

Qualitative Interviews of Patients with Meth-APAH: Understanding the Unmet Medical Need from the Patient Lens

AUTHORS:
Lana Melendres-Groves¹, Vinicio De Jesus Perez², Anjali Vaidya³, Hyein G. Lee⁴, Marinella Sandros⁵, David Lopez⁵, Ankita Adhia⁵, Natalie Gearhart⁵, Michelle Cho⁵, John F. Kingrey⁶

AFFILIATIONS:
¹University of New Mexico Health Sciences, New Mexico, USA
²Stanford Medicine, California, USA
³Temple Health, Pennsylvania, USA

⁴Putnam Associates, Boston, USA
⁵Johnson and Johnson, New Jersey, USA
⁶INTEGRIS Health, Oklahoma, USA

Background

- PAH is a complex, progressive and potentially fatal disease characterized by increased pulmonary vascular resistance, leading to right heart failure and premature mortality
- Toxin-induced PAH is a growing concern, particularly Meth-APAH, which is increasing in prevalence and reflecting the rise in methamphetamine use in the US and globally
- Patients with Meth-APAH navigate the complex intersection of low awareness, poorly understood pathophysiology, and socioeconomic and psychological barriers associated with substance use related disorders

Objective

To illuminate the clinical journey of patients with Meth-APAH, providing a deeper understanding of their experiences and highlighting key unmet needs

Methods and Participant Sample

20 adult (aged 18 or older) patients diagnosed with PAH with a history of methamphetamine use in the US participated in this research

- Structured interviews were conducted in July-August 2024
- Patients were recruited through a vendor specializing in rare disease patient voice and participants gave informed consent
- Participants were geographically distributed as follows: 40% West, 20% Midwest, 30% South, 10% Northeast
- The average age of patients at time of interviews was 50 years old; 90% were female; 75% were White; 30% had a college degree; 50% were full-time employed at time of diagnosis; 15% were uninsured at time of diagnosis
- Though most patients reported being under the care of a PAH specialist, 20% (N=4/20) were not seeing a PAH specialist for their PAH care while 10% (N=2/20) said they were unsure about their PAH physician's specialty

Interviews were structured around four key themes:

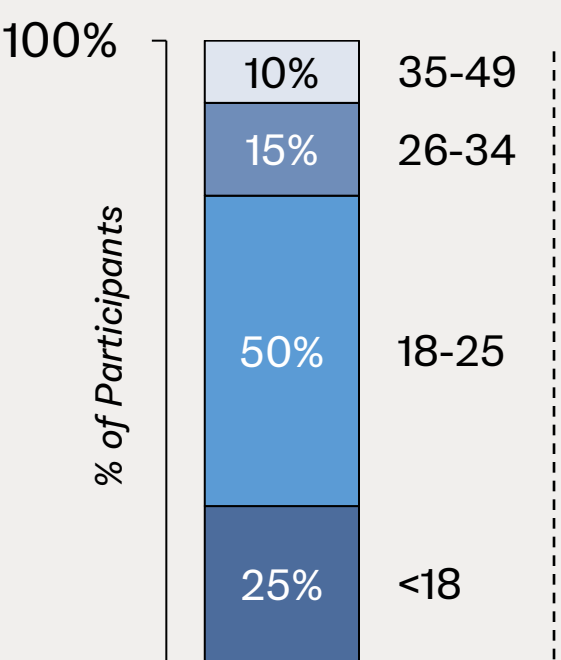
- Patient methamphetamine use history
- Path to Meth-APAH diagnosis
- Meth-APAH Treatment Experiences
- Challenges and Unmet needs in patient journey

