

# PHenomenal Hope 2025

*Knowledge, Research & Advocacy in PH*

## Qualitative interviews of patients with meth-APAH: Understanding the unmet medical need from the patient lens

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# 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 disorders related to substance use

meth-APAH, methamphetamine-associated pulmonary arterial hypertension; PAH, pulmonary arterial hypertension.

# Study objective

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

meth-APAH, methamphetamine-associated pulmonary arterial hypertension.

# Methods

- Adult patients ( $\geq 18$  years) diagnosed with PAH and with a history of methamphetamine use in the US participated
- Structured interviews were conducted in July and August 2024
- Patients were recruited through a vendor specializing in the rare disease patient voice
- Patients gave informed consent

## 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

# Participant sample

	Patients with meth-APAH (N=20)
<b>Current age, years, % (n)</b>	
26-34	5% (1)
35-49	50% (10)
50+	45% (9)
<b>Gender, % (n)</b>	
Female	90% (18)
Male	10% (2)
<b>Race, % (n)</b>	
Black	10% (2)
Multiracial <sup>a</sup>	5% (1)
Native American	10% (2)
White	75% (15)
<b>Geographical location, % (n)</b>	
Midwest	20% (4)
Northeast	10% (2)
South	30% (6)
West	40% (8)

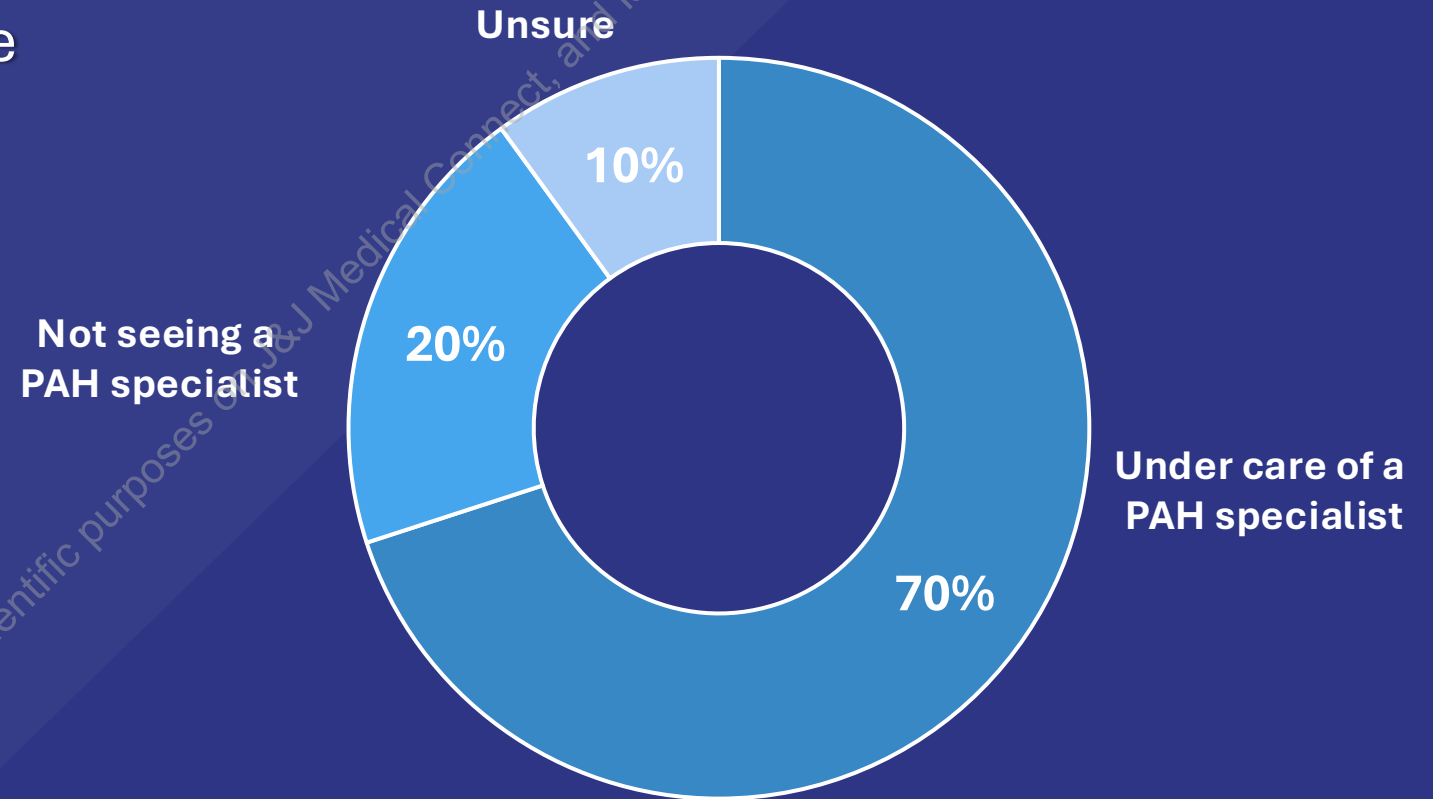
	Patients with meth-APAH (N=20)
<b>Educational attainment, % (n)</b>	
Did not finish high school	10% (2)
High school diploma / GED	60% (12)
Associate's degree	15% (3)
Bachelor's degree	15% (3)
<b>Employment status<sup>b</sup>, % (n)</b>	
Full-time	50% (10)
Part-time	15% (3)
Unemployed	35% (7)
<b>Health insurance status<sup>b</sup>, % (n)</b>	
Commercial	30% (6)
Medicaid	45% (9)
Medicare	10% (2)
Uninsured	15% (3)

