlap exists between the topics of each paragraph.

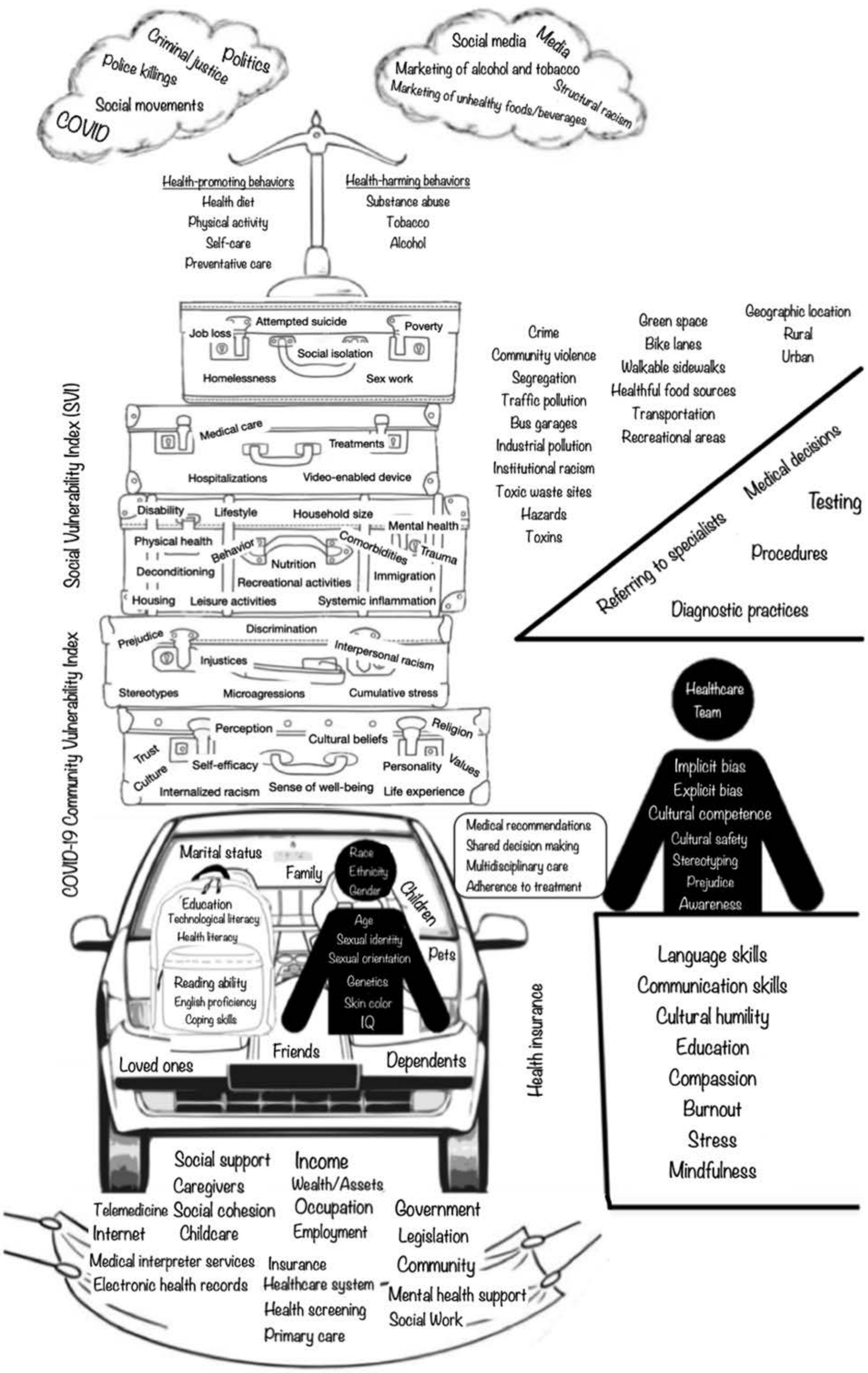

Figure 1: Psychosocial, economic, environmental, lifestyle, behavioral, experiential, technological, and biological factors and health that contribute to health disparities.

Racism and Discrimination

The COVID-19 pandemic is exacerbating stress, which makes it more difficult for marginalized groups to cope with discrimination, who in turn engage more in health-harming behaviors and less in health-promoting behaviors, which further increases the risk of poorer health outcomes. A rich source of social science literature conceptualizes racism, but integration of this research into medical and scientific literature geared toward health professionals is lacking, especially as it pertains to PAH.[32] *Structural racism* refers to the totality of ways in which societies foster racial discrimination, through mutually reinforcing inequitable systems (in housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, and so on) that in turn reinforce discriminatory beliefs, values, and distribution of resources, which together affect the risk of adverse health outcomes.[32] Racism and discrimination of minority and marginalized groups contributes to poorer mental and physical health outcomes, and these subsequent health disparities are increasingly relevant to the care of patients with PAH. Perceived racial and ethnic discrimination leads to negative stress. Emotional responses are known to be associated with long-term health consequences in cardiovascular disease and hypertension and are worth exploring in PAH.[2,31,33–41] Cardiovascular and psychological stress responses occur from the mere anticipation of prejudice.[42] Prior literature indicates a dose-response relationship between poor health and racial discrimination.[41]

Everyday discrimination is harmful to the physical and mental health of racial and ethnic minorities as well as Whites, indicating that the connection between health and perceived discrimination goes beyond racial discrimination.[38,43] Some potential pathways for negative health outcomes due to discrimination include economic and social deprivation, lack of access to adequate medical care, inequitable exposures to hazards, targeted marketing of substances that can harm health, barriers to engaging in healthy behaviors, and maladaptive coping mechanisms such as substance use.[2,29,31,32,35,44–47] Many of these socioeconomic factors shaped by discrimination already contribute to an increased risk for PAH and also put some groups at greater risk for COVID-19,[48] demonstrating an intersectionality between these two disease states.

African Americans are also at increased risk for other conditions that are known to be risk factors for PAH, such as sickle cell disease, systemic sclerosis, human immunodeficiency virus (HIV), and liver disease.[49] The health inequity becomes even more exaggerated because of the disproportionately higher amounts of health-harming products targeted at African-American and minority communities. Such products include alcohol, carbonated and sugar-sweetened beverages, high-fat foods, candy, other high-sugar desserts, and tobacco, including more harmful tobacco products such as mentholated cigarettes.[31] Targeted marketing toward minority communities of illegal substances like illicit opioids and heroin also occurs.[32] Methamphetamine use has increased since the start of the pandemic, and since liver disease and illegal drug use (methamphetamine, cocaine) are risk factors for PAH, these discriminatory elements are important to consider in PAH and may prove to be a barrier to cessation of substances of abuse.[4]

Much of the available research on discrimination addresses the impact on racial and ethnic minorities. However, many other forms of discrimination exist that impact older adults, women, people with disabilities, gay, lesbian, bisexual, transgender individuals, prisoners, and many others.[50] Very little research has been done with regard to the effects or prevalence of discrimination in PAH. Transgender individuals have an increased likelihood of being victims of discrimination and hate crimes and are often socially marginalized, thereby increasing their risk for unemployment, homelessness, and illegal activities such as sex work.[38,51] Transgender people, sex workers, and prisoners encounter more daily and severe discrimination and are at a greater likelihood of participating in health-harming behaviors like smoking, drug and alcohol abuse, in addition to attempted suicide, which increases their risk for poor health.[38,51] Also, a higher prevalence of HIV infection, mental health issues, suicidal ideation, substance abuse, and exposure to violence exists among these groups.[38] Because HIV and intravenous drug use are risk factors for PAH and have a worse prognosis than other forms of PAH, further research into the effect discrimination is having on PAH prevalence, time to diagnosis, prognosis, mortality, and other health outcomes in marginalized populations is warranted.[4]

Black Americans have been found to be exposed to more cumulative stress, which is in turn associated with greater social isolation.[52] People who are more socially isolated and have fewer social interactions with others are more likely to die prematurely and have worse mental and physical health.[41,52] Social isolation has been found to decrease the benefits of social support and impact overall physical health and systemic inflammation.[52] Social support and effective coping skills may help moderate the effects that racial discrimination has on health, which suggests a point of intervention relevant to the management of PAH, which can be targeted by health providers that support the importance of multidisciplinary care and community.[34,47]

Microaggressions are the everyday allegations, slights, and insults that people of color experience regularly in their interactions.[53,54] The stress surrounding experiencing microaggressions and discomfort in how to respond have been shown to result in elevated blood pressure. Microaggressions are experienced disproportionately by Black Americans and can result in self-esteem issues and depression.[53,54] It is therefore likely that subtle everyday instances of microaggressions also contribute to poorer health outcomes, including in PAH, especially when an increase in microaggressions to minorities has been observed during the COVID-19 pandemic.[55]

Environmental and Geospatial Determinants

Neighborhoods in the US continue to be racially and economically segregated. This form of structured racism contributes to health inequities through environmental exposures, crime, health care, public benefits and resources, housing, education, employment opportunities, and other determinants of health factors.[32,40,56] Adverse birth outcomes, decreased longevity, exposure to air pollution, increased risk of chronic disease, poverty, job loss, interpersonal trauma, exposure to violence, and increased rates of crime such as homicide affect health outcomes and are associated with residential segregation and structural racism.[32,52] *Community violence*, which includes violence as direct injury, injury of friends or family, witnessing violence, hearing gunshots, and learning about violence through neighbors or media, is rarely enquired about in the care of PAH patients. The physiologic stress response to community violence increases systemic inflammation, and behavioral changes in response to fear of harm can result in decreased physical activity, unhealthy diets, psychoactive substance use, increased isolation, and other actions that influence health as an attempt to cope or stay safe.[45] Police killings of unarmed Black Americans affect the mental health of people not directly involved or connected to the killings.[57] Thus, exposure to community violence likely exacerbates the stress, isolation, and disparate vulnerabilities caused by COVID-19, in particular in populations who already have a chronic disease, such as PAH.

Inequities in access to safe and adequate local public resources and facilities, including green space, bike lanes, walkable sidewalks, healthful foods, transportation, and recreational areas, influence health behaviors and maintenance.[52,58,59] These are determinants of health contributing to health disparities and may be important factors to consider when recommending healthy lifestyle behavior changes to patients with PAH. Overcoming environmental and socioeconomic barriers requires creative solutions and shared decision making to identify realistic personalized interventions that increase the likelihood of patients' ability to adhere to medical recommendations.