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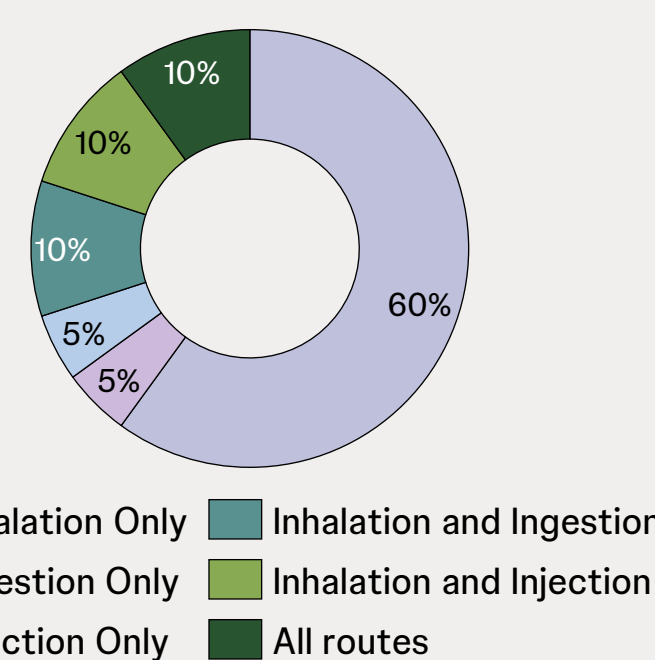
Results

1. Methamphetamine Use History

1.1 Age of First Meth Use

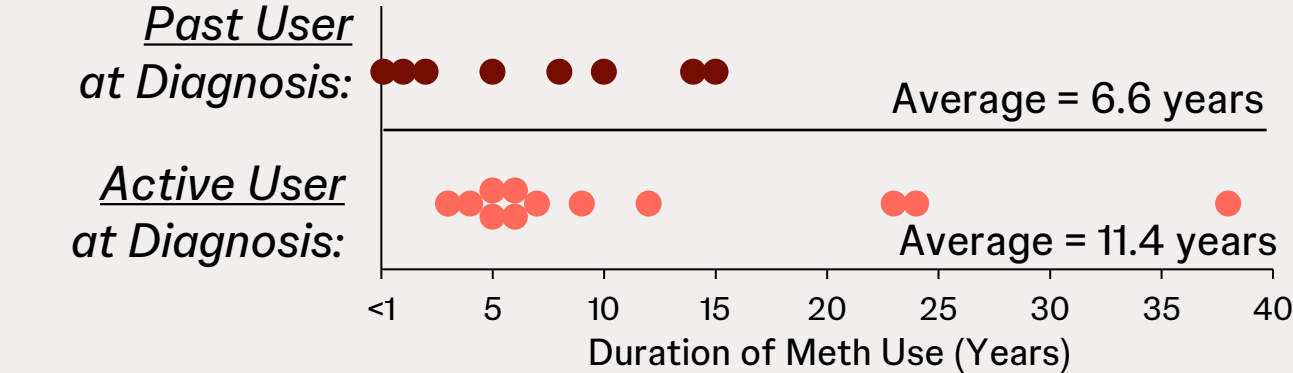


1.2 Route of Meth Use



- Most patients started using meth before the age of 25; they describe their use as daily or near daily
- Most common reasons for initiating meth use were peer or relationship pressures