<sup>a</sup>Patient identifies as Black and White. <sup>b</sup>At the time of diagnosis.

GED, general educational development test; meth-APAH, methamphetamine-associated pulmonary arterial hypertension.

# Participant sample (continued)

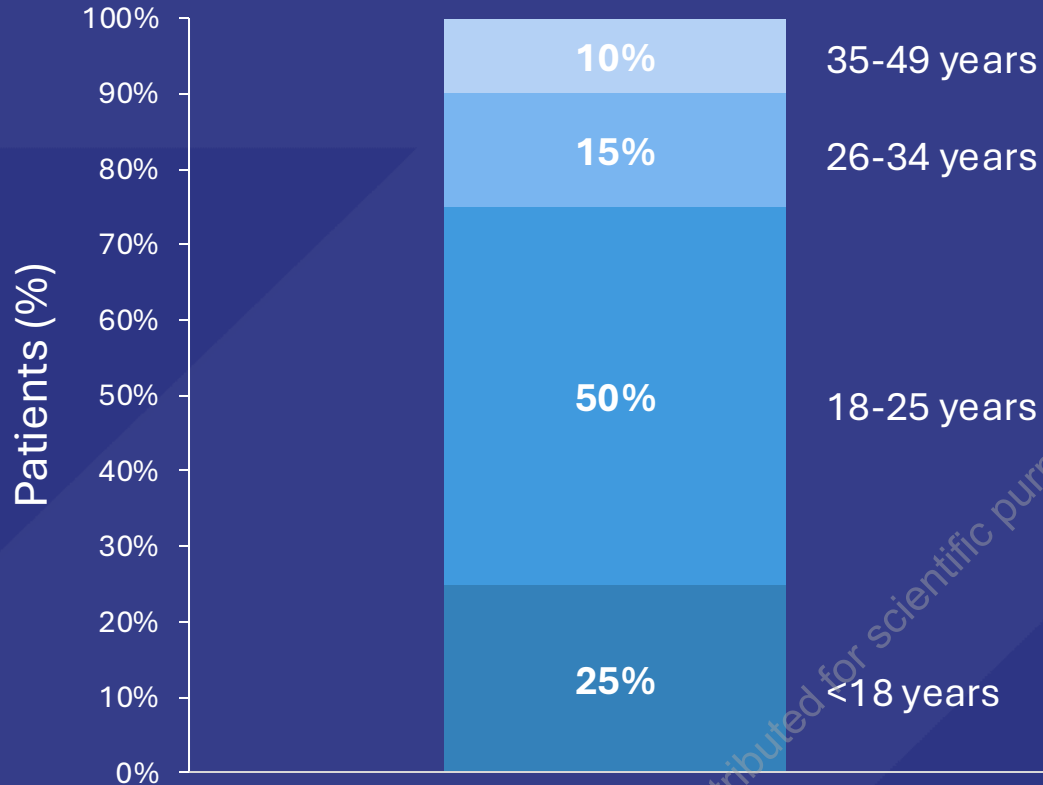
- Most patients were under the care of a PAH specialist



