

Social determinants of health in pulmonary arterial hypertension patients in the United States: Clinician perspective and health policy implications

Vijay R. Nadipelli¹  | Jean M. Elwing² | Willie H. Oglesby¹ | Karim El-Kersh³ 

¹Jefferson College of Population Health, Thomas Jefferson University, Philadelphia, Pennsylvania, USA

²Division of Pulmonary, Critical Care and Sleep Medicine, University of Cincinnati, Cincinnati, Ohio, USA

³Pulmonary, Critical Care, & Sleep Medicine Division, University of Nebraska Medical Center, Omaha, Nebraska, USA

Correspondence

Vijay R. Nadipelli, 12301 Bradford Landing Way, Glen Allen, VA 23059, USA.

Email: vijay.nadipelli@gmail.com

Funding information

None

Abstract

Social determinants of health (SDoH) can impact the vulnerable pulmonary arterial hypertension (PAH) population, especially during the COVID-19 pandemic. Providers' understanding of SDoH at the point of care and their impact is unknown. We conducted semi-structured virtual interviews with US clinicians at 17 pulmonary hypertension (PH) centers and one patient advocate from the Pulmonary Hypertension Association. We sought participants' perspective on SDoH in PAH and their impact. Transcripts were developed and analyzed for key themes to assess potential policy implications. Participants served a large PAH population and demonstrated high awareness of SDoH and its impact on treatment and outcomes. They reported that patients' SDoH, including socioeconomic status, health insurance, access to health care, education levels, health literacy, employment status, and insecurities associated with housing, food, transportation, and family support, impacted health and well-being. COVID-19-related social isolation, mental health, and substance abuse contributed to significant inequities in care provision and outcomes. While telemedicine helped clinicians manage patients remotely during the pandemic, there was a concern for patients with limited access to this medium. Participants reported no formal screening for SDoH at the point of care. With the recognition and the desire to act upon health inequities associated with SDoH, participants felt that it was vital for their centers to have a dedicated PH social worker and support staff to optimize care and outcomes. An approach that integrates SDoH in PAH care management, streamlined through institutional policy, could address health disparities leading to improved healthcare access, outcomes, and quality of care.

KEYWORDS

health equity, healthcare disparities, population health, rare disease, social needs

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *Pulmonary Circulation* published by John Wiley & Sons Ltd on behalf of Pulmonary Vascular Research Institute.

INTRODUCTION

Healthy People 2030, a national initiative of the US Department of Health and Human Services, defines social determinants of health (SDoH) as “the conditions in the environment where people are born, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risks.”¹ Traditionally the United States has focused on its healthcare system to improve health and health outcomes. However, there continues to be greater recognition that the nonmedical factors, including an individual’s socioeconomic status, housing, education, neighborhood, employment, social support, access to nutritious food, safe living environment, and access to healthcare as drivers of poor health and health outcomes.² Evidence from an analysis conducted over 30 years and reported in the year 2000 attributed SDoH to US adult deaths as follows; 245,000 due to low education, 176,000 due to racial segregation, 162,000 due to low social support, 133,000 due to individual-level poverty, and 119,000 due to income inequality.³

Provider knowledge of SDoH is vital to address individual social needs through community-level referrals for improved prognosis and quality of life in the context of socioeconomics and environment.⁴ Research also suggests that proper interventions to address SDoH can result in positive outcomes.⁵ The awareness and understanding of SDoH are evolving, focusing on chronic conditions such as hypertension and diabetes affecting large populations.⁶ However, smaller groups of people impacted by rare diseases have not been the focus of SDoH research despite a potentially similar devastating effect at an individual, family, community, and societal level.

Pulmonary arterial hypertension (PAH) is a rare and progressive disease that involves increased pulmonary vascular resistance, right ventricular pressure overload, right heart dysfunction, right heart failure, and premature death.⁷ Despite the overall poor prognosis, PAH patients experience a significant delay in diagnosis with an average time from symptom onset to diagnosis of about 3 years.⁸ While clinical, diagnostic, and therapeutic advances have been made in the last few decades, research efforts and evidence to understand the impact of SDoH on PAH patients remain sparse.^{9–12} The American Thoracic Society, in its 2017 official statement, identified the need for providers to understand the impact of social and environmental conditions on potential poor outcomes in PAH patients.¹³ A large number of PAH patients in the US receive care from pulmonologists and cardiologists in pulmonary hypertension centers (PHC) that may be accredited or nonaccredited by the

Pulmonary Hypertension Association (PHA).¹⁴ Awareness and knowledge of SDoH among the PH providers at these specialized centers and their ability to intervene to improve patient health outcomes is unknown. We aimed to study clinician awareness of SDoH in their PAH patients, current point-of-care practices, and potential implications for care management and health policy.

METHODS

We conducted 30-min semistructured virtual interviews¹⁵ with a convenience sample of clinicians actively engaged in treating PAH patients at US centers. In addition, one patient advocate from PHA was interviewed to represent the patient perspective. We developed an interview guide using open-ended questions and probes based on the Healthy People 2030 SDoH framework, including queries about healthcare access, education, employment, neighborhood, social, and community factors that may impact the PAH patients.¹ A test interview with one PH clinician from Pulmonary Hypertension Comprehensive Care Center (PHCCC) was conducted to ensure relevance and overall flow. Invitations to participate in the study were sent via email using contact information sourced from institutional and PHA websites. A brief preinterview questionnaire was emailed seeking information on participants’ demographics and practice characteristics that included an estimated PAH patient population profile.

Virtual interviews with interested participants were scheduled and conducted by a trained postgraduate student using Microsoft Teams. Interviews were recorded to develop transcripts with participant permission. After the interview, a brief 10-item SDoH screening tool, derived from the Health Leads Social Needs Screening Toolkit that was successfully implemented previously in patient care, was shared via email to seek participant feedback on its relevance and potential use in PAH routine clinical practice.^{16–19} As a thank you, participants were offered a \$50 Amazon e-gift card or a donation to a charity of their choice.

After completing the interviews’, deidentified transcripts were developed. We conducted qualitative analysis by reviewing and grouping frequently occurring themes of SDoH in PAH patients. Relevant quotations from participant interviews were highlighted to reinforce the key themes. Participant demographics and practice characteristics were entered in a Microsoft Excel spreadsheet and analyzed to develop aggregate summaries for each variable. We summarized feedback on the SDoH screening tool and discussed health policy implications.

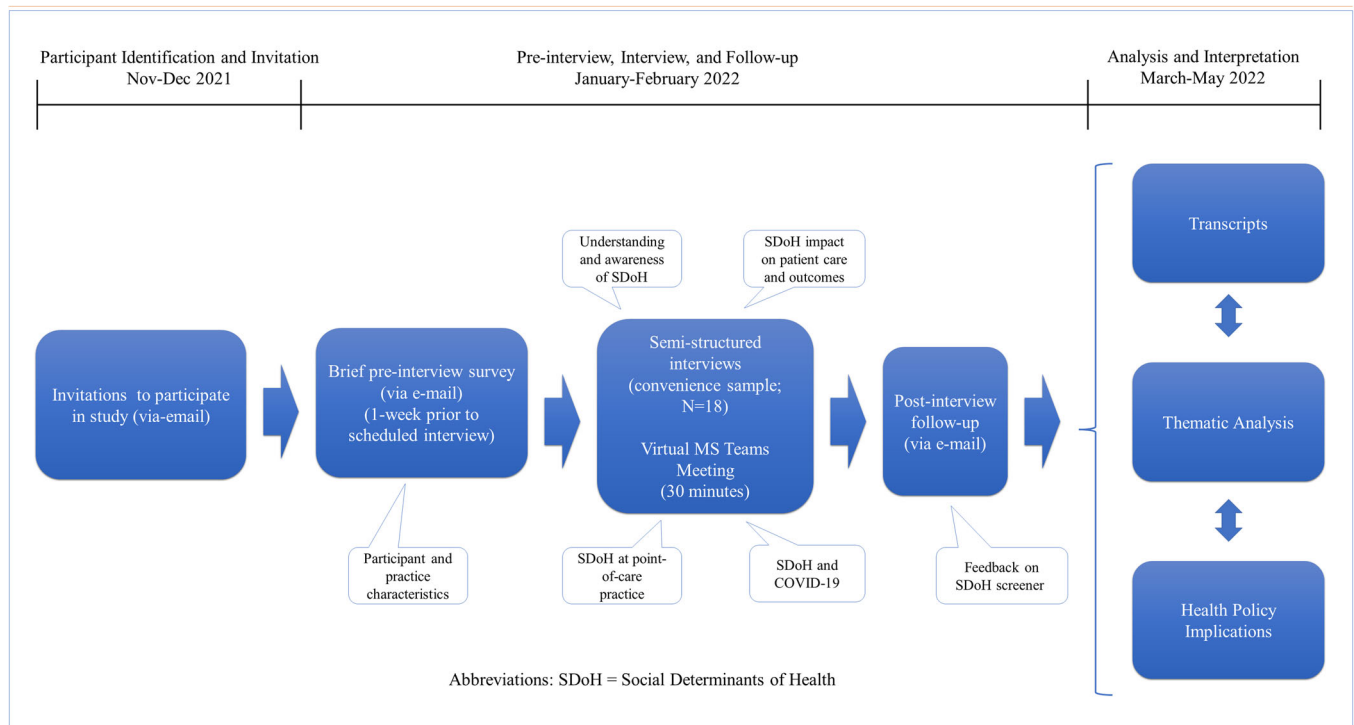


FIGURE 1 Study methods

Figure 1 highlights an overview of the study flow and procedures, including the study periods. This study involved information-gathering interviews, questions focused on information and opinions about processes, services, or policies, and did not gather personal information about living individuals. Our University's Office of Human Research deemed it does not require Institutional Review Board submission.