Exposure to certain toxins and drugs, pollution and other environmental stressors, and living conditions may play an important role in PAH development, pathogenesis, and prognosis.[3,60] Minorities are disproportionately exposed to occupational hazards, and toxic waste sites and bus garages are placed in or near neighborhoods where marginalized, racialized groups predominantly reside.[32] Poorer neighborhoods and African Americans may be located closer to higher traffic density roadways or sources of industrial pollution.[61,62]

Analysis from the REVEAL Registry using ZIP code-based median income showed a higher frequency of Black and Hispanic races in the <$60,000 income categories and the most subjects with functional class 3 and 4 PAH at baseline in the $40,000 income group. Also, a longer time to disease recognition was found in the lower income groups, but a longer time to disease was not associated with geographic region.[3,12] SES is a strong predictor of health and can directly influence housing and neighborhood options as well as geographical location. Previous research in PAH has shown an association between worse outcomes and lower SES, so further investigation of geospatial determinants of health in PAH are worth consideration.[23,41]

Socioeconomic Factors

SDHs and SES have been identified as fundamental causes behind health disparities and racial differences in health.[32,58,63] These terms often incorporate factors that can alter health-related behaviors such as neighborhoods, income, education, wealth, occupation, health insurance coverage, and marital status.[3,58] *Social cohesion* refers to the strength of relationships and the sense of solidarity among members of a community and involves shared group resources like a friend-of-a-friend's knowledge of a job opening.[64] Economic injustices, such as being paid less for the same work and receiving fewer promotions, despite meeting similar performance measures, are additional challenges and likely contribute to chronic stress and worsened health outcomes from discrimination.[32] Neighborhood social cohesion has been linked to meeting physical activity recommendations.[65] In turn, these contribute to less of a safety net and more vulnerability when dealing with a chronic disease such as PAH. Researchers of PAH suggest an association between low SES and worse outcomes in PAH.[3,20] A lower SES is strongly associated with a higher risk of death in idiopathic PAH.[66] This association is independent of clinical characteristics, hemodynamics, and treatment. Components of SES that could lead to disparities in health include the social environment, psychology, behavior, and physical environment.[67] SES also has behavioral components, potentially affecting the likelihood of enacting health-related activities such as exercise and scheduled medication taking.[68] A person's perceptions of risk and severity of disease impact his or her own behavior and subsequently the success of an intervention which can result in disparate outcomes between different socioeconomic groups in PAH.

COVID-19 may aggravate an already fragile SES of patients, which may have a negative impact on PAH outcomes. The economic impact of the COVID-19 pandemic has had disproportionate impact on lower SES groups and minority communities,[69] thereby compounding the health disparities already observed in PAH within these groups. Admittedly, the increased mortality risk associated with PAH observed in lower SES groups can be somewhat explained by hemodynamic factors, suggesting that delay in evaluation may be a contributing cause, although this is uncertain.[2,66] However, someone with lower SES may lack health literacy and education, thereby limiting access to care with subsequent increased behavior-related risk factors that contribute to less activity, more deconditioning, and in turn worse outcomes.[70]

Social vulnerability refers to the potential negative effects on communities caused by external stresses on human health, such as disease outbreaks.[71] The Centers for Disease Control and Prevention (CDC) Social Vulnerability Index (SVI) is a resource to help identify communities that may need support when a disaster occurs. More specific to the pandemic is another CDC resource, the COVID-19 Community Vulnerability Index, which combines the SVI with additional COVID-19-specific indicators to anticipate the communities that may experience the worst social and economic impacts.[72] These tools are typically used by public health officials but can be used by practitioners and researchers working with PAH to identify patients at greater risk due to the pandemic that may need referrals for additional social work, financial, and mental health expert support.

Lower levels of education achievement have been associated with a greater chronic disease risk, worse health outcomes, and less adherence to health screening, with higher frequency of being diagnosed with advanced disease than those with higher levels of education achievement.[31] People who read at lower levels are generally 2 to 3 times more likely to have adverse health outcomes than people who read at higher levels.[73] Linguistic barriers can result in inadequate health communication, racial stereotyping, language discrimination, and bias against patients in the US with limited English proficiency, which can lead to unfair treatment and health inequities.[2,74,75] The COVID-19 pandemic has amplified this unmet health communication need, which could be due to the increased demands on the health care system as a whole as well as the rapid increase in use of telehealth.[74,76]

To adequately prepare to care for patients with limited English proficiency, patient language abilities need to be documented and accessible in health system records.[74] Clinicians entering encounters that are not language concordant tend to resort to less effective medical interpreting methods out of convenience, urgency, or lack of access to appropriate resources. Such scenarios can result in communication challenges, time constraints, and in turn, suboptimal medical care. In the setting of the COVID-19 pandemic and the increase in telemedicine use, inadequate medical interpretation resources and utilization likely further compound health disparities, especially for individuals with complex medical illnesses such as PAH. To ensure respect and trust for both the patient and provider, a multidisciplinary approach incorporating medical interpreters and social workers is recommended.[3] A strategy proposed to reduce health inequities for linguistic minority patients and improve language-concordant care includes adding linguistic competencies, virtual strategies, and cultural humility skills to education and training curriculums.[74]

Health Care Access, Utilization, and Personal Health

Racial and ethnic minorities are at greater risk of inadequate access to health care facilities, lack of health insurance, and receipt of poorer quality medical care due to racial bias and discrimination.[32,62,77] Discrepancies in insurance status and access may explain why minorities in the US receive fewer procedures and lower quality care across all clinical interventions.[62,78] Gender and skin color have been shown to influence physician test ordering and diagnostic practices.[79] Relevance is compounded by the COVID-19 pandemic because of the observation that physicians refer African Americans less for screening when symptoms are present.[62] This is concerning for a disease such as PAH, which relies heavily on testing for diagnosing and treating patients, especially since early diagnosis and management in PAH are so critical to prognosis.[6] Whether this trend of decreased testing in minorities translates to less referrals to PAH specialists is worth investigating. If there is reduction in referrals to PAH specialists, then this would also result in less or delayed access to PAH-specific therapies.

Preventative care has been impacted dramatically by the adaptations to care delivery adopted during the COVID-19 pandemic.[80] Better utilization of preventative care can help reduce health and social inequities and improve overall health, especially in PAH. African-American adults have been shown to partake less in preventative health behaviors and have reduced health care engagement, which could be related to discrimination and mistrust.[52] Reported rates of delaying necessary care are higher in Latinos and African Americans.[2] Continued efforts have been made to reduce time to diagnosis in PAH by raising awareness and increasing access to specialists; however, racism has been associated with delaying and not getting health care.[81] Racism is therefore another avenue we should target in order to reduce time to diagnosis. PAH specialists are uniquely positioned to help patients navigate the health care system to improve their outcomes, for example, by establishing their patients with primary care providers, encouraging regular follow ups for preventative care, and empowering and teaching their patients to use health services when they need it.[82] In addition, increasing knowledge and awareness, particularly by primary care providers, around early diagnosis in PAH to help improve time to diagnosis, specialist referral, and early management of PAH can improve PAH health outcomes and prevent or decrease health disparities.[9,78]

Provider Bias

Physicians have poorer communication with minorities especially in race-discordant patient-clinician relationships.[83] Provider implicit bias and stereotyping have been linked to poor patient care ratings and poor visit communication, especially among Black patients.[83] A partial but important solution to this is diversifying the health care workforce, including PAH teams, to more effectively address patients' needs and social risk factors.[78,84] Recruitment efforts to increase diversity among research investigators and health care providers are encouraged by the American Association of Medical Colleges.[85] Researchers have indicated that underrepresented minorities, even those from high socioeconomic backgrounds, have a higher likelihood of working with underserved populations.[78] Additionally, racial concordance in the patient-clinician relationship has been associated with better overall health outcomes, patient-clinician communication, adherence to medical instructions, and patient satisfaction.[78,84] The US population is becoming increasingly diverse, and estimates show that current underrepresented populations will become the majority of the US population in fewer than 24 years.[78] To increase diversity among PAH providers, mentee selection by PAH leaders in the field will greatly impact whether the PAH workforce can meet the demands of the increasing prevalence of PAH.

Another critical challenge to overcoming the poor communication experienced by marginalized individuals in health care and disparate clinical practices in health services is addressing stereotyping, prejudice, and implicit (unconscious) and explicit (conscious) bias by health care providers.[31,77] It is unfortunate but worth noting that about 70% of health care providers exhibit implicit bias, which is about the same observed in the general population.[78,86] These implicit biases are normal, natural, subtle, and often subconscious.[77] Researchers on implicit biases have shown they may affect medical decisions and quality of communication with patients.[78,81,86]

Prejudice against minorities, stereotypes around health or behavior of minorities, and clinical uncertainty surrounding interactions with minorities contribute to disparities in health care.[83] More implicit bias and stereotyping has been associated with greater clinician-dominated visit dialogue, lower trust and confidence, less warmth and friendliness, negative patient ratings, less involvement of patients in treatment decisions, poorer communication, and ultimately poorer patient care.[78,83,87] Implicit association test scores representing more racial bias foresaw less smiling, social comments, speaking time, and speech fluency as well as more errors in speech.[87,88] Experiences of discrimination in health care settings may result in less adherence to recommendations, delaying medical care, and influencing future health service use.[31,81] In contrast, patient-centered communication has been correlated with increased trust by patients, which is linked to better continuity of care and greater adherence.[83] When diseases such as COVID-19 and PAH combine, which disproportionately affect Black populations, the impact of implicit bias becomes magnified, which therefore makes it worth determining and researching our own practice within PAH. Some potential ways to combat discrimination, implicit bias, and inequity in health care may include increasing awareness, lifelong education, and making a shift toward cultural safety.[32,89] Cultural safety requires that health providers question their own biases and prejudices.[89] Mindfulness practice or meditation training is an emerging intervention with evidence suggesting that it can reduce implicit bias activation, increase awareness, enhance control of responses once implicit bias is activated, elevate self-compassion, increase compassion toward patients, and decrease internal sources of cognitive load such as burnout, stress, and compassion fatigue.[90]

Due to systemic disinvestment and the inequitable distribution of health care services, it is more difficult to attract health care providers to predominantly minoritized and marginalized neighborhoods because, with fewer resources and opportunities, facilities are of less quality, reimbursement may be lower, and most clinicians do not have the same level of educational qualifications as more advantaged health care systems.[32] Health systems and providers in these areas may also be more challenging to access for increasing PAH awareness, which could result in fewer or slower referrals to specialty PAH centers for these patients. This could be contributing to the likely underdiagnosis of PAH. The increase in use and acceptance of telemedicine because of the COVID-19 pandemic makes it more convenient for many patients that live far from specialty care, but if the referring providers are unaware of the easier access, appropriate patients for referral may fall through the cracks.