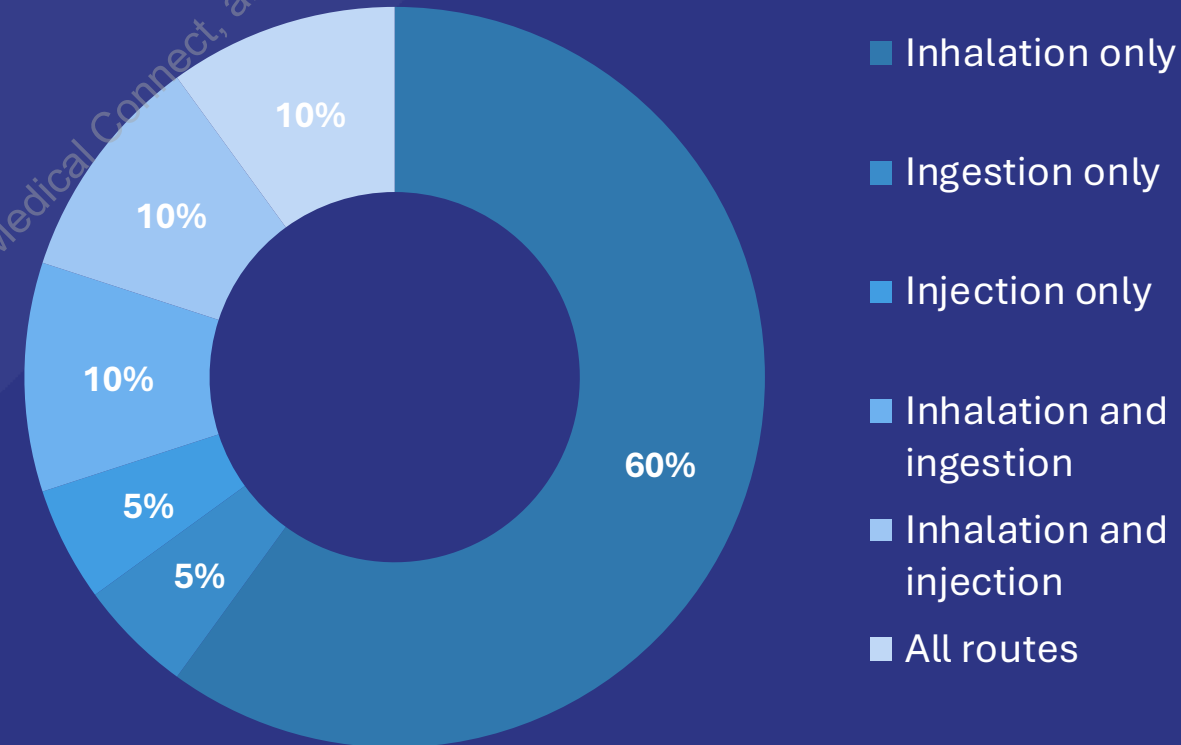
# History of methamphetamine use

# Age at first use and route of use

Age at first use



Route of use

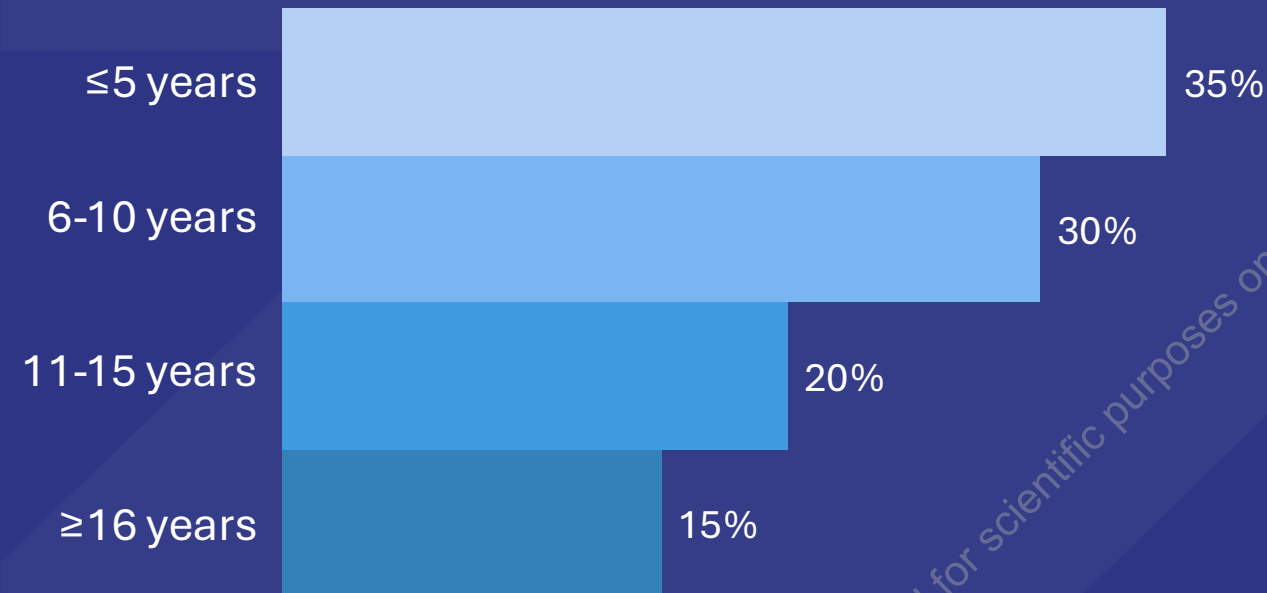


- Three-quarters of patients started methamphetamine use before age 25 years
- Most common reasons were social or relationship pressures and emotional or physical pain relief
- Most patients initially used methamphetamine via inhalation