RESULTS

Participant, practice, and PAH patient population characteristics

The study included 17 clinicians from the United States (Table 1), 15 (88%) from PHA accredited PHCCCs, two (12%) from nonaccredited PH centers, and one patient advocate from PHA. The 17 clinicians included 13 pulmonologists and four cardiologists with a group average of 19 years of experience in treating PH patients. The participants reported caring for an average of 321 PAH patients across centers with an average age of 52 years, predominantly women (73%) and of Caucasian (61%) race (Table 1). Patients were either unemployed (34%) or retired (23%), and a little over half were estimated to have public health insurance (51%) coverage such as Medicaid and Medicare. Patients had high

severity of illness as assessed by World Health Organization Functional Class (WHO FC) and required combination therapy with 2 or 3 medications (Table 1).

Participant awareness of SDoH

When asked what the term SDoH meant to them, study participants demonstrated a high awareness describing the interconnectivity, including an individual's health, healthcare access, socioeconomic status, and environmental factors (Figure 2a). In one participant's words, "it's an individual's condition or his or her environment." This participant described SDoH as "where you're born, your education, your access to health care, your economic situation, your social constructs, whether it's your interpersonal relationships, your religious organizations might be part of, and how that impacts your health and quality of life." Another participant opined that "I think the social determinants of health have a lot to do with our identity."

SDoH impact on PAH populations

Participants shared that patients' clinical care is impacted by several nonclinical factors, including health insurance coverage, transportation issues, employment, unstable

TABLE 1 PH clinician and practice characteristics

PH clinician characteristics	N = 17
PH clinician specialty, <i>n</i> (%)	
Pulmonologist	13 (76%)
Cardiologist	4 (24%)
PH clinician treatment experience, mean years (range)	19.3 (6–37)
PH clinician practice setting, <i>n</i> (%)	
PHA accredited PHCCC	15 (88%)
Nonaccredited PHC	2 (12%)
PHC geographic location, <i>n</i> (%)	
Northeast	6 (35%)
West	5 (29%)
Midwest	4 (24%)
Southwest	1 (6%)
Southeast	1 (6%)
PH clinician practice characteristics ^a	N = 17
Number of active PAH patients, mean (range)	321 (125–600)
Patient age, mean years (range)	52 (35–65)
Time to diagnosis, mean years (range)	1.5 (1–3)
Gender, mean % (range)	
Female	73% (60%–88%)
Male	27% (12%–40%)
Race/Ethnicity, mean % (range)	
Caucasian	61% (30%–90%)
African American	22% (2%–50%)
Hispanic	12% (0%–40%)
Asian	5% (0%–15%)
Employment status, mean % (range)	
Employed	43% (20%–90%)
Unemployed	34% (10%–60%)
Retired	23% (5%–90%)
Health insurance status, mean % (range)	
Public	51% (30%–90%)
Private	42% (5%–70%)
Uninsured	7% (0%–30%)
WHO functional class, mean %, (range)	
FCI	7% (0%–25%)
FCII	45% (30%–65%)
FCIII	40% (25%–75%)
FCIV	8% (2%–30%)

TABLE 1 (Continued)

PH clinician practice characteristics ^a	N = 17
PAH therapy, mean % (range)	
Monotherapy	11% (5%–48%)
Double therapy	52% (25%–85%)
Triple therapy	37% (10%–70%)

Abbreviations: FC, functional class; PAH, Pulmonary Arterial Hypertension; PH, Pulmonary Hypertension; PHA, Pulmonary Hypertension Association; PHC, Pulmonary Hypertension Center; PHCCC, Pulmonary Hypertension Comprehensive Care Center; WHO, World Health Organization.

^aClinician practice characteristics are based on subjective information provided by the participants.

housing, mental health, food insecurity, education levels, and health literacy (Figure 2b). One participant said, “I think these social determinants pervade everything we do and every aspect of the patients from the lead time to get diagnosed because it may put off symptoms because they don't have insurance and don't want to pay to get testing done. [SDoH is] in the background from well before we see the patient, and it continues throughout the entire patient experience.” The importance of living conditions and social support was expressed by another participant, “one of the important things is social support, how much support they have, especially if we are trying to talk about a complex regimen of therapy. If you need IV, SubQ [PAH therapy], you should have good social support. [For] one of my patients, when the specialty nurse went to the home to do teaching, it wasn't in the best hygienic condition that you would be comfortable having someone using parenteral therapy. Social support, living situation, and things like that would be very important.”

We describe the study participants' perspectives and experiences about the impact of specific SDoH on PAH patients.

Employment status and disability

Participants said patients' employment status and stability impact several aspects of their lives, including the economic situation, affordability, and access to food, housing, and transportation (Figure 3a). One participant noted the impact of employment on patients from multiple viewpoints; job directly influences their health insurance, coverage and access to care, and medication type. Work gives a sense of individual selfworth, keeps them active, and helps them manage their health. While dealing with the progressive nature of the disease, the

(a) What do SDoH mean to you?	(b) How do SDoH impact your patients?
<p>"I think social determinants of health are couple of things. One is what is your access to health, that would be first? But not just pulmonary hypertension but you know in general health. So, what's your access to health? Two, is your access to health equal to somebody else's access to health. Three is do you have access to similar clinical trials and or registries or whatever than somebody else does, and [four] or whatever number we're up to, are you treated the same way as somebody else who might be better off or [have] better insurance, whatever and then lastly, are you treated equally no matter what your sex, what your sexual orientation, what your ethnicity etc.?" – Pulmonologist, PHCCC</p>	<p>"I think what type of work a patient is doing and therefore the stresses that provides, so you know, for instance, I have one patient who comes to mind who works for one of the counties on their road crews and he doesn't have really far advanced disease, but what he has limits his ability to do his work and because of his education, backgrounds and training, he's not suitable for a desk job while someone else with the same degree of functional impairment from their PAH would be able to work at a desk job without any problems and would not have his employment being threatened by his disease." – Pulmonologist, PHCCC</p>
<p>"Gosh, there's so many, right? I think lower, you know, socioeconomic status effects, transportation in terms of coming to office visits, the frequency for which patients can be seen. This has been mitigated a little bit by telemedicine and the advances in telemedicine over the past couple of years that have been spurred by the pandemic, but I think so that's, you know, transportation to visits, insurance coverage. I think that, you know, other social determinants are really the community that you live in, the food you have access to. So, a lot of our patients you know, just don't have access to quality food and in their diet is not as good. They don't have access to rehab and gym and exercise." – Cardiologist, PHCCC</p>	<p>"I think there is a lot [impact of SDOH on PAH diagnosis], you know, patients you know present with, you know, they minimize shortness of breath, which is obviously the most common complaint, and it's minimized, and activities are curtailed just because you can't, you know, you don't want to get a \$500 bill just for an X ray when you're told that, oh, it's bronchitis or maybe you have, you know, a viral infection and so things are delayed until you get significant, you know, right heart failure in functional class 3 to 4 symptoms. Then you present to the ER with pulmonary right heart failure because things can't get much better. I think that's a story, that's been told time and time again." – Cardiologist, PHCCC</p>
<p>"Huh,... that's such a broad term, it could be for me, may straightaway mean a support structure, socioeconomic status, access to care, access to specialty care, access to a primary doctor. Level of motivation or education in the society and the patients with regards to, not only themselves, but health care and primary prevention, those kinds of things. So, there are so many layers and pages to it... I mean because [SDoH] is such an umbrella term, doesn't it? Social determinants, so depends on what you mean by that, but those are the few things that immediately come to my mind." – Pulmonologist, PHCCC</p>	<p>"I've had several patients who, you know, wouldn't call on a Friday because when they ran out of medications and waited until Monday to get refills for their medications because they assume that no one would be available to help them over the weekend as an example. And I think that those types of situations are unfortunately common..., understanding the importance of these medications, not only the access in that example getting refills, but also the education [to] understand that missing a dose is critically important and how that can impact her overall health" – Pulmonologist, PHCCC</p>
<p>"Oh, I mean, you know, nonclinical factors that impact their health care... I mean income, education, social support, health insurance, geography, you know, the proximity to our center, whether they're in a more rural or agrarian type, you know, area versus the city. You know all these are factors, I think that they all play a major role in their health care." – Pulmonologist, PHCCC</p>	<p>"So, mood, anxiety, support system, stability are all extremely important. They mean very different things for different patients. For you and I, it might be job related or spouse related. For another person, it may be their homeless shelter or their group home or the fact that someone is not there for them to take them to visits, which they need. So, I think those things vary based on your situation and unfortunately or fortunately we can flex in different situations through our lifetimes." – Pulmonologist, PHCCC</p>
<p>"I think the biggest thing which I feel is ethnic or racial disparities, which I feel in health care, which is very much prevalent and probably, well I should not say under recognized, it is recognized, but it is just not being adequately provided support to really, to fix those issues. I mean social economic status also affects, but I feel to a lesser extent. But I do feel that racial disparities definitely exist in there and that there maybe some implication because of the cultural variation also so, those are the three dominant things which I notice in my view." – Pulmonologist, PHCCC</p>	<p>"So, a lot of them have several, several aspects, financial challenges, access to care challenges, distance challenges, support challenges, psychiatric challenges, their mental ability to cope with such an illness. The affordability challenges as I just told you, that insurance coverage and obviously sometimes a combination of all these things can be summarized in a kind of it becomes almost a harassment to the patient. It becomes a stress because they can't, they feel helpless, they can't deal with all of these challenges at the same time. It's almost like harassment for them." – Pulmonologist, PHCCC</p>

