HPPD Patients Reveal Their Experiences

ON LIVING WITH HALLUCINOGEN PERSISTING PERCEPTION DISORDER

2019 SURVEY RESULTS

FACES OF HPPD

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Lewis, DM, Faces of HPPD: Hallucinogen Persisting Perception Disorder Patient Survey Results and a Descriptive Analysis of Patient Demographics, Medical Background, Drug Use History, Symptoms, and Treatments. Addictive Disorders and their Treatment. Forthcoming 2019.
Faces of HPPD Survey Results Published 2019*

An Internet Survey* was conducted between 2013 and 2017 and included 26 individuals across the globe who were diagnosed with Hallucinogen Persisting Perception Disorder (HPPD, a rare disorder that can afflict users of hallucinogen drugs).

Who Responded to the Survey
- 78% Male
- 92% White
- 69% College Educated
- 58% Employed
- 23% Unable to Work due to Condition
- 24.5 Years - Median Age (Now)
- 22.5 Years - Median Age at Time of Diagnosis
- 73% Single/Never Married

81% from North America
- 12% from Europe
- 8% from South America

How Long They Have Been Living with HPPD
- 1 Year or Less 12%
- 1+ to 3 Years 35%
- 3+ to 5 Years 23%
- 5+ to 10 Years 12%
- 10+ Years 19%

Top Pre-Existing Conditions (Before Being Diagnosed with HPPD)
- Mood Disorder (e.g., depression) 100%
- Panic Disorder 81%
- Anxiety Disorder 81%
- Sleep Disorder 46%
- Post-traumatic Stress Disorder (PTSD) 38%
- Attention Deficits (ADD/ADHD) 31%

Past Hallucinogen Use (Before Being Diagnosed with HPPD)
- LSD 73%
- Psilocybin 65%
- MDMA 46%
- Mescaline 23%
- Cactus 12%
- Synthetic Cathinones 8%
- PCP 4%

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Past Other/Non-Hallucinogenic Drug Use

- Marijuana: 81%
- Cocaine: 58%
- Alcohol: 54%
- Narcotics: 46%
- Amphetamines: 42%
- Benzodiazepines: 39%
- Synthetic Marijuana*: 23%

* in some cases, may be considered a "hallucinogen"

Current Drug Use

- Alcohol: 39%
- Benzodiazepines*: 35%
- Marijuana*: 19%
- Narcotics*: 8%
- Amphetamines: 4%
- LSD: 4%
- Psilocybin: 4%

Hallucinogens (of Any Kind): 4%

- Of These, 10% Dependent
  - Alcohol: 78% Dependent
  - Benzodiazepines*: 100% Dependent
  - Marijuana*: 50% Dependent

Visual Symptoms*

- Visual Snow: 96%
- Seeing Floaters: 96%
- Trailing Afterimages: 96%
- Poor Night Vision: 92%
- Difficulty Being Under Fluorescent Lights: 89%
- Halos Around Lights: 89%
- Illusions of Objects Moving: 89%
- Flashes of Light: 85%
- Auras: 81%
- Positive Afterimages: 77%
- Difficulty Reading: 69%
- Intense Colors: 69%
- Geometric Shapes: 69%
- Negative Afterimages: 65%
- Color Confusion: 62%
- Pareidolia Images: 50%
- Macropsia: 46%
- Micropsia: 46%
- Visual Hallucinations: 42%

* Symptoms are reported as those occurring after HPPD diagnosis (past plus current). Daily occurrences are calculated as a percentage of the number of subjects reporting the symptom and NOT percentage of TOTAL population - NOTE: these figures are presented differently than published in journal article.
Symptoms* - Psychiatric/Psychological/Neurological/Physical

<table>
<thead>
<tr>
<th>Symptom</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>96%</td>
</tr>
<tr>
<td>Depersonalization</td>
<td>92%</td>
</tr>
<tr>
<td>Poor Sleep</td>
<td>92%</td>
</tr>
<tr>
<td>Panic Attacks</td>
<td>89%</td>
</tr>
<tr>
<td>Paranoia</td>
<td>77%</td>
</tr>
<tr>
<td>Suicidal Feelings</td>
<td>69%</td>
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<tr>
<td>Poor Sleep</td>
<td>69%</td>
</tr>
<tr>
<td>Panic Attacks</td>
<td>69%</td>
</tr>
<tr>
<td>Headaches</td>
<td>69%</td>
</tr>
<tr>
<td>Out of Body Sensations</td>
<td>69%</td>
</tr>
<tr>
<td>Flashbacks/Vivid Memories</td>
<td>65%</td>
</tr>
<tr>
<td>Heart Palpitations</td>
<td>58%</td>
</tr>
<tr>
<td>Hearing Voices</td>
<td>54%</td>
</tr>
<tr>
<td>Delusions</td>
<td>46%</td>
</tr>
<tr>
<td>Attention Deficits</td>
<td>46%</td>
</tr>
<tr>
<td>Migraines</td>
<td>42%</td>
</tr>
<tr>
<td>Loss of Consciousness</td>
<td>35%</td>
</tr>
<tr>
<td>Smell Hallucinations</td>
<td>31%</td>
</tr>
<tr>
<td>Seizures</td>
<td>27%</td>
</tr>
<tr>
<td>Dyslexia since drug use</td>
<td>23%</td>
</tr>
</tbody>
</table>

Of these, 68% experience daily.

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HPPD Diagnosis & Treatment

3 Average # of Doctors

The average # of doctors patients saw before finally receiving a diagnosis of HPPD is 3. (Range = 1-7 doctors)

Medical Care Received from:

- Neurologist: 42%
- Primary Care Physician: 50%
- Counselor/Therapist: 62%
- Psychiatrist: 88%

Medications Prescribed:

- Benzodiazepines: 50%
- Neuroleptics: 81%
- Anticonvulsants: 81%

54% Respondents Report They Wear Sunglasses to Offset Visual Symptoms

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