- 30% escalated to multiple routes over time

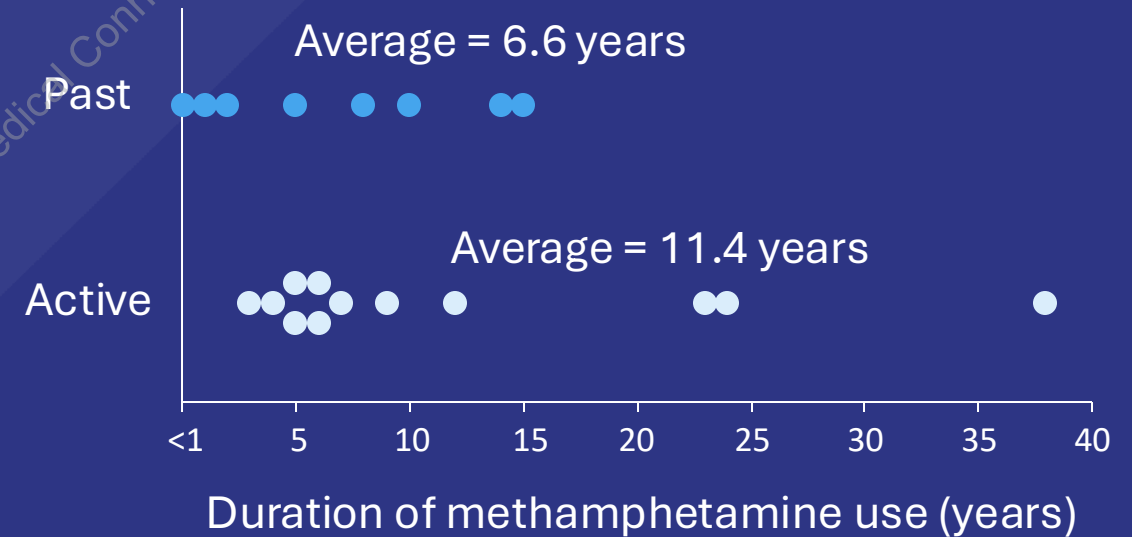


# Duration of methamphetamine use

Total duration of use



Total duration of use by past or active usage at Dx



- The duration of methamphetamine use varied greatly
- Past users were more likely to have used methamphetamine for a shorter time than active users

Dx, diagnosis.