SDoH = Social Determinants of Health; PHCCC = Pulmonary Hypertension Comprehensive Care Center

FIGURE 2 Social determinants of health awareness and impact

(a) How does employment status impact PAH patient's clinical care?	(b) How does housing impact PAH patient's clinical care?
<p>"I think at multiple levels, I mean obviously in our country their employment heavily influences their health insurance and whether they have coverage, what type of coverage, in the accessibility to medications and when they may not have accessibility, whether they're eligible for assistance programs. So, all of these things are tied to their employment. But I think employment also, you know, plays a role in their ability sometimes to maintain their health care, whether that's getting time off to come to their appointments, whether it's the ability to tend to their medical treatments in a consistent fashion." – Pulmonologist, PHCCC</p>	<p>"Absolutely. I mean, being a chronic disease that is significantly impactful on them on a day-to-day basis really impacts I think, or resonates off their home situation, and people who don't have a stable home situation and it just really compounds the problems that could be in the form of the diet they are able to eat and access to, you know, foods, access to supplies to, you know, sustain their treatments and in fact one of the most direct ways is their home situation goes a long way into us deciding what type of therapies they get. I mean some of our therapies are just not sustainable without a stable home situation. Whether that's power, electrical source, shipping, I mean address to receive their medications. A support person to help them with their treatments, and you know all of these things factor into that home situation and how it could impact their well-being as well as their, the sustainability of their medications." – Pulmonologist, PHCCC</p>
<p>"So many of these people take early retirement because of the constraints of the disease. Many of the younger people, however, have a fierce determination to remain employed, and so they really try to do everything they can to maintain employability...it's kind of like you know someone who has asthma so that's making the life for patients a lot easier, who will remain employed, but sometimes their medications become a constraint to employment, particularly with the continuous parenteral medications or with the current huge inhalers that people get embarrassed when you know people, see them using these contraptions." – Cardiologist, PHCCC</p>	<p>"An example was one of my patients, she was unfortunate that she lost her place she lives in and lost all of the furniture and everything because she was in the hospital for so long. And then now she's ready to go home. But some of her friends were able to provide a place for her. But that place was empty. Had no furniture or anything, so she was telling me I would go home, and I will sleep on the floor tonight because I don't have anything and for that patient I went, I bought an inflatable mattress and canned food and I give her cash money so she can, survive those few days after she gets out of the hospital. She was someone on parenteral therapy, so, you know, advanced disease, parenteral therapy, you cannot imagine this patient will go to an empty home and sleep on the floor. So sometimes even you have to go an extra step and help even if you have a social support and social worker, I mean. Because you know what will happen today when she goes home, right?" – Pulmonologist, PHCCC</p>
<p>"Yeah, I think you know the PH a lot of time will affect your ability to work, and we had patients who applied for disability because of their severe illness. Some of the patients will be able to continue to work. I think now COVID is even adding a second layer to that because you have a vulnerable group of patients with underlying medical condition and now depending on your risk of your employment, now we're not only considering the PAH, but you have underlying medical condition and then add to that the risk for exposure." – Pulmonologist, PHCCC</p>	<p>"I think housing comes up...housing comes up a lot...and the housing itself, I think, is an issue. Usually in a lot of our patients we have to submit these forms of the electricity and doesn't get turned off, so patients don't lose supply to their oxygen. You know, and there are other lifesaving equipment then it is interesting now. Even though patients who do have Internet when we do Zoom and you get, you get a window into where someone lives up to see you know, the way some, the situations that people are living in so I would say yes, kind of that housing is a reflection of the community and I think that housing is important. The community is important so I would say yes, I think that's very important, especially now right. If you can't socially distance if you're stuck living with seven other people, you're totally disadvantaged from other patients who you know have a single-family home and have more resources and can distance a little bit better." – Cardiologist, PHCCC</p>
<p>"The other thing I think is a big problem for patients in disease states like pulmonary hypertension is they have not had the ability to work long enough to have savings. So, when they get sick, they have no resources, their pool is not very deep in terms of their financial planning, they haven't had time to put money in a 401K or 457 or 403B because they have not gotten to that point in their life yet. So, if you're 40 years old and you have two kids, you're not going to have a very deep savings. You're not gonna have paid a lot of money into Medicare or to Social Security. So, you oftentimes get sick at a point where you don't have a lot of resources. So now you're stuck in a situation where you may not be able to have all the things you really would have had normally if you would have been able to go with your career, because you had to stop so short because you got sick." – Pulmonologist, PHCCC</p>	<p>"[That [stable housing] is important, because some of the medicines that we use require refrigeration and when people do not have homes and don't have refrigeration, it's very difficult for them to maintain therapy. In addition, these medicines are incredibly costly and often are shipped to patients in bulk. It's not like that you go to a pharmacy and pick them up. They have to be shipped to you, so if you don't have an appropriate shipping address, it becomes very detrimental to their continued therapy." – Cardiologist, PHCCC</p>

PAH=Pulmonary Arterial Hypertension; PHCCC = Pulmonary Hypertension Comprehensive Care Center

FIGURE 3 Employment and housing

type of employment—whether it involves sedentary work or requires physical activity, working hours, ability to take time off to attend to medical appointments, and other elements, may induce different levels of stress and anxiety while impacting health outcomes in the absence of appropriate accommodations.

Participants estimated that a significant number of their patients (35%–40%) were on disability. These included young people in their 20 and 30s who barely worked and retirees who had worked all their lives. It was noted that PAH patients experience difficulties seeking and qualifying for disability benefits from social security administration for their pulmonary hypertension, even when they are genuinely disabled. The laws and rules by which disability is determined are not the friendliest for PAH patients. In one participant's words, “[PAH patients] often have to file, get denied, seek a lawyer and appeal, and that costs, takes time and money. And again, these are the patients who're not working, and they don't have a nest egg, and so they're at the mercy of the system. They sometimes struggle even to get that disability, even when the health care community and I perfectly are aligned, in thinking that this is a disabled person, they can't work.” This participant described the vulnerability of PAH patients in seeking disability as intricately linked also to several other social and economic factors, “I think those that have means to the transportation and the finances and the education if you will are more likely to be successful and those living in their car who don't know how to manage their daily lives, to begin with, are less likely to be assertive enough to carry them down that pathway. Yeah, it's right, the disadvantaged are further disadvantaged because of their disadvantage.”

Housing insecurity

Participants recognized housing insecurity for PAH patients. It can present in several ways, including not having access to basic housing and housing with interrupted utilities, including electricity, gas, and water (Figure 3b). Air quality in the house, supported by appropriately designed ventilation, heating, and cooling, was necessary. The need for electricity to operate oxygen and medication infusion pumps and instances where power was cut off were cited as having a detrimental effect on outcomes. Most patients do not have generators as backup or the means to afford one. The housing location, that is, those living in distressed neighborhoods and patients impacted by domestic violence or violence outside the home, caused patients' anxiety, depression, and decrements in their quality of life, ultimately

worsening outcomes related to PAH. Stable housing and having an address to facilitate shipping of PAH specialty medications also impact treatment choice and health outcomes.