Telemedicine

An increase in telemedicine use and expansion in telemedicine reimbursement have occurred during the COVID-19 pandemic.[57,80] Telemedicine has the potential to mitigate or exacerbate health disparities. Although telemedicine has increased access to care for PAH patients during the COVID-19 pandemic with 97% of PAH centers now offering telehealth, it may have also created obstacles to care for certain patients without access to the Internet or video-enabled devices.[57] Patients with lower SES, who live in areas with limited broadband Internet coverage or who have low technological literacy, may be particularly affected. Researchers suggest female, older, poorer, and non-English-speaking patients are the most vulnerable to inequities in routine outpatient care because of inequitable access to telemedicine in the current COVID-19 era.[91] A recent observational study found Black people with larger household sizes and ZIP codes identifying them as having a lower mean income were less likely to use telemedicine.[92] Patients with limited English proficiency had >50% lower telemedicine utilization, which could be related to a variety of reasons that needs further investigation.[92] Some potential components include unsatisfactory or unavailable virtual interpreter services, loss of insurance, providers not being comfortable using virtual interpreter services, patient distrust, concern with privacy, scheduling barriers, and not knowing interpreter services were needed at the point of scheduling. More coordinated processes are needed to streamline and improve the patient experience for patients with linguistic barriers such as translating instructions, structured electronic documentation of language abilities and preferences, and making interpreter services available at all points of health care system contact.[91]

Access to the Internet and mobile technologies is a SDH.[74] Populations with lack of access to technology are usually the same populations that are underserved with poor health outcomes. Solutions are needed for reducing the digital divide. Using low-cost Wi-Fi hotspots, Internet service provider program offers, insurance coverage including full payment parity between audio and video visits, portable hotspots, and health care institutions providing creative services or partnering with service providers are potential solutions. Further investigation in this area is imperative. Other barriers that may need to be addressed include the device having video capabilities, reliability of the Internet connection, Wi-Fi signal strength, patient privacy, and user-friendly interface design and experience.

The decreased use of video and telemedicine by women may be of particular concern in PAH since there is a higher prevalence in women, and it is worth determining whether these results were influenced by the COVID-19 pandemic or if this will be a barrier to overcome in the future.[91] Proper attention to equity and the foundation for telemedicine being developed now are critical since, like other health informatics tools such as electronic health records (EHRs), telemedicine will continue to be used beyond the current pandemic.

Recommendations for SDH documentation in EHRs have been provided by the Institute of Medicine to help standardize integration, collection, and presentation of SDH metrics.[93,94] SDH information in EHRs can make information more available to care teams that could assist in clinical decision making and target outreach.[94,95] With regard to PAH, effectively designed and implemented EHRs could support providers in facilitating, tracking, and triaging patient referrals to PAH specialists and community resources, especially during the COVID-19 pandemic, when so many patients are at risk of being lost to follow-up due to cancelation of in-person clinics and concern with accessing health centers in general.

Research in PAH

Research examining racial differences in treatment of PAH has been limited. Differences in response and treatment benefit with endothelin receptor antagonists (ERAs) in women and Whites have been shown.[18] Variations in prescribing practices and medication use in PAH by race and ethnicity have been shown, but the reasons behind such patterns are unclear. Based on the REVEAL Registry, Black patients were less likely to be prescribed phosphodiesterase-5 inhibitors, and Hispanic patients were less likely to be prescribed ERA therapy.[23] Hispanic patients have been found to be treated with less PAH-specific medications in general.[18] Racial and ethnic minorities are less likely to have health insurance, and for minorities with PAH, the lack of health insurance may have the greatest impact on their quality of care and could play a part in prescribing patterns.[2] Reimbursement for PAH testing and treatment, in general, can be challenging, requiring a high administrative burden, so it is unsurprising that a discrepancy exists between PAH patients with versus without health insurance for PAH stages of diagnosis and PAH treatments received.[2]

Clinical research programs have been significantly impacted by COVID-19. Due to the pandemic, in-person intakes and enrollment into PAH registries, such as the Pulmonary Hypertension Association Registry, have been halted. This results in a risk of not capturing PAH patients during a large window of time when they are at higher risk and when there is more likelihood of creating a greater gap in health disparities. Historically, patient registries have inadequately represented racial and ethnic minorities.[3] It is important for registries to ensure adequate representations of minorities and to capture a diverse geographic group of patients. This is a challenge while the pandemic is ongoing. Current PAH registries may already be unrepresentative of the PAH patients who are most vulnerable, are discriminated against, are uninsured, have a lower SES, do not trust the health care system and its providers, and do not get referred or are unable to obtain access to PAH specialty centers. Additionally, PAH registries may not be capturing some of our sickest patients because they are less likely to be enrolled into registries due to the burden of obtaining consent and prioritizing patient care. To adequately capture the true impact of COVID-19 on PAH, including undiagnosed patients, we will need to explore novel ways of obtaining data from other sources, such as EHRs, death certificates, case studies, or even anecdotal sources, in turn diversifying those involved in our research program, both from an enrollment as well as operational standpoint. This may provide an opportunity to innovate and potentially create new ways and sources of collecting data.

A Call for Action

Previous work on multiple types of simultaneous socioeconomic hazards suggests that a more integrated, collaborative approach is necessary to consider a possible accumulation of risk from a mix of different types of harmful exposures.[29] For example, 25% of patients with PAH have depression, which is much higher than 6.7% of the general population. Despite this, less than a quarter of the PAH patients with depression have had their depression treated.[96] This form of intersectionality requires an expanded team of care providers to be involved in the management of PAH both during and beyond these socially complex times. There is also a need to consider the framework of intersectionality to address populations with multiple minority or marginalized identities as well as the role of technology and long-term effects of the COVID-19 pandemic in PAH prevalence, diagnosis, and management.[96,97] Since the nature, impact, and intensity of exposure to discrimination, health risks, behaviors, and influences change over time, taking a life course perspective of health inequities has been suggested. The work in studying and reforming health disparities in PAH requires transdisciplinary collaborations involving social scientists, health care professionals, economists, and policy experts, among others. A life course perspective considers whether experiences at specific periods of development are more harmful than others, how the harm from experiences may accumulate over time and increase risk of exposure later in life, whether events affecting one person can disrupt others in their network, stress proliferation, and how social change and historical events change one's pathway in life uniformly across birth cohorts or differentially among individuals.[98] Experiences with and responses to discrimination differ among different races, ethnicities, and gender, suggesting researchers of discrimination and PAH may need to consider other marginalized groups and intersectionality as well as examining these groups separately.[34,37,99] The magnitude to which effect measure modification exists may help guide future exploration to differentiate between confounders and mediators as more research in this area is conducted.

CONCLUSIONS

The COVID-19 pandemic has impacted every facet of life in 2020. Preexisting disparities in health care have been magnified, including as they pertain to PAH. Additional research to further identify and explore the interrelations between factors contributing to health inequity in PAH and how these have been exaggerated by the social and economic unrest from COVID-19 is needed to guide medical professionals on how to approach barriers and intervene effectively to eliminate and prevent health disparities.

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PULMONARY HYPERTENSION ROUNDTABLE

Pulmonary Hypertension and Telehealth in the Time of Coronavirus Disease 2019

This winter our Guest Editor, John J. Ryan, MD, MB, BCh, BAO, co-director of the Pulmonary Hypertension Program at the University of Utah in Salt Lake City, gathered with Jennalyn Mayeux, APRN, DNP, coordinator of the Pulmonary Hypertension Program at the University of Utah in Salt Lake City, and Mark Avdalovic, MD, of the Pulmonary and Critical Care Division at the University of California Davis, to discuss the impact that coronavirus disease 2019 (COVID-19) has had on clinical practice and the challenges and possibilities of telehealth in the world of pulmonary hypertension (PH).

Dr Ryan: We're delighted to be joined here today by Dr Mark Avdalovic, a pulmonologist and critical care faculty at the University of California Davis (UC Davis) Health, and by Jennalyn Mayeux, DNP, from the University of Utah Health Division of Pulmonary Medicine and Department of Internal Medicine. Thank you both for joining us.

The reason we're here is to touch on the clinical impact of the COVID-19 pandemic on our clinical practices. As we all know, it's had a transformational effect on healthcare delivery and we really want to get the details from you as to how it has impacted your clinical care and how you have adapted to it. Dr Avdalovic, within California there seems to have been an earlier wave in terms of COVID-19 in your region. How did you react to this and what adaptations did you make?

Dr Avdalovic: Thank you for inviting me. Here at UC Davis Health, with regard to the PH program, we had already started a telehealth outreach as part of our everyday business in terms of taking care of PH patients prior to COVID. I happen to lead the UC Davis Health telehealth program as well as leading the PH program, so I had been working fairly aggressively over the previous year to get all of our service lines to try and do at least 1% telehealth for their visits to help accommodate the large geographic outreach we do as a health system. Patients come to us from as far away as Oregon and sometimes even Arizona, so we have an almost 1000-mile (1609-km) circle that we have to accommodate.

For many of these patients, driving here for every one of their visits is not convenient, and for PH patients in particular, so we already had the infrastructure in play for telehealth. We knew when the pandemic first hit that we had to, number one, be careful about who should really come and physically see us. We incorporate a risk calculator, which I know many health systems probably have, weighing the contributions of things like age and preexisting illnesses in the likelihood of having a COVID complication. Those who were at pretty high risk and who were deemed as essentially a usual-care follow-up, maybe for touching in on how they're doing with their medications, their symptoms, new side effects, things like that, where perhaps the physical exam is not absolutely essential at that visit, we steer those patients toward telehealth. I would say that summarizes some of our initial accommodations in March, April, and May.