# Syncope during active methamphetamine use before meth-APAH diagnosis

25%

of patients experienced episodes of syncope during active use of methamphetamine before PAH diagnosis

45%

of patients who received medical attention during their time of active methamphetamine use received care due to involuntary hospitalizations for syncope

➤ all such hospitalizations led to a PAH diagnosis

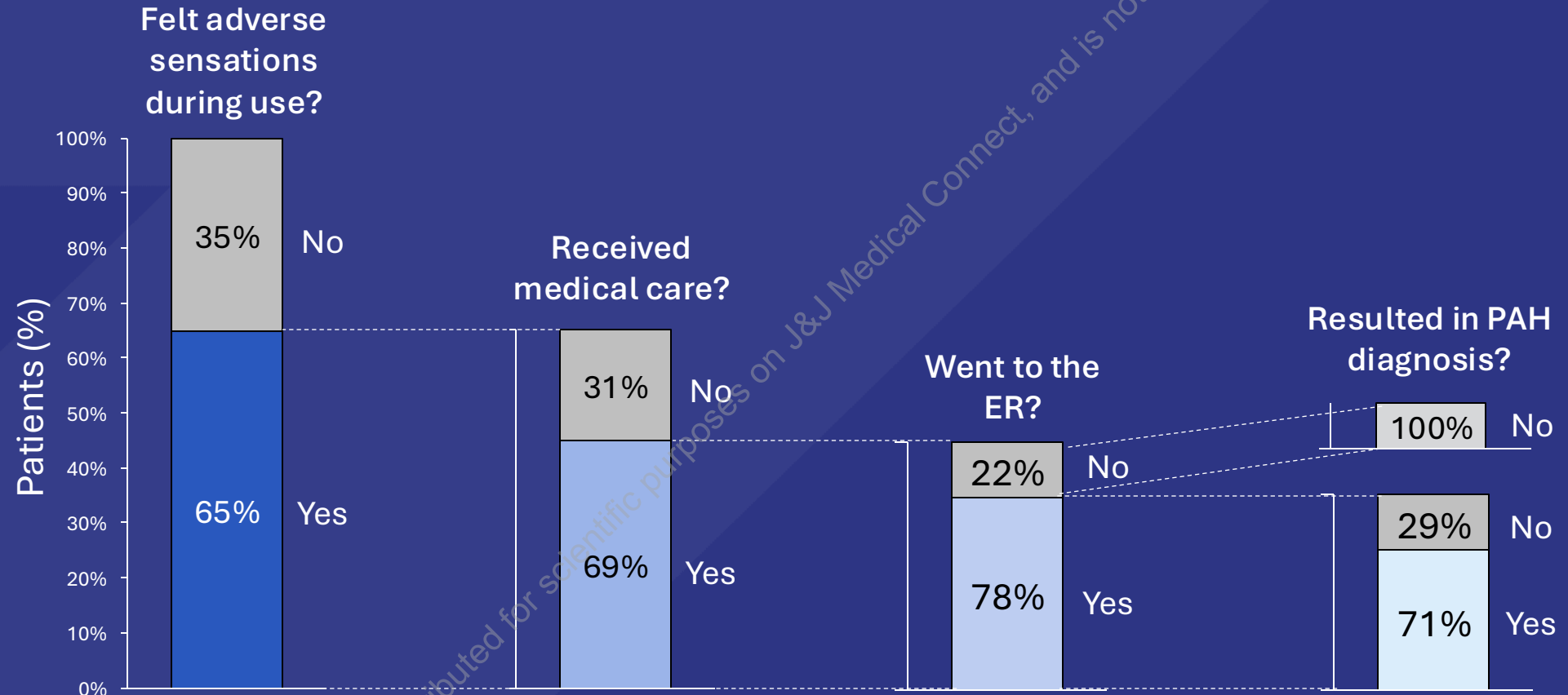
50%

of patients diagnosed with PAH while actively using methamphetamine were diagnosed following an episode of syncope

# Path to meth-APAH diagnosis

meth-APAH, methamphetamine-associated pulmonary arterial hypertension.

# Patient response to PAH symptoms during active methamphetamine use



ER, emergency room; PAH, pulmonary arterial hypertension.

