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

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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

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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.³ 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 using contact information sourced from institutional and PHA websites. A brief preinterview questionnaire was 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.³ 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.

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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 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.” 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...
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
FIGURE 2 Social determinants of health awareness and impact

(a) What do SDOH mean to you?

“I think social determinants of health are couple of things. One is what 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 fourth or whatever number we’ve got up to, are you treated the same way as somebody else who might be a bit 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, PHCC

(b) How do SDOH impact your patients?

“I think the way type of work a patient is doing and therefore the stresses that provides, so you know, for instance, I have a couple of patients who work for the counties on their road crews and he doesn’t have really for 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 limitation that would be a desk job without any problems and would not have his employment being threatened by his disease.” — Pulmonologist, PHCC

FIGURE 3 Employment and housing

(a) How does employment status impact PAH patient’s clinical care?

“I think at multiple levels, I mean obviously our country’s 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, PHCC

(b) How does housing impact PAH patient’s clinical care?

“Absolutely, I mean, being a chronic disease that is significantly impactful on us on a day-to-day basis really impacts I think, or resources 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 difficult things is that home situation goes a long way into deciding what type of therapy they’re going to 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 those things factor into the home situation and how could it impact their well-being as well as their, the sustainability of their medications.” — Pulmonologist, PHCC

Well, so this individual, you know his options are to try to get accommodations, try to continue working or go to out on disability, and that has dramatic implications. He’s the sole source of income for his family. So, you know, going out on disability and therefore, taking a decrement in his income because of that is causing a great deal of concern for him, while if he had the same level of disease and was an accountant, he would have no question that he be able to go to work and continue working without any adjustment to his schedule, work routine or anything like that.” — Pulmonologist, PHCC

“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 403B or 403b because they haven’t gotten to that point in their life yet. So, if you’ve 40 years old and you have two kids, you’re not going to have a very deep savings. You’re not gonna have a lot of money into Medicare or Social Security. So, you often get stuck 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, PHCC

“He’s 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 to that example getting refills, but also the education (I think) that missing a dose is critically important and how that can impact her overall health.” — Pulmonologist, PHCC

“So, mood, anxiety, support system, stability are all extremely important. They mean very different things for different patients. For you and I, 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 where they need to go. So, I think those things really depend on your situation and fortunately or unfortunately we can fit in different situations through our lifetimes.” — Pulmonologist, PHCC
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 30’s 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.
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
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

**FIGURE 6** COVID-19 and social determinants of health screening

(a) What impact did COVID-19 have on PAH patients?

*"So, do I 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 lifestyle just because of where 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

*"You know, initially with the pandemic and the movement to telehealth, we know, I 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 just mentioned. Social determinants of health has had a big impact on the efficacy of telehealth.”* – Cardiologist, PHCC

(b) Do you currently screen PAH patients for SDoH?

*"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 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

*"The support groups I think have been helpful and they’ve been canceled. Not completely, but certainly there’s impact 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 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 understood that come and many who are well off that come, and so it’s a pretty diverse group. But I also know the ones who don’t go and well and have gone, you know, they 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

*"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 Faultlight 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 non-profit, 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, 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

*"I certainly would say that, serving someone 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
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 socioeconomic disadvantages 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.

FIGURE 7 Integrated social determinants of health PH practice model

10-item SDoH screener

1 Reproduced with permission from Monsefore 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 Monsefore Health System’s Office of Community and Population Health.™

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/overview_project/0140-physician-guide-sohd.pdf [April 30, 2022]
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.  

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. 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.

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. 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.

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**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.

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