The other thing that's definitely affected us, and I know it has affected all practices for PH, is that the ventilation/perfusion (V/Q) scanning that we normally would like to have is no longer really offered by our radiologists. They will not do the ventilation portion. We're stuck with perfusion only. That has definitely created some issues, so we have to sort of combine computed tomography–scan lung images with perfusion on a V/Q to get the information we normally get from a full V/Q.

Similarly, for full pulmonary function testing (PFT)—that is, spirometry, lung volume, and diffusing capacity—we have to have those patients have a negative COVID test within 48 hours of having the PFT. The process of scheduling not only their PFTs but now a COVID test, usually done as a drive-through, then following up on that and making sure it's negative, then getting the PFT, that has certainly added to some of the administrative hurdles of the pandemic.

Certainly, some of our approaches have made it easier to maintain as full a clinic as possible. I will say that even with all of these attempts to make things easier for patients and seeing them via telehealth, we are at approximately, I would say, 80% of the clinic traffic that we normally would have at this time.

Dr Ryan: Great. There's a lot to build on there. Jennalyn, if you could weigh in about the changes you've made at the University of Utah program and how things have adapted both in the early stages of the pandemic and 9 months into it?

Dr Mayeux: We have had some or all of the same challenges, particularly with V/Q scans, PFTs, and the interruption of our traditional testing schedules and routines for our patients. In the beginning, our platforms were not readily accessible. There was a big learning curve for us and our patients because we did not have that infrastructure for telehealth built into our program yet, but we had some excellent staff that really helped us push through, and now we've used a couple of different platforms.

Our patients overall have been really receptive to it. The first few weeks and months we were getting so many questions about COVID, about risk, and I think there was a lot of appreciation from our patients to have this platform where they could still reach out to us and still have conversations, know that

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their care was still available and that their concerns were still being addressed, but also to give them some reassurance about what was going to happen in the months ahead of them. We also serve a 5-state region and the geographic distances are really challenging. I do have hope that in the future we can continue these telehealth programs and continue to improve access for our patients.

Our clinic visits are up despite the challenges on our pulmonary side and the attending schedules with COVID, so we have stayed busy. We still try to accommodate patients who are less familiar, less sophisticated in their technology adaptations. Patients with language barriers, we still bring them to the clinic, but we've really tried to reduce the amount of traffic in our clinic flow; we've each taken days to be present in clinic so that we can rotate through the rooms better. Overall there has been a lot of risk assessment from both sides with our patients, and it sends the right message that COVID-19 is a serious problem and we want to keep them as safe as possible.

Lastly, for the most part we've been able to keep patient care from being too interrupted, but as Utah is now surging, we've had more challenges with scheduling all of those long lists of procedures and workups that we want to bring patients from out of state in for. We're still getting them done in a semitimely fashion but it's definitely interrupted our testing.

Dr Ryan: That's very insightful from both of you. You both highlighted the initial response in March, April, May, but now we're in a kind of business-as-usual October, November, December response. I think having to transition has been, as Jennalyn said, a steep learning curve, and adapting to it has been important.

Mark, I wanted to touch on the people we're missing. You commented that the normal clinic traffic is 80% of what it was. Just to be explicit here, the 20% missing haven't gone away. They still have disease, and, as we know the Pulmonary Hypertension Association (PHA) has been a good advocate for, a large number of people out there with PH and pulmonary arterial hypertension are not getting diagnosed or getting diagnosed late. It sounds like both of you have set up good infrastructure for telehealth visits, but how do we reach that 20%? Who are they, and how do we reach them?

Dr Avdalovic: One thing I'm not sure of is which electronic health record you all use. We are on Epic. We were able to create, essentially, a workbench report that looks for patients who have been lost to follow-up. There's an algorithm that's applied and it is specific to the clinic that is asking that question. You have to log in under the clinic-specific Epic department and you can run a report over whatever time frame you want to look at. We like to look at the last 4 months, patients who were given an appointment and either never showed up, or asked to cancel and then never rescheduled. At some point, someone said, "I want to see you," and somehow that appointment never happened, whether it was a no-show or otherwise.

Also built into this report is the more generally truly lost to follow-up, where some of our patients choose to make their appointments at a later time. I may say, "I want to see you back in 4 months," and they'll say, "Okay, I'll make that appointment a few weeks from now," and then they don't bother. Well, we can search against that original request for 4 months, which is placed in the discharge portion of my note.

I'll be honest, in the beginning it was a little humbling how long that list was of patients who had been lost during this time, and so we're actively identifying them and reaching out to them. What we're finding is that some of them simply either can't do telehealth because of a technical reason—so we do offer telehealth via just simply a telephone call. We do try and make it as simple as possible, but in terms of being seen in person, many patients just feel very nervous about coming here, so we've tried to accommodate them as much as we can.

To answer your question, number one, we're trying to use the tools that are available to us to identify these people who've been lost to follow-up, but there's the other part you mentioned, which I think is equally important, that there are folks who are being worked up by our community partners and maybe that process has slowed down. When we see that, looking at our total referrals, they are down a bit—not a huge amount, but definitely down, particular during this time of year, when we'd be seeing a bit more. Compared with last year I think we're about 10% down on referrals. I do think that reflects what you brought up, that in the community patients aren't coming to the office, they're not being seen, and their symptoms are not being addressed.

Dr Mayeux: Yes, my concern is that the patients we're missing are the patients who need us the most. Those with low levels of health literacy, who don't understand, maybe, that we lose ground and may not get it back, or it may take us a longer time to get it back. We've done the same thing. We've tried to comb through charts. We are clearly not as able with Epic to pull the things that we probably should be able to, but we've done a lot of manual searching. We're catching patients whose med refills are coming up and we haven't seen them, patients who've made appointments and then canceled them.

Really, I think there's a fear of what telehealth is. There is some idea that the value is different by having a conversation and not having that hands-on physical assessment. But I find that our visits are longer. I ask more questions and actually find out probably more about the patients in those visits to really address what their concerns are and what their goals of care are and how can bridge the gaps between their concerns, their safety, and their health care.

Our referrals were slow in the beginning. We were able to get patients in really quickly at first, and now we're back to our usual referral times, as in the past. But I don't think our community referral sources are doing as many echocardiograms to catch those elevated pulmonary arterial pressures. I don't think that the testing is as robust for bringing up these abnormalities, so we are seeing that, too. The telephone calls have been invaluable, knowing that we can still have those good conversations with patients over the phone. Being able to be reimbursed for them, quite frankly, makes them a very good option for our patients. It does take a lot of phone calls. We write letters to patients when they're not coming in to try to reach them, but I will always be concerned that we are losing the patients who need us the most.

Dr Ryan: We've known already that there's a delay in referral to us, and I think what this has highlighted is that there's probably even more of a delay; or at least, any ground that would've been gained through advocacy programs, raising awareness of diagnosis, may have been lost because people just aren't going in to see their providers and then, as you rightly point out, there's a delay in doing an echo.

I want to touch on the diagnostic workup. With the barriers now for PFTs and V/Q scans, how do you prioritize people for diagnostic workups now? Do you anticipate that we're overdiagnosing Group 1 now, or missing Group 3? What are the consequences of these challenges to doing the thorough diagnostic workup? You look at the traditional McLaughlin and Archer 2009 American Heart Association/American College of Cardiology Foundation consensus statement, and that long list of testing is very hard for primary care providers to do. I think a large part of PH programs are acting as diagnostic centers. You can call up and say, "I have symptoms of PH," and traditionally we would have said, "We'll take it from here." Is that harder to do now?

Dr Mayeux: I think a lot of our challenges come internally from patients. They may want to have a conversation with us, but may not be excited to go to the PFT lab when they hear COVID testing is involved. Certainly, I think there's lag time there, particularly with those patients who were not straightforward. Those patients who are most likely Group 2, Group 3, are not able to get those sleep studies as quickly because they may not be doing titration studies within the sleep labs, so we're having a harder time discerning the groupings for those who definitely have overlapping comorbidities.

Then there's actually getting patients to come in for testing. It is easy to say, "You're going to have your echocardiogram at 11:00, your PFTs are at noon, and we'll see you in the office at 1:30." That algorithm has really changed with COVID testing, and with our office constraints as we try to reduce the traffic in clinic. I think we can still get the testing we need, but it's just more difficult with patients' desires, and then the ability of what we can do. We cannot do, for example, maximum inspiratory pressures and maximum expiratory pressures in within our PFT lab, but we can get the basic PFT. We can really look at patients and find those who are highest risk; we can still do tox screens so we can still find those methamphetamine (meth) users. We can still do a lot of the tests that help us stratify these patients, but it's the nitty-gritty, the perfusion scans with the ventilation component, the sleep studies; Group 3 patients are probably the most at risk of being lost.

Dr Avdalovic: I agree with what both of you have said, that part of what we do as a center here is the diagnosis and categorization of one's PH. Most of the referrals that come to us, the referring physician frankly assumes that the patient has Group 1 but has not done a complete workup. Our rates of identifying patients who have true precapillary disease that may benefit from vasodilator therapy is probably about 60% or 70%; the rest are reclassified into a more appropriate category. The group that ends up being reclassified, or appropriately classified, most frequently, in my opinion, is Group 3, and so that is the group that ends up being at risk with the lack of PFTs being as robust and frequent as we'd like; that is the group that I have some concern about.

Certainly, I think there is also some concern about Group 4 patients being missed and being misdiagnosed as Group 1 because the V/Q is not as precise as it is when it's done as a true V/Q. I would say that we're certainly not missing any surgical disease. That would be unusual to miss. It's interesting, as part of our office, that we have increased how many pulmonary angiograms we do. We probably didn't do as many this time last year. We might have done 5 or 8 pulmonary angiograms in a year and now we're doing quite a bit more. We might do 2 to 3 a month, just to be absolutely sure we're not missing something. That has definitely changed some of our workload.

Dr Ryan: I do think as well that there's an opportunity to use some scoring. Pretest probability, I think, has had a big impact as well. We do have the scoring systems such as the OPTICS scoring system that was recently published by Harm Bogaard, and then the VEST scoring system by Anjali Vaidya. We get an idea as to what is the likelihood of Group 1 versus Group 2, and then, with the pretest probability ahead of cardiac catheterization, in terms of trying to help people decide, "Do I really need a right heart catheterization? Is a right-heart catheterization here going to change my practice?"