# Setting of diagnosis by methamphetamine use status

User status at diagnosis	Setting of PAH diagnosis		Total
	ER	Outpatient clinic	
Active user at diagnosis	50%	10%	60%
Past user at diagnosis	15%	25%	40%
Total	65%	35%	

- Active users were more likely to be diagnosed at the ER, while past users were more likely to be diagnosed in an outpatient setting ( $p < 0.05$ , chi-square test)
- Most common reasons for ER visits were:
  - Active users: syncope, dyspnea
  - Past users: pneumonia-related complications

# Asking about 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 duration of use)

40%

of patients received a toxicology screen during their diagnosis

50%

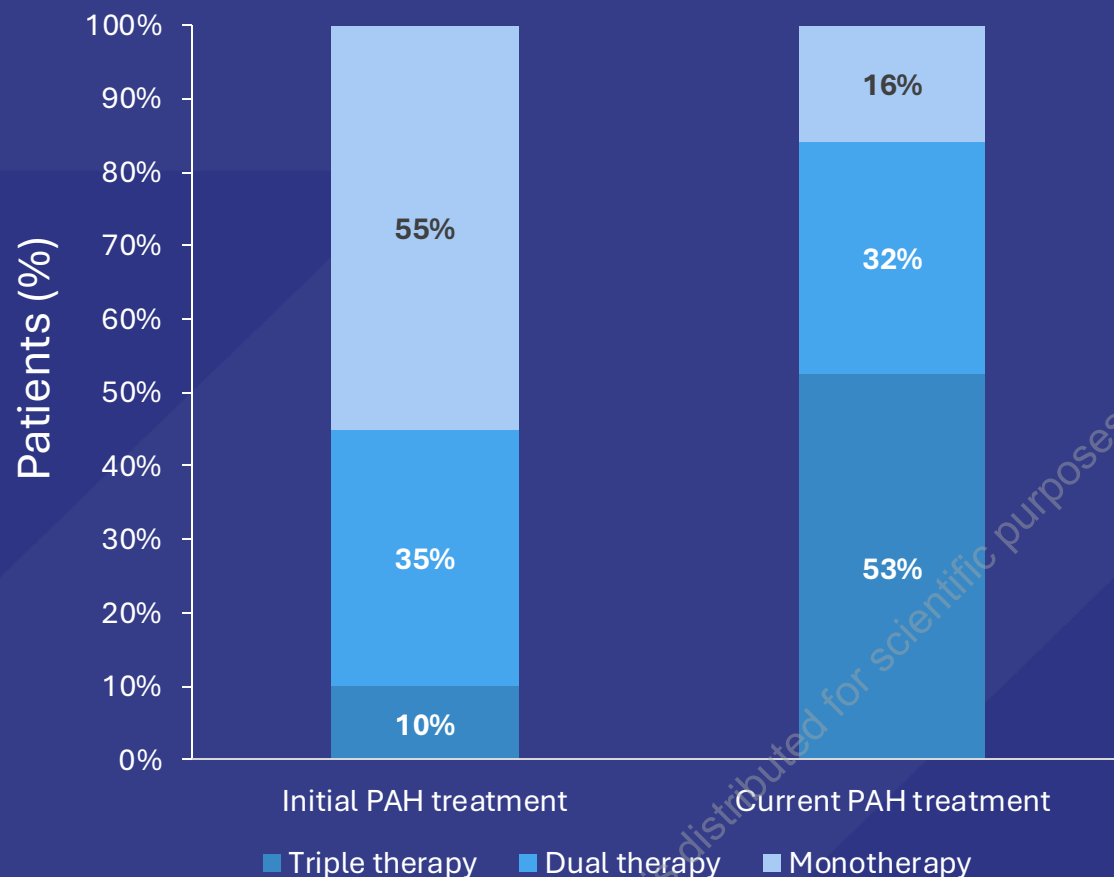
of patients who were actively using methamphetamine at diagnosis quit use immediately after diagnosis