1.3 Duration of Meth Use by Use at Diagnosis



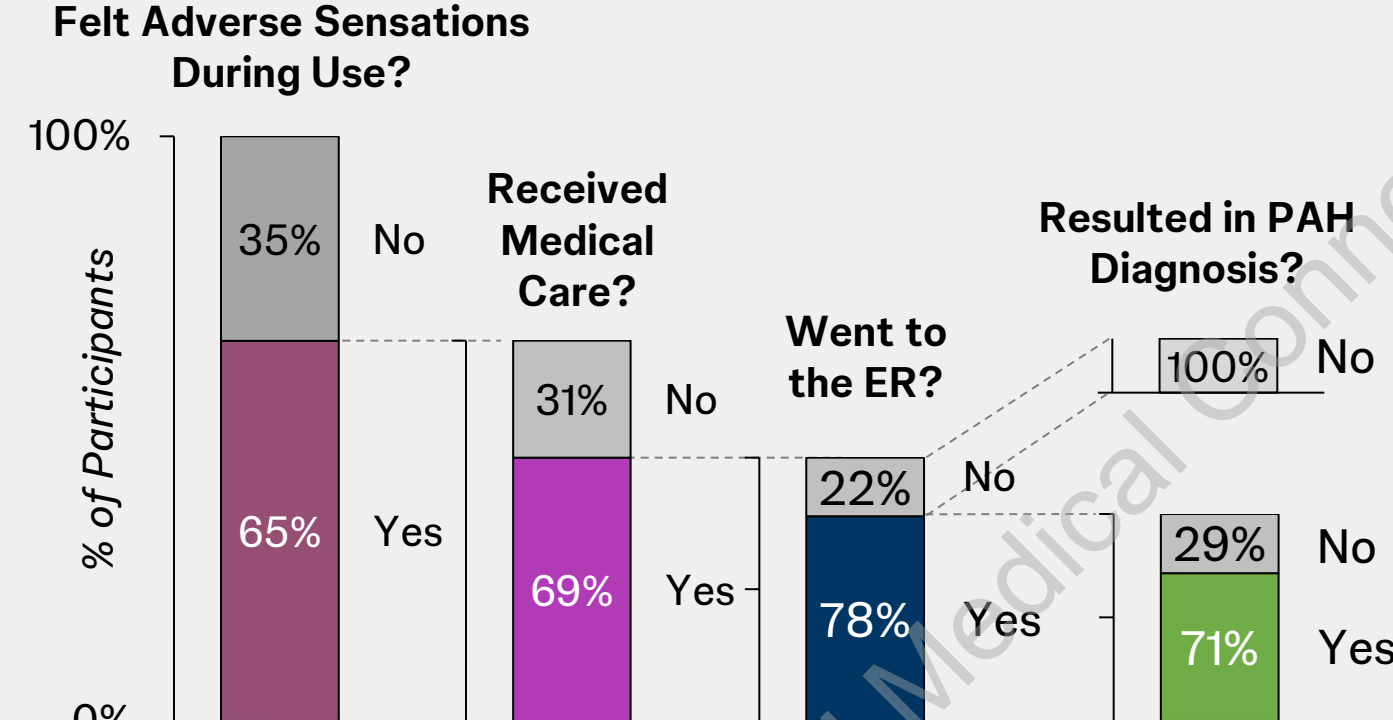
- Overall, the total duration of methamphetamine use ranged from less than 1 year to several decades

1.4 Syncope and Meth-APAH

- 25% of patients experienced episodes of syncope during their time of active meth use prior to their Meth-APAH diagnosis
- 45% of patients who received medical attention during their time of active meth use received care due to involuntarily hospitalizations for syncope – All such hospitalizations led to a PAH diagnosis
- 50% of patients diagnosed with PAH while actively using Meth-APAH were diagnosed following an episode of syncope

2. Journey to PAH Diagnosis

2.1 Patient Response to Feeling PAH Symptoms During Active Use



- Not all patients sought care during their times of methamphetamine use even when they felt discomfort
- For patients who received care at the ER – voluntarily or involuntarily (i.e., due to syncope or other serious event) – they were more likely to be diagnosed with PAH

2.2 Setting of Diagnosis by Meth Use Status

Use Status at Diagnosis	Setting of PAH Diagnosis		Total
	Emergency Room	Outpatient Clinic	
Active User At Diagnosis	50%	10%	60%
Past User At Diagnosis	15%	25%	40%
Total	65%	35%	

* The association between meth use status and setting of PAH diagnosis is statistically significant ($p < 0.05$, Chi-Square test)