If you have a 70-year-old male with a body mass index of 40 and an apnea-hypopnea index of 40 and nonadherent with continuous positive airway pressure, your right-heart catheterization is probably going to have a high wedge and high pulmonary artery pressures, and you're not going to start pulmonary artery hypertension–specific therapies. But if you have a 30-year-old woman with scleroderma and a blown-out right ventricle with interventricular septal flattening, it's more likely that you're going to have an impactful right-heart catheterization. I think that those are useful in terms of decision making for some of the diagnostic testing.

Mark, I want to turn to you. We've talked a lot about the people being referred in and new referrals, but I also want to get your thoughts on established patients. Obviously we have not visited each other's practices yet, but like everyone else in PH circles we were doing echocardiograms every 3 to 6 months, doing 6-minute walk distance every 3 to 6 months, doing brain natriuretic peptide every visit. We had this standard protocol in place—that you come to see us and we do everything. How have you changed that—what is the routine testing that you're now doing at that regular follow-up rather than relying on your *gestalt* and saying, “You know what, I think Mrs. Johnson is doing well,” or “I think she's doing poorly.” How do you gauge through the video chat? What objective measures are you using and how do you adapt to that?

Dr Avdalovic: Great question. I think there are certain techniques that we will occasionally employ during a telehealth visit. Number one, if they live in a 2-story house, I actually have them go up their staircase and come back down, and I'm looking to see how short of breath they are. Sometimes I will ask them very open-ended questions where I'm hoping that they have a very long response because I'd like to see how they do with a long multi-sentence response to a question.

One technique that I've adopted—and it's not my technique, I saw it early on in the pandemic—is to have the patient take a deep breath and then count out loud until they have to take another breath. Usually if you can get them to get to 30 then their functional capacity is at least reasonable. If they take a deep breath and then after counting number 10 or 11 they have to take another breath, that speaks to their lung capacity perhaps not being outstanding.

Those are little things that we do; however, at the end of the day, we are still trying to hit our calendar-specific targets for a patient. If that's a patient on a single drug that we comanage with a community physician—maybe on tadalafil, for example—we still want to see a yearly 6-minute walk and an echo depending on what else they have going on, maybe a PFT. Whereas when they are on 2 drugs, that frequency is close to every 6 months. If they're on 3 drugs, we're certainly getting an echo every 6 months and we might even cath them every year. It depends, but we're still trying to hit those basic targets as much as we can.

We are using our community partners maybe more than we have before. We're willing to accept the PFT that's done locally for the patients rather than bringing them in and trying to do a really long visit that has the echo, the PFT, the 6-minute walk all in one day when it's hard to get those things scheduled given the challenges. We have begun to accept some of the community tests. I'll be honest, it is a little frustrating, particularly with echocardiograms—I'd rather see the images myself than read a poor report. It gets a little frustrating, but in certain case-by-case examples, you have to accept the best that you have available to you.

Dr Ryan: Thanks for that insight. I agree, I think it's hard to be as absolute as we previously were about that. I think there is an opportunity for all of this to be quite empowering for patients, that we can tell them, “You tell me your blood pressure, you tell me your heart rate, and you go and get your brain natriuretic peptide” and then we'll get the results sent over to us. I think there is an opportunity to empower patients, but again, there are some people who will say it's too hard, or they don't have the resources available. Jennalyn, same question to you: What are you doing right now in terms of follow-up? How are you getting a sense of how people are doing when things are remote, and how do you react to and accommodate that?

Dr Mayeux: I think more now than ever, shared decision making is on the table. Between, “Okay, you have a community hospital, we honestly can get echo reports that are 3 sentences no longer than 4 words per sentence,” which doesn't give us all the information that we want but at least gives a little bit of an idea as to how a patient's doing; but maybe that saves them an overnight stay in the valley to keep them safe at home. Decision making between when we do the testing, where we do the testing, and even medication changes. Some patients are happy to say, “I don't want to change a thing right now but as we get more comfortable, we get through this,” and then I'm more willing to have maybe a specialty pharmacy person in their home or via telemedicine.

I talk a lot about scales being one of the most useful tools that patients have in their homes to help us and keeping those records of weights, because that really helps us get some insight into how those patients are doing. Pulse oximeters—get them out in their actual visit and show me what their heart rate and oxygen levels are doing. Walking around the room, same thing, to see how their oxygen responds. I think one of the most helpful things is having patients go get their medication bottles so we know precise doses of what medications they actually are taking, and how much of a medication they may be taking, and how many days a week they may be taking extra medication.

I think listening to how well a patient speaks to us is very helpful. I do think that we're going to end up in a world of hurt because our patients are not going to the grocery store, they're not walking around Costco to get that everyday physical activity or a few times a week to help them judge if they're getting worse or better. Our 6-minute-walk protocols are a little different now and patients struggle with that; this may just be our facility, but some of that testing is hard. Deconditioning and functional capacity are going to be really hard for us to assess. What's just being in our homes, not walking in the parks, not going down to see the neighbor, versus what's actually disease progress? We rely on a lot of labs and labs that are done at outside facilities may not be exactly equivalent to our labs either.

Dr Ryan: One thing I want to touch on is that with any PH program, it's a team sport, right? We have our medical assistants, clinic coordinators, study coordinators, APCs, MDs, social work, etc., the traditional things that have been incorporated into the PH comprehensive care centers. When we were in person, it was very easy to be a team. You'd see each other. Looking back, it's hard to believe that so many of us did fit into one small room! How are you keeping your team structure and that sense of common purpose?

Dr Avdalovic: Well, I'm embarrassed to say that we probably, most of the time, still try to do it the same way we used to. Our clinic space is large enough, and it turns out that the half-days that we are here when PH patients are being seen, it just happens to be that it's mostly our teams that are seeing patients. One of their half-days that we're here that isn't true and we've had to make some accommodations, but for the most part our pharmacist or nurse coordinators are here.

If they can't be, we have incorporated this unique tool within our telehealth platform that allows us to invite up to 10 different participants. Theoretically, 10 different people could be in 10 different locations, yet still join in the same visit. Not that we've ever done anything that complex, but it is technically possible. We utilize that a little bit. One of our faculty actually had COVID and had to do his visits from home. He would join remotely to visits that were sometimes actually happening in the clinic. We've taken these approaches to try and accommodate some of the changes that have come with the pandemic.

Dr Mayeux: We have had changes. We've had staffing structure changes. Amidst the pandemic we are restructuring our program to incorporate more nursing, which is going to be amazing for us. One of the most valuable things we have done together is to start weekly team conferences via Zoom. We will spend a lot of time informally in the same clinic area, able to review both pulmonary and cardiology patients because we are a multidisciplinary program, but we have these—as Dr Ryan likes to call them—Brady Bunch sessions where we all get on Zoom and present our challenging cases and go through images all together. I think the access has even been better, at least from an imaging standpoint, because we can scroll through. We have 3 pharmacists on our team who are incredible and they can join in wherever they are, if their responsibilities are inpatient or in clinic, and we can really connect together as a team to try to keep in touch with what's going on and most effectively treat patients who have overlapping disease processes.

Dr Ryan: Great, thank you both for your insight. Another question I have relates to misinformation. There's a lot of medical misinformation, a lot of misinformation in general, unfortunately, in our society at the moment. When patients come to you with questions about COVID, questions about vinegar and mouthwashes and even vaccines—even the more sophisticated questions about vaccines—how do you handle those questions? What do you tell them and what expectations do you lay out, or what resources do you provide to them?

Dr Mayeux: I never shy away from saying that there are things we don't know, particularly things COVID-related. We have a lot of vaccine questions coming at us these days and our patients ask, “Am I going to be able to get it? Am I getting it? Will you tell me to get it?” I really try to be honest with them that I would never expect them to do something, like get a vaccine, that I would not be willing to give myself or a family member. We just don't have a lot of that information and that hard evidence. When we do, we'll absolutely share it with them.

In the early days, I had a couple of patients ask me for prescriptions for hydroxychloroquine, and it was really a long educational session about passions versus evidence. I try to keep these conversations as grounded as possible, make it clear that we're not trying to keep anything from patients, but we will certainly treat them the best that we possibly can once we have good evidence to provide them safe care.

Dr Ryan: Mark, same question to you. How do you guide patients and provide them access to high-quality information at a time when the information is evolving so quickly and there are so many areas surrounding COVID-19 that we don't know about yet?

Dr Avdalovic: Well, I think I usually try to gauge or assess where they're coming from and what their concerns are. I have to say—I'm trying to use my words carefully here—I don't want to say disappointed, but certainly surprised at how many of our patients did not and still do not take the COVID pandemic seriously, in particular because they themselves are not the healthiest of people. I'm frequently stunned when I get a question, as I did last week, like “You make me wear this mask every time I come to clinic, don't you agree that this doesn't really do anything? Have you ever even seen a patient with COVID?” This is as we currently have, I believe, 80 COVID-positive patients in our hospital today. It's been stunning. I'm sure we all agree that this part of the conversation was one that we didn't anticipate, that the public health component would be so controversial.

I try and push them towards resources that I trust—our university has a website with frequently asked question about COVID and we share that resource. Certainly the Centers for Disease Control and Prevention, as well as every one of our counties, really, has excellent data so they can see what's happening in their own county and access information resources within those websites. The vaccine question has been coming up a lot here in the last week. I try to explain to them that I don't have complete control as to who's going to get it and who isn't, but that given a disease such as PH, they will more than likely fall into the high-risk group and be in the front of the lines.

Dr Ryan: Great. Just one more question, and I'll cut to the chase with it: the issue of licenses. Mark, you have to cover a wide area. How do you handle this issue?