# Meth-APAH treatment experiences

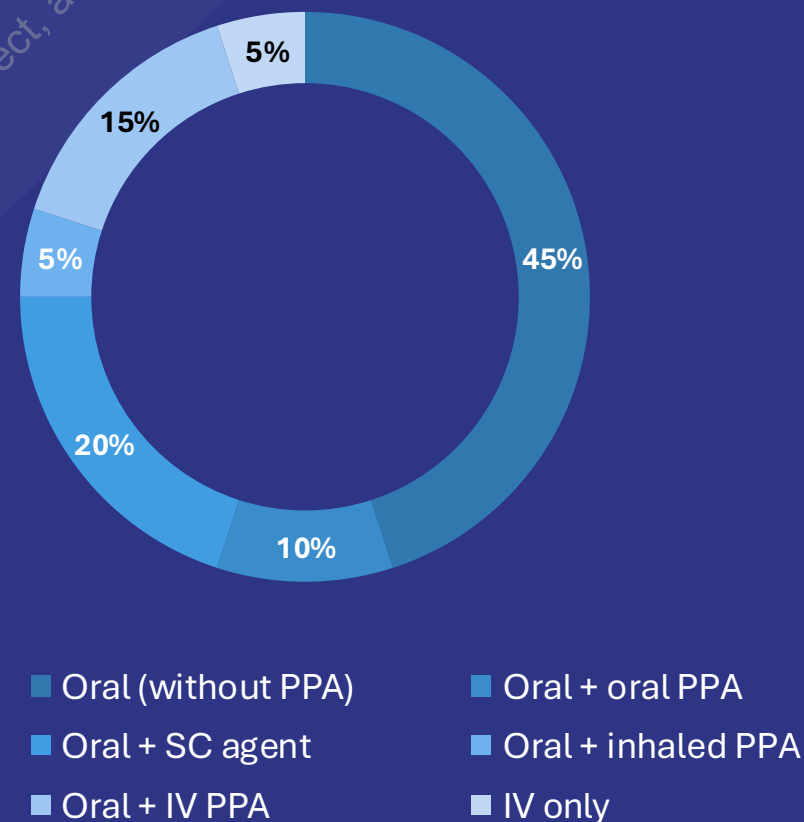
meth-APAH, methamphetamine-associated pulmonary arterial hypertension.

# PAH treatment over meth-APAH patient journey

## PAH treatment over journey



## Route of administration of PAH treatments

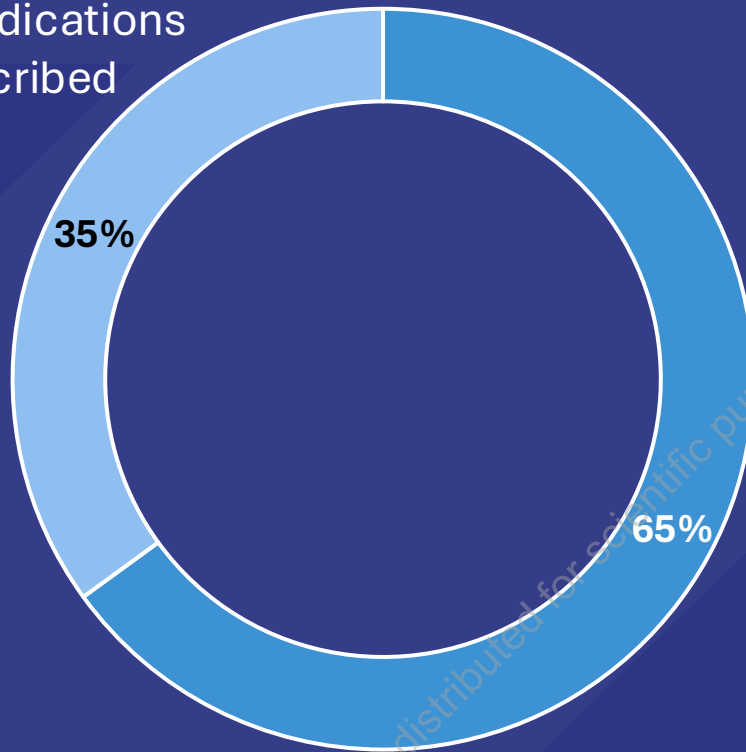


Most patients were initiated on a monotherapy and escalated over time to dual or triple therapy