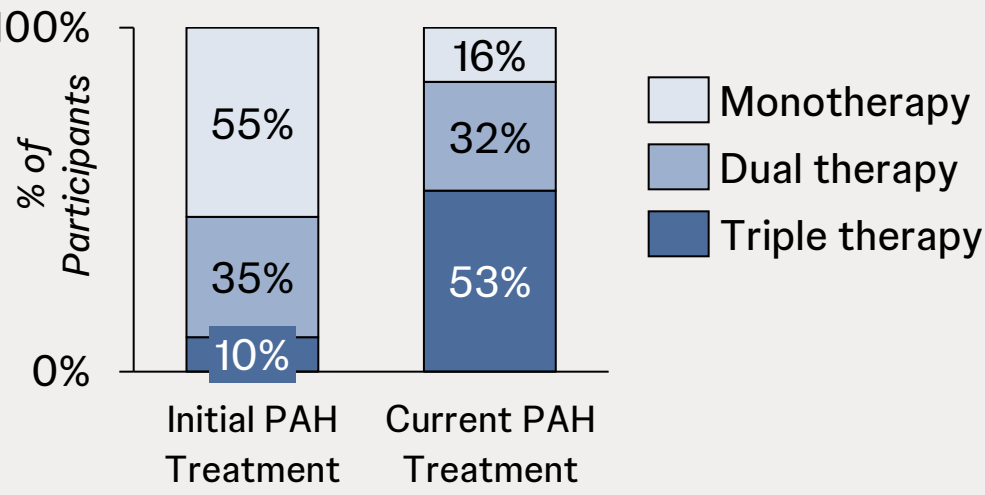
- Active users were more likely to be diagnosed at the ER, while past users were more likely to be diagnosed in the outpatient setting
- Most common reasons for ER visits were:
 - Active Users: syncope, dyspnea
 - Past Users: pneumonia-related complication

3. Meth-APAH Diagnosis and Treatment

3.1 Asking and Testing for Drug Use

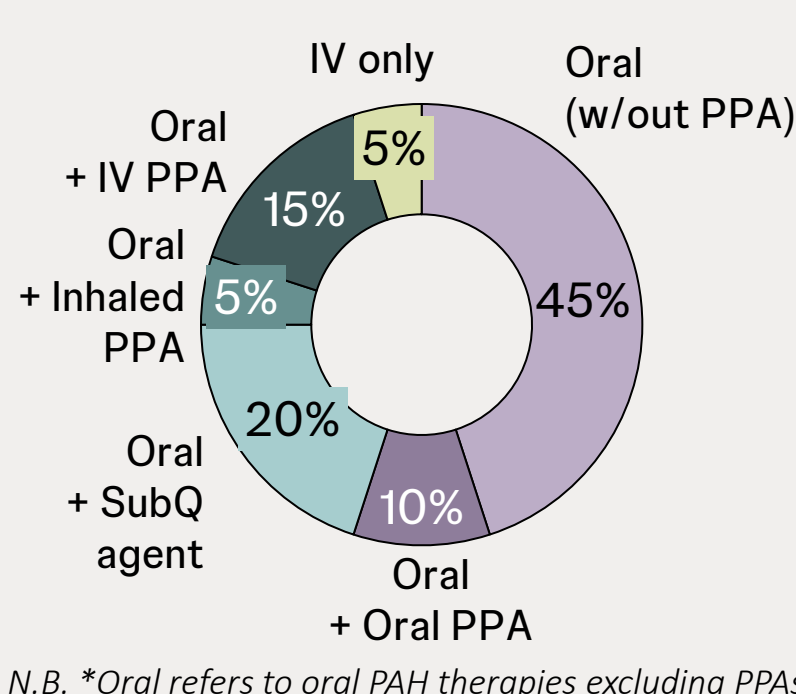
- 15% of patients were not asked about their drug use status or history
- 50% of patients were not asked about the details of their drug use (i.e., route or length of use)
- 40% of patients received a toxicology screen during their diagnosis
- 50% of patients who were actively using at diagnosis quit use immediately after diagnosis