Food insecurity

Participants reported that there were groups of PAH patients who had to choose between their food and medications. It was directly associated with the economic stressors of housing. Clinicians mentioned considering a complex web of social factors that directly impacted their clinical decision-making and care management for their patients. In one participant's words, “those [healthy meals] are not the meals that are being prepared, again, if you are working three jobs or have very poor income, or, if you live in a food desert or not even going to be able to access those, and so that's the problem, or, you don't have time to prepare them, or you don't have the resources to prepare them, right? You don't have a working stove or a gas line, or even in more extreme cases, you don't have electricity. So those are all circumstances where you're relying on either, and if you, unfortunately, suffer from homelessness and you're into things such as soup kitchens, which by definition have a lot of salts associated with them. So, then this poor nutrition is associated with an increased risk of hospitalization. It's associated with decreased efficacy of treatment, and it is associated with premature mortality.”

Transportation insecurity

The participants referred to the lack or limited access to transportation for PAH patients as a major issue with 10%–15% impacted severely based on their social factors, including where they live, income levels, and family support (Figure 4). There are a limited number of PH expert centers and are primarily located in urban areas requiring patients to travel long distances. Access to transportation impacts therapy choices. For example, complex therapy requires frequent follow-ups and in-person visits, and this can be challenging if the patient does not have access or means to reliable transportation. Lack or limited access to transportation and telehealth tools may delay care and result in the utilization of urgent care centers, emergency rooms, and hospitalizations for assessment and management. For patients, this results in poor health outcomes and higher healthcare resource utilization and ultimately increased costs for the health system.

Q. How does transportation impact PAH patient's clinical care?
<p>"Yeah, transportation is a huge part, you know, especially for disease state like this where there are so few experts, centers and patients are referred and come to see us sometimes from 2-300 miles away, and if they have challenges of transportation, we really may not be able to see them very often, especially when they're sick and certainly not in a hurry, and so that plays a huge part.... yes, it's definitely a huge issue in our disease state." – Pulmonologist, PHCCC</p>
<p>"Yeah, well, clearly the patients that we have, for example who live in their car don't have, they have transportation if their car is working but they don't really have the means to be on a parenteral therapy. Those patients that are continually using drugs are not ideal for parenteral therapy for obvious reasons. And so, you know, access, transportation, the limitation of money for taxi for somebody that's coming from more than a few miles away has played a role in some of our adherence issues those who [need to be] adherent to clinic visits and adherence to medical therapy itself." – Cardiologist, PHCCC</p>
<p>"Yeah, that's a real issue and you know, practicing in an urban center there are lot of people who don't want to drive into the city parking around. our center is not ideal. I have patients who don't wanna drive themselves into the city, so they have to either get a friend or family member to take them in. It is clearly a factor that impacts on some of the patients. There are other patients where it's not a big factor, but clearly that's another place where socioeconomic status may play a role, in that, whether or not you have a car yourself, whether or not you are with somebody who can take off from work to be able to drive you and things like that clearly correlates with whether or not you're an hourly wage employee versus or you know some other time." – Pulmonologist, PHCCC</p>
<p>"Yes, well transportation is usually a big issue. Most often these patients have to come with a caregiver and so they are dependent upon other people schedules. Many of these people do drive particularly there from rural areas, and you know again because of so, some of the cultural differences in our society where a lot of women don't drive. They are dependent on their spouses to bring them in for visits, and that can be significantly affected, particularly in areas that are affected most by climate. You know, in the new North and the Upper West you know where snow is a big issue. Snow and transportation makes it very difficult for people to get to their primary caregivers for this disease." – Cardiologist, PHCCC</p>
<p>"Big huge, huge, we have patients who have to drive 2-4 hours to our Center for clinics, and obviously it's, you know, it's not very practical. We can give vouchers for gas for some of our patients so that they can make, but obviously those are limited. For some patients, we offer tele-consults, but you know, I think that will work if you are clinically stable, patient. But if you are somebody who's not [emphasis] clinically stable, you need to be seen and not being able to see this patient is a huge, it's a huge issue that influences our capacity to intervene early and aggressively. What we're trying to do, and again, you know, depends on insurance coverage for so many patients is [that], I can identify centers or clinicians that I trust with the expertise to take care of these patients so that they don't have to drive so far are to actually see a specialist. But the truth is, transportation is a, it's a key determinant in terms of regulating the access to care for these patients." – Pulmonologist, PHCCC</p>

PAH=Pulmonary Arterial Hypertension; PHCCC = Pulmonary Hypertension Comprehensive Care Center

FIGURE 4 Transportation insecurity

Education and health literacy

Participants indicated that PAH patient outcomes were related to their education levels, contributing to their employability, income levels, and access to health insurance. It was noted that those without higher education face more significant challenges in accessing medical care impacting health outcomes negatively. PAH therapies involve complex treatment regimens. Some medications are delivered via automated pumps that require a basic understanding of device operations, alarms, changing medication titration settings, and troubleshooting in case of malfunction. Intellectual capacity and social support were noted as requirements for lung transplantation; when disadvantaged, they could not access these last-resort medical options. One participant shared, "I think both [level of education and disease education] is important. This is a disease that requires some degree of understanding and is difficult to explain. You know, it affects the heart, affects the lungs. You may have a systemic disease that affects a lot of different things in addition to the heart and the lungs. And so, you know, how does this medicine work. So, there is a basic level of understanding required to successfully manage this disease."

In addition to education levels, health literacy and an individual's ability to understand health information to

make appropriate health decisions were necessary for patients to manage their condition.

Language and cultural competency

Participants identified their patients' language, ethnic and cultural backgrounds as important determinants, and provider knowledge, understanding, and competencies directly impacted health outcomes. It was noted by participants from locations where large populations of various ethnicities, including Hispanics and Asians, were present; that the care team needed to interact in patients' native language due to cultural aspects impacting care. Participants highlighted that language barriers and cultural competency challenges might create disparities in care and outcomes for this population.

Racial and ethnic disparities

Most participants did not directly identify race-related or ethnic disparities in PAH patient diagnosis, treatment, and prognosis. However, recognized socioeconomic status, health literacy, employment, and income levels, irrespective of race, were reported to have similar barriers to accessing care. In one participant's words,

“I’m gonna say that I’m not sure that the relevant factor is race as much as socioeconomic status, health literacy, and you know, people that we would describe as economically disadvantaged no matter what race they have, had the same barriers to access to health care to early diagnosis. While if you’re upper-middle class, you may see your physician for [any ailment] you have, and [PAH] diagnosis may occur earlier. The likelihood of referral from a community setting to an academic medical center with an experienced PAH center may be more likely, so I think it really depends on socioeconomic status, perhaps more than race.”

While this was not the predominant view, another participant pointed to the potential underreporting of PAH in ethnicities of minorities such as African Americans, Hispanics, and Asians, likely indicating the impact of SDoH, “Yeah, pulmonary hypertension does not seem to be a disease that is affected by ethnicity, and so there are equal proportions likely in each of those ethnic groups. This is where social determinants of health become very important because many people with ethnicities other than Caucasians are underrepresented in the majority of our registries. So, though it’s clear that there is no genetic predisposition based on race, we know less about how this disease affects others, particularly in African descent, Hispanic descent, and so on, at least in the United States.”

Mental health and substance use disorders

Mental health was one of the more significant problems reported by study participants impacting their PAH patient outcomes (Figure 5). Many patients suffer from anxiety and depression as PAH is often a rapidly progressive and fatal disease. Mental health directly impacts their physical health. In one participant’s words, “the psychological milieu of the patient really affects the disease course.”

A quarter of the participants at PHCCCs with high substance use disorder prevalence reported it as a significant issue and was interrelated to several SDoH in their patients. Illicit substances such as methamphetamine and cocaine are known to induce PAH.^{20,21} The prognosis for these patients was better when they could stop using these substances, and proper treatment and mental health services were provided. One participant said, “we see a significant number of patients in our practice that have had some type of substance abuse. I’d say maybe you know 10%–15% of our clinic, and it can be a huge problem because especially if they are still actively using because adherence and access to care all those things [SDoH] are just magnified if they have a substance abuse that you know is another blanket that you layover, which directly impacts how we manage patients.” The SDoH associated with drug abuse was