Dr Avdalovic: We try and discuss telehealth issues with our compliance office on a monthly basis. My perspective on this is, if I practice medicine on a consistent basis in a state in which I am not licensed, technically that state could claim that I am practicing medicine in their state without a license. For example, Oregon is a very strict state when it comes to this type of thing. I have many patients based in Oregon. How do I navigate this? What I usually say to the patient, who for whatever reason has decided to do their visit via telehealth from their Oregon residence, is to emphasize that it would be in their best interest to have a local physician who is familiar with PH. I offer them the website from the PHA for them to peruse in order to find a local resource for PH. But I recognize that sometimes, geographically, I am the closest PH doctor to them and that good medicine comes first. If it's an established patient and they have either moved to Oregon or are living there as part of some pandemic response, we discuss that it would be ideal for them to be in California when we're having these visits; but then we go on and deal with their medical issues. I am very careful in my documentation that I've offered the patient a variety of different resources, and then we move on to the salient features of their clinical care.

Dr Ryan: Jennalyn, the last question I want to ask you goes back to our sickest patients. The initiation of parenteral prostacyclin always has been hard to do, always has been a tough discussion, and now we're purposely saying to our sickest patients that we need them to come into the hospital and do our most advanced testing. What are your thoughts on this and how has that changed?

Dr Mayeux: I don't think there's been one approach that we've taken with every patient. Once again, I'm very big on shared decision making. With our patients, we historically have always started our parenteral prostacyclins inpatient and we have initiated a subcutaneous patient at home, feeling out who is most responsible, but we really do want to limit the time in the hospital, maybe adapting to what unit a patient can go to in order to not have any overlap with COVID areas.

I don't think we have missed any new initiation on prostacyclins, but we have maybe delayed our patients who need to go from oral prostacyclin therapy to an intravenous or subcutaneous route. If something dramatically changes, we will make this happen as soon as possible, and that's mostly just been since we've undergone a surge lately and really have had bad issues in the last few weeks. Knowing that these patients know we're just a call away, we can always get them into the hospital, they'll always be a priority, but trying to manage their safety on both sides with PH as well as COVID risk.

Dr Avdalovic: I don't think that we've missed an opportunity to put a patient on parenteral therapy if we thought it was medically necessary. We do have a very large meth-using population. It's probably the largest meth-using population of any PH center in the United States, because we are in Northern California where meth got started. Parenteral therapy, intravenous therapy, is really not an option for the majority of those patients. We do test them very frequently for their tox status, but nevertheless I would be very careful about placing a catheter in a patient with recent meth activity who now has severe PH requiring parenteral therapy. We'll start them on subcutaneous if they're very severe. If they're mild, obviously we exhaust all of our oral options. If we've arrived at a point where we feel that a patient has the social support and capability to manage an intravenous approach and they are severe enough that they really will benefit from that, we have gone ahead regardless of the pandemic, and brought them in and gotten them started.

Dr Ryan: Yes, and think for the most part, as Jennalyn said, it's a shared decision-making discussion with patients and their support, ensuring they have the confidence in you and your team, to make sure that you're doing that as safely as possible.

For me, this has been a tremendous discussion with both of you. It has been so valuable to hear your insights and how you've adapted things so successfully amid the challenges you've faced. I know that you both have been working incredibly hard and putting on a lot of hats over these last 9 months, as care providers and as family members for your family outside of work, so there have been a lot of demands on your time. We do appreciate, on behalf of the editorial board of *Advances in Pulmonary Hypertension* and the PHA, both of you taking the time out of your schedules to be part of this today.

PH PROFESSIONAL NETWORK

The Benefits and Challenges in Delivering Telehealth in Pediatric Pulmonary Hypertension

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BACKGROUND

The COVID-19 pandemic has had an extraordinary impact on the health care system in the United States, including the rapid adoption and implementation of telehealth in many subspecialty clinics, including pediatric pulmonary hypertension (PH). Pediatric cardiology has been a leader in the telehealth field with home and remote monitoring through the use of blood pressure cuffs, oxygen saturation monitors, weight scales, feeding logs, cardiac implantable electronic devices, remote interpretation of electrocardiograms (ECGs) and echocardiograms, yet replacing routine clinic visits with virtual telehealth appointments is a new experience for most pediatric PH providers.

Pulmonary hypertension in infants and children is associated with idiopathic and heritable pulmonary arterial hypertension as well as a diverse group of pulmonary, cardiac, and systemic diseases.[1] Despite advances in medical therapies, there continues to be significant morbidity and mortality in infants and children with PH.[1] As there is no cure for PH, treatment is aimed at improving symptoms, exercise tolerance, and slowing the rate of disease progression. Disease management in PH often requires complex care involving pharmacologic and nonpharmacologic therapies, laboratory testing, symptom monitoring, and diagnostic imaging. However, most PH symptoms and adherence to the medical regimens have the potential to be observed with telehealth or remote monitoring.

Given the unprecedented demand on the health care system during the COVID-19 pandemic and to minimize the risk of exposure to patients and caregivers to the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), telehealth should be explored as a tool in treating infants and children with PH. This article examines the current systems and resources as well as the challenges, benefits, and future direction of telehealth in pediatric PH.

TELEHEALTH DEFINITIONS

Telehealth is the use of technology and devices such as computers (laptop or desktop), telephones, smartphones, and tablets to connect patients and health care professionals. The term telemedicine has been in use since the 1960s when closed circuit television was used for psychiatric consultations.[2] Telemedicine is a subset of telehealth that refers to direct patient care, and the distinction between telemedicine and telehealth is similar to the comparison between medical care and health care.[3] The modern era of telehealth services can be separated into the timing of the interaction, termed asynchronous or synchronous services.[4] *Asynchronous* telemedicine does not require real-time patient interaction. For example, teleradiology is asynchronous, wherein images are sent to a radiologist to review and interpret on their own.[5] On the other hand, live video conferencing is considered *synchronous* telemedicine, or real-time interactions between patients and health care providers.[3]

TELEHEALTH PLATFORMS

As COVID-19 surged in the United States in spring 2020, the Department of Health and Human Services issued a notification of enforcement discretion that health care providers were permitted to use widely available communication applications and platforms without the risk of penalties imposed by HIPAA.[6] This has allowed health care providers to serve patients in "good faith" when using various telehealth platforms. Health care providers may now use popular nonpublic-facing applications to deliver telehealth. Examples of nonpublic-facing video chat applications include Apple FaceTime, Facebook Messenger video chat, Google Hangouts video, Zoom, and Skype. Under this notice, health care providers may not provide telehealth on Facebook Live, Twitch, TikTok, or any other platforms that are public facing. Many large health care systems in the United States already had HIPAA-compliant telehealth platforms in place before the COVID-19 pandemic, and the chosen platform varies at each institution. See Table 1 for a list of HIPAA-compliant telehealth platforms.

Table 1. HIPAA-Compliant Telehealth Platforms

Updox
Doximity
Doxy.me
Zoom for Healthcare
Skype for Business/Microsoft teams
VSee and Google G Suite Hangouts Meet
Amazon Chime
GoToMeeting
Cisco Webex Meetings/Webex Teams
Spruce Health Care Messenger.

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TELEHEALTH LICENSING AND BILLING/REIMBURSEMENT

The COVID-19 pandemic has also prompted changes to telehealth reimbursement and licensing. On March 17, 2020, the Center for Medicare & Medicaid Services changed health care providers' reimbursement so that all telehealth services provided for Medicare patients are reimbursed at in-person office visit rates indefinitely, yet it remains unclear how long this rate of reimbursement will continue, and some private health insurance companies that followed the government's direction could go back to paying a fraction of the cost for telehealth visits.

As of March 2020, health care providers may now also furnish telehealth and other services using communications technology wherever the patient is located, including at home, even across state lines.[7] However, individual state laws and regulations influence pediatric telehealth programs more than national guidelines. Little standardization exists among states in pediatric telehealth and licensing board requirements, and telehealth practices vary widely from state to state. The Center for Connected Health Policy retains lists of each state's laws, regulations, and reimbursement in regard to telehealth.[8] Additionally, the Telehealth Resource Centers are another resource for state and region-specific telehealth information.[9] Finally, the American Academy of Pediatrics offers a comprehensive list of coding for telehealth services.[10]

CONDUCTING A TELEHEALTH ENCOUNTER

Telehealth Consent and Documentation

Before beginning the telehealth encounter, consent from the patient or parent/caregiver must be obtained and on file. Common language around telehealth consent states:

> I performed this consultation using real-time telehealth tools, including a live video connection between my location and the patient's location. Before initiating the consultation, I obtained informed verbal consent to perform this consultation using telehealth tools and answered all the questions about the telehealth interaction.

Interpreters

If the family or caregivers are not fluent in the same language, it is important to have a medical interpreter available for the entire telehealth visit.

History

Obtaining a patient history and review of symptoms is not location dependent and can be easily achieved during a telehealth encounter. The home environment may prompt a better history or symptom recall. Additionally, adherence to the medications or the medical regimen can be reviewed. Providers can examine medication vials and bottles to confirm correct dosage and administration.

Physical Exam

Although a patient's heart and lung sounds cannot be auscultated, or a liver edge and pulses palpated, the general appearance and mental state can be ascertained during a home telehealth exam. Providers may also inspect for pallor or cyanosis, labored breathing, edema, clubbing, and evidence of syndromes or genetic diseases. In addition, prostacyclin infusion insertion sites (central venous or subcutaneous catheter) may be observed over telehealth.

TELEHEALTH CHALLENGES

Although there was rapid adoption of telehealth within pediatric PH, several barriers in implementing and delivering telehealth exist.

Vital Signs

In most cases, vital signs cannot be obtained in the home environment. However, some medically complex patients may have home monitoring equipment, such as pulse oximeters. During a telehealth visit, such devices may allow for collection of vital signs, including heart rate, respiratory rate, and pulse oximetry. Parents may also be instructed to count pulse and respiratory rates. Additionally, if a home health nurse is available, he or she can obtain a full set of vital signs and growth measurements. However, at times, this in-home technology is not available, creating the challenge of obtaining important biometric data points.

Diagnostic Imaging and Testing

One of the biggest challenges of telehealth is the inability to perform diagnostic imaging, such as echocardiograms, ECGs, cardiopulmonary exercise testing, and pulmonary function testing at the time of service. In some cases, there may be an option for the patient to have imaging and/or testing completed and available to the provider before the telehealth appointment. This may be completed at their home institution or a satellite clinic. However, when this is not an option, telehealth visits should be reconsidered, as these studies are crucial to track progression of disease and develop a treatment plan.