3.2 PAH Treatment Over Journey



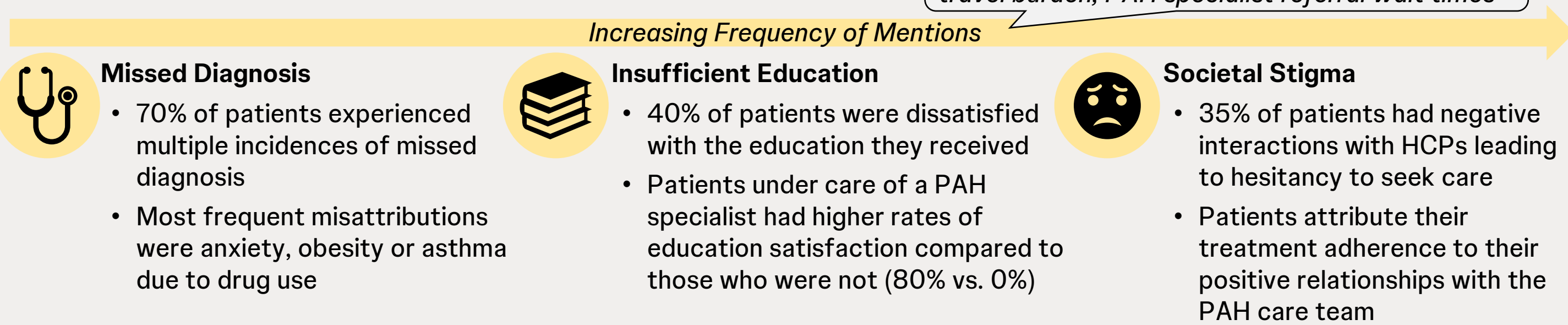
- Most patients were initiated on a monotherapy and escalated over time to dual or triple therapy

3.3 RoA of PAH Treatments



N.B. *Oral refers to oral PAH therapies excluding PPA's

4. Unmet Needs in Meth-APAH Patient Journey



Abbreviations ER=Emergency Room; HCP=Health Care Professional; HIV=Human Immunodeficiency Virus; HR=Heart Rate; Meth=Methamphetamine; Meth-APAH=Methamphetamine-associated Pulmonary Arterial Hypertension; PAH=Pulmonary Arterial Hypertension; PPA=Prostacyclin Pathway Agent; QoL=Quality of Life; RoA=Route of Administration

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Key takeaways

This first-of-its-kind study sheds light on challenges faced by patients with Meth-APAH and the urgent need for increased awareness, educational resources, collaboration with substance abuse specialists and empathy in Meth-APAH care



- Over half of the participants were still using meth when they were diagnosed with PAH
- The majority of participants were diagnosed following a severe event which led them to the ER, such as syncope or dyspnea
- Not all patients were asked about their drug use history and the majority were not asked to perform a toxicology screen



- Only 50% of the participants were asked about the details of their drug use by their treating physician



- Missed diagnosis, insufficient education and societal stigma were noted as the greatest challenges in the Meth-APAH patient journey

Implications of this Study

To improve patient experiences and outcomes in Meth-APAH care, the findings of this study call for:



Raising Awareness in Frontline HCPs

Given the high percentage of patients first presenting at the ER with severe symptoms such as syncope, raising awareness and increasing suspicion of Meth-APAH in frontline HCPs may help with timely diagnosis



Increased Patient Education on Meth-APAH

Many patients, especially those under care by a non-PAH specialist, would like more educational resources to empower them to know more about their diagnosis



Strategies for Compassionate Care

Patients appreciate straightforward, persistent, but caring attitudes from their PAH care teams; longer discussions and proactive check-ins build trust

Disclosures

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Pulmonary Hypertension



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