Q. How does mental health impact PAH patient’s clinical care?
<p>“OK, so mental health probably drives more of our care than we currently understand. Mental health is intertwined with so many things and spans all socioeconomic status, all marital status, all ages. The minute the world becomes overwhelming, it is very, very hard to take care of complex medical conditions. It’s very hard to attend appointments. It’s very hard to keep track of appointments, set, go to tests, take your medicines. So, if I notice people getting more unraveled with anxiety or they’re getting more depressed or notice they’re not sleeping very well, I try to address that as quickly as I can and offer them therapies. I offer them anti-anxiety therapy, antidepressants, counseling, psychology, psychiatry referrals, because if I can keep them feeling like they can control their world, they can control their disease, but once we lose that we can’t, we cannot keep people on their medications and doing well for the most part, it’s very hard.” – Pulmonologist, PHCCC</p>
<p>“It’s [mental health] incredibly important. There is a very large proportion of our patients [that] are clinically depressed and anxious, and so there is a large use of antidepressant medications, anti-anxiety medications in this population, one because social stigmata of the disease and two, because it is really, is a rapidly progressive disease and it’s fatal. And so those type of psychological diseases we see very frequently within our patient population and patients’ mental health directly correlates with their physical health. You know those who have very poor outlooks and depressed have a much shorter life expectancy than those people who take, you know, a more active fight against the disease.” – Cardiologist, PHCCC</p>
<p>“I think it’s important. We see significant number of patients with anxiety, depression and I think it affects your overall health, regardless of what primary disease you are dealing with, PH is a stressful disease. It’s complex, not only the disease itself, but what comes with the disease, including the treatment side effects, cost of the treatment, you know, having to be worried about. Are you able to secure medicine? Are you able to continue on that? Are you able to continue to deal with side effects? So, all of these things play in and so anxiety and stress and depression is not only coming from the disease itself but from other things, may be worrying about others that live with you and have to take care of you and provide care if you are feeling you are a burden that might also add to it. So, I think it is important.” – Pulmonologist, PHCCC</p>
<p>“Uh, you know, that’s probably one thing where our health care system doesn’t have the best access, but I think that’s true everywhere. There’s no question that depression plays an important role in these patients, especially when they’re first being diagnosed. Uh, I think it’s very common word. Patients will have gone to Google and searched on pulmonary hypertension, and they think they’re going to be dead in 2 1/2 years. So that’s gonna impact their ability to really do the rehab that we try to get them to do once we start them on medication. Uh, we’ve certainly referred patients to mental health care, but it’s not easy to get them to participate that often, in part because of transportation, and in part because of there’s not a lot of access to it, no matter who you are anyway.” – Pulmonologist, PHCCC</p>
<p>“I do think that there are opportunities for us as providers to be more direct about identifying and treating these [anxiety, depression] concomitant comorbid conditions that impact overall quality of life and prognosis, for [PAH] patients, unfortunately, you know a lot of times these diseases, and their treatment are beyond the scope of our training in pulmonary or cardiology.” – Pulmonologist, PHCCC</p>

PAH=Pulmonary Arterial Hypertension; PHCCC = Pulmonary Hypertension Comprehensive Care Center

FIGURE 5 Mental health

more complicated, including the social stigma associated with diagnosis, treatment, lack of pharmacotherapy, and inadequate or lack of treatment centers. These patients were known to be vulnerable and experiencing loss of employment, homelessness, food insecurity, domestic abuse, crime, and violence, often interfacing with the criminal justice system, posing significant PAH diagnosis and management challenges. The lack of access or resources for referral to the drug addiction centers and follow-through at the point of PAH care makes it further complicated. One participant had a dedicated PH social worker and case manager to provide referral services to addiction centers, but expressed doubt in efficiency at a system level, suggesting that integrating mental health services in PH care provision is vital for continuity of care focused on improving health outcomes.

COVID-19 pandemic and SDoH

Participants reported that COVID-19 impacted access to care. Many PAH patients were unable or unwilling to be hospitalized or to have an in-person clinic visit due to concern that they might contract COVID-19 or due to reductions in healthcare services resulting in capacity issues and inability to complete necessary testing such as right heart catheterizations, echocardiograms, 6-min walk tests, pulmonary function tests, ventilation-perfusion scans,

imaging, and the need for extra-precautions and measures between staff and patients (Figure 6a). Participants also reported COVID-19 impacted transport lines, resulting in shipping delays and sometimes affecting the delivery of life-saving PAH medications. PAH patients with jobs that required physical presence were not able to attend to their jobs due to their underlying condition, which resulted in further economic and mental burdens leading to more stress and anxiety. While participants reported the benefits of telemedicine to overcome some COVID-19 restrictions, they also noted some challenges associated with this tool in some patients who did not have access to optimal devices and the Internet to provide quality audio–video streaming.

Furthermore, the knowledge and ability to operate smart devices were reported to complicate the situation. This can be illustrated well in one of the participants' words, "some people can't do [quality telemedicine] visits because they don't have good Internet, or they don't have smartphones. So, where you live affects your ability to have good Internet, which affects how we're able to care for somebody in terms of communicating electronically."

SDoH screening and implementation

Participants reported that SDoH was neither screened nor routinely collected at the centers (Figure 6b). A quarter of participants said they collected health-related

(a) What impact did COVID-19 have on PAH patients?	(b) Do you currently screen PAH patients for SDoH?
<p>"So, I do think there are social determinants and that you're more likely to get COVID-19 and in those circumstances because you can't isolate you can't order over door dash to get your food. You do have to sit, stand in line. You do have to take the bus. You have to expose yourself to behaviors and lifestyles just because of those, your social place where you're right? You can't have the luxury to order all the things you need from Amazon. So, I think yes, I think it's affected, especially this last wave, a whole host of our patients who I would characterize as lower socioeconomic status, have all developed COVID-19 infection." – Pulmonologist, PHCC</p>	<p>"Yeah, I think if it [SDOH screener] did it automatically [integrated to EMR], I think that would be great, but I don't and I think you are asking about if I have quality of life screener as well. We don't have that either, other than me, kind of trying to guess what your quality of life is and the reason being is that there are so many things that we need to do and so many patients that we need to see, that need me doing screener, after screener after screener. I would never actually get to ask the patient how they're doing. Yeah, so it's a barrier." – Cardiologist, PHCC</p>
<p>"You know, initially with the pandemic and the movement to telehealth, you know, we had thought that we'd be able to broaden our catch because we are eliminating the need for travel to a medical center. However, we found out there were significant social determinants of health that limited telehealth. The ability of an older person to use electronics, the financial means to have an iPad or a smartphone, you know, internet access, and all of these were related to social determinants of health which made the adoption of telehealth more difficult and the people who really needed it. The people who are having trouble to begin with, still continue to have trouble because of those issues that I just mentioned. So social determinants of health has had a big impact on the efficacy of telehealth." - Cardiologist, PHCC</p>	<p>"I think so, I actually think it's [SDOH screener] a very good idea because as I mentioned, our patients generally are poor, so that would actually be a valuable tool. It'd be interesting to see the end responses that we get, and I think it may actually help us with our patients because there may be some patients, we think may actually be better than we make assumptions, that we think they may be better than they are, so I think it would be helpful. I think it would be helpful." - Pulmonologist, PHCC</p>
<p>"Well, [COVID-19] screwed up a lot of things in part because patients are very reluctant to come into clinic and into hospital, so it has delayed things and there's no way I can do a good assessment on a virtual visit. Just because, with these patients at physical exam actually does provide useful information. Also, patients tend to minimize things when they're doing it online. And often, what I found was that they want to hear more about what we're going through than to tell us what they're going through. So, it's really boxed patients into their homes almost as prisoners." - Pulmonologist, PHCC</p>	<p>"So, we have a lot of resources that many centers may not have or may have more. But I'm very lucky that I have what I have. I do believe that every center should have a social worker. We do not have a social worker. We have all of these resources but cannot secure social worker in our center. I mean, we have people we can reach out to, but not somebody dedicated to help our patients." – Pulmonologist, PHCC</p>
<p>"The support groups I think have been helpful and they've been curtailed. Not completely, but certainly there's impairment in the efficacy of what a support group can do in the last couple years because of COVID. But that community part is often dependent on how good the group is and the and how good the group is often depends on the one or two individuals that might be carrying the ball and organizing activities. When I go to these support group meetings, I see a big variability. I see many of our underserved that come and many who are well off that come, and so it's a pretty diverse group. But I also know the ones that don't go and will and or haven't gone, you know, I think they're missing out. Other than trying to encourage them, we don't have a good way to get them to come." – Cardiologist, PHCC</p>	<p>"We certainly appreciate and pick up on these things through all these interactions pretty early on, so that kind of front-loaded checklist may not impact us as much, but I think you know we're not the only people taking care of these patients. I mean, they go into the hospital, hospital staff takes care of them. And you know, they have, you know, we have outside partners and entities that work with these patients like specialty pharmacies. For instance, durable medical equipment companies. They won't know these patients as much, so it's such a checklist was there? I think all the other you know, players on that individual person's care team would have some better awareness of the issues of the patient." - Pulmonologist, PHCC</p>
<p>"I think that there are certainly people that we know in the community that PHA, the only point of contact that they have with us, is through Pathlight or quarterly newsletter because they're not active on the Internet. And it's an interesting, from an organizational perspective, I find it an interesting dilemma to wrestle with because, you know, as a modern nonprofit, we offer a significant portion of our programming online that you know that's how we do business these days. And so, it is very interesting to, you know, wrestle with that dilemma, how do we continue to serve folks who don't have that access? How do we reach them? It's an area that I think we would benefit to keep exploring." – Patient Advocate, PHA</p>	<p>"I certainly would say that, serving everyone who has been impacted by pulmonary hypertension, in a way that meets their needs, so, we recognize as an organization that it's not a one size fits all disease [and] that everybody has their own unique experience. And so, I think from that perspective, the more that we can learn as an organization about people's social determinants of health experience, the more effectively that we can serve folks, so broadly speaking, I think those unique experiences are important to the organization." – Patient Advocate, PHA</p>