Ancillary Services

Ancillary services that are vital to the multidisciplinary team, such as nutrition, respiratory therapy, pharmacy, social work, and behavioral health, may or may not be available to participate in a telehealth appointment. This will vary at each institution and may require follow up at a later date.

Patient/Caregiver Presence

In some instances, the ability for the health care encounter to occur in the home setting has given the misconception that either the caregiver or the child does not need to be present, but just as if they were in a specialty clinic, both patient and legally approved caregivers need to be present for telehealth appointments. If either the caregiver or patient is not available, the appointment will need to be rescheduled.

Technological Barriers

Both providers and patients or caregivers must have access to technological devices (ie, desktop computers, laptops, tablets, smartphones) and a stable Internet connection. Although numerous school districts in the United States are working to close the digital divide, this may continue to be challenging for low-income and rural patients and caregivers. Some communities, such as the Amish or the Mennonites, do not partake in technology for religious reasons.

TELEHEALTH BENEFITS

While there are numerous barriers to telehealth, there are several attributes that may enhance the quality of care a pediatric PH patient receives. Telehealth has the potential to increase accessibility of health care and education to patients, allow for better assessment of the home environment, and enrich the patient-provider relationship.

Accessibility

Many pediatric PH centers are regional programs, and it is not uncommon for patients and their caregivers to travel great distances to receive comprehensive care for their disease. As a result, significant financial implications for attending an in-person clinic appointment include the cost of gas and hotel rooms. There may also be missed work and the need for arrangement of childcare for siblings. The ease and convenience of telehealth allows the patient to receive quality care on a virtual platform in his or her own home, thus reducing the cost and burden associated with travel. This has the potential to reduce missed appointments and may result in earlier detection of disease progression or barriers to care.

Assessment of the Home Environment

Through telehealth, patients provide a virtual invitation into their home, which deepens providers' understanding of their patients and their home environments. Providers have the insight into a patient's level of resources that may not be gained in a traditional in-person office visit. This can assist the health care team in identifying barriers that may affect their patient's health and ability to adhere to his or her medical regimen. The visual sweep of a patient's home also puts into context the day-to-day life that a patient lives. It highlights the resiliency of families that have adapted their personal lives to make mini-hospital rooms for their patients with feeding tubes, monitors, and ventilator support. Being able to see the patient in his or her living room or bedroom is also a reminder that many more things define the patient aside from his or her PH.

Enhanced Patient/Provider Relationship

Patient and caregiver involvement are very important to the health care team, as they provide information surrounding overall well-being, symptoms, side effects, and the feasibility of treatment plans in a child's life. Telehealth may change the dynamics between the patient and provider, as it affords the health care team the ability to see a patient in the environment in which they are most comfortable. Children have a better sense of control at home versus in the clinic. They may be more relaxed, less reserved, and eager to share their favorite things over the video conference with their health care team. Similarly, caregiver involvement may change when participating in telehealth from their home, and telehealth may empower caregivers to take a more active role in developing a treatment plan. Telehealth can level the playing field between the patient and provider and move away from the asymmetric relationship that occurs inside a traditional clinic setting.

FUTURE DIRECTIONS OF TELEHEALTH

At this time, telehealth in pediatric PH is largely focused on clinical evaluation and replacement of in-person clinic appointments. However, there is an opportunity to explore several other interventions delivered over telehealth, including education, social support, and home monitoring devices.

Education

There is an opportunity to advance the education of pediatric PH patients and their caregivers on PH physiology, disease management, medications, and transition to adult PH services. Multiple studies have shown increased patient knowledge of disease and improvement in objective clinical outcomes when telehealth is used in patient education.[11] Providers may also feel like they have more time to focus on patient and caregiver education over telehealth rather than a rushed clinic setting.

Social Support

Patients, siblings, parents, and caregivers all experience the physical and mental challenges from living with or caring for a child with PH. Telehealth offers a platform to obtain support from providers and peers. For example, support groups may be offered by social workers or clinical psychologists over telehealth for patients, siblings, and caregivers. The barriers that might restrict support group attendance, such as time and distance, may be overcome when telehealth modalities are used.

Monitoring Devices

While many adult subspecialists have begun using home monitoring devices, they are not yet widely adopted by pediatric PH providers. As technologic advances are made, pediatric PH patients may be able to use devices that transmit data such as activity, weight, blood pressure, pulse oximetry, and ECG waveforms. These monitoring devices may enhance the telehealth encounter and overcome the barriers that providers view in the providing telehealth services.

CONCLUSIONS

The use of telehealth during the COVID-19 pandemic will likely have a lasting impact on the delivery of pediatric PH healthcare. During the current pandemic, legal restrictions such as reimbursement and out-of-state licensure issues have been alleviated, allowing pediatric PH programs to explore the use of telehealth in this patient population. However, it remains unclear how long these changes will remain in place. Additionally, having telehealth capabilities does not mean that every patient encounter is required to be through a virtual platform. A hybrid approach of in-person clinic visits and the use of telehealth may balance the challenges and benefits of each modality. Every pediatric PH center should identify the telehealth procedures that are ideal for their practice and patients to determine the best approach to care.

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Pulmonary Hypertension Clinical Trials and COVID-19: A Discussion With John Ryan and Roham Zamanian

In this special discussion for the Pulmonary Hypertension Association, Guest Editor John J. Ryan, MD, MB, BCh, BAO, of the Division of Cardiovascular Medicine at the University of Utah in Salt Lake City, Utah, spoke with Roham Zamanian, MD, Associate Professor of Medicine and Director, Adult Pulmonary Hypertension Program at Stanford University in Stanford, California, on the impact that COVID-19 has had on clinical trials for pulmonary hypertension.

Dr Ryan: My goodness, it's an incredible time we're in. What we want to touch on is the impact of the COVID-19 pandemic on pulmonary hypertension (PH) research. Based on your expertise in the field and the relationships you've built over the years, we felt that your perspective and experience would be representative of what a lot of people are dealing with. Can you talk to us about the impact of COVID-19 on your research program?

Dr Zamanian: That's a really broad question, but I think I would be remiss not to point out that I don't think anyone expected not to be impacted from a research perspective by an astronomical event like this. I think what you may hear, at least from our single center experience, are things that are, both in a good way and a bad way, impacting research in general but especially for a rare respiratory disorder.

Our perspective is as a center where we conduct basic, translational, and clinical research; and on the clinical side, we do our own academic studies, some National Institutes of Health (NIH) funded and some sponsor initiated. Across the board, this pandemic has strained and stressed our resources. I'm not the expert in the basic studies, but I can tell you that, from what I hear from my collaborators, the conduct of basic research has been impacted by the footprint of the laboratory bench environment, in other words, the limitations of having a number of postdoctoral and other research colleagues in a small laboratory environment.

When the pandemic initially hit, there were tremendous limitations, and as we moved on through more of a progressive easing of those limitations, the conversation very quickly became about how many postdocs per square meter would be allowed to be in an enclosed indoor laboratory bench environment. That's what I hear the most about from our bench researchers, and the limitations on mobilizing and activating postdoctoral researchers and research scientists back into the laboratory with or without COVID testing has been really, really interesting.

On the clinical translational side, same thing. What we saw initially was a rapid closure of exposure, meaning there were institutional mandates on interactions at the university medical center between our clinical research subjects and the clinical research team. I think one of the things that we learned early on was how important communication is at the Department of Medicine and at the university level. I don't think anyone was prepared to have these kinds of organized conversations about what would happen to clinical research.

We were stuck in a situation in which we felt that the experimental therapies being offered to these patients with a rare disease was, in a way, lifesaving; at least we felt that it was crucial that these were subjects who really needed to still experience the clinical research conduct. Initially, it was a fog-of-war situation where communication was difficult; we didn't know who to get permissions from, but eventually, the Department of Medicine set up a system where we proposed and got authorization for conduct of clinical studies that we felt were urgent.

To do this in a more organized way, the bottlenecks were the ability of patients to come on campus on the medical side to conduct their clinical research activities, the protocols by which our clinical research staff could come to the medical center to evaluate these patients, and what the proper environment was for those interactions to take place. Did the clinical research team need to get COVID tested? What about the subjects? Did they need to be tested every time they came in?

Within that tangle of issues was the idea that respiratory function test, pulmonary function testing, ventilation/perfusion testing, 6-minute walk testing—in the very early days, at least with the 6-minute walk—there were barriers to us conducting those indoors by American Thoracic Society (ATS) standards because of the belief that submaximal exceptional study would generate particles that could be dangerous to both the performing candidate and the respiratory therapist or research coordinator. Eventually, we devised protocols with masking, and if you wonder what masking would do for those exercise tolerance tests, we spun out protocols from that. It wasn't very quick for us to get back to pulmonary function testing. We had a whole lot of exceptions and requests to both sponsors and the NIH for exceptions of pulmonary function tests if we needed to perform them. For example, with the ventilation/perfusion tests, we could do with just the perfusion.

Dr Ryan: Thank you, Roham. As you look at this now and as you look toward the future, do you feel that there are particular groups in your research environments, either interventional procedures, drug investigation, basic science, that have been disproportionally affected, or is there a patient population in your study that has been disproportionately affected?

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Dr Zamanian: I think the things that the institution views as less justifiable are things that are viewed as lower priority, for example, the Pulmonary Hypertension Association (PHA) registry, very relevant to our conversation here today. The institution did its best, but there was a lot of hesitation, also for the patients who felt that they were stable enough and just wanted to have a telehealth medicine visit instead of coming in, and the tidal wave of follow ups and new enrollments that we have missed thus far probably bears the largest footprint of the impact of the pandemic.

I can tell you that biological sample collecting for our own biobank has been deeply affected because of both the hesitation of patients and conducting blood testing and sample handling in an era of a respiratory-transmitted disease. Now, for us, blood banking is less of an issue, but we have a program here for collecting exhaled breath condensate in patients with PH, and certainly that's not at all justifiable or dangerous depending on your perspective. A lot of these projects, certainly the ones that are more on the academic side or NIH funded, already have very lean budgets. Also, NIH trials that depend on 6-minute walking tests being collected at a certain point in time, those patients are now no longer allowed to come in for just a simple research visit. We lose those measurements as well.