# Adherence to PAH treatment

No, I sometimes do not take my PAH medications as prescribed

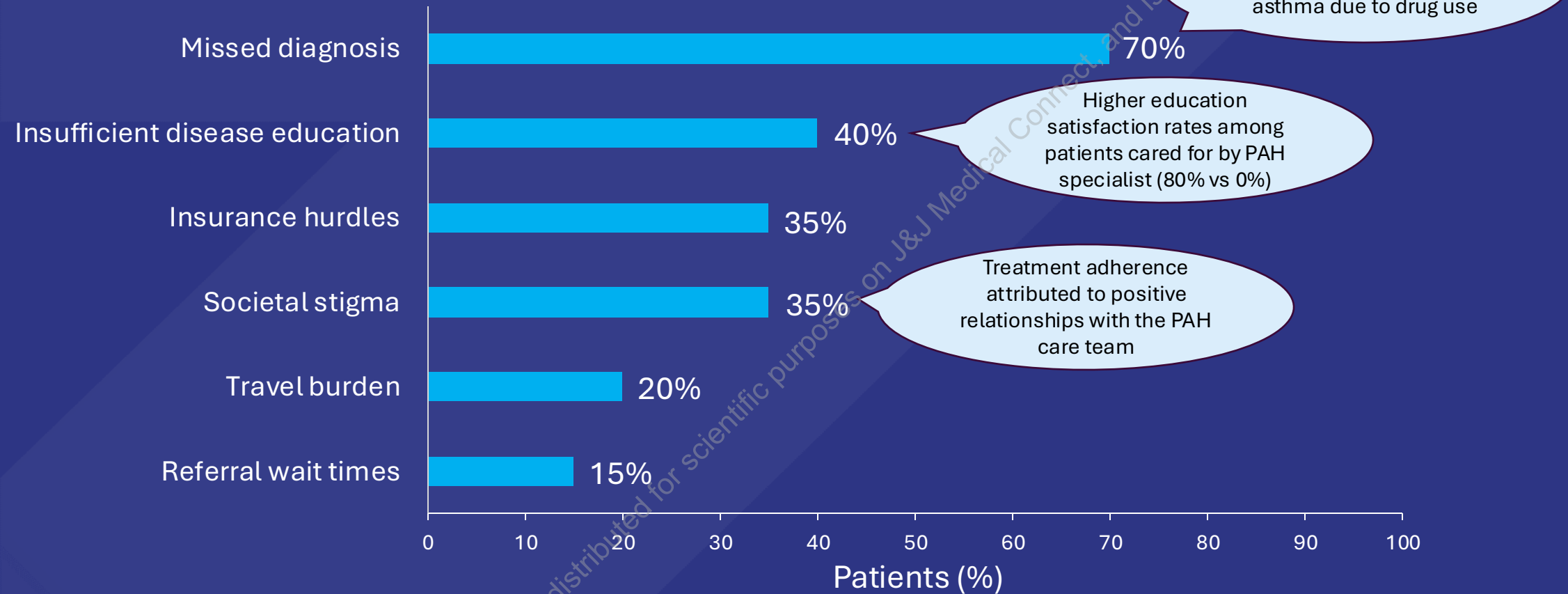


Yes, I take my PAH medications as prescribed

- Participants who were adherent credited their adherence to perceived benefits of the PAH treatments and supportive care teams
- Barriers to complete adherence included forgetfulness partly attributed to the complexity of some PAH medications, difficulties in tracking medication refills, and side effects such as infusion-site pain

# Challenges and unmet needs in the patient journey

# Unmet needs experienced by patients with meth-APAH



meth-APAH, methamphetamine-associated pulmonary arterial hypertension; PAH, pulmonary arterial hypertension.

# 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 methamphetamine when they were diagnosed with PAH
- Most participants were diagnosed following a severe event that led them to the ER, such as syncope or dyspnea
- Not all patients were asked about their drug use history, and most were not asked to perform a toxicology screen
- Only half 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 among 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 among 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

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# Disclosures

- LM-G and VdJP are consultants for Johnson & Johnson. AV is a consultant for Johnson & Johnson, Merck, and United Therapeutics. HGL has no conflicts to disclose. MS, DL, AA, NG, and MC are employees of Johnson & Johnson. JFK is a speaker and consultant for Johnson & Johnson, Liquidia, Merck, and United Therapeutics.

# Thank you!

<https://www.inmedicalconnect.com/media/attestation/congresses/pulmonary-hypertension/2025/team-phenomenal-hope/qualitative-interviews-of-patients-with-methamphetamine-associated-pulmonary-arterial-hypertension-u.pdf>

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