PAH=Pulmonary Arterial hypertension; PHCC = Pulmonary Hypertension Comprehensive Care Center; PHA = Pulmonary Hypertension Association

FIGURE 6 COVID-19 and social determinants of health screening

quality of life using standard patient-reported outcomes measures, including impact on psychosocial issues. However, these instruments were not designed to capture their social needs, that is, SDoH. Participants reported relying upon their interactions with patients, supplemented by what their nurses or administrative assistants inform them. One participant's words, "I think [screening for SDOH] is a bit challenging, but we rely upon our own interactions with our patients and what our nurses tell us, or our administrative assistants tell us. We review all our patients in the clinic who are attending the clinic the week before. So, we have a group meeting, and issues like this may come up regarding whether it's health care, literacy or economic issues, or other things like that might influence a patient's care, but I don't think we're specifically trained and being sensitive enough to pick up on all those factors. It's really the most gross examples that are being brought to our attention, you know, some." Another participant said, "we don't have a screening tool for [SDoH]. It's usually a case-by-case exploration and trying to feel the social situation for especially new patients and getting to know changes that happened to current patients. Still, we don't have, for example, an official screening tool that patients answer, and you can pick up some of those situations to help identify people at risk."

Participants responded favorably to the idea of implementing an easy-to-use, PH population relevant SDoH screener, "yeah. I think you need to have a dedicated questionnaire that will include [social] factors." Participants expressed interest in screening for SDOH of their PAH patients and acknowledged it was not on top of their list due to a lack of a tool and lack of resources to follow through on the social issues. The absence of a dedicated PH social worker was a significant barrier to bridging their patients' social needs through community referrals. The institutional barriers, according to one participant, were "social work is not one of those things that pay its own bills, and so when hospitals cut costs, social work and palliative work, are the ones that are cut first and so a lot of our patients don't have access to the social and palliative networks that they should be given access to." Also, participants responded favorably to the relevance and potential use of the 10-item SDoH questionnaire with the PH population at the point of care. One participant said, "I can't think of any other concept/field that should be covered in this sample tool." However, they raised relevant practical issues such as "I am curious how you propose to include this in the EMR, namely wherein the patient encounter and how often this would be applied. As you know, these determinants change over time, but there tends to be survey fatigue both by the patient and the provider.

Importantly, interpretation and intervention need to be specified and pathways defined to address issues identified; otherwise, the clinical utility is limited."

DISCUSSION

Our study is the first to bring an understanding of clinician awareness and knowledge of SDoH in the PAH patient population. Experienced clinicians from PHCCCs across the US were highly aware of SDoH and shared how their patients' socioeconomic factors impacted their clinical care. Our study findings provide PAH clinicians' views that support emerging evidence indicating that PAH patients with negative SDoH correlated with poor health outcomes.⁹⁻¹² Talwar et al. identified that lower income levels in PAH patients were associated with the worse disease as measured by higher WHO-FC at initial evaluation.⁹ A study focused on portopulmonary hypertension patients enrolled in the Pulmonary Arterial Hypertension Registry (PHAR) revealed that portopulmonary hypertension patients had a lower socioeconomic status when compared to idiopathic PAH patients with increased healthcare utilization.¹¹ In the same study, a lower education level was associated with more emergency department visits highlighting the impact of health disparities in this group of patients.¹¹ Another recent study reported that PAH patients of Hispanic ethnicity had impaired healthcare access, lower education levels, income levels, and higher levels of emergency room visits and hospitalizations than their non-Hispanic White counterparts despite having similar disease severity.¹² In this study, while the unadjusted analysis of transplant-free survival suggested a better survival in Hispanic PAH patients, this was no longer the case after adjustment for covariates that included SDoH, which highlights the importance of considering SDoH in PAH outcome studies.¹² While our study sought a view about disparities of care amongst races and ethnicities, we did not directly identify race-related disparities in patient diagnosis, treatment, and prognosis. However, participants recognized that poor socioeconomics disadvantaged patients irrespective of their race. There were mixed findings from recent studies and may call for further investigation.^{12,22-25}

Our study findings should be helpful in informing a future PH practice model that includes screening for social needs domains (housing instability, utility strain, food insecurity, transportation, financial resources strain, and exposure to violence, childcare, and behavioral and mental health) using the brief 10-item SDoH questionnaire upon patient's initial visit and at appropriate subsequent visits that can range every 6 or 12 months,

with due consideration for patient survey fatigue and provider burden. These data, when integrated to the patient's medical record, should present the clinician with a holistic view of their patient's clinical and nonclinical challenges and help proactively manage with the aid of a dedicated social worker and support staff to address barriers including transportation, unstable housing, and food insecurity through community referrals and partnerships that were previously successful with a positive patient and system-wide impact.^{26,27} We recognize that it may not be feasible to immediately implement a quick SDoH screening and execution plan as it involves buy-in from several institutional stakeholders, including the PHCCC leadership, interdisciplinary PH care team, and institutional administrators, with potentially conflicting priorities. For instance, the clinical team focuses on improving care for their patients, while the institutional administrators focus on financial and return on investment decisions. Initiatives such as the protocol for responding to and assessing patients' assets, risks, and experiences (PRAPARE) can be helpful for PHCCCs in implementing SDoH in their routine practice to improve population health outcomes.²⁷ To this effect, we present an integrated SDoH PH practice model for potential implementation at the PH centers of excellence (Figure 7).

Currently, PHA accreditation requirements include social work in the program staff and support services category, needing resources or an established referral

pattern.¹⁴ Our study findings indicate clinicians at PHCCCs are seeking dedicated social support. We believe PHA and other patient organizations have a significant role to play. For example, PHA may consider specifying social workers' full-time equivalent proportion in the accreditation criteria or requiring pilot quality improvement initiatives aligned with national SDoH-focused quality improvement initiatives.²⁶ This should help improve the uptake of SDoH screening, measurement, analysis, and point-of-care application to clinical decision-making focusing on patient outcomes.

Though we sought one patient advocate's perspective, our study heavily focused on clinicians' perspectives. Hence, it is crucial to explore PAH patients' perspectives on SDoH to advance patient-centered care. A recent survey indicated that nearly half of Americans (46%) were unaware of social drivers of health. Once defined as SDoH, 60% of Americans agreed that their local community faces at least some health issues related to SDoH.²⁸ Educational efforts from patient associations like PHA should include SDoH and their potential impact on individuals' health and life outcomes. These can be modules made available through PHA providers and patient education material. Additionally, the educational material on SDoH can be built into the patient peer support programs to bring awareness and share helpful resources for PAH patients and their families.

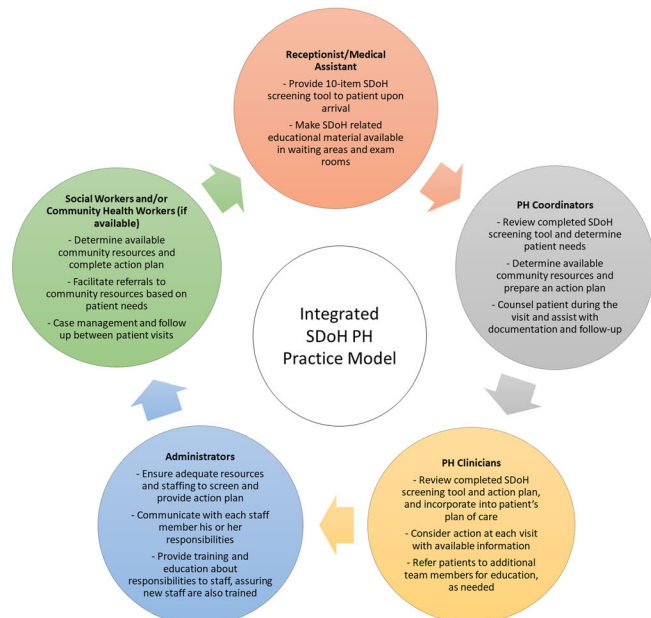
10-item SDoH screener †

		YES / NO
	Are you worried that in the next 2 months, you may not have a safe or stable place to live? (eviction, being kicked out, homelessness)	<input type="checkbox"/> Y <input type="checkbox"/> N
	Are you worried that the place you are living now is making you sick? (has mold, bugs/rodents, water leaks, not enough heat)	<input type="checkbox"/> Y <input type="checkbox"/> N
	In the last 12 months, did you worry that your food could run out before you got money to buy more?	<input type="checkbox"/> Y <input type="checkbox"/> N
	In the last 3 months, has the electric, gas, oil or water company threatened to shut off services to your home?	<input type="checkbox"/> Y <input type="checkbox"/> N
	In the last 3 months, has lack of transportation kept you from medical appointments or getting your medications?	<input type="checkbox"/> Y <input type="checkbox"/> N
	In the last 3 months, did you have to skip buying medications or going to doctor's appointments to save money?	<input type="checkbox"/> Y <input type="checkbox"/> N
	Do you need help getting child care or care for an elderly or sick adult?	<input type="checkbox"/> Y <input type="checkbox"/> N
	Do you need legal help? (child/family services, immigration, housing discrimination, domestic issues, etc.)	<input type="checkbox"/> Y <input type="checkbox"/> N
	Are you finding it so hard to get along with a partner, spouse, or family members that it is causing you stress?	<input type="checkbox"/> Y <input type="checkbox"/> N
	Does anyone in your life hurt you, threaten you, frighten you or make you feel unsafe?	<input type="checkbox"/> Y <input type="checkbox"/> N