But I think the pandemic isn't all a negative thing. The positives are, how do we conduct clinical research in a real-world environment? Can we take 6-minute walk testing to the patient's home, and can we collect registry information using telehealth approaches? I think it's a challenge, but it's rising up to that challenge and overcoming some of the limitations that's exciting, the opportunities that we can create for the future of research.

Dr Ryan: I agree. It does seem that, particularly with the PHA registry, with having to shift the inability to at least enroll people for a period of time, as well as with your inhalational work with biosamples, these do have the potential for long-term consequences, in terms of our general needs, because the PHA registry is, by definition, a longitudinal study. If we have missed 6 months, that has the potential to extrapolate long term into our understanding, so I do think the missing data could have a long-term impact and will take us some time to catch up on.

I think, at the same time that, if we can build this, if we can adapt it and draw upon the ways we've adapted, then potentially in catching up, we can do things better and actually use a lot of the tools that we've had to use over the last 9 months. What are the changes you've seen that even long term are now going to become standard for you? What positive changes have you seen that might make you say, "I never thought of doing clinical research this way before. Now, I can't imagine ever doing this another way"?

Dr Zamanian: I wish it was going to be as simple as that, but you're correct that there are going to be tools, that all this hard work we've all undertaken is actually going to pay off in the future. I think one of the positives that I see is this consideration from the institutional review boards to recognize, not only now in difficult times, but maybe going forward, what the telehealth or virtual world means in terms of patient-related research.

It was very, very unusual—unheard of—for us to be able to conduct consent electronically, and now we have a project that we call Dynamite TH, which is a telemedicine or telehealth mobile device platform that we can send electronically, and patients initiate their screening procedures from home before they come to the clinic. That's a really nice example of what is happening. Another thing is that the capacity of my research team on the clinical side to operate virtually, obviously learning how to work around Zoom and how to get things done, even things as simple as signatures. These are the skills in technology that have enabled us to do these virtual contacts and consenting for patients and operationalizing clinical trials.

The other thing that we've been successful in doing is getting our industry-sponsored colleagues and other sponsors to accept virtual site initiation visits. I don't know about you, John, but our institution would not permit medical monitors and still does not permit medical monitors to come in to monitor our site or even do a site initiation visit. What we've been stuck with is either they send the medical monitor into 14 days of quarantine, or 5 days before getting COVID tested, before they come on campus, or we just do this virtually.

I don't know what your experience has been, but those have been clear positives that are going to impact the access of patients to clinical trials in general. If a patient who wants to do a clinical trial lives 6 or 7 hours away from us, then we can think about how we would operationalize at least parts of the procedure from afar. What's been your experience?

Dr Ryan: Our interventional trials pose a particular challenge because of the things that you brought up; they require so many moving parts. The patient needs to come in. They need to stay in a bed. They need to go into a procedure. The device or monitor person from the interventional company traditionally was always there at the bedside or involved during the hospitalization or at randomization and so on. That, when we were restricting access to people such as you described, was a big challenge to figure out.

I do think, however, that if we can enroll people virtually—or remotely rather than virtually—if we can do that and then better prepare the people who have PH so that, if they live 6 or 7 hours away from us, they've already met the clinical trial person over the phone, over a video, when they come down. Hopefully, they feel like they already know me. Everyone's now expecting you because there's been a requirement to do this testing, with a lot fewer surprises. I'm hopeful that this will make the experience better and will enable us to reach more people. I do have a concern, however, that we have introduced a barrier in technology; technology is still not readily available to everyone. If you're not able to immediately access reliable Internet or a smartphone or computer to do consents or review documentation, then this is a barrier introduced to both your clinical and potentially your research care. I do have a concern that the people whom we will now be able to enroll into registries and trials might shift away from those who are socioeconomically disadvantaged. This is something that, within our registries and studies, we have to pay close attention to.

Dr Zamanian: That's a really important point. I completely agree with you. It's probably going to exacerbate that problem of access to care, requiring technology that you and I and others may take for granted.

Dr Ryan: Another thing I wanted to touch on is the issue of dissemination of research, how COVID-19 has affected that and will continue to affect us in 2021 and beyond.

The first issue is conferences, and it's the biggest one that I'm concerned about. That was how I met Brad Moran, and as you know, we've had incredibly strong collaborations and work very closely together. That's how I met Vinicio de Jesus Perez. That's how I met Anjali Vaidya. The people whom I work most closely with in my own research career, outside of my institution, I've met them at conferences, and I've learned about their research at conferences.

I can't see you and me going to a conference. I don't know when we're going to be at a conference together again physically. How do you feel that dissemination of research has been impacted positively or negatively? How do you see conferences and the role they play going forward?

Dr Zamanian: I feel very much like you. My own career development and my own experiences are highlighted by those personal interactions at conferences. The first poster that I presented at ATS, the first person who really gave me strong feedback was Paul Hassoun. I will forever remember that and learn from that. I do think I am also a very big proponent of those personal interactions because I feel conferences are a really exhilarating discussion environment. There is nothing as good as being in an audience asking questions, engaging with speakers, and speakers engaging back with the audience.

That's a big impact. I have not been able to understand or participate in any meaningful way with any conferences since the beginning of the pandemic. I haven't been able to do anything at ATS now, primarily because it's a big world now. It's divided, and on multiple days, it's all virtual. I don't know about you, but I have Zoom fatigue, or whatever platform you use. Then dealing with time zones as well, being able to balance personal and professional life while already strained in our professions with this pandemic, it's all become much, much worse.

The only positive I can think of is thinking about one of the missions of the Pulmonary Vascular Research Institute in terms of global dissemination of these kinds of interactions. I hope that we would turn back to in-person conferences, but it makes me feel that maybe some of this is positive for people in marginalized countries who are interested in rare diseases. For physicians in those countries who can't make it to a conference in person, now, if they have access to Wi-Fi or the Internet, being able to interact in that kind of environment may be a positive.

I am hopeful that, in the future, we can really go back to a conference environment much like what it was before, although I don't know when that would happen. If I had to guess, I'd say maybe in some combination of both, but I miss it, too, and I think it's a big detriment. Already in the rare disease field, we have our collaborations, as you said, but we're siloed by those collaborations.

The whole point of conferences is to meet people from outside the areas of your own expertise, and I feel like, since the pandemic, I've been—it's great to meet up with my existing collaborators. I love them, but I haven't had, probably because of all the barriers identified, haven't had a chance to make unique conversations with colleagues that I would otherwise have met just out of the blue.

Dr Ryan: I don't know the answer to this. Knowledge dissemination, conferences, you're right that the networking and social aspects, getting to know people, are key. Do you think that dissemination of knowledge has been affected by COVID-19? Is that a long-term issue? Do you feel that there's less dissemination or that it's more difficult? The way I think about it is that knowledge dissemination has become much more bite sized because, at least in the communities that you and I work in, and really every community, to be honest, I think people are able to take in less information.

Everyone is so busy. Children are being schooled at home. Work is bleeding from day into night. I think people can only take bite-sized information in, which has resulted in some disinformation as knowledge is being disseminated. There have been some positives; namely, it is quite easy now to see a social media post with a graphic illustration and capture the essence of a paper by looking at a centered illustration or something along those lines. What are your thoughts on the impact of COVID-19 on the dissemination of pulmonary vascular research?

Dr Zamanian: I think, first and foremost, the focus. This is not a criticism, but the focus of both respiratory and medical journals on publishing everything about COVID has put a strain on, and as you've alluded to, some of it is not very high-quality work. This pandemic is important, I understand, but that's been at the cost of the great work that hasn't been published quickly enough. We had a manuscript we submitted in February, and now it's in its first revision with a journal, a really well-respected journal. It took 6 months for us to get our reviews back. I think that's an impact. As to the dissemination of information otherwise, I'm proud to highlight my work. I love highlighting your work or Vinicio's work through Twitter or whatever social media, but I also feel, like you, that I don't see a broad enough attempt in an unbiased way to highlight work in pulmonary vascular disease through social media. Sometimes I don't know who is behind the Twitter accounts that post different things about the latest great thing about research in PH. They can put a PH in the name of their account, but it doesn't mean I know who that is. I hope there are some future initiatives that attempt to work on what you just said, a fair and rapid dissemination of important publications. Like you said, we all depend on those activities.

We have a PH grand rounds at Stanford that we do. We have begun to invite other colleagues to present at our grand rounds. At least that's a marginal way to allow some of that dissemination. I totally agree with you about the level of misinformation to where it impacts patients and the patient's beliefs. While I think this is the next best thing in PH, I think Dr Google was always there, but now it's become, as you said, bite sized, very quick, easy to consume, easier to misconstrue findings in our field. I think that's a difficult situation.

I don't know if I have the right answers here, but I do believe that, generally in science today, we need to have a platform that enables trust from the community of patients we serve. With how political things like mask wearing have become, what is going to keep someone or some entity from broadly disseminating disinformation in an unscientific way? I hope I'm just being paranoid about this, but this is something that we as a community, and certainly the advocacy programs such as PHA, need to keep in mind about these platforms, that they can disseminate information that is unbiased and truthful in the way that it is summarized.

Dr Ryan: I agree. I think I see two obligations for those in leadership, people like you and me and others we've talked about. One is to be advocates and harbingers of truth, to keep pushing forward with a good message, to keep our own presence felt because I think there is good that we can offer there.

The other aspect is that I do feel that, for the next generation of people coming behind us—the Roham Zamanians and John Ryans of 20 years ago—I suspect it is very hard for them to get their voices heard. I think we need to advocate and recognize our responsibility in terms of bringing the next generation through. I'm hopeful and optimistic that collaborations, obviously with PHA, who are very invested in future generations, and with other groups will be integral enough.

Dr Zamanian: You took the words right out of my mouth. I think that anyone who's lucky enough to have Dr Ryan as his or her mentor, these are the mentors that we need to be for our junior faculty. We're ready to excite people about coming into this field. It's more crucial than ever that we're selfless and promoting for our junior faculty. As a group, I think that's the trauma of COVID for them in an environment where a lot of them are already competing for incredibly difficult funding that I suspect is getting more difficult. We all need to advocate for their development.

Dr Ryan: Advocacy and more funding are something very near and dear to our hearts and those who will be reading this. Thank you so much, Roham, for joining me today.

Dr Zamanian: Thank you for giving me the opportunity and leading this. This is a really important topic.

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