Do you want help? Y N

Phone Number: _____

Best time to Call: _____



† Reproduced with permission from Montefiore Health System. This screening tool is a derivative of a recommended screening tool by Health Leads (<https://healthleadsusa.org/>) licensed under a Creative Commons Attribution-ShareAlike 4.0 International license (<https://creativecommons.org/licenses/by-sa/4.0/>) and was adapted by Montefiore Health System's Office of Community and Population Health.²⁶

Content adapted from American Academy of Family Physicians. Social Determinants of Health – Guide to Social Needs Screening. Accessed at https://www.aafp.org/dam/AAFP/documents/patient_care/everyone_project/hops19-physician-guide-sdoh.pdf [April 30, 2022]

PH=Pulmonary Hypertension; SDoH = Social Determinants of Health

FIGURE 7 Integrated social determinants of health PH practice model

The tsunami created by the COVID-19 pandemic greatly impacted PAH practice and patients. Although telemedicine mitigated particular COVID-19 challenges, some patients were disproportionately disadvantaged because of the inequities associated with Internet access, devices, and lack of technology savviness. This is particularly important as digital literacy and internet connectivity has been the “super social determinant of health” as they are intricately linked to all other SDoH.²⁹ It must be observed in the context of the role of digital outreach to impacted patient communities where the majority of modern patient advocacy organizations such as PHA’s outreach, educational and advocacy efforts are Internet-based. It behooves the PH community to pay close attention to the SDoH of internet inequity.

Our study findings should be considered with some limitations. We sought clinician subjective inputs on their practice characteristics; though consistent with the study methodology, it should be noted that these are nonvalidated qualitative estimates based on participant awareness and experience. The results may reflect clinicians at PHCCCs and may not be generalizable to clinicians at nonaccredited PH centers and clinics. There also may be a selfselection bias with only knowledgeable and interested providers accepting to participate in the study. Hence, they may have shown greater awareness of SDoH in their patients. Also, it is possible participants could have prepared for the interview topic, and as such there was high awareness. The clinician’s perspective on SDoH may not fully reflect PAH patients’ awareness, understanding, experience, and the extent of the SDoH on their health. Though we sought the perspective of a patient advocate from PHA, it identifies an opportunity to study SDoH impact on PAH patients’ health and living experience. While our study used a single coder, we ensured careful review and discussions to validate the consistency in the themes and to minimize potential interpretation bias of participant perspectives.

PH clinicians at PHCCCs were highly aware of the inequities in healthcare for PAH patients, an already vulnerable population, further negatively impacted due to their social and economic disadvantages. Health policy efforts at an institutional and national level must focus on screening and follow-up aided by referrals through community partnerships. Future research should include SDoH data integration to patient registries to methodically study the impact of SDoH on patient outcomes across PHCCCs.³⁰ The SDoH evidence obtained from such initiatives should be helpful for inclusion in PH risk-scoring algorithms to produce a holistic risk score inclusive of clinical and nonclinical data aiding in risk stratification to predict patients with the most significant health needs.³¹ SDoH should be integral to holistic care,

as we learned from our study participants that one size does not fit all, and PH care must be customized depending on patient needs. Efforts to consider the PAH patient’s SDoH are also consistent with efforts to integrate patient voice for patient-centered care.^{32,33} Health policy initiatives to inform SDoH integration to routine PAH care management is paramount to addressing disparities and improving equality in healthcare access, outcomes, and quality of care.

AUTHOR CONTRIBUTIONS

Vijay R. Nadipelli designed the study, prepared, and conducted semi-structured interviews. Willie H. Oglesby and Karim El-Kersh contributed to the final study design, participant interview content, and structure. Vijay R. Nadipelli developed interview transcripts and performed data analysis. Vijay R. Nadipelli, Jean M. Elwing, Willie H. Oglesby, and Karim El-Kersh reviewed and interpreted the results. Vijay R. Nadipelli drafted the first draft of the manuscript. Vijay R. Nadipelli, Jean M. Elwing, Willie H. Oglesby, and Karim El-Kersh contributed to and approved the final version of the manuscript.

ACKNOWLEDGMENTS

We thank the study participants from PH centers of excellence and the Pulmonary Hypertension Association and the individuals with PAH and their families they serve and whose life stories are embedded in study participant perspectives. Our gratitude to Kevin Fiori, MD, MPH, Director—Social Determinants of Health, Community and Population Health, Montefiore Health System (New York, USA), for his insights and permission to use the 10-item SDoH screening tool by the PH centers. This publication made possible in part by support from the Thomas Jefferson University Open Access Fund. This study received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

CONFLICTS OF INTEREST

Vijay R. Nadipelli is a Master of Science Health Policy Candidate at Thomas Jefferson University’s College of Population Health. Portions of this study were previously presented at the Pulmonary Hypertension Association Scientific Conference, Atlanta, Georgia, June 9–12, 2022. The culminating study has been submitted in fulfillment of Vijay R. Nadipelli’s institutional academic degree requirements. The other authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data supporting this study’s findings are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

As this study involved interviews, questions focused on information and opinions about processes, services, or policies and did not gather personal information about living individuals. Our University's Office of Human Research deemed it does not require Institutional Review Board submission.

ORCID

Vijay R. Nadipelli  <http://orcid.org/0000-0002-0314-729X>

Karim El-Kersh  <http://orcid.org/0000-0003-1285-3628>

REFERENCES

1. Social Determinants of Health [Internet]. <https://health.gov/healthypeople/priority-areas/social-determinants-health>
2. Artiga S, Hinton E. Beyond health care: the role of social determinants in promoting health and health equity, Henry J. Kaiser Family Foundation; 2022.
3. Galea S, Tracy M, Hoggatt KJ, Dimaggio C, Karpati A. Estimated deaths attributable to social factors in the United States. *Am J Public Health*. 2011;101(8):1456–65. <https://doi.org/10.2105/AJPH.2010.300086>
4. Andermann A. Taking action on the social determinants of health in clinical practice: a framework for health professionals. *CMAJ*. 2016;188(17–18):E474–83. <https://doi.org/10.1503/cmaj.160177>
5. Taylor LA, Tan AX, Coyle CE, Ndumele C, Rogan E, Canavan M, Curry LA, Bradley EH. Leveraging the social determinants of health: what works. *PLoS One*. 2016;11(8):e0160217. <https://doi.org/10.1371/journal.pone.0160217>
6. Cockerham WC, Hamby BW, Oates GR. The social determinants of chronic disease. *Am J Prev Med*. 2017;52(1S1):S5–12. <https://doi.org/10.1016/j.amepre.2016.09.010>
7. Galiè N, Torbicki A, Barst R, Darteville P, Haworth S, Higenbottam T, Olschewski H, Peacock A, Pietra G, Rubin LJ, Simonneau G. Guidelines on diagnosis and treatment of pulmonary arterial hypertension. *Rev Esp Cardiol*. 2005;58(5):523–66. <https://doi.org/10.1157/13074846>
8. Strange G, Gabbay E, Kermeen F, Williams T, Carrington M, Stewart S, Keogh A. Time from symptoms to definitive diagnosis of idiopathic pulmonary arterial hypertension: the delay study. *Pulm Circ*. 2013;3(1):89–94. <https://doi.org/10.4103/2045-8932.109919>
9. Talwar A, Sahni S, Talwar A, Kohn N, Klinger JR. Socioeconomic status affects pulmonary hypertension disease severity at time of first evaluation. *Pulm Circ*. 2016;6(2):191–5. <https://doi.org/10.1086/686489>
10. Helgeson SA, Menon D, Helmi H, Vadlamudi C, Moss JE, Zeiger TK, Burger CD. Psychosocial and financial burden of therapy in USA patients with pulmonary arterial hypertension. *Diseases*. 2020;8(2):22. <https://doi.org/10.3390/diseases8020022>
11. DuBrock HM, Burger CD, Bartolome SD, Feldman JP, Ivy DD, Rosenzweig EB, Sager JS, Presberg KW, Mathai SC, Lammi MR, Klinger JR, Eggert M, De Marco T, Elwing JM, Badesch D, Bull TM, Cadaret LM, Ramani G, Thenappan T, Ford HJ, Al-Naamani N, Simon MA, Mazimba S, Runo JR, Chakinala M, Horn EM, Ryan JJ, Frantz RP, Krowka MJ. Health disparities and treatment approaches in portopulmonary hypertension and idiopathic pulmonary arterial hypertension: an analysis of the pulmonary hypertension association registry. *Pulm Circ*. 2021;11(3):20458940211020910. <https://doi.org/10.1177/20458940211020910>
12. Bernardo RJ, Lu D, Ramirez RL, 3rd, Hedlin H, Kawut SM, Bull T, De Marco T, Ford HJ, Grinnan D, Klinger JR, McConnell JW, Berman-Rosenzweig E, Shlobin OA, Zamanian RT, de Jesus Perez VA. Hispanic ethnicity and social determinants of health in pulmonary arterial hypertension: the pulmonary hypertension association registry. *Ann Am Thorac Soc*. 2022. <https://doi.org/10.1513/AnnalsATS.202109-1051OC>
13. Talwar A, Garcia JGN, Tsai H, Moreno M, Lahm T, Zamanian RT, Machado R, Kawut SM, Selej M, Mathai S, D'Anna LH, Sahni S, Rodriguez EJ, Channick R, Fagan K, Gray M, Armstrong J, Rodriguez Lopez J, de Jesus Perez V. Health disparities in patients with pulmonary arterial hypertension: a blueprint for action. an official American thoracic society statement. *Am J Respir Crit Care Med*. 2017;196(8):e32–47. <https://doi.org/10.1164/rccm.201709-1821ST>
14. Gray MP, Onyeador O, Wirth JA. Update on the PHA pulmonary hypertension care center network: early experience with the national accreditation program. *Adv Pulm Hypertens*. 2018;16(4):179–84. <https://doi.org/10.21693/1933-088x-16.4.179>
15. DeJonckheere M, Vaughn LM. Semistructured interviewing in primary care research: a balance of relationship and rigour. *Fam Med Community Health*. 2019;7(2):e000057. <https://doi.org/10.1136/fmch-2018-000057>
16. Health Leads. The Health Leads Screening Toolkit. [Internet]. Health Leads. 2018 [cited 2022 April 30]. Available from: <https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/>
17. Herrera T, Fiori KP, Archer-Dyer H, Lounsbury DW, Wylie-Rosett J. Social determinants of health screening by preclinical medical students during the COVID-19 pandemic: service-based learning case study. *JMIR Med Educ*. 2022;8(1):e32818. <https://doi.org/10.2196/32818>
18. Fiori KP, Rehm CD, Sanderson D, Braganza S, Parsons A, Chodon T, Whiskey R, Bernard P, Rinke ML. Integrating social needs screening and community health workers in primary care: the community linkage to care program. *Clin Pediatr*. 2020;59(6):547–56. <https://doi.org/10.1177/0009922820908589>
19. Fiori K, Patel M, Sanderson D, Parsons A, Hodgson S, Scholnick J, Bathory E, White-Davis T, Wigod N, Chodon T, Rich A, Braganza S. From policy statement to practice: integrating social needs screening and referral assistance with community health workers in an urban academic health center. *J Prim Care Community Health*. 2019;10:2150132719899207. <https://doi.org/10.1177/2150132719899207>
20. Orcholowski ME, Yuan K, Rajasingh C, Tsai H, Shamskhou EA, Dhillon NK, Voelkel NF, Zamanian RT, de Jesus Perez VA. Drug-induced pulmonary arterial hypertension: a primer for clinicians and scientists. *Am J Physiol Lung Cell Mol Physiol*. 2018;314(6):L967–83. <https://doi.org/10.1152/ajplung.00553.2017>
21. Kolaitis NA, Zamanian RT, de Jesus Perez VA, Badesch DB, Benza RL, Burger CD, Chakinala MM, Elwing JM, Feldman J,

- Lammi MR, Mathai SC, McConnell JW, Presberg KW, Robinson JC, Sager J, Shlobin OA, Simon MA, Kawut SM, Glidden DV, Singer JP, De Marco T. Clinical differences and outcomes between methamphetamine-associated and idiopathic pulmonary arterial hypertension in the pulmonary hypertension association registry. *Ann Am Thorac Soc*. 2021;18(4):613–22. <https://doi.org/10.1513/AnnalsATS.202007-774OC>
22. Al-Naamani N, Paulus JK, Roberts KE, Pauciulo MW, Lutz K, Nichols WC, Kawut SM. Racial and ethnic differences in pulmonary arterial hypertension. *Pulm Circ*. 2017;7(4):793–6. <https://doi.org/10.1177/2045893217732213>
 23. Medrek SK, Sahay S. Ethnicity in pulmonary arterial hypertension: possibilities for novel phenotypes in the age of personalized medicine. *Chest*. 2018;153(2):310–20. <https://doi.org/10.1016/j.chest.2017.08.1159>
 24. Karnes JH, Wiener HW, Schwantes-An T-H, Natarajan B, Sweatt AJ, Chaturvedi A, Arora A, Batai K, Nair V, Steiner HE, Giles JB, Yu J, Hosseini M, Pauciulo MW, Lutz KA, Coleman AW, Feldman J, Vanderpool R, Tang H, Garcia J, Yuan JX, Kittles R, de Jesus Perez V, Zamanian RT, Rischard F, Tiwari HK, Nichols WC, Benza RL, Desai AA. Genetic admixture and survival in diverse populations with pulmonary arterial hypertension. *Am J Respir Crit Care Med*. 2020;201(11):1407–15. <https://doi.org/10.1164/rccm.201907-1447OC>
 25. Medrek S, Sahay S, Zhao C, Selej M, Frost A. Impact of race on survival in pulmonary arterial hypertension: results from the REVEAL registry. *J Heart Lung Transplant*. 2020;39(4):321–30. <https://doi.org/10.1016/j.healun.2019.11.024>
 26. Ncqa.org. Health Equity and Social Determinants of Health in HEDIS: Data for Measurement. [Internet]. 2021 June [cited 2022 April 30]. Available from: https://www.ncqa.org/wp-content/uploads/2021/06/20210622_NCQA_Health_Equity_Social_Determinants_of_Health_in_HEDIS.pdf
 27. Nachc.org. PRAPARE—Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences. [Internet]. 2019 March [cited 2022 April 30]. Available from: http://www.nachc.org/wp-content/uploads/2019/04/NACHC_PRAPARE_Full-Toolkit.pdf
 28. Thinkanthem.com. Driving Our Health: A Study Exploring Health Perceptions in America. [Internet]. 2021 June [cited 2022 April 30]. Available from: <https://www.thinkanthem.com/wp-content/uploads/Anthem-SDOH-Results-Report.pdf>
 29. Sieck CJ, Sheon A, Ancker JS, Castek J, Callahan B, Siefer A. Digital inclusion as a social determinant of health. *NPJ Digit Med*. 2021;4(1):52. <https://doi.org/10.1038/s41746-021-00413-8>
 30. Gray MP, Kawut SM. The pulmonary hypertension association registry: rationale, design, and role in quality improvement. *Adv Pulm Hypertens*. 2018;16(4):185–8. <https://doi.org/10.21693/1933-088x-16.4.185>
 31. Ford HJ, LeVarge B. The pursuit of risk assessment and stratification tools in pulmonary arterial hypertension. *Chest*. 2021;159(1):14–6. <https://doi.org/10.1016/j.chest.2020.10.026>
 32. McGoon MD, Ferrari P, Armstrong I, Denis M, Howard LS, Lowe G, Mehta S, Murakami N, Wong BA. The importance of patient perspectives in pulmonary hypertension. *Eur Respir J*. 2019;53(1):1801919. <https://doi.org/10.1183/13993003.01919-2018>
 33. Ferrari P, Skåra H. My life with pulmonary arterial hypertension: a patient perspective. *Eur Heart J Suppl*. 2019;21(Suppl K):K54–9. <https://doi.org/10.1093/eurheartj/suz208>

How to cite this article: Nadipelli VR, Elwing JM, Oglesby WH, El-Kersh K. Social determinants of health in pulmonary arterial hypertension patients in the United States: clinician perspective and health policy implications. *Pulm Circ*. 2022;12:e12111. <https://doi.org/10.1002/pul2.12111>